



ACI NSW Agency
for Clinical
Innovation

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**

GUIDE

Better health for people living with dementia: A guide on the role of allied health professionals



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UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA

Alzheimer's Australia is the peak body representing people with dementia, their families and carers. It provides advocacy, support services, education and information. More than 353,800 people have dementia in Australia. This number is projected to reach more than half a million by 2030.

[FIGHTDEMENTIA.ORG.AU](https://www.fightdementia.org.au)

For information and advice, contact the National Dementia Helpline on:

1800 100 500

The National Dementia Helpline is an Australian Government-funded initiative.

The National Dementia Helpline is a telephone information and support service available across Australia. The Helpline is for people with dementia, their carers, families and friends, as well as people concerned about memory loss, providing:

- understanding and support for people with dementia, their family and carers
- practical information and advice
- up-to-date written material about dementia
- information about other services
- details of the full range of services provided by Alzheimer's Australia.

As an occupational therapist, I had the privilege to work with many people whose lives had been changed irreversibly by a stroke, a head injury, a cerebral tumour, and other neurological conditions, to which allied health professionals brought their expertise and skills to support these people meet the challenges of their condition and what it brought to their lives.

In 2001, while working as an occupational therapist at a Sydney hospital, my husband was diagnosed with a younger onset dementia. A healthy, fit, intelligent man with a love for life and for his family, this was a shock – for him, for me, and for our two teenage children. During the subsequent 10 years of the progression of his condition, we learned a great deal from my husband. We learned about the enormous complexity of dementia. We came to better understand the complex changes in cognitive, perceptual and language abilities which challenge living your life with this condition. We also learned that life is different, but can continue to be enjoyable, fulfilling and rewarding – with support, informed guidance and assistance from people with understanding and expertise in the condition of dementia.

What we were not prepared for was the lack of allied health professionals available to work with the changing capacities and abilities for people with this progressive condition. Having worked in rehabilitation settings with skilled multidisciplinary teams and knowing the difference that allied health professionals could make for a person with a disability, it was alarming and bewildering that these services were not equally available for people with the disabilities which come with a dementia.

Better health for people living with dementia: a guide for health professionals, together with its companion resource for consumers, is a wonderful national initiative by Alzheimer's Australia through their National Quality Dementia Care Initiative, together with the Agency for Clinical Innovation (NSW). Through widespread consultation with people with dementia, carers and allied health professionals, this resource provides a much needed overview for all health professionals, about the vital role of allied health with people with dementia.

Hopefully this initiative will be just the beginning of an increased capacity of allied health professionals to understand the complex and varied needs of people living with dementia and to work in partnership to provide the support to live the life they deserve to live.

Joan Jackman

Wife of Michael – a courageous man who showed us how to live with dementia.

Introduction

A diagnosis of dementia heralds change for the person receiving the diagnosis and for those close to them.

Dementia is a progressive neurodegenerative disease which results in a gradual loss of cognition and abilities; however many skills remain intact.

There are many types of dementia and the rate and course of the progression varies between types and between individuals. Information and support for the person and their close family and/or friends is imperative. So is good health care and a healthy, active lifestyle. Allied health professionals across the many disciplines are well placed to provide many aspects of health care and services to people living with dementia.

This guide aims to encourage all health professionals to consider the role of allied health professionals in the health care of a person living with dementia and their carers.¹ It encourages health professionals to think about how allied health professionals can work with a person living with dementia to enable them to live to their full potential. And it informs allied health professionals, who may not have a direct role with aged and dementia health care, of the valuable support they and their colleagues can provide to people living with dementia.

Some people living with dementia have no, or few, other health conditions. Others will have comorbidities, such as vascular disease, diabetes and depression. Then, there are dementia-related health needs that may not be so well recognised, such as changes to cognition, communication, perception, mood and taste. As such, care can be complex and it can be easy to lose sight of what is most important to the person at the centre of the care. Helping the person with dementia to prioritise their needs may be an initial step in the partnership.

The recognition and treatment of health needs can be clouded by lingering stigma about dementia, the myth that dementia is a normal part of ageing and misconceptions about what a person living with dementia can and can't do and learn. Allied health professionals have an opportunity to provide optimism and help reduce the potential disability that surrounds these negative community attitudes.

In fact, there has been a tremendous growth in knowledge over the past decade about dementia and how it affects the person with it and also those close to them. This has been informed by research and by the growing voice of people with lived experience, and has led to a deeper understanding of how to work with a person living with dementia to enable a happier and more fulfilling life.

There has also been a shift in approach, with the *Clinical practice guidelines and principles of care for people with dementia 2016* stating that 'people with dementia should not be excluded from any health care services because of their diagnosis, whatever their age' (1:p17).

This shift is reflected in increasing evidence of what allied health professionals have to contribute in areas that were not always included in dementia health care, such as rehabilitation (2), behaviour management (3) and palliative care (1:p90). And an increasing recognition of the value of an inter-professional healthcare team approach: where a group of health professionals collaborate to frame a common understanding and develop an integrated approach to dementia health care (4).

¹ In this publication, the term 'carers' refers to people who are not paid to provide care. Carers in receipt of the Australian Government carer payment or carer allowance are included in this publication.

This guide draws from that growth in knowledge, and describes the many ways in which allied health professionals can use this information to work together and provide interventions for people living with dementia.²

This guide is about what allied health professionals can do, and in many instances, are already doing.³

We acknowledge that the availability of allied health professionals, and of those with experience in dementia health care, is not consistent across Australia. We also acknowledge that there can be some overlap between some of the allied health disciplines. There is a companion to this document for people living with dementia and their carers: ***Allied health professionals and you: A guide for people living with dementia and their carers.*** It provides information about allied health professionals and how they can contribute to the health care of a person living with dementia. It is available at <https://fightdementia.org.au/about-dementia/resources/allied-health-professionals> or at http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0003/310836/Allied-Health-Professionals-and-You.pdf

2 In addition to the allied health disciplines, this publication includes dementia advisors (and key workers), because many of them are allied health professionals. They may work in a dementia-specific service, such as a Dementia Advisory Service, or may be a sole worker attached to a government health service or a non-government provider. In addition to their discipline knowledge, they have usually completed further training and/or have considerable experience working with people living with dementia. They are not available in all states and territories.

3 Doctors and nurses also provide medical and health services to people living with dementia. However they are not the focus of this publication.

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Keeping a sense of self

Keeping a sense of self

The person with a diagnosis of dementia is first and foremost a person – was, is and will continue to be.

They have a lived history – a culture, family, personality, emotions, experiences, stories, memories and much more – that has meaning to them.

It is important to build on the things that have meaning. The person living with dementia might like attending church, or a mosque, or a synagogue, or a temple, or meditating. They might prefer their own company, or they might love a crowd. They might relish routine or prefer spontaneity. They might enjoy work, volunteering, listening to music, a hobby, bushwalking, creating beautiful things, gardening or caring for others.

Whoever they are and whatever their story, a person living with dementia will be happiest if they can be themselves, and be recognised for the person who they are.

Practice points

Allied health professionals:

- can take a wellness approach to provide person-centred dementia care
- can provide health care in accordance with the '10 principles of dignity in care' (1:p12).

A wellness approach in dementia care:

- emphasises the person and what they can do, ahead of the presenting health issue and what they can't do
- uses a rehabilitative framework to maximise independence and quality of life by giving a person the opportunity and confidence to retain and regain some of the skills they may have lost or be at risk of losing, or to develop alternate strategies where skills are gone
- focuses attention on what is meaningful to the person and what contributes to their wellbeing
- includes reablement and restorative care.⁴

A person-centred approach:

- puts the person in the centre of care
- treats people as partners in health care
- works alongside them to improve quality of life
- empowers people to make choices for living a healthy life
- enables engagement in occupations, activities and relationships with consideration of a person's capacity, culture, interests and life story.

⁴ 'Reablement includes time limited interventions targeted towards a person's specific goal to adapt to functional loss or regain confidence and capacity to resume activities. Restorative care involves evidence based interventions led by allied health professionals that allow a person to make a functional gain or improvement after a setback or to avoid a preventable injury.' (1: p52)

Noelene's story

Noelene loves music, loves to sing and to dance. She always has. Her house was full of music and she used to sing her children to sleep every night. Noelene's love of music and singing has not changed even though some other things have changed, like her memory, managing day to day tasks and preparing and eating food. When Noelene's skills in using her CD player changed, her son and daughter put all her music onto an iPod and with the press of just one button, Noelene could continue to enjoy all the music she loves.

Noelene's daughter noticed that her mother liked singing new songs on the radio and remembered all the words, even though she was not remembering other things. Her daughter contacted Ameer, a neuropsychologist who was conducting some research. Ameer taught Noelene a new song that she'd not heard before and Noelene was able to sing along to that song two weeks later.

Comment from neuropsychologist Ameer:

Noelene could not recall three words after a three minute delay and did not know who I was; but she could sing along to the song I had taught her two weeks before. This is very exciting as learning new information is something that is typically difficult for someone with severe dementia. Involving Noelene in singing has been a key ingredient of her happiness in residential care and of retaining the essence of who she is by engaging her in doing the thing she loves.



Staying connected

Connection with others is key to one's sense of self. For many people living with dementia, relationships change. Changes in communication, thinking, memory and behaviour are not widely understood. People report that friends drop away; others find attending their usual community events and groups more challenging.

Enabling a person living with dementia to maintain relationships with family, friends and colleagues and connection to their community of interest is important. So is creating opportunities to make new connections if former ones drop away. This is best achieved within the context of activities that build on what is meaningful to each individual. It requires seeing the person first; finding out who they are and working with them to create opportunities that enhance connection.

A person with dementia living alone is particularly vulnerable to becoming socially isolated. Allied health professionals have a role in connecting each person to social and community groups (1:p42).

Practice points

Occupational therapists:

- have expertise in assessing the routines and tasks involved in maintaining relationships and connecting people to their communities of interest
- identifying the person's existing skills, abilities and strengths that can be built into everyday activities
- identify obstacles that prevent people from doing what they want
- help carers understand when and how to provide the right sort of assistance, and when to step back
- work with the person living with dementia and their carer to get around obstacles by modifying the environment, suggesting technologies or developing strategies.

Diversional therapists:

- get to know the history, passions, skills, culture and interests of the person living with dementia
- increase engagement by finding or developing enjoyable leisure activities and outings.

Social workers and Aboriginal and Torres Strait Islander health workers:⁵

- navigate the service system to locate the right allied health professional or service
- work with other allied health professionals and community services to develop culturally appropriate, dementia-friendly opportunities.

Speech pathologists:

- work with carers to adapt their communication to stay in touch with the person living with dementia
- advise on the use of modalities other than speech.

⁵ Aboriginal and Torres Strait Islander health workers have differing titles throughout the states and territories. They have broad skills and cultural knowledge; they provide health care and can assist in navigating the health care and aged care systems.

Shaun's story

Shaun had always worked hard. When he developed dementia and had to retire earlier than he had planned to, he needed to make some big adjustments.

But adjust he has. He started working a vegetable patch at home, and now volunteers at two community gardens, earning a TAFE certificate along the way. He meets a men's group regularly. He volunteers at church. He reads.

And once a fortnight, he meets at a coffee club organised by a dementia advisor. Between 10 and 25 people, some with dementia, some carers, meet at the same café once a fortnight to talk and relax. An allied health professional is always present to provide support and information. Shaun has found them so good he's started going to others in neighbouring areas.

“ I enjoy them. I like to feel I can support and encourage people. This is a good way of helping others out. ”



Comment from social worker and dementia advisor Sue:

The aims of the café are to promote social inclusion and peer support, and to offer ongoing information and support in a relaxed way. They are a great way for people to feel connected with each other.

I think two of the most valuable aspects of this model are the peer support, and the fact that it is appropriate for people with dementia from the very early stages and throughout the progression of the disease. Peer support is very powerful. I can spend a lot of time informing people about services, but being able to talk to others that receive services is far more effective in helping people to accept them. Recently one of our participants was admitted to hospital and needed to move into residential care; his wife didn't drive so a couple of other carers from the group took her around to look at facilities and supported her throughout this very difficult time.

I have people attending the café that have been doing so since it started in 2008, they find this is a safe and supportive group regardless of the stage of dementia. Not all people will want to join a café; most come for the whole 2 hours, some just drop in for a few minutes, and some don't come for months but do attend when they need some information and support.

I find being involved in the cafés very personally and professionally rewarding.

Adjusting to the diagnosis and changing cognition



Adjusting to the diagnosis and changing cognition

Everybody's life changes with time. The life of a person living with dementia is changing more than most.

A diagnosis of dementia is likely to lead to, or uncover, a set of needs, both for the person living with dementia and for their carers, family and friends. They might be sad, frustrated or embarrassed at some of the restrictions that the condition places on them, or they may have less awareness or insight about their changes than those around them. They might have to accept help, and a loss of privacy.

All people living with dementia, and their carers and families, should be offered information and support. The *Clinical practice guidelines and principles of care for people with dementia 2016* (1:p42) recommend that the diagnosis of dementia is communicated to the person living with dementia by a medical practitioner, and that information and support be provided for a person living with dementia and their carers and family following the diagnosis of dementia. Information and support can help people adjust to change.

Yet, the support and information needs at the time of diagnosis will vary between people. Support and information are most useful when relevant to the person's needs at that time, and provided in a way that they can understand and in an amount they can digest.

The emotional needs will vary too, between people living with dementia, among the circle of carers around a person living with dementia, and over time.

Practice points

Occupational therapists and neuropsychologists:

- assess a person's cognition and the impact of cognitive change on their life
- explain cognitive changes and how they may impact on a person's life at that time and in the future
- provide input around decisions regarding activities of daily living and what is appropriate
- provide input around decisions about their continuation at, or level of involvement in, work.

Dementia advisors and key workers:

- provide information to make sense of the diagnosis and its impact
- link people to programs and refer them to other allied health professionals.

Aboriginal and Torres Strait Islander health workers:

- provide care, support, information and a link to services.

Counsellors, psychologists and social workers:

- provide emotional and psychological support through times of transition.

Other allied health professionals, such as speech pathologists, occupational therapists and dietitians:

- bring discipline-specific expertise to assist in adjusting to the changes brought about by cognitive impairment.

Information

The need for knowledge and the timeliness of receiving it varies from person to person, and from carer to carer. As the person with dementia changes, the type, the amount and the way of receiving information also changes. Carers often benefit from learning about strategies that help them adapt to changes and meet new challenges. By listening to the carer and assessing their current situation, the allied health professional can target the right information at the right time and provide the right amount.

Practice points

Allied health professionals who specialise in dementia:

- may provide education programs, or they can refer carers to programs run by other organisations (such as Alzheimer's Australia), or to publications and websites containing accurate and useful information.

All allied health professionals:

- can bring the knowledge, ideas and solutions that are specific to their discipline to suggest a strategy to deal with a troubling situation.



Health and wellbeing

Keeping physically active

Physical activity has many health benefits. People who are physically active feel stronger, sleep better, have better coordination and balance, and have a general sense of wellbeing.

Guidelines on physical activity apply to people living with dementia, and their carers too. There is a growing body of evidence that a person living with dementia can build strength and improve balance and mobility through physical activity and exercise.

For people living with dementia, exercise programs have also been shown to improve the performance of daily tasks such as dressing (1:p54). Exercise supports healthy brain function and some studies of people living with dementia have reported benefit to cognition and mood (1:p54). Exercise and physical activity can also improve cardiovascular health, help manage weight and reduce the risk of diabetes.

There are social and emotional benefits too, from getting out and meeting new people, to reducing stress, anxiety and depression. Physical activity may also reduce some of the behavioural and psychological symptoms of dementia.

Practice points

Physiotherapists:

- assess transfers, mobility, strength, balance and other fall risk factors
- develop individualised exercise programs to maintain or improve mobility, strength, balance and endurance
- help find types of physical activity that are both safe and enjoyable, such as dancing or Tai Chi
- recommend group exercise or other programs, such as a falls prevention program
- suggest an appropriate walking aid and provide training about how to use it safely
- assess range of movement, position sense and praxis
- assist in developing strategies to help manage identified impairments and maintain safety
- assess and treat musculoskeletal injuries and help manage pain
- aid recovery from surgery and other illnesses through rehabilitation
- help to manage other chronic diseases unrelated to dementia, such as lung and heart disease
- have a role in pain management.

Practice points

Occupational therapists:

- identify barriers to participation in physical activities and exercise
- minimise risks and impediments to maximise active enjoyment of life
- assess the home environment and prescribe modifications if needed
- prescribe aids or equipment to allow engagement in physical activity and exercise
- have a role in pain management.

Exercise physiologists:

- provide exercise programs to support people with the management of chronic disease.

Dietitians:

- provide advice on adequate nutrition to improve muscle strength, support physical exercise, reduce the risk of falls and improve independence and wellbeing.

Podiatrists:

- assess foot problems⁶
- maintain foot health – toenails, bunions, corns and arthritic joints
- advise about appropriate footwear
- treat pain.

Ken's story

Within a few months of being diagnosed with dementia, Ken was having trouble walking and was using a walker.

A physiotherapist made six visits to Ken at home. She introduced a program that aimed to make him more mobile. Ken's son John did the exercise program with him.



Ken joined a day rehab program, which added different exercises. John added those to the daily at-home routine.

Within six months, Ken could walk more than 2 kilometres unassisted and got around the house more easily, though still using a stick or a walker.

The exercise has dropped off a little, although he is still walking a kilometre a day. He is also doing a regular program of exercise and hydrotherapy twice weekly. Ken is happier than before, enjoying getting out of the house and moving more freely. Some of his boredom has eased. John believes the initial visits from the physio made an enormous difference.

Comment from physiotherapist Carmel:

Ken is a motivated gent who is keen to improve. My job was made easy by having an interested and involved carer who supervised the home program and ensured that it was undertaken regularly and correctly. He was then able to attend the day rehab unit to further his program with increased intensity and challenge of exercises. Now Ken is attending our Strong and Steady program to continue to improve his mobility and function.

⁶ Though such problems are probably not a consequence of dementia, they may be associated with pre-existing or comorbid health issues.

Preserving cognitive function

In recent decades, brain research has led to an explosion of new knowledge. Of particular interest to a person living with dementia is the expanding knowledge of neuroplasticity and the potential for preventing or delaying the various types of dementia. A lot has been learned; for example, that 'people with early stage dementia are capable of new learning and therefore rehabilitation interventions that aim to optimise independence may be appropriate' (1:p56).

While there is a lack of strong quality evidence regarding their efficacy(1:p57), some allied health professionals, particularly occupational therapists and neuropsychologists, run programs for cognitive stimulation, cognitive training and cognitive rehabilitation⁷ which have reported benefits. These allied health disciplines have a lot to contribute in this area as further research into their programs is undertaken.

There are many opportunities for a person living with dementia to exercise their cognition outside the types of programs mentioned above. Engaging in new learning can have a positive effect. This may be as varied as learning a musical instrument or a language, enrolling in a course, singing with a choir, or joining a dance class.

Keeping mentally active connects the person living with dementia to the world, and connection to the world keeps the person living with dementia mentally active. It may be through:

- seeing family and friends, or making new friends
- staying involved with their community, club, religious group or sporting group
- joining groups for activities, outings and fun.

Practice points

Occupational therapists:

- have expertise in assessing the impact of cognitive function on everyday functioning
- are able to determine the amount of cognitive support required for a person to complete an activity
- identify obstacles and barriers to participation
- work with the person living with dementia and their carer to get around obstacles by developing strategies, suggesting technologies or modifying the environment
- assess suitability for cognitive stimulation therapy, cognitive training or cognitive rehabilitation programs and may provide these.

Diversional therapists:

- get to know the history, passions, skills, culture and interests of the person living with dementia as engagement will occur best when there is a natural interest
- find suitable sources of mental stimulation.

Neuropsychologists and psychologists:

- assesses suitability for cognitive stimulation therapy, cognitive training or cognitive rehabilitation programs
- provide interventions based on that assessment.

Dietitians:

- provide optimal nutrition which enables a person to take full advantage of their cognitive capacity.

⁷ Cognitive stimulation therapy is engagement in a 'range of group activities and discussions aimed at general enhancement of cognitive and social functioning'. Cognitive training 'typically involves guided practice on a set of standard tasks designed to reflect particular cognitive functions, such as memory, attention, language or executive function'. Cognitive rehabilitation is an 'individualised approach to helping people with cognitive impairments in which those affected, and their families, work together with health care professionals to identify personally-relevant goals and devise strategies for addressing these. The emphasis is not on enhancing performance on cognitive tasks but on improving functioning in the everyday context'(1:p57).

Daniel's story

A couple of years after being diagnosed with Alzheimer's disease, Daniel joined a pilot study on cognitive stimulation therapy (CST) at a metropolitan teaching hospital. Daniel joined a group with eight others who were also living with dementia. Two trained allied health professionals ran these weekly groups.

Although he questioned the reason for attendance each week, Daniel never missed a session. He made friends with another man and they caught the bus together each week. Daniel made a great contribution to the group; he enjoyed hearing what others had to say and sharing his own strategies to assist his declining memory. Daniel saw the group as an exercise program for his brain, saying 'it must be useful because it makes me think'. Even though he was experiencing word finding difficulty, Daniel was a particularly vocal member of the group.

As the program came to an end, the occupational therapist referred him to a community gym. After medical clearance by his GP and assessment by the exercise physiologist at the gym, Daniel started going twice weekly, and has kept going for years.

He walks to the station and catches the train to the next suburb on his own. He enjoys the gym so much he has recruited several friends to join the gym, and they go for a coffee and a sandwich after each session.

Comment from occupational therapist Natalie: *CST is a non-pharmacological, multisensory intervention for people with mild to moderate dementia. It's based on the idea that consistent stimulation of memory, attention, language and other cognitive skills can potentially be useful in slowing the rate of cognitive decline associated with dementia. This CST program consisted of a 14-week course, followed by a 24-week maintenance course. Additional benefits observed include reducing apathy, reawakening of former interests and skills, establishing routine and structure and providing an opportunity for socialisation. In addition, carers received support, education and respite.*

Research has shown that keeping socially connected, having a well-balanced diet and doing exercise are important. Daniel was referred to other community programs to keep up the stimulation to his mind and body.



Eating well – food and nutrition

Food is one of the pleasures of life. Yet for many people living with dementia, the pleasure of eating is undermined by changes dementia brings about. These changes can be compounded by isolation, leading to weight loss and malnutrition for many.

The physical signs of malnutrition include:

- weight loss, as shown by loose clothes, loose rings or dentures, or prominent bones
- slow chewing, dribbling and difficulty swallowing.

The psychosocial signs include:

- depression, sadness or grieving
- not having enough money to purchase food and other essential items
- embarrassment about eating difficulties or avoiding eating with others.

There are also environmental signs such as:

- empty fridge and pantry, or an overly full fridge and pantry
- leftover meals or out of date food
- poor personal hygiene
- empty alcohol containers
- the need for multiple medications. (6)

On the other hand, overnutrition and obesity is a problem for some.

The causes of both undernutrition and overnutrition are usually multifactorial and a range of strategies are needed. Allied health professionals can drive many of these strategies.



Meal environment

Many people living with dementia will eat better if they have their meals in a suitable environment, such as their own home or a pleasant homelike environment with minimal distractions from TV, radio, mobile phones and loud conversations. The physical layout of the dining space, the features of the table setting, and the presentation of the food are all important, particularly as changes occur in visual perception, cognitive processing and the skills of sequencing tasks.

Many people living with dementia will also eat better if they share their meals with others. Difficulty with the sequence of eating or drinking can be helped by taking their cue from others. Allowing plenty of time is important.

Practice points

Occupational therapists:

- provide advice on the meal environment, particularly issues such as comfortable seating, easy layout, use of colour in the table setting and food presentation, adequate lighting, modified cutlery, and making food and drink easy to find and prepare
- work with carers, so that they are aware of the importance of the meal environment and eating with others
- work with and train community service and aged care providers.

Shopping and cooking

Some people living with dementia can no longer shop and/or cook as they once did. Or there might be carers involved who are new to the idea, or the repetitiveness, of shopping and cooking.

Also, many people living with dementia find that their food preferences change. They might develop a sweet tooth or a liking for food previously disliked, or vice versa. They might find it hard to eat a large meal.

Practice points

Dietitians:

- work with the person living with dementia to discover current preferences for types of food, size of meals and more
- give tips on shopping and cooking when the capacity for independence is declining
- advise on modification of existing routines to suit the changing circumstances
- advise on the fortification of foods to increase protein and energy value
- provide culturally appropriate food ideas to people from culturally and linguistically diverse backgrounds
- train and support carers new to regular shopping and cooking
- provide written education materials
- advise how to provide smaller meals more often, including finger food
- advise how to establish or re-establish regular meal routines
- organise alternative such as online shopping or home delivery
- work with and support carers
- work with and train community service and aged care providers.

Aboriginal and Torres Strait Islander health workers:

- provide culturally appropriate information and support for healthy nutrition
- link people to other allied health workers and programs
- work with and support carers
- work with and train community service and aged care providers.

Occupational therapists:

- review the setup of the kitchen
- encourage independence by working out ways to continue to be involved in shopping and cooking tasks
- educate and support carers to provide an appropriate level of supervision or assistance, such as setting up and initiating meals
- advise on assistive technology to make finding things easier and cooking food safer
- organise alternatives such as online shopping or home delivery

Social workers:

- provide links to meal services that support or replace the need to shop and cook.

Weight management

Weight loss is very common for people living with dementia. While for some this can seem, at first, to be reasonable, it can be a sign of inadequate energy intake and undernutrition. It can be due to many different, yet often interrelated, factors.

Practice points

All allied health professionals:

- ensure people are checked for treatable medical conditions.

Dietitians:

- screen for malnutrition
- provide advice and assistance around food planning, choosing and buying dietary supplements and choosing foods with high energy and protein
- checking whether previous dietary restrictions still apply, and how to manage them if they do
- ensure nutritional and fluid intake is adequate for a person on a texture-modified diet
- work with and support carers
- work with and train community service and aged care providers.

Swallowing

Some people living with dementia develop dysphagia, which is distressing for both the person living with dementia and their carer and family.

Practice points

Speech pathologists:

- diagnose treatable conditions
- provide advice on modifying the texture and thickness of food and drink
- provide strategies for swallowing medications
- provide advice on maintaining the social aspects of mealtime
- look at routines, communication and maintaining cues in a mealtime context
- work with and train community service and aged care providers.

Oral health

Poorly fitting dentures, damaged teeth and gum disease can all contribute to poor nutrition and poor health overall.

Practice points

All health professionals:

- can observe oral issues that affect eating and advise a dental check-up.

Dental professionals:

- screen for oral health problems
- examine people with known issues
- provide strategies and helpful hints for teeth-cleaning
- assess and provide advice about a dry mouth
- work with and train community service and aged care providers.

Yang's story

Yang was hospitalised after a fall at home. Her low weight concerned the hospital staff, so after she was discharged, a dietitian did a home visit.

Yang's husband Soo has some health problems of his own, and was finding the extra care Yang needed plus the preparation of food quite overwhelming. To take some of the stress off him, Yang was spending several days a week in the homes of different relatives.

Yang and Soo were going to the club daily for fish and chips, just to get a cooked meal, and eating biscuits between meals.

Their daughter Jin helped where she could – with shopping, transport and dropping in home-made meals – but Jin also worked full time and had a family.

The dietitian made lots of suggestions, which the family took on board. These included:

- arranging more in-home care so Yang could spend more time at home, eating in an environment that was familiar and consistent
- changing the table setting – for example, removing the highly patterned place mats which were distracting Yang

- offering smaller and more nutritious meals
- adding high energy snacks between meals
- adding a high protein drink two to three times a day.

Jin says she's learned a lot. Her mother loves the high protein drink, and now has more energy and sleeps better. She's also putting on some weight.

Comment from dietitian Vicky:

The main nutrition intervention and education was provided through Yang's daughter Jin.

It involved:

- *education about the importance of nutrition in ageing, dementia, muscle strength, health and wellbeing; and about the different stages of dementia and how it affects the person's eating and behaviours*
- *discussion about culturally appropriate high protein and high energy food ideas and provision of a translated pictorial resource – the family incorporated these ideas as snacks*
- *discussion of ways of fortifying current meals*
- *discussion about appropriate table setting, regular mealtime routine and familiar eating environment*
- *the use of a high protein supplement.*

Intimacy and sexuality

People with dementia continue to need loving, safe relationships and caring touch. However they will vary in their individual ways of giving and receiving affection, and the ways in which dementia affects that capacity. As a result of the condition, some people with dementia may become demanding and insensitive to the needs of others, and less able to provide caring support for their family and friends. They may also experience changes in the expression of their sexuality. Some people continue to desire sexual contact while others may lose interest in sexual activity.

Others may display inappropriate sexual behaviours. Partners may experience a range of feelings about continuing a sexual relationship with someone who has dementia. These may include feelings of rejection, loss, distaste and guilt (5).

Practice points

Psychologists, social workers and counsellors:

- provide information and support around intimacy and sexuality.



Speech and communicating

The loss of communication that can come with dementia can be very distressing.

It affects the person living with dementia directly and has ripple effects for everybody around them. And it comes at a time when communicating is as important as it has ever been.

A comprehensive communication assessment by a speech pathologist can help with understanding a person's communicative strengths and weaknesses. This will allow the development of a care plan that includes the best strategies to enable an individual's communication. Early intervention can provide a person living with dementia, their carers and their family with strategies to continue to maximise communication.

Practice points

Speech pathologists:

- identify the retained abilities and strengths, which often include early life memories, procedural memory, social rituals, intonation and melody of speech, and the ability to read aloud, recite and sing
- create a communication-friendly environment
- create opportunities for meaningful, satisfying communications
- develop strategies to deal with communication breakdown
- guide carers in the use of memory/communication aids
- assist with individual reminiscence work, including the production of a life story, whether in print, digital or other form.

Cai's story

For Cai, dementia significantly affects her ability to speak. At times it is distressing, both to her and to her husband Huynh, who cared for Cai while she was living at home. Cai saw a speech pathologist, who used different approaches at different times to support Cai's communications. At one time, Cai was helped by a word relearning program that she used each day at home on her laptop. Cai also enjoys participating in a choir for people with communication impairment. She enjoys the social contact and loves music, so really gets involved in the singing. Now a memory book has helped Cai settle into new accommodation.

'It has a dozen pages,' says Huynh. 'On the left is a photo and on the right is some text. It is very valuable – it helps her talk about who she is, what her life was like before, and who and what is important to her.'

Comment from speech pathologist Cathy:

Behavioural interventions offer much to improve satisfaction and quality of life. As communication changes over time, so too do the needs of the individual and their family and caregivers. Comprehensive review by the speech pathologist at regular time intervals allows for monitoring symptom severity and emergence of new areas of language impairment. This monitoring of progression allows for planning appropriate interventions, education and support at the optimal time.



At home with dementia

Home environment

Recent research investigating what makes an environment 'dementia-friendly' has resulted in the articulation of principles, the development of audit tools and advances in design and technology that can enable a person living with dementia to stay at home.

When applied, these principles, design features and technologies can increase safety and reduce stress for the person living with dementia.

In practical terms, this translates to a home with:

- a layout that is easy to navigate
- lighting that is comfortable and consistent
- a low noise level
- a comfortable range of temperature
- minimal clutter
- furniture that is easy to get into and out of
- communications systems – telephones, doorbells and more – that are able to be found, heard and used easily.

The preferences of the person living with dementia and others living in the home will inform the practical application of the new knowledge.

Assistive technology is broadly defined as devices or systems that enable independence, safety and wellbeing. For people living with dementia, this refers to devices and technology that assist with memory and cognition, way finding and safe walking, leisure and socialising, and monitoring health.

Technology is developing rapidly and becoming 'smarter' and more accessible for a person living with dementia and their carer as it targets an increasing range of everyday issues. However, it has to be carefully tailored to individual experience, preferences and needs.

Practice points

Occupational therapists:

- assess the home environment and advise what minor adjustments can be made easily, such as labelling kitchen cupboards to enable items to be more easily located, and what major changes might be worth investing in
- provide advice around assistive technologies that can help with safe use of home appliances, medication management, emergency help, sleep disturbance, locating misplaced items, orientation, safe walking and way finding
- help the person living with dementia and any carers understand the cognitive components of daily tasks and activities, and how to adapt the tasks, taking into account the person's cognitive strengths and losses
- assess people's ability to manage personal care and aim to increase independence with all activities of daily living.

Kevin's story

Kevin wasn't nicknamed Mr Gadget for nothing. He could turn his hand to anything – he mastered computers, fixed washing machines, put up shelves. He also had a day job; he was a professional man running his own practice. So being diagnosed with Alzheimer's disease at the age of 66 was a big shock for Kevin and his family.

Soon after this diagnosis, an occupational therapist came to the house to work out with Kevin and his wife how they could use his strengths to aid his memory. Mr Gadget had a labelling machine – so they used this to label all the cupboards and shelves to prompt him to put things away in the correct place, and to find them again. He labelled the microwave with step by step instructions on how to cook his oats for breakfast each morning, which meant he could continue to do this for himself.

Kevin likes routine and structure; so the occupational therapist worked with Kevin and his wife Diane to introduce a weekly timetable of arrangements and activities that Kevin enjoys; it also gives Diane the time and space to continue her interests and pursuits as a mother, friend and grandmother.



The weekly timetable includes a discussion group, a men's lunch group, and going for walks, with friends and family members being included in regular weekly time slots. A big clock with the date as well as the time prompts Kevin to keep track of his timetable.

Comment from occupational therapist Natalie: *Meeting Kevin soon after his diagnosis was great as I could identify the many strengths he had and target OT strategies to build on those strengths to aid him through his memory decline. It also meant that I could begin a relationship with Kevin and his wife that would continue as the disease progressed. From time to time, as changes occurred, I was consulted to provide strategies to support Diane; for example, laying his clothes out so he does not have to choose; offering him two choices that she knows he would like when choosing from a menu at a restaurant. Besides working one to one with family, the OT role extends to the community and encourages involvement in other programs at the appropriate time; for example a referral to a carer support group for Diane as the changes of behaviour in her husband became more stressful and difficult to understand; and referring Kevin to an exercise program where he receives support to prompt his memory about the exercises, and where he has great social connections.*

Moving house

While most people want to live in their own homes for as long as possible, some will make the decision to move after they receive a diagnosis of dementia. They might move cities to be closer to family; move into town to be closer to services; move into a retirement village; or move in to live with a son or a daughter.

Moving house, going on holidays and adjusting to unfamiliar environments becomes more challenging as cognitive abilities decline. For some, the benefits of staying with the familiar outweigh the benefits of being closer to loved ones in an unfamiliar environment.

Taking a pro-active approach to moving house can minimise stress and lead to a more positive experience.

Medication management

Polypharmacy is a problem for many people, particularly people with multiple comorbidities. Medications can also contribute to falls, confusion, hypotension and delirium in people living with dementia.

Practice points

Any allied health professional working with a person living with dementia can:

- start the conversation and explore options about moving house. It may be better received if the allied health professional has a good long-term relationship with the person.

Speech pathologists:

- advise the best way to present information taking into account preserved communication skills
- assess the need for and provide augmentative strategies such as use of pictures to help the person remain included in the decision-making process.

Occupational therapists:

- assess the new environment and make recommendations based on routines and activities that are important to the person living with dementia and their family.

Counsellors, social workers and psychologists:

- can provide counselling and emotional support.

Practice points

Pharmacists provide a medication review to:

- examine all medications that a person is taking
- assess for drug-drug and drug-nutrient interactions
- assess and make suggestions to improve the likelihood of compliance
- suggest medication changes to the person's usual doctor
- suggest strategies or technologies to reduce medications mishaps by enabling a person living with dementia to take the right dose at the right time.

Occupational therapists:

- assess a person's capacity to manage medications and identify areas of difficulty
- suggest strategies or technologies to reduce medications mishaps by enabling a person living with dementia to take the right dose at the right time.

Dietitians:

- assess for drug-nutrient interactions.

Services to enable

Enabling a person living with dementia to live comfortably and safely at home may require, at some point, help in the home. People's needs differ, so ensuring that the assistance targets the needs and choices of the person living with dementia is crucial. Such assistance may be help with domestic tasks for one person; accessing the community for another; shopping assistance; or accompanying a person on a daily walk. People who live alone are likely to need assistance earlier than people who live with family.

Practice points

Many allied health professionals:

- discuss options and make referrals for services that provide domestic assistance, personal care, shopping assistance or community access.

Social workers:

- provide information about navigating the service system
- provide advice around services and financial support available.

Occupational therapists:

- can help with the practical side of financial management, such as budgeting and bill payment.

Counsellors, social workers and psychologists:

- provide emotional and psychological support as people adapt to their changed circumstances.



Driving and getting around

While many people living with dementia can continue to drive safely for a time, there will come a point when driving must cease. It is a difficult transition for many people.

Engaging a person living with dementia and their carers from the earliest opportunity in discussions about driving and what local options are available is important.

Some choose to give up their licence. Some prefer to have a full driving assessment to assist in making that decision – this can be discussed early and planned for. Others choose not to hand in their licence, but are happy to let others do all the driving.

Practice points

Social workers and any allied health professional who works with dementia:

- can start the discussion about the transition and explore other transport options such as public transport, community transport, taxi vouchers and companion cards.

Occupational therapists:

- assess a person's capacity and abilities in the many domains required for safe driving
- can provide training in community mobility skills especially if driving is no longer an option.

Neuropsychologists:

- assess cognitive changes that may impact on driving ability and make recommendation for on-road driving assessment.

Michael's story

When Michael was diagnosed with Alzheimer's disease, it was recommended that he have a specialised occupational therapy driving assessment due to slowing of his reaction time and a reduction in his decision-making judgement. Michael passed, with the recommendation to continue driving with an unrestricted licence. He would need to repeat this specialist driving assessment yearly, or sooner if his symptoms declined more rapidly.

After some time, his driving skills changed, and Michael was having problems finding his way around. Michael and his wife decided to downsize to an apartment which was on the bus route; Michael gave up his driver's license and embraced public transport. He asked to wear an ID band on his wrist, with his name, address and wife's contact details. Two years later, Michael continues to be a keen user of public transport.



Changed behaviours

Dementia affects how a person thinks, feels and communicates.

Being unable to communicate what you are thinking and how you are feeling can be frustrating and distressing.

A person may express in their behaviour what they cannot get across in other ways. These are often described as behavioural and psychological symptoms of dementia, or BPSDs. They are symptoms of disturbed perception, thought content, mood and behaviour. Alternatively, they are described as the expression of unmet needs. Both terms reflect that the behaviour is not wilful, but might be an attempt to meet a need which the person living with dementia is not able to identify or communicate.

BPSDs can include aggression, agitation, irritability, apathy, sleep problems, wandering, social and sexual disinhibition, verbal outbursts, delusions, hallucinations, anxiety and depression. They can be exacerbated by pain, unfamiliar environments, overstimulation and unhelpful responses.

These changes in behaviour can be confusing for both the person living with dementia and for the people around them.

Practice points

Neuropsychologists:

- assess what cognitive difficulties may underpin behavioural changes
- offer strategies to assist the person living with dementia and their carers how to best manage them.

Occupational therapists:

- observe a person in their usual environment to determine what may contribute to changed behaviour
- can provide an understanding of a person's functional cognition and how this impacts on ability to communicate needs
- provide a carer with coping strategies and help establish changes in routines that may improve the situation
- in consultation with a person and their carer, prescribes activities within cognitive ability to engage the person in familiar and enjoyable tasks
- adapt the environment to facilitate optimal functioning and minimise distress.

Other allied health professionals who specialise in dementia:

- may be able to offer support and suggest strategies.

Felipe's story

Felipe migrated to Australia with his wife and two children in his mid-fifties. He was a very active man who had played soccer professionally. After settling in Australia, Felipe worked two full-time jobs – one by day, and one at night – to support his family. After retiring, Felipe remained very active, taking up kayaking in his late seventies, paddling for hours most days. When health problems prevented Felipe keeping up with his exercise and fitness, he became depressed. He then developed dementia.

The combination of depression and dementia hit Felipe very hard; he became forgetful, got angry easily, started getting up many times through the night and became very agitated when his beloved wife went to hospital.

Felipe received multidisciplinary intervention from a dementia service when things at home became too difficult for him and his family. Under the care of a team of medical and allied health professionals, Felipe improved.

He saw the clinical neuropsychologist for assessment of his cognition and mood, as well as for regular counselling to talk through his feelings about the changes that were taking place. An interpreter who Felipe had known for some time relayed his 'poetic and philosophical nature' that was not observable by others, as he had lost the ability to express freely in English. Physiotherapy developed a tailored program to build his strength and fitness. An occupational therapist supported his engagement with valued and meaningful activities. A social worker assisted the family in their decision to accept an aged care facility placement for Felipe, and provided the practical support to make this happen. Felipe started exercising again and also started watching replays of European football, which he enjoyed. His family was given support and education about communicating with Felipe in different ways. With all these strategies and some medication changes, Felipe's depression improved, and he became somewhat fitter and happier again.



Carers

In the world of dementia, the term carer is very broad. It includes wives and husbands, partners, sons and daughters, in-laws, nieces and nephews, friends and neighbours.

Some people who fit this broad definition prefer not to think of themselves as a carer, and a person living with dementia won't always want to think of themselves as having a carer.

But for the purpose of this guide, the term carer will be used to refer to people who provide unpaid support to the person with dementia.

The caring role can be both positive and negative for the carer. It can bring people together, and bring a sense of joy and fulfilment. It can also lead to strain, stress and depression (7).

Research has shown that carers often want:

- to be recognised as partners in care – to be included, to be listened to, and to have their expertise and personal knowledge of the person living with dementia taken into account
- information – about the nature and progression of dementia, the likely impacts on the person they care for, the impact on them and other carers, and strategies to assist and manage changes (see 'Adjusting to the diagnosis and changing cognition', p13)
- emotional and psychological support – in their role as carer, particularly with the feelings of loss, grief and loss of personal identity
- help with navigating the system
- time for themselves, respite, a break.

Recognition as partners in care

Providing recognition, respect and support to carers is now enshrined in federal (8) and some states' legislation and is integral to the role of all allied health professionals working with people living with dementia.

Practice points

Allied health professionals are well placed to:

- include carers as partners in health care.

Emotional and psychological support

Allied health professionals can provide emotional and psychological support just through talking and listening. Having their experiences of caring – the positives and negatives, the losses and the grief – heard and validated can bring a sense of relief to carers.

Carer support groups provide a place to talk, listen and learn from others in a similar situation. Carers report that attending support groups has positive effects for their health and wellbeing (9). This is largely due to the practice of 'mutual aid' and shared problem-solving resulting in feeling heard, normalising feelings and reducing isolation.

Some support groups for carers of a person living with dementia are facilitated by allied health professionals with skills in group work. Some groups invite guest speakers to provide information about various topics suggested by the members of the group.

Practice points

Counsellors, psychologists and social workers:

- can listen in a non-judgemental and supportive way, and help carers identify and understand their thoughts, feelings and behaviours, and develop strategies to assist.

Occupational therapists, psychologists and neuropsychologists:

- can provide explanations about the abilities and strengths of a person living with dementia, and where cognitive impairment can impact on everyday function. This understanding can support carers to provide specific care, while encouraging independence where possible.

Dementia advisors, key workers, psychologists and social workers:

- facilitate carer support groups.

Eleanor's story

Eleanor has been caring for her mother since her mum fell and fractured her skull, which caused a delirium and revealed she had an underlying dementia. Eleanor initially lived nearby, visiting often, then moved in with her mum. She is determined to maintain her own life as much as possible, with teaching commitments and time away from home. But there are a lot of restrictions, and she finds it very challenging. She finds the carers' support group she attends invaluable, despite being initially sceptical. Part of its value lies in talking to people in similar circumstances and being able to vent feelings without judgement. But it's also seeing that others, too, need time out and need support.

On top of that, there are the skills and insights gained from the allied health professional who leads discussions, and from some of the techniques taught at the group, such as meditation.

Comment from dementia advisor and psychologist Anne:

From the beginning, Eleanor felt she needed to maintain her own life to be able to provide the care she does, and that she needed a break from time to time. Going to the support group has normalised those feelings for her and given her some specific skills she found useful, such as mindfulness. The support group meets each month in a public library, and there's a set theme with either a talk from a guest speaker, or some discussion led by me. It's been going a long time now, and is well attended.

Navigating the system

Whether seeking services for the person living with dementia or themselves, carers often need a helping hand in navigating the national, state and local service systems.

Practice points

Social workers, dementia advisors, key workers and others who specialise in working with people living with dementia:

- provide help with navigating the system
- provide information about costs and fees for services
- provide advice on the range of government payments and concessions available.

Time out for carers

Taking time for themselves can be challenging for carers. Carers may benefit from:

- counselling to help them to identify that they need some time out
- a support group to feel OK about taking it
- help in navigating the system to find the right service to provide the respite to make it happen.

Practice points

Social workers, dementia advisors, key workers and others who specialise in working with people living with dementia:

- provide information about and referral to respite services.

Norma's story

Norma cares for her husband Todd. While she finds it manageable, she needs a break. She's been using two different services, depending on her needs. She can get up to three hours respite at home when a carer comes to visit, or she can get a full day by taking Todd to a respite service for a full day, or even overnight. While she's been using respite intermittently, the respite service has recommended that she take Todd there each Friday to give herself a scheduled break.

'It is what it is,' she says. 'There's no point wishing it was any other way. But I couldn't do it without the respite.'

Comment from dementia advisor and psychologist Anne: *Norma has been attending a carers' support group for some time, and it's probably played a part in Norma getting the respite she needs. I believe the support group has given Norma confidence as a carer. It's given her specific knowledge, sometimes from the guest speakers we have, and sometimes drawing on my experience and the experience of others in the group. But it's also allowed her to see that others need a break and support as well, and it's normalised the experience for her.*

Nutrition for carers

Maintaining a balanced and nutritious diet can be a strain for carers. The nature of their role puts them at risk of having poor eating habits and nutrition themselves.

This is particularly so for some carers who may not have prepared food all that often in their lives. Or for those who are frail, or have health or mobility problems, or who are exhausted and feel overwhelmed by the added tasks of providing nutritious food.

Practice points

All allied health professionals:

- have a role to play in the identification of carer stress and any associated issues of nutrition.

Dietitians, occupational therapists and dental professionals:

- have a direct role in offering support to carers
- identify problems early to maximise help and minimise distress
- provide information and training to assist them in their caring role.



Planning ahead

Many people find it difficult to plan for the future. For people living with dementia, it is probably more important, and it can be difficult.

There are many things to consider, including who will make financial, legal and care decisions in the future. Also, a person's capacity to make decisions varies over time, and varies between situations. This needs to be taken into account at all times and in all decisions.

It is important that the person living with dementia, like any adult, has a will. It is also important that a person with capacity appoint decision makers for the future and make an advance care plan. Although the laws and terminology differ between states, mechanisms are available in each state.

Allied health professionals also have an advocacy role for vulnerable people; these may include people living alone, those with no-one they would like to nominate to be involved, and those who have not made plans and may require guardianship.

Practice points

Social workers (and other allied health professionals who specialise in working with people living with dementia):

- encourage open discussion about the future
- point towards professional advice about planning ahead.

Occupational therapists:

- may be involved in doing functional assessments for guardianship applications.

Transition to residential aged care facility



Transition to residential aged care facility

In the later stages of dementia most people will require total care.

Whether this care is provided at home or in a residential care facility will depend on the person, the carer, the family and their situation.

For people who live alone, the move to residential care may come sooner than for those who live with family. The timing may also be influenced by the presence of comorbidities. For many people, the move is rushed as it follows a crisis at home or an admission to hospital. This can increase the stress and distress for all involved.

Moving into residential care is a time of upheaval for the person living with dementia, their carers and family. Adjustment to residential care is more than a discrete event (10). It begins with thinking about and planning the move, and continues with the actual move into care and beyond as people settle in and adjust to change.

People going through this major transition do better when given holistic support.

Health professionals working in aged care assessment teams, community services, aged care facilities, hospitals and health care can provide information, explore options, assist with practical tasks and provide emotional support.

Practice points

Dementia advisors and social workers:

- start discussions with a person living with dementia and their carers and families about plans for the future
- provide information about the processes, such as forms, finances and assessments, involved in a move to residential aged care
- link people to local services, such as Centrelink and aged care facilities
- link people to emotional support.

Occupational therapists:

- can advise on what is needed to enable the person to be maintained at home, including equipment and services to assist
- provide support and guidance for the carer in the safe, functional use of equipment and devices.

Counsellors, psychologists and social workers:

- provide support and counselling to enable carers to talk through their many feelings, including loss and grief.



Palliative care and end of life

The choice to care for a person living with dementia at home is a very personal decision – both for the person living with dementia and those who care for them.

Carers and family who choose to care for their loved one at home will require support from medical, nursing and allied health staff and community services to provide palliative care and end of life care.

The palliative approach is recommended for a person in the later and end stages of dementia (1:p90) as is, where indicated and available, the involvement of palliative care professionals. Some people living with dementia will have, or will develop, comorbidities that add to the complexity of care at home.

As cognitive impairment may impact on the person's ability to consent or adhere to treatment, the person's advance care directive, if it exists, should guide the treatment and care provided (1:p90).

Health care professionals can collaborate with the person who has dementia and their families to develop an end of life plan, and to put it into practice when the time comes. However planning for end of life may be made difficult due to the unpredictable nature of the disease.

Rapid physical changes at the end of life require sound guidance from medical practitioners to assist with pharmacological changes; from nursing to assist with continence and skin care; and from a range of allied health professionals to provide guidance and practical advice.

Practice points

Occupational therapists:

- provide information to the person living with dementia and carers to enable them to make an informed decision about the choice to care for their loved one at home
- assess the needs of the person living with dementia and their carers
- prescribe a range of equipment, arrange brokerage and train the carers to use it.

Physiotherapists:

- help the person living with dementia to maintain mobility (standing and walking as able) and range of movement
- optimise respiratory function
- help prevent skin breakdown with advice regarding appropriate positioning
- suggest equipment to help with transfers and mobility
- advise and train carers to provide physical assistance in a way that is safe for both themselves and the person living with dementia.

Dietitians:

- provide expertise about food and nutrition and where to access supplements
- provide education, support and reassurance when the time comes to cease nutrition and hydration.

Practice points

Speech pathologists:

- assess and provide education and options around any deterioration in eating, drinking and swallowing, such as comfort feeding and the use of safe swallowing strategies
- help the carers understand changes in communication and implement strategies to support the person's needs to be understood as much as possible.

Social workers:

- provide emotional support and guidance
- liaise between services and health professionals.

Resources

Knowledge about dementia is expanding as the voices of people with dementia, research and clinical experience all contribute to building the knowledge base. This list of resources points health professionals to key documents and websites that have national relevance and are publicly available.

Academic literature is referenced in many of the key documents. Books are available at the Alzheimer's Australia libraries in each state and territory.

Alzheimer's Australia

For information and advice: National Dementia Helpline on 1800 100 500.

The website contains help sheets and publications that cover issues discussed in this booklet.

<https://fightdementia.org.au/>

Library and Information Service.

To keep up to date with new resources and research, sign up to the library's blog. <http://alzheimersnswlibrary.blogspot.com.au/>

Clinical guidelines

Clinical practice guidelines and principles of care for people with dementia. 2016. Guideline Adaptation Committee. NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. <http://sydney.edu.au/medicine/cdpc/documents/resources/dementia-guidelines-full-document-website.pdf>

Keeping a sense of self and adjusting to change

Community café toolkit: Your manual and tools for establishing a café for people living with dementia. 2016. Alzheimer's Australia. <https://fightdementia.org.au/community-caf%3%a9-toolkit>

Connections matter: Helping older people stay socially active. 2014. beyondblue. <http://resources.beyondblue.org.au/prism/file?token=BL/1366>

Family and friends matter: how to stay connected to a person living with dementia. 2013. Alzheimer's Australia. <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Family-and-friends-matter.pdf>

Living alone with dementia. Discussion paper 7, June 2013 Alzheimer's Australia NSW. <https://nsw.fightdementia.org.au/files/20130619-NSW-PUB-LivingAlone.pdf>

Nurturing the heart: creativity, art therapy and dementia, by Patricia Baines. 2007. Alzheimer's Australia. https://fightdementia.org.au/sites/default/files/20070900_Nat_QDC_QDC3NurturingHeart.pdf

Relate, motivate, appreciate, by Cameron J Camp. 2013. Alzheimer's Australia Vic. Includes a video and Montessori resource. <http://qualitydementiacare.org.au/dementia-care-projects/relate-motivate-appreciate/>

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Education and training for health professionals

Centre for Dementia Learning, Alzheimer's Australia, provides a comprehensive suite of education and consultancy services nationally. www.dementialearning.com.au

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Acknowledgements

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For information and advice contact the
National Dementia Helpline on:

1800 100 500

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