



DEMENTIA AND STROKE OR CORONARY HEART DISEASE

A toolkit for community care workers

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**

Acknowledgements

This booklet is part of the Dementia and Stroke or Coronary Heart Disease Toolkit. This Toolkit sits within the Dementia and Chronic Conditions Series. The Toolkit has been designed primarily for community care workers. The information and recommendations it contains are based on independent research, expert opinion and scientific evidence available at the time of writing. The information was acquired and developed from a variety of sources, including but not limited to collaborations with the Heart Foundation and National Stroke Foundation.

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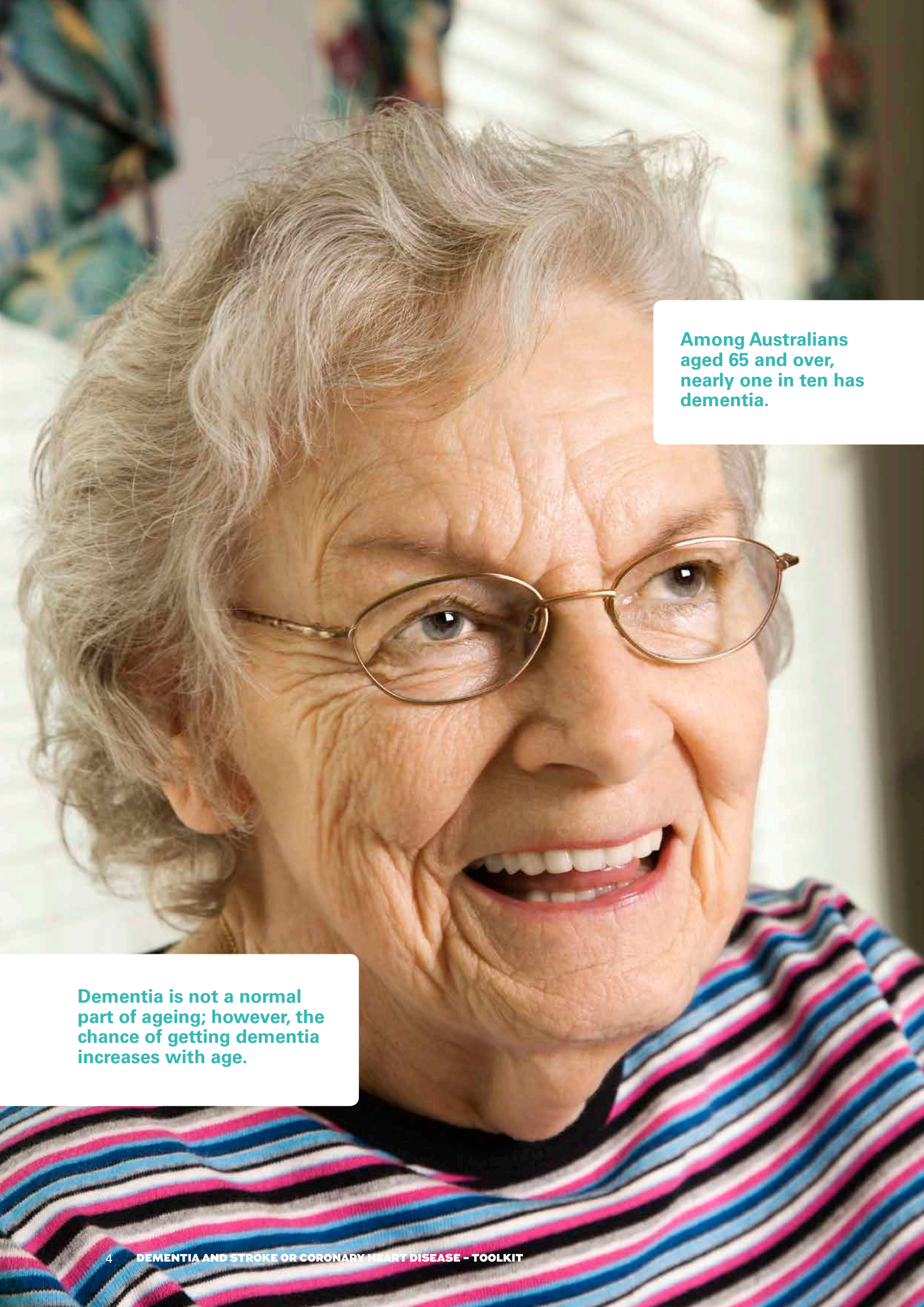
Introduction

Dementia, stroke and coronary heart disease don't always happen with ageing. However, they become more common as people get older.

This kit is for workers in community care settings who support people with dementia and stroke or coronary heart disease. Although this kit is mainly about community care, it can be used in other areas. The kit is made up of the following:

1. This booklet, which explains:
 - the three conditions
 - the link between dementia, stroke and coronary heart disease
 - how dementia can affect a person with stroke or heart disease
 - how stroke or heart disease can affect a person with dementia
 - helpful tips
 - community services and programs
 - who to contact for more information and support.
2. An information booklet for people with dementia, their family and friends.
3. Five Fact Sheets that support the information in this booklet.
4. A DVD including the above information which can also be viewed on YouTube.

All parts of this kit are available at: fightdementia.org.au/dcc



Among Australians
aged 65 and over,
nearly one in ten has
dementia.

Dementia is not a normal
part of ageing; however, the
chance of getting dementia
increases with age.

What is dementia?

Dementia is a term that describes a group of symptoms caused by diseases affecting the brain. There are many different causes of dementia. The most common causes are Alzheimer's disease, vascular dementia, Lewy body disease and frontotemporal dementia (see definitions below). Changes to blood vessels that supply blood to the brain can contribute to getting dementia.

Dementia affects thinking, behaviour and the ability to do everyday activities. The main effect of dementia is on thinking, memory, attention, language, planning, judgement or spatial skills that affect daily life. Because of these changes, dementia can also affect a person's family, social and working life.

Dementia is often talked about in three stages.

Mild or early-stage	Moderate or middle-stage	Severe or late-stage
Problems happen in a number of areas (such as memory and personal care), but the person can still do things with some support.	Problems become more obvious and more support is needed for the person to stay living at home.	Problems become more severe. The person relies on care and support from others.

For more information see the Alzheimer's Australia Victoria website at vic.fightdementia.org.au

Definitions

Alzheimer's disease is a disorder that attacks the brain's cells resulting in loss of memory, thinking and language skills, and behavioural changes.

Vascular dementia is the broad term for dementia linked with blood vessel disease of the brain.

Lewy body disease is caused by death of cells in the brain. The name comes from the presence of abnormal structures, called Lewy bodies, which develop inside nerve cells.

Frontotemporal dementia is the name given to dementia when there is degeneration in one or both of the frontal or temporal lobes of the brain.

What is a stroke?

A stroke occurs when the blood flow to the brain is interrupted or cut off. This can happen because a blood vessel gets blocked by a clot or a blood vessel bursts.

Brain cells can quickly die if they don't get the blood supply that they need. For some types of stroke, getting the right treatment straight away might keep some of these brain cells alive.

Call 000 for urgent treatment if anyone is showing signs of a stroke, no matter how long the signs last.

The most common signs of a stroke are:

*How do you know if someone's having a **stroke**? Think...*

F.A.S.T.

Think F.A.S.T. Act FAST!

CALL 000

 <p>FACE Check their FACE. Has their mouth drooped?</p>	 <p>ARMS Can they lift both ARMS?</p>
 <p>SPEECH Is their SPEECH slurred? Do they understand you?</p>	 <p>TIME TIME is critical. If you see any of these signs, call 000 now!</p>

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The F.A.S.T. test is an easy way to remember the most common signs of stroke. Other signs of stroke may include one, or a combination of: loss of vision, sudden blurring or decreased vision, headache and difficulty swallowing.

It is not known how stroke causes dementia. A series of strokes and changes to the small vessels in the brain can lead to memory and thinking problems. This may be the start of vascular dementia or Alzheimer's disease.

To learn more about stroke, and the other possible signs of a stroke, see the National Stroke Foundation website at strokefoundation.com.au or call StrokeLine on 1800 787 653.

What is coronary heart disease?

Coronary heart disease affects the blood vessels that take blood to the heart muscle. Coronary heart disease is also called ischaemic heart disease (IHD) and coronary artery disease (CAD).

The cause of coronary heart disease is a slow build-up of fatty deposits on the inner wall of the blood vessels that take blood to the heart (the coronary arteries). These fatty deposits slowly clog the

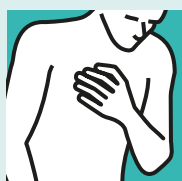
arteries and reduce the flow of blood to the heart. If the blood flow is not restored quickly, ideally within 90 minutes of the first symptom, heart muscle cells may start to die. Coronary heart disease starts when people are young and builds up by middle age.

In many cases, the first sign of coronary heart disease may be a heart attack.

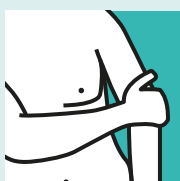
Call 000 for urgent treatment if you or someone else experiences warning signs of a heart attack.

Warning signs

A heart attack can show as discomfort in these parts of the upper body:



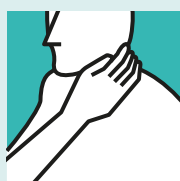
Chest



Arm(s)



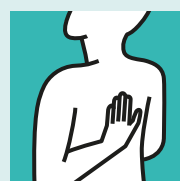
Shoulder(s)



Neck



Jaw



Back

There may be a choking feeling in the throat.

The arms may feel heavy or useless.

Another sign of coronary heart disease is angina. Angina is pain that starts when there is not enough blood or oxygen going to the heart muscle. Sometimes angina pain fades away with rest or by using angina medicine. This does not result in heart damage.

Coronary heart disease can lead to an irregular heartbeat called atrial fibrillation (AF). AF can cause

blood clots in the heart. These clots can break away and move to the brain. AF can lead to stroke or dementia.

Blood thinning medicines (for example, warfarin) can help stop blood clots forming.

To learn more about coronary heart disease and how to recognise the signs of a heart attack, see the Heart Foundation website at heartfoundation.org.au



What is the link between dementia, stroke and coronary heart disease?

There is no single cause of dementia, stroke or coronary heart disease. These three conditions are linked by factors that cause damage to blood vessels (vascular risk factors) which lead to blood vessel disease.

High blood pressure (especially in middle life) is the most harmful. This is treatable but also something that can be changed.

Other risk factors that can be influenced include:

- diabetes
- smoking
- high cholesterol
- being overweight or obese
- unhealthy teeth and gums
- depression
- too much alcohol
- poor diet and lack of exercise
- social isolation.

What can be done to lower the chances of getting dementia, stroke or coronary heart disease? The first step is to start by managing these risk factors. This may be through use of medicines, but it can also be done by living a more healthy lifestyle: keeping active, being social and eating well.

Many things can harm blood vessels, and blood vessel disease can lead to dementia, stroke and coronary heart disease.

If someone has had a heart attack or stroke, their chance of having a second one is much higher.



How can dementia affect a person with stroke or coronary heart disease?

	Fact	What can you do?
Pain	<p>Dementia does not usually cause pain; however people with some types of dementia may feel more pain.</p> <p>People with dementia may not be able to talk about their pain clearly.</p>	<ul style="list-style-type: none"> • If you think someone with dementia is in pain and is having trouble telling you about it: <ul style="list-style-type: none"> – look for non-verbal signs of pain – speak to the carer if they are with you and tell your supervisor. • For more tips on what non-verbal signs to look out for, see Fact Sheet 2. • Write in the case notes any changes you observe.
Depression and anxiety	<p>People with dementia can lose confidence and self-esteem as they start having to rely more on others. This can lead to depression.</p> <p>When dementia, depression and anxiety happen together, it can affect someone's interest in exercise and make social isolation worse. This can increase their chance of a heart attack or stroke.</p> <p>Some people with dementia may become worried and anxious because they notice negative feelings and situations around them.</p>	<ul style="list-style-type: none"> • Speak to the carer if they are with you and tell your supervisor if: <ul style="list-style-type: none"> – you are worried about changes in mood and behaviour in someone with dementia – the person has lost interest in exercise and outings. • Write in the case notes any changes you observe. • Always be patient and speak with a calm voice and in short sentences. • For more tips on communicating and connecting with a person with dementia, see Fact Sheet 3.
Physical activity	<p>Walking is good exercise for people with dementia, heart disease and stroke, but having dementia can mean they might get lost.</p> <p>Doing some gardening or simply walking in/ around the house can also be good exercise. These activities can help reduce anxiety for people with dementia without the chance of getting lost.</p>	<ul style="list-style-type: none"> • Check the care plan to see if the person with dementia can leave the house on their own. • Make sure the person wears appropriate clothing and footwear during exercise.
Medicines	<p>Dementia can make it hard for people to manage their medicines even if they have been doing it for years.</p> <p>Some medicines for dementia can make the person feel dizzy and unsteady. This can lead to falls and injury.</p>	<ul style="list-style-type: none"> • Speak to the carer if they are with you and your supervisor about any concerns you have, especially if you: <ul style="list-style-type: none"> – think someone with dementia is not taking their medicine – see they are unsteady on their feet • Write in the case notes any changes you observe.

How can coronary heart disease or stroke affect a person with dementia?

	Fact	What can you do?
Pain	<p>Angina can cause pain that people with dementia may have trouble telling you about.</p> <p>After a stroke, people may feel shoulder pain, pain from stiffness or pain from tightness. In both dementia and stroke, a person with dementia may not be able to tell you when they feel pain.</p>	<ul style="list-style-type: none"> • Speak to the carer if they are with you and check the support plan. • Tell your supervisor if you think that a person with dementia is in pain but is not able to talk about it. • Look for non-verbal signs of pain. For more tips about what to look out for, see Fact Sheet 2. • Write in the case notes any changes you observe.
Depression and anxiety	<p>Depression and anxiety often happen together after a stroke or heart attack.</p> <p>Depression and anxiety are different to dementia, and need to be treated. If they are not treated, it can take longer to recover from a stroke or heart attack.</p>	<ul style="list-style-type: none"> • Speak to the carer if they are there with you and tell your supervisor if: <ul style="list-style-type: none"> – you are worried about changes in mood and behaviour in someone with dementia – the person has lost interest in exercise and outings. • Write in the case notes any changes you observe.
Physical activity	<p>A person affected by coronary heart disease can experience angina if they walk too fast, too far or exercise too hard.</p> <p>A person affected by stroke may not be able to walk without a walking aid (e.g. a walking frame or a walking stick). Weakness in their arms and legs can affect their ability to exercise on their own.</p>	<ul style="list-style-type: none"> • If a person has angina, get them to rest often during any exercise. Tell your supervisor about this and write in the case notes what you observe. • Check the support plan to see if: <ul style="list-style-type: none"> – the person with dementia needs a walking aid – they need help to move around.
Medicines	<p>Most people with heart disease or stroke take medicine to lower blood pressure. If the blood pressure falls too low, a person can feel dizzy or light-headed. This is not normal and can increase their chance of falling.</p> <p>People with coronary heart disease and/or stroke may take blood thinning medicines. This type of medicine means the person will bleed or bruise more if they are hurt.</p>	<ul style="list-style-type: none"> • Speak to the carer if they are with you and tell your supervisor if someone is unsteady on their feet. • If someone is taking blood thinning medicine, take extra care when helping with tasks like shaving. • Write in the case notes any changes you observe.

Other points to think about

Home Medicines Review

People with dementia who live at home and take a mix of different medicines every day may find a Home Medicines Review (HMR) useful. An HMR can help them to cope better with all of their medicines. They will need a referral from their doctor to have an HMR done by their pharmacist. The doctor will speak with the pharmacist about the results once it is done.

- If someone needs tips about taking medicines you can give them a copy of Fact Sheet 1 'Tips for taking Medicines'.

Changes in mood and behaviours

Changes in the mood and behaviours of a person with dementia are very common. This may place great stress on families and carers.

- For more information about behaviour changes in someone with dementia see the Alzheimer's Australia Vic Help Sheet titled 'Changed Behaviours' at fightdementia.org.au under the section on **Changed Behaviours and Dementia**.
- For more information about mood and behaviour changes after stroke, see the National Stroke Foundation Fact Sheet at strokefoundation.com.au/site/media/FS11_Emotional_web.pdf

Communication and connection

Communication is not just about words. A lot is said through body language. This means the expressions on your face, how you stand and move your body and what you do with your hands. Your tone of voice (how high or low, loud or soft) can also have a big effect.

A person with dementia may become less able to communicate as their condition gets worse. If they are unsure about the meaning of words that are being said, they will pay more attention to body language and tone of voice. They can easily pick up on negative body language such as sighs and raised eyebrows, and this can make them anxious and bring about changes in mood and behaviour.

- For tips on communication from people with dementia, see the Alzheimer's Australia brochure 'Talk to me' under **Publications** at fightdementia.org.au/research-and-publications/publications
- For more tips as language and communication change, see Fact Sheet 3.

Diabetes

People with diabetes have a higher chance of getting dementia, stroke and coronary heart disease than people who don't have diabetes.

- For information on how diabetes is linked to dementia, see the Dementia and Diabetes Toolkit on fightdementia.org.au/dcc

Eating and swallowing

After a stroke and in the later stages of dementia someone may not eat well because of:

- loss of appetite
- forgetting to eat
- problems with swallowing (called dysphagia)
- problems using a knife and fork.

Swallowing problems due to dementia or stroke can make it hard to take medicines. If tablets are hard to swallow, some medicines come in other forms.

- For more information about supporting someone to eat well, see Fact Sheet 4.

Support for carers

The physical and emotional demands of caring for someone with dementia can be high. More time and energy will be put into giving support as the condition gets worse. Carers need to look after themselves too.

- Carers Victoria has free counselling for partners, family members and friends who care for a person with dementia. Carers can get useful factsheets at carersvictoria.org.au/advice/look-after-yourself/factsheets
- Alzheimer's Australia has Help Sheets available at fightdementia.org.au/about-dementia-and-memory-loss/help-sheets
Go to the section titled **Looking after families and carers** for the following information:
 - Help Sheet 01: Taking a break
 - Help Sheet 02: Taking care of yourself
 - Help Sheet 03: Feelings
- Commonwealth Respite and Carelink Centres (open 24 hours) provide free and confidential information on local carer support, disability and community services. They also offer counselling support across Victoria. For details, see page 20.

Case Study 1: Mrs P.



Mrs P, who is 84 years old, lives in Melbourne with her daughter, Sandra. Three years ago, Mrs P had angina and was diagnosed with coronary heart disease. She now has stable angina and uses a Nitrolingual spray as needed.

There are 'spares' of the sprays in different places so she can have them at short notice. She keeps them in her purse, on the kitchen counter and on her bedside cabinet.

Having dementia means the changes in her brain make it hard for Mrs P to say what she means clearly. Mrs P has trouble telling her daughter when she has pain.

Sandra has learned that she needs to look out for changes to how her mother acts and other non-verbal signs to see if she has pain.

Scenario:

Imagine you have been looking after Mrs P for a few months. You know that she can get angina when she walks more than a hundred metres. You are aware that earlier this morning, she went to the hairdresser with her daughter.

Sandra has just gone to the shops for about half an hour. You have finished helping Mrs P with her lunch. Some afternoons, she likes to walk out to the letter box to see if the post has come. You walk out and back together. A few minutes after this short walk, you see that Mrs P's face looks like she is in pain even though she can't tell you this.



Q1. What do you think might be some of the signs that Mrs P is in pain?



Q2. What should you do to help Mrs P?



Q3. Who should you tell about this?

Answers

Q1.

Some signs to look out for are:

- a pained look on her face
- irritability
- unusual anger and aggression
- not wanting to move.

For more non-verbal signs to look out for, see Fact Sheet 2.

Q2.

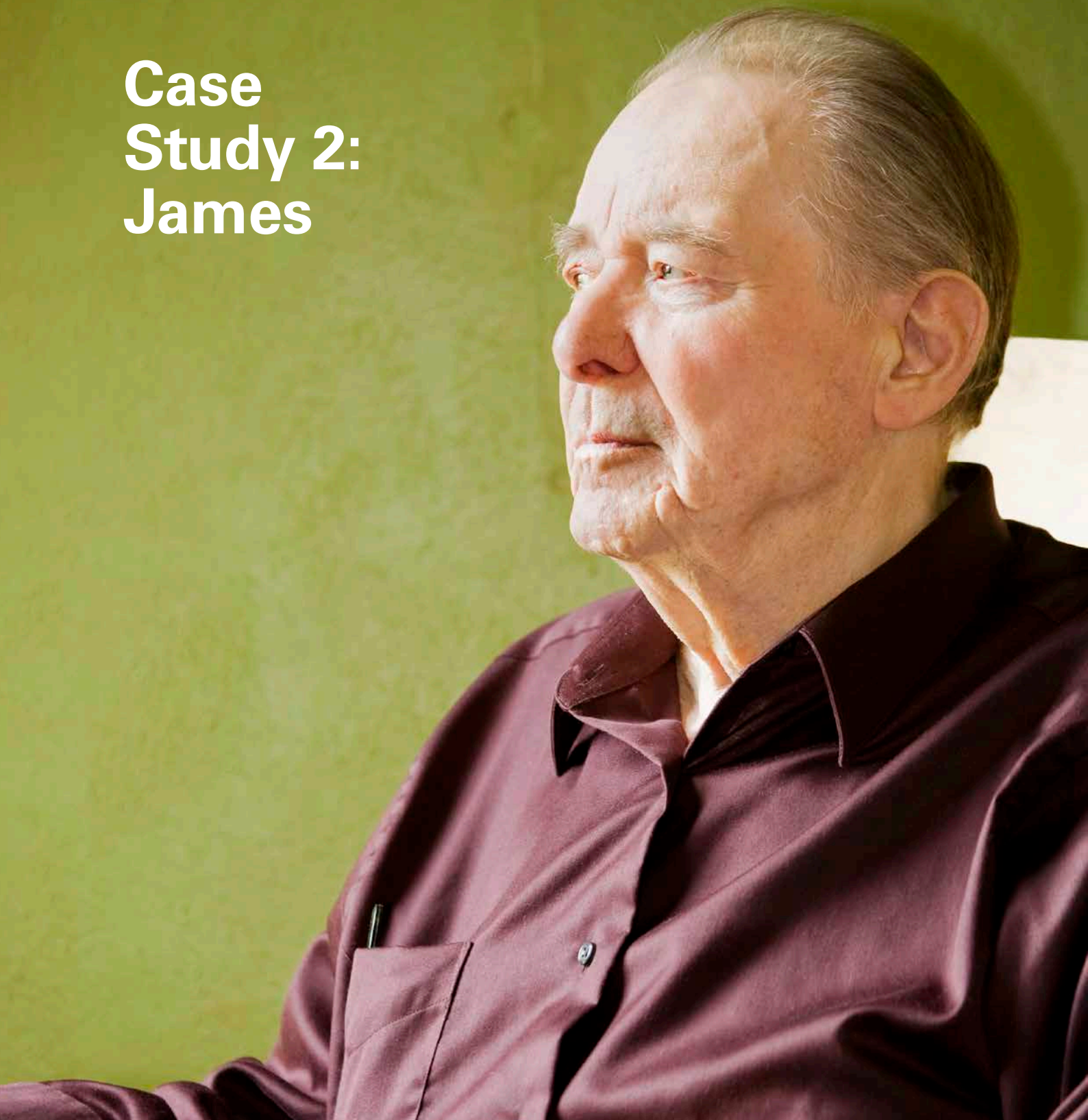
- Prompt about using her spray.
- Prompt about sitting and resting.
- Monitor the situation frequently to make sure it's not getting worse.

Q3.

- Call the office staff or your supervisor as soon as you are able. The staff or your supervisor will contact the carer or next of kin if they think it is needed.
- Write in the case notes any changes you observe.

Know your agency's policies and follow them.

Case Study 2: James



James is 70 years old. Five years ago, he had a stroke which affected his memory, speech and balance. Two years ago, his memory problems worsened and he was recently diagnosed with vascular dementia.

Before the stroke, James liked hiking, but since the stroke, he can't walk very far unaided without losing his balance.

James lives with his son and has a good relationship with his neighbour, Lim. They used to go hiking together. Lim visits a few times a week. Once a week James and Lim have lunch at the pub across the street.

Scenario:

You have been helping James shower and dress twice a week for the past few months. Usually, he is easygoing and ready to start the day when you get there. Last month he had two falls while trying to get to the toilet by himself in the night. He got a few large bruises but no other physical injuries.

Over the past week, you've seen that:

1. James is less keen to get out of bed in the mornings.
2. It takes him longer to walk to the shower.

3. He grumbles more often when you try and get him dressed.
 4. He complains that Lim never visits him anymore, but you know they had lunch together last week.
- Today, when you arrive to get him out of bed, he says he wants to stay in bed and tells you to leave him alone. To encourage him, you remind him that today, Lim is joining him at the pub for lunch. He yells that Lim never visits him and that they are in fact no longer friends. He accuses you of not knowing anything.



Q1. What might be happening with James that has led to his change in mood and behaviour today?



Q2. What should you do?



Q3. Who should you tell about this?

Answers

Q1.

Note: See tables on pages 10 and 11 of this booklet, especially the points about depression and anxiety.

- James' recent falls may be a large part of the reason he doesn't want to get out of bed today.
- He may be frustrated that he needs to rely on others more since his falls, even for getting out of bed.
- He may be losing confidence in his ability to get around the house. This may be affecting his self-esteem.
- Consider that his low mood may be depression.

Q2.

Don't take his response personally.

- Ask questions to try and find out why he is feeling this way.
- Be empathetic, validate his experience.
- Be flexible, make time to talk and listen.
- Don't force him to get out of bed.

Q3.

- Report this incident to the office or your supervisor.
- Write in the case notes the changes you have seen today.

Know your agency's policies and follow them.

Community services and programs

Many organisations have services to help someone to stay living at home.



Health services

The doctor is a key health professional. Others are medical specialists, physiotherapists, occupational therapists, social workers, psychologists, community nurses and care workers.

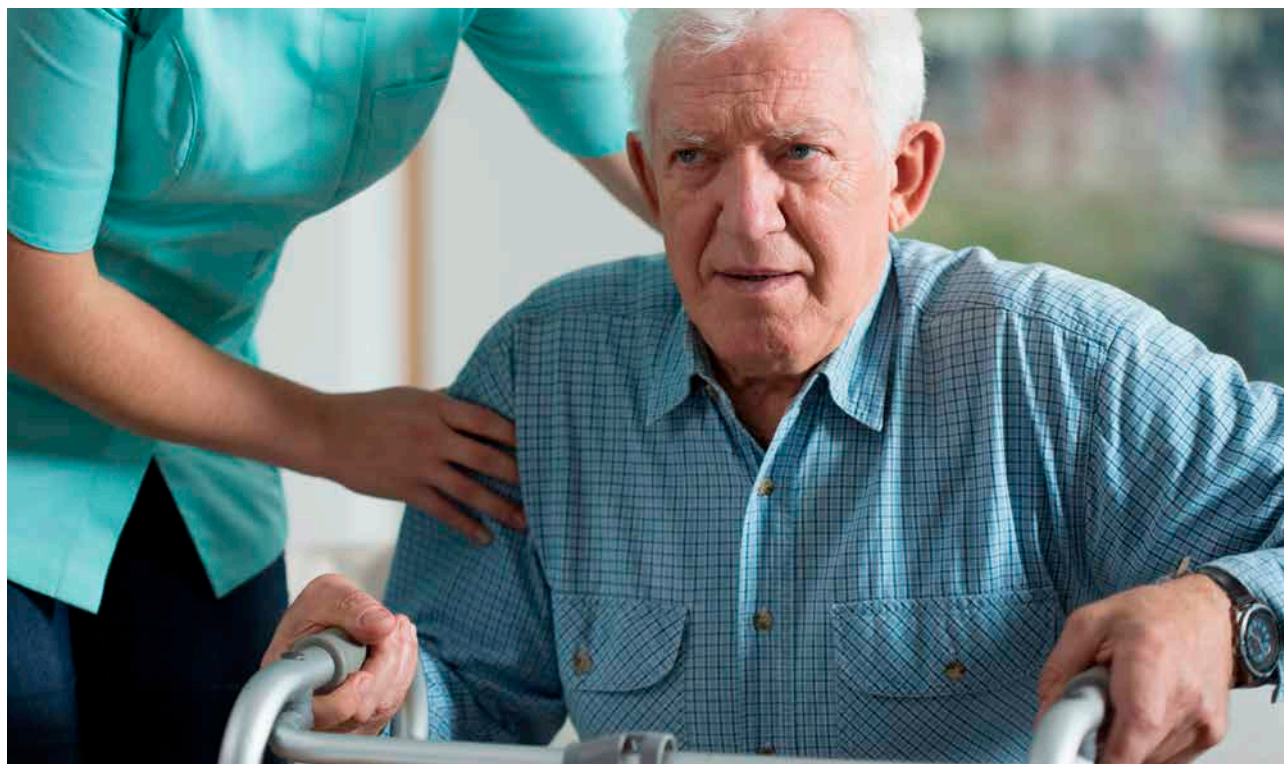
People with dementia need to be able to talk comfortably with health care workers. To help them with this, Fact Sheet 5 has questions they may wish to ask their doctor or other health care workers. Having many people involved in support can make it hard for people with dementia to remember what has been said. You can ask them or their carer to make notes of the talks they have with their health care workers.

Carers' support services such as Commonwealth Respite and Carelink Centres (24 hours, state-wide), Carers Victoria and Alzheimer's Australia Vic offer counselling support for people with dementia and their carers. For details, see page 20.

Home support services – The Home and Community Care (HACC) program

HACC is funded by the Commonwealth and Victorian Governments. It has basic support services for older people and people with disabilities who find it hard to do day-to-day things but who want to stay living at home.

The program also supports families and friends by providing respite for the carer from their usual care role. Planned Activity Groups (PAGs) provide a range of enjoyable and meaningful activities. For contact details, see page 20.



Rehabilitation programs

Rehabilitation programs after a stroke or heart attack can help people return to full, active and happy lives.

Older people with dementia should not be excluded from rehabilitation¹. Rehabilitation can improve the quality of life for people with dementia and their family or carers.

Cardiac rehabilitation

Cardiac rehabilitation can help people with coronary heart disease or other heart problems to live more healthy lives. It can also lower the chance of having more heart problems.

Referral to a cardiac rehabilitation program is made by a physiotherapist or doctor. People with dementia and their family or friends can get advice from a health worker by calling the Heart Foundation's Health Information Service on **1300 36 27 87** (local call cost).

Stroke rehabilitation

Stroke rehabilitation can improve life after stroke by helping people cope with the effects of stroke and to live a healthier life.

Referral to a stroke rehabilitation program is usually made by a doctor. People with dementia and their family or friends can get advice from a health worker by calling the National Stroke Foundation's StrokeLine on **1800 787 653** (free).

A post-stroke checklist developed by the National Stroke Foundation and the World Stroke Organization can help people talk with their health care workers about some common problems they might have after a stroke. You can see this checklist at strokefoundation.com.au/site/media/Interactive_PostStrokeCHECKLIST_2013.pdf

¹ Australian Physiotherapy Association Position Statement: Supporting Older Australians. 2012, accessed on 22 April 2015. <physiotherapy.asn.au/DocumentsFolder/APAWCM/Advocacy/PositionStatement_2017_SupportingOlderAustralians.pdf>

Contacts

Carers' support

Commonwealth Respite and Carelink Centre

1800 052 222

<http://www9.health.gov.au/ccsd>

Information about respite services in your local area during business hours or **1800 059 059** for emergency respite support outside standard business hours.

Carers' Victoria

1800 242 636

carersvic.org.au

Training to help community care staff work together with partners, families and friends of people whom they are supporting.

Community services

My Aged Care website

1800 200 422

myagedcare.gov.au/about-us

Help to find out about the aged care system. There is also a national contact centre.

The Aged Care Assessment Service (ACAS)

myagedcare.gov.au/service-finders

Go to the 'Assessments' tab on this webpage.

Teams that help people and their carers work out what kind of care will best meet their needs. They do assessments for people needing community services or aged care residential services.

People with dementia can refer themselves for assessment. Their family members can also put in referrals to this service.

Home and Community Care (HACC) Assessment Services

myagedcare.gov.au/service-finders

A basic home help program funded by the Australian Government to help people to stay living at home.

Continence Foundation of Australia

1800 33 00 66

continence.org.au

Help for people with continence problems and their family and carers.

Royal District Nursing Service (RDNS)

1300 334 455

rdns.com.au

Offers home nursing care services.

Dementia

Alzheimer's Australia Vic

vic.fightdementia.org.au

Support, information, education and counselling for people with cognitive concerns and their families and friends.

National Dementia Helpline

1800 100 500

Information and support for people with dementia, their carers, families and friends, as well as anyone concerned about memory loss.

Cognitive, Dementia and Memory Service (CDAMS)

health.vic.gov.au/subacute/cdams.htm

A Victorian diagnostic clinic that supports people with memory loss or changes to their thinking as well as their carers.

Dementia Behaviour Management Advisory Service (DBMAS)

1800 699 799

dbmas.org.au

Support for carers of people with dementia who experience behaviours that may affect care.

Stroke or coronary heart disease

Heart Foundation

heartfoundation.org.au

Support for a healthy heart and access to quality services for people with risk factors for heart disease, or who have had a cardiac event.

Heartmoves for Falls Prevention

heartmoves.org.au/about-heartmovesforfallsprevention

An exercise program with strength and balance exercises.

National Stroke Foundation

strokefoundation.com.au

A national not-for-profit organisation that works with stroke survivors, carers, health professionals, government and the public to reduce the impact of stroke on the Australian community.

StrokeLine

1800 STROKE (787 653)

Free information and advice from a health professional.



National Dementia Helpline 1800 100 500
fightdementia.org.au

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