

DEMENTIA AND STROKE OR CORONARY HEART DISEASE

Information for people with dementia, their families and friends

UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA

Acknowledgements

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Introduction

This booklet is for people living with dementia and stroke or coronary heart disease. The booklet can also be helpful for your family and friends.

Dementia, stroke and coronary heart disease are not a normal part of ageing. They are more common as people get older.

There is a link between dementia, stroke and coronary heart disease.

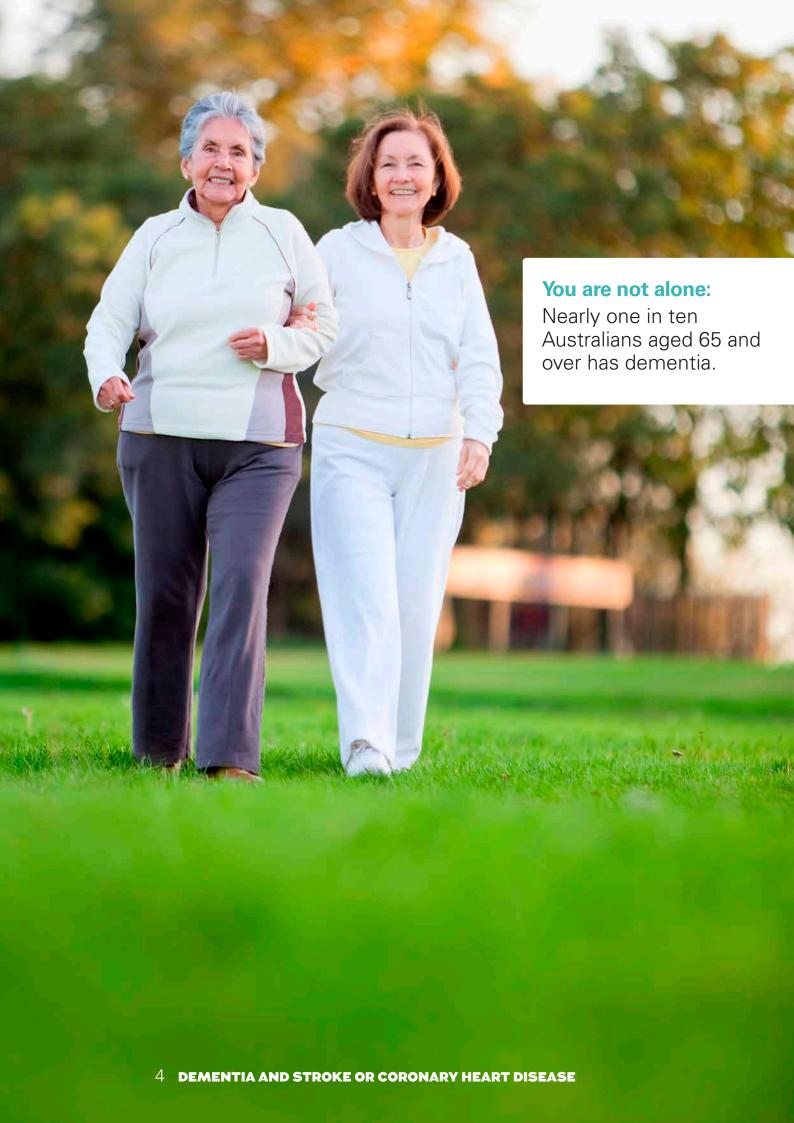
Read on to learn more about:

- the three conditions
- how the conditions are linked
- making the most of living with them
- other people's experiences
- getting help in the community
- who to contact for more information and support.

This booklet is part of a kit that is available at:

fightdementia.org.au/dcc

You can also access this information by watching the YouTube video available at this site or on the DVD included in the toolkit.



What is dementia?

Dementia is a term that describes a group of symptoms caused by diseases affecting the brain. The most common causes of dementia are Alzheimer's disease, vascular dementia, Lewy body disease and frontotemporal dementia. There are many other causes.

Dementia can have a big impact on your family life, social life and working life because over time, it can affect:

- memory
- mood and behaviour
- judgement and ability to plan
- concentration and motivation
- communication, and
- ability to do everyday things.

Remember: dementia is not a normal part of ageing...

however, the chance of getting dementia increases with age.

Dementia is often talked about in three stages.

Mild or early-stage	Moderate or middle-stage	Severe or late-stage
You may notice changes with your memory or with some everyday things but you can still do most things with a bit of support.	Your difficulties are becoming more obvious and you may need more support to stay living at home.	You will need care and support from others.

To read more about dementia, see the Alzheimer's Australia Vic website at vic.fightdementia.org.au

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.

Call 000 immediately if you or someone else has signs of a stroke, no matter how long the signs last.

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.

The most common signs of a stroke are:



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The F.A.S.T. test is an easy way to remember the most common signs of stroke but they are not the only signs. To learn more about stroke and the 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?

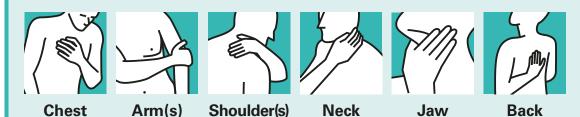
Coronary heart disease affects the blood vessels that take blood to the heart muscle.

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

Warning signs

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



You may have a choking feeling in your throat. Your arms may feel heavy or useless or you may have chest pain or tightness.

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.

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

What is the link between dementia and stroke or 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 is also something that you can change.

Other risk factors you can influence 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.

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

What can be done to lower your 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.

Making the most of life with dementia and stroke or coronary heart disease

There are five main ways to make the most of your life with dementia and stroke or coronary heart disease.



Keeping active



Eating well



Managing your medicines



Dealing with pain



Recognising depression and anxiety



Keeping active is important for everybody. Physical activity is good for you, and it doesn't have to be hard.

You can still exercise even if you have a weakness, are restricted or have limited movement.

'Doing any physical activity is better than doing none.1' If you currently do no physical activity, start by doing something simple. For example, you can try activities such as:

- walking around your neighbourhood
- doing some gardening
- getting outdoors
- visiting a neighbour for a chat
- dancing by yourself or with others.

Move more – sit less.

It is even better if you choose something you enjoy that can increase your heart rate a little, make you feel warm and gets you a bit out of breath. Slowly build it up over time.

Ask your doctor or physiotherapist about what type of activity program is best for you.

Be active on most, preferably all days.²

Break up long periods of sitting as often as you can.

¹ Australia's Physical Activity and Sedentary Behaviour Guidelines 2014. The Department of Health, accessed on 22 April 2015 <health.gov.au/ internet/main/publishing.nsf/content/healthpubhlth-strateg-phys-act-guidelines>

² Brown WJ, Moorhead GE and Marshall AL, 2008. Choose Health: Be active: A physical activity guide for older Australians. The Department of Health, accessed on 22 April 2015 <health.gov.au/ internet/main/publishing.nsf/Content/phd-physical-choose-health>



Healthy eating and drinking are important for looking after yourself.

This means eating different foods including vegetables, fruit, fish, grains, nuts, beans, lentils and lean meat.

Even if you don't feel hungry, eating regularly will give you energy to do everyday things.

Drinking water is also important. The body needs water so the blood can carry nutrients to where they are needed. One of the first signs of dehydration is feeling thirsty. Other common signs of dehydration are headaches, confusion and irritability, and lack of concentration. Drink water regularly especially in warmer weather or if you are exercising.

You can have a small glass of fruit or vegetable juice occasionally but it should not replace water. Try adding sparkling or still water to increase the amount of water you drink. Avoid sports drinks, cordial and soft drinks because they have a lot of sugar.

If you are having trouble eating or swallowing, or you don't feel hungry, consult your doctor, who can help you to find out why.





Mabel and Chris

Mabel had a stroke which caused problems with her memory, speech and balance. She couldn't exercise like she used to. A few years after the stroke, her memory problems got worse and she was diagnosed with vascular dementia. She lives with her partner Chris, who works part-time.

Mabel's memory problem has affected her eating habits. Sometimes, she forgets she has eaten and looks for more food. Mabel particularly enjoys bananas, sweets and chocolates. Not exercising and eating too much has led to Mabel putting on weight which upsets her.

Together, Mabel and Chris have worked out some ideas to make sure she eats well at home:

- In the morning before going to work, Chris leaves a plate of toast (which does not need refrigerating) on the kitchen table with a reminder note.
- As snacks, he leaves a couple of bananas on the kitchen counter every day. Twice a week he leaves a chocolate bar.
- For lunch, he leaves a sandwich in the fridge with a reminder. note. He gives her a reminder phone call at lunchtime.

One day a week, a carer comes to help with showering and dressing and takes Mabel out to lunch. On the other days, she eats lunch when she attends respite.

Mabel wants to do more exercise so they are thinking about:

- taking walks around their neighbourhood daily
- exercising regularly at the respite service.

Managing your medicines

Always take your prescribed medicines. If you are living at home and take a mix of different medicines every day, your pharmacist can do a Home Medicines Review (HMR) to help you manage these. You can also ask your pharmacist to pack the medicines for you; for example, in a Webster pack. You will need a referral from your doctor to have an HMR, so discuss this with them.

Fact Sheet 1 has more useful tips on ways to remember to take your medicines.

Taking many different medicines can cause problems including:

Dizziness

Most people with heart disease or stroke take medicine to lower their blood pressure. If your blood pressure falls too low, you may feel dizzy or light-headed. This is not normal and can increase your chance of falling. Other medicines for dementia can also make you feel dizzy and unsteady. Tell your doctor about any falls and if you are worried about your balance.

Dry mouth

Medicines for dementia can cause a dry mouth, making food taste unpleasant and harder to swallow, and you may not want to eat as much. Having a dry mouth is often painful and uncomfortable. Speak to your doctor who can help you deal with this.

Blood thinning effects

People with coronary heart disease or stroke often take blood thinning medicines. This type of medicine means that people may bleed or bruise easily. Take extra care with things like shaving or preparing food (e.g. peeling, chopping or cutting foods).



If you have coronary heart disease, you may get angina. This can feel like pressure, squeezing, burning or tightness in your chest. For some people, it can feel like indigestion.

Get to know yourself:

- Don't push yourself too hard when doing physical activities.
- Know how much exercise you can do without getting angina.
- Always stop exercising before you have chest pain or discomfort (if possible).

After having a stroke, you may feel shoulder pain, pain from stiff muscles or joints, or pain from tight muscles.

You can:

- put your affected arm on an armrest or pillow to reduce shoulder pain
- keep your muscles moving by exercising
- get your physiotherapist to show you some stretching exercises.

When you have dementia it may be hard to explain to someone that you are in pain.

Your carers may find it helpful to know what signs to look out for. See Fact Sheet 2 for some examples.







Sally and Laura

Laura has Alzheimer's disease and lives with her daughter, Sally. Recently, Laura had angina and was diagnosed with coronary heart disease. She takes several medicines for dementia. Now, she also takes blood pressure and blood thinning tablets daily and uses Nitrolingual spray for her angina.

Some days Laura doesn't remember that she has heart disease. Sally often needs to remind her mum to take her medicine. To help Laura remember to take her tablets, they use a Medicine Planner (for an example, see Fact Sheet 1). This sheet sits on the wall above her medicine box. Laura can see it every time she opens the box to take her tablets.

See Fact Sheet 1 'Tips for managing medicines', which has other ideas for remembering to take medicines.



Laura enjoys going for walks but sometimes, if she walks too far or too fast, she gets angina. She doesn't always remember to carry her Nitrolingual spray. Lately, Sally also goes with her mum on the walks so they can spend more time together. She always makes sure her mum has her Nitrolingual spray in her pocket. If Laura starts to feel out of breath, she finds it helpful to stop and rest by sitting or leaning on her walking frame. At other times, she leans against a tree or a neighbour's fence.

If someone with heart disease has trouble walking and talking, it can be a sign that they are exercising too hard.

Dementia can make it hard for someone to tell others they are in pain. To find out more about signs that suggest someone might be in pain, see Fact Sheet 2.



Depression and anxiety often happen together and have been linked with heart disease, stroke and dementia.

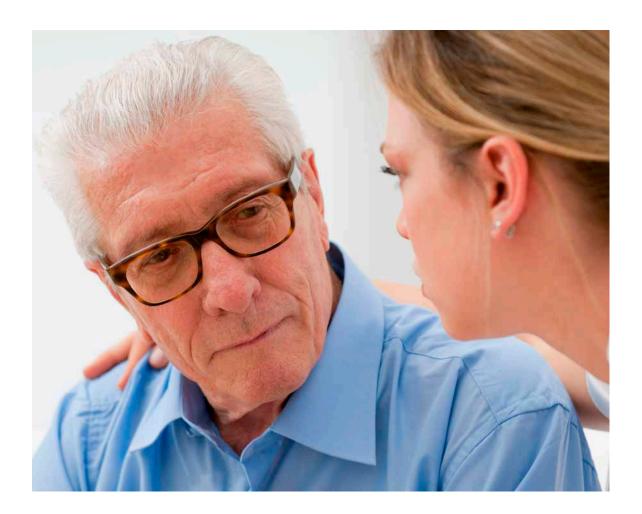
Depression is more than a low mood or feeling sad, and it needs treatment. People with depression often feel sad, down or miserable most of the time. They find it hard to be interested in normal day-to-day activities. They may reduce conversations and interactions with friends and family, and isolate themselves at home.

Depression not only affects the brain and behaviour – it affects the entire body. Tiredness, headaches and muscle pains are common symptoms. Other physical symptoms are sleep problems or a loss or change of appetite.

Anxiety is more than just feeling stressed or worried. For some people these feelings seem to just happen or continue after a stressful time has passed. Anxiety may show as anger or unusual irritability.

When dementia, depression and anxiety happen together, it can make it hard for a person to cope with daily life.





It can be hard to tell the difference between dementia, depression and anxiety if they occur together.

Dealing with more than one health problem at a time can be hard, so you may need support. Speak to your doctor or other health professional if you are concerned.

See Fact Sheet 5 for examples of questions you may want to ask your health worker.

Depression and anxiety are different from dementia, and need to be treated. If they are not treated, it can take longer to recover from a stroke or heart attack.

Support in the community

Family and friends

Getting support from family and friends can help you to keep doing the things you enjoy or need to do each day. Let people know how they can help. Your family and friends might also need support to care for you.

They can contact carers support services such as the Commonwealth Respite and Carelink Centre, Carers Victoria and Alzheimer's Australia Vic. All these organisations offer counselling services. See pages 23 to 25 for details.

Services

Different services and programs can help you to stay living at home.

Your doctor is your main contact. Others can help too: medical specialists, physiotherapists, occupational therapists, social workers, community nurses, psychologists and care workers. It can be hard to remember what people say. So, it can be helpful to write your own notes or ask your health workers to write down what they say. Having someone with you at appointments can also be useful so they can help write notes or explain anything that you are not clear about.

The Home and Community Care program (HACC) is a Commonwealth and Victorian Government program. It has basic support services for people who find it hard to do everyday things but who want to stay living at home. The program supports families and friends too. See page 24 for HACC contact information.

Rehabilitation programs

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

People with dementia can help set their own goals for rehabilitation. Rehabilitation can make day-to-day living better for people with dementia and their family or partner carers.

Older people with dementia should not be excluded from rehabilitation³ based on age or diagnoses.

Cardiac rehabilitation

Cardiac rehabilitation can help people with coronary heart disease or other heart problems to live healthier lives. It can lower the chance of further heart problems.

Referral to a cardiac rehabilitation program is made by a physiotherapist or doctor. You 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 help people who have had a stroke by supporting them to cope with the effects of stroke and live a more healthy life.

Referral to a stroke rehabilitation program is often made by a doctor. You 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. The checklist is at strokefoundation.com.au/site/media/Interactive PostStrokeCHECKLIST_2013.pdf

³ 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.

Carer's 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

Information 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

1300 33 00 66

continence.org.au

Support for people with continence problems and their families and carers.

Royal District Nursing Service (RDNS)

1300 33 44 55

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

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

Advice and guidance 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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