DEMENTIA AND DIABETES

Information for people living with dementia and diabetes, their families and friends

UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA
Acknowledgements

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People with diabetes have an increased risk of developing dementia. Dementia affects thinking, behaviour and the ability to perform everyday tasks. It can make managing diabetes more difficult. This information booklet explains the link between diabetes and dementia, how to reduce the risk of dementia and how to manage diabetes when living with dementia. We encourage you to share it with your partner, family and friends, and keep it for future reference.

Key Messages

- Dementia is a condition that affects brain functions including thinking, emotions and behaviour. Dementia can reduce quality of life and life expectancy. Early symptoms of dementia can include memory loss, confusion and difficulty in performing everyday tasks such as managing your diabetes.

- People with diabetes have an increased risk of developing dementia; however, most people with diabetes will not develop dementia. The risk of developing dementia in the general population is around 10%; for people with diabetes this risk increases to around 20%.

- Keeping blood glucose levels within your target range, and maintaining a healthy weight and blood pressure can reduce your risk of developing dementia. Other healthy lifestyle choices such as not smoking and staying physically and mentally active also reduce your risk of dementia.

- Dementia is difficult to diagnose, especially in the early stages. Discuss any concerns about your memory or thinking abilities or difficulties managing your diabetes with your doctor. Early detection is important. Family and friends may be able to help you to notice changes.

- Managing diabetes involves a number of daily tasks; this can be challenging, especially for people who have dementia. In the early stages of dementia, people with diabetes may still be able to manage many of their self-care tasks by following simple, regular routines and using written reminders and other strategies. As the dementia progresses, you will need more support from others.

- If you are diagnosed with dementia, your medicines and blood glucose levels should be reviewed by your doctor. A simplified medicine routine and different blood glucose targets may be appropriate.

- Hypoglycaemia (blood glucose below 4 mmol/L), often called a ‘hypo’, has been linked to a higher risk of dementia. If you have a risk of hypos, let people around you know the signs and symptoms you get when you have a hypo and what they can do to help you if this happens.
What is diabetes?

Diabetes is a condition in which there is too much glucose (a type of sugar) in your blood. Blood glucose levels are controlled by insulin, a hormone made by your pancreas. In people with diabetes, the pancreas may not make enough insulin, or the insulin may not work properly (insulin resistance). This causes your blood glucose levels to rise above the normal range, which can lead to health problems, such as eye and kidney disease.

Around 280 Australians are diagnosed with diabetes every day; about 20% (or 1 in 5) of older people have diabetes. Type 2 diabetes is the most common form of diabetes. Other types of diabetes are type 1 diabetes and gestational diabetes (diabetes diagnosed in pregnancy).

Diabetes can be managed with healthy eating, exercise and medicines (which may include insulin).

What is dementia?

Dementia describes a collection of symptoms that are caused by diseases affecting the brain. Dementia is not one specific disease; there are many different types of dementia. The most common types are Alzheimer’s disease, vascular dementia, Lewy body disease and frontotemporal dementia.

Dementia affects thinking, behaviour and the ability to perform everyday tasks. The hallmark of dementia is cognitive impairment (a decline in the thinking functions of the brain such as memory, attention, language, planning, judgement or spatial skills) that is significant enough to interfere with a person's daily activities.

The risk of developing dementia increases with age; however, dementia is not a normal part of ageing. Among Australians aged 65 and over, almost 1 in 10 have dementia. Among those aged 85 and over, the number is 3 in 10.

The course of dementia is often described as occurring in three stages:

- Mild or early-stage dementia – Problems occur in a number of areas (such as memory and personal care), but the person can still function with minimal help.
- Moderate or middle-stage dementia – Problems become more obvious, and increasing levels of help are required to allow the person to function in their home and community.
- Severe or late-stage dementia – Problems become more severe. The person relies on care and support from others.
What is mild cognitive impairment (MCI)?

Mild cognitive impairment (MCI) is generally defined as cognitive (thinking) impairment that is less severe than that seen in dementia. MCI does not significantly interfere with daily life, but people with MCI have more cognitive problems than would be expected in someone of a similar age. MCI is often caused by the same diseases that cause dementia. Diseases that cause MCI and dementia build up in the brain over many years and cause a gradual decline in cognitive function. Someone diagnosed with MCI may eventually develop dementia. However, MCI can have other causes and does not always lead to dementia.

What is the link between dementia and diabetes?

Most people with diabetes do not develop dementia, but they do have an increased risk. Population studies suggest people with type 2 diabetes, on average, have double the risk of developing dementia compared with people who do not have diabetes. For people who do not have diabetes, the chance of developing dementia is about 10%, for people with type 2 diabetes the risk is about 20%. The reason for this is not completely understood; it is likely to involve many different factors, including the following:

- High blood glucose levels (hyperglycaemia) can damage the body cells and blood vessels including the cells and blood vessels in the brain.
- When brain blood vessels are damaged, brain cells may not get enough oxygen and nutrients to function properly and may die. This is called 'cerebrovascular disease' and it can contribute to MCI and dementia.
- Insulin resistance causes the body to make high levels of insulin. High levels of insulin can cause damage to blood vessels and cells in the brain.
- Diabetes may contribute to the build-up of proteins in the brain associated with Alzheimer's disease.

The research that links diabetes and dementia often does not distinguish between diabetes types and it is not clear if the increased risk of dementia is the same for people with type 1 diabetes. However, since anyone can develop dementia, the information in this toolkit about early symptoms and reducing the risk of dementia may also be helpful to people with type 1 diabetes.
What are the signs and symptoms of dementia?

The early signs and symptoms of dementia (or MCI) are usually subtle and may not be obvious to you and the people in your life. Signs and symptoms depend on the cause or type of dementia. In most cases, symptoms develop slowly and get worse over time. Common signs and symptoms of dementia include:

- forgetting recent events or conversations
- forgetting appointments or things to do
- confusing times or places
- losing things frequently (e.g. wallet or keys)
- becoming lost when out walking or driving
- difficulties with language or communication
- difficulty managing money
- personality changes
- not caring about things that used to be important to you
- stopping doing activities you used to enjoy
- reduced ability in doing well-known tasks (e.g. cooking)
- changes to physical abilities and slowing in movement.

Having these symptoms does not necessarily mean you have dementia. These symptoms may have other causes and many of these causes are treatable. Having your blood glucose levels frequently above target range, depression and poor sleep quality can cause some of these symptoms.

Signs of thinking problems in people who have diabetes include:

- unexplained weight loss
- not completing your usual diabetes self-care tasks or making mistakes in these tasks
- worsening of usual blood glucose levels and frequent hypos.

If you notice any symptoms or signs of dementia or MCI, speak to your doctor as soon as possible. Early detection and treatment of dementia is important, so don’t wait for problems to become severe.

How is dementia diagnosed?

The general practitioner (GP) is usually the first contact when concerns about thinking or memory arise. The GP will ask you questions about your medical history and may carry out a brief test of memory and concentration. If your GP is concerned about the possibility of dementia, you will be referred to a specialist. This may be a geriatrician, a neurologist or an old age psychiatrist, or a specialist memory clinic.

Specialists have a more detailed knowledge of the memory and behaviour changes associated with dementia. They may perform or arrange in-depth assessments, brain scans and blood tests.

If you have an appointment to speak to a doctor about having signs and symptoms of dementia, consider:

- taking a family member or friend for support to the appointment, they may be able to provide the doctor with additional information
- writing down any concerns and questions you have beforehand and taking these to the appointment
- taking a notepad to the appointment to write down any important information provided by the doctor.

A diagnosis means you get the right medical care and accurate information; you will also have access to appropriate advice and support. Early diagnosis gives you more time to plan for future care and living arrangements and to deal with legal and financial matters. A diagnosis helps you to understand the signs and symptoms you have been having.

Discuss any problems you are having with your diabetes management with the doctor. The doctor can give you information on what additional support is available.
How is dementia treated?

At present there are no medicines or treatments that can cure dementia. There are some medicines that can slow down the rate of decline in abilities. In Australia, a specialist must confirm the diagnosis of dementia for you to be eligible for some subsidised dementia medicines.

Dementia often causes a number of behavioural and psychological symptoms which can be upsetting. These may include depression, apathy, anxiety, sleeplessness, hallucinations, ideas of persecution, misidentification of relatives or places, agitation and aggressive behaviour. These symptoms might be improved by reassurance, a change in the environment or removal of the source of any distress, such as pain. Sometimes other medicines may be needed to manage these symptoms.

What can I do to reduce the risk of dementia?

You can take steps to reduce your risk of diabetes complications; this may also reduce the risk of dementia:

- Follow your doctor’s recommendations about the best plan for monitoring and managing your blood glucose level, blood pressure and cholesterol level.
- Take all your prescribed medicines on time.
- Eat nutritious foods, including fruits, vegetables, whole grains, lean meats or low-fat alternatives, and low-fat milk and cheese or alternatives.
- Eat at regular intervals during the day.
- If you are overweight, eat a nutritious diet and exercise to lose weight.
- Keep physically active; try to exercise at least 30 minutes most days of the week, and reduce sitting time.

A help sheet with tips about protecting brain health for people with diabetes is available from Alzheimer’s Australia Vic.
How might dementia affect diabetes management?

People who have diabetes and dementia (or MCI) generally have more difficulties with diabetes tasks. They are less likely to access specialist diabetes clinics and are more likely to be admitted to hospital.

The symptoms of dementia get more severe over time. In the early stages of dementia you may still be able to manage many of your diabetes care tasks independently, but might sometimes have difficulty remembering if you have taken your medicine or when you last ate. Over time, tasks such as measuring blood glucose levels, injecting insulin or taking medicines, preparing meals, eating regularly and staying physically active can be more difficult.

The risk of hypoglycaemia

Some people with diabetes are at risk of hypoglycaemia – commonly known as a hypo. A hypo occurs when the blood glucose level falls below 4 mmol/L. Hypos have been linked to a higher risk of dementia. This is another reason why it is important to avoid hypos, and to keep your blood glucose levels within the target range. People who take insulin are at the greatest risk of hypos; however hypos can also occur in people who take other medicines for their diabetes (sulfonylureas).

If you think you are having a hypo (or someone you know is having a hypo), if possible, confirm with a blood glucose meter that your blood glucose level is below 4 mmol/L. If a blood glucose meter is not available, and you think you are having a hypo, it is safest to treat yourself as if you are having a hypo.

If you are at risk of hypos, carry your blood glucose meter and hypo treatments with you at all times. Tell people you regularly spend time with about your usual signs and symptoms and what they can do to help you when this happens.

If you regularly check your blood glucose levels, completing a blood glucose diary will help you to spot patterns and make sense of the numbers you are getting. You can also share this information with people who are supporting you so they can help you in managing your blood glucose levels. A simple blood glucose diary is available from Alzheimer’s Australia Vic.
Living with diabetes and dementia

Talk to your doctor or diabetes care team
Your medicines and target blood glucose levels should be reviewed with your doctor. A more simple medicine routine and different blood glucose targets may be needed.

Speak to your doctor or pharmacist for tips on how to manage your medicines. Alzheimer’s Australia Vic also has tips for managing medicines, and a medicine planner for people with diabetes and dementia.

Involves other people
Tell people you spend time with about the signs and symptoms you have when your blood glucose is too low or too high and what they can do to help you when this happens.

Community care and district nursing services can support you with diabetes care tasks. Other services offer support such as respite for carers, day care programs, and other practical support for people with diabetic complications. Speak to your doctor if you or someone you know needs support.

You may want to think about joining a dementia or diabetes support group. Talking with other people who have problems like your own can be helpful. Family members may also want to join a support group. Ask your doctor about support groups for people with dementia or diabetes and their families and friends.

Eat well and regularly
Try to eat small meals regularly. Eat a variety of foods including fruit and vegetables, and drink water and other drinks that do not contain sugar. If shopping or cooking is becoming difficult, meal delivery services can provide healthy meals. Speak to your doctor about these services. A registered dietician or diabetes educator can help with meal planning.

Keep track of your weight and report any significant changes to a doctor, as this might indicate a need for more support.

Plan ahead and be prepared
If you are at risk of hypos, always keep your blood glucose testing supplies and treatment for low blood sugar with you. Always wear or carry identification that says you have diabetes.

Illness or infections can cause your blood sugar to rise, so it’s important to plan for these situations. Talk to your doctor about creating a sick-day plan. Questions to ask include the following:

- How often should I monitor my blood sugar during an illness?
- Does my insulin injection or medicine dose change when I’m sick?
- What if I’m unable to eat or drink?
- When do I seek medical help?

Keep moving
Staying active can be difficult but is important for people with diabetes and people with dementia. Remember you may need to adjust your medicine if you change your physical activity. Talk to your doctor about a safe exercise plan. They may check your heart and your feet to be sure you have no special problems. If you have high blood pressure or eye or foot problems, you may need to avoid some kinds of exercise. See a podiatrist and wear comfortable, well-fitted shoes to protect your feet.
Use routine and reminders

Work out a set daily routine. Write things down in your diary or on a whiteboard and keep lists. Fill a weekly pillbox (dosette box) or use a Webster pack. Labels and signs on shelves, cupboards and doors can help in locating items around the house.

If several people are involved in your daily care at different times of the day, keep a communication book to allow everyone to keep track of meals, activity and medication.

Understand dementia and diabetes

People with diabetes and dementia, their families and carers can benefit from understanding these conditions. If you take medicine for your diabetes or dementia, ask your doctor to explain how these work.

Alzheimer’s Australia Vic provides information, support, counselling, training and education to people with dementia, their families and carers. Your doctor and local diabetes organisations can also refer you to other organisations that can offer you support.

Further information and services

Diabetes

Diabetes Australia – Vic
www.diabetesvic.org.au
1300 136 588
(8.30am to 4.30pm Mon to Fri)
The national body for people affected by all types of diabetes and those at risk.

Baker IDI
www.bakeridi.edu.au
A heart and diabetes institute located in Melbourne. They offer education programs for people with diabetes and health professional training.

MCI and dementia

Alzheimer’s Australia
www.fightdementia.org.au
Offers support, information, education and counselling to all people with cognitive concerns, their families and friends.

The National Dementia Helpline
1800 100 500
(business hours)
A telephone information and support service available across Australia. It is available for people with dementia, their carers, families and friends, as well as for people concerned about memory loss.

Cognitive, Dementia and Memory Service (CDAMS)
A specialist diagnostic clinic that aims to assist people with memory loss, or changes to their thinking, and those who support them.

Dementia Behaviour Management Advisory Service (DBMAS)
1800 699 799
(24 hours)
Support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (BPSD) that are having an impact on their care.

Help for managing diabetes care at home

Royal District Nursing Service (RDNS)
www.rdns.com.au
