

# Managing diabetes in a person with dementia



Diabetes is a condition that causes a person's blood sugars to be too high. It occurs when the body does not produce enough – or any – of the hormone insulin, which controls how the body converts glucose (sugar) from food and drink to energy.

If a person has dementia and diabetes, they may need additional support with managing their diabetes to avoid complications.

#### **Types of diabetes**

The two most common forms of diabetes are:

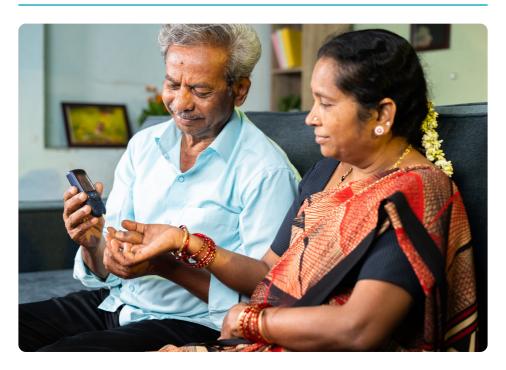
**Type 1 diabetes:** a lifelong condition where the body's immune system attacks and destroys the cells that produce insulin. Everyone with type 1 diabetes needs to take insulin.

**Type 2 diabetes:** this is where the body does not produce enough insulin, or the body's cells do not react to insulin properly. Some people can manage type 2 diabetes through lifestyle – for example through diet, exercise and maintaining a healthy weight – but medication may be necessary.

You may hear the term type 3 diabetes used in connection with dementia. This is based on the theory that in Alzheimer's disease, nerve cells in the brain may become resistant to the effects of insulin, leading to a build-up of abnormal proteins. However, type 3 diabetes is not an official diagnosis, and more research is needed into any link between diabetes and Alzheimer's disease.

#### Does diabetes cause dementia?

Research shows that type 2 diabetes increases the risk of developing dementia. The reasons are uncertain, but people with diabetes are more likely to develop high blood pressure and cholesterol, which are risk factors for dementia.



People with type 1 diabetes who experience severe blood sugar highs and lows may also be at increased risk of dementia.

The risk of developing dementia increases with the length of time the person has lived with diabetes and its severity. However, having diabetes does not mean that someone will definitely develop dementia.

#### Living with diabetes and dementia

It is important for everyone with diabetes to ensure their condition is managed by following a healthy diet, being physically active, taking medication if required and attending health checks. This will help to avoid long-term complications caused by high blood sugar, and prevent blood sugars dropping to a dangerously low level – known as hypoglycaemia or a 'hypo'.

Dementia can make it harder for someone to manage their diabetes

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independently due to changes in their memory, concentration, or diet. As the person's dementia progresses, they are likely to need support to:

- take any prescribed diabetes medications regularly
- ensure they do not take too much medication, or take it too frequently
- administer their own insulin injections safely if they need them
- interpret their blood sugar results
- make decisions about adjusting their insulin doses or treating hypos
- eat and drink regularly and healthily to keep their blood sugar stable
- take physical exercise
- maintain a healthy weight
- stay hydrated
- discuss any concerns with their GP or diabetes specialist
- attend their annual diabetes review and any other appointments

## Supporting a person with dementia to manage their diabetes medication

A person with diabetes may need to take medication, which could include:

 insulin – administered through a syringe, insulin pen or a pump attached to the body. Everyone with type 1 diabetes will need to take insulin, as will some people with type 2 diabetes

- tablets most commonly metformin, which many people with type 2 diabetes need to take
- prescribed appetite suppressant injections

It is particularly important for the person to take any medication as prescribed, whether for their diabetes, dementia and/or other health conditions. They may need your support with this. These tips may help:

- If the person has a specialist diabetes nurse, ask them to explain their medication regime and target blood sugar levels
- The person's optimum blood sugar levels may be revised after a diagnosis of dementia to reduce the risk of hypos, so ensure you are kept up to date with their latest treatment and management plan
- If the person struggles to remember to take their medication, try
  using prompts like a calendar or wall chart, alarms/alerts on their
  smartphone, voice reminders on a smart speaker, or using a pill
  organiser box
- If you are worried that a person may take more medication than they should, or take it too frequently, consider storing it in a locked box or cupboard
- If the person cannot safely inject their own medication, ask their specialist diabetes nurse to show you/other carers how to do it or consider if diabetes technology could help – please see p6
- If a person lives alone, a member of the local community nursing team may be able to visit and give them their insulin injections
- Talk to the person's GP or diabetes specialist about whether their medication regime could be reviewed and simplified – for

- example by reducing the number of medications they take and how often they take them
- Also, speak to their GP, specialist or a community pharmacist about whether their diabetes tablets may need to be changed – some may make the person more confused
- If the person is finding their tablets hard to swallow, taste unpleasant or make them feel sick, speak to their GP or pharmacist as the medication may be available in another form such as liquid

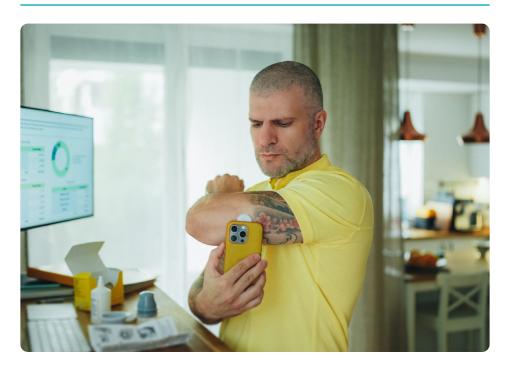
#### Technology to help a person with dementia manage their diabetes

There are several types of technology that can be used to help a person manage their diabetes, particularly if their blood sugars need to be tested frequently or they need insulin injections more than once a day.

**Insulin pens:** an easy-to-use alternative to a traditional syringe. They come with a cartridge of insulin rather than a vial that needs to be drawn up. The person's dose can be pre-set to ensure they take the right amount.

**Smart insulin pen:** this can automatically record the person's last dose of insulin to help you monitor if they have taken the right dose at the right time. The information can be sent automatically to an app on the person's phone. The pen can also send alerts if an injection is missed.

**Insulin pump/patch:** a small electronic device worn on the body which releases insulin at the right times, day and night, so the person does not have to inject themselves. This can help keep their blood sugar levels in the target range and avoid them missing insulin doses or taking too much.



#### Flash glucose monitors/continuous glucose monitors (CGM):

these are sensors worn on the body (usually on the back of the upper arm) that monitor the person's blood sugars around the clock. This information is sent to their smartphone. If you support the person with their diabetes management, it can also be sent to your phone. You can set an alarm to sound if blood sugars are too high or low. The most common type of flash/CGM is the Freestyle Libre system.

**Smartphone apps:** these can help people manage their diabetes, for example by counting their carbohydrate intake, setting medication alerts and tracking blood sugar levels over time.

Not all of this technology is available free on the NHS, so it is important to discuss the person's suitability and eligibility with their diabetes specialist.

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Please see Sources of support on p18 for information on technology and diabetes.

#### **Changes in diet and nutrition**

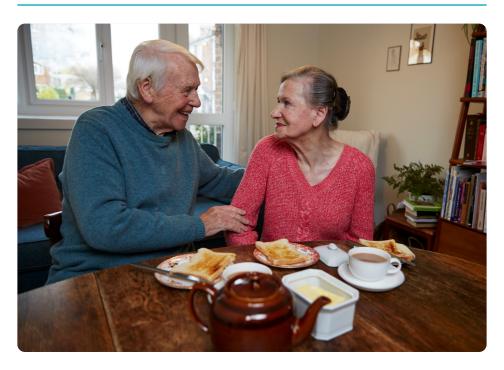
Dementia often has an impact on a person's appetite and ability to eat and drink. This may affect how they manage their diabetes. You may start to notice the person:

- has changes in tastes or food choices for example, liking foods they used to dislike or vice versa
- craves sweet foods
- has difficulty expressing hunger/thirst
- overeats and gains weight
- loses their appetite or interest in food
- forgets to eat/drink
- needs support preparing food/drinks
- struggles to handle cutlery and eat independently
- has difficulties chewing or swallowing

It is important to update the person's diabetic team with any changes in their eating habits or weight, as their treatment regime and goals may need to be reviewed. It may be helpful for the person to be weighed every month, and a record kept to identify any changes.

Please see Sources of support on p17 for more information on eating and drinking with dementia.

People with dementia often do not drink enough and can quickly become dehydrated. This could increase their confusion and their



chance of developing a urinary tract infection (UTI), which can lead to high blood sugar levels in people with diabetes. The person may need help to ensure they drink enough – please see Sources of support on p17 for our information on hydration.

If the person becomes excessively thirsty it is important that their blood sugars are checked. If they are extremely high, they will require a review by the GP/diabetic nurse.

#### **Visual changes**

Some people with dementia experience changes in vision, such as difficulty recognising and distinguishing objects, seeing specific colours, and perceiving depth. These changes may affect how well a person can see their insulin doses, locate their tablets, or prepare and eat food.

However, diabetes can also affect a person's vision. It can cause diabetic retinopathy (damage to the back of the eye, known as the retina) and increase the risk of glaucoma (damage to the optic nerve caused by pressure in the eye). Both could lead to blindness.

It is important not to assume that any vision changes are caused by the person's dementia and to ensure they have regular eye tests and mention any changes to their optician or diabetes specialist.

Please see Sources of support on p18 for information on diabetic retinopathy.

#### Hypoglycaemia

Hypoglycaemia, or a 'hypo', is an episode of low blood sugar, which could be dangerous and even life-threatening. It may occur if the person takes too much diabetic medication, misses meals, drinks too much alcohol or exercises intensely.

It may be difficult to tell if a person with dementia is experiencing a hypo as the symptoms could be similar to those of dementia, including:

- irritability/anxiety
- difficulty concentrating
- confusion
- erratic or irrational behaviour

There may also be physical signs of low blood sugar, including:

- trembling
- sweating/night sweats
- dizziness

- palpitations
- fast heart rate
- hunger
- looking pale
- headache
- in a severe hypo, becoming unresponsive and losing consciousness

A hypo needs to be treated promptly, so it is important to recognise the differences – which may be subtle – between the signs of a hypo and the person's dementia symptoms. If the person seems particularly agitated, anxious, and confused, test their blood sugar levels. If they are low, you can take steps to address this, for example by giving them a sugary drink, dextrose/glucose sweets or jelly babies.

If the person goes into a severe hypo, acting quickly is vital, so it is a good idea to familiarise yourself with what to do – please see Sources of support on p19 for Diabetes UK's information on treating a severe hypo. You should also call the person's GP or NHS 111 for urgent advice.

It is helpful to keep a record of the person's hypos to identify any patterns and help their healthcare team assess whether there are better ways to manage their blood sugar levels.

It is also a good idea for the person with diabetes and dementia to carry a form of ID that explains their diagnoses, such as an ID card, medical alert jewellery, or an up-to-date health record on their phone. This will help them get the support they need if they become confused or unwell in public.

#### **Dementia, sundowning and hypos**

Many people with dementia become increasingly confused, anxious, and unsettled in the evening. They may have a strong sense of being in the wrong place - for example, they may ask to go home, even if they are at home, or believe they need to collect their children from school, even if they are now adults. This is known as sundowning.

While this is common in people with dementia, it is important not to assume that a person with diabetes is sundowning, as it could be a sign of low blood sugar. If this is not addressed, the person may become unresponsive, lose consciousness and be admitted to hospital.

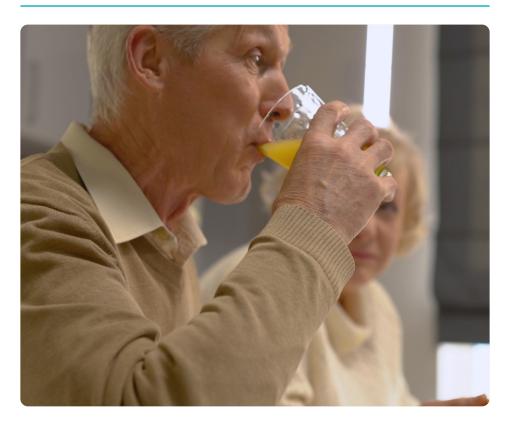
For this reason, if the person becomes very confused and agitated in the evening, check their blood sugar levels. If they are low, you can encourage them to have a sugary drink or sweets to raise them to within their target range. This could help to prevent them becoming seriously unwell and avoid an unnecessary hospital admission.

Please see Sources of support on p17 for more information on sundowning.

#### Diabetes, infection, and delirium

People with diabetes are at greater risk of developing infections due to high blood sugar levels. They may be ill for longer or become more seriously ill. Having an infection may itself affect the person's blood sugars, so if you are concerned that they are ill, please speak to their GP.

A person with dementia is more likely to develop delirium if they have an infection. This is a state of sudden, intense confusion and disorientation that needs to be recognised and treated immediately. If there is a change in a person's cognitive abilities, contact their GP as soon as possible to identify if they are experiencing delirium.



Please see Sources of support on p17 for information on delirium.

#### Dementia and diabetic annual reviews

Everyone with dementia should have an annual review with their GP. This should include:

- discussing any new symptoms/changes
- reviewing medication and other treatments
- talking through their support needs
- discussing how the person's carers are managing and any support they need

The annual dementia review is an opportunity to talk about future care decisions, including advance care planning. This might include filling in a ReSPECT form, which sets out personalised recommendations for the person's care and treatment in an emergency where they cannot make or express their own choices.

These decisions can be difficult to think about, especially if the person has only recently been diagnosed with dementia, but their GP can help you explore the options, so they receive the best care in the future.

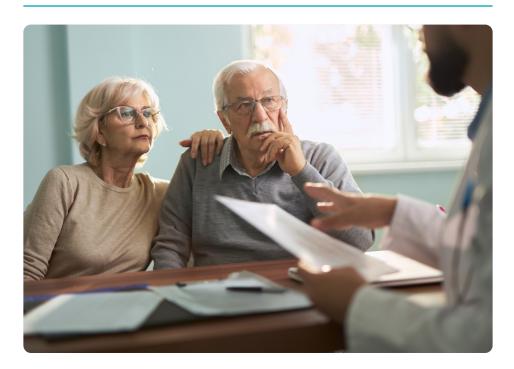
Please see Sources of support on p17-18 for information on advance care planning and ReSPECT.

People with diabetes should also have an annual diabetes review with their GP or diabetes specialist. This should include:

- a blood test to look at their average blood sugar levels (HbA1c) over the last three months
- a cholesterol test.
- blood and urine tests to check their kidney function
- blood pressure, height, and weight checks
- a check of their feet diabetes can cause reduced circulation and sensation in the feet, which may mean the person is unaware of any problems and put them at risk of infection

The person will also be invited for a separate eye screening appointment to check for diabetic retinopathy.

It is a good idea to go with the person to their dementia and diabetic reviews so you can share any new information (for example, changes in their diet, physical activity, alcohol intake



or smoking) and understand any advice they are given around managing their conditions.

If the person is not invited for their diabetes or dementia review, you should contact their healthcare professional to request them. It is useful to make a note of when they should happen in case the person with dementia forgets they are due or needs help arranging the appointments.

#### Hospital admissions for people with dementia and diabetes

At some point, it is possible that the person you care for will need to be admitted to hospital, whether due to their diabetes or another condition. This can be particularly confusing and unsettling for a person with dementia due to the unfamiliar people, surroundings and routines, but there are some things you can do to make sure they are well cared for.

- Consider keeping a hospital bag prepared in case of emergency
- Compile a record of essential information about the person (such as their past and present life, likes and dislikes, routines etc) to help hospital staff get to know them and tailor their care to their needs. You could do this by creating a life story or using the 'This is me' template – please see Sources of support on p19
- Ensure everyone involved in the hospital admission, including paramedics, is aware that the person has both dementia and diabetes, and share any useful advice – such as tips for communication
- Make sure the person takes any medication they need for diabetes, dementia and/or other conditions, and any medical equipment they use (eg syringes), labelled with their name
- It is a good idea for the person to wear a wristband that states they have diabetes in case they cannot communicate this themselves. These are available from Diabetes UK – please see Sources of support on p18
- Ensure that the person is reviewed by the hospital diabetes team before they are discharged, and you are aware of any changes to their diabetes medication and treatment goals

### Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, 'Dementia: what next?' at **Odementia.** dementia.

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **o8oo 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December) or email **ohelpline@dementiauk.org** 

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit **3 dementiauk.org/book** 

#### **Dementia UK resources**

#### **Advance care planning**

dementiauk.org/advance-care-planning

#### Creating a life story

dementiauk.org/life-story

#### Eating and drinking with dementia

dementiauk.org/eating-and-drinking

#### Good hydration for a person with dementia

dementiauk.org/hydration

#### **Delirium**

dementiauk.org/delirium

#### Managing medication for a person with dementia

dementiauk.org/medication-management

#### Staying healthy with dementia

dementiauk.org/staying-healthy

#### Other resources

#### **Diabetes UK**

odiabetes.org.uk

Helpline: 0345 123 2399

#### **Diabetes Community**

odiabetes.co.uk

#### **Diabetes and foot problems**

diabetes.org.uk/feet

#### Diabetes health checks (annual review)

Odiabetes.org.uk/about-diabetes/looking-after-diabetes/careto-expect

#### **Diabetic retinopathy**

nhs.uk/conditions/diabetic-retinopathy

#### Diabetes UK shop (selling wristbands and other useful products)

shop.diabetes.org.uk

#### **NHS: insulin**

nhs.uk/medicines/insulin

#### **NHS:** metformin

nhs.uk/medicines/metformin

#### **ReSPECT planning**

resus.org.uk/respect

#### **Technology and diabetes**

diabetes.org.uk/technology

#### 'This is me' template

alzheimers.org.uk/sites/default/files/2020-03/this\_is\_ me\_1553.pdf

#### Treating severe hypoglycaemia

diabetes.org.uk/about-diabetes/complications/hypos#severe

#### Type 1 diabetes

odiabetes.org.uk/type-1-diabetes

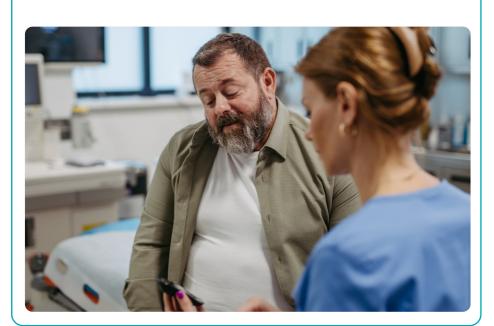
#### Type 2 diabetes

diabetes.org.uk/type-2-diabetes

#### What is HbA1c?

#### What is a hypo?

diabetes.org.uk/about-diabetes/complications/hypos



To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:

o8oo 888 6678 or Ohelpline@dementiauk.org

Book a virtual appointment:

dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit odementiauk.org/donate
- Scan the QR code

Thank you.













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