

Patient information from BMJ

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Diabetes insipidus

Diabetes insipidus is a rare hormone problem where the body struggles to retain water. It causes people to urinate a lot more than usual, and to feel very thirsty as a result.

If you have been diagnosed with diabetes insipidus, you can use our information to talk to your doctor about the best treatments for you.

What is diabetes insipidus?

When most people think of diabetes, they think of type 1 or type 2 diabetes (the full name is **diabetes mellitus**), which affects how the body uses blood sugar as energy. The condition is caused by lack of a hormone called **insulin**.

Diabetes insipidus is a different condition. It's usually caused by low levels of a different hormone, called **vasopressin**. Vasopressin helps to control the amount of water in your body.

- If there is too much water in your body, your kidneys make more urine, and you need to urinate.
- If your water levels are running low, your brain releases vasopressin, which makes your kidneys produce less urine and conserve water.

If you don't have enough vasopressin, your kidneys don't know when to stop producing urine, and you want to urinate more often than is usual. This makes you feel thirsty, so that you want to drink a lot more than is usual.

What causes diabetes insipidus?

Diabetes insipidus is usually caused by a lack of vasopressin. But it can also happen if you've got enough of the hormone but your kidneys don't react to it properly.

Diabetes insipidus can be genetic (inherited from your parents). But other things can cause it, too. These include:

- **Kidney** disease
- Having had kidney surgery

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- A thyroid condition called **Hashimoto's thyroiditis**
- **Head injuries**
- Benign brain tumours (benign means that they are not cancer)
- Other hormone problems, including **type 1 diabetes mellitus**
- Having high levels of some minerals: for example, calcium or potassium
- Some **medicines** (for example, **lithium** is known to cause diabetes insipidus in some people. Lithium is used to treat conditions including bipolar disorder and depression), and
- Pregnancy, but this is temporary.

What are the symptoms?

The main symptoms of diabetes insipidus are:

- Feeling very thirsty much of the time (doctors call this **polydipsia**)
- Needing to urinate often, even during the night, and producing large quantities of urine (doctors call this **polyuria**), and
- Producing urine that is very clear, and that has little or no colour or smell.

If your doctor thinks that you might have diabetes insipidus, they will ask you questions about:

- Any other medical problems you have
- Whether anyone in your family has had similar symptoms
- If you have ever had treatment for kidney problems
- Any medicines you are taking, and
- If you have ever had a head injury.

Your doctor will probably also want to do several **tests**, which might include:

- Blood tests
- Urine tests
- A scan of your brain
- A **urine volume test**, where you measure how much urine you produce in one 24-hour period
- A **water deprivation test**, where you don't drink anything for several hours. If you continue to produce large amounts of pale urine, even when not drinking any fluids, this suggests that you might have diabetes insipidus
- A **desmopressin test**. Your doctor gives you a small amount of a drug called desmopressin, which is similar to the hormone vasopressin that your body produces naturally. If you feel less thirsty and you don't urinate as much, this suggests that you might have diabetes insipidus.

What treatments are available?

Treatments for diabetes insipidus vary depending on what has caused the problem and on how severe your symptoms are.

Mild symptoms

If you've got **mild symptoms** your doctor might just suggest that you make sure that you drink enough fluids to avoid dehydration.

More severe symptoms

If your symptoms are more severe, your doctor might recommend that you take a medicine called **desmopressin**. This medicine acts in the same way as the hormone vasopressin, to help your kidneys work normally.

The amount of desmopressin your body needs can vary, and getting to understand how much your body needs can take time. Your doctor should discuss this with you, and explain what to do if there are signs that your dose is too high.

For example, if you take too much desmopressin, or if you drink too much fluid while taking it, your body might retain too much water.

This can lead to a dangerous problem called **hyponatraemia**, where your blood becomes too diluted by excess water and doesn't contain enough of certain minerals, such as sodium.

Symptoms of hyponatraemia (low blood sodium) include:

- Headaches
- Dizziness
- Confusion, and
- Nausea.

Doctors often advise people with diabetes insipidus who have symptoms of hyponatraemia to skip the next dose of their medicine. This allows the body to lose any excess fluid.

If you've got severe symptoms of hyponatraemia or you are worried, **get medical help straight away**.

Nephrogenic diabetes insipidus

In most people, diabetes insipidus is caused by low levels of vasopressin. But some people have diabetes insipidus even though they make enough vasopressin. This is because their kidneys don't react properly to the hormone.

This is called **nephrogenic** diabetes insipidus. Several things can cause this type of diabetes insipidus, and some of them can be treated.

For example, taking **lithium** for any reason can cause this type of diabetes. People who take lithium are sometimes able to switch to a different medicine.

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But if the cause of the symptoms can't be treated, nephrogenic diabetes insipidus can be difficult to treat. The focus will probably be on making sure you don't become dehydrated.

What to expect in the future

Diabetes insipidus can sometimes get better by itself.

For example, diabetes insipidus that happens in pregnancy should clear up within about six weeks of giving birth. Symptoms caused by injury to the brain or by surgery can also be temporary.

But for most people diabetes insipidus is a lifelong condition, and people have to learn to manage their symptoms over the long term. This involves learning about the condition, and about how to vary your dose of medicine according to your symptoms.

People with diabetes insipidus should have regular check-ups with their doctor, and regular tests, including scans of the bladder to check for any problems that can sometimes develop over time.

You might be able to find a source of information and health where you live. For example, in the UK, the **Pituitary Foundation** (pituitary.org.uk) provides in-depth information and advice for people with diabetes insipidus.

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