Patient information

Cranial Diabetes Insipidus

Diabetes and Endocrinology

What is Diabetes Insipidus?

Diabetes Insipidus, referred to as D.I., is a condition where the kidneys are unable to control the amount of urine produced. It is very different from diabetes mellitus, when there is too much sugar in the blood.

The amount of urine produced by the kidneys is regulated by a hormone called anti-diuretic hormone (ADH), or vasopressin. ADH is made by a part of the brain called the hypothalamus and is stored just below the brain, in the pituitary gland, until needed. ADH helps to retain water in the body by stopping the kidneys from producing urine. Adults usually pass around three litres (five pints) of urine per day.

There are two types of Diabetes Insipidus:

Cranial diabetes insipidus occurs when there is not enough ADH in the body to regulate the amount of urine produced. This is the most common cause of diabetes insipidus and may be as a result of pituitary surgery, brain tumour, infection or head injury.

Nephrogenic diabetes insipidus occurs when there is enough ADH in the body, but the kidneys fail to respond to it. This can run in families or it can be caused by kidney damage.

What are the symptoms?

The two main symptoms of diabetes insipidus are an excessive thirst and needing to pass large amounts of urine. It is possible for you to pass as much as 20 litres (35 pints) in 24hrs.

How is it diagnosed?

You will be invited to attend to come into hospital for a test called an Arginine stimulated Co-peptin test.

- You will be asked to attend our patient investigations unit located at Broadgreen Hospital, having fasted from midnight prior to the test.
- You must not eat, drink any tea/coffee/alcohol or smoke from midnight until after the test is completed.
- You may drink water up until 2 hours before the test and then nothing at all until after the test.

- You must stop taking any desmopressin (antidiuretic medication) or diuretics for at least 24 hours prior to the test.
- You can continue your usual pituitary hormone replacement.
- You will have your weight, blood pressure and pulse checked at the start of the test. You will rest for 30 mins. A baseline blood sample is obtained. You will then be given some medication via a cannula (needle) in you vein. This will be given as an infusion over 30 minutes. After this, further blood samples will be taken and sent to the lab for analysis.
- Once the test is complete, the cannula will be removed and will be allowed to eat and drink normally.
- When the doctors have your results, they will be able to confirm the diagnosis and offer appropriate treatment.

How will I be treated?

You will be prescribed a treatment called Desmopressin or DDAVP. This drug can be taken as a tablet that is swallowed, a tablet that melts on your tongue or as a nasal inhalation. You should notice an improvement straight away but it may take some time before the correct dose for you is found.

What are the side effects of the medication?

Desmopressin is very safe to use and there are few side effects. However if you take too much desmopressin, or drink too much fluid while taking it, it can cause your body to retain too much water and lead to low salt levels in the body.

This can result in:

- Headaches, dizziness, nausea and abdominal pains .
- Feeling bloated.
- In severe cases, you can become drowsy and confused.

Therefore, you should never take more than your recommended dose of desmopressin, so please tell your doctor if you have any side effects. Try not to stop taking your medication before you have spoken to your doctor, as they may decide to change your medication or give you something to help with the side effects.

You should also restrict your fluid intake for at least one hour after taking your desmopressin dose and limit your fluids to approximately one pint. This will help to reduce the symptoms mentioned above.

How long will I be treated for?

If the cause is due to surgery, then treatment may only be for a few days. If the D.I. does not settle, then treatment will be continued for the rest of your life.

Your medication will be decreased slowly to try to get to the lowest dose you need to regulate your fluid intake and urine output and to keep you as comfortable as we can.

What will happen if I decide not to have treatment?

If you have diabetes insipidus and decide not to take desmopressin, your body will find it difficult to retain enough water, despite the fact that you may be drinking fluids constantly. This can lead to dehydration and electrolyte (minerals in your blood) imbalance.

You may experience some or all of the following symptoms:

- Dry mouth and lips.
- Eyes may appear sunken.
- Headaches, dizziness, confusion and irritability.
- Fatigue.
- Muscle pains.
- Fits and eventually a coma.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.

The Endocrinology Specialist Nurses
Tel: 0151 706 2417
Text phone number: 18001 0151 706 2417

There is also a very good patient support group, which offers excellent advice via leaflet and telephone contact. They also hold local area group meetings.

National Support Office
The Pituitary Foundation
86 Colston Street
Bristol
BS1 5BB
Tel: 0117 370 1320
www.pituitary.org.uk

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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