ENGLISH

Hormone Disorders

Diabetes Insipidus

Patient's Guide

Average readability

ESPE
European Society for Paediatric Endocrinology

Child Growth Foundation
Supporting children & adults with rare growth conditions

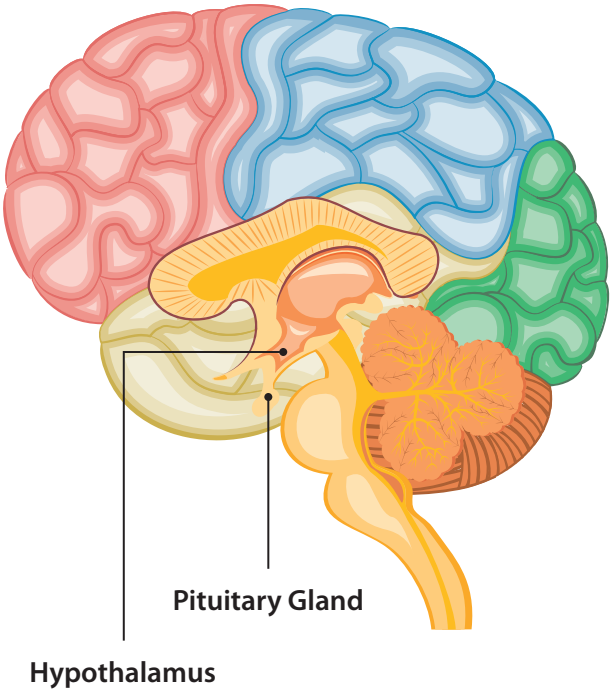
BSPED

Introduction

The aim of this leaflet is to describe a condition known as Diabetes Insipidus. It will discuss information on how it is diagnosed, treated and some of the problems it may cause. Hopefully, this leaflet will help you to understand this condition and give you a basis for discussions with your GP or specialist team.

What are hormones?

Hormones are "messengers" used around the body to produce an effect. These are produced in the brain by the **hypothalamus** and **pituitary gland**. Any deficiency of a hormone may be the result of problems in one or both of these parts of the brain.

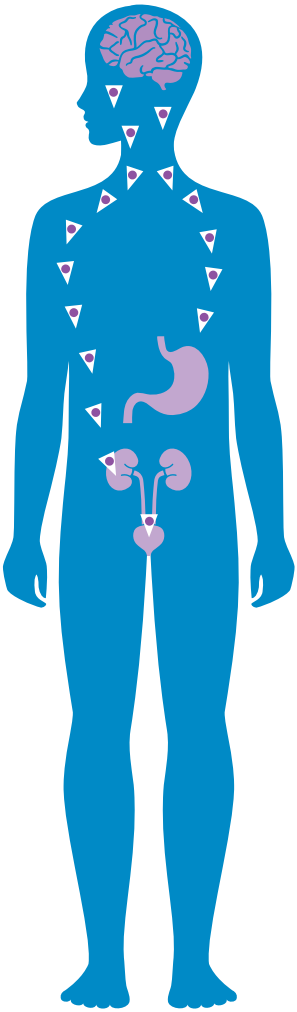


What is diabetes insipidus?

When working properly, the hypothalamus and pituitary gland work to regulate the body's fluid balance. They do this by producing and sending a "messenger" around the body to tell the organs when to retain or when to eliminate water. This "messenger" is a hormone known as Vasopressin.

Without Vasopressin the body will not retain fluids, even if we drink large amounts of liquid. The inability of the brain to produce Vasopressin leads to a condition known as Diabetes Insipidus or **"water diabetes"**.

Water diabetes is not the same as the more common condition Diabetes Mellitus or "sugar diabetes".



What causes water diabetes?

Water diabetes occurs when the pituitary gland, responsible for producing vasopressin, is not working normally. This malfunction may result from the presence of a small tumour near this gland or because of swelling.

Water diabetes can also be the result of surgery near the pituitary gland. However, this type of water diabetes is usually temporary and doesn't require treatment.

Most commonly there is a genetic problem, which stops the pituitary gland from working properly. In some cases it may affect the newborn baby who will have problems with dehydration. In other cases, the symptoms may not appear until the child is up to 1 year old.

What are the symptoms of water diabetes?

The most common symptoms of this condition are:

- **Passing large volumes of urine:** there is a need to go to the toilet frequently.
- **Increased thirst:** excessive output of urine leads to a severe loss of fluid in the body. As a result, thirst will be triggered and this may be constant throughout the day or night.

How is the diagnosis made?

The diagnosis of water diabetes can usually be made by comparing the concentration of blood and urine in early morning samples. This needs to be done after an overnight fast, and before eating or drinking anything.

If the concentration of the blood is high, and the concentration of the urine is low, this shows that there is a lack of control of the body's fluid levels. This confirms the diagnosis of water diabetes.

Other tests that are used include the "water deprivation test". This is done in hospital and may require the individual to be admitted overnight. This test measures the concentration of urine and the blood when fluids are withdrawn.

How is water diabetes treated?

Water diabetes is treated by providing the body with a synthetic form of Vasopressin known as **DDAVP**. DDAVP acts like the natural hormone but lasts longer in the body. It may be given in tablets, intranasal drops or by injection.

It is very important to adjust the dose for children and babies/ infants, as they often need only very small doses. In patients who take DDAVP as a spray or drops, their nose can become very sensitive, making it uncomfortable to continue taking their treatment in this form. If so, your specialist may advise you to use the tablets instead.

Sometimes your specialist may advise you to use a combination of these different types of DDAVP to have more control over your symptoms.

It is important not to exceed the dose of DDAVP as indicated by your specialist. Taking too much DDAVP may result in a build up of fluid and convulsions. Under-treatment is less dangerous and causes more urine to pass and increased thirst.

What happens if there is no sense of thirst?

The brain has a "thirst centre" which triggers our desire to drink fluids. In some individuals this thirst centre is damaged following surgery for a brain tumour. This results in a lack of a sense of thirst. This condition sometimes occurs with water diabetes and can be very dangerous.

It is very important to know whether your child has this condition. Individuals who have no sense of thirst need to be encouraged to drink. Your doctor will provide you with an idea of how much fluid is needed each day. This may be called a fluid "prescription". The amount of fluid needed will depend on the size of the individual. In addition, it may have to go up during hot weather and minor infections as at these times extra fluid is lost through sweating.

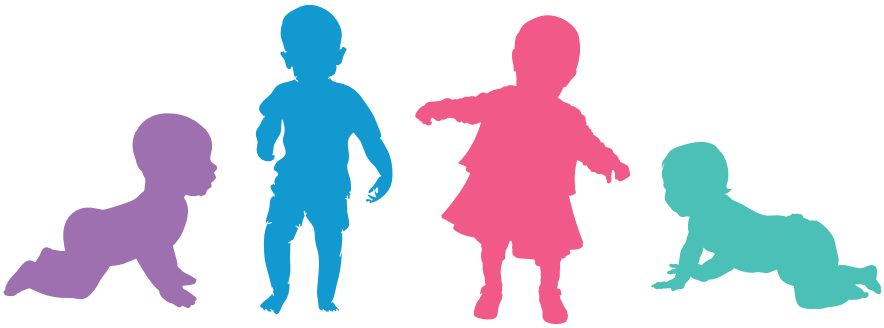
It is important to follow the fluid prescription to keep up with the body's fluid requirements.

Why is water diabetes a very serious condition in small babies?

Water diabetes in small babies leads to the loss of large amounts of urine and excessive thirst. Often, it may be difficult for the parents to recognise this.

As with older children, DDAVP can be given to babies in the form of tablets. The dose of each individual tablet is too large for small babies. As a result, your specialist will advise you how the tablets should be broken.

Alternatively, DDAVP can be given as drops into the nose. However, **very small doses** are needed in this form. Your doctor will ask the pharmacy to make up a diluted solution so that the dose can be accurately assessed and the volume that needs to be given is not too large.



Measuring urine loss in small babies can be quite difficult. In time, most parents can recognise if their baby is passing more or less urine than normal. This means that sometimes, extra water needs to be offered to your baby to make sure he/she does not get dehydrated.

The problems are much greater in babies who are lacking a sense of thirst. It's critical to establish this at a very early stage. Babies will not take extra free water and they will need to have a water prescription to avoid dehydration.

The risks of dehydration during very hot weather or illness are quite high in small babies with water diabetes. Illness where vomiting or diarrhoea develops will usually require a short stay in hospital.

What are other sources of useful information?

The goal of this leaflet is to provide a basic overview on the diagnosis and treatment of water diabetes.

Educational material can also be found by contacting the following organisations:

- **European Society for Paediatric Endocrinology**
  Starling House
  1600 Bristol Parkway North
  Bristol
  BS34 8YU
  espe@eurospe.org
  Telephone +44 (0) 1454 642246
  www.eurospe.org

- **British Society of Paediatric Endocrinology and Diabetes**
  bsped@endocrinology.org
  https://www.bsped.org.uk/

- **Child Growth Foundation**
  info@childgrowthfoundation.org
  Telephone +44 (0) 208 995 0257
  www.childgrowthfoundation.org

- **The Endocrine Society**
  www.endo-society.org

You can also consult your specialist team for additional information in your local area.

Diabetes Insipidus

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This leaflet is part of the **Hormone Disorders Series**

The following are also available:

- Growth Hormone Deficiency
- Puberty and the Growth Hormone Deficient Child
- Precocious Puberty
- Emergency Information for Children with Cortisol and GH Deficiencies and those Experiencing Recurrent Hypoglycaemia
- Congenital Adrenal Hyperplasia
- Growth Hormone Deficiency in Young Adults
- Constitutional Delay of Growth and Puberty
- Multiple Pituitary Hormone Deficiency
- Craniopharyngioma
- Intrauterine Growth Retardation or Small for Gestational Age
- Hyperthyroidism
- Hypothyroidism
- Type 2 Diabetes and Obesity

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