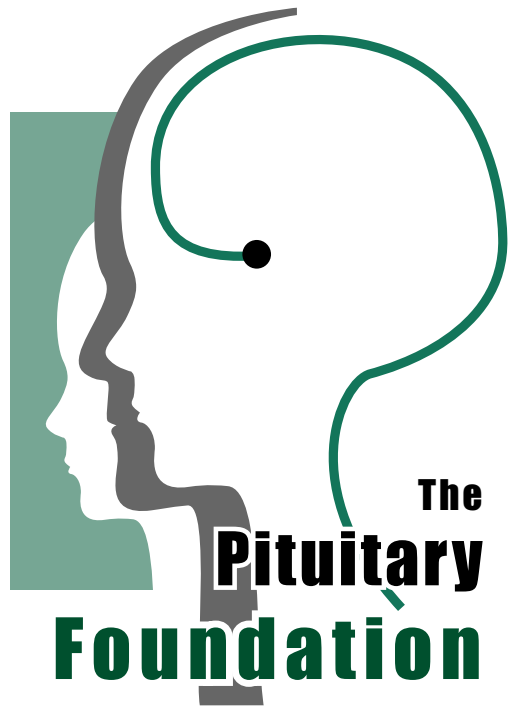


THE PITUITARY FOUNDATION INFORMATION LEAFLETS

# DIABETES INSIPIDUS



The  
**Pituitary  
Foundation**

*Working to support pituitary patients,  
their carers & families*

SERIES : CONDITIONS

# The Pituitary Foundation

The Pituitary Foundation is a charity working in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions, their carers, family and friends.

Our aims are to offer support through the pituitary journey, provide information to the community, and act as the patient voice to raise awareness and improve services.



## About this leaflet

The aim of this leaflet is to provide information about Diabetes Insipidus.

You may find that not all of the information applies to you in particular, but we hope it helps you to understand your condition better and offers you a basis for discussion with your GP and endocrinologist.

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# What is **Diabetes Insipidus (DI)** and why do we get it?

**Diabetes insipidus (DI)** is caused by a problem with either the production, or action of the hormone Vasopressin. If you have DI, your kidneys are unable to retain water. This leads to the production of large volumes of urine and in turn, through increased urine volume leading to increased thirst. DI can occur at any age but is mostly found in adults. It is a rare disorder, affecting only about 1 in 25,000 people.

To understand DI we need to understand a little about how the body regulates water balance – the difference between how much water the body takes in and how much it passes out. Water balance is very important for the body. A large proportion of what we are is made up of water; in addition the amount of water we have in our circulation is a critical factor in determining the balance of salt in our bodies. As with any function that is important, the body has a sensitive mechanism for regulating water balance. Like any good mechanism it is also simple, involving two key components:

- **Vasopressin (AVP)** – which regulates the amount of water passed out of the body in urine
- **Thirst and drinking** – which determines the amount of water the body takes in

**AVP** (sometimes called anti-diuretic hormone or ADH) is a hormone made by the rear most part of the pituitary gland (the posterior). This gland is located at the base of the brain, and is about 3 to 5 centimetres behind the bridge of the nose. AVP circulates in the bloodstream and acts on the kidneys to reduce the amount of water that is passed out in urine.

How AVP and thirst work together is best described with the help of the bath tub analogy.

As with a bath tub, the body likes to keep the level of water it contains at the right level for its purposes.

There are only two ways the level of water can be altered:

- Water can be let in to the bath through turning the taps on; just as thirst and drinking can allow more water into the body
- Water can be let out of the bath through taking the plug out; just as the body can let more water out by reducing the amount of AVP produced, and so letting more water to be passed out of the body as urine

Unlike a bath tub, the body is very good at sensing the level of water it has on board. If it does not have enough and is dehydrated, it triggers us to drink more through activating thirst (turning on the taps). At the same time, it makes more AVP and so reduces water loss in urine (it puts the plug in). On the other hand, if the body senses the level of water is too much, it turns the thirst off (turning taps off) and makes less AVP (taking the plug out of the plug hole).

The level of water is therefore maintained through a combined approach.

Together, AVP and thirst maintain water balance very effectively in both situations where water is either easy to find, or is scarce. DI occurs when this mechanism regulating water balance breaks down.

# There are two forms of **Diabetes Insipidus (DI):**

## **1 Cranial Diabetes Insipidus (CDI)**

CDI is caused by the relative or absolute lack of AVP. The lack of AVP means that the kidney cannot retain the amount of water that the body needs it to, and produces a lot of dilute urine. The body is therefore reliant on only one of its two mechanisms to keep the amount of water in the body at the correct level, thirst and drinking. People with CDI pass a lot of water and are thirsty all of the time; they pass large amounts of urine frequently through the day and often have to pass urine several times at night. Daily urine output is over 3 litres in adults with CDI, and people with CDI drink a lot of fluid and often feel thirsty.

Sometimes CDI occurs on its own; however in many cases, it is accompanied by loss of other hormones made by the pituitary. This may be through a problem in the development of the pituitary gland; a tumour within or near the gland; or the result of surgery to, or near to the gland.

DI following pituitary surgery may be temporary, only lasting a week or two. In some cases it may be permanent.

## **2 Nephrogenic Diabetes Insipidus (NDI)**

NDI occurs when the kidneys cannot respond to the AVP secreted by the pituitary gland; it is very rare. It is either caused by an abnormality in the mechanism which recognizes AVP in the kidney; this can be inherited, in which case it is present from early life, or may develop as an adult. In some cases it is due to the toxic affects of specific chemicals or drugs.

It is very important to point out that DI is not related to the type of diabetes most people have heard of - **DIABETES MELLITUS** which is very common and can also cause symptoms of passing a lot of urine and being thirsty.

In DI, there is **NO** problem with the level of sugar in the blood or urine. This is very important as friends, relatives and health care workers may make assumptions about the condition you have, based on the more common condition.

## What does it feel like to have DI?



The main symptoms that you will feel are thirst (no matter how much you drink) and the need to pass urine very frequently, even during the night.

You will pass large volumes of urine; you may pass as much as 4 - 10 litres of urine a day.

It is important that you do not try to prevent this by ignoring your thirst and drinking less, or you will disturb the balance of water in your body.

You may well have symptoms of dehydration, for example feeling shivery and nauseous with headaches.

People with DI have mentioned that their excessive thirst can be compared with eating 4 or 5 dry cream crackers one after the other, without any drinks.

Most patients do have a thirst mechanism, but a few patients don't. This is called **HYPODIPSIA**.

The combination of DI and hypodipsia is unusual and requires special attention from patients, carers and doctors.



## How is it diagnosed?

### What tests are carried out & how will these feel?

Investigation methods for patients with excessive urine production would be:

- Measurement of 24 hour urine output
- Measurement of plasma osmolality from a blood test (a measure of sodium and glucose circulating in the blood)
  - Water deprivation test (described below)
  - Therapeutic trial of Desmopressin (DDAVP)

The water deprivation test deprives you of fluid for 6-8 hours to see if there is a reduction in the volume of urine.

You can expect to feel quite thirsty during this test. The next stage is to give you a small quantity of AVP, usually as an injection. If you have CDI, you should notice a reduction in the amount of urine you pass.

This shows that your kidney is responding to the hormone.

If you have NDI, this response does not occur or is impaired, as the kidney does not recognize the effect of the hormone in small doses. Once you are allowed to drink again, you will begin to feel better. If you need other hormone treatments, you will need to continue taking them during the test.

This test can be performed as a day case.

## How is DI treated?

CDI is treated with an AVP like drug called Desmopressin, or DDAVP. This medication acts specifically on the kidneys in the same way as natural AVP, though it lasts longer than natural AVP as it is more resistant to breakdown.



A variety of different preparations are available, each of which is given by a different route: injection, nasal drops, nasal spray, tablets to be taken and swallowed, or tablets that melt in the mouth. All are effective and it is a matter of finding the best match for each individual, based on preference and lifestyle. The spray and the tablets are popular choices.

Depending on the severity of the DI, these are generally taken between 1 - 3 times a day; some people have to take the medication 4 times a day. Doses vary between people, again based partly on degree of their symptoms. An ideal aim is for a patient to pass around 2 litres of urine over 24 hours whilst taking their DDAVP.

A good test of satisfactory management of fluid levels is to weigh yourself each morning.

A varying body weight on a day to day basis can help you monitor fluid balance when you start treatment. Remember that 1 litre of water weighs 1 kilogram.

Treatment has remarkably few side effects. Those who use the nasal spray may find some problems with the drug working when they have a heavy cold. If you use the tablets, some people find that they work less well when they have an upset stomach.

Some people can run into problems if the balance of treatment means that they are taking in more water than they are passing out; this can lead to the gradual development of water overload and a drop in the level of sodium in the blood stream (hyponatraemia). This is best addressed through re-balancing treatment through looking at how much DDAVP is given and how much fluid is being taken in.

You will gradually feel better once you are taking Desmopressin. Overall, the treatment of DI is straightforward, but if you are experiencing any difficulty controlling your DI please do talk to your endocrinologist.



## Aftercare

It is possible that your condition will require long-term monitoring and this will be shared by your endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with DI your GP is treating and they might find it helpful to have a copy of our **Pituitary Disease Fact File for General Practitioners**.

It is advisable to have your sodium level regularly tested, say every 6 or 12 months. This may be carried out by your GP.



# How will **Diabetes Insipidus (DI)** affect my life?

## Prescriptions

You will be entitled to free prescriptions. You will need a **Prescription Charge Exemption Certificate (FP92)** which you can get from your Health Authority. To obtain the certificate you must complete form **FP92A (EC92A in Scotland)** which is available from your doctor, hospital or pharmacist.

The form (which will need to be signed by your doctor) tells you what to do. These certificates only last for a finite period after which they must be renewed. Your health authority may automatically send out an application for renewal.

Information about free prescriptions and the full list of medical conditions which qualify for exemption from prescription charges can be found in leaflet **HC11**, available from pharmacies and main Post Offices or see [www.dh.gov.uk](http://www.dh.gov.uk).

If you are not sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form **FP57**) when you pay; you can't get one at a later date. This form tells you how to get your money back.

From April 1999, people between 16 and 60 who claim free prescriptions will be asked to provide proof that they are entitled to do so every time they collect a prescription. For further information, phone the **Free Prescription Advice Line** on **0800 917 7711**.



## Driving

You have a legal obligation to advise the Driver and Vehicle Licensing Agency (DVLA) if there is any reason why you should not drive. Many DI patients will find there are no restrictions on their driving, but you should check with your doctor as the rules change from time to time. Your doctor or specialist may seek direct advice from the DVLA by contacting the

**Medical Adviser, The Drivers' Medical Branch, 2 Sandringham Park,  
Swansea Vale, Llansamlet, Swansea SA6 8QD. Telephone: 0870 0600 0301.**

## Employment Problems

Contact the **Disablement Employment Adviser (or DEA)** at your local Department of Social Security. Often the DEA's are also very knowledgeable about benefits and entitlements generally.

Also contact your local **Citizens Advice Bureau** for the most up to date information on employment rights and benefits.

# How will **Diabetes Insipidus (DI)** affect my life?

## Insurance & Pensions

As a general guide, if you have primary DI with no complications, you should be able to obtain insurance at normal rates. If your DI results from an underlying cause such as pituitary tumour, your case would be assessed and any loadings would depend on your medical condition.

If your tumour has been completely removed you should be accepted at normal rates.

Of course, each insurance company will have its own practices.

Because of the potential confusion between diabetes mellitus (DM) and diabetes insipidus (DI), particularly in the minds of the insurers, it is important to emphasize that DI is due to vasopressin (anti-diuretic hormone) deficiency and has nothing to do with sugar diabetes.

Pensions can normally be arranged without difficulty. For further information please call **The Pituitary Foundation** or see our website for up to date insurers contact details which other patients have used, with success, and have informed us about these companies.

## MedicAlert®

It is a good idea to wear a **MedicAlert®** bracelet or equivalent as the information on it will help doctors if you have an accident and are unconscious. An application form can be obtained from the

**MedicAlert Foundation, 1 Bridgewharf, 156 Caledonian Road, London N1 9UU.**

**Telephone: 0800 581 420 or see [www.medicalert.org.uk](http://www.medicalert.org.uk).**

There are other personal medical information systems, please see our website for more details.

## Toilet Facilities Card

The Pituitary Foundation has produced a small credit size card to help DI patients who need a toilet when they are out. The card explains about DI and the urgent need for the card holder to use a toilet which may not be available to the general public. If you would like a card, please contact The Foundation.



## National Key Scheme (NKS)

The NKS offers independent access by disabled people to around 7000 locked public toilets around the country. Further details can be found at [www.radar.org.uk](http://www.radar.org.uk) or by calling 020 7250 3222



**Q** What happens if my desmopressin has been kept out of the fridge?

**A** Although intra-nasal desmopressin can be kept at room temperature for a limited period, long term exposure to temperatures above 8 °C may reduce the effectiveness. Please contact your doctor or pharmacist for advice if you are concerned that your medication has been left out of the fridge, or if the fridge is broken. Both the tablet form of DDAVP and Desmospray are stable at room temperatures; there is no need to store these in a fridge.



**Q** What should I do if the spray is blocked or the tube is missing or damaged?

**A** You should take the whole product to the chemist who will replace it free of charge.

**Q** Can I still use desmopressin if I have a cold or hay fever that gives rise to a blocked nose?

**A** If only one nostril is blocked, then using the clear nostril should give the right result. If both nostrils are blocked, your doctor may recommend temporary use of the tablets.

**Q** I have been having more headaches than normal recently and seem to be putting on weight. Could this be caused by desmopressin?

**A** If you drink large volumes of fluids and take too much desmopressin, your body may become overloaded with fluid, which could result in headaches, dizziness and abnormal weight gain. In turn, this could result in a low sodium level in the blood, which is called hyponatraemia. It is important that you contact your doctor if you experience these symptoms as you may be taking more desmopressin than you need. Your doctor will help you to find the right dose of desmopressin and will advise you on the amount of fluid you should drink.



**Q** If I can't remember whether I have taken a dose of desmopressin, should I take another one just in case?

**A** It is better to miss a dose than to risk taking twice the amount.

**Q** Is it safe to take other prescribed medicines alongside desmopressin?

**A** If your doctor prescribes any medicines, you should point out that you are taking desmopressin.

**Q** If I have an upset stomach while I am on holiday, what should I do?

**A** Mild holiday diarrhoea is no problem. Only if you have any vomiting and/or serious diarrhoea do you need to see a doctor.

**Q** Is it OK to take my desmopressin through airport X-ray machines?

**A** Yes, it's fine. For travelling with medication information please see our website.

**Q** What happens if I am in a hot climate or taking strenuous exercise which causes me to sweat?

**A** As with anyone else, you should increase your liquid intake in such circumstances; your thirst should prompt you to do this.



- Q** Will alcohol cause me any problems?
- A** You should be careful about drinking large volumes of alcoholic drinks. Alcohol tends to reduce vasopressin secretion. Check with your doctor for advice on your specific drinking habits.
- Q** My lifestyle means that it is inconvenient to take my desmopressin at the prescribed times and it is also awkward to keep leaving the room to use the toilet. What can I do?
- A** If you have any difficulties with your lifestyle due to DI, do contact your doctor, who will be able to advise you about varying the timing of doses. Don't experiment with this yourself, however.
- Q** If pregnant, do I take more DDAVP?
- A** You may have to increase your normal dose to overcome changes in the body, which have increased concentrations of an enzyme destroying DDAVP.



## WHAT DI MEANS TO ME

### - One Patient's Story

My name is Lisa. I'm 26 and I am a pharmacist. Towards the end of 1991 I began to feel unwell, although it was nothing specific. I was also aware that I was drinking more than usual and even waking up in the night to drink and go to the toilet. At first I thought it might go away, but as the weeks passed I began to worry. One of the worst things was the lack of sleep. At this point I decided to visit my GP.

I was aware that I had some of the symptoms of diabetes mellitus, so was not surprised to have the standard tests for it. The results were normal so my GP suggested I come back in a few weeks if no better. During those few weeks I began to believe that no one believed me and that maybe there wasn't anything really wrong as everything seemed so vague and non-specific. By the time I returned to my GP I was feeling dreadful. I was drinking anything between 5-10 litres of water a day, constantly going to the toilet and getting very little sleep. My GP referred me to the Westminster Hospital, and reassured me that, although he did believe there was something wrong, he did not think it was anything sinister.

I had my first appointment at the end of June 1992, explaining my symptoms and how I felt to the consultant who arranged for me to have a water deprivation test the following week. The results showed I had DI.

I started taking medication at the beginning of July 1992. The treatment involves administration of desmopressin which at that time was only available as a nasal solution or spray. The effects were not dramatic but over the next week or so I began to feel a lot better, the amount of water that I was drinking reduced and so did the need to go to the toilet during the night. Over the next year I accepted that I have a medical condition which may or may not be for life and no-one really knows why I developed the problem in the first place!

One of the most difficult things is trying to explain to people what DI is. Most people hear the word 'diabetes' and automatically think of insulin and needles. Insurance companies are the worse - they hear 'diabetes' and either refuse to insure you completely or charge you a fortune! The is very little information on diabetes insipidus to be found, even in medical textbooks, so it's not really surprising that most people have never heard of it. Hopefully the Pituitary Foundation is improving matters by helping people to understand about DI and pituitary disease generally and by providing a self-help group for patients.

Anyway at least I get free prescriptions!

## Become a member of The Pituitary Foundation

Being a subscribed member of The Pituitary Foundation will greatly help our awareness efforts, assist The Foundation's aims to be the 'voice' of the patient and quite simply allow us to do the work that needs to be done.

If you would like to become a subscribed member, please complete the form below and send to us at:

The Pituitary Foundation, PO Box 1944, Bristol, BS99 2UB



Pituitary Foundation - Membership Application Form			
Name: (Mr/Mrs/Ms)			
Address:			
Postcode:			
Telephone No:			
Email address:			
Please tick the type of Membership you require:			
Individual	_____ £15 per annum	Family	_____ £25 per annum
		Life Membership	_____ £150
Please make cheques payable to 'The Pituitary Foundation'			

## Donate to The Pituitary Foundation

This leaflet was provided free of charge. We hope the information helped you; if you would like to help us, your donation will assist us in continuing this service. Please complete the form below, with your donation and send to

The Pituitary Foundation, PO Box 1944, Bristol, BS99 2UB



YOU CAN HELP...			
Name:			
Address:			
Postcode:			
I enclose a donation of	£		
I am a UK taxpayer	YES / NO		
Please treat all donations that I have made for 6 years prior to this declaration, and all that I make from this date, until I notify you otherwise, as Gift Aid donations			
Signature			Date
Please make cheques payable to 'The Pituitary Foundation'			

## HelpLine

Monday - Friday 9:00am – 5:00pm  
0845 450 0375

## Endocrine Nurse Helpline

available scheduled hours  
0845 450 0377

**Website:** [www.pituitary.org.uk](http://www.pituitary.org.uk)

**Email:** [helpline@pituitary.org.uk](mailto:helpline@pituitary.org.uk)

## More Information

The **Pituitary Foundation** publishes a library of leaflets on pituitary conditions, treatments and well-being issues.

For more information please visit our website, or call our HelpLine.

## The Pituitary Foundation

P.O. Box 1944

Bristol

BS99 2UB

[www.pituitary.org.uk](http://www.pituitary.org.uk)

HelpLine: 0845 450 0375

Administration Line: 0845 450 0376

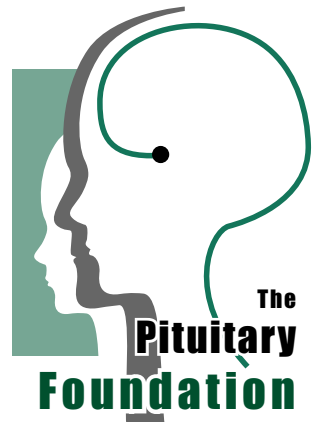
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*Working to support **pituitary patients**,  
their **carers & families***

**DISCLAIMER** All information is general. If you or your carer, have any concern about your treatment or any side effects please read the Patient Information leaflet enclosed with your medication or consult your GP or endocrinologist