



Patient & Family Guide

2024

Central Diabetes Insipidus (DI)



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What is central diabetes insipidus (DI)?

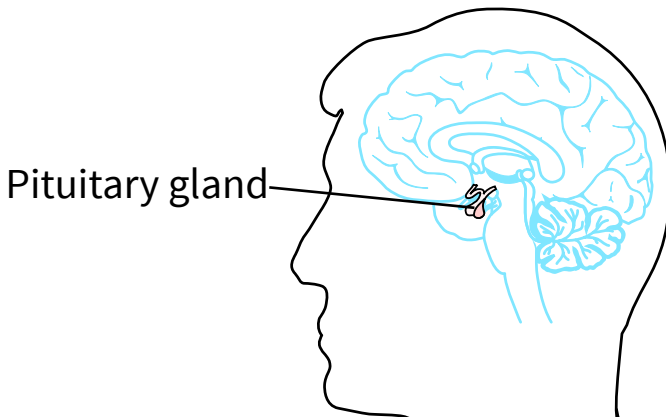
- Central diabetes insipidus (also called diabetes insipidus or DI) is a condition that causes the water in your body to be out of balance. DI is rare.
- Usually, the amount of fluid you take in or drink equals the amount of fluid that leaves your body when you urinate (pee).
- When you have DI, your body makes a lot of diluted (weak) urine. This causes your body to urinate more fluid than you take in or drink. This can make you feel dry and very thirsty.

- DI can easily cause dehydration (not having enough fluids).
- If you have DI, dehydration is a serious risk and can be dangerous.
- **If you have DI, drink a lot of fluids (like water) if you are thirsty. This will help to prevent you from becoming dehydrated.**

Note: DI is not the same as diabetes mellitus. Diabetes mellitus causes too much sugar in the blood. DI has nothing to do with blood sugar.

What is vasopressin (ADH)?

- Your water balance is controlled by a hormone called vasopressin (also called ADH).
- This hormone is stored in and released by the pituitary gland (a small pea-sized gland at the base of your brain, just above the back of your nose).



- Vasopressin keeps your water balanced by sensing how concentrated (diluted) your body fluids are. It prevents dehydration by taking water from your kidneys back into your blood.
- Damage to the pituitary gland can cause you to have less vasopressin. Not having enough vasopressin prevents your body from taking water from your kidneys back into your blood. This causes you to urinate a lot of diluted urine and get dehydrated more easily.

What causes DI?

- Since vasopressin is stored in and released by the pituitary gland, any condition that damages this gland can cause DI. These include:
 - › Head injuries
 - › Infections
 - › Bleeding in the pituitary gland
 - › Pituitary tumours
 - › Neurological surgeries (surgeries on the nervous system)
 - › Radiation to the brain
- Some people have DI only for a short time after having pituitary gland surgery, but in some cases it may be permanent.

What are the symptoms of DI?

- › Polyuria (urinating too much clear, diluted urine)
- › Polydipsia (extreme [very bad] thirst)
- › Extreme tiredness (this is usually from getting up often during the night to urinate)

How is DI diagnosed?

You may have tests to measure your urine and blood concentrations. These tests may include:

- Blood test to check your sodium (sodium can increase if you are dehydrated)
- Urine test for specific gravity (to check how dilute your urine is)
- Urine and serum osmolality (to check how concentrated your urine is)
- Water deprivation test: This test may be done to check you for DI.
 - › **You will not be able to drink any fluids for several hours (usually for the morning).** During this time, your blood and urine will be collected and tested.
 - › You will be weighed and your urine will be measured.
 - › If you urinate a lot during the test, you may be given vasopressin to check how your body responds.

How is DI treated?

- Before leaving the hospital, your health care team will test your blood and urine.
- If the tests confirm that you have DI, you will be started on synthetic (man-made) vasopressin (desmopressin, also called DDAVP®).
- DDAVP® comes in pills, a nasal spray, or an injection. Your doctor will talk with you about what type is right for you. Your health care team will watch you closely to make sure that you are taking the right dose (amount) for you.
- The goals of treatment with DDAVP® are:
 - › to balance the concentration of your body fluids. This is measured by doing blood tests.
 - › to prevent you from having to urinate a lot.
- An important part of your treatment is to balance how much fluid you take in with how much you urinate. **If DI is not treated, you could get seriously dehydrated.**

Nova Scotia DI funding

- Nova Scotia residents who have DI and who **do not** have private insurance coverage for medication may get help paying for their DDAVP® through Nova Scotia Pharmacare.

To use this service:

- › Your doctor must tell Nova Scotia Pharmacare in writing.
- › You must get your medication from the Metropolitan Dispensary in the IWK Health Centre.

If you cannot balance how much fluid you take in and how much you urinate, call your primary health care provider (family doctor or nurse practitioner). Signs of this imbalance include:

- › **Urinating a lot of clear, odourless (no smell) fluid**
- › **Being very thirsty**

For more information: Genetic and Rare Diseases Information Center (GARD)

- › <https://rarediseases.info.nih.gov/diseases/6015/central-diabetes-insipidus>
- › Phone (toll-free): 1-888-205-2311

Scan the QR code on your device (open the camera on your device, point the camera at the code, and tap the banner or border that appears)



This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

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Prepared by: Endocrinology

Illustration by: LifeART Super Anatomy 1 Images, Copyright © 1994,
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Designed by: Nova Scotia Health Library Services

WK85-1096 © August 2024 Nova Scotia Health Authority
To be reviewed August 2027 or sooner, if needed.