

Understanding Diabetes Insipidus

Diabetes insipidus, or DI, is a condition in which the kidneys are unable to regulate the amount of fluid in the body. Children with DI are very thirsty and urinate frequently. This handout will discuss DI and its causes and symptoms. It will also talk about how we treat DI and the outlook for children with DI.

WHAT IS DIABETES INSIPIDUS?

Diabetes insipidus (DI) is a condition in which the kidneys cannot regulate the amount of fluid in the body. This causes the body to make too much urine, which can cause dehydration.

There are 2 types of diabetes insipidus. Each type of DI is treated by a different type of doctor.

- **Central or neurogenic DI** is when the pituitary gland (a small gland just below the brain that controls other glands in the body) doesn't release vasopressin into the bloodstream. Children with central or neurogenic DI are treated by endocrinologists (endocrine gland doctors).
- **Nephrogenic DI** is when the kidneys don't respond to vasopressin. Children with nephrogenic DI are treated by nephrologists (kidney doctors).

What is vasopressin?

Vasopressin is a hormone that helps keep the right amount of water in the body. It is often called antidiuretic hormone or ADH.

Vasopressin is made by the hypothalamus (a small part of the brain just above the pituitary gland) and stored in the pituitary gland for the body to use. The back part of the pituitary gland stores the vasopressin until the body needs it.

Normally, when the body needs to hold onto fluid, the pituitary gland releases vasopressin to the kidneys. This makes the kidneys retain fluid so the body doesn't become dehydrated. This causes the kidneys to make less urine than usual.

When there is a problem with vasopressin, the kidneys lose too much fluid. This causes dehydration and frequent urination.

WHAT ARE THE SYMPTOMS OF DI?

Children with DI might show these symptoms:

- **Extreme thirst**
If your child doesn't have enough to drink, he/she might find fluids from unusual places, like a garden hose, bathtub or fish tank.
- **Needing to urinate more often than usual, especially at night.**
Some children might wet the bed at night.
- **Preferring ice cold water to other liquids**
- **Weight loss in children**
Children might lose weight because they are too busy drinking water and urinating and not eating enough food.
- **Weight gain in babies**
Babies might gain weight from drinking too much milk in order to get enough fluid.
- **Dehydration**

WHAT CAUSES DI?

The causes of central or neurogenic DI and nephrogenic DI are different.

Central or neurogenic DI can be caused by:

- **Damage to the hypothalamus or pituitary gland**
- **Head trauma**
- **An infection, tumor or growth near the hypothalamus or pituitary gland**
- **Surgery near the hypothalamus or pituitary gland**
- **Poor development of the hypothalamus or pituitary gland before birth**
- **Randomly and for no explained reason**
We call this **idiopathic DI**, which means we don't know the cause or reason of the central or neurogenic DI.

Nephrogenic DI can be caused by:

- **Genetic problems in which the kidney doesn't properly respond to vasopressin or other parts of the kidney's water-saving machinery**
- **Medications, such as lithium and demeclocycline (an antibiotic)**
- **Urinary tract infections (UTI)**
- **Imbalance of certain blood chemicals, like calcium and potassium**
- **Damage to the kidney tubules (tubes inside the kidneys that transfer water and salt into urine)**

HOW DO WE TREAT DI?

Central or neurogenic DI and nephrogenic DI are treated differently.

We treat **central or neurogenic DI** by giving medication to provide the vasopressin effects that the body needs. This medication comes in 2 forms, which are:

- **Vasopressin given as an injection**
The effects of the **vasopressin injection** last for only a few minutes.
- **As a medication called desmopressin**
The effects of desmopressin last for 8-24 hours. Desmopressin can be given as a nasal sniff (a mist you sniff through your nose), a pill or an injection. It is usually given about 2 times a day. When your child takes desmopressin, it's a good idea to make sure your child has urinated before taking the next dose. This will help make sure your child doesn't become overloaded with fluid.

We can also help treat DI by making sure children drink fluids only when they are thirsty and not just because they want or like a drink. This will help prevent them from becoming overloaded with fluid.

Sometimes, it can be difficult to treat babies with central DI with desmopressin because they need to take in so much fluid to get the nutrition they need. They often do better when they are treated with **hydrochlorothiazide**, given as a pill or liquid and a diluted (watered down), low protein formula until they are mostly taking solid foods. Hydrochlorothiazide works on the kidneys to help hold onto the water your baby's body needs.

*If you are concerned or have questions,
please call us at (617)726-2909.
We want to hear from you!*

We treat **nephrogenic DI** in a few ways, such as:

- **Following a low-protein diet**
- **Drinking fluids that are mostly plain water**
- **Giving drugs like hydrochlorothiazide**

Because nephrogenic DI is sometimes caused by kidney damage, treating the reason for the kidney damage can help the kidneys heal so they can respond to vasopressin normally. This might include:

- **Stopping medications that cause nephrogenic DI**
- **Treating a kidney infection**
- **Correcting imbalances in calcium and potassium**

WHAT IS THE OUTLOOK FOR MY CHILD WITH DI?

Children with **central or neurogenic DI** do well when they are treated appropriately with medication. If your child has idiopathic DI, he/she will need frequent examinations, including MRIs of the pituitary gland, to see if there is a cause that we haven't been able to find.

The outcomes of children with a known reason for central or neurogenic DI depend on the cause of the DI. For example, if your child had a head injury, he/she should lead a normal life if the brain injury heals. However, your child will still need to take medication for DI. Sometimes, central or neurogenic DI from a head injury or after surgery slowly gets better on its own. This is because the nerve fibers from the hypothalamus that were cut off slowly grow back and store vasopressin again.

Children with **nephrogenic DI** often do quite well if their DI was caused by a medication that can be stopped or from a chemical abnormality that can be controlled. Children who are born with nephrogenic DI should be treated carefully to protect their kidneys as much as possible. They should also stay hydrated, even when they are sick, so their brain development is protected. This is especially true for young children

WHEN SHOULD I CALL MY DOCTOR?

You should call the doctor if your child:

- **Is vomiting or has diarrhea from an illness**
He/she should be seen immediately by a doctor so they don't develop severe dehydration.
- **Is hospitalized, has surgery or needs intravenous (IV) fluids**
Ask your other health care providers to contact your child's endocrinologist or nephrologist. The doctor who treats your child's DI can help decide which IV fluids and medications your child should have.

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For more information please call

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