Hypopituitarism
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Hypopituitarism

This booklet has been written for you and your family. We hope it will help you to learn about hypopituitarism. The booklet will define hypopituitarism as well as discuss its symptoms and treatments.

There is a lot to know about hypopituitarism. Your doctor and nurse will discuss with you the details of this condition. This booklet is meant to serve as a supplement to their teaching. We would like you to become involved in your treatment. Please ask the nurse or doctor to explain anything that may not be clear.

What Is Hypopituitarism?

It is a decrease or absence of one or more of the pituitary hormones. “Hypo” means “less than normal”. The term panhypopituitarism may be used when ALL of these hormones are deficient (“pan” means “all”).

The pituitary is called the “master” gland. It is a pea-sized gland found in the middle of the skull. This gland will release its hormones in response to messages sent from the part of the brain called the hypothalamus. It is called the “master” gland because its hormones signal all the other endocrine glands to produce their own hormones.
The **target glands** are those glands in the body that make **hormones** in response to signals from the pituitary gland. These target glands are:

- the thyroid gland
- the adrenal gland
- the ovaries in females, and the testes (testicles) in males

**Hormones** are the chemical messengers. They are released from a gland into the bloodstream. The bloodstream then carries the hormones to the tissues and organs of the body that use them.

The front part of the pituitary makes many kinds of hormones that are needed for the body to function. The hormones that come from the front pituitary gland are: Thyroid Stimulating Hormone (TSH), Adrenocorticotropic hormone (ACTH), Growth Hormone (GH), and the Gonadotropins – Follicle Stimulating Hormone (FSH) and Luteinizing Hormone (LH).

The back part of the pituitary is a storehouse for the Antidiuretic hormone (ADH).
What Causes Hypopituitarism?

In many cases, we do not know what causes it. We do know that, in most cases, it is not hereditary. Parents do not pass it on to their children.

Hypopituitarism may be **congenital**. This means that the pituitary or hypothalamus did not form normally before birth. In other cases it may be **acquired**. This occurs if there was damage to the pituitary or hypothalamus during or after birth. Hypopituitarism can be caused by a tumor in the pituitary area of the brain, a severe head injury, or an infection in the central nervous system (such as encephalitis). Radiation therapy to the part of the brain where the gland is found may cause hypopituitarism. It also occurs if the pituitary gland is removed.

What It Means to You

At this time, you may be missing one, some, or perhaps all of these hormones. You and your family need to have some knowledge of **all** of the pituitary hormones. The doctors and nurses watch for signs and symptoms of other hormone deficiencies when you are seen in clinic. But, what you observe between visits is crucial as well.

When there are not enough of the pituitary hormones being released in your body, the target glands (thyroid, adrenal, ovaries, or testes) are not able to get the correct messages. Therefore, the glands do not produce their own hormones. For example, the thyroid gland is not “told” to make thyroid hormone when there is a lack of thyroid-stimulating hormone (TSH) from the pituitary. Without normal levels of the target gland hormones, your body is not able to function as it should.

Hypopituitarism is almost always permanent, but it can be treated. Treatment involves replacing the hormones with a pill, a shot, or nasal (nose) spray. Your body can use these hormones in place of the natural ones that your body is not making. Next we will discuss each hormone and what it means if you lack this hormone.

I. Thyroid-Stimulating Hormone (TSH) Deficiency

The thyroid is a small gland found in the neck, in front of the wind-pipe. It makes and releases thyroid hormones (see drawing). A lack of thyroid-stimulating hormone means the thyroid is not making this hormone.

![Diagram of thyroid hormone production](image-url)
Thyroid hormones are needed for physical and mental growth. It helps to make the body function as it should. Some ways your doctor or nurse can figure out if you are lacking thyroid hormones are:

- Symptoms - (listed below)
- Physical exam, which includes growth rate during childhood and adolescence
- Blood tests that measure levels of the thyroid hormones and thyroid-stimulating hormone. These tests are called a T₄, T₃, and TSH levels.

If your thyroid hormone level is too low, a daily pill(s) is prescribed by the doctor to replace the hormone. The pill often prescribed is called Synthroid® (levothyroxine sodium). You will take this pill daily. You will most likely need to take it for the rest of your life.

To be certain that this hormone is being replaced in the correct amount; you will need clinic visits for check-ups and blood tests.

Between clinic visits, you will need to know what signs and symptoms may occur if too few or too many thyroid hormone pills are being taken.

**Too Little Thyroid Hormone or Not Enough Thyroid Medicine**

- feeling cold (often when others do not feel cold)
- cool, dry skin
- constipation
- fatigue and increased sleep
- slow growth in height; weight gain
- poor appetite
- calm and quiet disposition
- coarse, dry, thin hair

**Too Much Thyroid Medicine**

- feeling hot (often when others do not feel hot)
- moist, sweaty skin
- diarrhea
- trouble sleeping, feeling nervous or restless, short attention span
- normal or rapid growth in height; weight loss
- increased appetite
- irritability
- fine hair which can sometimes fall out
II. Adrenocorticotropic Hormone (ACTH) Deficiency

A lack of the hormone ACTH results in a lack of cortisol. This hormone is made by the adrenal glands. These two glands are found on top of the kidneys in the middle of the back.

Cortisol keeps the body’s blood sugar at a normal level. It also helps the body deal with physical stress, such as fever or injury. Some of the ways your doctor figures out if you are not able to make proper amounts of cortisol are:

- Symptoms such as changes in the way you feel. This includes how well you keep up with your daily routines and handle illness.
- Physical exam, which include checking your height and weight.
- Blood and urine tests to measure amounts of cortisol.

If too little cortisol is being made, hydrocortisone (Cortef®) is prescribed. Hydrocortisone is taken as a pill. It is taken 2-3 times daily throughout life. If for any reason you cannot take the medicine by mouth, it must be given as a shot. The dose prescribed will be enough for normal daily tasks when you are well. It is very important that the dosage be increased with fever, some illnesses, and injury. Guidelines for how to handle these times are outlined in a Health Facts for You called “Guidelines for the Child Who is Cortisol Dependent.” Your nurse and doctor will instruct you about this important information.

Again, you need to be aware of the symptoms that may suggest too little or too much cortisol (hydrocortisone).
Too Little Cortisol or Not Enough Hydrocortisone

- weakness or extreme tiredness
- illnesses such as colds and flu seem to be more severe and last much longer than expected
- nausea or vomiting
- diarrhea
- cold, clammy skin
- fast pulse
- fast breathing
- dizziness
- confusion
- severe pains in abdomen, legs, lower back
- lower than normal body temperature

Too Much Hydrocortisone

- decreased growth rate
- increased weight, especially in face and abdomen
- increased bruising

III. Growth Hormone (GH) Deficiency

Growth hormone is a pituitary hormone. It affects the growth of bone and body tissues. Unlike the other hormones discussed, GH does not stimulate a specific target gland. This hormone stimulates the body's organs, bones, and tissues.

When lacking enough growth hormone, a child grows very slowly. In time the child is much smaller and younger looking than the child’s same age peers. The child may have a slightly chubby or “baby face” look.

Ways your doctor will decide if you are lacking GH are

- Growth rate: an exam of your height over a certain length of time compared to your past growth rate.
- Blood test: a growth hormone test (blood samples are taken after a 6-hour fast and an oral or injected medicine).
- Bone age x-ray: a hand x-ray that tells us how slow or fast your bones are growing.
If you are found to be lacking GH, and you are not growing as you should, GH can be replaced with a shot. It is most often given once a day. GH does not work if given by mouth. GH is given until your growth is complete, or stopped when you reach an adult height. When GH deficiency is severe, it may be necessary to continue GH treatment into adulthood to maintain healthy bones, muscles, and energy level.

The clinic nurse will teach you or your parent to give the GH shots at home.

Side effects from taking GH are few and rare. Sometimes swelling may occur. This will go away. Rarely, it can cause the blood sugar to rise to higher than normal levels. And, if you notice headaches or pain in your hips or legs, contact your doctor promptly.

While getting GH shots, your growth rate is watched closely. Clinic visits are scheduled every 3-6 months. During these visits, your height and weight are checked. Sometimes bone age x-rays and blood tests are done.

IV. Gonadotropin (FSH, LH) Deficiency

Gonadotropins are the hormones that begin the process of sexual growth. In girls, these hormones tell the ovaries to make the hormones that cause breast development, menstrual periods, and other changes such as, rapid growth in height and change of body shape.

In boys, these hormones tell the testes (testicles) to begin making sperm. Testosterone is the hormone that causes increased size of the penis and testes, facial hair growth, a lower voice, and other body changes such as, rapid growth in height and muscle mass.
If you are missing some or all of the other pituitary hormones, you may be missing gonadotropin hormones as well. We may not know for certain until you are near the teen years when puberty should be starting. Some ways your doctor can figure out if you are not able to make enough of these hormones are:

- Physical exam of breasts in girls and genital areas in both sexes.
- Growth rate
- Bone age x-ray
- Blood tests

If you appear to be lacking these hormones, replacement of the sex hormones is the treatment needed to begin sexual development. Sex hormones in girls are estrogen and progesterone. The sex hormone replaced in boys is testosterone. Now we will look at how these hormones are taken in both girls and boys.

**Treatment for Girls**

Sex hormones are given either in pill (oral) or patch form for girls.

**Pills:** If pills are used, one estrogen hormone pill (Premarin®) is taken per day. After some months, a second pill, a progesterone hormone (Provera®), is added for some of the days of the month. A monthly “cycling” schedule is maintained in an attempt to mimic the way the ovaries should be making hormones. At the end of each monthly cycle, a menstrual period or bleed will occur for a number of days. These periods are often a bit shorter and involve less bleeding than periods in girls who produce their own hormones.

After several cycles, your doctor may change to a single pill that combines both hormones. This is really the same kind of tablet that is called an oral contraceptive.

**Patch:** Another way that estrogen is given is with a skin patch containing estrogen alone. Skin patches are worn on the hip or buttock, and changed either once or twice a week.

Effects of estrogen are
- increased height
- a slow growth of breast tissue
- a change to a more feminine body shape
- mood changes and swings
- increased appetite
- slight changes in voice
- interest in sexual activity

These sex hormones do not cause growth of pubic and underarm hair which may be sparse in patients with hypopituitarism.
Treatment for Boys

Sex hormones for boys are most safely given by injection (shot) or by placing a gel or patch onto the skin.

The hormone (testosterone) injections are given into a large muscle in the hip (gluteus) or the thigh every 3-4 weeks. Most often, treatment for younger teen boys begins with these shots, and most often the nurse or doctor in your local doctor’s office will give them. Some parents and the boys themselves prefer to learn how to give the shots for greater ease. The clinic nurse can teach you how to prepare and inject the testosterone, if you prefer.

For older teen boys, and grown men, a testosterone gel or patch may be prescribed instead of the injections. The gel is applied onto the skin each day, and the patch is placed on the skin and changed each day. Your doctor, nurse or pharmacist can instruct you about how to apply these and about what areas of skin to use and to not use.

Effects of testosterone are
- increased height
- growth of underarm, pubic, and some body hair
- increase in the size of the penis
- beginning of penis erection and ejaculation
- increased muscle throughout the body with a gradual change to a masculine body shape
- mood changes and swings
- increased appetite
- a deepening in voice
- interest in sexual activity

The size of the testes does not change much as they are not making the testosterone.

In both girls and boys, clinic visits every few months are needed when sex hormone treatment is started. Sometimes, doses need to be changed to assure that these body changes are not taking place too slowly or too quickly. For the same reason, bone age x-rays of the hand and blood tests are done at some of these clinic visits.

Once growth is complete and a dose is figured out, visits will be much less often. These hormones are given well into adult life. While it is not life threatening to stop these hormones, they provide a means to a normal adult life. As the teens and young adults mature, they are able to have normal sexual function. Lack of gonadotropins can affect fertility. Since new findings related to fertility are always being explored, you may wish to consult with fertility specialists in the future. Later in adult life, you with your doctor’s guidance may decide to stop or decrease hormone replacement.
V. Antidiuretic Hormone (ADH) Deficiency

The back (or “posterior”) part of the pituitary acts as a storehouse for an important hormone called ADH. ADH helps the body to retain the water that it needs to work as it should.

When ADH is lacking, the kidneys cannot concentrate urine. The two most noted warning signals are:

- excessive thirst
- frequent urination, often very dilute, pale-colored urine

This can lead to severe dehydration if not enough fluids are taken to “keep up” with the amount of fluid being lost as urine. Severe dehydration calls for immediate medical treatment. ADH deficiency is also called diabetes insipidus or “D.I.” This is not the same as the more common diabetes mellitus or “sugar diabetes”.

Ways your doctor will decide if you are lacking ADH are listed below.

- Increased urination and thirst.
- Loss of weight.
- Laboratory tests of both blood and urine.

When the pituitary gland does not release ADH, this hormone can be replaced with a medicine called desmopressin or DDAVP which comes either as a pill or a nasal spray. Desmopressin helps the body in the same way that ADH does. It allows the body to hold onto the fluid it needs. The doctor, nurse, or pharmacist will instruct you on its use. Most often, it needs to be given at least once per day throughout life.

Listed below are signs of too little or too much ADH

**Too Little ADH or Not Enough Desmopressin (DDAVP)**

- Frequent and increased urination of pale-colored urine
- Increased thirst
- Dehydration, if fluid intake not enough (symptoms include dry tongue, sunken look to eyes, tearless cry)
- If untreated, can lead to increased sleepiness and, in time, coma
Too Much Desmopressin (DDAVP)

- Decreased urination of concentrated, very yellow urine
- Decreased thirst
- Less urine output than intake of fluids
- Weight gain (puffiness)
- If untreated, can lead to confusion, increased sleepiness, and, perhaps, seizures

If these symptoms are noted, changes in the dose of medicine may be needed. Sometimes, it may appear that the usual dose not work as well when a cold, allergy, or other cause of nasal congestion exists. It is important to clear the nose of mucous before the medicine is given. Adults and older children can merely blow the nose well. Infants and young children may need to have the mucous cleared by using a bulb syringe. Your nurse and doctor will provide you with a more complete explanation about the treatment of ADH deficiency. They will discuss with you what you need to know about safety and what to do in an emergency.

Your Future with Hypopituitarism

There are ways you can help yourself have a healthy life with hypopituitarism. First you need to have a good understanding of your condition. Along with this knowledge, you need to make sure you take the correct hormone replacement treatment. Part of good health also includes regular clinic visits with your doctor. While your treatment is prescribed by a doctor, the key to doing well is up to you. Here are a few guidelines to help.

- Know your medicines and take them as prescribed. It is vital that you do this. Talk to your doctor, nurse or pharmacist if you are not sure how to take them. It may be helpful to ask for ways to remember to take them on time.

- For ACTH and ADH deficiencies, you need to be sure to always wear your Medic-Alert bracelet. In case of accident or sudden illness, the information on this bracelet can be life-saving.

- As your life changes, you may need to inform new people in your life (teacher, roommate, spouse) about your medical needs. This is very important if you are cortisol dependent. If you are not sure how to explain your needs, talk to your nurse or doctor. They can help find a good way to explain it to others. It may be helpful to use this booklet as a guide.

- For further information, call your doctor or nurse or contact the American Family Children’s Hospital Pediatric Specialty Clinic at (608) 263-6420.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 12/2017 University of Wisconsin Hospitals and Clinics Authority, All rights reserved. Produced by the Department of Nursing. HF#4619
## Notes about Your Care

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More Notes About Your Care

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