

# NIH Clinical Center Patient Education Materials

## Managing adrenal insufficiency

This information was developed by the patient care staff of the NIH Clinical Center to help patients with adrenal insufficiency (AI) understand their condition and how to take care of it. It explains what causes adrenal insufficiency and how it can be controlled. If left untreated, adrenal insufficiency can cause serious illness or death. But by working with their doctors and nurses, patients can learn how to manage this condition.

### What are the adrenal glands?

Your body has two adrenal glands. Each gland is located above a kidney. The adrenal glands secrete many hormones needed for the body's normal functioning. People with AI do not have enough of the hormones cortisol and aldosterone.

Cortisol helps the body use sugar and protein for energy and enables the body to recover from infections and stresses (for example, surgery, illness).

### What is adrenal insufficiency?

Adrenal insufficiency means that there is not enough cortisol. Some causes of AI also lead to low aldosterone levels.

Without the right levels of these hormones, your body cannot maintain essential life functions.

Aldosterone maintains the right amount of salt, potassium, and water in the body.

Adrenal insufficiency may be permanent or temporary. When AI is permanent, medication must be taken daily for the rest of the patient's life.

Causes of permanent AI include the following:

- Addison's Disease
- Congenital adrenal hyperplasia (CAH) discovered in childhood
- complete surgical removal of the pituitary gland
- surgical removal of the adrenals

Temporary adrenal insufficiency is brought on by some medications, infections or surgeries, or when the proper medication is not taken. Causes of temporary AI include the following:

- transsphenoidal surgery for Cushing disease that removes a tumor from the pituitary gland
- removal of a tumor that has been causing the adrenal glands to make too much cortisol
- medical treatment for Cushing's Syndrome with drugs that lower cortisol levels
- medical treatment with steroids for prolonged periods of time

### What are the signs and symptoms of adrenal insufficiency?

When your essential life functions are not being maintained because of a lack of adrenal hormones, you will not feel well. Your symptoms could include:

- unusual tiredness and weakness
- dizziness when standing up
- nausea, vomiting, diarrhea
- loss of appetite
- stomach ache
- joint aches and pains

Other symptoms you may experience over time include:

- weight loss
- darkened skin
- craving for salt

If any of these symptoms appear, and you know that you are at risk for AI, call your local doctor immediately.

## **What medication is used to treat AI?**

To keep your AI under control, you must take medication daily to replace missing hormones. This medication is in pill form and must be taken in the amounts and at the times prescribed by your doctor. This medication is often referred to as your replacement dose. Many medicines can replace the action of cortisol; they are called glucocorticoids. At NIH usually hydrocortisone or dexamethasone or prednisone is recommended.

You may be told to take your medication one to three times a day. Be sure to follow the instructions for taking your medication.

If you are also missing the hormone aldosterone, your body cannot maintain the right levels of sodium (salt) and fluids. To replace aldosterone, you will be given a drug called fludrocortisone (Florinef).

Adults usually take tablets of Florinef. Children with AI who have trouble swallowing pills can take Florinef tablets dissolved in water or crushed. Occasionally, you will also be given salt tablets.

## **What are the side effects of these drugs?**

Replacement doses of hydrocortisone cause almost no side effects. Sometimes, however, an upset stomach may occur. If this happens, take your medication with meals. If you notice anything else out of the ordinary, call your local doctor.

If the dose is too high, patients can gain weight or develop signs of Cushing's syndrome.

## **What do I do when I don't feel well?**

There may be times when you do not feel well. When you are sick be sure to take the right amount of medication at the right time of day. If you feel sick for more than three days, contact your doctor.

There may also be times when you will need to take more than your normal replacement dose of hydrocortisone.

Normally functioning adrenal glands produce more hydrocortisone when the body is under the physical stress of fever (over 100 degrees Fahrenheit), infection, surgery, vomiting, or diarrhea. It is important to drink plenty of sugar and salt containing fluids when you are sick to prevent dehydration or low blood sugar.

The fact that you have AI means that your body cannot deal with these stresses by making more cortisol. Just as you must replace your basic cortisol needs with your replacement dose, you must also replace your increased needs with an extra dose of oral or injectable glucocorticoid. If you are sick with fever (over 100 degrees Fahrenheit), infection, vomiting, or diarrhea you may need to take extra glucocorticoid medicine and you should call your local doctor right away.

Your health care provider may give you written instructions for sick days ("sick day rules").

Generally, this means doubling your usual hydrocortisone dose for 1 to 3 days. It is important to discuss the decision to increase the dose with your doctor.

It is important that you increase your hormone dose only for physical stresses.

You should not increase it for mental stress (such as a bad day at work, anxiety, or loneliness).

## **What if I am so ill that I cannot take my medication?**

If you are too ill to take your pills, or you cannot keep them down (i.e. vomiting), you must take a glucocorticoid medicine by injection. You or someone who lives with you will need to learn how to give you this injection.

The shot will take the place of both hydrocortisone and Florinef pills. If you find it necessary to give yourself injectable medication, call your local doctor or go to the nearest hospital emergency room immediately after giving the injection.

## **How much medicine should I take once I feel better?**

As soon as your illness is over and the symptoms are gone (for example, fever, vomiting, diarrhea), you can usually return to taking your usual amount of medication. You should discuss this with your local doctor.

## **How do I give myself an injection?**

Injectable glucocorticoid is given intramuscularly, which means that it is injected into a large muscle. When giving yourself an injection, the easiest and best place to give it is in the thigh on the same side as your dominant hand (for example, the right thigh if you are right-handed).

Adults should always carry injectable medication with them.

If you have a child with AI, you or the child's caregiver must always carry the child's medication. If the child is in school, the school nurse must know about your child's condition and be able to provide emergency care such as giving an injection of glucocorticoid.

How to give an injection of hydrocortisone

1. Wash your hands
2. Assemble your equipment
3. Mix the medication vial by pushing down on top of the vial to release the cork
4. Shake the vial to mix the medication solution well
5. Use alcohol to clean the rubber stopper on the vial
6. Take the cap off the syringe and put the needle into the vial
7. Draw up the medication:
  - a. Adults should use all the medication in the vial.
  - b. For a child, use the dose prescribed by the doctor
8. Replace the needle cap
9. Select your injection site.

To inject yourself safely, become familiar with your body. Uncover your thigh and look at it. Now, draw an imaginary line in the middle of your thigh to divide it in half lengthwise. The outer portion is where you will be injecting. Now, imagine your thigh divided into three equal portions, from the knee to the hip. The outer portion of the inner third of your thigh is where you will do the injection.

10. Use alcohol to cleanse the injection site on your skin
11. Remove the cap from the needle. Hold the syringe like a dart.
12. Using your thumb and first two fingers, spread your skin while pushing down lightly.
13. Dart the needle into the thigh injection site, going straight in at a 90-degree angle.

14. Hold the syringe in place. Pull back the plunger to make sure you are not injecting into a large blood vessel. If blood appears in the syringe, withdraw the syringe and discard it.

**If this is the only dose of medication you have, inject the medication.**

If you have another vial of medication, prepare another syringe with medication, and inject yourself in a slightly different place.

15. After injecting the medication, put tissue or gauze near the needle, and pull the needle out quickly.

16. Massage the injection site gently.

17. Place the syringe and needle in a hard, unbreakable container (such as an empty coffee can with a lid) before disposing of it.

18. Call your local doctor.

## **What else do I need to know about adrenal insufficiency?**

You can control adrenal insufficiency by taking an active role in your care. Taking care of yourself involves:

- learning about your disease
- taking your medication every day
- recognizing illness in your life and taking special care of yourself
- getting regular medical check-ups
- wearing a Medic-Alert bracelet at all times (This will be given to you before you leave the NIH Clinical Center).
- Inform your other health care providers of the diagnosis of AI before any surgical procedure to determine whether “stress dosing” is needed.

If you follow the guidelines here and the instructions of your health care team, you will be able to lead a full and productive life. Only you can take care of yourself.

## **Glossary**

### *Addison’s disease*

An illness caused by the failure of the adrenal glands to secrete enough adrenal hormones.

### *Adrenal glands*

Two glands, each located above a kidney, that secrete cortisol and other essential hormones.

### *Aldosterone*

A hormone made by the adrenal glands that regulates salt, potassium, and water in the body.

### *Congenital Adrenal Hyperplasia (CAH)*

A deficiency of adrenal hormones that is present from birth.

### *Cortisol*

A hormone secreted by the adrenal glands that regulates carbohydrate and protein metabolism.

### *Cushing’s disease*

A pituitary tumor that makes too much ACTH and causes Cushing syndrome

### *Cushing’s syndrome*

An illness caused when too much cortisol is made by the adrenal glands.

*Glucocorticoid*

A hormone that is produced by the adrenal cortex that is involved in carbohydrate, protein, and fat metabolism and has anti-inflammatory properties

*Hydrocortisone*

A form of cortisol. This is the drug used to replace cortisol in the body.

*Transsphenoidal surgery*

Highly specialized neurosurgery in which tumors are removed from the pituitary gland.

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