

Patient information from BMJ

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Primary adrenal insufficiency (Addison disease): what is it?

Primary adrenal insufficiency, or Addison disease, is a rare condition that affects the body's ability to produce certain hormones. It causes extreme tiredness and weakness and can be life threatening if not treated. But drug treatments can help most people live a normal life.

What is primary adrenal insufficiency (Addison disease)?

Primary adrenal insufficiency (PAI) is a condition that affects two small glands that sit just above the kidneys, called the **adrenal glands**. These glands produce hormones, including two called cortisol and aldosterone.

PAI used to be called **Addison disease**, and this is probably the name by which most people still know the condition.

If you have PAI these glands are damaged and can't produce enough of these hormones. This causes symptoms including extreme tiredness. If left untreated the condition can be life threatening.

Several things can cause PAI. Finding the cause in each person is important in helping find the best treatment.

In most people PAI is what's called an **autoimmune** condition. This means that the body's immune system, which usually protects against infection, attacks some of the body's tissues instead. In this case the immune system's antibodies attack the adrenal glands.

Other, less common, causes of PAI include:

- tuberculosis, HIV, and some other infections
- cancer
- some medications
- bleeding in and around the adrenal glands that destroys them.

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People with autoimmune diseases, such as type 1 diabetes, rheumatoid arthritis, or the most common type of hypothyroidism, can develop antibodies against the adrenal glands. But they usually don't have symptoms.

What are the symptoms?

The main early symptoms of PAI are:

- fatigue (tiredness)
- loss of appetite, which after a while leads to a lot of weight loss
- muscle weakness.

As the condition develops it can cause brownish patches on the skin (called **hyperpigmentation**), especially on:

- areas where the skin creases, such as the palms and knuckles
- skin exposed to the sun, and
- areas of skin exposed to frequent friction.

Other, less common, symptoms include:

- muscle pain
- nausea, vomiting, and stomach cramps
- a craving for salt
- dizziness.

PAI can be hard for doctors to diagnose, especially in its early stages. This is because symptoms like tiredness and weakness are similar to those of common conditions, such as flu. As a result, many people are not diagnosed until they have what's called an **adrenal crisis**.

During an adrenal crisis your levels of the hormones usually produced by the adrenal glands have fallen dangerously low and you are seriously ill. An adrenal crisis can be life threatening.

If your doctor suspects that you have PAI you will need a blood test to check your hormone levels. But if your doctor suspects that you are having an adrenal crisis (by which time you will probably already be having emergency treatment in the hospital) he or she will not wait for the results of tests before treating you.

What will happen?

If you have PAI you will need to take your prescribed medication for the rest of your life. Your doctor will discuss with you how to take your medication, and about times when you may need to take more than usual. For more information see our leaflet: *Primary adrenal insufficiency (Addison disease): what treatments work?*

Not taking your medication means that your symptoms will return, and that you could have an adrenal crisis. So it's important to always make sure that your supply of medications doesn't run too low.

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Once your condition is stable (under control) you will need to see your doctor and perhaps a specialist every year to discuss your condition and how your medication is working.

There are various things you can do to stay healthy. For example, everyone with PAI should carry a medical alert card or wear a medical alert bracelet. If you are in an accident or lose consciousness (black out) for any reason, your doctor will then know that you need your corticosteroid medication.

You should also keep emergency shots at home in case you lose consciousness or are in an accident. Family members should be taught how to give you these shots, in case you can't, because of an adrenal crisis or for any other reason.

And it's important to keep an eye on when your emergency shots are due to reach their expiry date, so that you get replacements in plenty of time.

You can find training on how to give the injections online. And your doctor might be able to direct you to other useful online resources and support groups.

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