

Patient information

Addison's Disease

Diabetes and Endocrinology Department

What is Addison's disease?

Addison's disease affects the way in which your adrenal glands work. The adrenal glands are two small organs, which are situated on the top of each kidney. They do not affect the way your kidneys work. The adrenal glands make a steroid hormone known as cortisol.

Why do I need cortisol?

Cortisol is needed to ensure all the tissues in the body work correctly. During any type of stress or illness, your body would increase the amount of cortisol made. In Addison's disease the body's ability to increase the amount of cortisol made is lost. This means that there is a shortage of cortisol within the body.

What else do the Adrenal glands do?

The Adrenal glands also produce a hormone known as aldosterone. This hormone works to keep the balance of salts within the blood stream at the correct levels.

What happens to me as a result of Addison's disease?

You may feel tired and worn out. Loss of appetite and loss of weight is also a common feature. Sometimes nausea and vomiting can be present. You may feel the cold more easily and dizziness can develop. This is especially noticed when getting up out of a chair or when getting out of bed. There can be some changes in your skin colour, making you look tanned.

If untreated, the shortage of both hormones can lead to dehydration. This can result in serious illness, with a potential for you to become unconscious.

Why does Addison's disease happen?

The most common reason is the body's own immune system destroys the glands. This means the glands become smaller or damaged. Some infections can result in damage to the adrenal glands. If you have had an operation where both the adrenal glands were removed then you will need the same treatment as a person with Addison's disease.

How is it diagnosed?

Routine blood tests are not always accurate in showing the correct cortisol level. This is because the amount of cortisol present in the blood stream changes during the day.

A 'synacthen' test is needed to confirm the diagnosis. This involves a series of blood tests taken before and after an injection of a synthetic, or man-made, hormone, called synacthen.

This synthetic hormone is given to try to get your adrenal glands to produce more cortisol. The injection is given into a muscle, usually your leg or buttock, and can sting when it first goes in.

This test will be carried out as an out-patient at the Royal Liverpool University Hospital. A separate leaflet is available about the test. Please ask for PIF 823.

What treatment is there?

Hydrocortisone tablets are used to replace cortisol. You will need to take these every day for the rest of your life.

The usual dose is 20 to 30 milligrams per day. This is taken in two or three doses during the daytime. The first dose should be taken as soon as possible after you wake up. If you can, leave the tablets at your bedside with a drink and take them before you get up. The other doses should be spread throughout the day.

Ideally, the last dose should be taken around 4pm, but no later than 6pm. By following this pattern, you mimic what your body would do naturally.

It is important that you do not miss any doses. If you do forget to take your dose you should take it as soon as you remember. You should carry on with the next dose as normal for that day. Do not take extra doses to make up for any you may miss.

To replace the aldosterone, a medication called Fludrocortisone is used. The dose of this can vary a great deal between patients. The exact dose for you will be determined by your blood pressure readings.

Is there an alternative treatment?

There are other forms of 'steroid' tablets that will replace cortisol for you. These are Prednisolone and Dexamethasone. These tablets are more potent or stronger in action than Hydrocortisone and so you will need to take smaller doses of them.

Making changes to the dose of these can be difficult as they are effective in the body longer than Hydrocortisone. This can also mean we cannot copy the body's cortisol production as well as we can with Hydrocortisone.

There is no alternative to Fludrocortisone.

What will I feel like on the treatment?

You should feel much improved soon after starting the treatment. Your energy levels will increase and the dizziness and any nausea should clear up. You will find your appetite returns. Your skin colour should return to normal.

How do I know the dose is right for me?

If your replacement tablets need adjusting, you may begin to have the same type of problems that led you to seek help.

This could include dizziness, loss of appetite, weight loss or darkening of skin colour. If you feel this is happening to you then you should contact your doctor immediately as your tablets may need to be adjusted.

What if I want to stop taking the tablets?

You should not do this without medical advice. As you are unable to produce your own cortisol and aldosterone, you need this treatment to stay well. Without it you risk serious illness, even death.

Please discuss any concerns you have regarding your medication with the doctors at clinic. If you prefer, you can contact the specialist nurses, whose number is at the end of this leaflet.

What if I become unwell?

We recommend you should try to copy the normal reaction of the adrenal glands, which would be to produce more cortisol. During a mild illness, such as a cold without a high temperature, you should continue to take your tablets as usual.

If you have diarrhoea, double all of your normal daily doses of hydrocortisone. If the diarrhoea does not settle within 48 hours you need to seek medical advice immediately, such as your family doctor (GP) or your nearest Emergency Department.

This is because you will probably need an injection of hydrocortisone as it is unlikely you will be absorbing your hydrocortisone tablets.

In the case of vomiting, if you vomit once, double all of your normal daily doses of hydrocortisone. If there is further vomiting you need to seek urgent medical advice immediately, preferably by attending your nearest Emergency Department.

This is because you will probably need an injection of hydrocortisone as it is unlikely you will be absorbing your hydrocortisone tablets.

If you have a temperature, along with an infection, for example a chest infection or throat infection, you should double all of your normal daily doses of hydrocortisone and you will need to see your family doctor within 48 hours.

If you are treated with antibiotics, you should double all your daily doses of hydrocortisone for the duration of antibiotic treatment.

If you are unable to make an appointment with your family doctor then you will need to attend an NHS walk-in centre or Accident and Emergency Department within 48 hours. Continue to take double of all of your usual daily doses until you have seen a doctor.

If you are having dental treatment or undergoing surgery you need to inform your doctor or dentist, before your treatment, that you take hydrocortisone.

Your hydrocortisone doses will need to be increased for the day before, the day of and the day after your treatment.

If you experience some extra emotional stresses, due to life events such as bereavement or sitting examinations then you may need to double all of your daily doses of hydrocortisone for three to four days.

What else do I need to know?

You should always carry with you some form of identification which states that you are on steroid tablets. This can be a blue 'steroid card' which you can get from your pharmacist and medical identification jewellery you purchase yourself.

It is also a good idea to carry a list of your medication with you and to leave a copy of this list with your partner and / or parents.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.

The Endocrinology Specialist Nurses

Tel: 0151 706 2417

Text phone number: 18001 0151 706 2417

Related Patient information leaflets:

Hydrocortisone replacement therapy (PIF 019)

Hydrocortisone replacement therapy-what to do during illness and/or stress (PIF 1021)

Addison's Disease Self Help Group

www.adshg.org.uk or www.addisons.org.uk

Email: info@addisons.org.uk

Medical alert jewellery (some examples)

www.medicalert.org.uk

www.medicaltags.co.uk (SOS talisman)

www.theidbandco.com

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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