

Patient information

Conn's Syndrome

Diabetes and Endocrinology

What is Conn's syndrome?

Conn's syndrome is a disease of the Adrenal glands resulting in an excess production of a hormone called Aldosterone. Your doctor may also refer to the condition as Primary Hyperaldosteronism. Conn's syndrome is rare but is curable.

Two types of abnormality may cause this condition.

- 1) Adrenal adenoma which is a benign (non cancerous) tumour of one or both of the glands.
- 2) A general enlargement (hyperplasia) of one or both of the glands.

The reason for why this happens in one person and not another is not yet known.

What are the symptoms?

High blood pressure is the main symptom and can often be the only one you will have.

Other symptoms may happen because of the high levels of the hormone Aldosterone circulating in the blood. Aldosterone makes the kidneys retain sodium (salt) and increases the loss of Potassium in the urine. This will lead to a fall in the Potassium level in your blood. Not everybody who has Conns syndrome will have low potassium levels in their blood.

Low levels of potassium can cause muscle weakness, fatigue, increased thirst and muscle cramps. High levels of sodium cause blood pressure to rise, sometimes to levels that can put you at risk of heart attack or stroke. You may experience headaches or blurred vision.

Please remember these can be symptoms of other illnesses as well so if you have any of these it does not always mean that you have Conn's syndrome.

How is Conn's syndrome diagnosed?

Conn's syndrome is something most Doctors will think about when treating patients with high blood pressure. If your blood pressure is difficult to control with medication, or your blood pressure is difficult to control with medication and your blood tests show a low potassium level, then investigations for Conn's syndrome will be performed.

Your doctor will measure the Aldosterone and Renin levels in your blood. Renin is measured because the kidneys release this when more salt is needed. It works on the adrenal glands to get them to produce more Aldosterone. Higher levels of Aldosterone cause the kidneys to retain sodium and so increase salt levels. This is how the system is normally maintained.

In Conn's syndrome while the Aldosterone is high, the Renin level will be low.

If Conn's is suspected, your Endocrinologist will ask you to come in for a series of tests. You may be asked to stop your antihypertensive medications up to six weeks before these tests depending on what it is you are taking. You will be advised of this when your appointment is made.

These tests will be performed on the programmed investigation unit at the Royal Liverpool University Hospital. You will not have to fast (go without food or drink), and the first test is performed as a day case. On the morning of the test, you will need to attend at 8am in the morning. You will have blood samples taken for Renin and Aldosterone. You will also have your blood pressure recorded.

After this you will be allowed home. If an Adrenal adenoma is suspected, you will be asked to attend for a CT/MRI scan of your abdomen; this will be done as an outpatient.

You may then have to have more detailed monitoring of your blood pressure and Renin/Aldosterone levels. If so, then you will be asked to come back to the programmed investigation unit for further testing. This time you will be expected to stay for five days. Blood samples will be taken and your blood pressure will be monitored. You will also be given sodium (salt) tablets, in divided doses, each day. This will let us know how sensitive your body is to salt stimulation, as high salt levels should suppress Renin and therefore Aldosterone production.

The blood tests taken during this stay will be the same as those on your first visit as well as bloods to look at the salt levels in your body. You will also have to complete a 24 hour urine collection as part of this more detailed monitoring of your Renin and Aldosterone levels.

What is the treatment?

If the cause of your problems is an adenoma affecting one adrenal gland only, then you will be referred to a surgeon who will remove the gland. This will be performed using keyhole surgery. Your surgeon will discuss the surgery in detail with you. They will also explain to you any potential risks. If the cause is found to be hyperplasia or you are found to have an adenoma in both adrenal glands then you will be treated with the drug Spironolactone, which acts by blocking the effect of aldosterone. This will then return your ability to maintain sodium and potassium balance to normal. This will also have the effect of helping to control your blood pressure.

What side effects are there with Spironolactone?

You may have some indigestion and nausea (feeling sickly), this can mean you have to take lower doses but this will usually settle fairly quickly.

Some women can find they have periods more often, maybe every two weeks.

Breast tenderness and increase in breast size can occur, especially in men. This can be helped by reducing the dose of Spironolactone.

What are the benefits of treatment?

Both surgery and medication should reduce your level of Aldosterone. This will help you in maintaining the correct balance of sodium and potassium. This should in turn help with controlling your blood pressure so that the risks of heart attack or stroke are reduced. You should also feel less tired and have more muscle strength.

What are the alternatives?

The alternative if you are unsuitable for surgery or refuse surgery is medication as discussed above. There is no alternative to the medication.

If you need medication to control your symptoms and you do not take it, then you may be at greater risk of having a stroke or heart attack. You may continue to feel tired and have reduced muscle strength.

Spironolactone is the drug that blocks the effects of Aldosterone. You may need less of this over time but you will most likely remain on this treatment for life. You may also need other tablets to help control your blood pressure and potassium.

What happens afterwards?

Treatment of Conn's syndrome is usually successful.

Patients with an adenoma will usually be able to stop medical treatment after their surgery and blood pressure will return to normal.

However, your Endocrinologist may wish to follow your condition for life, as there is the possibility that the adenoma will return.

Patients with hyperplasia will have life long monitoring of their condition for effectiveness and side effects of drug treatment.

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

Author: Diabetes and Endocrinology Speciality

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