

Patient information factsheet

Inferior petrosal sinus sampling

We have given you this factsheet because you have been diagnosed with Cushing's syndrome (a condition caused by having too much of a steroid hormone called cortisol in your body). Your doctor has referred you for a test called inferior petrosal sinus sampling to determine whether you have a specific type of Cushing's syndrome called Cushing's disease.

This factsheet explains what Cushing's disease is, what inferior petrosal sinus sampling is and what the test involves, so you know what to expect. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What is Cushing's disease?

Cushing's disease is a specific type of Cushing's syndrome. It is caused by a small benign (non-cancerous) tumour in the pituitary gland (a pea-sized gland in your brain). As the tumour grows, it causes the gland to produce too much adrenocorticotrophic hormone (ACTH), which in turn causes the adrenal glands to make too much cortisol.

What is inferior petrosal sinus sampling?

Inferior petrosal sinus sampling is a test that involves taking small samples of blood from the main veins draining your pituitary gland to check whether it is producing too much ACTH.

Why do I need this test?

This test will help your doctor determine whether a tumour in your pituitary gland is the source of the problem.

The result of this test will help your doctor to decide on the best treatment option for you or whether you need any further investigations.

Are there any risks?

This is a safe test, but as with all medical procedures, there are some possible risks. These include:

- technical difficulties (if we are unable to perform the test, we may try repeating the test or we may discuss alternative treatment options with you)
- damage to your blood vessels (this can cause minor bleeding and/or bruising)
- increased risk of cancer (all x-rays use ionising radiation which increases your risk of cancer but for this test, the risk is low, and we will not expose you to any more x-rays than is necessary)
- blood clots (we will give you an anticoagulant medicine called heparin during the test to help prevent blood clots forming)

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- an allergic reaction to the x-ray contrast (a dye that makes blood vessels show up clearly on x-ray images)
- stroke (this is rare and occurs in less than one in 100 people)

We will discuss all the potential risks with you in more detail and answer any questions you may have before we ask you for your consent.

Are there any alternatives?

Inferior petrosal sinus sampling is currently the best test to determine whether a person has Cushing's disease. In the rare event that we're unable to perform the test or the test is inconclusive, we may refer you for a specialist positron emission tomography (PET) scan (a scan that uses a mildly radioactive liquid to show up areas of your body where cells are more active than normal). If this is the case, we will discuss this scan with you in more detail.

How should I prepare for this test?

It is important that you contact us for advice as soon as you receive your appointment letter if you:

- are pregnant, think you may be pregnant or are currently breastfeeding
- have a known allergy to x-ray contrast

Pre-assessment appointment

We may ask you to come into hospital before your test for a pre-assessment appointment. At this appointment, we will assess your general health and check you are suitable for this test. We will also perform a blood test.

Medication

You will need to temporarily stop taking medications for Cushing's syndrome, such as metyrapone, before the test. Your doctor will advise when to stop taking the medications and when to start taking the medications again.

You may also need to temporarily stop treatment to prevent blood clots (thromboprophylaxis) before the test. If this is the case, we will advise you when to stop the treatment and when to start the treatment again.

Continue to take all your other medications as normal with a small glass of water (unless you have been advised otherwise).

Eating and drinking

On the day of your test, you may have a light breakfast before 6am and you may continue to drink clear fluids up until the time of your test.

Items to bring with you

You may wish to bring a dressing gown and slippers with you to the hospital.

Arrange for someone to collect you and stay with you overnight

You will not be able to drive yourself home after this test and we do not recommend using public transport to get home in case you feel unwell. For this reason, it is important that you arrange for someone to collect you from hospital and take you home by car after the test and stay with you overnight.

What will happen before the test?

When you arrive on the ward, we may ask you to have a blood test (if you haven't already had one). We will then explain the test to you, including the benefits and risks, and answer any questions you may have. If you are happy to proceed with the test, we will ask you to sign a consent form.

We will then ask you to change into a hospital gown and remove your underwear. We will then insert a cannula (a thin plastic tube) into a vein in either the back of your hand or your arm using a needle. This may sting briefly. The cannula will allow us to give a hormone directly into your bloodstream during the test.

For this test, we will use a local anaesthetic (a medicine that numbs an area of the body so you don't feel any pain) and we may give you a sedative (a medication that makes you feel sleepy and relaxes you), if necessary. Please note that if you choose to have a sedative, this will be an oral tablet and we will give it to you an hour before the test to allow it time to take effect.

The test can take more than an hour in total, so we recommend going to the toilet just before your test.

What will happen during the test?

The test will be performed in the radiology department. There will be several members of staff in the room during the test, including an interventional radiologist (a doctor who specialises in performing image-guided procedures), a radiographer (a healthcare professional who operates special scanning machines that make images for medical purposes), theatre nurses and endocrine nurses.

We will ask you to lie on the x-ray table. We will then place sterile drapes over you and clean and shave an area on both sides of your groin.

We will then move the x-ray machine into position over you. The x-ray machine may come close to you during the test, but it will not touch you.

We will then inject a local anaesthetic into your groin area. This will sting briefly before going numb. Once the area is numb, we will then insert a catheter (a thin plastic tube) into the main vein in each side of your groin (femoral vein). This should not be painful, but it may briefly cause you to feel some extra heartbeats. We will pass the catheters through the other veins in your body up until they reach the base of your skull (near your pituitary gland). You will not feel the catheters moving inside you.

We will then inject an x-ray contrast through the catheters in your groin to help the blood vessels in your brain show up on our x-ray machine. The x-ray contrast may cause you to experience a buzzing sound in your ears or an earache. If you feel unwell at any point, please let us know. We will check that both catheters are in the correct position and then move the x-ray machine away.

We will then inject a small amount of a hormone called desmopressin into your bloodstream via your cannula. This will cause your pituitary gland to produce more ACTH for a short period of time. The injection may make you feel warm and nauseous (feel sick). This is normal and will pass within a few minutes.

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We will then take multiple blood samples from the catheters over the next 10 to 15 minutes. It is important that you stay still during the test. Moving your head or body may cause the catheters in your neck to move and may affect the results and accuracy of the test.

After we have collected all the necessary blood samples, we will remove the catheters and apply a gentle pressure to your groin area for five to ten minutes to help stop any bleeding.

What will happen after the test?

We will take you back to the ward to recover. While you recover, it is important that you:

- lie flat on your back and remain still for at least one hour (we will let you know when you can sit up and start moving)
- keep your head on the pillow
- keep your legs flat on the bed

If you feel your wound site is bleeding, place your hand over the dressing and apply a gentle continuous pressure and call a nurse for help.

We will carry out regular observations, including checking your groin wound sites and heart rate.

You should be able to eat and drink on returning to the ward, but please check with us first.

Most people can go home after four hours, as long as they are feeling well and have no complications. We will let you know when you can leave hospital, as the recovery time is different for everyone.

At home

You should limit your fluid intake to two litres for the first 24 hours after your test.

Sometimes people experience some bruising around their groin after the test. This is usually nothing to worry about and will fade over a few days.

You should rest for the next two to three days and avoid activities that may strain the top of your legs, such as lifting, running and cycling. We advise taking this time off work to recover.

Do not operate machinery or drive for 48 hours after the test.

When should I seek medical help?

Go to your nearest emergency department immediately if you experience any of the symptoms below in the first few days after your test:

- a swollen, warm leg
- shortness of breath
- a lump in your groin that gradually develops and expands in time with your heartbeat

When will I receive my results?

We will send your blood samples to a laboratory to be analysed. This usually takes one to two weeks. Your doctor will then review your test results and contact you to discuss your results or arrange a clinic appointment to see you.

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Contact us

If you have any further questions or concerns, please contact us.

Endocrine nurse

Telephone: **023 8120 4710** (Monday to Friday, 9am to 5pm)

Useful links

www.nhs.uk/conditions/cushings-syndrome

www.pituitary.org.uk/information/cushings-disease

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**