Is it

CUSHING’S DISEASE?

A patient’s guide to diagnostic testing
Disclaimer

This book is intended as a general introduction to the topic and in no way should be seen as a substitute for your own doctor’s or health professional’s advice. All care is taken to ensure that the information contained in this book is free from error and/or omissions; however, no responsibility can be accepted by the Australian Pituitary Foundation, author, editor, or any person involved in the preparation of this book for loss occasioned to any person acting or refraining from action as a result of material in this book. Before commencing any health treatment, always consult your doctor.
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About the Australian Pituitary Foundation
The mission of the Australian Pituitary Foundation Ltd (APF) is to provide support for those who have experienced pituitary gland conditions. We promote awareness and disseminate information among the medical community, public, pituitary patients and their families. We welcome anyone with an interest in pituitary disorders to join us – see page 21 for contact details.

About this booklet
This booklet aims to provide information for people going through the sometimes frustrating process of determining if they have Cushing’s disease. It covers tests you may have while you are being diagnosed. The booklet also includes tips from APF members – these are indicated in italics.

A book, ‘Understanding Your Pituitary Problems’, is also available from the APF upon joining. The book addresses the symptoms, diagnosis and treatment of Cushing’s disease and other major pituitary conditions, and helps patients and their families understand and manage their illness.

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Cushing’s disease develops when a tumour in the pituitary gland causes it to produce too much of a hormone called ‘adrenocorticotrophic hormone’ (ACTH). In turn, this hormone tells your body to make too much cortisol.

Cortisol is a steroid hormone which is essential for life. It is released by the adrenal glands, which sit on top of your kidneys. Cortisol is the main hormone that helps your body deal with stress (such as injury or infection). Too much cortisol can increase blood sugar and even cause diabetes mellitus, though this should reverse if the cortisol level is returned to normal.

Cushing’s disease is a rare condition, and probably affects somewhere between 300 and 1200 Australians. It is five times more common in women than it is in men, and is most common in women over the age of 30. The condition is named after Harvey Cushing, the doctor who first identified it in 1912.

Figure 1. Possible symptoms of Cushing’s disease.
You may have heard the terms *Cushing’s syndrome* and *Cushing’s disease*. *Cushing’s syndrome* refers to a pattern of symptoms that occur because you have too much cortisol in your body. These symptoms can include things like weight gain, irregular periods, excess body hair, feeling tired and so on. There are several causes of Cushing’s syndrome including long-term use of corticosteroid medication, severe depression or excessive alcohol use.

*Cushing’s disease* refers to Cushing’s syndrome that is caused by the body producing too much ACTH. Usually, a benign tumour in the pituitary gland is the reason for the excess release of ACTH. Occasionally, an ACTH-secreting tumour somewhere else in the body (an ‘ectopic’ tumour) can be the cause. Cushing’s disease causes around 70% of cases of Cushing’s syndrome.

Tumours of the adrenal glands (adrenal tumour) can also cause Cushing’s syndrome. In this case, the adrenal tumour directly secretes excess cortisol and the pituitary is not involved. As a result, in these cases ACTH remains within the normal range.

Because there are many possible causes of Cushing’s syndrome, there are many diagnostic tests to help doctors narrow down the true cause of each patient’s problems.

**DIAGNOSING CUSHING’S DISEASE**

Diagnosing Cushing’s disease can be a long and frustrating process. As the most obvious symptoms of weight gain, diabetes and menstrual irregularity can be caused by other (more common) conditions, doctors will usually think of these other conditions first. You will probably hear a lot of well-meant but off-the-mark advice about diet and exercise. You may also undergo a lot of testing for conditions or diseases you may not have.

*For nearly 15 years I went to doctors, specialists, alternative practitioners – all of whom couldn’t help. I had tests for every disease imaginable – all negative. I was diagnosed with depression, mental illnesses, told to seek psychiatric help.*

Sometimes people get lucky and are diagnosed more quickly.
It was diagnosed by chance – I was lucky to go to a doctor just out of uni who was still keen and with knowledge fresh in his head. He picked it up straight away.

Once Cushing’s disease is suspected, further tests will be needed to confirm the diagnosis. The next section walks you through some of these tests. The exact details of each procedure may vary from centre to centre, but the following descriptions aim to give you an idea of what to expect. However, it is important that you always follow your doctor’s or pathology centre’s instructions rather than relying on information in this booklet.

For all tests, the APF recommend you request a copy of your results, which you keep in your own folder at home. This can be a valuable asset when visiting specialists who haven’t seen you before. Having all your results together in one place is extremely useful to help doctors piece together the diagnostic puzzle of Cushing’s disease.

**TESTING FOR CUSHING’S DISEASE: WHAT TO EXPECT**

**COMMON TESTS**

As mentioned above, narrowing down the cause of Cushing’s syndrome in an individual requires a lot of diagnostic testing. Doctors must determine if Cushing’s syndrome is caused by a pituitary, ectopic or adrenal tumour; or from some other cause entirely (such as corticosteroid medications or alcohol abuse).

No single test for Cushing’s disease is completely reliable, so a combination of tests is usually given during the diagnostic process. The exact tests you have will depend on results of your previous tests, what’s available in your area, and your endocrinologist’s preferences. You are not likely to have all of the following tests, but you will have some of them.

Some people have cyclic Cushing’s syndrome, which means that they have episodes of excessive cortisol secretion, followed by normal levels, followed by another episode of excessive secretion. These fluctuations can lead to confusing test results, so tests may have to be repeated several times to ‘catch’ the patient’s cortisol levels during an abnormal cycle.
Physical examination
The first thing your doctor will do is check for physical signs and symptoms of Cushing's disease. The following checklist contains symptoms that can be present in this condition. Tick the ones that apply to you.

<table>
<thead>
<tr>
<th>Physical manifestation</th>
<th>Possible Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin bruises easily and heals poorly</td>
<td>A fatty hump between the shoulders (‘buffalo hump’)</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>Moon-shaped face</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>Decreased sex drive and fertility</td>
</tr>
<tr>
<td>Red stretch marks on stomach, back or thighs</td>
<td>High blood sugar or diabetes</td>
</tr>
<tr>
<td>Fluid retention or swelling</td>
<td>Tiredness, fatigue</td>
</tr>
<tr>
<td>Excess body and facial hair</td>
<td>Personality changes, mood swings, depression</td>
</tr>
<tr>
<td>Weight gain (particularly around the torso), possibly with arms and legs remaining thin</td>
<td>Brittle bones (osteoporosis)</td>
</tr>
<tr>
<td>Acne (on face and/or body)</td>
<td>Low back pain</td>
</tr>
<tr>
<td>Increased thirst, frequent urination</td>
<td>In women: irregular periods</td>
</tr>
<tr>
<td></td>
<td>In children: slow growth</td>
</tr>
</tbody>
</table>

Table 1. Checklist of possible signs and symptoms in Cushing’s disease.
You can track the changes in your body by looking back over old photos. It can be helpful to take these to the doctor to help them understand how your body has changed and why you are concerned about it. The following ‘before, during and after’ photo series shows the dramatic physical changes in one APF member.
Figure 2. Before, during and after photos of one APF member with Cushing’s disease.

Blood tests

The first tests you are likely to have are baseline blood tests. These will include standard blood tests, such as a full blood count and blood sugar levels (separate tubes of blood will be needed for those tests) along with tests for liver and kidney function. You are also likely to be tested for levels of all pituitary hormones to give a picture of what’s happening with your pituitary function. For Cushing’s disease, the most important results are your plasma ACTH and plasma cortisol levels.
Plasma ACTH, plasma cortisol levels

**Purpose:** The plasma ACTH test checks the level of adrenocorticotropic hormone in your blood. This is the hormone that the pituitary tumour overproduces in Cushing’s disease. The plasma cortisol test checks the level of cortisol in your blood.

**Procedure:** These are like ordinary blood tests where you attend a pathology centre and a nurse takes blood from a vein in your arm. You may be asked to fast the night before, but you can still drink water – staying hydrated can help the procedure go more smoothly. A sterile needle is inserted in your arm and blood is withdrawn into a vial. The procedure is performed around 8 am (when normal cortisol levels peak) and only takes a few minutes. It may take a couple of days for your results to reach your doctor.

**Meaning of results:** In Cushing’s disease, measuring the cortisol or ACTH level from a single blood sample is unhelpful as a diagnostic test. So while your doctor will note the results of this blood test, further special tests to assess the level of cortisol output form the basis of the diagnostic work-up.

24-hour urinary free cortisol

**Purpose:** Measures the level of cortisol secreted over an entire day, thereby levelling out peaks and troughs seen at particular times of day.

**Procedure:** This test involves collecting ALL the urine you pass in a 24-hour period into a large collection jug. Usually, you pass urine into a container and then pour it into the large collection jug. The jug is kept refrigerated and taken to the pathology centre after the 24-hour period is over. Your testing centre should provide you with an instruction sheet for this test – make sure you follow the directions exactly so that you get a valid result.

You start by choosing a suitable time in your daily schedule to release your full bladder into the toilet on the morning of the test. You are then required to collect all the urine you pass for the next 24 hours, including the next morning’s full bladder captured in the container at exactly the same time as you began the day before. For this reason, it is good to pick a day when you will be home all day.

If you forget to collect some of your urine, the test will not be valid and you will need to start again on another day. If you need to do a bowel movement, you should void your urine into the collection container first to avoid missing any urine. The collection container does not have to be sterile; it just needs to be clean and kept refrigerated over the collection period.
Meaning of results: High levels of free cortisol in the urine indicate Cushing’s syndrome. However, in mild cases of Cushing’s the levels may fall within the normal range. Cortisol levels may also be high in some other conditions, such as depression, chronic alcoholism and eating disorders. Because of this, other tests will usually be ordered as well as the 24-hour urinary free cortisol.

If your diagnosis is confirmed as Cushing’s disease, you may need to do this test annually as part of your long-term follow-up.

24-hour urinary free cortisol – top tips from APF members

- Make sure the collection agency gives you the correct bottle, as I once had to re-do a test since they gave me the wrong bottle. If the person is unsure, make sure they check.

- My husband and I have a joke about labelling the collection bottle “not cordial”... I also wrote on the label of the bottle before I put it in the fridge – it was easier than trying to write on it after the label got damp and cold.

- I have done many 24 hour urine collections and so far only one place has given me a plastic disposable funnel to use to direct urine into bottle. As a female I found the best way is to find a large plastic container like an ice cream container, wash and rinse it extremely thoroughly, and wee into that as if it was the toilet. Then unscrew the lid of the urine container and pour it in. Sometimes standing in the shower is good. Be careful not to spill any.

- I ask for 2 containers because I know that I produce a large amount of urine (some hot days 5 litres)! If you have filled the one container that pathology have given you within the 24 hours, you then need to race back to pathology for another one or hunt around the home for an empty coke bottle, wash and rinse it out extremely thoroughly and use that to collect the extra urine. Don’t be caught short. Every drop needs to be collected over the 24 hours.

- Be prepared at the end of the 24 hours that the bottle smells a bit when you open it.

- When taking the full container back – put it in at least two plastic bags to carry it.

- Delivering it to pathology doesn’t worry me anymore, no paper bags and embarrassed looks. It’s a part of life isn’t it?
Midnight salivary cortisol

**Purpose:** A screening test to check cortisol levels. In normal healthy people, cortisol levels should be at their lowest at midnight: in people with Cushing’s syndrome cortisol levels don’t decrease. This test may not be available in all centres.

**Procedure:** You collect your saliva sample yourself at home, at midnight. Do not brush your teeth, or eat or drink anything for 15 minutes prior to collecting the sample. To take the sample, take the top off the container and tip the container so the swab falls into your mouth. Don’t touch the swab with your fingers. Roll the swab around in your mouth for about 2 minutes (do not chew). Then place the swab back in its container without touching it with your hands, and replace the cap. Write the collection time down and take it in to the pathology centre the next morning.

**Meaning of results:** A high level of cortisol in saliva collected at midnight indicates Cushing’s syndrome. This test may give a ‘false positive’ (high saliva cortisol level) in shift workers who do not usually sleep at night.

Overnight dexamethasone suppression test

**Purpose:** This is a widely used screening test to determine whether your body is producing too much cortisol. Dexamethasone should suppress the production of cortisol to a very low level in normal healthy people.

**Procedure:** You take a dexamethasone tablet (usually 1 mg) at 11 pm, then attend a pathology centre early the next morning (around 8 am) for a blood test to check your serum cortisol level.

**Meaning of results:** In people with Cushing’s syndrome, cortisol production is not suppressed to the low levels seen with normal healthy people. Further testing will investigate if the cause is a pituitary or adrenal tumour. The reliability of this test is influenced by different medications such as oral contraceptives and anticonvulsants.

Sometimes cortisol levels in people with mild or cyclical Cushing’s syndrome will be suppressed by dexamethasone; if this is the case, further testing will be needed to confirm a diagnosis.
High-dose dexamethasone suppression test

**Purpose:** The high-dose dexamethasone test can help determine whether the problem is in the pituitary gland or elsewhere in the body (e.g. adrenal glands, lung, pancreas or other site). High doses of dexamethasone usually suppress cortisol levels in a person with a pituitary adenoma, but not in someone with an ectopic ACTH-producing tumour.

**Procedure:** This test can be done in two ways.

1. **Oral.** Your cortisol level is taken on the morning of the test. You take 8 mg of dexamethasone at 11 pm, and then blood is taken at 8 am the next day for another cortisol measurement.

2. **Intravenous.** You attend a specialty centre for a day, but don’t need to stay overnight. You need to fast the night before and not take any of your regular medications until after the test. Two cannulas are inserted, one into each of your arms. You receive 5 mg of dexamethasone over 5 hours via one of the cannulas. Blood is taken every half an hour from the other cannula to test your ACTH and cortisol levels.

This test used to be performed by taking dexamethasone tablets over several days and doing repeated urine tests, but now the simpler overnight or one-day methods are typically used.

**Meaning of results:** If Cushing’s disease is the cause of your high cortisol levels and symptoms, you will have an abnormal response to the low-dose test but a normal response to the high-dose test.

<table>
<thead>
<tr>
<th>Cushing’s syndrome caused by...</th>
<th>Change in cortisol levels with...</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low-dose test</td>
</tr>
<tr>
<td>Pituitary tumour (Cushing’s disease)</td>
<td>No change</td>
</tr>
<tr>
<td>Adrenal tumour</td>
<td>No change</td>
</tr>
<tr>
<td>Ectopic ACTH-producing tumour</td>
<td>No change</td>
</tr>
</tbody>
</table>

Table 2. Dexamethasone suppression test results vary depending on the cause of Cushing’s syndrome.
Magnetic resonance imaging (MRI)

**Purpose:** To scan the brain to check the pituitary gland for a tumour. Knowing the size and location of a tumour is essential prior to any surgical intervention.

**Procedure:** MRI is an advanced scanning method that uses a powerful magnet and radio waves to produce a detailed image of a particular body part – in this case, the brain and pituitary gland. The images are produced without use of x-rays, and the procedure is safe and painless. It takes approximately 15 to 60 minutes to take a full picture of your brain. During the procedure, your whole body goes into the MRI machine, which some find claustrophobic. The machine also makes a lot of noise; music headphones or ear plugs are often available to help you manage this.

You will attend a scanning centre or a hospital for this procedure. Due to the strong magnetic fields produced by the machine, it is very dangerous to have anything metal in the room. For this reason you must change into a robe to make sure there are no metal buttons or zips to cause problems. You will be asked if you have a pacemaker or any metal implants (such as a hip replacement), as if you have these you cannot have an MRI. You need to take off all jewellery and take out any piercings. Take this seriously as the magnetic fields involved are very strong.

*One time a doctor came in to give me an injection of contrast dye and we heard a loud bang. He had walked into the room with his pen in his coat pocket and when he approached the MRI machine the magnetic field flung the pen from his coat pocket to hit the far wall at great speed.*

The staff will put a cannula in your arm so they can inject a contrast solution later during the scan. When you get into the room, you lie down on the table and the staff give you earplugs and a panic button to hold so that if you feel you need to stop the test, you can tell them immediately. Your head is placed in a headrest to limit your movement. When the table retracts into the machine you may need to squeeze your arms together a little in order to fit into the machine comfortably.

Members of staff talk to you through a speaker at times throughout the test to tell you how long each scan takes and check if you are okay. They may also position a mirror to reflect images of the staff in the booth. This enables you to see them if you look up, which can be comforting. The machine is very noisy,
so the earplugs and/or music can help to dull the noise. The table may shift a little between scans to position you correctly for the next scan.

After the initial scans are completed, you are moved out of the tunnel a little and a contrast dye is injected (usually into a cannula placed in the back of your hand), then a second set of scans are made. You may feel a cold sensation travelling up your arm as the dye is injected. The dye (usually gadolinium) helps to outline the tumour and differentiate it from normal pituitary tissue.

Some people are worried about moving during a scan. You will need to keep as still as possible, but small movements like blinking or swallowing should be okay. Make sure you ask the technicians about any specific concerns you have before the scan – remember, no question is a dumb question, the technician is there to make this process as easy for you as possible.

After the procedure is over, you should sit up slowly and take your time getting up to prevent dizziness. Staff will remove the cannula used to inject the contrast dye, and bandage the area.

**Meaning of results:** If you have a pituitary tumour, the MRI should show where it is and how big it is. This information helps with planning your treatment. However, in some cases MRIs give ‘false negative’ results – that is, a small tumour is present, but does not show up on the scans. The potential for a false negative result is a reason why a combination of tests is used during the diagnosis of Cushing’s disease.

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**Coping with an MRI – top tips from APF members**

- *Some people find having an MRI scan of the head is a scary experience. Patients who have been through it offer these tips for coping.*

- *Know what you are there for. Understand that this is part of finding out information that is going to help with your diagnosis. Arrive in plenty of time. Make sure you go to the toilet beforehand as the whole scanning procedure may last an hour or so.*

- *If you are claustrophobic in any way, it is best to let people know before, not during. [It is preferable to do this when you make the appointment, so that staff can discuss options to assist you]*
Is it Cushing’s disease?

Coping with an MRI – top tips from APF members (Cont.)

• I found it best to close the eyes and pretend you are trying to go to sleep in your own bed – the thumping after a while becomes rhythmic. The music is drowned out but it is good to have it in the background. You are given a button, which is on a long lead, to push if you get into trouble, that is comforting.

• Take the offer of music if it is given. It does help.

• Wearing an eye mask alleviated my knowing how close the top of the machine was to my face. I have a plan in my head before I go in the machine to plan my next holiday away, right from the initial planning, to the packing of the suitcase and the journey itself! It keeps my mind occupied.

• Remember, it doesn’t hurt at all.

• I kept reminding myself that it would all be over soon and to relax. Nothing lasts forever.

• Breathe deeply and relax! I used it as an enforced break to actually try and have a rest; it was almost like meditating.

• Just know that worrying about it doesn’t help. You will be fine, and you will keep still and calm, even though you think that you won’t.

OTHER TESTS

For some patients, a few other tests may be needed.

Inferior petrosal sinus sampling (IPSS)

Purpose: This test helps determine if a pituitary tumour is the source of your increased ACTH levels. This test is not always required, but may be done if an MRI has failed to find a pituitary tumour, or if results of the high-dose dexamethasone test are ambiguous or do not agree with the MRI results. The inferior petrosal sinuses are the veins that drain blood directly from the pituitary gland. If the ACTH level in blood from the inferior petrosal sinuses is higher than the ACTH level in blood from your arm, it indicates the pituitary is the source of the problem.
**Procedure:** IPSS is performed at a major hospital by specially trained technicians.

You will need to fast from the night before (water only from midnight onwards). You will go to the radiology department of the hospital, change into a hospital gown and lie down on a table positioned under an x-ray machine. You will be lightly sedated and given pain relief to help you keep still during the procedure, but you remain awake.

Staff will partially shave your groin area, apply local anaesthetic to numb each side, and make a small cut allowing them to insert a fine catheter and pass it up the veins and all the way from the groin to the inferior petrosal sinuses in your head.

![Diagram of catheter location for IPSS](image)

A small needle is also inserted into your arm to allow a blood sample to be taken from that site. A contrast dye is injected and the radiologist takes x-rays to confirm the catheters are in the right place. Blood samples are taken from the left and right petrosal sinuses and the arm vein at exactly the same time.

After baseline measurements, corticotropin-releasing hormone (CRH) is injected via an arm vein. If you have a pituitary tumour, this will cause ACTH to rise; if you have an ectopic tumour, ACTH will not change. Further samples are taken for 10 to 15 minutes, and another x-ray may be taken to confirm the catheters were not dislodged during the procedure. The catheters are taken out and pressure applied to your groin wounds to minimise bruising (as patients with Cushing’s disease bruise easily, you may find you still develop bruises in your groin and arm after this procedure).
The entire process can take around four hours. You need to remain lying down for at least two hours after the test. You should not do any strenuous activity for two days after the procedure. Your nurse will advise on how to dress your wounds where the catheters were inserted, if required.

**Meaning of results:** Higher levels of ACTH in the bloods samples taken from the inferior petrosal sinuses compared with samples taken from the arm vein indicate the presence of a pituitary adenoma. Similar levels of ACTH in the sinuses and the arm suggest an ectopic ACTH-producing tumour might be responsible for your high ACTH levels.

Sometimes the level of ACTH from the left and right petrosal sinus is compared to provide a clue as to the site of the pituitary tumour. This information assists the neurosurgeon to locate small tumours that are not evident on the MRI.

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**IPSS – top tips from APF members**

- *It is an invasive test, but luckily it does not last that long. Ask for as much pain relief as you can. If they don't tell you something, instead of assuming, ask them.*

- *One of my coping mechanisms was to learn as much as I could about procedures and I found that really useful. I became very clinical about everything and that enabled me to deal better with my emotions.*

- *Be prepared for your back to ache and understand that although the local area in your groin has an anaesthetic, you will still ‘feel’ what’s happening without the pain. I can remember a feeling of pin pricking happening in my neck when the internal blood sampling was happening. I could hear it! The noise was like sucking on the remainder of a milkshake inside your head!* 

- *If you have cyclical Cushing's, make sure you have a blood test the day before the procedure to make sure the condition is ‘switched on’. Be brave, all the doctors are there with you. You should trust the doctors and know that they will do everything in their power to make sure you are okay – knowing this is somehow comforting when you are at that point.*
**Visual field test**

**Purpose:** To check for blind spots or loss of peripheral vision caused by a pituitary tumour pressing on your optic nerve.

**Procedure:** An optometrist or ophthalmologist can perform this test. You sit down and your chin is placed in a rest so that your head keeps still during the procedure. One eye is covered so that only one eye is tested at a time. In front of you there is a convex dish (like a miniature satellite dish) with a light in the centre; you will be asked to focus on this central light. You are given a button, which you press each time you see a light flash anywhere in the dish, no matter how bright or dim it is. Lights will randomly flash around the dish, some in front of you and some in your peripheral vision to the sides. The machine charts your responses, taking about 10 minutes to test each eye. At the end you may be given a printout of your visual fields – if this is not offered, ask for a copy for your own records. This is usually a straightforward test for patients and is not difficult or stressful.

![Diagram](image)

**Figure 4. Sample results of visual field testing.**

In Figure 2 the areas shaded darkest are where the patient was unable to see flashing lights. The left eye is affected more than the right eye. A normal result would be no areas of dark shading apart from the “blind spot”.

This black area shows where there is no vision.

This dark patch shows the normal “blind spot”, which is present in everyone.
Meaning of results: The resultant plot on graph paper gives your specialist an accurate picture of any pressure on the optic nerves that connect the eyeball to the brain. You should be aware that results can have an impact on your life – for example, if you are found to have severely affected peripheral vision, you may not be allowed to drive any more. If treatment corrects the problem, you may be able to resume driving after all the necessary medical and road authority checks have been completed.

Computed tomography (CT) scans

Purpose: To locate an ACTH-secreting tumour. If you have metal implants in your body (such as a pacemaker, or hip or knee replacement) and cannot have an MRI, a CT scan of the head will be done instead to locate your tumour. Alternatively, in the rare cases where an MRI does not locate a pituitary tumour, it is possible that an ectopic tumour elsewhere in the body could be causing the increased ACTH secretion. Your doctor may order CT scans of the chest or abdomen to look for such a tumour.

Procedure: You attend a hospital radiology department or an imaging centre, change into a gown and lie down on the CT scanner bed. You lie still while the bed moves through a doughnut-shaped scanner, which takes a series of detailed x-rays from different angles. A dye may be injected into a vein or swallowed to improve the outline of the tissues.

I had a CT before an MRI and in comparison I found it much less stressful…. Most of my body was outside the scanner so I didn’t feel claustrophobic, and the scans were quite short so it was easy to stay still.

A CT scan is rather straightforward and no more intrusive than an x-ray. Not at all intimidating.

Meaning of results: The radiologist will examine the scans and report if any tumours are visible. If they are, information on their location and size will be determined, which is essential for treatment planning.

Bone mineral density (BMD)

Purpose: Determines if you have osteoporosis (thinning of the bones) by measuring how much calcium and other minerals are present in your bones (usually your lower spine and hip). This information is used to predict your risk of bone fractures in the future. This is an important investigation in patients with Cushing’s disease or Cushing’s syndrome because of the high risk of osteoporosis.
Procedure: BMD testing is carried out in a hospital radiology department or imaging centre and is a painless procedure. Usually you don’t need to get changed, but you should remove any jewellery. You lie still on a cushioned table and a scanner passes over your body, taking x-rays of your lower spine and hip. This is known as a central DEXA scan (Dual-Energy X-ray Absorptiometry).

BMD can also be tested using small machines sometimes found in pharmacies or shopping centres; however, these are less reliable than a central DEXA scan.

Meaning of results: Results are usually reported as a T score and a Z score. The T score compares your result with that of healthy young women, while a Z scores compares your result with that of other people the same age, sex and race as you. Negative scores indicate your bones are thinner than the standard you are being compared to. Higher negative numbers indicate higher fracture risk.

### BMD – top tips from APF members

- **It is an easy test and does not take long...** You do not have to get changed into special gowns. You are not fully surrounded by the machine and the machine does not touch you. You need to lie as still as possible. Once it is over you can go straight away. No contrast injections needed.

- **Make sure that the machine is suitable for your weight.** I went to have my first one and was told that the machine was not powerful enough to scan through my weight, so I had to go to another town where they had a more powerful machine. Ask when you make the booking to avoid extra hassles.
The first-line treatment for Cushing’s disease is surgery to remove the pituitary tumour. This is usually performed through the nasal passages to minimise damage and scarring. It is important that this is carried out by an experienced neurosurgeon with a special interest in pituitary surgery. Surgery does not always remove the entire tumour as sometimes this is not possible. In such cases further surgery at a later date may be suggested; alternatively, radiotherapy, medication or other treatment options may be used. Decisions will be made by your medical team based on your specific circumstances and your treatment may be quite different to another person with Cushing’s disease.

After successful surgery, you will need glucocorticoid medication to replace cortisol until the normal pituitary gland and adrenal gland function recovers. This can take a few months or even a few years to settle down. In some cases, the tumour may be so entwined with the normal pituitary gland that part or all of the pituitary needs to be removed along with the tumour. If this is the case, you will need long-term hormone replacement therapy.

Cortisol helps the body deal with stress, such as that associated with injury or infection. If you are cortisol deficient and become sick, your body can have a hard time coping with it. This can lead to something called adrenal crisis, where blood pressure drops and you can go into a coma if you don’t receive a hydrocortisone injection urgently.

If you have cortisol deficiency, you should wear a medical identification tag (such as a MedicAlert® necklace or bracelet) to alert emergency medical staff to your condition. You may be taught how to give yourself an emergency injection of hydrocortisone and when this might be needed – discuss this with your doctor.

You may actually feel worse for a while after surgery, while your body recovers from its prolonged ‘overdose’ of cortisol. Symptoms such as headache, fatigue, aches and pains are very common. Lifetime follow-up is needed in all Cushing’s disease patients to monitor for any side effects of treatment and to check for recurrence, as approximately one-quarter of patients experience a recurrence within 5 years following surgery.
MORE INFORMATION

There are some wonderful sources of information available on Cushing’s disease. The following list is a starting point.

• **Australian Pituitary Foundation.** The APF has information on Cushing’s disease available on its website (www.pituitary.asn.au). The APF also organises educational sessions across Australia and can put you in touch with other Australians with your condition. See below for information about how to join.

• **Pituitary associations worldwide.** Other international pituitary associations have produced excellent web pages and booklets on this disease.
  * The Pituitary Foundation (www.pituitary.org.uk). Follow links to Pituitary Conditions, then ‘Cushing’s disease’.
  * Pituitary Network Association (www.pituitary.org). Search their website for ‘Cushing’s disease’.

• **Comprehensive information and support.** The website www.cushings-help.com has collected extensive information on Cushing’s syndrome and Cushing’s disease in one convenient online location. This site also has an online forum enabling peer support among its international membership.

• **Web resources.** The site www.healthinsite.gov.au contains links to reliable sources of information on many diseases. Use the search function to look for links on Cushing’s.

• **Books on Cushing’s disease.** Cushing’s patients have written books describing their experience with this pituitary condition. Search large online bookstores or ask your local bookstore to locate available titles that might interest you.

SUPPORT AND NETWORKING

Support for yourself and your loved ones will be vital during your journey with Cushing’s disease.

Please consider joining the APF if you haven’t already done so. It has branches in every state, which organise regular social gatherings where you can meet others dealing with the same issues confronting you. The APF also has an exclusive patient support register and an online members-only forum allowing you to ask questions of others and share experiences. Furthermore, the APF has a collection of stories from people who have experienced diagnosis and treatment for Cushing’s disease. See www.pituitary.asn.au or contact the APF for details.
JOIN THE APF

You can join the APF by filling in the membership form, available on its website www.pituitary.asn.au (click on the Membership section).

The APF’s objectives are to:

- provide a forum for the exchange of information and ideas and for the discussion of problems related to pituitary disorders
- promote public awareness of pituitary disorders and the need for government support
- act as a resource group providing support and disseminating information
- encourage scientific research for the prevention, alleviation, care, treatment and cure of pituitary disorders.

For further information, contact:

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The APF’s mission is to provide support to those who have experienced pituitary gland conditions. We promote awareness and disseminate information helpful to the medical community, public, pituitary patients and their families.

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