Patient information

Phaechromocytoma

Diabetes and Endocrinology

What is a Phaeochromocytoma?

This is a rare condition where the body produces too much of the hormones adrenaline or noradrenaline or both.

What causes a Phaeochromocytoma?

The usual cause is a tumour of the inner core of the adrenal gland known as the adrenal medulla. This tumour overproduces both adrenaline and noradrenaline.

They can also be caused by the overproduction of noradrenaline from another source known as the sympathetic nerve chain.

This chain comprises a series of nerves with “swellings” called ganglions or nodules. The nerves stretch from the head to the bladder and are along either side of the spine.

Normally, this nerve chain releases noradrenaline to maintain the body’s proper functioning. In rare cases it can become cancerous and overproduce noradrenaline. This is known as ganglioneuroma or sympathoblastoma.

Is adrenaline/noradrenaline important?

This is needed to prepare the body for action in times of extreme stress, the ‘fight or flight’ response. When adrenalin is produced, blood flow to the heart and muscles is increased, more oxygen is taken in and the pupils of the eyes dilate.

Along with this, the blood vessels to the skin close down, to reduce possible blood loss through injury. These effects on the heart, blood vessels and muscles lead to an increase in blood pressure.

How common are these tumours?

Phaeocromocytomas are quite rare and are only responsible for less than 0.2% of all cases of hypertension (high blood pressure). However, many people will have one without any problems as approximately 50% are detected during postmortem. They usually occur in the 40-to-50-year age group but can occur at any time from childhood onwards.

Is it cancer?

Most phaeocromocytomas are benign. They do not spread to other organs or areas in the body. However, about 10% will be of the type that does spread, most commonly to liver, bone and lymph nodes.

What happens to me if I have a Phaeocromocytoma?

Excess adrenaline can be produced either in bursts or continually.

A major sign is high blood pressure (hypertension) that does not respond to routine medication.

Other symptoms will include feelings of anxiety and apprehension, palpitations, chest pains and shortness of breath, severe headaches and visual disturbances, sweating and flushing or pallor.

These symptoms are in response to a sudden surge of adrenaline and the symptoms may be different for each attack.

Often patients describe sudden onset of attacks with thumping severe headache, profuse sweating and yet look pale. They have fast heart palpitations, extreme anxiety as if about to die, body tremor, and if measured, a very high blood pressure. After some time (usually less than 15 minutes but in 80% as long as one hour) the attack subsides and patients report feeling washed out.

The frequency of attacks can vary from once every two months to many times per day but usually become more frequent as time goes by. Between attacks, blood pressure may remain raised but in some reverts to normal.

About half of patients will have a postural fall in blood pressure (low blood pressure when standing) even if the supine pressure (blood pressure when lying down) is normal. The severity of the crisis is not dependent on the size of the tumour but on its over-activity; small tumours can be very overactive.

Can I prevent an attack?

The attacks are in response to the excess of adrenaline produced by the tumour; however there may be some things that trigger an attack that you can control. These include physical activities such as bending forwards, lifting and straining, and some exercise.

Medicines can occasionally trigger an attack; these include the anti-sickness medication, Maxalon, some anti-depressants and the contrast dye used in some x-rays and scans. Some foods can also increase the chance of an attack these include caffeine, bananas, alcohol and marmite.

How is it diagnosed?

Blood tests are not usually used alone in diagnosing a phaeochromocytoma.

Collections of urine taken over 24-hour periods for several days are very useful in detecting surges of adrenaline. These tests will form a major part in arriving at your diagnosis and may need to be performed several times before a surge of adrenalin can be seen.

Various scans can be taken of your abdomen, most commonly a CT scan or an MRI scan. Both involve you lying still on an X-ray bed, which is then positioned into the round tube of the scanner machine.

This can be very narrow so it is important that you tell the X-ray staff if you may be claustrophobic. Closing your eyes before you go into the machine may help.

Other scans can be performed in the Nuclear Medicine Department, these involve an injection of a substance known as MIBG, (Radioactive labelled meta-iodobenzyl guanidine) which is taken up by the tumour and would then show up on the scan pictures.

Depending on the results obtained you may find you have one or all of these scans.

What treatment is there?

Surgery is used to remove the tumour and most often the affected adrenal gland with it. The surgeon will explain in detail the procedure and the aftercare when you are seen in clinic. The operation can be performed in two ways.

The surgeon may decide you are suitable to have the procedure laproscopically, using several small incisions (cuts) through which to insert the surgical instrument and camera. This type of surgery can mean a quicker recovery time for you.

If this approach is not possible then the surgeon would use one big incision to enter your abdomen and remove your adrenal gland. This would mean a slightly longer recovery time as the wound may take longer to heal.

However, it is important to block the action of the excess noradrenaline / adrenaline before the operation.

The reason for this is that the anaesthetic and handling of the tumour at the time of operation can cause a crisis. In a crisis the tumour releases massive amounts of hormone resulting in a dangerously high level of blood pressure that could cause a heart attack or brain haemorrhage.

To reduce this risk, your endocrinologist will arrange for you to have the action of noradrenaline / adrenaline blocked by a special medicine known as an ‘alpha blocker’ e.g. Phenoxybenzamine.

This medicine is usually started in hospital because it can cause your blood pressure to drop very quickly to a dangerous level. If that were to happen you may need to be stabilised by infusions of fluid into one of your veins.

The drug dosage will be gradually increased until maximum effect is achieved and this can take several days.

When the ‘alpha blocker’ is fully effective your specialist will add another drug called a ‘beta blocker’ (usually Propanolol) to reduce the force of your heart beat and prevent any fast palpitations.

What happens after the operation?

You will be cared for in a high dependency unit until the doctors are sure your blood pressure is stable, you will then move to a surgical ward until you are discharged.

During your time on the wards your recovery will be monitored closely and your blood pressure will be checked regularly.

You will slowly reduce the tablets you will have been given to control the adrenaline output and stabilise your blood pressure, so that you eventually stop these medications.

Your surgeon will arrange to review you in the outpatient clinic four to six weeks after you are discharged home so that they can assess your recovery.

You will also continue to be seen in the Endocrine clinic on a regular basis and we will recheck the levels of adrenaline in 24-hour urine collections through this clinic. It is likely that you will continue to attend the Endocrine clinic long term, possibly life-long.

What if surgery is not possible?

If your tumour cannot be operated on then it can be treated with the meta-iodobenzyl guanidine (MIBG) also used as part of the investigations to reach a diagnosis.
You will be given higher doses of MIBG than you were when investigated and will need to attend the Nuclear Medicine Department on several occasions.

You will also need continued monitoring of your catecholamine (the breakdown products of adrenaline/noradrenaline) output to assess the effectiveness of the treatment. This is achieved by measuring the amounts in your urine, so you will be asked to provide urine collected over a 24-hour period at regular intervals.

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.

Endocrinology Specialist Nurses
Tel: 0151 706 2417
Text phone number 18001 0151 7062417

Related Patient information leaflets:

Trans-sphenoidal surgery (PIF 249)

Pituitary radiotherapy (PIF 1062)

www.Amend.org.uk

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