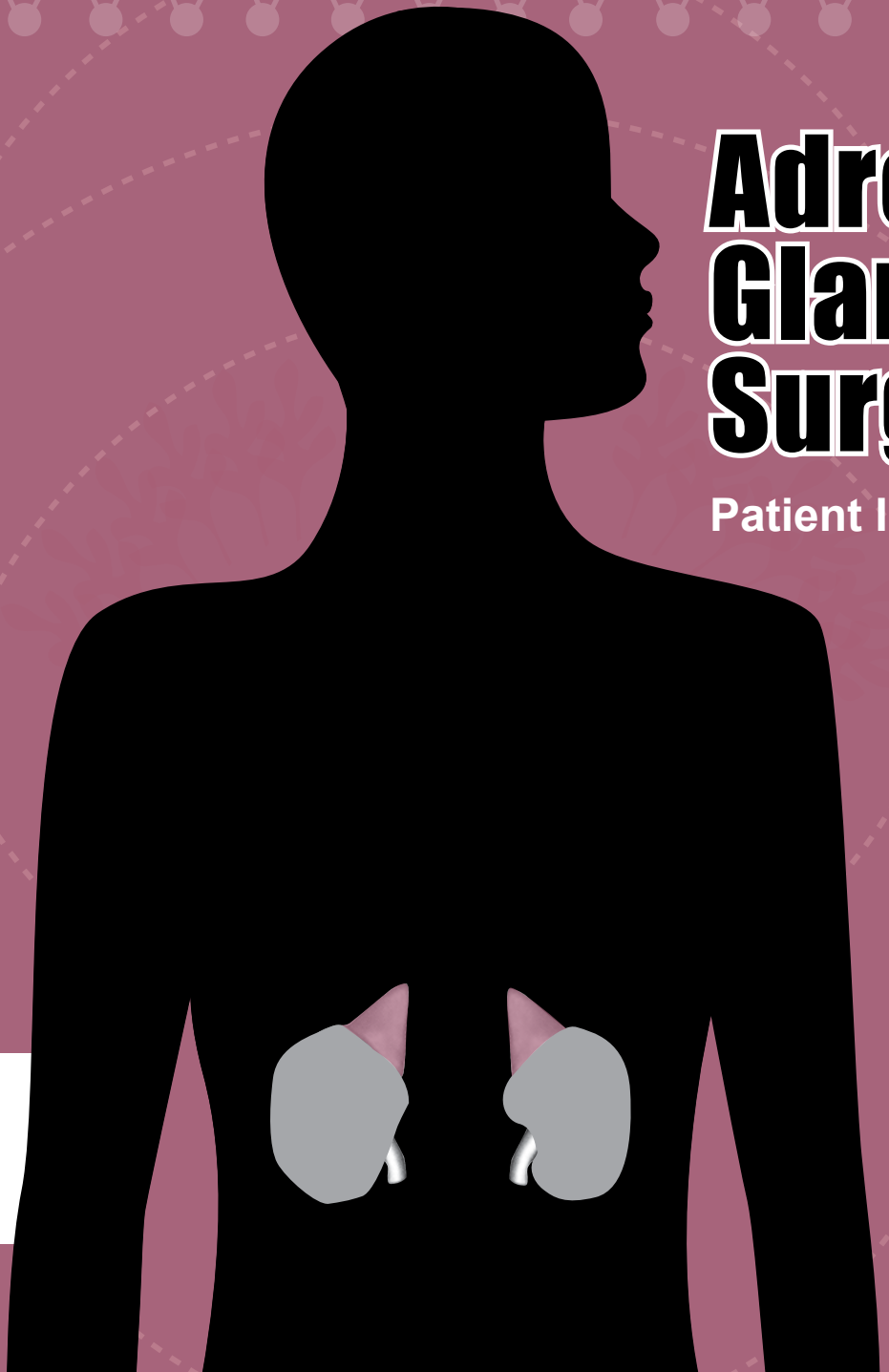
Adrenal Gland Surgery

Patient Information



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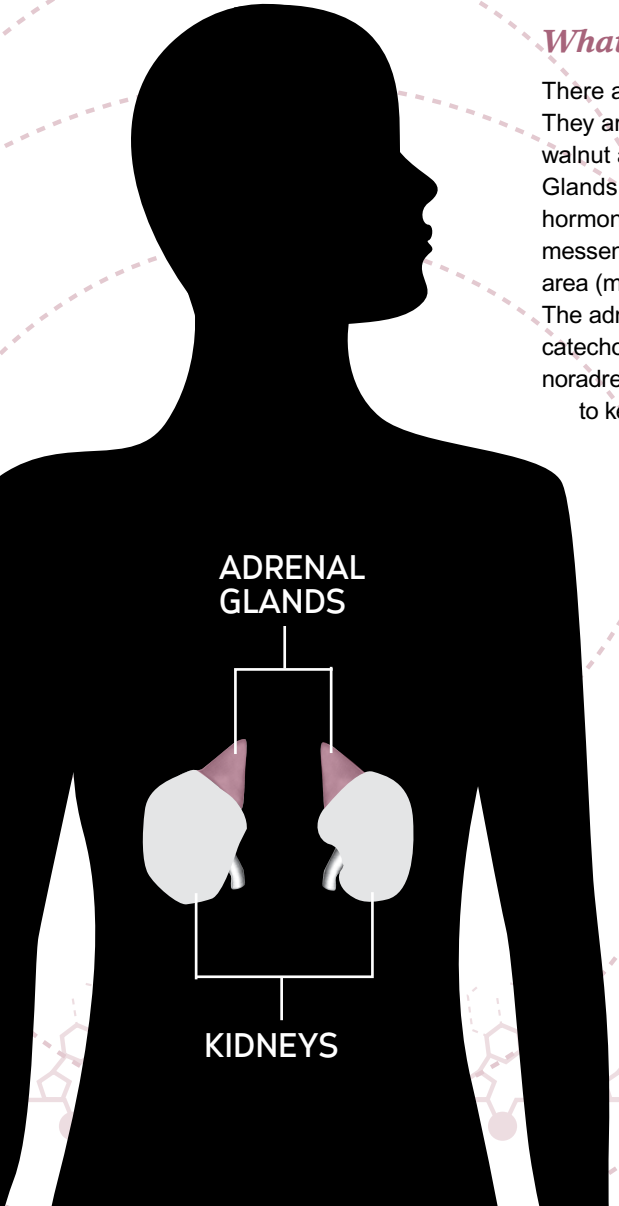
Adrenal Gland Surgery

This Information Leaflet is for anyone in the UK who may be about to have surgery to remove an adrenal gland. Research has shown that the more adrenal operations a surgeon does in a year, the better a patient is likely to do during and after the operation. This leaflet explains what an adrenal gland is, why an operation may be needed, and who should care for you during your treatment.



What is an adrenal gland?

There are two adrenal glands in the body. They are each about the size of a whole walnut and sit just on top of the kidneys. Glands make a number of important hormones which are the body's chemical messengers. An adrenal gland has an inner area (medulla) and an outer area (cortex). The adrenal medulla makes hormones called catecholamines, including adrenaline and noradrenaline. These hormones help the body to keep blood pressure at the right level and to deal with sudden stress.

The adrenal cortex makes hormones called steroids. These include cortisol (also known as glucocorticoid) and aldosterone (also known as mineralocorticoid). These hormones also help the body to keep blood pressure at the right level and to deal with stress. They also help to keep the salt and sugar levels in the body at the right level.

When is adrenal surgery needed?

An adrenal gland may need to be removed if it is found to contain a lump (tumour). Adrenal tumours develop when cells in the gland grow and divide out of control. Tumours can be benign (not cancer) or malignant (cancer) and can cause a wide range of symptoms due to the release of higher than normal levels of hormones.

Many tumours in the adrenal gland will make the hormones relevant to where the tumour is found in the gland. For example, a tumour in the medulla may make catecholamines, and a tumour in the cortex may make steroids. Together with the hormones made by the normal cells, this can cause levels that are higher than normal in the body.

Symptoms of high levels of adrenal hormones include:

- Sudden headaches
- Fast or uneven heartbeat (palpitations)
- Breathlessness
- Sweating more than normal
- Tiredness
- Mood changes (depression, anxiety)
- Feeling sick (with or without being sick)
- Weight gain
- High blood pressure
- Easy bruising
- More hair than usual on the face and body in women
- Acne
- Mood changes

In most cases, surgery to remove the gland with the tumour will sort out these symptoms. It is possible to live a normal life with just one remaining adrenal gland, but if both must be removed, a person will need to take tablets to replace the hormones for the rest of their life.

The operation to remove both adrenal glands at the same time is called a bilateral adrenalectomy. The removal of both adrenals can be performed in one operation or less often, in two separate operations. In both cases, removing both adrenal glands causes a condition called adrenal insufficiency. This means that there are not enough adrenal hormones in the body and a patient must take lifelong medication to replace them. In addition, if one adrenal gland that was making excess of the hormone cortisol is removed, the other adrenal gland may be 'asleep'. This can lead to temporary adrenal insufficiency and the need to take adrenal hormone replacement medication for up to around a year.

What types of adrenal tumour are there?

Adrenal tumours may be benign (not cancer) or malignant (cancer). Both types of tumour may make hormones (functioning) or they may not (non-functioning). Adrenal tumours include:

- Adrenal incidentaloma – usually a benign tumour often found by accident on scans done for other reasons. These may be removed if it is not clear that it is benign, if it is causing symptoms by making excess hormones, or if it grows in size. The vast majority do not need to be removed.
- Adrenocortical cancer (ACC) – a very rare form of cancer.
- Phaeochromocytoma – a functional tumour of the adrenal medulla that is usually benign. When they occur outside of the adrenal gland they are called a paraganglioma. Both phaeochromocytomas and paragangliomas can occur as part of conditions that can be passed down in families.

Who should do the surgery?

Research has shown that the more adrenal operations a surgeon does in a year, the better a patient will do during and after the operation. Although current treatment guidelines suggest that an adrenal surgeon should do more than six (6) adrenal surgeries in one year, the GIRFT Report (Getting it Right First Time) recommends that this is the minimum number with higher numbers being better. Despite this, few surgeons in the UK do more than 6, and in expert centres some surgeons do as many as 30-40 operations per year.

Having a surgeon experienced in adrenal surgery is very important because adrenalectomy can be a technically challenging operation, and the surgeons in more expert centres work in a large team that is expert in the overall management of patients with adrenal disease (see MDT below). In addition, catecholamine-producing tumours can cause problems before and during the operation by making sudden large amounts of hormones. This sudden surge of hormones is dangerous and needs to be planned for carefully by a surgeon and hospital team (multidisciplinary team) who are used to dealing with this. Special drugs may be needed before and during the surgery to keep blood pressure under control and avoid stroke or heart attack.

Many (though not all) adrenal surgeons publish the number of surgeries they do as part of an audit run by the British Association of Endocrine and Thyroid Surgeons. You can find these lists at www.baets.org.uk/audit. Guidance for adrenal surgery from the BAETS can be found at https://goo.gl/KNaAcd.

What is a multidisciplinary team (MDT)?

A multidisciplinary team is also known as an MDT. An MDT is made up of the different types of doctors and other health care workers needed to care for and treat people with rare and complex diseases. The MDT will work together to make sure that you receive the best treatment possible. MDTs are usually found in larger university training hospitals.

The main adrenal MDT will include:

- Surgeon who does more than 6 adrenal operations each year
- Endocrinologist (hormone doctor) experienced in treating adrenal disease
- Radiologist (scan doctor) experienced in adrenal scanning
- Pathologist (laboratory test doctor) experienced in adrenal disease
- Endocrine Nurse Specialist
- MDT coordinator

Other MDT members will include:

- Anaesthetist (doctor who makes patients sleep for operations and manages pain)
- Oncologist (cancer doctor)
- Nuclear medicine doctor (doctor who performs special radioactive scans and treatments)
- Clinical geneticist (doctor who tests for diseases that can be passed down in families)
- Chemical Pathologist
- Interventional Radiologist

Why is an MDT important?

Research has shown that, in the UK, if you are cared for by an MDT, you are more likely to:

- Receive a correct diagnosis of your disease
- Receive correct staging of your disease (if and how far it may have spread)
- Be offered a choice of treatments
- Receive better coordinated care through treatment and testing
- Be treated in line with policies and guidelines for your disease
- Be offered the right information
- Have your emotional well-being and social needs addressed.

What questions should I ask?

It is very important to understand why you are having surgery, what will happen during the surgery, and if your surgeon is the best one to do it. You should never be made to feel that you cannot ask questions, so do not be shy in asking the following:

1. How many operations to remove adrenal glands do you do each year?

If the answer is less than 6 operations in one year, ask for a referral for a second opinion to a hospital where the surgeon does more than 6 each year, and preferably higher.

2. Do you have a multidisciplinary team (MDT) with whom you will discuss my treatment?

If the answer is ‘no’, ask for a referral

for a second opinion to a hospital where there is an MDT with experience of treating adrenal tumours.

3. Who will look after me after the surgery?

This may be the surgeon or another member of the MDT such as an endocrinologist (hormone doctor). You will be cared for by the hospital where you have your operation for a period of time, and then may receive care later on from a hospital nearer to where you live.

4. Am I at risk of adrenal insufficiency after the operation?

The answer will vary depending on the type of tumour that you have. The expert adrenal surgeon and endocrinologist will be able to answer your question immediately or tell you that tests will be done before the operation to assess this.

If in doubt, you can always ask your GP for help in finding the right hospital and MDT.

Where can I get more information and/or support?

More information and a range of support services for patients in the UK are provided by the Association for Multiple Endocrine Neoplasia Disorders (AMEND), ACC Support UK and Phaeo Para Support UK:

AMEND (information and support services for phaeochromocytoma)

T: 01892 516076

E: info@amend.org.uk

W: www.amend.org.uk

Phaeo Para Support UK (information and support services for familial phaeochromocytoma and paraganglioma syndromes – part of AMEND)

T: 01892 516076

E: info@phaeoparasupport.org.uk

W: www.phaeoparasupport.org.uk

ACC Support UK (information and support services for adrenocortical cancer, ACC)

T: 01892 516076

E: info@accsupport.org.uk

W: www.accsupport.org.uk

Afterword

The aim of this book is to answer those questions, sometimes in great detail, that someone may come across when facing adrenal surgery. It is not for use in self-diagnosis. It is possible that not all of this information will be relevant to you. This book is not intended to replace clinical care decisions and you should always discuss any concerns you may have carefully with your specialist. Every care has been taken to ensure that the information contained in this book is accurate, nevertheless, AMEND cannot accept responsibility for any clinical decisions.

About AMEND

AMEND is a Charitable Incorporated Organisation registered in England and Wales (number 1153890). It provides support services and information resources to families affected by multiple endocrine neoplasia and related endocrine tumours. AMEND encourages research into the conditions by awarding annual research awards. It hosts regular free patient information events every year and runs social media forums connecting patients from around the world. We rely entirely upon donations in order to provide all our resources for free. In collaboration with the Neuroendocrine Cancer UK we also run ACC Support UK which provides information resources and support services to those affected by adrenocortical cancer (ACC).

How AMEND can Help

AMEND provides a free counselling service for members. AMEND can also put you in contact with others who have undergone adrenal surgery to offer support through sharing their experience.

If you have found this resource useful, please visit our website for more information on AMEND or to make a donation: www.amend.org.uk

Authors

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