

Adrenal Insufficiency

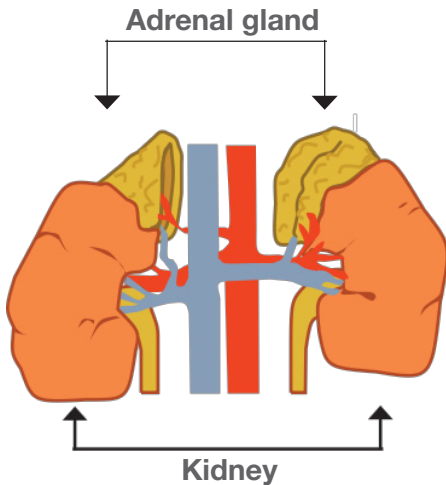


A Guide for
Young adults

We have written this leaflet to give you information about adrenal insufficiency.

If you have any questions please speak to your endocrine doctor or endocrine nurse.

What are the adrenal glands?



The adrenal glands lie just above the kidneys and make hormones, including a steroid hormone called cortisol.

Cortisol is vital for health because it:

- helps the body to respond to stress;
- helps to control blood pressure;
- helps to control blood sugar levels;
- helps the immune system to work.

What is adrenal insufficiency?

Adrenal insufficiency happens when the adrenal glands cannot produce enough cortisol. This problem can be present from birth, or may develop during childhood or adulthood.

Adrenal insufficiency can also occur if you have been treated with long-term high-dose steroids (such as prednisolone) for a chronic health problem such as severe asthma, inflammatory bowel disease, kidney problems or arthritis. The high-dose steroids switch off the adrenal glands' ability to make cortisol.

A synacthen test can confirm whether your body is able to produce enough cortisol to cope with periods of illness. An information leaflet about this test is available on the SPEG website (website address at end of this leaflet). You would have this test as an outpatient in hospital.

Why is it important to detect adrenal insufficiency?

People with adrenal insufficiency need to take regular steroid tablets to replace what the body is not making. This is usually given as a tablet called hydrocortisone. If you do not take your medication regularly you can become very unwell.

You will need extra hydrocortisone during illness to help your body cope with this extra stress. Tummy bugs may make it difficult to take medication if you are being sick and to absorb medication if your bowel movements are loose. If you are unable to take hydrocortisone by mouth, you may need to be given it as an emergency injection.

Your doctor or nurse will give you an emergency kit and show you how to give the injection. It may also be useful for someone else at home to be taught how to give the injection. It is important that you take the kit with you if you are away from home for a significant period, such as when you go on holiday. Please check regularly that the hydrocortisone in the kit has not gone past its expiry date.

If you have been on high-dose steroids for another condition for more than three months you should have an emergency management plan like the one on the next page. (Your endocrinologist may alter some of the advice on the plan.)



What to do when you are unwell

Situation	Change to usual dose of hydrocortisone
Cold with no fever	No change.
Fever, flu or infection	Double your usual dose as follows. Your doctor can use this space to write your usual dose.
Being sick more than once, diarrhoea or severe illness	Emergency 100mg injection, if you cannot keep down a dose of tablets.
Surgical procedures	<ul style="list-style-type: none">• Minor surgery, for example having a tooth taken out: take double your usual main dose beforehand.• Operation in hospital: tell the staff that you have an adrenal insufficiency. You should be given extra doses in an intravenous drip for 24 to 72 hours.
Severe shock, for example bereavement or road traffic accident	100mg injection or take 20mg as tablets if you are able to.
Long-haul flight over 12 hours	Double your usual dose on the day of the flight.
General stress, for example exams	No change.

If you are at school and need an injection of hydrocortisone, teaching staff are not expected to give this, but training is available if they ask for it, for trips to remote places for example. Your nurse specialist can visit your school and give them information about your condition and what to do if there is an emergency.

Length of change	Is this an emergency? When do I get help?
	Not an emergency
For as long as the fever lasts.	See your GP if you are still unwell after 48 hours.
Return to your usual dose once stable.	Take an injection at home and seek urgent medical help
<ul style="list-style-type: none"> • Return to your usual dose immediately after. • Very quickly reduce to your usual dose. Medical staff should be able to advise you on reducing the dose. 	<p>Tell the anaesthetist and dentist or surgeon before the operation that you take hydrocortisone.</p> <p>Discuss with your endocrine team, who may have a procedure to follow for surgery.</p>
See your GP or A and E for further advice.	Sudden and severe shock may be classed as an emergency.. Seek urgent medical help
One double dose should be enough.	Not an emergency.
	Ask your GP if you are concerned.

You need to make sure that:

- you are wearing or carrying a form of medical alert stating that you have adrenal insufficiency;
- you have enough supplies of hydrocortisone and that the medication is not out of date;
- you have an emergency management plan; and
- you have an emergency hydrocortisone kit. Make sure the medication is not out of date (or due to go out of date soon).

If you are at school this should be in a box labelled as an emergency kit with a picture of you on it and with a plan inside stating what to do. A picture guide on injection technique may also be helpful.





Travel advice

Make sure you travel with enough medication for the time you are away. Allow for any increases in dose or unexpected delays while returning home. It would be a good idea to take double your usual dose in case you are ill and need to increase it.

Always keep your medication in your hand luggage if you are flying on holiday.

Your nurse specialist can give you a letter for Customs to explain why you are travelling with needles and syringes.

Keep your adrenal insufficiency card with the medication at all times.

My Cortisol app

Great Ormond Street Hospital have developed an app 'My Cortisol' for downloading.

Nurse contact details:



Doctor contact details:



SPEG is a network of healthcare professionals in Scotland who have a particular interest in the care of children and young adults who have endocrine conditions.

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For more information

visit our website: www.speg.scot.nhs.uk

