

Adrenal Insufficiency

A guide for parents

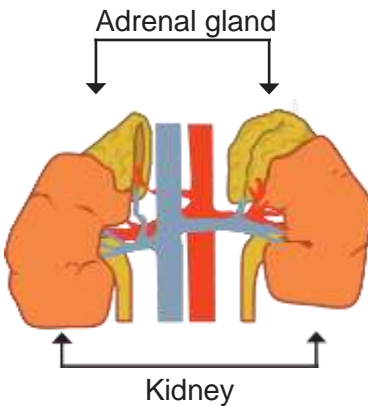


We have written this leaflet to give you information you may need about adrenal insufficiency in your child.

If you have any questions, please talk to your endocrine doctor, local paediatrician or endocrine nurse.

When we say child in this document we also mean a young person.

What is the adrenal gland?



There are two adrenal glands. They are small glands that lie just above each kidney.

Cells in the adrenal glands make various hormones.

- Cortisol (steroid hormone)
- Aldosterone (salt balance hormone)
- Androgens (weak male hormones)

This guide relates to the hormone cortisol.

What is adrenal insufficiency?

Adrenal insufficiency happens when the adrenal gland is not able to produce enough cortisol.

This problem can be present from birth, or may develop during childhood.

Adrenal insufficiency can also occur if a child is treated with high-dose steroids (most commonly prednisolone) for a long-term health problem, for example 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 child is able to produce enough cortisol to cope with periods of illness.

The synacthen test involves injecting synacthen (a synthetic hormone) into a small plastic tube (cannula) which has been inserted into a vein. This then stimulates the adrenal glands to produce cortisol. The cortisol that is produced can be measured from the blood samples taken from the cannula. Your child will have this test as a day patient at hospital.

Why is adrenal insufficiency important to detect?

Children with adrenal insufficiency need to take regular steroid medicine by mouth to replace what the body is not making. This is usually given as a tablet called hydrocortisone.

Children with adrenal insufficiency may run into problems during times of illness or accidents. In these situations, children will need more than the normal amount of hydrocortisone, and the illness may also affect their ability to take their medication. When severe, these situations can lead to serious consequences for the child's health. If a child is unable to take the hydrocortisone by mouth, they may need to have it as an injection.

Your doctor or nurse will give you an emergency kit and show you how to use it. It is important that your child has this kit with them at all times.

All children on lifelong or long-term high-dose steroids (for a period of more than three months) must have an emergency management plan.

What happens if my child is unwell?

(a) Mild illness

A mild illness may include fever, a sore throat or a bad cold, or your child may just feel generally unwell and off their food. They should still be able to go to school. In line with your sick-day management plan, they may need to have an extra dose of hydrocortisone through the day.

(b) Moderate illness

A moderate illness would include high fever (your child would have a temperature of over 38.5°C or be very hot to touch), vomiting or severe diarrhoea (or both), flu or upset tummy, or chickenpox. Follow your sick-day management plan.

Your child would not be expected to be at school.

However, if your child becomes unwell at school, the school should contact you and ask you to collect them.

(c) Severe illness or major accident

A severe illness would include a vomiting bug, if your child was unable to keep down any fluids, or if they were involved in a serious accident, broke a bone or had a significant injury which needed medical attention.

If your child has a severe illness or major accident, they will need an injection of hydrocortisone into the muscle in the thigh (called an intramuscular injection). Your nurse specialist will show you how to give this injection.

Call 999

Your child should be brought straight to the hospital.

An alert has been placed on the Scottish Ambulance Service system and also on the hospital computer system which will tell staff that

your child has adrenal insufficiency.

The dose of hydrocortisone that your child needs by injection will have been worked out for you by the doctor and nurse looking after your child.

If your child is at school and needs an injection, teaching staff are not expected to give this (but we can give them training if they ask, for example trips to remote places). Your nurse specialist can visit your child's school and tell them about your child's condition and what to do if there is an emergency.

Chickenpox

Some children can become very unwell with chickenpox. If your child is unable to keep down their oral medication, you should give them the hydrocortisone injection and contact the hospital.

Hydrocortisone

Hydrocortisone is a steroid medication which is equivalent to the natural steroid cortisol. This medication is necessary as your child is unable to produce enough of their own cortisol.

How to prepare the correct daily dose of oral hydrocortisone for your child

Hydrocortisone can come in a few different preparations. Your nurse specialist will discuss with you the type of hydrocortisone you will be given and how to prepare the dose your child needs.

Notes:

If your child will not swallow a tablet, follow these guidelines.

1. Place the correct size of tablet on a tablespoon.
2. Place the back of another tablespoon onto the tablet and press down. This will crush the tablet.
3. Keep doing this until a small amount of powder is made.
4. Add a small amount of milk, juice or yoghurt to the powder and mix well.
5. Give this mixture to your child followed by a small drink to make sure they swallow all of the medicine.

You need to make sure of the following.

- You have enough supplies of hydrocortisone medication and it is in date.
- You have an emergency management plan.
- Your child is wearing or carrying a form of medical alert stating that they have adrenal insufficiency.
- You have an emergency hydrocortisone kit. Make sure that the medication in the kit is in date and will not go out of date in the near future. At school this should be in a box labelled as an emergency kit with a picture of your child on it and with a plan inside stating what is to do. A picture guide on injection technique may also be helpful.



- You should complete a healthcare plan for your child's nursery or school in line with school or nursery policy.
- There is also a leaflet guide for schools available.

You should tell school or nursery staff:

- if your child needs a dose of hydrocortisone or medication during the school day and any changes to that dose.

Travel advice

Make sure you travel with enough medication for the whole time you are away. Allow for any increases in dose or unexpected delays while returning home.

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

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

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

What are the responsibilities of the school or nursery?

Adrenal insufficiency should not affect your child's day-to-day attendance at school. If any problems arise it would be during illness. Most of the time, your child will take their medication in line with local school policy. Please contact your local paediatric team about any issues related to medication.

Summary

1. Day to day

- Your child may need medication at lunchtime.

2. Mild illness

- Your child's medication may need to be increased.
- They may need to take their medication at school.

3. Moderate illness

- Your child's medication will need to be increased.
- They will not be at school while they are ill.
- If they become unwell at school, the school should contact you.

4. Severe illness or accident

Emergency

Ambulance needed



Phone 999



Emergency injection of hydrocortisone needed

Nurse's contact details:

Doctor's contact details:

This leaflet was produced by the SPEG Nurses Sub-Group.
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