

Condition guide —

Adrenal Insufficiency

Adrenal insufficiency can occur when the body doesn't naturally produce the hormone cortisol. In this guide, learn more about adrenal insufficiency, how to treat it, and what to do when you are sick.

The Pituitary Foundation

For hormones • For health • For life

Notes

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An explanation of hormones



What is the pituitary gland?

The pituitary gland is a small pea-sized gland located just below the brain which secretes hormones.

Hormones are chemicals that carry messages from one cell to another through the bloodstream. The pituitary gland controls several hormone glands in the body, including the thyroid, adrenals, ovaries and testes. It also secretes several hormones directly (growth hormone, prolactin, vasopressin and oxytocin).

The pituitary gland is therefore described as the master gland. If the pituitary gland is not producing sufficient amounts of hormones this is called hypopituitarism. In some cases hormones can be over-produced (or are in excess), for example, cortisol, prolactin and growth hormone.



What is adrenal insufficiency?

In people who have adrenal insufficiency, the adrenal glands stop working properly. The adrenal glands produce a hormone called cortisol, also known as the stress hormone. Cortisol is often referred to as a 'steroid', and is crucial to keeping your body functioning correctly.

There are several signs and symptoms that can occur with adrenal insufficiency. You may not experience them all:

- General tiredness/fatigue for no apparent reason
- Dizziness
- Nausea/diarrhea
- Loss of appetite and weight loss
- Feeling cold/shivery
- Low blood pressure
- Heaviness/aches/pains especially in legs and lower back.

What causes adrenal insufficiency?

Adrenal insufficiency has multiple causes, which can be grouped into three different types of adrenal insufficiency:

1. Primary (adrenal, also called Addison's Disease)

- 2. Secondary (pituitary)
- 3. Tertiary (hypothalamus).

The type you may develop from your pituitary condition is secondary adrenal insufficiency.

The pituitary gland produces a hormone called ACTH, which tells your adrenal glands what to do. If the pituitary gland stops sending these hormone signals, the adrenal glands are unable to produce the hormone cortisol.

How is adrenal insufficiency diagnosed?

Diagnosis happens through assessment by your endocrine team of your general health and wellbeing, along with blood testing of your cortisol level. You may spend a morning in a day unit to have bloods taken before and after an injection of synthetic ACTH. The results will enable your specialist to assess if you have any adrenal insufficiency. Your diagnosis may be due to another pituitary condition, requiring further tests.

> Things weren't entirely back to normal [after my surgery] and the exercise was no longer what it used to be because of exhaustion kicking in so quickly. It started to become harder and harder just to do my 20-minute walk into work. Add that to the small talk, office chat ... and then actually doing my work I soon found that working a 9-5 just wasn't easy.



I was diagnosed with Addison's disease [adrenal insufficiency] and, that coupled with a non-functioning pituitary gland, meant everyday life was damn hard.

Catherine was diagnosed with adrenal insufficiency after having a pitutiary tumour

How is adrenal insufficiency treated?

Adrenal insufficiency is treated with replacement steroid tablets. There are several alternative medications available. Your endocrinologist will recommend the most appropriate one for you.

Your endocrinologist will determine your daily dose based on your individual requirements.

Hydrocortisone (cortisol) tablets

These are taken by mouth and your total dose is usually split over two or three times throughout the day. For example, when you wake up, at around midday and finally no later than 6pm.

Hydrocortisone is best taken with water and is better absorbed if taken before food.

Prednisolone tablets

Prednisolone tablets are also taken by mouth, once or twice daily.

Plenadren (slow-release hydrocortisone) tablets

Plenadren is taken once daily, at least 30 minutes before your breakfast, preferably between 6.00am and 8.00am in the morning.

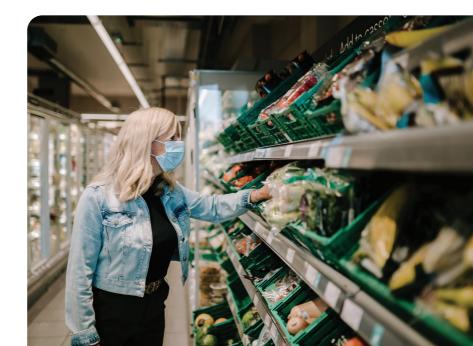
Sick Day Rules

During normal health and life, when we become ill or suffer injuries, our bodies produce increased levels of cortisol to help us survive those stresses.

Now that you are unable to produce your own cortisol, you need to be aware of when to provide an increased cortisol level during illness or acute onset stress.

The amount of increase needed, the way the cortisol is given and the length of time the increase is needed, will vary depending on the situation you are experiencing.

The table on the following pages outlines the more common life events when an increase in cortisol cover would be needed. It provides advice about how long the increase should be for and in what form the cortisol should be given (tablets, injection to muscle or direct into vein).



Illness or Situation Action to take

Adrenal crisis – weak, dizzy, nausea, vomiting faint, disorientation, loss of consciousness	Have emergency injection if possible; dial 999 and state 'adrenal crisis'. This is urgent, and hospital admission is needed to stabilise. An uncomplicated crisis without infection can be discharged after a period of stabilisation in A&E
Temperature higher than 38°C, signs of infection or proven to have infection (urine tract, chest, tonsillitis etc.)	2-3 times all normal doses of hydrocortisone for duration of infection. Level of care needed: GP/Self care, if symptoms not resolved at 48 hours see GP may need antibiotic treatment
Antibiotic treatment for infections	Double all normal doses for duration of antibiotics (usually 3-7 days).
Vomiting with/without diarrhoea	Take extra dose immediately at onset of vomiting. Emergency 100mg injection if vomiting recurs within 30mins of taking extra dose. Level of care needed: Urgent if unable to tolerate fluids and emergency injection used need admission to stabilise. GP if able to tolerate fluids and retain oral Hydrocortisone, check Sodium within range. May need anti-sickness treatment.
Diarrhoea (frequent watery stools)	If no vomiting, double all doses of hydrocortisone until diarrhoea settles. If signs of adrenal crisis, follow advice for that. Level of care needed: Self care/GP. Urgent if signs of adrenal crisis.
Significant accident/falls/injury	If able, double hydrocortisone dose as soon as incident happens. If significant injury e.g. broken bone, give emergency injection. Level of care needed: Self care. Urgent if significant injury as need hydrocortisone cover and injury treated

Illness or Situation	Action to take
Severe shock i.e., bereavement, road traffic accident, witness to trauma	Take 20mg hydrocortisone as tablets if able or double usual dose of prednisolone if able. May need to use emergency injection if shock severe. Level of care needed: See GP or hospital for further advice. Sudden and severe shock may be classed as emergency – seek medical attention if in doubt.
Long haul flight over 12 hours	Double usual dose on day of flight. One double dose should suffice.
General stress, exams, etc.	Not usually required. Ask GP if concerned.
Dental treatments - Extraction with anaesthetic - Root canal - local anaesthetic - Filling, dental hygiene	 - 100mg intra muscular (via injection) just before extraction. - Double dose 1 hr prior to surgery. - Double dose 1 hr prior to procedure. For all these procedures you should double dose for 24 hours then return to normal
Surgery	
Surgery with longor short recovery – e.g. heart, bowel	100mg intravenus with anaesthetic, then 100mg IV every 6hrs or 200mg continuous IV over 24hrs until able to eat/drink. Then double normal dose for 48hrs, then taper back to normal. Level of care needed: Tell the anaesthetist and surgeon that you take hydrocortisone before the operation. Replacement at time of surgery and immediately post operatively should be managed by surgical teams.

Illness or Situation	Action to take
Minor surgery- cataract, hernia	100mg intra muscular (via injection) pre anaesthetic, double normal dose for 24 hrs post surgery, then normal doses. Level of care needed: Tell the anaesthetist and surgeon that you take hydrocortisone before the operation. Replacement at time of surgery and immediately post operatively should be managed by surgical teams.
Minor surgery with local anaesthetic – mole removal	Take extra dose 1 hour pre procedure, extra dose 1 hour post procedure, then normal doses.
Colonoscopy/Barium enema	Double your usual dose as soon as the preparatory laxatives take effect and for duration of the preparation. For colonoscopy only: a 100mg injection 30 minutes before procedure to be given by doctor. Take usual dose on morning of procedure. Some centres may want to admit you to hospital the night before to give the bowel prep and provide hydrocortisone cover. Level of cover needed: Drink lots of water to prevent dehydration. Tell the doctor before procedure that you take hydrocortisone.
Gastroscopy	100mg intra muscular or intra venous at start of procedure. Level of cover needed: Tell the doctor before procedure that you take hydrocortisone. Double dose for 24 hours.
Cytoscopy	100mg intra muscular immediately pre- procedure. Level of cover needed: Double dose 24hr then resume as normal. Tell the doctor before procedure that you take hydrocortisone.

What is an adrenal crisis?

Adrenal crisis is a life-threatening situation where the level of your cortisol is inadequate for an acutely stressful situation.

Common causes of adrenal crisis are:

- Sudden onset diarrhoea and/or vomiting,
- A rise in body temperature to above 38°C
- Significant accident or injury

• Significant psychological stress such as bereavements or witnessing trauma.

What are the symptoms of an adrenal crisis?

The list below summarises the symptoms often-reported by people reduced cortisol levels leading to adrenal crisis. You may not experience them all:

- Headache
- Nausea
- Irritable/restless
- Clumsiness
- Fatigue
- Pale skin (if you have a darker skin tone this may look ashen or grey)
- Muscle aches
- Weakness
- Cold/shivery
- Spasms
- Dizziness (especially on standing)
- Abdominal pain/cramps/ diarrhoea
- Vomiting
- Reduced or loss of consciousness
- Seizures.
- 10

If you have more than one of these symptoms at the same time, your cortisol levels are likely to be too low for your current illness or stressful situation.

Similarly, if you find symptoms start to accumulate, e.g. headache, followed by nausea, then feel shivery cold, with leg aches and fatigue, this may also indicate inadequate cortisol levels.

Taking extra cortisol by mouth as instructed for sick day cover at this time can often prevent a full-blown adrenal crisis.

What to do if you have an adrenal crisis?

If you are having an adrenal crisis, you should call 999. State that you are having an **"adrenal crisis/Addisonian crisis."** Tell the call handler your symptoms e.g. vomiting, diarrhoea, dehydration, injury, shock.

You should have an emergency hydrocortisone injection (information on how to do this on page 14-15). You may be able to deliver this yourself, or ask somebody with you to give it to you. We would recommend ensuring your support network are familiar with how to give the hydrocortisone injection.

We have a factsheet that you can give to healthcare professionals if you are having an adrenal crisis. Find it on our website: www.pituitary.org.uk/product/hydrocortisone-ambulance-factsheet/

You can also find out more about what to do in an emergency: www.pituitary.org.uk/emergency-information/

When do I know that I would need an emergency injection?

If you cannot absorb your tablets, or your usual replacement was not sufficient for an acute shock or illness, you will need an emergency hydrocortisone injection. This may be due to vomiting, or you may be experiencing an adrenal crisis.

This may happen gradually or perhaps quite quickly. You would feel weak, sickly and lightheaded.

Steroid Emergency Cards

The NHS has released a steroid emergency card for adults, which is important if you are steroid dependent (i.e. adrenal insufficiency). The card has an area for you to fill in your details, as well as information for medical professionals on how to treat an adrenal crisis. It is a useful addition to your emergency kit.

Your GP, pharmacist or endocrinologist will be able to provide you with an NHS steroid emergency card. Alternatively, you can order one through our website.

Identification Emblems

Several companies provide internationally recognised identification emblems and medical alert jewellery. These emblems alert medical professionals to your adrenal insufficiency. This offers peace of mind should you develop adrenal crisis and struggle to explain your condition.

UK providers include MedicAlert Foundation, Medi-Tag, Message in a Bottle, Universal Medical ID and UTAG. Alternatively, silicone wristbands are available through our online shop.

You can also create add your condition to the emergency section of your phone. Some people add information to their lock screen, or have a card in their phone case.





I do still get a lot of adrenal fatigue. But I tend to be able to recognise the signs now and mostly stop it going into crisis. Over the last few years I've got more knowledgeable and used to listening to my body more. You also have to learn not to overdo things otherwise you pay for pushing yourself too hard. Although that's not always easy to do.

Nadine who has adrenal insufficiency and Cushing's disease.

Emergency Injection

Your GP should provide you with a prescription for this, along with the necessary needles and syringes needed to inject.

Injections should be 100mg of hydrocortisone and there are two formulations available:

- Hydrocortisone 100mg powder for solution for injection or infusion 2ml vial with diluent (previously known as Solu-Cortef)
- Hydrocortisone sodium phosphate (previously known as Efcortesol).

You should store these in an emergency kit which is available at all times should you develop an adrenal crisis. Your kit can also include printed instructions on how to inject.

Your emergency injection kit should include:

- 1x drawing up needle (usually has a green hub)
- 1x blue injection needle
- 1x 2ml (min) syringe
- Either 1 x ampoule hydrocortisone sodium phosphate (as shown above left) or 1
- x 2-part (powder and solution) hydrocortisone injection, (as shown above right).

Giving the emergency injection

As far as possible ensure the person needing the injection is safe and that the injection site is as clean as possible. If able, wash and dry hands. Open packages of drawing up (green) needle and syringe.



To draw up, attach 'drawing up needle' to syringe.



Ensure all liquid is in the lower part of the ampoule and break off the top by holding with the blue dot facing and 'snapping' backwards. Use a tissue to avoid scratches to your fingers.



Place the tip of the needle (attached to syringe) into the opening of the ampoule - this can be tilted but ensure not to lose any liquid.

Using one finger and thumb to draw plunger toward you, and one finger to secure syringe, draw the liquid into the syringe. When all liquid is in the syringe, discard the empty ampoule in sharps disposal (if available).



At this point for the powder/liquid version, hold the powder bottle on flat surface and remove yellow plastic cap. Insert needle through rubber bung at top and push syringe plunger to inject all liquid into bottle. Keeping the plunger depressed, remove needle ensuring all the solution remains in the bottle (a vacuum will form which will try and draw the liquid back into the syringe).

Mix the liquid and powder together with a 'swirling' motion. This

should only take a few seconds. When mixed turn bottle upside down in one hand, insert needle through rubber bung so tip is just in the liquid and draw the fluid into syringe.

Expel all air and bubbles in syringe and remove drawing up needle - dispose of in sharps disposal bin.

Attach blue injection needle.

6 To give injection: Injection is given into muscle. Generally, the thigh muscle will be easiest to use.

The injection should be given in the upper outer mid portion of the thigh and at a 90-degree angle (practice pad in use for pictures).



To give injection:

- Hold the barrel of the syringe between forefinger and thumb in your dominant hand.
- Remove the needle cover.
- Use the non-dominant hand to support the skin at the injection site.
- Ensure the area to be injected is clean and dry, you can wipe with a medi-swab if one is available.
- Insert the needle into the skin with a smooth and steady push.
- Move non-dominant hand to support needle and syringe.
- Use dominant hand to depress plunger with a smooth pressure until all liquid has been injected.
- Move non-dominant hand back to support leg and holding syringe barrel between forefinger and thumb of dominant hand, remove from the leg.
- Apply light pressure to injection site using cotton swab or clean tissue for a few seconds, there is no need to rub.

More information

We have a full range of booklets to support people with their pituitary conditions, as well as information across our website. You can find this at www.pituitary.org.uk.

If you would like more support then we have a range of services that may be suitable:

Endocrine Nurse helpline Our specialist endocrine nurses can provide medical guidance.

Information and Support Helpline Our volunteers and staff run helpline allows you to speak to others with pituitary conditions, and ask practical questions about living with a pituitary condition.



Telephone Buddy

This service provides one to one support with someone with a similar pituitary journey as you. For example, someone with the same condition, or a parent of someone with a condition.



Support Groups

We have a number of volunteer-led support groups across the UK, which host meetings with endocrinologists and peer support for patients.



Events

We host online and in-person events with endocrinologists on specific conditions/topics. These give people the opportunity to hear from professionals and ask questions.

About The Pituitary Foundation

We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 30 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

Become a member and support our work

Becoming a member is an excellent way to show your commitment to our work at The Pituitary Foundation.

As members you'll enjoy a range of benefits including free copies of Pituitary Life magazine – full of great articles from endocrinologists and inspiring stories from people living with pituitary conditions. You'll also be able to have a say on how the charity is run, and get early access to our fantastic events.

A yearly donation of £25 allows us to continue our work now and in the future.

You can become a member at: www.pituitary.org.uk/membership

All information in this guide is general. If you have any concern about your treatment or any side effects please read the Patient Information booklet enclosed with your medication, or consult your GP or endocrinologist.

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