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

Contents

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/diarrhoea
- 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 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.

Once adrenal insufficiency has been diagnosed, you may have your ACTH levels measured. This helps to distinguish between primary (adrenal) and central (pituitary or hypothalamic) adrenal insufficiency. Cortisol levels can also be measured in saliva, and research is under way to establish how this test can best be used in the diagnosis of adrenal insufficiency. If your adrenal insufficiency is caused by a pituitary condition then you may require further tests of your hormone levels.

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 pituitary 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 6:00pm.

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 (for example tablets, injection into muscle or directly into vein).

You should always seek medical advice if you have needed to use your emergency injection (explained later in this booklet), or if an increased dose of your tablets has not helped to resolve your symptoms.

Illness or Situation	Action to take
Adrenal crisis – severe vomiting, severe diarrhoea, severe weakness, faint, loss of consciousness	Have emergency injection of 100 mg hydrocortisone into the muscle, if possible. Self-administer or have it administered by someone else. 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.
If severely unwell (for example, with sepsis) or in intensive care unit	Give 100 mg intramuscular emergency injection or intravenous (IV) hydrocortisone. Then give 200 mg IV over 24 hours, or 50 mg intramuscular/IV 4 times a day. In-hospital intensive care is needed. Also seek endocrinology specialist advice.
Temperature higher than 38°C, signs of infection or proven to have infection (urine tract, chest, tonsillitis etc.) Note: *Some people do not always have a temperature during infection. If there is a clear sign of infection, please follow the recommended increase dosing but if unsure, contact your GP or endocrine team.*	Take hydrocortisone 20 mg at the onset and continue with double the dose or 10 mg every 6 hours. If on prednisolone, take 10 mg per day (can be divided into 5 mg twice a day). Continue the above dose for 24–48 hours or until you feel better. **Level of care needed:** GP/self-care, if symptoms not resolved at 48 hours see GP as may need antibiotic treatment. If condition worsens, call NHS 111 or 999.
Antibiotic treatment for infections (this excludes prophylactic /preventative antibiotic regimen)	Take hydrocortisone 20 mg at the onset and continue with double the dose or 10 mg every 6 hours. If on prednisolone, take 10 mg per day (can be divided into 5 mg twice a day). Continue throughout course of antibiotics (usually 5–7 days). **Level of care needed:** GP/self-care, if symptoms persist after antibiotics see GP. If condition worsens, call NHS 111.

Illness or Situation	Action to take
Vomiting with/without diarrhoea	Take hydrocortisone 20 mg at the onset and continue double the dose or 10 mg every 6 hours. If on prednisolone, take 10 mg per day (can be split into 5 mg twice a day). Continue the above dose for 24–48 hours, or until you feel better. **Note:** If vomiting recurs within 30 mins of taking hydrocortisone, take another 20 mg of another hydrocortisone tablet. If vomited again within 30 mins, administer emergency 100 mg hydrocortisone injection into the muscle. **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)	Take hydrocortisone 20 mg at the onset and continue double the dose or 10 mg every 6 hours. If on prednisolone, take 10 mg per day (can be divided into 5 mg twice per day). Continue the above dose for 24–48 hours or until you feel better. **Note:** If severe diarrhoea, (3 or more episodes of loose/watery stools in a day) and accompanied with weakness and nausea, administer hydrocortisone 100 mg in the muscle. **Level of care needed:** Self-care/GP. Ensure adequate hydration with electrolyte replacement. Urgent if unable to tolerate fluids and/or severe diarrhoea, administer emergency injection and call NHS 999. May need admission to stabilise.

Illness or Situation	Action to take
Significant accident/ falls/injury	Take hydrocortisone 20 mg at the onset and continue double the dose or 10 mg every 6 hours. If on prednisolone, take 10 mg per day (can be divided into 5 mg twice a day). If significant injury i.e., head injury or broken bone, administer emergency injection. **Level of care needed:** Self care. Urgent if significant injury as need hydrocortisone cover and injury treated
Severe shock, e.g. bereavement, road traffic accident, witness to trauma	Take hydrocortisone 20 mg at the onset and continue double the dose or 10 mg every 6 hours. If on prednisolone, take 10 mg per day (can be divided into 5 mg twice per day). If severe shock, i.e., sudden death of an immediate family member, an emergency injection may be needed if showing signs of adrenal crisis. **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. Call NHS 111/999.
Long-haul flight over 12 hours	Take hydrocortisone 20 mg one hour before the flight and continue hydrocortisone 10 mg every 6 hours. If on prednisolone, take 10 mg one hour before the flight. Reduce back to normal dose after 24 hours.
General stress, e.g. exams, etc.	Not usually required. Ask GP or endocrine team if concerned. Alternatively, can also contact our Nurse Endocrine Helpline.

Illness or Situation	Action to take
Major dental surgery, e.g., dental extraction under local or general anaesthetic	Use hydrocortisone 100 mg intramuscular injection before induction of anaesthetics. Take 10 mg hydrocortisone every 6 hours for 24 hours, then return to normal dose. **Level of care needed:** Dentists/anaesthetists to monitor during procedure and follow adrenal crisis management guideline if needed.
Minor dental surgery e.g., root canal	Take hydrocortisone 20 mg one hour before the surgery then continue double the dose of hydrocortisone or 10 mg every 6 hours for 24 hours then return to normal dose. If on prednisolone, take your usual dose in the morning then take 10 mg one hour before the surgery. **Level of care needed:** Dentists/anaesthetists to monitor during procedure and follow adrenal crisis management guideline if needed. GP/self-care to monitor for any signs of post-procedural complications and follow sick day rules as appropriate.
Minor dental procedures e.g., cleaning, scaling, polish, fillings	Take hydrocortisone 20 mg one hour before the procedure. If on prednisolone, take your usual dose in the morning and then 10 mg one hour prior to the procedure. Return to usual dose the next day. **Level of care needed:** Dentists/anaesthetists to monitor during the procedure and follow adrenal crisis management guideline if needed. GP/self-care to monitor for any signs of post-procedural complications and follow sick day rules as appropriate.

Illness or Situation	Action to take
Surgery with longer recovery under general anaesthetic, e.g., heart, bowel, kidney	Hydrocortisone 100 mg IV with anaesthetic, then 50 mg IV every 6 hours or 200 mg continuous IV over 24 hours until able to eat/drink. Then hydrocortisone 10 mg tablets every 6 hours for 24 hours, then return to usual dose. **Level of care needed:** In-hospital monitoring and post-op review by the surgical team. GP/self-care to monitor for any signs of post-procedural complications and follow sick day rules as appropriate.
Minor surgery (day case), e.g., cataract, hernia	Hydrocortisone 100 mg intramuscular injection prior to anaesthetic, then hydrocortisone 10 mg every 6 hours for 24–48 hours, then return to usual dose. **Level of care needed:** In-hospital monitoring and post-op review by the surgical team. GP/self-care to monitor for any signs of post-procedural complications and follow sick day rules as appropriate.
Minor surgery with local anaesthetic, e.g., mole removal	Take hydrocortisone 20 mg one hour before the procedure. If on prednisolone, take your usual dose in the morning and then 10 mg one hour prior to the procedure. Return to usual dose the next day. **Level of care needed:** In-hospital monitoring and post-op review by the surgical team. GP/self-care to monitor for any signs of post-procedural complications and follow sick day rules as appropriate.

Illness or Situation	Action to take
Colonoscopy/ Barium enema	Take hydrocortisone 20 mg as soon as the preparatory laxatives take effect and then 10 mg every 6 hours throughout the preparation. If on prednisolone, take 10 mg per day (can be divided into 5 mg twice per day). **For colonoscopy only:** A 100 mg hydrocortisone injection 30 minutes before procedure to be given by a doctor. Take usual dose on the morning of the procedure. Some centres many want to admit you to hospital the night before to give the bowel prep and provide hydrocortisone cover. **Level of care needed:** In-hospital monitoring and post-op review by the admitting team (endocrine/ gastroenterology). GP/self-care to monitor for any signs of pre-procedural adrenal crisis symptoms and post-procedural complications and follow sick day rules as appropriate.
Gastroscopy/cystoscopy	100 mg intramuscular or intravenous at start of procedure. **Level of care needed:** In-hospital monitoring by the gastroenterology/urology team.

Illness or Situation	Action to take
Pregnancy; immediately once confirmed pregnancy; first and second trimester	Take usual dose and follow sick day rules if needed. **Level of care needed:** Inform endocrine team regarding pregnancy and inform obstetrics team that you are steroid-dependent.
Pregnancy; hyperemesis gravidarum (severe morning sickness)	Immediately administer 100 mg hydrocortisone intramuscularly and go to the emergency department or early pregnancy unit. **Hospital guidance:** • At the hospital, give antiemetics and hydration • For people who have been admitted to hospital with hyperemesis gravidarum, give 200 mg intravenous hydrocortisone over 24 hours or 50 mg intramuscular or intravenous hydrocortisone 4 times a day • Seek specialist advice from the obstetric medicine team or endocrinology team about the dosage and duration of high-dose hydrocortisone during the hospital stay • After discharge, follow sick-day dosing until daily vomiting stops **Level of care needed:** Urgent – manage in an inpatient setting rather than outpatient setting.
Pregnancy; third trimester (depending on clinical symptoms, sodium levels and blood pressure)	Consider increasing the dose. Discuss with obstetrics and endocrine team.

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 with 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

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 (page 7) 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 pages 18-19). 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 (e.g. you have 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 100 mg powder for solution for injection or infusion 2 ml 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 2 ml (min) syringe
- Either 1 x ampoule hydrocortisone sodium phosphate or 1 x 2-part (powder and solution) hydrocortisone injection

Giving the emergency injection

1 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.

2 

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

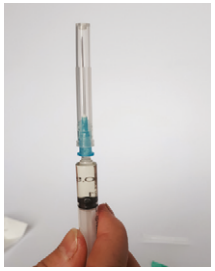
3 

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.

4 

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).

5 

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).

- 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.
- Dispose of in sharps disposal bin. You don't need to replace the needle cover.

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 volunteer 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 offer 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.

Our publications are supported financially by several pharmaceutical companies, in line with ABPI guidelines, including Ipsen, Merck, Sandoz and Sparrow Pharmaceuticals.

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July 2024