Addison's Disease Self-Help Group (ADSHG)
Registered charity 1179825

ADDISON'S Self Help Group

ADDISON'S Clinical Advisory Panel

Managing your adrenal insufficiency, including Addison's disease

Becoming an expert patient; being aware, prepared and understood.

Contents

Introduction

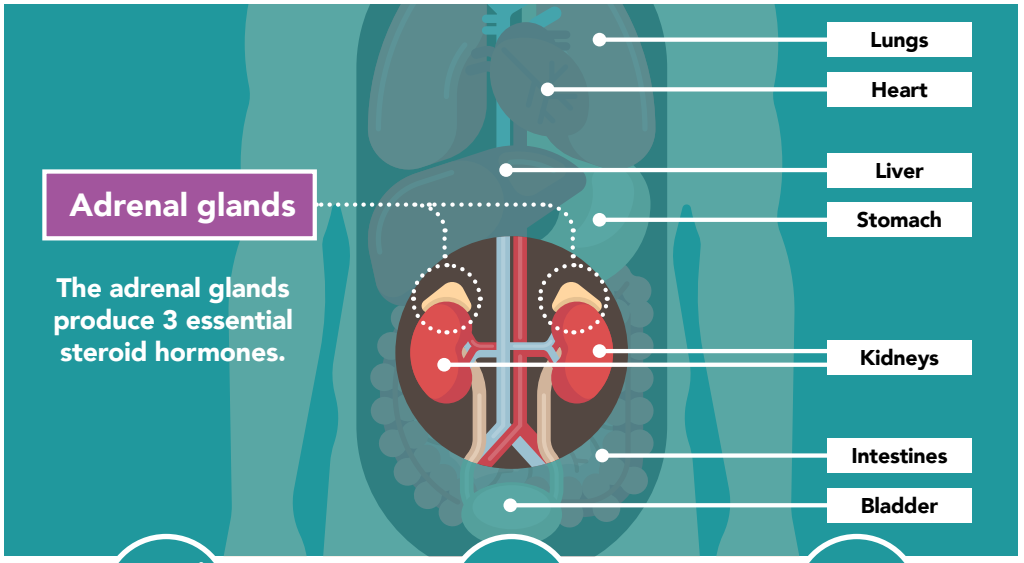
This leaflet is to help you on your journey with your diagnosis of Addison's or adrenal insufficiency. We would like to support you in becoming confident about your condition so that you can understand how it might affect you, and can be prepared in case of an adrenal crisis. By being aware, being prepared, and being understood, we believe you will feel able to better manage your condition and help those around you, including your healthcare team, to give you the best possible level of care and support. We have much more information available on our website, and if you are not already a member of our charity, we would recommend it as a way of staying up-to-date and finding a whole community of others with experience and understanding of Addison's and adrenal insufficiency.

1 Be Aware

WHAT ARE ADDISON'S AND ADRENAL INSUFFICIENCY?

Addison's disease (AD) is a type of adrenal insufficiency also known as primary adrenal insufficiency. It occurs when the adrenal glands, that sit above your kidneys, are unable to produce steroid hormones essential for life, particularly cortisol. Addison's is a rare endocrine condition which occurs in approximately 1:10,000 people of all ages and genders.

ADRENAL GLANDS & AFFECTED HORMONES:



Cortisol

Cortisol is life-essential. It helps control your metabolism, blood sugar, energy, appetite and stress.

Aldosterone

Aldosterone helps the body manage its blood pressure and salt/fluid balance.

DHEA

DHEA is important to help give the body stamina and libido.

There are three types of adrenal insufficiency, sharing some common symptoms. Each has different causes and alter the levels of steroid hormones produced by the adrenal glands to varying degrees.

Primary adrenal insufficiency

Also known as Addison's disease, it was first described by Dr Thomas Addison in the 1850s. It is most commonly an autoimmune condition, where the body mistakenly attacks and destroys the cells of the adrenal glands, preventing them from functioning properly. The exact cause of this autoimmune attack is still unknown. In Addison's disease, the adrenal glands are unable to produce cortisol, aldosterone and DHEA.

Secondary adrenal insufficiency

This is caused by a problem within the part of the brain that 'controls' the adrenal glands (the pituitary gland). There are several different reasons why the pituitary gland might not work as it should. Underproduction of a hormone called ACTH (adrenocorticotropic hormone), leads to reduced cortisol secretion from the adrenal glands.

Tertiary adrenal insufficiency

This can occur as a result of taking long-term steroid medication for other conditions, for example, asthma, skin or joint conditions. The balance between hormones produced by the hypothalamus in the brain, the pituitary gland and the adrenal glands is affected, and stopping the glucocorticoid medication may cause adrenal insufficiency.

SYMPTOMS OF ADRENAL INSUFFICIENCY

People with adrenal insufficiency typically report some or all of the following symptoms:

- dizziness on standing
- nausea or vomiting
- abdominal pains
- poor appetite and weight loss
- overwhelming exhaustion
- muscle weakness and cramps
- difficulty concentrating / brain fog
- deepening skin pigmentation (looking like they have a sun tan even when they haven't been out in the sun) - AD only
- salt cravings - AD only

ADRENAL CRISIS: A LIFE-THREATENING SITUATION

People with Addison's and adrenal insufficiency are steroid dependent. Without sufficient steroid hormone replacement, all patients with adrenal insufficiency are at risk of a life-threatening emergency called an adrenal crisis. They have to follow a strict medication regime; taking glucocorticoid treatment at carefully timed intervals every day to replace what their body can't produce.

An adrenal crisis is experienced when the body's need for cortisol outstrips the ability of the adrenal glands to produce it. We look later at the potential triggers of adrenal crisis.

It requires time-critical and life-saving medical treatment. This takes the form of an emergency injection of hydrocortisone, either self-administered, or administered by someone close by, or a medical professional. This needs to be followed up by a hospital visit for intravenous fluids.

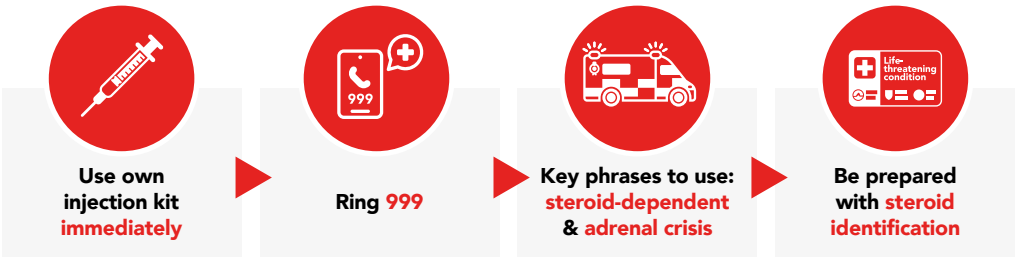
Adrenal crisis danger signs include:

- Extreme weakness, feeling terrible, vomiting, headache
- Light-headedness or dizziness on sitting up or standing up
- Feeling very cold, uncontrollable shaking
- Back, limb or abdominal pain
- Confusion, drowsiness, loss of consciousness

These may be similar symptoms to your pre-diagnosis illness.

Treatment of an Adrenal Crisis

If you feel severely unwell, you will require an emergency injection of hydrocortisone (use your emergency injection kit), followed by urgent hospital treatment; **call 999 and state 'adrenal crisis' and 'steroid dependent'.** You will need IV fluids and potentially need further treatment with hydrocortisone until you have stabilized.



When you, or someone with you, calls for a doctor or ambulance, it is important that you use the words **'steroid dependent'** and **'adrenal crisis'** so that they understand the critical nature of your situation.

ADRENAL INSUFFICIENCY DIAGNOSIS

Some of the symptoms for Addison's and adrenal insufficiency are shared by other autoimmune and endocrine conditions, so it is not always straightforward to diagnose.

Your GP will do blood tests to

a. measure the levels of cortisol in your blood by doing what is called a 9am serum cortisol test.

b. measure the levels of Urea and Electrolytes in your blood which helps them assess the balance of electrolytes, such as sodium and potassium, in the body.

Depending on the results of your blood tests, they will then make a referral for you to be seen by an endocrinologist who will confirm your diagnosis with further investigations;

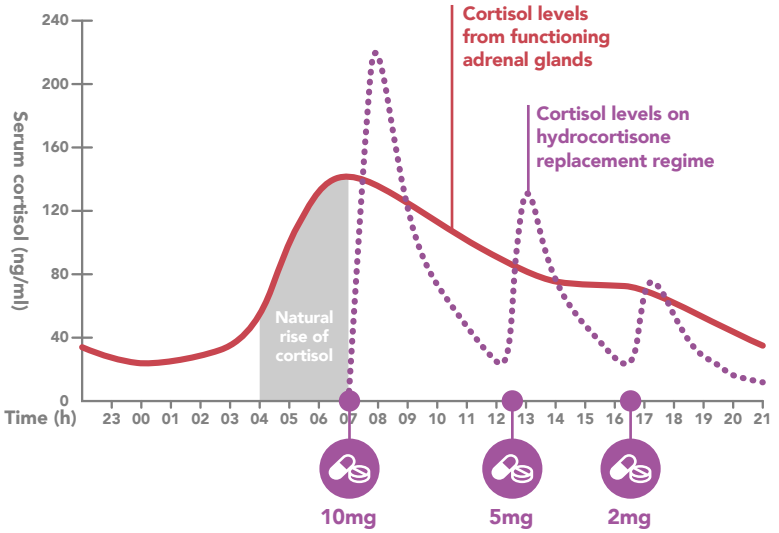
- Synacthen (ACTH stimulation) test measures how much cortisol your body can produce. It involves taking two blood samples: the first as a 'baseline' to measure the cortisol levels in your blood at rest. You are then given an injection of the hormone ACTH which is produced by your pituitary gland and stimulates your adrenal gland to produce cortisol. The second blood sample is taken 30-60 minutes after this. With healthy adrenal glands, cortisol levels in the second sample will exceed 420 - 450 nmol/L.
- Aldosterone function: measured by a plasma renin, sodium and potassium test.
- Antibody blood test: this is to look into why your adrenal glands aren't working properly. If it is negative, further tests and an adrenal scan might be needed.

For more information on diagnosis, go to
www.addisonsdisease.org.uk/what-is-addisons-disease

Scan for Diagnosis information

TREATMENT AND MEDICATION

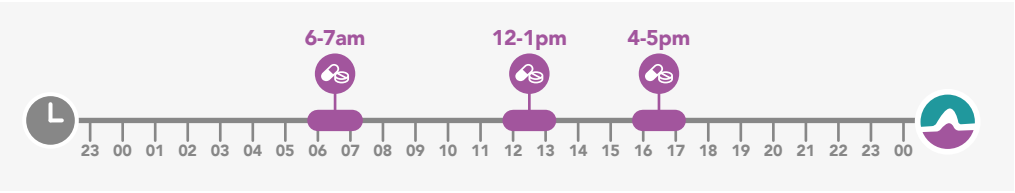
If you have a diagnosis of Addison's disease or adrenal insufficiency **it is essential that you follow a strict medication regime**, taking replacement steroid treatment (glucocorticoids) at carefully timed intervals every day to replace what your body can't produce.



The red line on the graph shows cortisol levels in the body from 'normally functioning' adrenal glands. As you can see, there is a natural rise first thing in the morning. The dotted purple lines show how spacing out hydrocortisone medication can try to replicate the 'normal' curve. The dose in the graph is just one example - different people will be prescribed different doses and sometimes different types of glucocorticoid medication.

To try and 'mirror' the natural cortisol 'curve', most people take their steroid medication 3 times a day:

1. When you first wake up (e.g. 6-7am). This is usually the biggest dose.
2. A 'top up' dose at 'lunchtime' (e.g. 12 or 1pm).
3. A further 'top up' dose at around 4 or 5 pm in the evening.



In the UK it is likely that you will be prescribed:

Hydrocortisone 15-25 mg/day

This medication is chemically exactly the same as 'natural' cortisol. Most people are prescribed this as the first steroid replacement medicine to try, following diagnosis. It is taken in 2 or 3 divided doses.

Prednisolone (3-5 mg/day)

Where conventional hydrocortisone treatment is not proving effective or where people are struggling with a 3x a day medication regime, low dose prednisolone may be prescribed. It is chemically similar to natural cortisol but lasts longer in the body. It is 'stronger' (more potent) than hydrocortisone. It is most often taken in a single dose on waking.

Fludrocortisone 50 mcg-200 mcg/day (for AD patients only)

This is a mineralocorticoid and replaces the missing steroid hormone aldosterone. It is usually taken in one or two daily doses. A higher dose (up to 500mcg) might be needed in children, younger adults or during the last trimester of pregnancy. Fludrocortisone should be stored at room temperature (below 25°C), in a dry environment, to avoid degradation.

You may also be prescribed:

DHEA 25-50 mg/day

This may be supplied by your hospital pharmacy on a 'named patient' basis, for ongoing fatigue or low libido, following discussion with your endocrine team. There is not clear evidence to support its use and some doctors may not be able to prescribe it.

EMERGENCY INJECTION KIT

As clarified in the **NICE Guidelines for the Identification and Management of Adrenal Insufficiency** (published in Aug 2024), Addison's and secondary adrenal insufficiency patients should also be prescribed 2 or 3 emergency injection kits for use in case of a perceived or actual risk of adrenal crisis. People with tertiary AI and a history of adrenal crisis should also be considered for an emergency injection kit.

These are prescribed as 3-5 vials of either;

Hydrocortisone Sodium Phosphate
(100 mg) – 1ml liquid ampoule OR

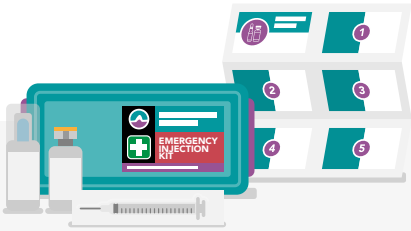
Hydrocortisone Sodium Succinate
100 mg powder / Hydrocortisone 100 mg Powder for Solution, for injection or infusion – 1 x 2 ml vial with dilutant (5 ml or 10 ml water)

The kit(s) should also contain 2 x intramuscular (IM) needles (blue) and 2 x 2 ml syringes, and written instructions in an easy-to-understand format, on how to prepare and give the injection, and dispose of needles and syringes. Best practice is to also include an NHS steroid emergency card.

How to get an emergency injection kit

1. Ask your endocrinologist or endocrine team to provide you with an emergency injection kit / kits, and to support you in learning how to feel confident using it. They should provide you with a prescription for the medication which will be added to your repeat prescriptions, as well as directly providing you the needles and syringes. Ask them for an NHS Emergency Steroid Card.
2. Ask your pharmacy to fulfil your prescription for the medication. Ask your endocrine team or your GP to provide you with replacement needles and syringes for your kit if you use them, or they are 'out-of-date'. Your GP is not able to prescribe you the needles and syringes as they are not currently on drug tariff, however many GPs will still be able to provide you with needles and syringes for a 'build your own' kit.
3. You can also purchase ready made Emergency Injection Kits (Small or Large) from the ADSHG shop. Please note; they do not include your medication, which needs to be obtained with your prescription.

Scan to shop for Emergency Injection Kit Catalogue



ADSHG emergency injection kit

Learning how to administer an injection

1. Ask for training from your endocrine team for you and your carer/supporters.
2. Watch online training videos that are specific to your medication type and type of needle e.g. **www.addisonsdisease.org.uk/emergency**
3. Attend ADSHG events for 'hands-on' emergency injection training.
4. Build your confidence by regularly re-visiting the training on our website and YouTube channel and using our practice 'at-home' Injection Training Kits. **www.addisonsdisease.org.uk/injection-training**

Prescription charges

Prescriptions are issued free of charge in Scotland, Wales and Northern Ireland. English residents are entitled to apply for exemption from standard prescription charges, which must be certified by your GP on a Medical Exemption Form.

POSSIBLE SIDE EFFECTS TO MEDICATION

Most people do not experience long-term side effects with their steroid medication as it is replacing what the body would usually produce, rather than being over and above 'usual' levels (unlike the high doses that can be used to treat conditions like asthma).

Infrequent side effects

A few people find they experience gastric irritation from hydrocortisone and need to line their stomach with a glass of milk or rice milk before taking their first dose of the day. People on corticosteroid replacement therapy who experience, or are at risk of gastric irritation, may be prescribed a proton pump inhibitor (PPI) such as Omeprazole.

Overmedication

There is no known toxic dose of hydrocortisone, so if you take more than you need for a short period (e.g. during a temporary illness), it will do no harm.

If, however, you take a dose that is too high **for a long period of time** and are overmedicated, there are long-term risks of osteoporosis, excessive weight gain, cardiovascular affects, Type 2 diabetes or glaucoma.

ADDITIONAL CONDITIONS

Many people with autoimmune Addison's disease, will develop other autoimmune conditions as well, such as hypothyroidism, Graves disease, coeliac disease, Type 1 diabetes or pernicious anaemia (vitamin B12 deficiency), so it is very important to have regular endocrine appointments and to report any new symptoms.

DISABILITY

Whilst not everyone might identify as having a disability, people with Addison's and adrenal insufficiency are covered by the definition of disability under the Equality Act 2010, or if you live in Northern Ireland – the Disability Discrimination Act 1995. This is because Addison's and adrenal insufficiency are often life-long conditions (depending on the type and cause), and can seriously affect a person's ability to do normal day-to-day activities. People with Addison's and adrenal insufficiency can experience an adrenal crisis which is fatal if left untreated.

2 Be Prepared

THE ESSENTIALS IN MANAGING YOUR CONDITION

1. **Tablet time:** take your tablets every day, at the right time of day. You may be advised to take them twice, three or four times a day. Three times a day is the most common. They replace what your body would have produced naturally and are essential for life. Take your medication with water.
2. **Be patient:** It can take several months after diagnosis to get the balance of your medication adjusted to the right dose and timing. You will need to work with your doctors to monitor any new symptoms which might mean you need to adjust your medication.
3. **Have enough medication:**
   - ALWAYS carry spare medication with you, in case you need it for stress dosing (see Sick Day Rules section).
   - Order your repeat prescription in plenty of time, ideally keeping a 3-6 month supply so you don't run out, and have the option to increase your dose as needed.
   - A repeat prescription length of 3 months at a time is recommended, in case of unexpected supply shortages.
   - Take double what you need with you on holiday, plus your injection kit(s).
4. **Wear medical alert devices** with wording such as 'Steroid Dependent' and 'Adrenal Insufficiency', such as a Medi-tag bracelet or necklace, and use stickers or images on your phone, keyrings or fridge. The ADSHG shop sells a variety of medic alerts.
5. **Training:** Check that you and your closest family/friends/colleagues are trained to administer an emergency injection (**www.addisonsdisease.org.uk/emergency**).
6. **Steroid Emergency Card:** Make sure that you carry either an NHS Steroid Emergency card or an ADSHG Steroid Emergency Card (both available from our shop).

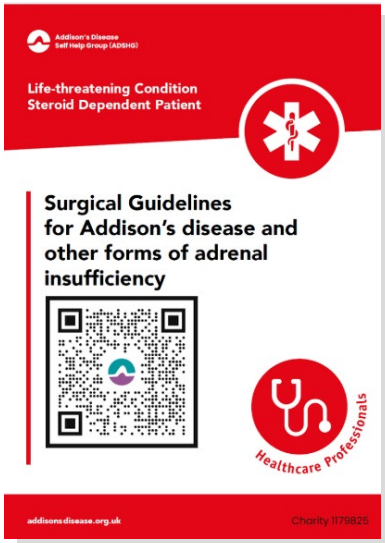
Scan for Adrenal Crisis Emergency Help Guide

7. **Kit check:** Check your emergency injection kits regularly to ensure that the medication and needles are still in date.
8. **Share your kit:** Tell your close work colleagues, family and friends about your diagnosis and where your emergency injection kit is kept.
9. **Summary Care Records:** Ask your GP to ensure that your Summary Care Records are updated to clearly state **'Steroid Dependent'** and **'At Risk of Adrenal Crisis'** See www.addisonsdisease.org.uk/summary-care-record-letter-for-gps for our template letter.
10. **Medical Records:** Ask your GP to scan a copy of the ADSHG **Adrenal Crisis** and **Surgical Guidelines** leaflets into your personal records (www.addisonsdisease.org.uk/surgery).
11. **Jabs:** You are strongly recommended to receive the annual winter flu vaccine as flu-like infections are a known cause of adrenal crisis in steroid-dependent people.
12. **Travel:** Carry your medication and injection kit in your hand luggage when travelling by air, along with a doctors note explaining why you need to carry needles and syringes. Take extra medication and an additional emergency kit with you.

Emergency steroid card and medic alert wristbands

Scan for information on Summary Care Records

Scan for Adrenal Crisis Guidelines



SICK DAY RULES

When the body experiences either physical or severe emotional stress, e.g. during illness, injury and physical or psychological trauma, it needs more cortisol than usual. As a result, you will need to take extra medication on top of your usual daily dose to meet the increased cortisol need. This extra medication is known as 'stress dosing' or 'updosing'. You will also need to take extra if you are not able to take, or are not absorbing, your usual daily dose due to vomiting or diarrhoea.

In cases of vomiting or shock, people with Addison's and adrenal insufficiency can experience a sudden drop in blood pressure and if you do not take enough extra medication, you may experience an adrenal crisis.

The Sick Day Rules are a set of guidelines that have been developed by clinicians to help keep you safe and reduce the chances of an adrenal crisis. As everyone's medication needs are different, they are guidance rather than concrete rules. *Always listen to your body and understand that minor ailments can have a potentially serious effect on anyone with a steroid-dependent adrenal condition.*

Always follow the Sick Day Rules for the following:

- Vomiting and/or diarrhoea (but you are still able to tolerate food and drink)
- An illness needing rest or time in bed due to weakness, or a course of antibiotics
- A fracture or other major physical trauma
- A fever
- Intense psychological and emotional stress e.g. bereavement (increase dose for 1-2 days)

You are also likely to need to updose to some degree with common ailments such as colds, coughs and headaches, even if you are not ill enough to be off work, or in bed.

Sick Day Rule Dosing

Hydrocortisone users

Usual dose is 10-25 mg

40 mg in 24 hours in 2-4 doses

Start by taking 20 mg immediately.

Usual dose is 25 mg or more

Double usual in 24 hours in 2-4 doses

Start by taking 20 mg immediately.

Prednisolone users

Usual dose is 3-10 mg

10 mg in 24 hours in 1-2 doses

Start by taking 5 mg immediately.

Usual dose is more than 10 mg

Continue with your usual dose in 2 doses

Plenadren and Efmody (previously Chronocort) users

Switch to regular hydrocortisone and take at least 40 mg in 24 hours in 4 doses.

40 mg in 24 hours in 4 doses

Escalating your updosing: when to administer an emergency injection

1. **If your temperature is over 39°C**, it can be a sign of severe infection or the start of an adrenal crisis. Take 20 mg of hydrocortisone every 6 hours (or 5 mg of prednisolone /prednisolone) and seek immediate medical advice.
2. **If you have vomited within 30 mins of taking a repeat Sick Day dose of medication for vomiting earlier.** or for persistent severe diarrhoea, as both will affect your body being able to absorb your oral steroid medication.
3. In the case of major injury and where you are not able to inject 100 mg IM hydrocortisone, you should take a minimum of 40 mg hydrocortisone orally to avoid shock.
4. If you still feel severely unwell after increasing your daily oral hydrocortisone to at least 40 mg.
5. During a period of severe illness you collapse, experience giddiness on standing, confusion, severe lethargy or loss of consciousness.

Addison's disease only: Fludrocortisone dose. If your increased dose of hydrocortisone is now 50 mg or more and continues at this high level for over 7 days, it is recommended to stop your fludrocortisone dose (it is not needed if you are on very high levels of hydrocortisone).

How long to updose for

Always listen to your body and updose for your period of illness or stress. As a guideline, updose for 48 hours. If you are feeling better, go back to your usual dose.

If you continue to feel unwell, continue to updose and speak to your GP or endocrine team for more advice.

Updosing during antibiotic treatment

If you are prescribed a course of antibiotics for 5-7 days, you are advised to updose for the full period of taking the antibiotics. If you feel 'back to normal' at this time, it is okay to lower your dose back down (see section on Tapering).

The exception is if you take antibiotics for something like a skin condition that doesn't make you feel unwell, in which case you may not need to updose. Be alert to feeling low cortisol symptoms.

For a longer course of antibiotics (3-4 weeks), check with your endocrinologist. If you are on a course of Rifampicin for 6 months for a diagnosis of TB, you need to updose for the full 6 months.

Tapering

A common question we are asked is, *if you are on an increased dose of medication when following Surgical Guidelines or Sick Day Rules, do you need to gradually return to your usual medication regime (tapering), rather than lower the dose suddenly?* The advice from our Clinical Advisory Panel, based on research evidence is as follows:

- If you are feeling back to your 'normal self', you can reduce straight back to your normal replacement dose.
- If you have had a more severe illness, you may feel better gradually and therefore you can gradually taper down your increased dose of steroids, in line with feeling better, until you are back at your usual steroid replacement dosage.

Everyone is different and you need to listen to your body. If you start to feel unwell when you start to taper down, updose again and seek medical advice from your GP or endocrinology team.

What else can I do?

- Sip rehydration / electrolyte fluids with vomiting / diarrhoea.
- Take bed rest and time off work as needed to aid your recovery.
- Increase your fluids (water is best).
- Take paracetamol for pain.

Other precautions

Ensure all anaesthetic, dental and surgical staff are aware of **the need for extra oral medication if you are having a minor or major procedure** and that they have checked the Surgical Guidelines for the correct level of steroid cover (**www.addisonsdisease.org.uk/surgery**).

We recommend taking the ADSHG hospital folder with you each time you go to hospital for either emergency or elective treatment. This will help you clearly signpost your needs to the team looking after you. It is available from our online shop.

ADSHG leaflets and forms

MONITORING & MAINTENANCE

1. Your GP will provide regular healthcare, such as support for minor illnesses and will issue repeat prescriptions for your medication.
2. You need to ensure that your GP understands the nature of your steroid dependence and your potential need for emergency care. Ensure they read the guidance in the ADSHG Leaflet: Diagnosing and Caring for the Addison's patient: Information for GPs (**www.addisonsdisease.org.uk/diagnosing-addisons-disease-a-guide-for-gps**).
3. You will be under the supervision of an endocrinologist and may or may not also have access to an endocrine nurse specialist. Usually, your endocrinologist will want to see you as an outpatient every 6-12 months, depending on the stability of your Addison's disease or adrenal insufficiency, and whether you have any other conditions.
4. As mentioned earlier, the NICE Guidelines recommend that people with Addison's or secondary AI are are issued with 2 emergency injection kits and an NHS Emergency Steroid Card. They recommend that people with tertiary AI and a history of adrenal crisis are also considered for an emergency injection kit.

QUALITY OF LIFE

Having a rare condition like Addison's and adrenal insufficiency can be challenging, especially as it is an invisible disability. Not all healthcare professionals have heard of, or treated someone with adrenal insufficiency. It is important that people with this condition become 'experts' in their own health and self-management. This does not mean you have to be an expert on Addison's or adrenal insufficiency, but it refers to you taking time to understand how your body feels, and listening to your body so you can recognise your low cortisol symptoms.

As with many health conditions, the challenges vary a lot between different people. Sometimes people will have more than one health condition, which can lead to increased complications, and a larger impact on health and wellbeing. Sometimes people will find that, as long as they carefully manage their medication, they are able to do the things they want to do in their life.

Longevity: With correct adherance to your medication, you can expect to have a normal life span.

Diet: There is no need to adopt a special diet or dietary restrictions, although it is advisable to avoid a low salt diet. Grapefruit and real liquorice can amplify the effects of your steroid medication, so are best avoided.

Exercise & Sport: Once you have recovered from your pre-diagnosis illness, some people can reach a normal level of physical fitness, presuming other health conditions are not limiting this.

Gentle exercise such as swimming or walking does not usually require any changes to your usual medication regime.

Challenging physical exercise, such as a competitive sport, will mean you need extra medication. You may need to 'updose' e.g. double your normal dose during the exercise period.

For any sports where there is a risk of physical injury, you must ensure you have an emergency injection kit with you, and that a teammate has been trained to administer an emergency injection if needed. You should follow the usual recommendations regarding exercise to achieve a healthy, balanced lifestyle.

Driving: There is no restriction on driving and in the UK and Republic of Ireland (RoI). You are only required to inform the licensing authority about your condition if you hold an HGV (group 2) licence. Where you have additional medical conditions, please check whether these must be declared. Your private car insurance company may wish to be informed about your condition. We recommend keeping an emergency injection kit in the car with you, in case of emergency.

Energy levels: Regardless of your fitness level, most people will experience episodes of unusual fatigue. You will need to allow your body to catch up with extra rest. Some people use the 'spoon theory' as a metaphor to help explain their need to pace their day, and rest, to others, and themselves! Imagine each activity through the day 'costs' a spoon. Once those spoons are used up, the person does not have the energy to do more - so you need to try not to use all your spoons up at once!

Having a family: With the right medical support, women can expect to have a healthy pregnancy and normal childbirth (**www.addisonsdisease.org.uk/addisons-adrenal-insufficiency-and-pregnancy**). Specialist endocrine monitoring from the first trimester and throughout the pregnancy is advisable due to the risk of pregnancy related nausea and vomiting affecting the absorption of your medication. Hyperemesis gravidarum and ongoing morning sickness should be managed within a hospital setting. Increased hydrocortisone may also be needed in the last trimester. Hydrocortisone is inactivated in the placenta and does NOT affect the unborn baby. Parenteral steroids will be needed for childbirth: see the ADSHG Surgical Guidelines (**www.addisonsdisease.org.uk/surgery**)

3 Be Understood

Addison's and adrenal insufficiency are rare, and it is an invisible disability. Many people will not have heard of it and might find it hard to understand, including family, friends and employers. This is why you need to become an expert patient so you can know your low cortisol symptoms and can help guide them to information and training on what to do, particularly in the case of an adrenal crisis.

You are also likely to come across healthcare professionals that have not treated someone with adrenal insufficiency before. This can feel frustrating as it can be tiring to feel that you need to help educate them; this is one of the challenges of having a rare condition.

We recommend that you use your NHS Steroid Emergency Card to help identify your needs, and to direct them to more information. You need to ensure that you also use medic alert items to make it clear that you are steroid-dependent, in case you are in adrenal crisis and are not able to tell them.

As these are rare conditions, some people struggle to get the right support from their healthcare team, particularly around the management of adrenal crisis.

If you are going to A&E as a result of an actual or suspected adrenal crisis, we recommend:

1. You follow our emergency instructions and immediately administer 100 mg of hydrocortisone using your emergency injection kit.
2. Wherever possible, have a carer / friend / advocate with you when you go to A&E, so that even if you are feeling confused or very unwell, they can help explain the urgency of your situation.
3. Take your NHS Steroid Emergency Card and your steroid dependent medic alert devices.
4. Take a completed Adrenal Crisis form and a Medical Summary including your latest prescription (both are included in our Hospital Folder, are free to download from our website, or are available to purchase individually from our online shop).
5. Take your own emergency injection kit with you, in case you need to re-administer a second 100 mg of hydrocortisone if you continue to feel very unwell after the first injection and are not assessed in a timely manner.
6. Take a copy of our Glucocorticoid Medication and Emergency Injection Refusal Letters, in case you need to show them to a healthcare professional (see Resources and References section on the back of this brochure).

One of the key roles of the Addison's Disease Self-Help Group (ADSHG), is to ensure that healthcare professionals understand the thoughts and views of those in the Addison's and adrenal insufficiency community. For over 40 years, the UK based charity has been working to:

Support

Providing resources and building a community that helps people self-manage their AD and AI and improve their quality of life.

Connect

Making it possible for the voice of people with AD and AI to influence, inform and improve the way the healthcare service delivers their care.

Advance

Funding, contributing to and promoting the development of new innovations and research to improve quality of life.

We work closely with paramedics and healthcare professionals all over the UK to raise awareness of adrenal insufficiency and to support them in offering you the best standard of care. We help explain the challenges facing our community, and how they can help.

Clinical Advisory Panel

We are fortunate to benefit from the expert guidance of a team of endocrinology healthcare professionals who review our information and ensure it is up-to-date and medically accurate.

BECOME A MEMBER OF THE ADSHG

We are proud to provide an online forum as one of the key benefits of membership to the ADSHG. A wealth of information is available through direct contact with other experienced members of our community, as well as access to historic posts on topics ranging from exercise, diet, adrenal crisis, hospital visit, pregnancy, employment and more. If you are looking for a safe, supportive and responsive space to ask questions about your condition, then we would highly recommend becoming a member.

We offer 12 months membership from £33/year, and additional benefits include access to our face-to-face member events, regional social meetings, twice-yearly magazines, regular newsletters and member emails.

Scan to join the ADSHG

RESOURCES AND REFERENCES

Scan for Surgical Guidelines

Scan for NICE Guidelines

Scan for Emergency Injection Training

Scan for Sick Day Rules

Scan for Refusal Letters

Scan for Online Shop

For further advice please contact:
Email: enquiries@addisons.org.uk
Website: addisonsdisease.org.uk

The Addison's Disease Self-Help Group works to support people with Addison's and adrenal insufficiency and to promote better medical understanding of this rare condition.

The ADSHG is supported and advised by a Clinical Advisory Panel: a group of medical professionals with an interest in adrenal medicine. Registered charity 1179825, established 1984.

This leaflet has been authored by the ADSHG and reviewed by the Clinical Advisory Panel.

Last Reviewed: **February 2026**

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