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

ADDISON'S Self Help Group

ADDISON'S Clinical Advisory Panel

Understanding Steroid Medication & Sick Day Rules for Adrenal Insufficiency

This guide is to help you to learn about how to best manage your medication, alongside your lifestyle.

For All

Contents

This booklet is written specifically for 16+

For babies, children and young people under 16 years: see BSPED detailed consensus guidelines on adrenal insufficiency which is available on: **www.bsped.org.uk/clinical-resources/bsped-adrenal-insufficiency-consensus-guidelines/**

Introduction

Treatment for adrenal insufficiency, including Addison's disease, requires the daily, time-critical, replacement of missing steroid hormones that are essential for life, particularly cortisol. In people living with adrenal insufficiency, if steroid medication is missed or not increased during illness or stress, this can lead to a life-threatening medical emergency called adrenal crisis.

This guide is to help you to learn how to best manage your medication, alongside your lifestyle, on days when you feel 'well' physically and emotionally, and on days that you don't.

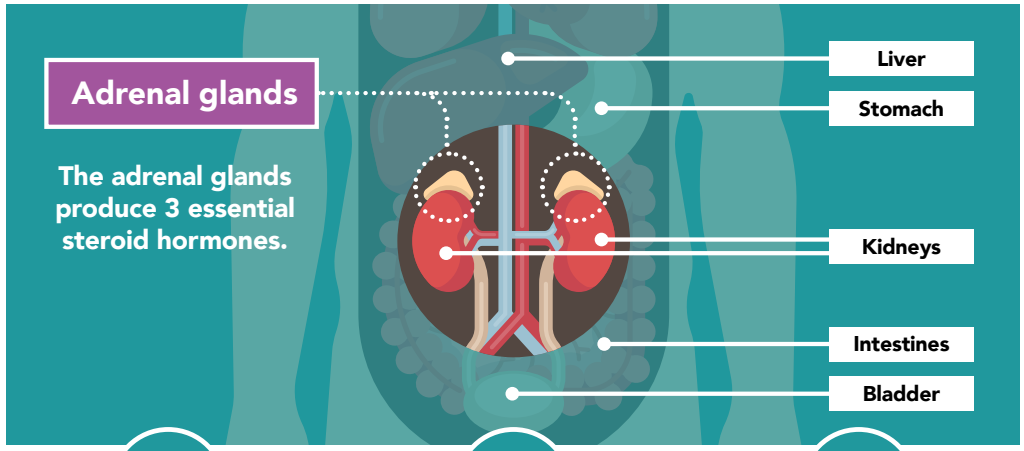
It is written specifically for people over 16 years old with a diagnosis of adrenal insufficiency of any type.

Primary: Addison's disease, congenital adrenal hyperplasia and other causes, such as adrenal gland removal.

Secondary: where the pituitary gland is affected.

Tertiary: where those who are on steroid treatment for a non-endocrine condition, including inhalers, tablets, creams, nasal sprays and injections, are no longer able to produce sufficient cortisol as a result.

ADRENAL GLANDS & AFFECTED HORMONES:



Cortisol

Cortisol is essential for life. 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.

1 Treatment

People with adrenal insufficiency are steroid-dependent, which means they need daily replacement of cortisol. This is usually taken as hydrocortisone or prednisolone tablets. Some people may be prescribed newer formulations of hydrocortisone: dual-release hydrocortisone tablets (Plenadren®) or modified-release hydrocortisone capsules (Efmody®, previously Chronocort®).

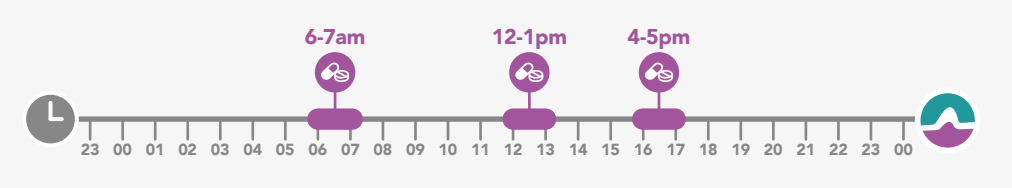
The aim of steroid replacement medication is to mimic the body's natural daily rhythm of cortisol as closely as possible. The medications are time-critical: missing or delaying a dose can make you feel unwell within hours.

Hydrocortisone Medication

Hydrocortisone is often the first steroid medication prescribed after a diagnosis of adrenal insufficiency because it is chemically identical to cortisol produced by the body.

Many people with adrenal insufficiency take hydrocortisone three times a day:

1. When you first wake up, around 6-7am. This is usually the biggest dose.
2. A 'top up' dose at midday or lunchtime (around 12-1pm).
3. A smaller 'top up' dose at 4 or 5pm, which should usually be taken at least 5-6 hours before bedtime.



Some people instead take hydrocortisone twice daily:

1. When you first wake up around 6-7am. This is usually the biggest dose.
2. A second dose in the early afternoon, around 1-2pm.

Whether hydrocortisone is taken two or three times per day depends on several factors, including individual symptoms and your endocrinologist's recommendation. The exact timing of doses may vary between individuals, so it is important to discuss your dosing schedule with your doctor or endocrine team.

Alternative steroid medications

Some adults may be prescribed prednisolone instead of hydrocortisone, particularly if they are finding their symptoms are not sufficiently managed on hydrocortisone. Prednisolone is usually taken once a day in the morning, on waking.

Other possible options include 'dual-release' hydrocortisone tablets (Plenadren®), taken once a day on waking, or 'modified-release' hydrocortisone capsules (Efmody®), taken twice a day, on waking and at bedtime. For further information about the different types of glucocorticoid medications, see **www.addisonsdisease.org.uk/medication**

If you can't take your normal oral medication (e.g. being 'nil by mouth' for an operation or being unable to keep tablets down due to vomiting), then you need to take your steroid by another route (i.e., into your muscle with an injection (IM) or intravenously (IV) if you are in hospital). For further information on how to manage your steroid medication during minor and major surgical procedures, please refer to our Surgical Guidelines (**www.addisonsdisease.org.uk/surgery**)

Further Information for Glucocorticoid Medications

Scan for Surgical Guidelines

ADJUSTING YOUR STEROID MEDICATION

Everyone with adrenal insufficiency, regardless of the type, needs to know how to adjust their replacement steroid medication during periods when their body's need for cortisol is greater than their normal medication dose. This lack of sufficient cortisol puts them at risk of a potentially life-threatening emergency called an **adrenal crisis**. These periods are triggered by physical stress (e.g., moderate and serious illness and injury), periods of psychological stress or during types of strenuous exercise.

This need for extra medication is known as **'updosing'** or **'stress dosing'**. Clinicians have developed **guidelines** to support patients with adrenal insufficiency, including Addison's disease, in managing their medication regime at these times, known as **'Sick Day Rules'**. Being aware of, and confident following the Sick Day Rules is a key part of preventing adrenal crisis.

2 Adrenal Crisis

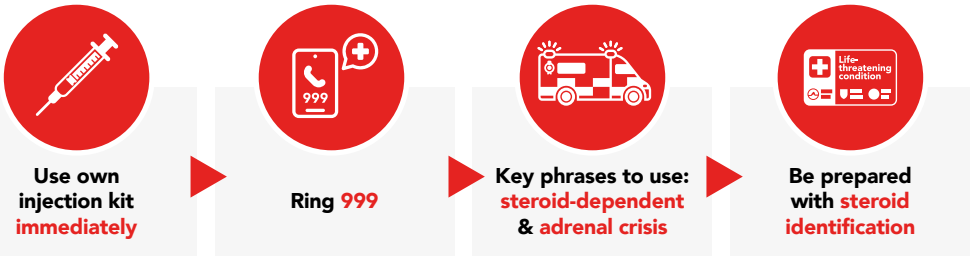
ADRENAL CRISIS

Adrenal crisis is a potentially life- threatening medical emergency and is fatal, if left untreated.

Symptoms include:

- Stomach ache, nausea and/vomiting or severe diarrhoea.
- Feeling very weak.
- Light-headedness or dizziness on sitting or standing up.
- Feeling very cold or feverish.
- Feeling terrible.
- Pain, which can be anywhere in the body.
- Headache, confusion, feeling sleepy or fainting.
- Collapse or loss of consciousness.

In the case of suspected adrenal crisis follow the steps below immediately:



If in doubt, err on the side of caution and inject.

Remember, there is no risk of overdose or toxic effects from additional or increased hydrocortisone doses when given in an emergency situation or for a few days.

Calling an ambulance

Get a friend/loved one to call 999 if possible – it is easier for them to manage the process.

If you are struggling to administer the injection, but are able to tolerate tablets, it is worth taking an additional 50 mg hydrocortisone while waiting for the ambulance.

Sit/lie somewhere safe, warm and accessible. Make sure your front/back door is unlocked. Have your Steroid Emergency Card clearly visible.

Common Triggers of Adrenal crisis

- Stomach bug (e.g. vomiting and/or diarrhoea)
- Severe virus or infection (e.g. flu or a urinary tract infection)
- Stopping steroid medication suddenly
- Not increasing your steroid dose when you are unwell
- Not taking your medication on time (e.g. when in hospital)
- Not being given sufficient medication during surgery or invasive medical procedures
- Physical trauma
- Severe psychological/emotional stress

Ways to prevent adrenal crisis

Be Aware	Be Prepared	Be Understood
• Follow the Sick Day Rules and know what to do when unwell. • Never stop your steroid treatment suddenly or skip doses. • Only reduce your prescribed daily replacement steroid dose in discussion with a healthcare professional (HCP). • Know when you might need to take a 'one-off' extra dose of medication to adjust to a change in your routine.	• Ensure you have a sufficient supply of your steroid medications to take when unwell. • Always carry a supply of steroid medication and your emergency hydrocortisone injection kit with you. • Wear medical ID jewellery to 'advertise' your steroid-dependent status. • Carry a Steroid Emergency Card: NHS or ADSHG.	• If you are unwell, make sure that the person treating you knows you are at risk of adrenal crisis and show them your Steroid Emergency Card (NHS or other form).

3 Sick Day Rules

SICK DAY RULE 1

Increase your normal steroid replacement dose

This should always be applied in the following situations but increasing your dose may also be required in other situations. You should learn the signs of your own 'low cortisol symptoms'.

- A fever of more than 37.5°C
- An illness requiring rest or time in bed due to weakness
- An illness requiring treatment with antibiotics
- Vomiting or diarrhoea where you are still able to tolerate food and drink. For vomiting within 30 mins of taking your usual dose: ensure you take an increased dose again immediately as you will not have absorbed the steroids you have taken. If you cannot keep that increased dose down, follow Sick Day Rule 2. Sip rehydration sachets if possible.
- For intense psychological and emotional stress increase dose for 1-2 days. For longer term psychological stress, such as bereavement, where you continue to experience low cortisol symptoms, discuss your dosing with your healthcare team.
- After a major injury where you are at risk of going into shock, if an emergency hydrocortisone injection is not immediately available or cannot be administered without delay, take at least 40 mg of hydrocortisone orally straight away. Depending on the extent of the injury, and the effect of taking the 40 mg hydrocortisone, you may need to continue to updose or be ready to administer an emergency injection.

'At a Glance': Dosing in a 24-hour period

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 more than 25 mg

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

For more detailed information on Sick Day Rule dosing, please see the table on page 8 and 9.

SICK DAY RULES

Detailed information: Dosing in a 24-hr period

Steroid Medication	Usual daily dose (when well)	Sick Day Rule Dose	No. of doses	Instructions
Hydrocortisone	**10-25 mg**	**At least 40 mg**	**2-4 doses**	Increase your daily oral hydrocortisone to at least 40 mg. Start by taking 20 mg hydrocortisone immediately then the rest divided into 2-4 doses (e.g. 10 mg every 6 hours).
Hydrocortisone	**More than 25 mg**	**40-60 mg**	**2-4 doses**	Start by taking 20 mg hydrocortisone immediately. For most patients, increasing to 40 mg in 24hrs will be enough, but for those of you with a high routine hydrocortisone dose, you may need to increase to 50-60 mg, divided into 2-4 doses.
Prednisolone	**3-10 mg**	**10 mg/day**	**1-2 doses**	Increase your daily oral prednisolone to 10 mg. This can be taken once daily (10 mg in the morning) or split into two doses (e.g. 5 mg immediately and 5 mg about 12 hours later).
Prednisolone	**More than 10 mg**	Continue your usual daily dose	**1-2 doses**	Higher doses are usually not needed. If preferred, your daily dose can be split into two equal doses taken about 12 hours apart.
Plenadren and Efmody (previously Chronocort)		**At least 40 mg** of regular (immediate release) hydrocortisone	**4 doses**	Temporarily switch to regular (immediate release) hydrocortisone tablets and take 10 mg every 6 hours. Take at least 40 mg over the course of 24 hours.

This table is intended as a general guide and may not cover every situation. If you are unsure what to do, seek advice from your endocrine team and follow their guidance.

Contact your GP or endocrine team if you are still unwell after 48 hours.

High Fever

If you have a fever over 38°C it indicates a severe infection or can be the start of an adrenal crisis.

- Take 20 mg of hydrocortisone (or 5 mg of prednisolone) every 6 hours.
- Seek immediate medical advice from your GP or 111.
- Take paracetamol to help reduce your temperature.
- Increase your fluids (by drinking water).
- Be prepared to use your hydrocortisone injection if you have symptoms of adrenal crisis.

Fludrocortisone dose

Primary adrenal insufficiency only
(Addison's disease or Congenital Adrenal Hyperplasia):

Almost all people with Addison's disease and many people with congenital adrenal hyperplasia (primary adrenal insufficiency) need fludrocortisone every day. This replaces aldosterone, a hormone that stops your kidneys leaking salt, which causes low blood pressure, low blood sodium levels, muscle cramps and salt cravings. Patients with secondary or tertiary adrenal insufficiency do not need fludrocortisone. If you are prescribed fludrocortisone and become unwell, continue taking your usual dose while following the Sick Day Rules.

In some situations, fludrocortisone may be temporarily stopped, for example if you need high doses of hydrocortisone (50 mg or more per day) for more than 7 days, because high-dose hydrocortisone also provides "fludrocortisone-like" effects.

However, you should only stop your fludrocortisone on the advice of a healthcare professional.

SICK DAY RULE 2

Administer an emergency injection of hydrocortisone

This guidance is to be applied to avoid or treat adrenal crisis in an urgent and potentially serious scenario.

Inject hydrocortisone 100 mg intramuscularly for one or more of the following:

- You have vomited within 30 minutes of taking a repeat increased dose of medication (in line with Sick Day Rule 1) and are therefore not able to absorb your oral steroid medications.
- You have persistent, severe, diarrhoea which will affect your body being able to absorb your oral steroid medications.
- You still feel severely unwell even after following Sick Day Rule 1 and increasing your daily oral hydrocortisone to at least 40 mg.
- During a period of severe illness you collapse, experience dizziness on standing, confusion, severe lethargy or are unable to get out of bed (even if you have been following the Sick Day Rules).
- You are unable to take oral steroid medications (e.g. before a surgical procedure or investigation (see our Surgical Guidelines).).
- You experience a fracture or any similar significant injury.
- Loss of consciousness.

If you need an injection of hydrocortisone and are unable to give it to yourself, you must seek urgent medical support.

Call 999 and say that you are a steroid dependent patient at risk of adrenal crisis.

After an emergency injection of hydrocortisone you should attend the emergency department for fluids and monitoring, as you may need further doses of hydrocortisone, and may need support in treating the underlying cause of the adrenal crisis.

4 FAQs

Here we try and address the most common questions we get asked in relation to medication and Sick Day Rules:

Q: Should I updose every time I am unwell or in pain?

A: Updosing may be required, depending on the individual scenario, during common ailments such as colds, coughs, headaches, with less significant injuries, or with pain such as period pain. Listen to your body and updose if you experience low cortisol symptoms.

Q: How long do I updose for?

A: Always listen to your body and updose for your period of illness or stress. As a guideline, updose for 48 hours initially. 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.

Q: Do I need to see my GP every time I follow the Sick Day Rules?

A: You will need to use your judgement as to when you make an appointment to see your GP. They are there to support you, and you may need medical help to diagnose and treat the underlying cause or condition that is making you unwell. However, it is likely that you will not always need to see your GP when you follow the Sick Day Rules. If you are unsure, it is usually safer to take a cautious approach. Think through the following considerations:

- Do you know what is causing the underlying illness and do you have access to treatment for it? If not, you might want to see your GP to get treatment for it.
- Are you confident that you are taking the right medication/following the Sick Day Rules appropriately? If not, you might want to seek support from your GP or endocrine team.
- Do you have access to sufficient medication to follow the Sick Day Rules? If not, you will need to contact your GP/Pharmacy for an early repeat prescription.
- Have you been following the Sick Day Rules for longer than 48 hours and are not starting to feel better? You may want to contact your GP to let them know that you are unwell, following Sick Day Rules and would like to have a monitoring appointment.

Q: Do I updose if I am feeling stressed (psychologically/emotionally)?

A: It is more difficult to define how emotional and psychological challenges affect the stress response and how to manage cortisol replacement. Each challenge is unique and individuals may respond in different ways.

Coping with psychological stress

Whether to temporarily increase the dose of steroids in case of emotional and psychological stress should be considered on a case-by-case basis and you, as the one who knows your body best, are best suited to do this.

It is not advisable to routinely take stress dose of glucocorticoids for minor stressful life events, but a top-up should be considered when coping with more serious life events, and when your symptoms suggest that you are not getting enough cortisol. Emotional triggers may be grief and loss, a job interview, or a final-year exam for example.

Find out more by reading our 'Coping with psychological stress' page.

Q: Do I need to taper back down to my usual replacement dose after up-dosing?

A: 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 (fatigue, loss of appetite or low mood) when you lower your dose, updose again and seek medical advice from your GP or endocrinology team.

Q: Do I need to updose if I am taking antibiotics?

A: 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 question 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 for 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.

Q: How do I get extra medication to be able to use the Sick Day Rules?

A: You will require a sufficient supply of oral glucocorticoids for you to build up enough medication to follow the Sick Day Rules. This avoids you having to involve the GP/pharmacist each time and allows you to updose when you need to, with no delays. If you don't already receive a 3-month repeat prescription of your essential steroid medication, use our **GP template letter** (**www.addisonsdisease.org.uk/Pages/Category/publications**) to request one. Asking for your prescription early will allow you to build stock and this should then be 'rotated' with your usual repeat prescription medication, to ensure that this stock does not go out of date.

Q: Do I need to updose if I am doing strenuous physical activity?

A: If you are about to complete some strenuous activity, such as a long-distance run or marathon, or competitive sports event, you may benefit from taking an additional dose of steroid medication before the event. This will depend on your individual circumstances, level of fitness and how used to the exercise you are.

Q: Do I follow the Sick Day Rules if I am pregnant and have morning sickness?

A: Specialist endocrine monitoring from the first trimester and throughout the pregnancy is advisable if you have adrenal insufficiency, 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. Hydrocortisone and prednisolone are inactivated in the placenta and do NOT affect the unborn baby.

For further information, refer to the ADSHG website page on Pregnancy: **www.addisonsdisease.org.uk/addisons-adrenal-insufficiency-and-pregnancy**

Addisons and pregnancy

Q: Do I follow the Sick Day Rules for period pain?

A: This will depend on the level of pain you are feeling, and how you feel generally. If you have particularly painful periods, then it is worth you discussing how to manage that with your endocrinologist. Everyone is different, but one guideline is that if you notice your 'low cortisol signs' then you should updose.

Q: What else can I do when I am unwell?

A: Get some rest and stay hydrated. Make sure you drink regularly. You can monitor how concentrated (dark) your urine looks. This will give you a guide if you need to drink more fluids. Water is the best fluid when you are feeling unwell.

Q: Can I updose too much?

A: There is no risk of overdose or toxic effects from additional or increased hydrocortisone doses when given in an emergency situation or for a few days.

However, adverse side effects such as weight gain, diabetes and immune suppression are likely to occur if hydrocortisone is given in higher than needed doses in the longer term, i.e. over weeks or months. Listen to your body and learn your low cortisol symptoms.

Q: Is it worth me trying a different type of medication (e.g. prednisolone rather than hydrocortisone)?

A: If you are experiencing low cortisol symptoms regularly, or you feel that your quality of life is being significantly impacted by your symptoms, you may want to discuss trying a different medication, i.e switching from prednisolone to hydrocortisone, or hydrocortisone to prednisolone. We know from anecdotal reports that some people find one suits them better than another. For people with complex health needs and severely impacted quality of life, you may want to talk to your endocrinologist about modified release hydrocortisone. Always discuss your concerns and wishes with your endocrinology team when considering a medication regimen change. For more information, see our website information on cortisol replacement: **www.addisonsdisease.org.uk/cortisol-replacement-medication**

About Cortisol Replacement

5 Extra Doses

OCCASIONAL EXTRA DOSES - 'MEDICATION TWEAKS'

Your endocrinologist will help you to find a regular daily medication regimen that is the best one for you. They will also help you to understand the Sick Day Rules that we have discussed above.

However, we all know that not everyday is the same in terms of routine, or all that it might bring, physically or emotionally. As a result, there might be a day when your body needs more cortisol than your usual replacement doses are providing.

Through the FAQs below, we aim to help you manage this.

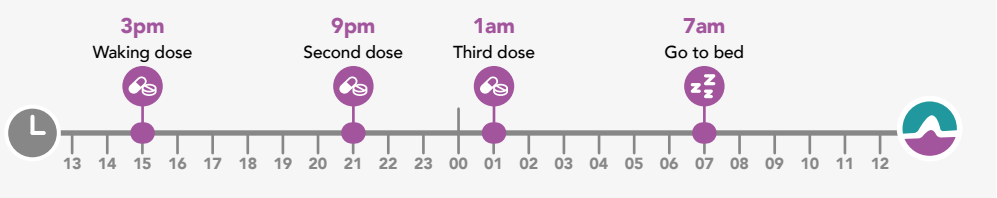
It is one of the challenges of a diagnosis of adrenal insufficiency, particularly when you are first diagnosed. Taking an extra dose 'here and there' is not harmful, but you do need to be careful not to 'over-replace' regularly as this can have negative health effects such as decreased bone density, weight gain and mood changes. If you find you feel you need extra or increased doses regularly, you must speak to your endocrinologist.

An additional challenge is that everyone is different and responds to their medication differently, so whilst we try and give you guidance, there will always be advice that works for some people and not for others. It is therefore crucially important that you learn to listen to your body, and the signs that it gives you when your cortisol is low, which is YOUR signal to respond.

EXTRA DOSES AND DIFFERENT MEDICATION REGIME FAQS

Q: How do I manage my medication if I work night shifts?

A: If you work night shifts, then you need to take your hydrocortisone to align with the waking hours that are normal for you and your job. For example, if you wake up at 15.00 in the afternoon, that is when you take your waking dose. See the example medication routine below:



Q: How do I manage if I am travelling across a time zone?

A: **During the flight:**
Follow your usual medication schedule while you are on the flight where possible, or take 10 mg hydrocortisone every 6 hours during the flight and continue this schedule until you go to sleep in the new time zone.

After arrival:
When it is morning in the new time zone, take your usual waking dose and resume your normal daily schedule.

If flying causes significant stress:
If you find flying stressful (e.g. fear of flying), you may take an extra 10-20 mg hydrocortisone (or 2.5-5 mg prednisolone) about 1 hour before boarding.

If you experience jet lag:
You may take an additional 5-10 mg hydrocortisone if needed. This can be repeated every 6 hours if symptoms persist. Listen to your body.

Travelling to hot climates:
If you take fludrocortisone and are travelling to a hot country, discuss this with your endocrine team before travelling. Your doctor may advise temporarily increasing your fludrocortisone dose. Make sure to drink plenty of fluids in hot weather.

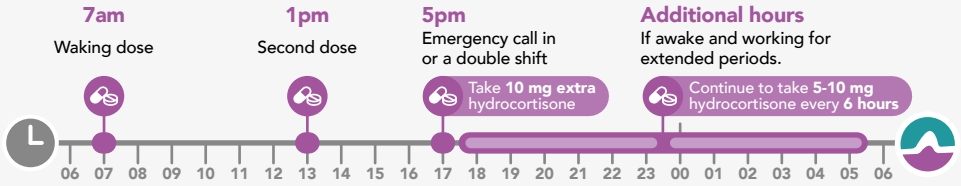
For further information go to
www.addisonsdisease.org.uk/travelling

Preparation for travelling

Q: What happens if my routine is unpredictable?

A: If you have a job where your working hours are unpredictable (e.g. emergency services or coastguard), you may sometimes need additional hydrocortisone doses if you stay awake and working for extended periods.

In these situations, you can take an extra 10 mg dose of hydrocortisone every 6 hours while you are awake and actively working. See the example below:



Q: How do I manage my medication if I have a 'long day'?

A: If you are working late or going out and expect to stay awake later than usual, you may need an extra dose of steroid medication. You can take an additional 5-10 mg hydrocortisone (or 2.5 mg prednisolone) later in the day, for example before going out or if you are staying up late.

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.

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