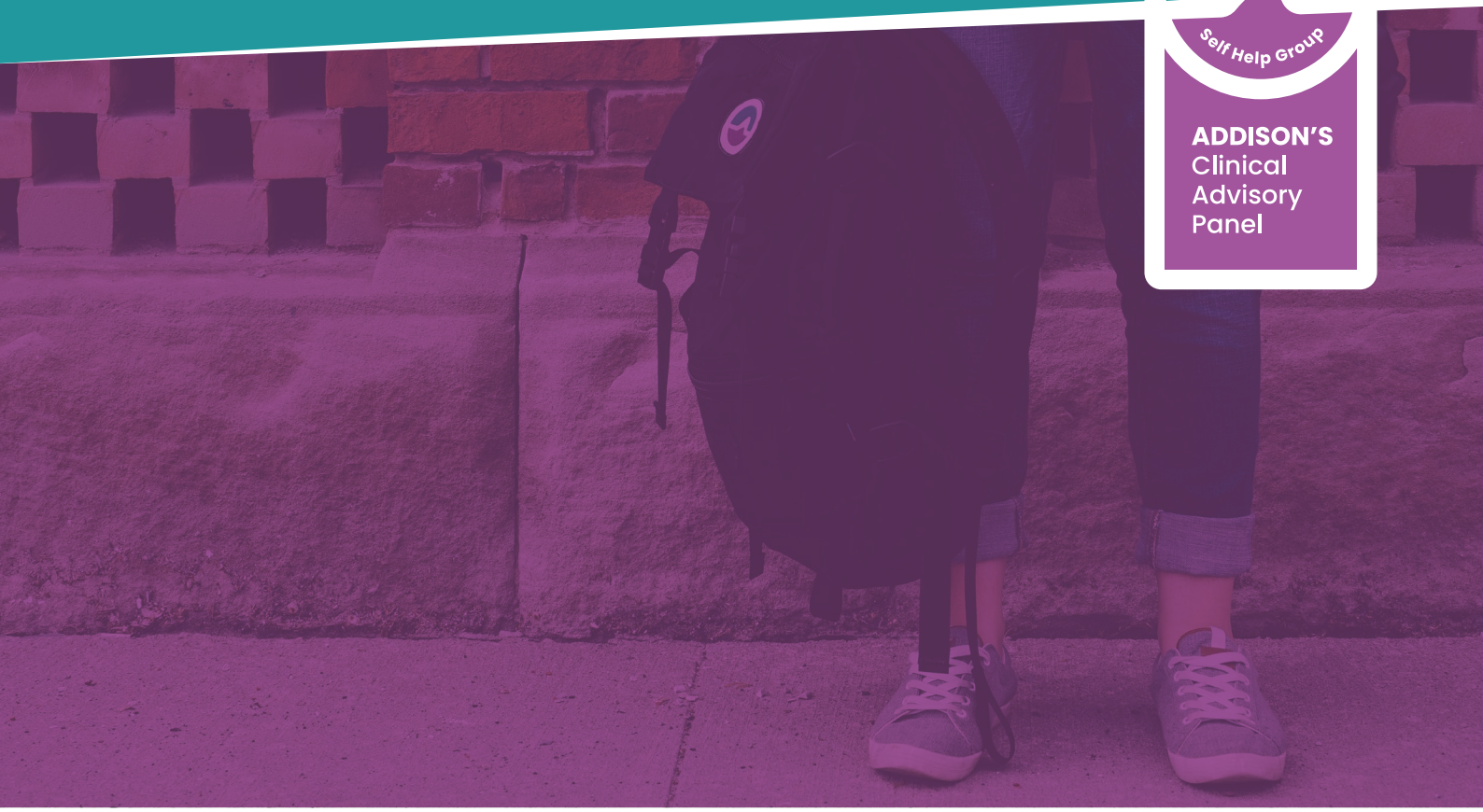
Addison's Disease Self-Help Group (ADSHG)
Registered UK charity 1179825

ADDISON'S Self Help Group

ADDISON'S Clinical Advisory Panel



Managing Adrenal Insufficiency, including Addison's Disease, during Secondary School

For All

A guide for young people aged 11–18, their families and their school team.

AUTHOR GROUP

This leaflet is the result of input from a multi-disciplinary working group, brought together by the Addison's Disease Self-Help Group.

Project Lead:
Cathy Thompson, Director, Addison's Disease Self-Help Group

Authors:

Francine Allgood
Francine is a university lecturer and a mother of two. Her eldest daughter was diagnosed with Addison's disease at the age of 12. The transition to secondary school following an adrenal crisis which resulted in a diagnosis was challenging. During the following years, the school worked with us to ensure a safe environment was provided. It has been an honour to be involved in producing what I hope will be an invaluable resource for secondary schools, young people with Addison's and adrenal insufficiency and parents and carers.

Chloe Mezzetti
In her role as Community Fundraising Manager at the ADSHG, Chloe supports and guides fundraisers while leading fundraising campaigns and contributing to awareness initiatives to engage the wider community. She is thrilled to bring her lived experience of Addison's disease to the working group, helping develop a resource that supports children and young people with adrenal insufficiency, including Addison's.

Joanne Brown
Joanne is an Endocrine Clinical Nurse Specialist working for Stockport NHS Foundation Trust. She has an interest in supporting patients with adrenal insufficiency and has appreciated the opportunity to be involved with the development of this booklet. She often supports the ADSHG by raising awareness and sharing her expertise.

Philippa Sharman
Philippa is the Communications and Health Liaison Manager at the ADSHG, working with healthcare professionals, researchers and organisations to improve education, awareness and safer care for people with steroid-dependency. She listens to the community's lived experiences, putting in place what they need in order to be aware, be prepared and be understood. Philippa has been involved with the charity since her diagnosis in her early teens and has managed Addison's through school, university and working life, both in the day-to-day and in an emergency.

Kate Davies
Kate is a Children's Advanced Nurse Practitioner, specialising in paediatric endocrinology since 2000. She holds a BSc in Psychology, two MScs, and has advanced clinical skills, including Non-Medical Prescribing. Kate is also a Nurse Teacher, with expertise in growth, puberty, adrenal disorders, and neuro-endocrine late effects of brain tumours. She began her PhD in 2021 on congenital adrenal hyperplasia and is an Associate Professor in Paediatric Prescribing and Endocrinology. She is a Nurse Advisor on the Living with CAH committee.

Cathy Thompson
As Director of the ADSHG, Cathy oversees ADSHG projects and campaigns, keeping in line with the strategy set by the charity's Trustee Board, and always working towards our vision of a world where Addison's disease and adrenal insufficiency are recognised early, and managed effectively so that anyone affected can live confidently and thrive.

Fiona Ledson
Fiona is an experienced Head of Physical Education with a strong passion for student wellbeing and inclusive practices. Her commitment to raising awareness of Addison's disease grew after her daughter's diagnosis. Fiona advocates for students with the condition, highlighting challenges they face and promoting resources to help schools offer safe, informed, and compassionate support. Combining her education expertise and personal insight, Fiona is dedicated to ensuring students with Addison's disease thrive both academically and personally.

A heartfelt thank you to ADSHG volunteer **Jennifer Campbell** for her meticulous proofreading of this booklet.

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Introduction

We want every child with adrenal insufficiency to feel safe and confident at school. Our achievable vision of good care for school-age students with adrenal insufficiency is one in which:

- Schools, local authorities and health services work together, in collaboration with students and their families or carers, to make sure they meet the needs of young people with adrenal insufficiency.
- Every school has a 'medical condition at school' policy, which is reviewed every year.
- Every student with adrenal insufficiency has an Individual Healthcare Plan (IHP), which details exactly what their needs are and who will help them.
- Every student with adrenal insufficiency is listened to, and their views are considered. It should not be assumed that all children with adrenal insufficiency have the same needs.
- No child with adrenal insufficiency is excluded from any part of the school curriculum as a result of their condition, or denied access to extracurricular activities, including overnight stays and trips abroad.
- All school staff should know what to do in case of emergency.
- Parents/guardians provide up-to-date information about the young person's adrenal insufficiency needs and all the supplies needed to manage their condition in school. Schools and parents/guardians agree on a clear method of communication.
- Every student with adrenal insufficiency is allowed to administer an emergency injection of hydrocortisone, as required, in public or in private.
- Students with adrenal insufficiency are never to be left alone when in adrenal crisis or prevented from managing their adrenal crisis. They are always permitted access to their medication and emergency injection kit.
- Students with adrenal insufficiency are not penalised for poor attendance when absence is related to their condition.
- When students with adrenal insufficiency have exams, specific plans are included in that year's IHP and agreed between the school, the student and their parents/guardians.
- Healthcare professional teams are either directly (where resources permit) or indirectly (via parents/guardians) involved in a student's care, to give them the skills and confidence to look after a student with adrenal insufficiency, and to follow an emergency care plan.
- School educational staff who are involved in a student's teaching are ALL to be aware of the student's condition and their IHP. They are given sufficient awareness training on adrenal insufficiency to give them the skills and confidence to support that student and help recognise the signs of adrenal crisis.

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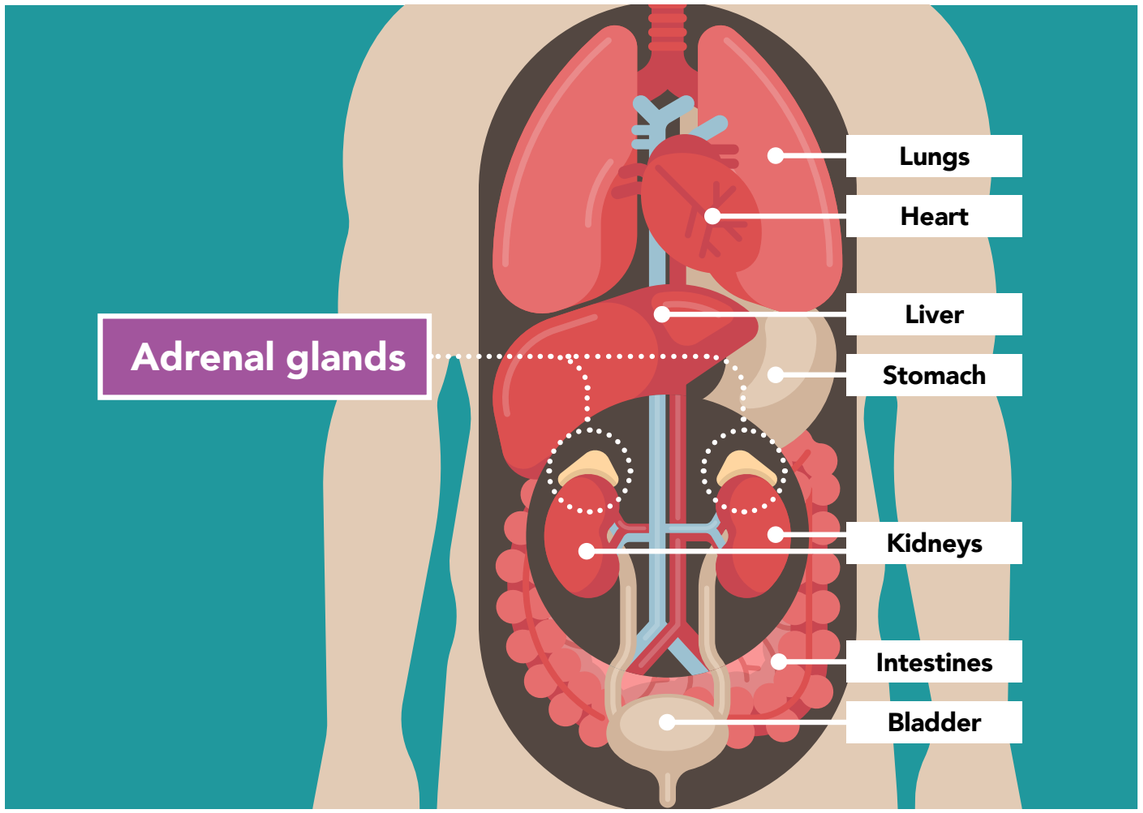
1 What are Addison's Disease (AD) and Adrenal Insufficiency?

What are Addison's disease (AD) and adrenal insufficiency?

Adrenal insufficiency is a rare endocrine condition affecting some or all adrenal gland function. The adrenal glands sit on top of the kidneys and produce steroid hormones that are essential for life.



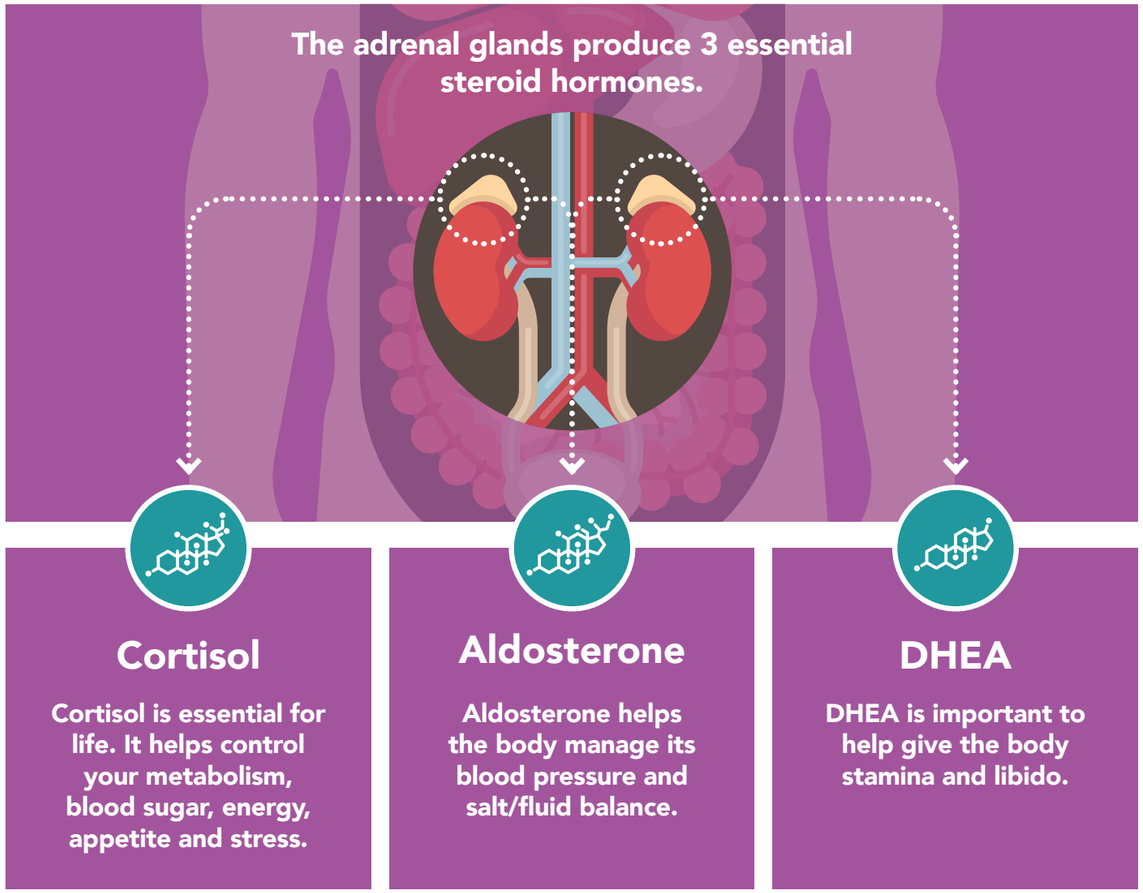
Adrenal insufficiency can be one of 3 types:

- Primary (known as Addison's disease, after the doctor who discovered it, Thomas Addison)
- Secondary OR
- Tertiary

The production of steroid hormones by the adrenal gland is affected to a greater or lesser degree in all types of adrenal insufficiency, due to different causes. Everyone with adrenal insufficiency will experience their condition differently and may be on different treatment programs.

Essential Hormones

Three essential hormones are produced by a healthy adrenal gland.



Lack of hormone production depends on the type of adrenal insufficiency:

- Primary (Addison's disease): Production of all three hormones above is affected
- Secondary and tertiary: Production of cortisol is primarily affected

Symptoms

The symptoms of undiagnosed adrenal insufficiency are:

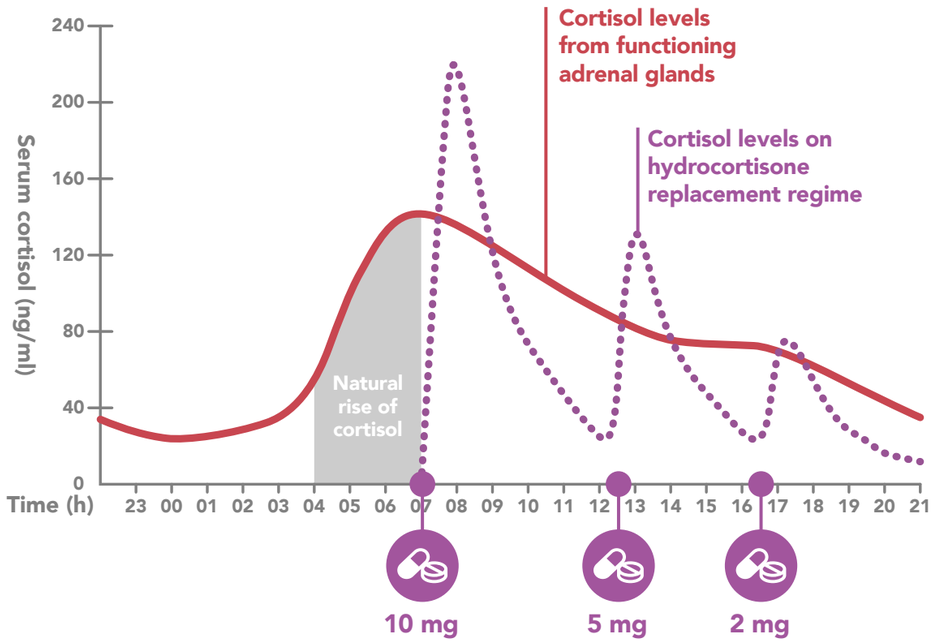
- Nausea and loss of appetite, leading to weight loss
- Muscle pain and weakness
- Extreme fatigue
- Headaches and dizziness
- Confusion or brain fog
- Changes to pigmentation (colour) of the skin in some people - they may look sun-tanned. This is only the case with Addison's disease.

Management

Addison's disease (primary adrenal insufficiency) is a lifelong condition. This is also often, but not always, the case for secondary and tertiary adrenal insufficiency.

As cortisol is essential for life, and as they cannot produce enough for survival, people with adrenal insufficiency need to take replacement medication. This makes them steroid-dependent.

A diagnosis of Addison's disease or adrenal insufficiency means following a strict medication regime, taking replacement steroid treatment (glucocorticoids) at carefully timed intervals every day to replace the missing cortisol. It also means needing to be educated in how to use an emergency hydrocortisone injection.



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.

A significant change in their dose, their ability to absorb it, or the timing of the dose can lead to a potentially life-threatening medical emergency called an **adrenal crisis**. It is therefore essential that they follow their prescribed medication plan (see page 13 on medication).

In times of physiological or extreme psychological stress, the body requires an increased amount of cortisol. People with adrenal insufficiency need to increase their usual daily replacement medication during these times: this is known as following the Sick Day Rules (see page 6).

Fluid balance in students with Addison's disease

Most students with a diagnosis of Primary Adrenal Insufficiency (PAI) cannot produce the essential steroid hormone aldosterone which manages the balance of fluids in the body. They need to take a daily replacement dose with a medication called fludrocortisone.

Fludrocortisone is usually taken once daily, on waking, and typically needs to be increased moderately during periods of hotter weather (above 30° C) or for prolonged exercise (>5 hours).

Salt in the diet should be taken as needed by young people with PAI. Salt cravings should be indulged and may mean an insufficient fludrocortisone dose.

Some students with pituitary failure may need to take desmopressin to regulate their fluid balance.

Steroid-dependent students will be more vulnerable to dehydration than their peers and during hotter weather, they are likely to need encouragement to keep sipping fluids such as sports drinks. This also applies on trips and for events like sports day.

Dehydration can result in low cortisol symptoms, and severe dehydration can require extra steroids to stabilise the young person's condition. Children and teens can lack awareness of the early warning signs of dehydration, so it is a good idea for staff to ensure the steroid-dependent student is carrying a water bottle during hotter weather, and to remind them to drink.

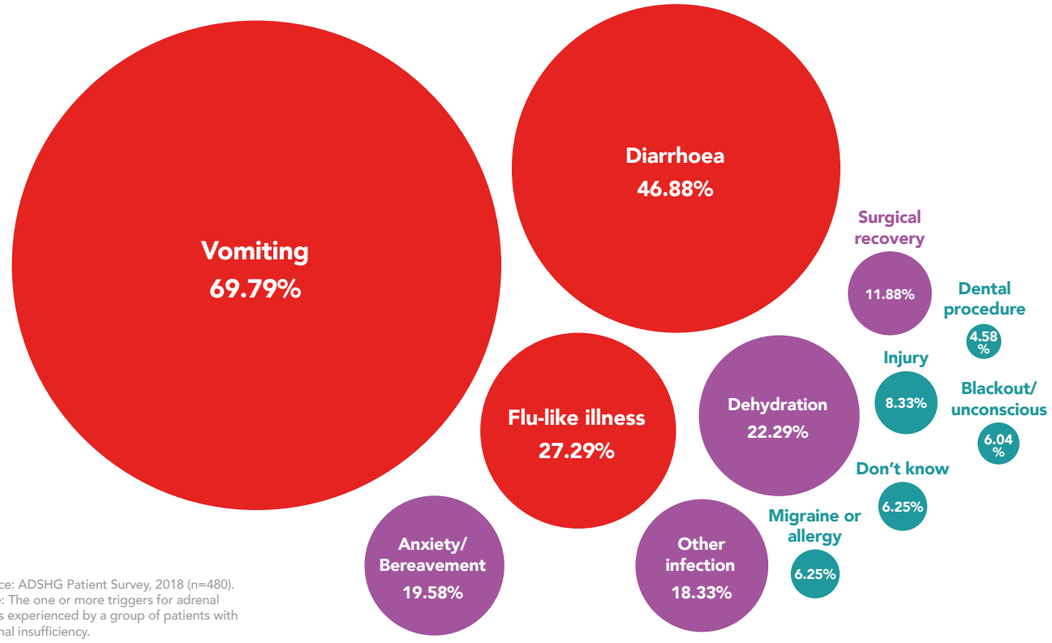
As the student may need to eat or drink during lessons for medical reasons, this should be included as part of the reasonable adjustments put in place by the school and included on the IHP. This information should be shared with all teaching staff to avoid the student having to repeatedly explain themselves. Students may want to discreetly remind teachers at the start of lessons.

WHAT ARE ADDISON'S DISEASE (AD) AND ADRENAL INSUFFICIENCY?

What is Adrenal Crisis?

Adrenal crisis is a life-threatening medical emergency that is caused by the body not having enough cortisol to function. It can be triggered by a number of physical stressors, but also psychological/emotional stressors.

Adrenal Crisis Triggers



Source: ADSHG Patient Survey, 2018 (n=480).
Note: The one or more triggers for adrenal crises experienced by a group of patients with adrenal insufficiency.

Symptoms to look out for

It is important to understand that an adrenal crisis can develop very quickly, particularly in young people. Everyone's symptoms will be slightly different. In those who are newly diagnosed or struggling to understand how to best manage their condition, it is essential that the people around them are there to look out for signs of a developing crisis, and to act immediately.

- Severe nausea and vomiting
- Headaches
- Dizziness or confusion
- Extreme fatigue and weakness
- Chills or fever
- Abdominal pain
- Low blood pressure
- Low blood sugar (hypoglycaemia)
- Pale (although undiagnosed people may appear tanned due to a change in their skin pigmentation caused by the condition). This may be harder to notice in darker skinned children.
- Loss of consciousness

Adrenal crisis requires time-critical emergency management - see the Emergency Flowchart (page 10) and **www.addisonsdisease.org.uk/emergency** for more information.

An instruction video on how to administer an emergency injection of hydrocortisone sodium succinate powder 100 mg for solution, is available at **www.addisonsdisease.org.uk/emergency**

Emergency Flowchart and Emergency Hydrocortisone Injection Video

What are Sick Day Rules?

The Sick Day Rules are a set of guidelines to help keep people with adrenal insufficiency safe and reduce the chances of an adrenal crisis when they are feeling off-colour, injured, ill or under significant stress. As everyone's medication needs are different, they are guidance rather than concrete rules.

Minor ailments can have a potentially serious effect on anyone with a steroid-dependent adrenal condition. This can either be due to their normal dose of steroids not being enough whilst they are unwell, or due to the symptoms of their illness interfering with how they absorb their steroid medication.

The Sick Day Rules advise 'stress dosing' or 'updosing' medication during the period of illness or stress. Students must be supported to follow the guidance on stress dosing.

Under-16s Sick Day Rules and Dosing

In under-16's the Sick Day dose is calculated according to weight:

This information is taken from the BSPED Adrenal Insufficiency Consensus Guidelines

25–34 kg	35–54 kg	55–69 kg	70–90 kg
7.5 mg x4/day	10 mg x4/day	12.5 mg x4/day	15 mg x4/day

Mild illness / injury

Minor bumps & playground injuries, a minor cold with no fever. Maintain usual steroid replacement dose.

Moderate illness

Fever, flu, infection and childhood illness - usually not well enough for school. **Sick day dose is weight dependent. Continue as long as the illness lasts.**

Vomiting or diarrhoea

Continue oral Sick Day dosing as long as illness lasts IF tolerated (kept down for 20mins after taking). **If not tolerated, give a 100 mg IM injection of hydrocortisone. Call 999 and say 'adrenal crisis'.**

Severe illness

If drowsy or unresponsive, or with major trauma or severe shock e.g. suspected fracture, road traffic accident, head injury with loss of consciousness, **give 100 mg IM injection of hydrocortisone. Call 999 and say 'adrenal crisis'.**

BSPED Adrenal Insufficiency Consensus Guidelines

Over-16s Sick Day Rules and dosing

The Sick Day Rules should be used in the following situations: minor injuries/playground bumps, nausea/diarrhoea (where the young person can still tolerate food and drink), fever and moderate illness requiring rest. They should also be followed for an illness requiring antibiotics and in times of severe stress.

Consideration should also be given to giving a Sick Day dose if the student feels unwell with low cortisol symptoms and has been experiencing what may seem like "minor" ailments, such as period pains or emotional stress (exams).

In the case of vomiting and/or diarrhoea, rehydration/electrolyte fluids should be sipped alongside the increased dose.

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

It is sensible to consult a GP if the young person is still unwell after 48 hours of following Sick Day Rules to investigate the cause of the illness. Sick Day dosing should be continued until the acute illness or trauma has resolved.

Where low cortisol symptoms are getting worse in spite of Sick Day dosing, or in the following situations:

Inject hydrocortisone 100 mg intramuscularly (IM)

Vomiting within 30 minutes of taking a repeat Sick Day dose of medication, or severe and persistent diarrhoea, both of which will interfere with absorption of usual glucocorticoid medication.

Light-headedness and dizziness on standing, confusion.

Severe lethargy or unable to get out of bed, collapse or loss of consciousness.

Severe injury or physical trauma.

You are unable to take oral steroid medications, e.g. before a surgical procedure or investigation (see Surgical Guidelines).

If in doubt, err on the side of caution and inject. Remember, there is no risk of overdose from hydrocortisone in an emergency situation, or for short term use; however there are side effects of long-term over replacement.

Having a diagnosis of Addison's or adrenal insufficiency as a young person

Addison's disease and adrenal insufficiency are rare and are an 'invisible 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 generally life-long conditions and can seriously affect a person's ability to do normal day-to-day activities.

Young people given a diagnosis are likely to find it difficult to adjust, not only physically (managing the time-critical medication regime and Sick Day Rules), but also psychologically (see page 26 on emotional support). It is a condition that requires careful management at a time in a young person's life when they will not want to be thinking about their health condition.

Be aware that young people:

- May be less aware of the low cortisol signs that signal a deterioration in health and the risk of an adrenal crisis. They may not feel, or report, warning signs.
- Are at risk of a fast deterioration into adrenal crisis.
- May not wish to take medication whilst at school, putting their health at risk.
- May not wish to wear medical alert/ID due to wanting to fit in rather than stand out.
- Are exposed to many minor ailments/illnesses in a school environment and have not yet developed immunity to many of these.
- May take longer to settle on the right medication regime due to the fact that they are growing, and going through puberty.
- May want/need to stay off school whilst following Sick Day Rules, for either their, or their parents/guardians preference, in terms of being cautious and being able to monitor them.
- Want to be able to do the same activities and have the same experiences as their peers.

Puberty and adrenal insufficiency

The onset of puberty may be affected by adrenal insufficiency, and it may start either earlier or later than 'normal'. During puberty and periods of growth, the body has differing needs for cortisol which can be difficult to match with replacement medication.

Most teenagers with Addison's disease also need increased maintenance doses of fludrocortisone during their pubertal growth spurt. However, there may be a lag of some months before this is recognised. If a student starts to display subtle signs from the symptoms list on page 5 – particularly muscle spasms, dizziness or thirst – this may indicate that their regular medication regime needs increasing for the increased hormonal demands of puberty.

As such, young people going through puberty may require more careful monitoring than those at other stages of development.

Periods, menstrual cycle and low cortisol overlap

Hormones fluctuate during a menstrual cycle, which can make cortisol replacement less predictable in some females. Some females will feel fatigued, dizzy or unwell at certain points during their cycle, which can also be signs of low cortisol (and a requirement to updose). These differences can be hard to navigate as a young person, and there will be a degree of trial and error as they learn to 'read their body'. Period cramps may also be painful and may become a problem. The young person can track their symptoms in a diary to see if there are any patterns associated with their period and signs of an adrenal crisis. Be aware and supportive of these personal situations and if in doubt, the young person should updose and rest.

2 Key Considerations in the School Environment

Adrenal Crisis

Emergency Flowchart

All staff working with the student should be aware of the Emergency Flowchart giving visual guidance on when additional medication should be administered and when to administer emergency hydrocortisone by injection and call 999.

The ADSHG have it available in 3 formats:

1. A3 poster to go on the wall of the health centre/sick room as a prompt.
2. Included as a page in the student's IHP.
3. A4 portrait digital download for printing 'at home'.

Secondary School Resources

Emergency medications

Spare doses of hydrocortisone should be readily available for a student to use for Sick Day dosing.

In line with BSPED recommendations, if the young person takes fludrocortisone (Primary adrenal insufficiency or CAH diagnosis), no change in fludrocortisone dose is required as part of Sick Day Rules.

Hydrocortisone emergency injection kits need to be readily available for the students or another person to use. The school should check that the contents of emergency injection kits given to them are in date (medication and syringes/needles).

If emergency hydrocortisone is administered, it must be recorded clearly and communicated to parents/paramedics as required.

Additional scenarios where an additional dose of medication might be required:

1. During strenuous physical activity or during competitive team games, a student may require an extra dose of hydrocortisone - see page 18 on PE.
2. During periods of emotional stress e.g. exam periods.

Emergency Injection Kits

The NICE guidelines for the Identification and Management of Adrenal Insufficiency[2] recommend that all people with a diagnosis of Addison's or secondary adrenal insufficiency are provided with 2 or 3 emergency management kits. Young people are likely to need 3, which allows for one to be kept at home, one with the person and one at school (during term-time).

Each emergency injection kit should contain:

- Hydrocortisone sodium succinate 100 mg powder and 2 ml, 5 ml / 10 ml water for injection (1 vial)
- 2 x blue needles
- 2 x 2 ml syringes
- Written instructions (available from the ADSHG online shop) in an easy-to-understand format on how to prepare and give emergency intramuscular hydrocortisone and how to safely dispose of needles and syringes.
- Steroid Emergency Card
- Glucose gel (young people under 16)

Some people choose to also store some spare glucocorticoid tablets in their emergency injection kit.

These items should be stored together in a container, with a securely closing lid, and kept at room temperature. Where room temperatures are high e.g., during a heatwave, the kit should be kept in a cool area or can be kept in the fridge until temperatures return to normal.

Often people will have different sized kits, depending on where they are keeping them, e.g. a larger kit with 4 or 5 'sets' of equipment to keep at home and a smaller kit with perhaps 2 'sets' of equipment in a bag that they have with them.

The kits should be checked regularly to ensure that the equipment and medication are still in date - this is a parental responsibility and is most often done at the end of each academic term for school 'stored' kits.

Out of date medication should be disposed of safely. Replacements need to be arranged by the parent/guardian via the GP. They should ask the GP to prescribe medication on a minimum of a 3-month basis to ensure sufficient stock can be held at school as well as spare medication kept at home.

Refer to the ADSHG website page, 'Working with your GP', for further information on this, should you need it.

NICE Guidelines

Working with your GP

Individual Healthcare Plan (IHP)

Every child with Addison's disease or adrenal insufficiency will need an Individual Healthcare Plan (IHP).

The headteacher should arrange an initial meeting that includes the young person (as appropriate), their parents/guardians, relevant healthcare professional (e.g. endocrine nurse) and relevant members of staff, e.g. SENDCO. This meeting may happen before transition to a new school, or following diagnosis with adrenal insufficiency. We have developed an example IHP template that can be used directly or used as a reference point. The IHP for a young person with Addison's or adrenal insufficiency should include:

- Roles and responsibilities, including what the student can manage themselves.
- Diagnosis and relevant medical history.
- Description of symptoms to be aware of that might indicate adrenal crisis, and what staff should do in the situation where they occur.
- Medication plan: medication and dosage, medication storage and access to medication, including written permission from parents and headteacher for medication to be administered during the school day/school activities.
- Potential impact on learning/behaviour and how support can be provided, including any reasonable adjustments required. Where there is an Education, Health Care Plan (EHCP) in place, this should be linked into.
- Any specific support needed around the young person's educational, emotional and social needs, including how absences will be managed, support for catching up with lessons and any counselling arrangements.
- A plan for emergencies: see Emergency Flowchart on page 10 (see QR code below).
- Staff training requirements and communication protocol (considering confidentiality). The IHP should record the following training details:
  - by whom
  - to whom
  - how frequently
  - how supply staff training will be managed
- Additional risk factors/triggers/considerations such as PE, school trips, exams, food and snacks.
- Additional resources: copy of Sick Day Rules, Surgical Guidelines and Adrenal Insufficiency Action Plan.
- Contact information: parents/Next of Kin (NOK), healthcare support, GP.

Review: The IHP should be reviewed annually with input from the school, parents/guardian, young person and their HCP as appropriate.

Distribution: The IHP should be distributed to the student, anyone with a duty of care for the student during the school day or on school trips, and key stakeholders outside of the school environment, e.g. parents/guardians, endocrine team.

Resources: We have created a template IHP for a student with adrenal insufficiency, including Addison's: scan the QR code below.

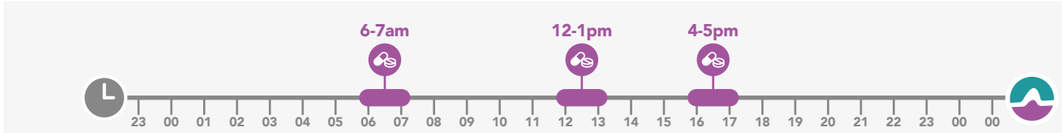
Indiviual Healthcare Plan (IHP) template

Daily Steroid Replacement Medication Regimen

Hydrocortisone is a time-critical medication. Doses should not be omitted or missed.

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

1. When they 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 e.g. at 4 or 5pm in the evening.



> **Our daughter's medical information isn't just up on the staff room wall; there are details on the computer system which all staff use, and for example, signs in the kitchen for the kitchen staff, explaining where her emergency kit is and what to do in an emergency. We've been incredibly fortunate with her schools.**
>
> Jackie, mother to A

This means that young people are likely to need to take a dose at lunchtime, as well as needing to 'updose' in line with Sick Day Rules. The school will require written consent to provide prescription medication to a young person at school.

The varying demands of a school day can make it challenging for young people to reliably remember their lunchtime dose. Some young people may be tempted to see if they can avoid taking medication in front of their peers, but most commonly a missed dose is due to forgetting during a busy day.

Access to daily medication

Wherever possible, young people should be allowed to carry their own medicines and relevant devices or should be able to access their medicines for self-medication quickly and easily. Young people who can take their medicines themselves or manage procedures may still require an appropriate level of supervision. If it is not appropriate for a child to self-manage, relevant staff should help to administer medicines and manage procedures for them.[3]

The young person might be encouraged to manage their medication by having easy access to it during the school day. Students should know where their medicines are at all times and be able to access them immediately. If medication is stored in the health bay, the student might miss more lesson time and might be less motivated to go and get it, then missing a dose, risking low cortisol and potentially triggering an adrenal crisis. As part of the IHP, the medication plan should include agreement between the school, parents and young person as to where medication is kept and how it is logged. If a child refuses to take medicine or carry out a necessary procedure, staff should not force them to do so, but follow the procedure agreed in the IHP. Parents should be informed so that alternative options can be considered.[3]

A **medication log** should be kept by the school: this is not intended to be a record of every time medication is self-administered by a student, but rather for school staff to record when medication should be taken and a record of when, what and how much medication school staff have administered.

School Medication Log template

> **Our 12-year-old has to go to the medical room to take his tablet and if he doesn't appear, they phone looking for him. I think by his reckoning that going for his tablet is less embarrassing than being called for it!**
>
> Christine, mother to F

Access to spare medication

Spare medication might be needed to follow the Sick Day Rules or for the scenario where medication is forgotten, e.g. left at home or on the bus! Therefore, spare medication should be kept in the school medicine cabinet/health bay. Schools should keep controlled drugs that have been prescribed for a student securely stored in a non-portable container and only named staff should have access. Controlled drugs should be easily accessible in an emergency. Spare medication should be recorded on the medication log.

Missed doses

Students who forget to take a dose should attend the health centre (or wherever their medication has been agreed to be kept) to ensure they receive a dose of medication immediately. For younger students, consider a Buddy system to accompany the student to the health centre for medication. School staff should contact NOK to inform them of missed doses so they can be alert to any low cortisol symptoms and also to highlight any needs for re-education on the importance of taking medication.

Support from the health centre/sick room

If a student feels unwell, they should not go to the health centre alone in case of dizziness/confusion which can be signs of adrenal crisis. If there is a pupil in the sick room already with, or suspected of having, gastroenteritis (vomiting or diarrhoea), then the student with adrenal insufficiency should go to a separate room to avoid risk as this is a significant trigger for adrenal crisis.

Storage

- All medication should be stored in their original packaging.
- All medication should be clearly labelled with the student's name, date of birth and expiry dates.
- All medication must have clear instructions regarding administration, including dose and frequency.
- Store medication as per instructions e.g. at room temperature.
- At the end of each school term, medications should be sent home with the student so that the parent/guardian can check contents and expiry dates.
- In-date medications should be returned to school with the student at the beginning of term.
- The storage location of the medication should be written into the young person's IHP.

Safe disposal

Sharps boxes should always be used for the disposal of needles and other sharps where an emergency injection of hydrocortisone has been given.

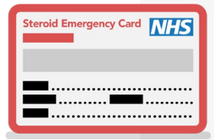
Credit: BD Eclipse blue needle with 'Safeslip' technology.

KEY CONSIDERATIONS IN THE SCHOOL ENVIRONMENT

Steroid Emergency Cards

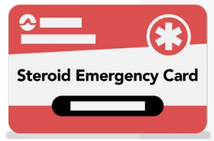
It is strongly recommended for people with Addison's and adrenal insufficiency to carry a Steroid Emergency Card with them, highlighting their steroid-dependent status and helping inform healthcare professionals that they are at risk of adrenal crisis.

There are a number of different types of Steroid Emergency Card and young people can choose which they wish to carry, but whichever one they have should be filled in with their personal details.



NHS Steroid Emergency Card

Available from your endocrinology team, theoretically from the GP and also available from the ADSHG online shop. Captures basic personal information and an overview of the emergency management of adrenal crisis.



ADSHG Steroid Emergency Card

Available from the ADSHG online shop. Comprehensive health information as well as giving instructions on the emergency management of adrenal crisis.

BSPED Adrenal Insufficiency Card

Available from your endocrinology team. Aimed at **under-16s**. Comprehensive personal and health information and instructions on the emergency management of adrenal crisis in children and young people.

Hospital / Trust Specific Cards

Some health trusts also produce an Emergency Steroid Patient Card, aimed at the 'patient' rather than healthcare professionals. They highlight endocrine team contacts, Sick Day Rule reminders, and Emergency Management of Adrenal Crisis reminders.

Medical ID Jewellery and Medic Alerts

There are a number of different ways young people can highlight that they have a medical condition requiring intervention in an emergency, and offering medics on the scene a link to further resources. Whether or not a student chooses to use/wear one of these is often down to personal choice, confidence, and how they feel about others knowing about their condition. Medical ID jewellery/medic alert items should be encouraged and should not be excluded due to school rules about wearing jewellery.

Bracelets

Simple silicone bands are available that state 'steroid-dependent', but there are also some better designed, more expensive items available online that look more like 'normal' jewellery, which some young people might feel more comfortable with.

Necklaces

Whilst available, these are not as strongly recommended due to the fact they are worn around the neck, which can get in the way in the case of an emergency, and can also be a safety hazard during sports or outdoor activities. If a student has chosen to wear a medical tag attached to a neck chain, they should be permitted to wear it during classes but encouraged to buy an additional wristband to wear instead during PE.

Keyrings

Available from the ADSHG online shop, these can be put on the outside of school rucksacks/PE bags.

Spare medication box with label

Some young people devise their own medic alert, for example, using an empty tictac box with a label on it, using it to store their daily medication. People with a steroid-dependent condition are also encouraged to carry a Steroid Emergency Card (see previous section).

> **Our 12-year-old just doesn't seem to get the importance of wearing a medical tag and it is invariably shoved in a pocket or lying at the bottom of a school bag. He gets his hydrocortisone tablet the period before lunch which does help with the 'I'm too busy at lunchtime' excuse.**
>
> Christine, mother to F

Staff Training

The Supporting Pupils with Medical Conditions (2014) Statutory Guidance[3] addresses staff training requirements and the school Medical Conditions policy should include how any staff training will be implemented as well as appropriate support for staff.

It is important that there have been clear discussions and documentation around what staff training involves and refers to, for example:

- Awareness of roles and responsibilities and statutory requirements for the school to follow.
- An understanding around adrenal insufficiency and recognising adrenal crisis by school staff.
- Awareness, confidence and competence for all relevant staff to follow an emergency care plan as detailed in an IHP.
- Confidence and competence to administer an emergency dose of hydrocortisone by IM injection.

Suitable training should have been identified during the development or review of an IHP. Some staff may already have some knowledge of the specific support needed by a young person with a medical condition and so extensive training may not be required. Staff who provide support to pupils with medical conditions should be included in meetings where this is discussed.[3]

Note that supporting a pupil with adrenal insufficiency does not require confidence and competence in administering an emergency injection of hydrocortisone, in fact, the statutory guidance specifically states that "*Staff must not give prescription medicines or undertake healthcare procedures without appropriate training (updated to reflect requirements within individual healthcare plans).*" However, it does require that:

"*Training should be sufficient to ensure that staff are competent and have confidence in their ability to support pupils with medical conditions, and to fulfil the requirements as set out in individual healthcare plans. They will need an understanding of the specific medical conditions they are being asked to deal with, their implications and preventative measures.*"[3]
This reinforces the importance of ALL STAFF understanding adrenal insufficiency and recognising the signs of adrenal crisis, as well as, critically, being able to follow the Emergency Flowchart.

Whilst there is no legal obligation for there to be staff with training in administration of an emergency hydrocortisone injection in the school, it is clearly in the interests of all parties to approach this pragmatically to ensure that an adrenal crisis can be managed safely. This should be part of the school's risk assessment, and the young person's IHP.

Emergency management scenarios involving an intramuscular (IM) hydrocortisone injection using a student's own emergency injection kit should be jointly explored with appropriate parties. Both self-administration by the young person, and administration by competent and confident 'others' e.g. the school nurse/first aider, a member of staff or a fellow student, should be explored. It is important that the student's wishes guide who they would like to be involved in supporting them in an emergency, and that there is consideration of where the injection would be administered (e.g. arm/thigh etc.).

Giving an emergency injection: options for support in developing competency

1. The student's endocrine team may be able to offer some form of support; this may range from signposting and discussion to virtual or in-person training. Due to resource constraints,, endocrine nursing staff may not be able to be involved at all. Please liaise with the endocrine nurse involved to clarify their training protocols.
2. Parents: It is often the young person's parents/carers who are in the best position to offer support to the school around competency and confidence. They may be able to come into school to give in-person training for key staff and potentially certain pupils that the young person spends time with.
3. Proactive awareness training: using online assets such as injection videos from the ADSHG, see resources section.

The IHP should record the following training details:

- By whom
- To whom
- How frequently
- How supply staff training will be managed
- 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, so if in doubt, use the injection.
- The injection is to be used to PREVENT, as well as to treat an adrenal crisis.

PE and Sports

Whether or not a young person requires an increased dose of steroids ahead of, or during a period of physical activity, such as a PE lesson, depends on several factors:

1. The individual and their level of fitness.
2. How strenuous the exercise is.
3. The duration of exercise.
4. The temperature/risk of dehydration.

It is the school's responsibility to ensure that PE teachers and sports instructors/team coaches are aware of the student's medical needs, have been briefed on low cortisol symptoms and are aware of the correct response to any medical emergency.

> **"When our son was well enough to return to school after his diagnosis, we all breathed a sigh of relief that he made it through the first day, especially the school nurse! Three days in and my husband rang me at work. Our son had played football at lunch time and fallen three times, been patched up and gone to class. Twenty minutes later he collapsed, kept drifting off, had stars in front of his eyes and couldn't stand without falling. The school called an ambulance and we found ourselves back in A&E. He was kept in overnight and once stable we returned home with a very fed up 15 year old.**
>
> Katie, mother to L

Mild exercise for a single PE lesson might or might not require any additional medication. However, the following recommendations should always be followed:

1. The young person should be aware of what level of exercise they will be doing (i.e. planning and communication about the PE lesson). They are the best judge of whether they are likely to need to updose 30 minutes or so ahead of the session. They should have access to their steroid medication so they can updose if they feel it is necessary. Where an extra steroid medication dose is routinely needed ahead of physical activity, this should preferably be written into the IHP.
2. Strenuous or extended exercise (e.g. long distance running or competitive sports) may necessitate updosing. How much will depend on the variables listed above. In general, the more physically demanding the activity, and the longer the duration, the higher the likelihood that updosing will be required.
3. PE activity increases the risk of an injury, a common trigger of adrenal crisis, so it is essential that a student's emergency injection kit is accessible and that they, and the PE teacher, and potentially teammates, are aware of where it is and ideally, how to support administering it.
4. As physical activity can cause dehydration, the student must have access to water and keep well hydrated, particularly in hot weather or for extended sessions of sport. Rehydration fluids (such as sports drinks) should be permitted as needed, in addition to water. Staff should prompt the student to drink regularly and be aware of early warning signs of dehydration.
5. There is a higher risk of low blood sugar during adrenal crisis. Consider the need for the student to have access to additional glucose. This might be provided by parents for use/storage at school as a glucogel, access to a juice box, or jelly babies for example. Younger children (under-16s) are more likely to require additional glucose than older students.

School trips and Duke of Edinburgh Award (DofE)

Young people whose steroid dependence is well managed can expect to achieve normal levels of fitness and should be encouraged to participate in the usual range of school activities outside of the classroom. Schools should make arrangements for the inclusion of pupils in such activities with any adjustments as required, unless evidence from a clinician states that this is not possible.[3]

With appropriate planning, most students with adrenal insufficiency can confidently take part in school trips and extra-curricular activities. As well as providing equitable opportunities to other students, it will build their confidence in doing something different and build their sense of involvement and inclusion.

Where a young person has unstable adrenal insufficiency, or complex additional health needs, expert input will be needed from their healthcare team to enable the student to be fully involved in the appropriate aspects of all school offerings.

If the school has any concerns about a student's participation in a particular school trip or activity, they should request that the parents/guardians obtain written guidance from the young person's endocrine consultant about the correct medical management for those circumstances.

Pre-Trip planning

1. Involve the student, parent/guardian and a healthcare professional (as required).
2. Start planning collaboratively as soon as possible, and at least 6 weeks ahead of the school trip for a local day trip, and longer for a residential or international trip.
3. Be aware of the student's preferences for sharing details of their condition with others when making plans.
4. Use the student's IHP as a foundation for planning what additional aspects of care will be needed during an off-school site day trip, or a residential trip.
5. Use the ADSHG School Trip Record and checklists to ensure that everything needed is prepared and taken on the trip.

ADSHG School Trip Record

Considerations

Carers: staff numbers, rota and student keyworker.

Safeguarding: staff ratios to allow for managing an illness or medical emergency during day or night.

Training: ensure that anyone with a duty of care for students on the trip is confident in their understanding of Addison's and adrenal insufficiency, knows how to recognise signs of adrenal crisis, and understands the emergency treatment protocols as agreed in the IHP.

Travel by air: emergency injection kits must be carried in hand luggage if flying, with a GP letter (see below).

Changing time zones: when crossing time zones, the student will need to adjust their medication regime. They should have their morning dose of glucocorticoid replacement medication every 6-8 hrs during the travel, and on arrival in the new time zone, should go back to their usual timings (to fit with day/night in their new destination).

Water & Diet: ensure sufficient water to stay hydrated during flying/long journeys, and access to carbohydrate snacks/glucose gels as appropriate (will be noted in IHP if required).

Medication: ensure sufficient supply for the full duration of the trip (to include sufficient for following Sick Day Rules). Follow guidance on storage and consider suitable access to it by staff and the student during travel, during the day and at night.

Medic ID jewellery: see separate section, but especially important on trips.

Emergency injection kits: ensure medication and needles/syringes are in date, and that instructions are included.

Adrenal crisis treatment form/BSPED adrenal insufficiency card: ensure it is up to date and accurate. Consider translating into language of destination country if appropriate/travelling abroad. Translations in 18 languages are available on the ADSHG website (www.addisonsdisease.org.uk/travelling).

GP letter: parents to supply a GP/endocrinologist letter stating the reason for needing emergency injection kits.

Contacting parents/guardians: plan contact schedule, who will contact whom, when and how.

Insurance: the school must have a suitable level of insurance, and any requirements of the policy should be included in the medical conditions policy.

Adaptations

1. **Routes:** adaptations should be considered. The young person with Addison's or adrenal insufficiency may not be able to complete a traditional route, and as such, their group may need to have variations in terms of distance or terrain. Emergency access to the route should be a key consideration.
2. **Kit:** the young person may also not be able to carry their full kit for the entire expedition, so again, consideration might need to be given to what kit they carry.
3. **Food:** ensuring that the young person has additional carbohydrate-based snacks to prevent hypoglycaemia (a risk after strenuous physical activity) as well as access to plenty of water is important, particularly as DofE expeditions traditionally take place in the spring and summer months, when the temperature might be higher.
4. **Access to a phone:** discuss with staff the suitability of having access to a fully charged mobile phone and additional power bank, in case of an emergency.

Absences and Missed Education

There are several reasons why a young person with Addison's or adrenal insufficiency will miss both individual lessons during a day, and full day(s) of school.

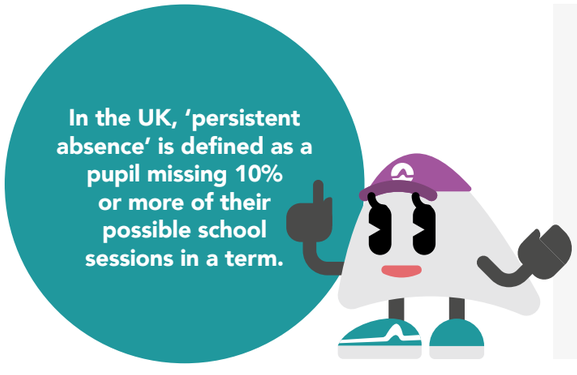
> **Our daughter used to suffer in the mornings. Her body was so empty of cortisol that to get out of bed, she would use her arms to lift her legs out of the bed. She would often become unwell during the school day, feeling under the weather with nausea and generalised weakness. Interestingly, I would always get the call at 10.30. Even with extra hydrocortisone, she just couldn't make it. This pattern only settled after she substantially increased her medication regime and when she finally went through puberty and her major growth spurt. Then things settled down and she coped better with the stress of exams (with some planning)!**
>
> Hazel, mother to C

1. Some of the symptoms for adrenal insufficiency are shared by other autoimmune and endocrine conditions, so it is not always straightforward to diagnose. Symptoms often develop slowly over time which can delay diagnosis. It is likely that young people will already have an increased level of absence from school due to ill health, before being given their diagnosis. Diagnosis may finally be given as a result of an adrenal crisis (medical emergency), by which time the person is in a poor state of health and return to health is slower.
2. Diagnosis requires several tests, some of which are done by a GP (e.g. 9 am serum cortisol test and other blood tests) and some of which need to be carried out by an endocrine team. Whilst GP appointments may be easier to access due to local community practices, endocrine teams are based out of hospitals, which may mean longer time off school for appointments, and less flexibility with finding appointments out of school hours.
3. Treatment with glucocorticoid replacement medication is effective but it takes time for the correct medication regime to be found and there is a significant amount of 'trial and error' at the start. This is amplified in young people by the effects of emotional stress and puberty.
4. Young people with adrenal insufficiency are required to follow the Sick Day Rules when they experience physiological or extreme emotional stress. There is therefore an increased effect on these young people, of 'common, everyday illnesses' that circulate within a school environment. Due to the significant risk of adrenal crisis posed by exposure to illnesses involving vomiting and diarrhoea, it is advisable for the student to avoid contact with those who are unwell, which may mean additional time off school.
5. The young person will require regular endocrine check-ups; at least 6 monthly, but more frequently when newly diagnosed.
6. After following Sick Day Rules a student may take longer to return to feeling well enough to attend school or parents may not feel confident with their child returning to school if they are still 'updosing'.
7. Many people with autoimmune Addison's will develop other autoimmune conditions (e.g. Type 1 Diabetes, coeliac disease and thyroid conditions), which can add complexities to the effective management of their health.

> **My daughter's school has been really supportive – massive staff awareness of her and her condition, reduced timetable, direct continuation of exam arrangements and when she was off poorly, the teachers photocopied up all the work to stick in her book so she could focus on getting better.**
>
> Jackie, mother to A

Managing school absences

1. Ensuring that the school and teachers understand the reasons why the young person with adrenal insufficiency might have a much higher level of absence. Realising that the usual approach to student absence (letters to parents highlighting absence) will not be effective and can lead to frustration.
2. An open dialogue between the school, young person and their parents/guardians, which seeks to maximise the young person's attendance at school whilst understanding when it is not realistic or possible.
3. Best practice is for an agreed procedure to ensure the student receives a copy of information provided during missed lessons. This is most likely to be an email sent out to the student and/or parents/guardian or posted onto whichever app is being used by the school to communicate work with students and their family. The student can then download information/assignments. In the simplest of cases, it could even be a box file in the staff room with the student's name on it, for staff to leave copies in, that the family can arrange to collect or to be posted out.
4. A recognition that extended absence from school can affect not only a young person's academic studies, but also their sense of involvement and confidence. The school SENDCO and individual subject teachers are in a powerful position to help minimise the effect on the student, through regular and empathetic communication and thinking laterally in terms of how to manage missed lessons. This may include options for catching up online, signposting to resources the student can use at home, and making time to check in with the student when they return to school after an absence.



Reduced timetable

When attendance is significantly affected, the school may consider a temporary reduced timetable to support their wellbeing and learning. This does not mean lowering expectations.

In some cases, especially at Key Stage 4, trying to manage a full timetable when attendance is limited can lead to stress and poor outcomes. It can be more helpful for a young person to focus on fewer GCSE subjects and do well, rather than attempting too many and struggling to keep up.

Any reduced timetable should:

- Be short-term and regularly reviewed.
- Be based on medical evidence.
- Take account of attendance, progress and wellbeing.
- Be agreed with the student and their parents/carers.

The school must also involve the local authority, usually through the PEAR (Pupils Educationally at Risk) panel, and may seek advice from the Clinically Vulnerable representative. This helps ensure the arrangement is appropriate and that the young person continues to receive a suitable education.

It is important to note that this can take time. It usually takes several months to gather the evidence to show that a reduced timetable is necessary. However, when agreed, a reduced timetable can be a key support in helping a young person succeed at KS4, while protecting their health and wellbeing.

> **Our 15-year-old son has been off for a week with a bug, but we are getting the work to help him, simply by emailing the teachers direct. They have all been willing to provide work or run through the work missed when he returns. Thankfully he is at a school that really cares.**
>
> Jackie, mother to A

Exams

Examinations can be a significant source of psychological and emotional stress for all students but for those living with Addison's disease or adrenal insufficiency, this stress takes on an added medical dimension. Students with these conditions are unable to produce a normal physiological stress response due to impaired cortisol production, which makes managing exam season particularly important, and sometimes challenging, for students and families.

Many students find that coursework-based subjects are more manageable than exam-heavy options. These preferences should be considered when selecting GCSEs, A-levels or National Qualifications.

The impact of exam stress

According to the NICE Guidelines, "*Periods of sudden, intense psychological and emotional stress, for example a bereavement, exams, or significant life events such as getting married or divorced*"[2] are all types of psychological stress. Examinations at all levels, whether end-of-term tests, GCSEs, National Qualifications or A-levels, can provoke this kind of stress. In addition, if a student has also had prolonged absence from school, assessments may feel even more daunting and stressful.

Steroid-dependent students may therefore need extra steroid medication during exams and in the period leading up to them, as a result of exam-related anxiety (see the Sick Day Rules on page 6 for information on updosing due to psychological stress). Symptoms may include fatigue, nausea, dizziness or even adrenal crisis.

Any additional steroid medication/doses taken should be documented in the school's Medication Log and any required adjustments should be discussed in advance with the student's family or carer.

> **We find that we have to juggle doses during exam season because of the stress and we also keep her well supplied with snacks. That was a huge advantage of the rest breaks and separate room - she could have a drink and snack halfway through if needed.**
>
> Karen, mother to K

Access arrangements (applied for by the school to the examining boards)

These are agreed before sitting the exam and involve arranging **reasonable adjustments** to make exams more accessible for students with disabilities, temporary illnesses or special educational needs. Schools are encouraged to liaise closely with the student's family or carers to implement reasonable adjustments, which might include:

- Permission to take steroid tablets, water and snacks into the exam room.
- Prompting to take medication during the exam.
- Supervised rest breaks.
- Sitting exams in a separate, quieter room.
- 25% extra time (when medically justified).
- Scheduled rest days between exams.
- The option to reschedule exams or sit them at home with proper supervision.

Access arrangements, including the length and frequency of supervised rest breaks allowed, may differ between different exam/qualification awarding bodies.

> **My daughter has exams in a separate room, 25% extra time, and is allowed to ask for rest breaks or to eat or drink or take medicine – though she hasn't actually done this as she likes to get it all over with as soon as possible!**
>
> Philippa, mother to T

> **For my A-Levels, my exams were scheduled so there were rest days or decent breaks in between. This meant I sat some of my exams in a separate room, which was so handy for taking my tablets too. The scheduling took quite a bit of organising but was so worth it as I felt awful for my AS Levels when I didn't realise how much the build-up of revising and stress on the day would have on me. I ended up with such bad brain fog and then was pretty ill after and annoyingly it showed in my exam results too. But for my A-Levels it was totally different and for my English exam I was with another girl in my year who had a different health condition, so that was nice as I didn't feel like the odd one out!**
>
> Alice, student

Medication

If a student might need to updose or to take a regular replacement glucocorticoid during an exam, then an agreement needs to be made about the process for taking medication into the examination room. Any packaging with writing (including blister packs/med box) are not permitted. Loose medication is not allowed due to the inability to identify it as the prescribed medication. The solution is usually for the invigilator to witness the medication being taken out of its blister pack just before the exam, and being put into a small, unmarked medication pot, which they then place on the student's table for access during the exam as required.

Schools must apply for special access arrangements by submitting a request to the relevant examination board, accompanied by a supporting letter from the student's GP or consultant, specifying the medical condition and explaining how symptoms like fatigue, difficulty concentrating, inability of the body to cope with stress and possible requirement for unplanned additional medication, may affect performance.

Parents/guardians are encouraged to initiate these discussions with the school early in the academic year.

> **We emphasised to our daughter that the key wording from the exam boards about access arrangements was that they were not to give candidates an unfair advantage but to prevent them being disadvantaged. I think she realised that she wouldn't do as well and so would be disadvantaged if she didn't have them.**
>
> Karen, mother to K

Special Considerations

These are requested **after** a student has taken an exam and involve seeking an adjustment to a mark or grade because a student's performance was affected by their temporary illness, injury or personal circumstance.

Being granted special considerations requires evidence to prove what has happened and may be difficult to obtain. Students with Addison's or adrenal insufficiency might be able to apply for special considerations if they can prove their condition has affected their performance in an exam.

The process for requesting special considerations and access arrangements is the same for students in England, Wales and Northern Ireland.

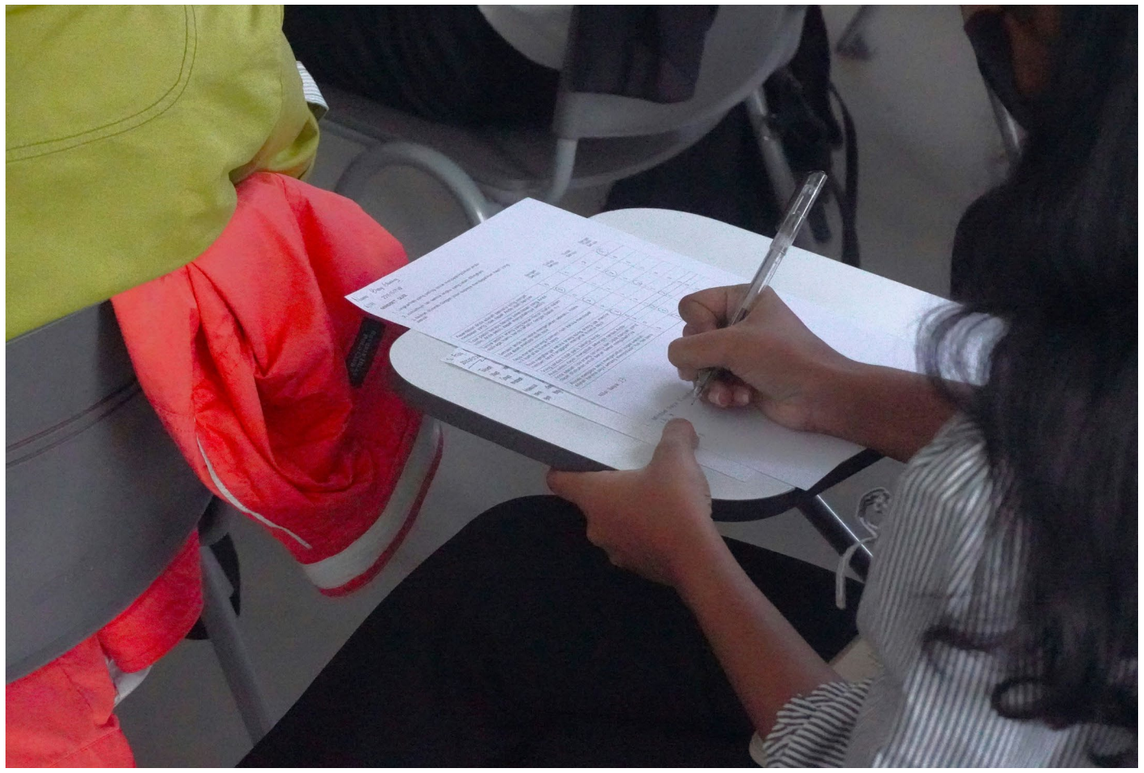
Planning and communication

Proactive communication between families or carers, schools and medical teams is essential.

Parents/guardians should:

- Seek written guidance from a GP or consultant about exam management.
- Ensure the school has accurate and accessible records for any exam-related queries.
- Contact the school's exam officer immediately if the student is unwell on the day of an exam.
- Be prepared to provide medical confirmation if a student misses a scheduled public exam.

Students themselves, if possible, should also be supported in learning how to advocate for their needs.



Information for Scottish Students

The process for granting reasonable adjustments for students is slightly different in Scotland. An **exceptional circumstances service** is in place for students who are unable to sit the exam or whose results may be impacted by personal circumstances, such as a medical condition.

Qualifications Scotland (formed in Feb 2026 to replace the Scottish Qualifications Authority) indicates that "*Schools, colleges or training providers are not required to specify the nature of the medical condition when submitting a request, but they must hold documentation such as a letter or statement from the head of centre confirming that it affected the learner.*"

Therefore, the school must provide alternative evidence for the exam component of the relevant qualification. Qualifications Scotland considers a range of evidence that must cover the specific skills, knowledge and understanding requirements of the course.

For more information, please visit the Qualifications Scotland website.

Qualifications Scotland Website

Emotional Support for Students

A young person with a diagnosis of adrenal insufficiency is likely to have already started a 'journey' that begins even before their official diagnosis, when they are feeling increasingly unwell and requiring time off school, but without any clear reason why.

We all have different coping strategies, which in young people, may be influenced by how their families cope. There will be a physical and emotional shock of receiving the diagnosis of a lifelong, rare condition which is life-threatening. With diagnosis can come a host of emotions that might include fear, sadness, uncertainty, denial and anger; feelings commonly associated with loss, grief and mourning. These feelings are likely to shift and change, and may endure, at least periodically, for many years.

Everyone finds their own way of coping, and some young people may cope better than others. Some may be better at hiding their true feelings than others.

Invisible condition: remind the student that because their challenges can't always be seen ("but you don't look sick") doesn't mean they aren't real and tough. It's important that positive and inspiring messages are shared, but it is also important to allow the student to share the hard parts without being labelled as negative.

Freedom to express their emotions: young people need to have the freedom to express their fears and emotions if they are ready and able to. This may be to family, friends, school staff, others with adrenal insufficiency, or professional support (counsellor). Where the young person does not want, or feel able, to talk to someone, they may feel able to keep a journal, to offload frustrations and concerns, or find another creative outlet such as art or music. Talking when doing an activity can help open the conversation in a less intense manner but still with privacy.

A comprehensive support structure: due to many of the factors discussed in this leaflet (increased absence from school, medication management, risk of adrenal crisis etc.), students with adrenal insufficiency are under increased pressure in the school environment. This can be best managed by careful planning between them, their family or carers and the school. In addition, the student may have already been through traumatic medical experiences. If possible, agree a space for them to go when feeling unsure or overwhelmed.

Professional support: some hospitals and GPs are able to make counselling support available to young people with severe long-term conditions to help them come to terms with their medication dependency, the debilitating and potentially life-threatening nature of their condition, and learn techniques for maintaining psychological resilience. Students can also access free resources such as those from Rareminds Wellbeing Hub.

Access to a mobile phone: the young person may feel more confident and less anxious if they have permission to have access to a fully charged mobile phone. Whilst school rules often forbid students from having access to their phone during the day, this rule should be considered on an individual basis for students with adrenal insufficiency.

Rareminds Wellbeing Hub

KEY CONSIDERATIONS IN THE SCHOOL ENVIRONMENT

> **Some people in my class were really nice when I came back to school. Others just didn't get it because I didn't look unwell (not hard with makeup!). I had FOMO not just from missing school but also meeting up after school too. It took a while to learn what I needed to do to pace myself, keeping notes on the notes app in my iPhone helped, so now I feel I understand my body more.**
>
> **I have a medic alert bracelet I really like, a pretty wallet card for my Steroid Emergency Card (which I also have saved in the pictures on my phone) and a little tub for my pills which my friends call "tablet time" when my watch buzzes with my alarm. I can feel proud that I manage a rare condition at the same time as feeling held back and angry at it. It's a bit of a rollercoaster!**
>
> Alice – diagnosed aged 15

Invisible disabilities are physical, mental or neurological conditions that are not visible from the outside, but can limit or challenge a person's health, movement, senses or activities.

Transition

Students change school most often due to transitioning from the primary to secondary school system (in some areas via a 'middle school' system) but may also move schools for a host of other reasons. It is an opportunity to review what has worked in the current school environment, to bring best practice to the next school environment, and to have a review or update, where needed, of the young person's IHP.

Preparing for Higher Education

As students transition into higher education, the challenges of managing adrenal insufficiency alongside academic pressure and a more independent lifestyle can become more complex. Balancing medication with the flexibility of university life and the stress of final assessments requires planning and self-awareness. Higher education institutions should be made aware of the student's condition early, with formal arrangements (e.g. learning support plans, exam accommodations or access to health services) put in place as needed.

> **Our son has a place at one of the local sixth form colleges and we've had several discussions with the team that support students with medical needs. They have been so helpful. If he has health issues, they have offered to help with extra lessons, recording a lesson, transcribing it, or sending the resources. They have confirmed that there will be someone trained to administer an emergency hydrocortisone injection. There will be a member of staff who will get to know him, be able to monitor his well-being and offer help if necessary and maintain communication with us as parents too.**
>
> Diane, mother to C

3 School Roles and Responsibilities

Headteacher

1. Ensure conformity with statutory regulations around pupil inclusion, student wellbeing and safeguarding.
2. Ensure compliance with statutory guidance on 'Supporting pupils with medical conditions at School' (Department of Education).[3]
3. Ensure comprehensive school policies are reviewed and updated, notably the Medical Conditions Policy (see page 31).

Statutory Guidance from Department of Education

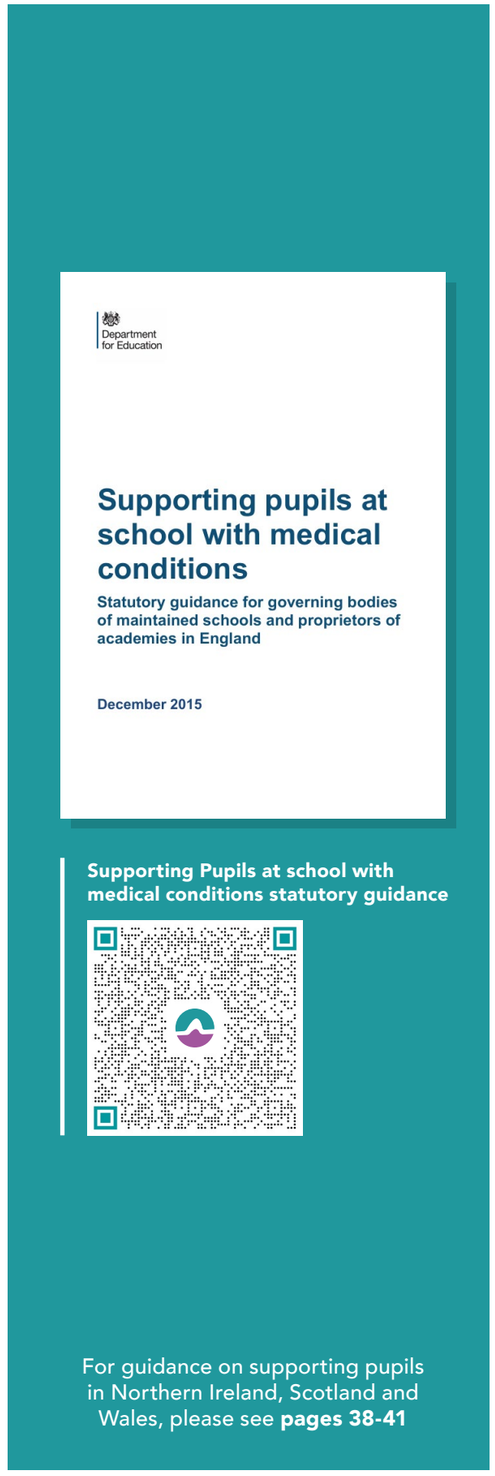
> **The school nurse and hospital paediatric endocrine nurse helped us to draw up the Individual Healthcare Plan in school, to cover emergency protocol, and were able to advise me on what other schools do and what would be appropriate to expect in terms of support for exams and assessments. We also spoke to the school's SENDCO and have regular meetings with the pastoral staff who see her on a daily basis. They are the ones who ring me when she is ill at school.**
>
> Philippa, mother to T

Medical Conditions Policy

It is the responsibility of the school governing body to ensure that the school Medical Conditions Policy is in place, but the implementation will most likely be the responsibility of the Headteacher.

The policy should:

- Recognise that medical conditions can be life-threatening.
- Understand how they might affect a young person's ability to learn.
- Understand that every medical condition is different and every student should be treated as an individual.
- Include reference to suitable Staff Training (see page 17).
- Set out arrangements for whole-school awareness training so all staff are aware of the policy for supporting pupils with medical conditions and their role in implementing that policy.
- Include a complaints procedure.
- Be reviewed and updated regularly.
- Include transition arrangements.
- Define the roles and responsibilities of all those involved in arrangements to support pupils at school with medical conditions.
- Have a named and assigned person responsible for the policy.
- Be written in consultation with parents/guardians, education and health staff.
- Clearly explain how the policy will be implemented.
- Be available for families or carers, and members of staff to read.
- Be developed in consultation with health and social care professionals, students and families or carers to ensure that the needs of the young person with medical conditions are properly understood and effectively supported.
- Ensure that, in line with the **Supporting Pupils at school with medical conditions statutory guidance**[3], staff training is sufficient to ensure that staff are competent and have confidence in their ability to support students with medical conditions, and to fulfil the requirements as set out in individual healthcare plans. They will need a detailed understanding of the specific medical conditions they are being asked to deal with, their implications and preventative measures.
- Promote a culture of inclusivity and maximising the potential of each individual student.
- Ensure the school has a suitable level of insurance, and any requirements of the policy should be included in the medical conditions policy.
- Ensure that staff turnover, training, rotas, away days, staff leave, and requirements for staff to leave the school premises for other reasons (e.g. other school trips / sports matches) are all considered when looking at provision of effective support for pupils.



Supporting Pupils at school with medical conditions statutory guidance

For guidance on supporting pupils in Northern Ireland, Scotland and Wales, please see **pages 38-41**

Teacher

- Be fully aware of the contents of the IHP for your student.
- Ensure you treat each student as an individual.
- Understand and recognise the symptoms of adrenal crisis. Understand that confusion and fatigue are symptoms of adrenal crisis and be alert that this might present as behavioural changes.
- Facilitate the prevention of adrenal crisis through supporting timely medication management by the student.
- Know how to follow the **Emergency Flowchart** on page 10. Implement the plan in a timely way; it is a time-critical scenario. **Do not hesitate to call 999 in the case of adrenal crisis, using the keywords 'adrenal crisis'.**
- Do not let a student who is feeling unwell leave the class on their own to get support.
- Know who the members of staff, or others, are who are trained/competent to administer an emergency injection.
- If the student is absent due to medical appointments or being unwell, support them to 'catch up' by discussing what will work best with them and their parents/guardian.
- Where you notice ongoing changes in a student's concentration or stamina, it might suggest a need for a change in their replacement medication regimen, so it should be discussed with their parents/guardian.
- Where you suspect that a self-administering student may be skipping their medication during the school day, you should discuss this with their parents/guardian.

School nurse/first aider

In line with the Department of Education statutory guidance: 'Supporting Pupils at school with medical conditions'[3], your role is to offer direct support to the student with adrenal insufficiency, and to help the school to support and look after those students.

- You should have up-to-date IHP and medical records for all students in your care with adrenal insufficiency, which should be reviewed and updated as necessary at the end of each school academic year (and the review date recorded).
- Storing and administering medication: spare glucocorticoid medication for stress/Sick Day dosing, or hydrocortisone emergency injection kits must be accessible to relevant members of staff and the student.
- Whilst it is a parental responsibility to provide the school with medication and supplies that are in date (ideally termly), it is wise for the school nurse/first aider to also clearly keep a record of expiry dates and alert the family if they are close to the expiry date so further medication can be ordered.
- If not already confident and competent to administer an emergency injection, it may be that you are able to liaise with the family/carer of the young person to seek/receive training.
- You should be confident to implement the **Emergency Flowchart** on page 10 and record your actions accordingly. You should follow it to act to prevent adrenal crisis and **without hesitation, call 999 for emergency care support, using the keywords 'adrenal crisis'.**
- Depending on local arrangements and your level of confidence and competence, you may choose to be involved in assisting the organisation of awareness training for other staff.

Special Educational Needs and Disabilities Coordinator (SENDCO)

SENDCOs oversee the implementation of the UK's 'Special Educational Needs and Disability (SEND) Code of Practice: 0-25 years coordinate support, and liaise with external parties.

If the student has an Education, Health and Care Plan (EHCP) then this must be linked to in their IHP, so that there is recognition of how their medical conditions may affect their learning.

The SENDCO is often responsible for inclusion; ensuring that a student with adrenal insufficiency is not excluded from any part of school life as a result of their condition.

This may include:

- Ensuring they are not sent home unnecessarily.
- Ensuring that they can take part in PE and all other lessons.
- Ensuring that they can attend school trips and take part in extra-curricular activities, without it being necessary for a parent or carer to accompany them.
- Providing the young person with appropriate emotional or mental health support to enable their confidence in the school environment.

The SENDCO will likely need to work together with the young person's medical team as a key communicator and advocate of the young person's needs.

> **"I work within a large secondary school SEND department. We offer students who do not feel confident about asking for help a personal passport, which is worded by the young person and attached to the inside cover of their planner. This explains their current needs and the ways the teacher can help them overcome their difficulties within the classroom. When necessary, they can just hand over their planner for the teacher to read at the beginning of the lesson.**
>
> Hilary

4 Parent/Guardian Roles and Responsibilities

Parent/Guardian Roles and Responsibilities

It is natural for family members/carers of a young person with adrenal insufficiency to have concerns about how they will be supported. As a parent/guardian, you are likely to know them best, and it is important that, alongside them, you are central to creating a support system that you are confident will meet their individual needs.

All mainstream UK schools are expected to provide a range of support for children with identified additional needs, at the level the child needs, when they need it. A young person who is defined as having a disability under the Equality Act 2010 (which includes Addison's and adrenal insufficiency) has a legal right to reasonable adjustments.

Support is based on the needs of the young person concerned. As a parent or guardian, you are in a key position to be able to help ensure the best support at secondary school. You will need to work closely with your young person, their healthcare team and the school to ensure joined up communication.

There are some specific roles you need to undertake:

- **Ensuring the school are aware of your young person's diagnosis** as soon as possible and the need for an Individual Healthcare Plan (IHP). If your young person is moving school, ensure you share the information with the new school as soon as their place has been accepted.
- **Meeting with the school to develop an IHP** (see page 12). Before the meeting, ask to see any medical policies that the school has (usually available on the school's website). Make notes to plan the meeting. You can use the ADSHG IHP template, or the school may want to use their own template, which is fine as long as it covers the right information. Make sure you know who is writing up notes and the IHP, how often it will be reviewed, and who it will be distributed to.
- **Become familiar with your legal rights**, which vary slightly depending on which UK country you are in (see page 37 for the section on Statutory guidance).
- **Consent for medication:** You will need to provide written consent to the school for them to be able to give prescription medicine to your young person.
- **Ensuring that medication and injection materials kept at the school are replenished when they reach their expiry date.** Medicines you provide to the school must be in-date, labelled and provided in the original container as dispensed by a pharmacist, and include instructions for administration, dosage and storage. You may want to agree with the school an exception to this in relation to storage of an emergency injection kit. You may want to agree with the school that all stored medication and kits will be sent home at the end of each academic term for checking and replenishing.
- **Training and supporting members of school staff to understand the individual needs of your young person.** It is likely that your young person's endocrine nursing team will not be able to provide emergency injection training to school staff on the school site due to low resources, high school staff turnover, and timetabling issues. You will want to explore the topic of emergency injection training with the school, and where you are able to do so, support staff training and awareness. Whilst staff training is not mandatory, it is essential that staff are aware and able to implement the Emergency Flowchart.
- **Communicate regularly and honestly with the school** to ensure joined up care for your young person. This may mean using a log book to note down anything that has happened of relevance on a daily basis, or agreeing to send an email to your young person's tutor if there is information to share that could impact on their time at school and how best to manage their health.
- **Be available:** You, or another nominated adult, need to be contactable at all times.
- **Offer consistency during transition from one school to another:** If your young person is moving from one school to another, and has already had an IHP at their first school, you can use this as a basis for developing a new IHP at the new school. The new school is responsible for scheduling an IHP meeting with your young person, you, and any relevant healthcare professional.

Indiviual Healthcare Plan (IHP) template

Making a complaint

There are countless examples of best practice in schools across the UK, but there are also scenarios where things don't go to plan. Often these will be down to inadequate communication or planning.

Working through and sharing this leaflet as well as using our templates as a guide will help reduce this risk. School staff might just not understand what they need to do differently, so it is important to be clear about your concerns before taking any formal action.

However, it is important that you know what steps to take if you do need to address a complaint about the care of your young person in school.

1. Share your concerns informally with a relevant staff member: This may be your young person's tutor, head of year or SENDCO. Often the first step is a face-to-face conversation. This can be followed up by putting your concerns in writing to the most appropriate party. If unresolved, escalate it to the headteacher.
2. Follow the school's complaints procedure. If unresolved through direct communication with the parties involved in the complaints procedure, then you may choose to escalate your complaint to the school's governing body.

If the issue involves Disability Discrimination: If you believe the school has discriminated against your young person due to their disability, you can:

- First follow the suggestions above and the school's complaints process.
- If unresolved, you may choose to submit a formal complaint to the Special Educational Needs and Disability (SEND) Tribunal. To do this, you need to be a parent or carer of the young person. The complaint should be about a school or pupil referral unit maintained by a local authority, or an academy free school.

What you can complain about:

- Exclusion due to disability.
- Failure to make reasonable adjustments.
- Lack of support for special educational needs.

Note that you must complain within 6 months of the discrimination occurring. However, related past events may be included if they form part of an ongoing issue.

GOV.UK SEND tribunal

To submit a complaint to the SEND Tribunal:

- Use Form SEND4A (for parents) or SEND4B (for young people).
- Include up to 5 witnesses if relevant.
- Contact details:
  Email: **sendistqueries@justice.gov.uk**
  Phone: **0300 303 5857**

You can find the full guide and forms on GOV.UK's SEND Tribunal page.

Making a formal complaint to the Department for Education: This should only occur if it comes within scope of section 496/497 of the Education Act 1996 and after other attempts at resolution have been exhausted. In the case of academies, it will be relevant to consider whether the academy has breached the terms of its Funding Agreement or failed to comply with any other legal obligation placed on it.

Getting support:

It can be very upsetting to feel that your young person isn't getting the right care or support at school. We know that it can be hard to make your voice heard. ADSHG members may find it helpful to use our member forum to explore how other parents have managed under similar circumstances, to share ideas and to be understood (**www.addisonsdisease.org.uk/online-forum**).

Free Help and Advice

- IPSEA (Independent Provider of Special Education Advice): Offers legal guides and template letters on IPSEA's support page.
- IASS (Information, Advice and Support Services Network): Local services offering free support.
- Legal Aid: May be available depending on your circumstances.

PARENT/GUARDIAN ROLES AND RESPONSIBILITIES

Statutory Requirements

Different UK nations have different legislation governing looking after children with medical conditions at school. The main pieces of legislation are covered here, with signposting for more information. Please be aware that legislation does evolve and change and this information is NOT evergreen.

England

'Supporting Pupils at School with Medical Conditions' provides statutory guidance for governing bodies of maintained schools, proprietors of academies and managing committees of pupil referral units in England. The guidance falls under **Section 100 of the Children and Families Act (2014)**.

Children with adrenal insufficiency, including Addison's disease, are covered under this act, and its statutory guidance.

The key points from the statutory guidance are:

- Pupils at school with medical conditions should be properly supported to have full access to education, including school trips and physical education.
- Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions.
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported.

The guidance specifies what policies should include and Section 14 relates to what might be included on an Individual Healthcare Plan (IHP). Section 21 relates to the Managing of Medicines on School premises and specifies that children should know where their medicines are at all times and be able to access them immediately.

Where relevant, they should know who holds the key to the storage facility. Whilst emergency hydrocortisone injections are not quoted, it states that, "*Medicines and devices such as asthma inhalers, blood glucose testing meters and adrenaline pens should be always readily available to children and not locked away. This is particularly important to consider when outside of school premises, e.g. on school trips*".

Supporting Pupils at school with medical conditions statutory guidance

As well as including statutory guidance, this document presents non-statutory, pragmatic advice and is well worth reading.

There are several other pieces of relevant legislation:

1. **The Education Act (2002)**

   Sections 21 and 175 of the Education Act 2002 detail how governing bodies of maintained schools must support the wellbeing of students and take responsibility for the safeguarding of children at the school.

2. **Section 3 of the Children Act (1989)**

   Places a duty on any person who looks after a child to do everything reasonable in the circumstances for safeguarding. This relates to knowing what to do in an emergency, such as an adrenal crisis.

3. **Legal duties on local authorities**

   Local authorities have legal requirements to help make sure schools can support a child with adrenal insufficiency, including Addison's successfully. The requirements of local authorities refer to all children in the local authority, and they do not depend on the kind of school the child attends.

4. **Children Act (2004)**

   Section 10: If schools are struggling to get the support and training they need to allow them to look after a child with adrenal insufficiency properly, this section of the Children Act is relevant. It establishes a duty for the local authority to encourage collaboration between the authority and relevant partners.

   These may include the governing body of a maintained school, the proprietor of an academy, clinical commissioning groups and the NHS Commissioning Board. They must make arrangements to improve the wellbeing of children, including their physical and mental health, ensure protection from harm and neglect, and education. If a school cannot get the support it needs to look after a child with Addison's or another form of adrenal insufficiency, then they must approach their local authority for support.

   Section 17: places a duty on children's services to provide help and support to a child in need, safeguarding the child and promoting their welfare. This duty extends to providing help to their family where needed, including financial assistance or housing. If a school is looking after a child with adrenal insufficiency inadequately, which is putting the child in danger, the local authority must step in.

5. **Special educational needs and disability code of practice: 0-25 years**: statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities (Jan 2015, updated Sept 2024)

   The SEND Code of Practice: 0-25 years[4] sets out statutory guidance for identifying, assessing, and supporting children and young people with special educational needs and disabilities in England. It ensures they receive tailored support across education, health, and care to help them achieve the best possible outcomes and prepare for adulthood.

   The key principles in relation to secondary school-aged children are:

   - **Early identification of SEND needs and support:** Teachers are responsible for identifying pupils who may need additional help and adapting teaching accordingly.
   - **Graduated approach:** Support follows a 4-part cycle: Assess - Plan - Do - Review. SEND support should be regularly reviewed and refined based on outcomes.
   - **Pupil and parent/guardian involvement:** Young people aged 16+ have the right to make decisions about their support. From age 11, pupils should be involved in discussions about their learning and support needs. Schools must work in partnership with families and guardians throughout.
   - **Education, Health & Care Plans (EHCPs):** If SEND support is not sufficient, an EHCP may be requested. EHCPs outline the child's needs, desired outcomes and provision required. Secondary schools must help prepare pupils with EHCPs for adulthood, including employment, independent living and participation in society.
   - **Transition Planning: From year 9 (age 13-14):** EHCP reviews must include a focus on preparing for adulthood. This includes planning for further education, training, employment and independent living.
   - **Inclusive Education:** Schools must ensure pupils with SEND are fully included in mainstream education unless a specialist setting is deemed necessary. Reasonable adjustments must be made under the Equality Act 2010 to avoid discrimination.
   - **SENDCO Role:** Every school must have a qualified SENDCO to oversee the implementation of the Code, coordinate support, and liaise with external agencies.
   - **Access to Impartial Advice:** Young people and their families or carers must have access to impartial information, advice, and support services. Local authorities must provide a local offer detailing available SEND services.

Special Educational Needs and Disability Code of Practice

Northern Ireland

Special Educational Needs and Disability Act (N.Ireland) 2016

The SEND Act (NI) 2016 is part of the Special Educational Needs (SEN) Framework and reforms how schools, the Education Authority (EA), and health bodies identify, assess, and support pupils with SEN. It also strengthens the rights of children–particularly those of compulsory school age and above.

1. SEND Order 2016 requires secondary schools to appoint an LSC (Learning Support Co-ordinator), which replaces the SENCO role. The LSC is responsible for coordinating SEN provision, ensuring interventions happen, and supporting staff.
2. Schools must create and review a Personal Learning Plan (PLP) for every pupil identified with SEN and transfer the PLP when a pupil moves school (with consent). The PLP should support transitions between subject teachers, key stages, and qualifications.
3. The Act reduces statutory time limits for the completion of SEN assessments by the EA, to give earlier support and reduce waiting times for secondary pupils with learning or health barriers.
4. EA and Health & Social Care Trusts must cooperate to identify, assess and provide SEN-related support and services, producing joint plans to help deliver co-ordinated support, with obvious benefits for young people with medical needs.
5. Young people (generally 16+) gain new legal rights to participate directly in decisions about their SEN, which impacts particularly at transition points eg when making GCSE choices or deciding what happens post 16 years old, including:
   - A legal right to express their views in decisions about SEN provision.
   - Rights in their own name, rather than those rights belonging only to their parents.
   - The EA must seek and have regard to the views of the child, as far as reasonably practicable.
6. The Act emphasises the importance of young people taking part in decisions about their SEN and ensuring that they receive information and support to participate meaningfully.

In addition to the above points which focus on the young person, are the following:

- The EA must consult on and publish an annual plan outlining how SEN provision will be delivered regionally.
- The Act includes expanded rights for appeals against decisions not to amend a statement and rights for young people (16+) to appeal in their own name.

Finally, it also puts a duty on the Boards of Governors in secondary schools to ensure that SEN provision is effective and appropriately resourced, including appointing the LSC and overseeing the implementation of a SEN policy.

Dispute Avoidance and Resolution Service (DARS)

If a parent/guardian is unhappy about the treatment of their child in school, they can contact the Dispute Avoidance and Resolution Service (DARS) which was established as an independent, confidential, voluntary and informal service. It is independent of the Special Education section, and there is a DARS contact in each Education and Library Board.

Special Educational Needs and Disability Act (Northern Ireland) 2016

Dispute Avoidance and Resolution Service (DARS)

Scotland

Relevant legislation includes:

- Children and Young Person (Scotland) Act 2014
- NHS (Scotland) Act 1978
- The Functions of Health Boards (Scotland) Order 1991
- The Education (Disability Strategies and Pupils' Educational Records (Scotland) Act (2002)
- Standards in Scotland's Schools etc Act 2000
- Education (Scotland) Act 1980 and the Education (Additional Support for Learning) (Scotland) Act 2004 (Additional support for learning: Key facts - Enquire)

The last of these are the most current and relevant for parents of young people with adrenal insufficiency at school.

Education (Additional Support for Learning) (Scotland) Act 2004 (as amended by the 2009 Act)

This places duties on education authorities to identify, meet and keep under review, the additional support needs of all pupils for whom they are responsible, including pupils with adrenal insufficiency. The Education (Disability Strategies and Pupils' Educational Records (Scotland) Act (2002) also places duties on bodies responsible for schools to prepare an accessibility strategy which sets out their plans to ensure access to the curriculum, physical environment of schools and school information.

The concept of 'additional support needs' applies to any child or young person who, for whatever reason, needs additional support for learning. These needs can arise from any factor which causes a barrier to learning including social, emotional, cognitive, linguistic, disability, or family and care circumstances. Issues arising from managing adrenal insufficiency while at school can count as an additional support need.

The impact will vary from young person to young person but it is how these factors impact on the individual child's learning that is important, and this will determine the level of support that is needed.

Education authorities must:

- Make enough and efficient provision for each child or young person with additional support needs, for whose education they are responsible.
- Keep under consideration the needs and the level of support for each child or young person with additional support needs.
- Take account of the additional support needs of children when providing school education generally.

Parents/guardians have the right to:

- Request the education authority to find out if their young person has additional support needs.
- Request the education authority to find out if their young person needs a Co-ordinated Support Plan, or to review an existing plan.
- Request a specific type of assessment or examination.

For more information visit **www.gov.scot/publications/supporting-children-young-people-healthcare-needs-schools**

Wales

The **Supporting Learners with Healthcare Needs** is guidance issued under the following legislation:

Education Act (2002) Section 175:

Places a duty on local authorities and governing bodies to make arrangements to ensure their functions are exercised with a view to safeguarding and promoting the welfare of children in school or another place of learning. This includes supporting children with healthcare needs. In meeting the duties under section 175 of the Education Act 2002, local authorities and governing bodies must have regard to guidance issued by the Welsh Ministers under this section.

Section 21(5):

Places a duty on governing bodies to promote the wellbeing of learners at the school so far as related to the matters mentioned in section 25[(2)] of the Children Act 2004, which includes physical and mental health and emotional well being, education, training and recreation, and social wellbeing.

Key points

- Learners with healthcare needs should be properly supported to have full access to education, including trips and physical education.
- Governing bodies must ensure that arrangements are in place to support learners with healthcare needs.
- Governing bodies should ensure that education setting staff consult the relevant professionals, learners and parents to ensure the needs of the learner with healthcare needs are properly understood and effectively supported.

Section 2.7 notes guidance as regards emergency procedures, such as an adrenal crisis:

- Governing bodies should ensure a policy is in place for handling emergency situations.
- Staff should know who is responsible for the policy, nominated first aiders and how to deal with common healthcare needs.
- In situations requiring emergency assistance, 999 should be called immediately.
- The location of learners' healthcare records and emergency contact details should be known to staff.
- Where a learner has an IHP, this should clearly define what constitutes an emergency and explain what to do.
- Staff should be made aware of emergency symptoms and procedures.
- Other learners in the education setting should also know what to do in general terms in an emergency, such as informing a member of staff immediately.
- If a learner needs to be taken to hospital, a staff member should stay with the learner until a parent arrives. This includes accompanying them in an ambulance to hospital. The member of staff should have details of any known healthcare needs and medication.

Section 2.8 relates to Staff Training and pertinent points relating to a child with adrenal insufficiency are:

- Where an IHP reflects complex needs requiring staff to have specific training (such as injection administration), that healthcare professionals can be asked to provide advice suitable for education settings as well as learners and families.
- Training should be sufficient to ensure staff are competent, have confidence in their ability to support learners and fulfil IHP requirements. Crucially, this training should involve input from the learner and parents.
- All staff, irrespective of whether they have volunteered to assist or support learners with healthcare needs, may come into contact with learners who have healthcare needs. New and temporary staff should especially be made aware of what preventative and emergency measures are in place so staff can recognise the need for intervention and react quickly.
- If the trained staff who are usually responsible for administering medication are not available, the IHP should set out alternative arrangements. This also needs to be addressed in risk assessment and planning of off-site activities.

5 For Students

For Students

In this resource pack we have aimed to include factual information that will help you, your family or carers and your school best support you to manage your condition while you are at secondary school. However, you and your needs are individual, and every school is slightly different, so you may need to use this pack as a guide, and then 'tweak it' to fit your situation better.

There will inevitably be a lot for you to think about relating to managing your condition during the school day and it might be helpful to hear what other students have shared:

> **I am 17 years old and have been diagnosed for a year and 4 months. At first I found school very tough but I'm handling it well at the moment. At first I had trouble with my grades and I had days where I just cried and didn't know what to do. Since then, I've had exams which I coped well with, due to the help of my teachers. I had brain fog at the beginning and had trouble learning things, but it all gets better after a while.**
>
> Isobel, ADSHG member

Student top tips

- Communicate your needs - if you get tired easily, make sure that you let your school know. They need to meet your needs, but can only do that if you talk to them. If they won't listen, don't understand or need 'evidence', ask your medical professional to back you up.
- Bring packets of something salty to school with you so you have it to hand if you need it. Your school record (IHP) needs to say that you are allowed to have access to snacks and/or drinks in lessons in case you need them. Sometimes it's easiest to remind teachers at the beginning of a lesson so they don't say anything!
- You will have good and bad days (flare-ups) and sometimes you won't know why! It can go from easy to frustrating, infuriating and upsetting. At times you'll cope really well; at others you won't. Be kind to yourself – you're only human.
- Your medication is like food and water! You are giving your body what it needs naturally each day and more when it needs it.
- Try to acknowledge privately and publicly that it's difficult, but also that you have the strength to handle it.
- Try to work out a relationship with your adrenal insufficiency. It may feel like it takes up a lot of your life, but you are still "you", a person with passions and dreams, even when unwell.
- Growing up is tough enough, and you're dealing with more than the average young person, so make sure to give yourself credit!
- It can help to practise an answer to questions like, "why do you have pills?" or "what do you have needles for?", so if you're asked by people who don't know you when you're out and about, you can reply easily, quickly and with confidence so it doesn't seem like a big deal.
- If you feel you can, show your friends your medication and injection kit. They could even practise injecting into an orange! Your friends will learn life-saving skills that could help more people than just you.
- If you're staying up late to study or pushing the boundaries socially, make sure to factor in your steroid dosing and health the next day.
- Remember that lots of people live with 'invisible conditions', such as Type 1 Diabetes and are told, "*but you don't look sick*". Your condition may be rare, but you're part of a strong community.

FAQs

Q: Should I share my health information with friends?

A: This really is your choice, and what matters most is what makes you feel comfortable and safe. Some people find it helpful to tell their friends, especially if those friends might notice you needing medication or a break sometimes. It can make things feel easier because they understand what's going on and can look out for you if you're not feeling great.

You can always start small by telling one person you trust, or keep it simple with something like, "*I've got a medical condition, so I need to take medication throughout the day. It's replacing what my body doesn't naturally make anymore.*" You don't have to explain everything, but you can practice how you would explain it to people so you feel more comfortable.

Q: How should I carry my meds?

A: There are some great different pill pot options on the internet as well as the ADSHG website. Have a search and get something you like, so you won't mind always having it with you.

This can range from a weekly pill box, with a morning, lunchtime and afternoon section for each day, and you put your tablets into this at the start of the week. Then you can also have a smaller pill pot (such as the ADSHG "pill pocket") which you keep in your bag with extra steroid tablets in it, so you can updose if needed. These pill pots can be handy if you're splitting pills (from 10 mg to 5 mg for example) as you have a pot to store the other half! Or you can keep a spare blister pack of medication in your bag too.

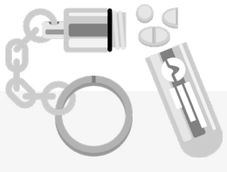
Q: Is my condition going to stop me going on to further education? Will it impact my career options?

A: Having adrenal insufficiency, including Addison's, doesn't mean you can't go on to college, university, or do the career you want. You may just need to plan a bit more for time off, medical appointments, or extra support. Jobs that are very physically demanding might need extra checks, as might jobs in extreme environments, but there are lots of careers where you can succeed. Being open with teachers or employers about your needs can make a big difference, and with the right support, your condition shouldn't stop you reaching your goals.

Visit **www.addisonsdisease.org.uk/famous-lives** to read about celebrities, sportspeople and politicians who have lived with adrenal insufficiency, including Addison's to gain insight and inspiration!

Q: Do I need to have my emergency injection kit with me all the time?

A: Yes, even if you feel fine because you never know when accidents or illness might happen. Having it with you means you can treat an adrenal crisis straight away. Think of it like a safety tool, better to have it and not need it than need it and not have it. Having your kit ready usually means you're treated faster, which can cut down hospital time and help you get back to normal sooner.



Keyring Pill Pot

Injection Kits

More helpful kits from ADSHG Shop

References & Resources

(1) British Society for Paediatric Endocrinology and Diabetes (BSPED) Adrenal Insufficiency Consensus Guidelines

(2) NICE Guidelines for the Identification and Management of Adrenal Insufficiency (NG243) Aug 2024

(3) Supporting Pupils at School with Medical Conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England (Dec 2015). Department for Education.

(4) SEND code of practice: 0 to 25 years: Guidance on the special educational needs and disability (SEND) system for children and young people aged 0 to 25 (updated Sept 2024). Department for Education and Department of Health & Social Care.

Resources

Addison's Disease Self-Help Group (ADSHG):
Supports all those affected by adrenal inusfficiency, including Addison's disease.
www.addisonsdisease.org.uk

ADSHG Young Person's page:
For resources aimed at young people with adrenal insufficiency.
www.addisonsdisease.org.uk/young-adults-addisons

ADSHG Online Shop:
Products to purchase online that help you manage your adrenal insufficiency, including Addison's disease, by being prepared and being understood. Shop hospital folders, to medical ID jewellery, to emergency injection and injection training kits.
www.addisonsdisease.org.uk/shop

Citizens Advice Bureau:
Online free advice from Citizens Advice to help you find a way forward, whatever the problem.
www.citizensadvice.org.uk

Cortisol deficiency | Great Ormond Street Hospital
www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/cortisol-deficiency

Department for Education: Schools - Statutory Guidance:
Setting out what schools and local authorities must do to comply with the law.
www.gov.uk/government/collections/statutory-guidance-schools

Equality Advisory Support Service:
Information and advice about discrimination and human rights issues.
www.equalityadvisoryservice.com

GOV.UK's SEND Tribunal page
www.gov.uk/children-with-special-educational-needs

Health Conditions in School Alliance:
Making sure that children with health conditions get the support they need.
www.healthconditionsinschools.org.uk

Independent Provider of Special Education Advice (IPSEA):
Taking action when things go wrong at nursery, school or college.
www.ipsea.org.uk

NHS - Addison's disease:
NHS information on Addison's disease.
www.nhs.uk/conditions/addisons-disease

Rareminds Wellbeing Hub:
Resources and information to help you live as well as possible with your rare condition.
resourceshub.rarebeacon.org/courses/wellbeing-hub

Qualifications Scotland Examination Exceptional Circumstances Consideration Service (EECCS)
www.sqa.org.uk/sqa/109851.html

Society for Endocrinology (SfE): Adrenal Crisis Information.
www.endocrinology.org/clinical-practice/clinical-guidance/adrenal-crisis

Patient Support Groups offering support for young people with adrenal insufficiency

Addison's Disease Self-Help Group (ADSHG):
UK charity supporting people affected by Addison's disease and adrenal insufficiency and raising awareness with healthcare professionals to save lives.

AlexTLC:
Alex TLC provides invaluable support and information to people affected by leukodystrophy.

Duchenne UK:
UK charity for Duchenne muscular dystrophy.

Living with CAH:
UK charity supporting people with congenital adrenal hyperplasia and their families and friends

MIND: Mental Health Charity. Information, support and campaigning for people with mental health problems.

Muscular Dystrophy UK:
Connecting the community of people living with muscular dystrophy.

Pituitary Foundation:
UK charity supporting everyone in the pituitary community, every step of the way.

SCOPE:
Campaigning to transform attitudes to disability, tackle injustice and inspire action. We create opportunities and provide information and support that empowers.

Glossary

AD: Addison's disease

ADSHG: Addison's Disease Self-Help Group

BSPED: British Society for Paediatric Endocrinology & Diabetes

DHEA: Dehydroepiandrosterone (glucocorticoid hormone produced by the adrenal gland)

DofE: Duke of Edinburgh Award

EA: Education Authority

EHCP: Educational Health and Care Plan

GP: General Practitioner

IHP: Individual Healthcare Plan

LSC: Learning Support Co-ordinator

NOK: Next of Kin

PAI: Primary adrenal insufficiency

PEAR: Pupils Educationally At Risk

PLP: Personal Learning Plan

SAI: Secondary adrenal insufficiency

SEND: Special Educational Needs and DIsability

SENDCO: Special Educational Needs and Disabilities Coordinator

TAI: Tertiary adrenal insufficiency

RESOURCES AND REFERENCES

Scan for Surgical Guidelines

Scan for Adrenal Crisis Guidelines

Scan for Sick Day Rules

Scan for School Trip Record & IHP template

Scan for Adrenal Insufficiency Action Plan

Scan for Emergency Injection Video

Scan for ADSHG online shop

Scan for BSPED Guidelines

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

The Addison's Disease Self-Help Group works to support people with adrenal insufficiency, including Addison's disease, 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 a working group consisting of the ADSHG, parents, teachers and paediatric and endocrine health experts.

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