Adrenal Insufficiency Support Pack

Name: .....

Date of birth: .....

Your photo here

MEDICAL ALERT

ADRENAL INSUFFICIENCY

Steroid dependent

Emergency contact details:

Name: .....

Phone number: .....

Name: .....

Phone number: .....

Child Growth Foundation


Child
Growth
Foundation

Adrenal Insufficiency Support Pack

The purpose of this folder is to help keep you safe with Adrenal Insufficiency.

It has information and awareness tools, that have been created by the Child Growth Foundation and other agencies.

The contents of this pack can help you explain to others how and why you may need some support. If you run out of any of the information, please get in touch with us for replacements.

Please complete your personal details and add your individualised care plans (as described below) given to you by your Endocrinologist/Endocrine Nurse.

Contents of this booklet:

- What is Adrenal Insufficiency
- BSPED Adrenal Insufficiency Card
- Great Ormond Street Hospital (GOSH) Leaflet* - How to give an emergency injection of Hydrocortisone
- Sick day rules flow sheet for parents and carers
- Replacement Hydrocortisone therapy flow sheet for schools
- Transition to Adult Care Tips
- Information for ambulance crew

Please add:

- Individualised Care Plans given to you by your Endocrine Team

Awareness tools enclosed in folder:

- 'Emergency Medicine Inside' Sticker
- Medical Alert Stickers
- Medical Alert Keyring

**Some centres may or may not teach slightly different techniques to patients , parents and carers from what is described in these instructions such as advising to give the injection through clothing. GOSH has kindly provided these instructions as a general guide, please follow the techniques taught to you by your health care team and discuss any concerns or questions with them.*

What is Adrenal Insufficiency?

Adrenal Insufficiency is a condition where there is inadequate release or action of the hormones: glucocorticoids, mainly the steroid hormone called cortisol.

Children with Adrenal Insufficiency require cortisol replacement therapy daily. At times of physiological stress, such as illness, trauma or surgery, there is an increased requirement of this replacement therapy, which left untreated can lead to adrenal crisis. Without prompt treatment, adrenal crisis is life threatening.

Children with adrenal insufficiency are typically given hydrocortisone as steroid replacement therapy. For patients on hydrocortisone steroid therapy, educating them, their families, and carers about times of illness or stress, usually called sick day dose/rules, is important in preventing adrenal crises. Sick day dose/rules are sometimes called stress day dose/rules, they mean the same thing.

What causes Adrenal Insufficiency?

Adrenal insufficiency can be classified into three categories:

Primary:

Results from the dysfunction of the adrenal glands. Causes of this dysfunction could be conditions such as Congenital Adrenal Hypo/Hyperplasia, Addisons disease, other autoimmune conditions, adrenoleukodystrophy, tumours, infections, bleeding, removal of the adrenal glands, the individual taking medication that disrupts steroid production.

Secondary and tertiary:

This type of adrenal insufficiency is a result of the dysfunction of either the pituitary gland **(secondary)** or hypothalamus **(tertiary)** such as hypopituitarism, pituitary and hypothalamic tumours, radiation or surgery to the pituitary gland/brain, long term steroid use to treat other diseases.

Management and guidelines for Adrenal Insufficiency

The British Society for Paediatric Endocrinology & Diabetes (BSPED) provides up to date guidance on management protocols for health care professionals managing patients with Adrenal Insufficiency.

Please scan this QR code through your smartphone camera for the BSPED Adrenal Insufficiency Consensus Guidelines:



British Society for Paediatric Endocrinology and Diabetes: Adrenal Insufficiency Card

PAEDIATRIC STEROID CARE PLAN FOR SICK DAYS AND EMERGENCIES

IMPORTANT MEDICAL INFORMATION FOR PARENTS/CARERS & HEALTHCARE STAFF

This patient has adrenal insufficiency and is steroid dependent. Steroids should never be missed. Any stress situation, such as illness or surgery will require additional treatment

Name	**Address**
DOB	
NHS / CHI Number	
GP Contact Details	**Next of Kin Contact Details**
Paediatric Lead Consultant & Hospital	**Paediatric Endocrine Team Contact Details**
Diagnosis	**Date of Issue**

Steroid Treatment Regimen		
Medication (and preparation) *e.g., Hydrocortisone (10mg tablet)*	Time *e.g., 6am*	Dose *e.g., 5mg (half a tablet)*

Oral sick day steroid treatment regimen in the event of an illness (See back page for more information on when this is required)		
Medication (and preparation)	Time	Dose
If patient takes fludrocortisone, no change in dose is necessary		

Emergency Steroid Injection

If they show no sign of improvement, have persistent vomiting or diarrhoea, become drowsy or unresponsive, or have had a major accident or injury give intramuscular (IM) injection of hydrocortisone immediately

Age less than 1-year:	Age 1 to 5 years:	Age 6 years and over:
25mg	50mg	100mg

Dial 999 stating they are having an ADRENAL CRISIS; they should be taken to the nearest A&E without delay

Sick days: When to give additional steroids			
Situation	**Change to usual steroid dose**	**Length of change**	**When to get help?**
Minor Illness			
Mild cold / runny nose with no fever. Minor playground bumps and bruises	No change		
Moderate or severe illness			
Fever, flu, infection, childhood illnesses (usually not well enough to go to school)	Sick day doses required	For as long as the illness lasts	Contact GP or medical team if not improving after 24-48 hours
Vomiting or diarrhoea	Sick day doses required		
	If sick day dose tolerated (kept down for at least 30 minutes with no frequent diarrhoea or vomiting), then continue oral sick day dosing		
	If sick day dose not tolerated, give IM hydrocortisone injection		Dial 999 and inform them that the patient is having an adrenal crisis
Drowsy and unresponsive	**Give IM hydrocortisone injection**		
Major trauma or severe shock (e.g., suspected fracture, road traffic accident, head injury with loss of consciousness).	**Give IM hydrocortisone injection**		
Other (discuss with medical			
Routine or travel vaccinations	Consider 1 or 2 doses of sick day steroids. Continue if symptomatic		
Long haul flight	Give usual morning dose at 6 to 8 hourly intervals		
Child or centre specific recommendations			
Surgical and dental procedures			
Minor surgery (e.g., dental extraction under local anaesthetic)	Sick day dose prior to procedure Return to usual dose immediately afterwards	Continue sick day doses for up to 24 hours if in pain or unwell	Inform medical staff including dentist and anaesthetist that you/your child have adrenal insufficiency and take steroids
Major surgery (e.g., operation requiring general anaesthetic)	Sick day steroids (oral or IV) on day of procedure even when fasting. Intravenous hydrocortisone given on induction as per local hospital protocol	As per local policy or contact treatment centre for advice	

Important information for medical emergency teams

If this patient is unwell and brought to hospital, the following management should be instituted promptly:

1. **Administer Emergency IM/IV hydrocortisone**

   Age less than 1-year 25mg
   Age 1 to 5 years 50mg
   Age 6 years and over 100mg

   (Check if this has been given by parent, caregiver, or ambulance crew)

2. Check **blood glucose**. Give 2ml/kg 10% dextrose IV if glucose <3mmol/L

3. If **circulation** is compromised, give 10 ml/kg 0.9% saline bolus

4. Obtain U&E & **start IV fluids** 0.9% Saline/5% dextrose at a maintenance rate

5. **Ongoing hydrocortisone doses**:
   - Continue with IV hydrocortisone 2mg/kg (max 100mg) every 4-6 hours (or hydrocortisone infusion if very unwell).
   - Once stable, the IV bolus dose of hydrocortisone is 1mg/kg (max 50mg) every 6 hours
   - For neonates (< 28 days) the IV bolus dose of hydrocortisone is 4mg/kg every 4-6 hours. Once stable the IV bolus dose is 2mg/kg every 6 hours.
   - Please refer to BSPED guidance for fill details.

6. Once tolerating oral fluids, swap to oral sick day dosing until back to normal self (usually 2-3 days of sick day dosing).

Important: Please observe until patient is tolerating oral steroids at sick day dosing. Contact your acute paediatric or paediatric endocrine team if admission is required.

If the patient needs a **general anaesthetic or surgery,** please contact the paediatric endocrine team for a perioperative plan.

The recommended doses for hydrocortisone can also be found on the BSPED website below.

For further information scan the **QR code** or visit **website** to see BSPED guidance:

https://www.bsped.org.uk/adrenal-insufficiency

NHS

How to give an emergency injection of Hydrocortisone 100mg Powder
(hydrocortisone sodium succinate)

Information for families

Great Ormond Street Hospital for Children NHS Foundation Trust
University College London Hospitals NHS Trust

How to give an emergency injection of Hydrocortisone

1



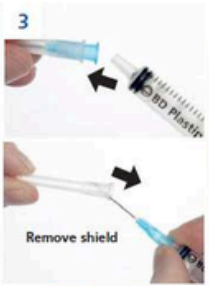
Equipment

2



Open WFI and Hydrocortisone

3



Attach needle and syringe

4



Draw up 1ml water

5



Remove air

6



Add to Hydrocortisone

7



Mix gently

8



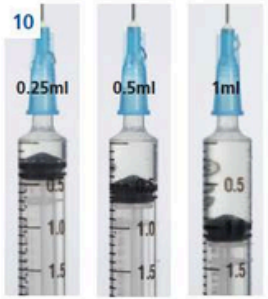
Withdraw dose

9



Remove air

10



Dose Under 1yr = 25mgs

Dose 1-5 yrs = 50mgs

Dose 6+ yrs = 100mgs

11



Find site

12



Give medication

Emergency advice from Great Ormond Street Hospital

Tel: 020 7405 9200 and ask for the endocrine registrar on call (24 hours)

999 child is having an ADRENAL CRISIS

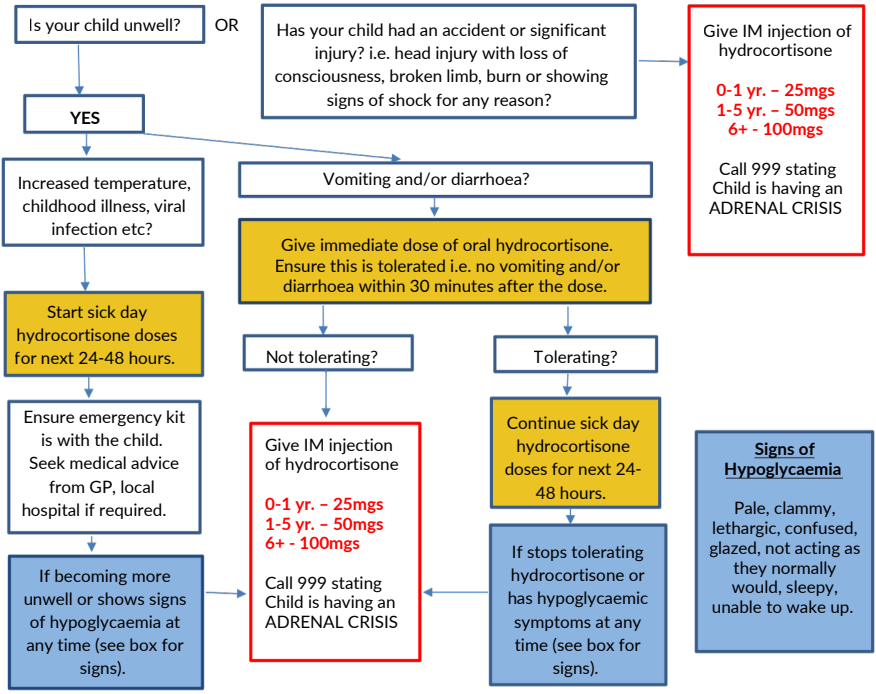
Emergency advice from University College London Hospital

Tel: 0845 155 5000 and ask for the paediatric endocrine registrar on call (24 hours)

Sick day rules flow sheet for parents and carers

Child's name			**Consultant**	
Date of birth				
Daily Maintenance Hydrocortisone dose	**Time**	**Dose**	Hydrocortisone doses when **unwell** To be given at the following times:	mg

NB: A sick day dose should be given at the point of ..... becoming unwell even if the dose is not due.
Subsequent sick day doses can be given at the prescribed times/ every 6 hours.



If at any stage you become concerned about your child becoming unwell, please see your GP, or speak to your medical team. If signs of adrenal crisis call 999 for an ambulance to take your child to the nearest accident and emergency department.

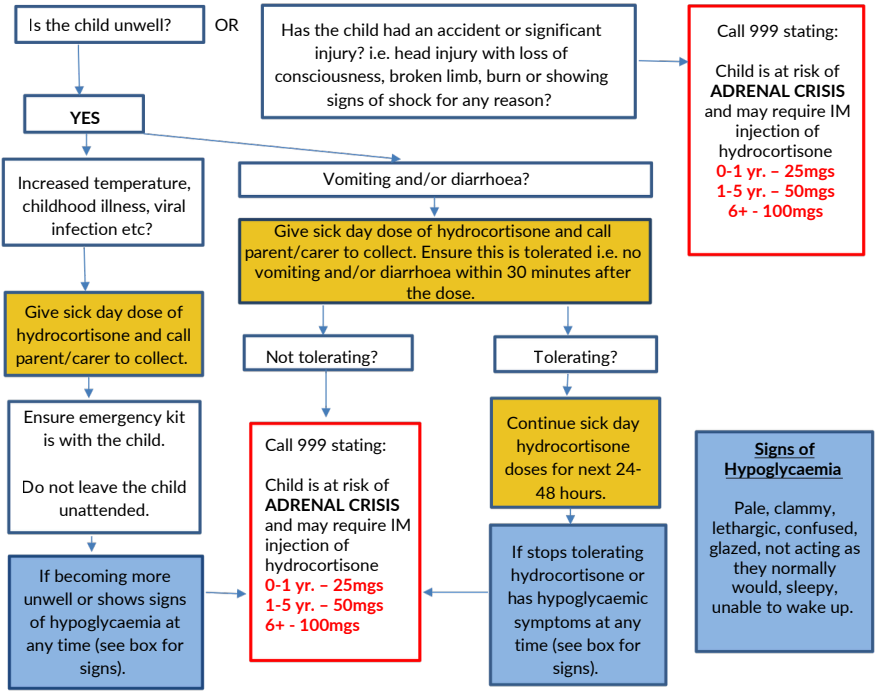
Always state your child is on steroids and take this flow sheet with you to show the medical and nursing teams.

Adapted for use with kind permission of Great Ormond Street Hospital, Endocrine Clinical Nurse Specialists Team

Replacement Hydrocortisone Therapy flow sheet for schools

Child's name			**Consultant**	
Date of birth				
Daily Maintenance Hydrocortisone dose	**Time**	**Dose**	'Sick Day' Hydrocortisone dose	mg

NB: A sick day dose should be given at the point of ..... becoming unwell, even if a dose is not due. Parents/carers should be notified of the time it was given so they can continue sick day doses 6 hourly.

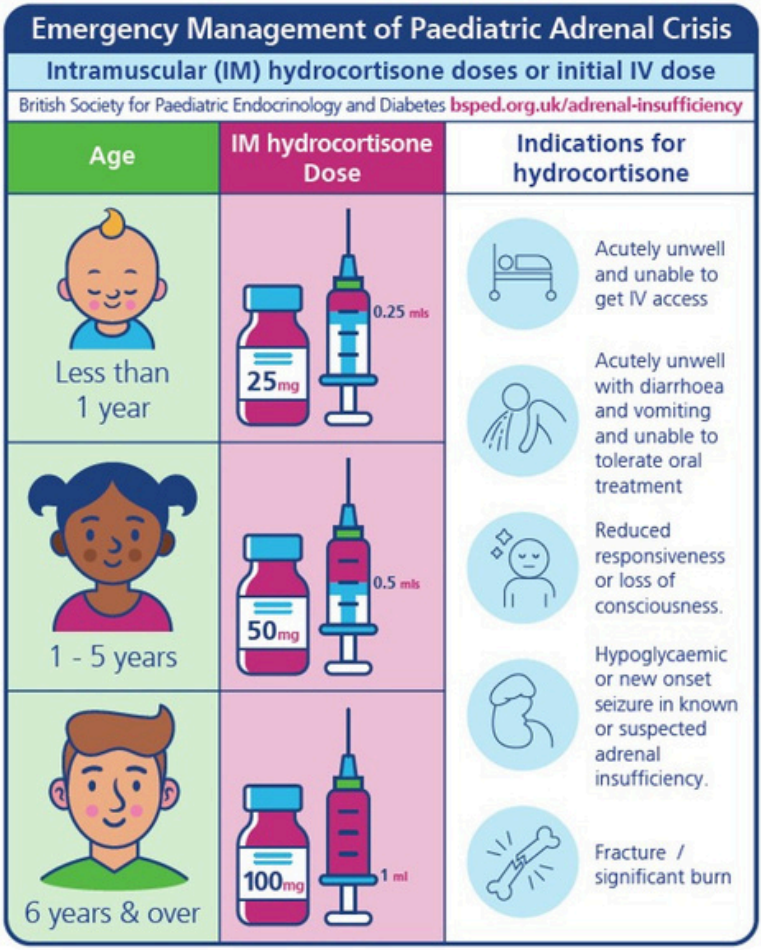


If at any stage you become concerned about the child becoming more unwell, or they have had a significant accident or injury, please call 999 for an ambulance to take them to the emergency department.

Always state the child is on steroids and take this flow sheet with you to show the medical and nursing teams.

Adapted for use with kind permission of Great Ormond Street Hospital, Endocrine Clinical Nurse Specialists Team

Information for Ambulance Crew



FAO PARAMEDICS - The JRCALC drug protocol for hydrocortisone allows paramedics to give IM hydrocortisone to patients when needed, please access the protocol via your personal login, or scan here:

Transition to Adult Care Tips

- Talk to your family, nurse or doctor when you feel ready to learn more about your condition.
- It is good to ask lots of questions to make sure you understand how to keep yourself safe.
- You will need to understand when and why it's so important to take increased doses of steroids (or have an intramuscular injection) at times of illness.
- The doctor or nurse will be able to show you how to give yourself an intramuscular injection. It's good to refresh your memory every now and then on how to do this; download the My Cortisol app for videos.

My Cortisol app on Google Play

My Cortisol app on iOS

- Think about ways to help remind you to take your medication every day. This could be a reminder on your phone or a pillbox kept safely somewhere in your home.
- It is up to you whether you tell your friends about your AI, but it may be helpful if someone knows so that if you become unwell when you are with them they know what to do to help.
- You will need to order your prescriptions in plenty of time, your family will be able to tell you how. If you forget, it is possible to get an emergency prescription by speaking to a doctor or pharmacist, or ringing 111. Never leave yourself without any medication at all.
- If you move away from home it is important to register at the local GP as soon as you move so that they can get you set up on their system.
- You may not need to attend as many appointments as you get older but it is still really important that you do go when you are asked to.
- Carry something with you that lets others know that you have AI in case of emergency. This could be a card in your wallet or purse, screenshot of an alert card on your phone's lock screen, jewellery or a keyring.
- Remember, if you are ever unsure ask your family or doctor for help.

Acknowledgements

Many thanks to:

Sally Tollerfield
Dr Talat Mushtaq
Jessica Watts
Great Ormond Street Hospital
British Society for Paediatric Endocrinology

Disclaimer

We have taken every care to ensure the accuracy of the information contained in this publication.

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The information enclosed should not be used as a substitute for the advice from a clinician, GP or other healthcare professional.

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Your feedback helps us to ensure we are delivering information to the highest standard. If you have any comments or suggestions, please contact us at info@childgrowthfoundation.org or on 020 8798 2139.

Funding

The CGF is an independent charity that relies entirely on the generosity of individuals, groups and organisations to continue our work. If you have found this information pack helpful, please consider becoming a member, fundraising for our charity and/or making a donation at www.childgrowthfoundation.org.

Further information

If you have any questions regarding the information contained in this booklet or would like to speak to our nursing team through our Support Line please contact:

Tel: 020 8995 0257
Email: support@childgrowthfoundation.org
Website: www.childgrowthfoundation.org/support

Publication date: March 2024
Revised: October 2026



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Charity registered in England & Wales | Charity number: 1172807 | Company number: CE010204

UGB101026V2