

Guidance on replacement and long-term therapeutic corticosteroids for steroid-dependent patients

Diabetes

This leaflet will explain several important aspects of taking steroid tablets and provide guidance on the precautions that you need to take, in terms of day-to-day life, during ill health as well as around the time of an operation. Please go through the information in the leaflet. Should you have any further queries, please feel free to contact us on the details given at the end of this document.

What are steroids?

Steroids are hormones produced by the adrenal glands under the influence of another hormone called ACTH, which is produced by the pituitary gland. The most important steroid, cortisol, plays a vital role in maintaining and regulating body functions and is essential for survival.

Inability to produce steroids may be because of the failure of either the adrenal gland to produce steroids (Addison's disease), or the pituitary gland to produce ACTH.

What is 'replacement' and 'therapeutic' use of steroids?

- Replacement steroids: Replacement steroids are required for individuals who are unable to produce the normal amount of steroids
- Therapeutic steroids: Therapeutic steroids are given to 'top-up' normal amounts of steroids produced by the body to suppress inflammation in various conditions such as asthma, rheumatoid arthritis, polymyalgia rheumatica and other inflammatory or autoimmune conditions.

What does 'long term' use of steroids mean?

The definition of what constitutes 'long term' use of steroid can vary depending on the dose and type of steroids being prescribed. However, in most situations the use of steroids, for more than 3-4 weeks duration is considered 'long-term' steroid use.

What are the types of steroids prescribed?

- Hydrocortisone is the most common steroid used for patients who require replacement steroids. It works like naturally produced cortisol, a steroid hormone we need for life
- Some patients may be prescribed other forms of steroids such as prednisolone or dexamethasone. These are longer acting steroids which are used for therapeutic reasons. The details of how to use these steroids will be provided by the clinicians who have recommended their use.

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available
- If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111
- Keep the environment clean and tidy
- Let's work together to keep infections out of our hospitals and care homes.

How should I take my steroid tablets?

- Please take your tablets every day without fail, and at the correct time of day. Please do not miss any dose if you are on replacement steroids; these are essential for life
- If you are on hydrocortisone the usual daily dose is around 20 mg, but it may be a little higher or lower in some individuals
- The dose is typically split in three doses throughout the day which should be taken as below:
 - The first dose immediately after waking up
 - The second dose at lunchtime between 12-2pm
 - The third dose should be taken between 4-5pm (taking after 6pm may disturb your sleep)
 - Always ensure that you have spare steroid tablets with you at home and always carry your medications when you go travelling.

For prednisolone and dexamethasone (“therapeutic” steroids), the doctors who prescribe these would provide further guidance on how these medications need to be taken.

What could go wrong if I do not take enough medication?

- These tablets should never be discontinued or significantly reduced without medical advice
- If you miss taking this medication, or if you do not take it regularly or in the correct dosage, you may have symptoms of weakness, nausea or loss of appetite. You can also become acutely ill with an adrenal crisis
- Adrenal crisis is a state of acute cortisol deficiency. Warning signs include: severe nausea, headache, dizziness, extreme weakness, chills or fever, confusion. This can progress to a sudden drop in blood pressure, blood glucose and several other serious features.

Are there any side effects from my medication?

For patients on replacement steroids

- When hydrocortisone is used as a replacement steroid, it is prescribed at the lowest required dose, roughly equivalent to the amount of steroids that the body naturally produces. Such low doses, as well as temporarily increased doses needed to cover acute illness usually do not have any side effects
- Most people do not experience long-term side effects, because steroid medication is prescribed as a replacement dose (unless taken in excess against medical advice)
- A few people find they experience gastric irritation from hydrocortisone, and need to protect their stomach lining with a glass of milk or food before taking their first dose of the day
- Side effects such as the ones described in the next paragraph are more likely to occur if the replacement dose is taken consistently at a higher dose than that prescribed, as in this case, it functions similar to therapeutic steroids.

For patients on therapeutic steroids

- Therapeutic dose steroids can have side effects; the common ones are osteoporosis, weight gain, muscle weakness, type 2 diabetes and glaucoma
- However, the likelihood and further details of possible side effects will be discussed with you by the doctors who prescribe such steroid treatments.

What sports and exercise can I do?

- If you are taking steroid tablets, it would not interfere with your ability to achieve full fitness, provided there are no other health concerns
- Gentle exercise such as gardening or walking does not usually require extra medication

- Depending on the degree of physical activity, you may benefit from taking a small additional dose of steroid (for example 2.5 to 5 mg of hydrocortisone) before engaging in major activity such as long distance running marathon, major sports or competitive dancing
- If in doubt or if you need advice, contact your specialist
- For any sports with a risk of physical injury, you must ensure that a teammate has been trained to administer an emergency injection of hydrocortisone if needed (details can be found under 'Learning how to inject an emergency injection kit (Hydrocortisone rescue pack) at the end of this document.

Can I travel abroad?

- When travelling abroad, it is advised that you carry twice the amount of steroids you need in case you have to double the dose due to illness
- It is also useful to take hydrocortisone injection kit with you in case of emergency, especially if you are visiting remote areas. You can get this kit from your Endocrinology team or your GP
- If travelling abroad, you will need a letter from your doctor or specialist nurse explaining what the injection kit is for
- If you need training on how to use the emergency hydrocortisone injection kit, please contact your Endocrinology team who can arrange this for you.

What happens if I become unwell?

Sick day rules

- If you become unwell, your body would normally increase the output of steroids from your adrenal glands. Therefore, if you are taking steroid tablets, it is essential to mimic the natural response by increasing the dose of steroids to cope with stress
- The amount of extra steroid dose(s) you will require will depend on the severity of the physical stress you are experiencing.

Colds and other minor illnesses

- If you do not have fever, usually you do not need any extra steroid cover. If in doubt, check your temperature with your thermometer.

Infection with temperature and/or on antibiotics

- A temperature of 38 degrees or more usually suggests presence of infection and you would need to double the dose of steroids until your temperature is back to normal , except for patients on fludrocortisone
- If you are prescribed antibiotics, take double your steroid dose until you finish the course of antibiotics
- Inform your GP that you had a serious illness requiring you to increase your medications.

For patients on fludrocortisone

- Fludrocortisone is a mineralocorticoid medication i.e. a medication which may be prescribed in addition to hydrocortisone to maintain normal blood pressure
- If you are on fludrocortisone, you do not need to increase your fludrocortisone dose while you are ill, because the higher dose of hydrocortisone provides sufficient extra mineralocorticoid support.

Illness with vomiting and/or diarrhoea

- If you vomit shortly after your steroid dose, take two more doses right away
- Please ensure that you take the next steroid dose at the time prescribed, and continue the subsequent doses without any break in regularity
- Keep an anti-sickness tablet (or suppository) at hand, or request your GP to prescribe it for you

- If the symptoms continue, please arrange to have an adult companion in the house in case you experience some mental confusion. It is important that a responsible adult is aware of your condition
- Arrange a house call from your GP if necessary
- If vomiting/diarrhoea persist and you are unable to keep things down, you would need an emergency injection of hydrocortisone to make up for the body's inability to absorb your steroid tablet. Make preparations to give yourself an emergency injection, should it become necessary, and then go to the nearest hospital for intravenous fluids. (See below on training for self-injection)
- If you need to attend the hospital, explain that you are experiencing an adrenal crisis and require intravenous steroids and intravenous fluids to stabilize your condition, and produce the standard letter that you must always carry.

Medical illness requiring hospital admission

- If you are admitted to the hospital for a medical illness, please inform the medical and nursing team that you are on steroids, to ensure that no doses are missed and sick-day rules are followed
- You should produce the standard letter that you carry, to help the medical team to follow the correct process
- You may be given steroids by means of an injection which may need to be continued for a few days before tablets are restarted.

Surgery/Anaesthesia

- If you come into hospital, please inform the staff that you are on steroids
- For surgery requiring anaesthesia, you will be given steroids by means of an injection before the surgery and after the surgery; you may need to continue to take injections for a few hours or days before your steroid tablets are restarted
- During the period of recovery from surgery, steroid tablets may be prescribed at a higher dose than usual for a few days, to meet the increased steroid requirements of the body during this period.

Shock and major accidents

- If you are involved in a serious road accident or are injured in some other type of accident, you will need an emergency injection to stabilize your condition which may be followed by higher dose of steroid tablets, depending on medical advice
- Anyone who spends a lot of time travelling by car should arrange with their doctor to have an injection kit in the glove box, (preferably in an insulated container). If you go horse riding you should also make sure you have an injection kit with you.

What if I go to the dentist?

- If you are visiting your dentist just for a check-up or cleaning, there is no need to increase your steroids
- If you are having treatment like fillings done, double your steroid doses for 24 hours on the day of the procedure
- All major dental work like tooth removal/root canal treatment may need to be carried out in hospital. It is advisable to inform your dentist before the appointment that you are on steroid tablets. He may seek advice from an endocrinologist to adjust your steroid doses depending on the type of the dental procedure.

What do I need to keep with me at all times?

Steroid Card

- Patients on long-term corticosteroid treatment are given a steroid card to carry with them
- The card provides vital information about your name, date of birth, NHS number and your need for steroids. It also provides details of what action to take to counter acute crisis
- This card is to be carried with you always and shown it to anyone who treats you.

Steroid wristbands

- This is a custom-made medical ID jewellery on which is engraved your most vital medical information to aid initial care decision, whilst your full medical record is available
- It is not provided by the NHS, however many companies and online sites provide a variable range of wristbands at different prices.

Standard letter

- You will be issued a standard letter which you should bring with you during hospital admission for illness or surgery and show it to your attending Doctor (Physician, Surgeon or Anaesthetist).

Learning how to inject an emergency injection kit (Hydrocortisone rescue pack)

- After the start of long-term steroids, you should be issued an emergency injection kit to be used in case of emergencies like severe illness or when you are vomiting and unable to take tablets orally
- Once you have your kit, both you and a family member, should learn how to give an emergency injection of hydrocortisone. Learning how to do this is very important. It does not take very long and it can be life-saving. Regularly check your kit to make sure the vials are in date. Request replacements either from your GP, or your specialist, for any out of date vials
- Education in Wolverhampton Diabetes/Endocrine Centre:
 - Education about injection can be provided by nursing staff (by appointment) along with an information leaflet and Youtube video links
- Further information about when to give and how to give Hydrocortisone rescue pack can be found by following the link: <https://www.addisonsdisease.org.uk/the-emergency-injection-for-the-treatment-of-adrenal-crisis>
- Watch this short video: <https://ispri.ng/6nLGQ> which summarizes the above information and the links contained for additional information.

If you have any other questions feel free to speak to your specialist at your next appointment.

You can also obtain more information from the following websites:

Pituitary foundation: www.pituitary.org.uk

Addison's disease: www.Addshg.org.uk

CAH: www.ahn.org.uk

Contact Details

Dr H N Buch / Dr C Hariman / Dr J Young
Secretary 01902 695371

Dr R Raghavan / Dr P Kumar
Secretary 01902 695314

Dr V N Cherukuri
Secretary 01902 695313

Dr A Viswanath / Dr K Jadoon
Secretary 01902 695315

Endocrine Enquiries Email: rwh-tr.endocrineenquiries@nhs.net

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。