

Torbay and South Devon
NHS Foundation Trust

INFORMATION FOR PATIENTS:

STEROID REPLACEMENT THERAPY

What are the tablets I am taking?

You will be taking a steroid called HYDROCORTISONE. This replaces the steroid Cortisol normally produced by the adrenal gland.

You may be given other forms of steroid such as PREDNISOLONE or DEXAMETHASONE but these do the same job

Sometimes a second type of steroid called FLUDROCORTISONE is needed to help with balancing your blood pressure

The dose you are taking is intended to replace the amount your body would normally produce. For most people around 20 milligrams of Hydrocortisone per day is enough but this may vary according to the individual.

If you are taking Prednisolone you would require around 5 milligrams per day and if you are taking Dexamethasone you would need around 0.75 milligrams

The dose is usually divided into two or three smaller doses through the day. This is to mimic how the body produces Cortisol naturally.

What if I can't take my tablets?

Steroids are vital for life so it is important that you take your steroids every day.

There may be times when you are unwell and at these times you will require more steroid (See Sick day rules)

If you have to stop your medication for any reason such as an operation you must inform the staff looking after you that you will require steroid replacement.

If you are unable to take your steroids by mouth they can be given via an injection into your muscle or directly into a vein.

What are the ‘Sick Day Rules’?

When you become unwell your body should produce more steroids to help you cope with this. For a person on steroid replacement this is done by increasing the amount of steroid taken

Your body will also produce more steroids if you have a stressful event such as an accident or dental work.

Some patients say that emotional stress such as an emotional shock or even an interview can make them feel unwell so they take extra steroid.

The current recommendations do not require you to take extra steroids if you feel emotionally stressed but please talk to the endocrine team if you have any concerns about this

As you are now requiring steroid replacement you have to learn when to increase your steroid dose. The following is a simple guideline but feel free to discuss specific concerns with the endocrine team.

| | |
|----------------------|---|
| Cough/Cold | Simple cold with ‘runny nose’ Increase may not be required |
| Temperature | If you have a high temperature this suggests an infection Take double doses of steroids until your temperature is back to normal |
| Antibiotics | If you are prescribed antibiotics Take double doses for the course of the antibiotics |
| Dental | Check up No increase required Treatment Double doses for 24 hours |
| Minor surgery | If you have minor surgery at your GP practice Double doses for 24 hours |

What are the side effects of steroids?

For patients on replacement steroids, the side effects are minimal. This is because the amount being taken is about the same as the body would produce naturally.

If you have a stomach upset which gives you symptoms of diarrhoea and/or vomiting it is important that you are given steroids by another means. Steroid side effects such as weight gain, bone thinning and diabetes are more common in patients having much bigger doses in addition to the amount being produced naturally.

If you are sick after taking a steroid dose, take another dose, plus an extra one straight away. If you are still following this as well you should have an emergency injection and seek medical advice via 999.

Sometimes even small doses of steroids can cause indigestion - please talk to the endocrine team if necessary. The endocrine team will discuss this with you and more detailed information is available below

We recommend you keep an emergency hydrocortisone injection kit with you at all times. A short step by step video on how to give the injection is available on this website.

It is important that health professionals looking after you are aware of your need for steroid replacement.

We would suggest you ask family members, friends and colleagues to watch the video and have an awareness of when to give the injection.

For this reason it is recommended that you obtain a Medic-Alert which is recognised nationally and internationally, is available all day every day and can provide important information at a glance.

Information about Medic-Alert is available at <https://www.medicalert.org.uk/>

Your endocrine nurse can help you complete the registration document if you choose to use this.

It is important that you learn as much as you can about how your body responds to illness or stress.

What can happen if I don't take my steroids?

The endocrine team are available to help you through the early stages of learning about steroids and your diagnosis.

This is done in a safe and supportive environment. Adrenal Crisis Ambulance Service is available to help manage medical emergencies locally. An alert notice is also printed and placed in your medical records (Torbay Hospital patients only).

The lack of steroid can cause many symptoms which may include a low blood sugar, very low blood pressure, confusion, abdominal or back pain, or reduced level of consciousness. If left untreated the person may collapse and more rarely may have a fit.

If you wish you can give permission for your GP to share medical information with the ambulance service. This can help speed up treatment.

Adrenal crisis is treated by giving steroid by injection initially. Treatment **MUST** then continue in hospital and will include fluid replacement and treatment of other symptoms.

Information about this is available at <http://www.maguox.ac.uk/wordpress/wp-content/uploads/2018/08/Summary-Care-Record-Information1.pdf>

Inject yourself or ask the trained family member to inject you **and** you should call an ambulance.

Contact details are included in this booklet and you are welcome to ask as many questions as you need to in order to feel confident

Why am I taking Steroids?

You require steroid replacement because your body is unable to make your own steroid (Cortisol)

Cortisol is produced in the adrenal glands and is under the control of the pituitary gland. It is essential for life and there are several reasons why steroid production may decline or cease

Pituitary:

If the pituitary is unable to send the chemical signals to the adrenal glands

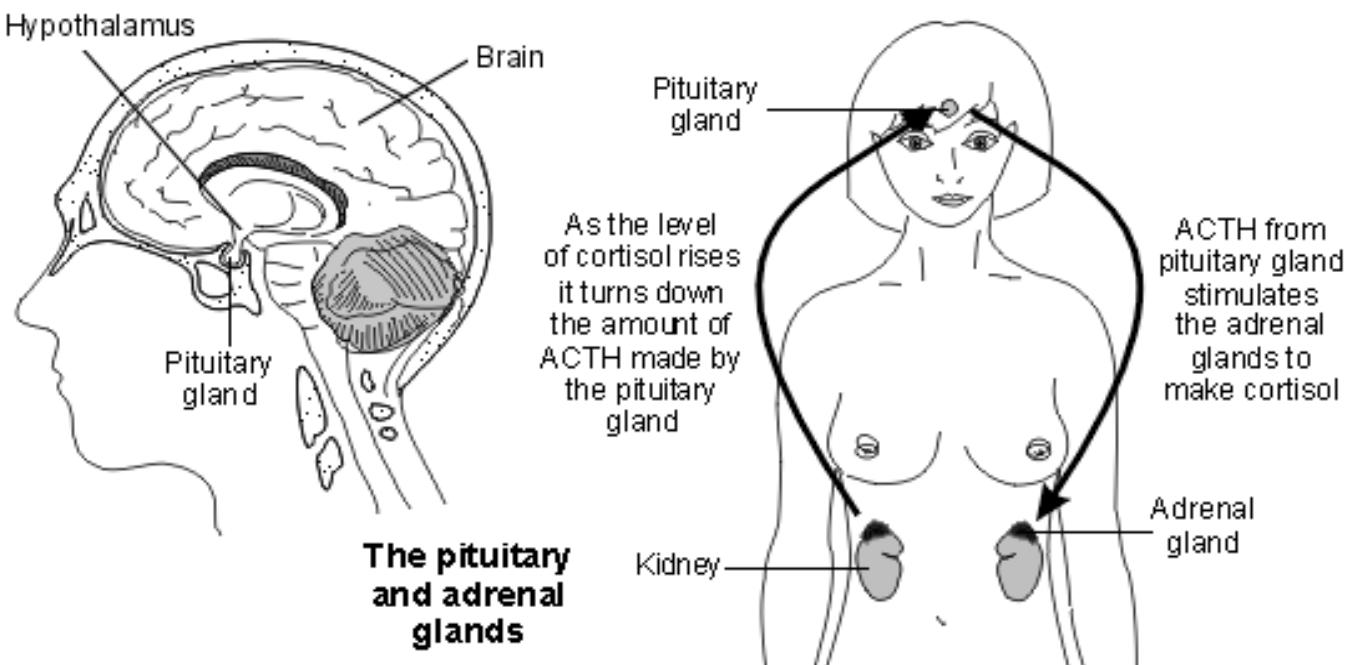
Adrenal:

If the adrenal glands are unable to respond to the chemical signalling from the pituitary.

This may be due to a genetic condition called Congenital Adrenal Hyperplasia (CAH) , if the adrenal glands fail because of illness (Addison's) or following surgical removal

Iatrogenic

The adrenal gland may stop making steroids drug because of steroid medication being used to treat other disorders



Further information

This booklet is intended to provide general information only.

The endocrine team will provide you with personalised advice and guidance

Contacts

Endocrine Nurse

Sue Cox

Contact via Torbay hospital switchboard on 01803 614567 and ask for pager number #6457
Email: endocrinologynurses.sdhct@nhs.net

Medical staff

Contact via the medical secretary

Dr Smith, Gilroy & Spyer: 01803 654923 (direct line)
Dr Lissett, Stride & Dr Redford: 01803 655028 (direct line)

Useful websites

Pituitary Foundation www.pituitary.org.uk

Addison's' disease www.adshg.org.uk

CAH www.ahn.org.uk

Checklist?

You may not require all the items listed here- your endocrine team will discuss with you what is needed for you as an individual

| | | |
|--|---------------------------|--------------------------|
| Have I got a Medic Alert | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I got a copy of my Ambulance Service flagging notice? | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I given consent for Enhanced Summary Care Record? | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I got an Emergency injection kit? | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I watched the step by step injection video? | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I downloaded the app for the video on to my phone? | Yes <input type="radio"/> | No <input type="radio"/> |
| Does a member of my family or friends know how and when to use it? | Yes <input type="radio"/> | No <input type="radio"/> |
| Do I understand the Sick day Rules? | Yes <input type="radio"/> | No <input type="radio"/> |
| I am going on holiday—have I got a travel letter? | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I read the travel advice? | Yes <input type="radio"/> | No <input type="radio"/> |
| Have I received information about why I need steroid replacement? | Yes <input type="radio"/> | No <input type="radio"/> |

