

Steroids for the treatment of immunotherapy related adverse effects

Information for patients, relatives and carers

① For more information, please contact:

For York Hospital Patients

The Magnolia Centre 01904 726516

For Scarborough Hospital Patients

The Macmillan Unit on 01723 342447

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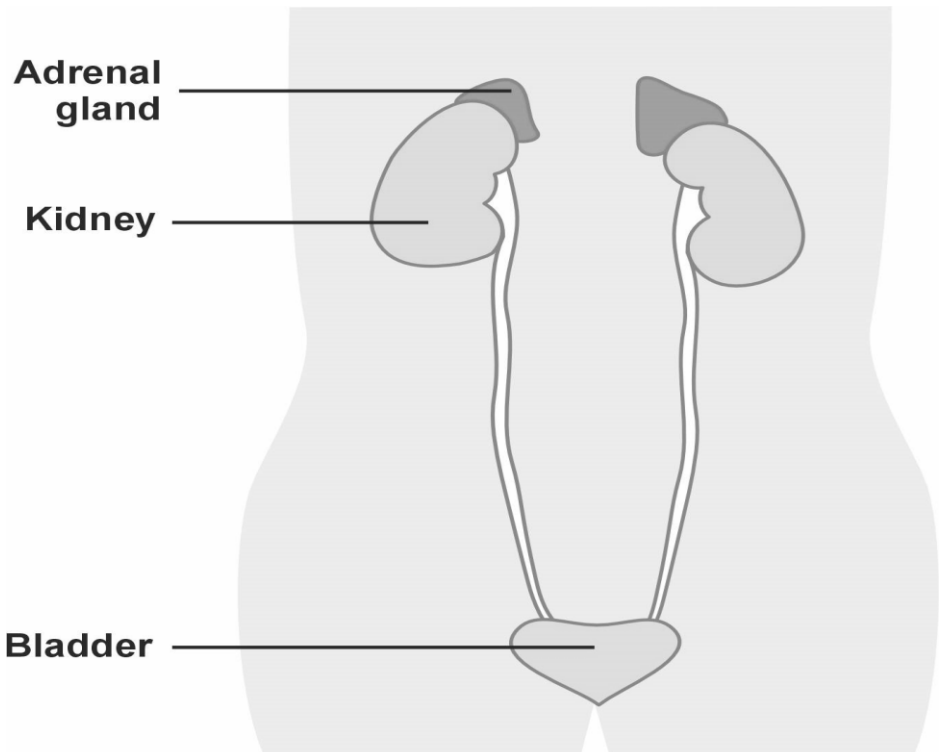
Why have I been given this leaflet?

You have been given this leaflet because you have been recently identified as having an immune related adverse event (immunotherapy toxicity) whilst you are receiving immunotherapy as part of your cancer treatment. As part of the management for these toxicities, you will receive steroid therapy. It is important that you read this leaflet as developing an immune related adverse event can also develop after your immunotherapy treatment has stopped.

What are steroids?

Steroids, also known as corticosteroids or glucocorticoids, are anti-inflammatory medicines used to treat a range of conditions. Steroids are a man-made version of hormones normally produced by the adrenal glands. These are two small glands found above the kidneys.

Steroids also reduce the activity of the immune system which is the body's natural defence against illness and infection.



Why have I been started on steroids?

Immunotherapy enables the immune system to recognise, target and eliminate cancer cells, wherever they are in the body. Sometimes immunotherapy can cause side effects, as a result of the immune system being over stimulated and mistakenly attacks healthy parts of the body.

Steroids work by stopping the immune system from damaging your good cells and reduce your symptoms from any side effects of the immunotherapy.

Steroid emergency card

When you begin steroid treatment, we will give you a steroid emergency card. Always carry it with you and show it to anyone who provides medical treatment for any condition. You must do this while you are taking steroids and for a further two years after stopping them.

Are there any side effects from taking steroids?

Taking steroids for fewer than three weeks is unlikely to cause any significant side effects. However, you may get some side effects if you take them for longer or at a high dose. Some patients may not experience any side effects at all. Possible side effects of steroids include:

- Indigestion or heartburn.
- Increased appetite, which could lead to weight gain when used long term.
- Difficulty sleeping.
- Mood and behaviour changes, such as feeling irritable or anxious.
- Increased risk of infection, especially chickenpox, shingles and measles.
- High blood sugars or diabetes.
- Weakening of the bones (osteoporosis).
- High blood pressure.
- Cushing's syndrome. This can cause symptoms such as thin skin, easily bruised skin, a build-up of fat on the neck and shoulders and a red, puffy, rounded face.
- Eye problems, such as glaucoma or cataracts.
- Mental health problems, such as feeling low, depressed or, in rare cases, having suicidal thoughts.

How do I deal with side effects?

Most side effects will pass once treatment stops. Tell your clinician or call the 24 hour patient helpline (see page 13) if you notice any new symptoms or side effects.

If possible, you should take steroids in the morning to reduce trouble sleeping.

You will be given a tablet to take 30-60 minutes before steroids to protect your stomach from irritation. We also recommended to take your steroid tablets with food. If you are on steroids for more than three weeks, your clinician might prescribe:

- Bone strengthening medication to prevent the weakening of your bones.
- A low dose of antibiotic to prevent you from getting an infection.

What should I do if I miss a dose or take too much?

If you forget a dose, take it as soon as you remember. If it is almost time for your next dose, skip the one you missed. Do not take a double dose to make up for a forgotten dose. Accidentally taking too many steroid tablets is unlikely to be harmful if it is a one-off.

How will I be monitored whilst on steroids?

Your immunotherapy team will contact you at least once weekly to discuss your general wellbeing; to do an assessment of your toxicities; and to assess your responsiveness to the steroid therapy. Sometimes it may be necessary to attend a face-to-face appointment in the hospital. You may also need to have a blood test.

Weaning off steroids

Your clinician will advise you on how to lower your steroid dose safely. This is to reduce the risk of complications. It is also why you must take steroids exactly as prescribed.

Weaning off steroids helps prevent withdrawal symptoms and reduces the risk of your adverse effect from coming back. It also gives your adrenal glands time to resume their normal function. Your clinician will tell you if you need a morning blood test to check your cortisol levels. This usually occurs when you are on your lowest dose of steroid.

Before this test, you will need to stop taking your steroids because they can affect your test results. Your clinician will give you detailed advice on how to do this. Depending on the test results, we will advise you if it is safe to stop steroids completely.

If your cortisol levels are too low, you may need to continue taking a low dose of steroids. We will also refer you to another team to undergo further investigations for hormone-related conditions.

Instructions for reducing doses of steroid treatment

This section is to be completed by your clinician at the point of dispensing your steroids. Use the comments section if your steroid dose has changed, for example, your dose was increased via a telephone consultation in agreement with your clinician.

Patient name

Hospital number

Indication

Date steroid therapy first started

Estimated duration of treatment

Starting steroid dose

Additional instructions

Steroid dose reducing chart

Tablets supplied

Strength of tablets supplied Date

	Number of tablets to be taken		
Date	Dose to be taken	After breakfast	Comments

Steroid dose reducing chart

Tablets supplied

Strength of tablets supplied Date

	Number of tablets to be taken		
Date	Dose to be taken	After breakfast	Comments

Steroid dose reducing chart

Tablets supplied

Strength of tablets supplied Date

	Number of tablets to be taken		
Date	Dose to be taken	After breakfast	Comments

Contact us

If you have any questions or worries about steroids, please speak to your cancer team. If you feel unwell, call the 24 hour patient helpline:

For York Hospital Patients

Mon-Fri, 8:00am-5pm **01904 726516**

Out of hours: contact ward 31 **01904 726031**

For Scarborough Hospital Patients

Mon-Fri, 8:00am-5pm **01723 342447**

Out of hours: contact ward 31 **01904 726031**

Space for your notes and questions

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact the Magnolia Centre on 01904 726516.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:

www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

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