

Steroids: for the treatment of immunotherapy related adverse effects

Cancer Services

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Information for Patients

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Why have I been given this leaflet?

You have been provided with this leaflet because you have been recently identified as having an Immune Related adverse event (Immuno Toxicity) whilst you are receiving Immunotherapy as part of your cancer treatment. As part of the management for these toxicities you will be receiving Steroid Therapy. It is important that you read this leaflet in addition to the 'Steroid Sick Day Rules' leaflet which your Immunotherapy Clinical Nurse Specialist will give to you

What are steroids?

Steroids, also called corticosteroids 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 which 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 attacking healthy parts of the body.

The most common side effects are skin rashes, diarrhoea leading to inflammation of the bowel (this is called colitis) or hormone imbalances related to your thyroid, adrenal or pituitary glands. Immunotherapy can, however, affect any organ of the body.

Steroids work by stopping the immune system from damaging your good cells and

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hopefully improve your symptoms from any side effects of the Immunotherapy.

How long will I have to take steroids?

Everyone is different and each person's body responds differently. You will be monitored closely when you are on steroids to check they are working to reduce your symptoms. Your Immunotherapy Clinical Nurse Specialist will contact you at least once weekly for the duration of the steroid treatment to assess your symptoms; responsiveness to treatment and your general well being.

Stopping taking steroids

You should not reduce your steroid dose or stop taking steroids abruptly without advice from your doctor or specialist nurse.

If you have been taking steroids for more than a few days, the dose should be gradually reduced. This is described as Steroid Tapering. This process will usually take between 3-6 weeks depending of responsive to treatment. Stopping too quickly or suddenly can cause additional problems with your adrenal glands, which make important hormones for the day-to-day function of your body. This is known as 'adrenal insufficiency' and can be dangerous to your health.

Symptoms of adrenal insufficiency include:

- Feeling extremely tired
- Feeling nauseous or being sick
- Dizziness
- Loss of appetite and weight loss

Your original symptoms from any side effects may also come back suddenly if you stop steroids abruptly.

Are there any side effects with taking steroids?

Taking steroid tablets for less than three weeks is unlikely to cause any significant side effects. However, you may get some side effects if you need to take them for longer or at a high dose. Often, patients experience no side effects from steroids.

Side effects of steroid tablets can include:

- Indigestion or heartburn.
- Increased appetite, which could lead to weight gain when used long term.
- Difficulty sleeping.
- Changes in mood and behaviour, such as feeling irritable or anxious.
- An increased risk of infections – especially chickenpox, shingles, and measles
- High blood sugars or diabetes.
- Weakening of the bones (osteoporosis).
- High blood pressure.

- Cushing's syndrome, which can cause symptoms such as thin skin that bruises easily, a build-up of fat on the neck and shoulders and a red, puffy, rounded face.
- Eye conditions, such as glaucoma and cataracts.
- Mental health problems, such as depression or suicidal thought.

Most side effects will pass once treatment stops. Tell your doctor or nurse if you notice any new symptoms. If possible, you should take your steroids in the morning to reduce trouble sleeping.

You will be given a tablet to take alongside your steroids to protect your stomach from irritation and it is also recommended to take your steroid tablets with food.

If you are on steroids for more than three weeks, your doctor or specialist nurse might prescribe a bone strengthening drug to prevent the weakening of your bones and a low dose of antibiotics 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 Clinical Nurse Specialist will contact you at least once weekly to discuss your general well being; to undertake an assessment of your toxicities; and assess your responsiveness to the steroid therapy. On occasions, it may be necessary to attend for a face-to-face appointment in the hospital. It may also be necessary for you to have a blood test taken. Your Immunotherapy Clinical Nurse Specialist will help you to arrange an appointment if you are unable to arrange something locally to you.

Your Immunotherapy Clinical Nurse Specialist will also have provided you with a Steroid Alert Card - it is important that you carry this with you at all times. If there is an occasion where you present for treatment because you are unwell or to you your GP please show them this card.

What happens next?

When you have completed the steroid therapy and there is no further evidence of your symptoms, you will be asked to have a blood cortisol level taken—this usually taken between 5-7 days upon completion. Your Immunotherapy Nurse Specialist will provide you with clear instruction regarding this. If this has returned to within normal levels, you will be referred back to your Oncology Consultant to discuss an ongoing treatment plan.

If the blood cortisol level is not within normal levels, or if you have ongoing symptoms from your immune related toxicity, it may be necessary to refer you to specialist team for additional management - your Immunotherapy Clinical Nurse Specialist will advise you of this.

If any of your symptoms worsen, please contact the 24 hr Emergency Help Line number - **08081782212**.



Useful contact numbers (non emergency)

Chemotherapy Suite: 0116 258 6107 Monday - Friday 08:00 to 18:00hrs

Immunotherapy Clinical Nurse Specialists: 0116 204 7985 Monday—Friday 09:00 to 16:00hrs

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Previous reference:

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