

Steroids

Steroids are often part of treatment for both Hodgkin and non-Hodgkin lymphoma, including cutaneous (skin) lymphoma.

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What are steroids?

Steroids are hormones (chemical messengers) that are made naturally in your body.

Corticosteroids are a type of steroid. Our bodies make corticosteroids in the adrenal glands, which lie just above the kidneys.

Corticosteroids have an important role in:

- metabolism (the digestion of food to get energy)
- controlling the balance of salt and water in your body
- regulating your blood pressure
- fighting infection (immunity)
- reducing inflammation (swelling) and allergic reactions
- regulating your mood.

Corticosteroid medication is made in the laboratory and is sometimes used to treat cancer. The types of corticosteroids most often used to treat lymphoma are prednisolone, methylprednisolone and dexamethasone.

Other types of steroids are:

- sex steroids – oestrogen, progesterone and testosterone, which are involved in sexual development and fertility
 - anabolic steroids – man-made chemicals that copy the effects of the male hormone testosterone. They are prescribed only rarely and are never used to treat lymphoma.
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When might I have treatment with steroids?

You might be given steroids alone or as a part of your **treatment for lymphoma** to:

- Treat the lymphoma – steroids are poisonous to lymphocytes (**white blood cells** from which lymphomas develop). You might have steroids alone to treat some **types of lymphoma** (such as **cutaneous T-cell lymphoma**, a type of **skin lymphoma**), or as 'prephase treatment'.
- Increase your appetite to help you eat more and to boost your energy levels. This might be part of prephase treatment for a few days before you start chemotherapy if you are very unwell or frail.
- Increase the effectiveness of **chemotherapy** – you might have a **regimen** (drug combination) that includes steroids and chemotherapy, for example 'CHOP', which includes the steroid prednisolone.
- Reduce **side effects** of chemotherapy, such as **nausea** (feeling sick).
- Treat an allergic reaction to another anti-lymphoma drug, such as to **rituximab** (an **antibody therapy**).

Until I received a diagnosis, I was given a low grade steroid. This greatly improved how I felt on a day-to-day basis – with no obvious after effects.

Kathleen, diagnosed with lymphoma

How do I take steroids?

You might be given steroids:

- orally (by mouth) in the form of tablets or liquid
- intramuscularly (by an injection into a muscle, usually in your thigh)
- intravenously (into a vein), through a **cannula or central line** (a thin, plastic tube)
- topically (directly onto the skin) as an ointment or cream.

What are the possible side effects of steroids?

Steroids can help to improve symptoms of lymphoma and to reduce side effects of chemotherapy. As with all treatments, however, they can have side effects. Most side effects are a heightened form of the natural effects of your body's own corticosteroid hormones.

Some people worry about the possible side effects; however, these are usually short-term and go away once you stop taking steroid medication.

Not everyone experiences side effects – whether you develop them depends on the dose and how long you have steroids for. Age can also be a factor; young children and elderly people more commonly experience side effects.

Below, we outline the most **common side effects** of steroid medication, followed by some of the **less common side effects**.

If you have any side effects from your steroid medication, tell your medical team so that they can help you cope with them – do not just stop taking them.

If you are taking steroids for a long time, your body begins to adapt to the changed hormone levels. This can lead to adrenal suppression (where you don't produce enough of your own natural steroids). When this happens, it is important not to stop taking steroid medication suddenly because withdrawal symptoms can be severe. Your doctor can help you to safely and gradually reduce your steroid medication.

Common side effects of steroids

When used to treat lymphoma, the most common side effects of steroids are:

- myopathy (muscle aches and weakness)
- indigestion or heartburn
- increased appetite and weight gain
- fluid retention
- changes in blood glucose (sugar) levels
- changes in mood
- difficulty sleeping
- higher risk of infection.

Myopathy (muscle aches and weakness)

Steroid medication can affect your muscles, most commonly causing weakness around the muscles in your hips and shoulders. Your legs might feel weaker than usual. Standing, climbing stairs and getting up from a chair may be more difficult than before you started steroid medication. Weakness in your arms can make tasks such as hanging washing and getting dressed more difficult.

Myopathy is more common in older people.

Indigestion or heartburn

Steroid tablets can irritate the lining of your stomach and cause indigestion or heartburn.

You might be prescribed stomach-protecting medicines such as ranitidine. **Some over-the-counter medicines for indigestion and heartburn (such as antacids) can interact with steroids. Do not take such medicines without checking with your doctor.**

Increased appetite and weight gain

Steroids can increase your appetite, leading you to eat more and gain weight. They can also temporarily affect how your body stores fat. It may start to build up in your face, giving it a puffy-like appearance. You may also lose weight from your arms and legs.

Some people find that their weight increases even without an increased appetite. This can happen for various reasons including changes to your metabolism, which affects how quickly you burn calories.

Part of my treatment was steroids and I put on loads of weight. I just didn't feel like myself...

Helen, diagnosed with primary mediastinal large B-cell lymphoma (PMBL)

Although it can be upsetting to gain weight, continue to eat a **healthy diet**. Your weight should return to normal once you stop taking steroids.

Steroids play an important role in regulating the balance of water and salt in your body. Sometimes, steroid medication causes you to keep too much fluid in your body (known as 'fluid retention' or 'water retention'). This can cause bloating, swollen ankles, hands and/or feet, and puffiness around your eyes.

To ease fluid retention, avoid standing for long periods of time. You might also find that it helps to raise your legs when you are lying down. Taking gentle **exercise**, such as a short walk, can help, too.

Changes in blood glucose (sugar) levels

Natural steroids made in your body raise the level of glucose (sugar) in your blood. Insulin (another hormone) lowers the level of glucose. Together, steroids and insulin balance your blood glucose levels.

Steroid medication disrupts this balance and may cause high levels of blood glucose. Avoid foods and drinks with high levels of sugar during this time. Usually, the imbalance is temporary. However, occasionally, it leads to **diabetes** or may uncover previously undiagnosed diabetes. It is important to recognise the symptoms of diabetes in case you need treatment.

Tell your doctor straightaway if you have any of the common symptoms of diabetes:

- being very thirsty
- passing a lot of urine, especially at night
- blurred vision
- frequent infections (such as **thrush**)
- cuts and grazes that take a long time to heal
- losing weight without trying to
- feeling more tired than usual.

Your doctor should investigate the causes of your symptoms and advise you accordingly. Let your healthcare professionals know that you have had, or are taking, steroids.

If you already have diabetes, monitor your blood glucose levels carefully while you are on steroid medication. You should be referred to a specialist diabetes nurse for further advice, which may include adjusting your medication. If you don't receive this support, ask for it.

Changes in mood

The steroids that occur naturally in your body regulate how excited and nervous you feel. Steroid medication can affect your mood. Some people feel happier than usual while others feel an unpleasant edginess. Steroids can also make you feel down, short-tempered and irritable. Very rarely, they cause confusion. Some people feel low or flat for a while once they stop taking steroids.

Effects on your mood can come and go quite quickly after you start taking steroids. Let your medical team know if steroids affect your mood. They might stop your steroids gradually to help manage how you feel.

Difficulty sleeping

Some people have difficulty **sleeping** when they are on steroid medication. It may help to take your steroids first thing in the morning, when your body's natural steroid levels are higher. Speak to your medical team for further advice.

I found that taking steroids as early as possible, with food, helped reduce sleep issues and avoided indigestion.

Corrin, diagnosed with diffuse large B-cell lymphoma (DLBCL)

Increased risk of infection

Steroids can affect your **immune system** and reduce your ability to fight infection. In particular, you might get more viral infections, such as cold sores and **shingles**. Fungal infections (such as thrush) are also very common when you are taking steroids.

Tell your doctor straightaway if you develop **signs of infection**.

Less common side effects of steroids

Other side effects of steroids used in the treatment of lymphoma are rare. They usually happen if you take steroids for months or at least a few weeks.

Tell your medical team or your GP if you have any of these side effects so that they can help you to cope with them.

- **Skin changes** – a high dose of steroids can make your skin more thin and fragile, causing you to bruise more easily than usual. Your skin may also become more oily, which can cause acne (spots) – this is more common in younger people.

- **Aches and weakness in your bones** – if you have high doses of steroids for more than a few months, you could develop **osteoporosis** (weak bones). This is extremely uncommon with the types of steroids used in the treatment of lymphoma. However, in older people who have also had chemotherapy, it can increase the risk of fracture, particularly of the vertebrae (spinal bones). If your doctor feels you are at an increased risk of osteoporosis, they may prescribe medicines to protect you against it or suggest a **dual energy X-ray absorptiometry** (DEXA) scan to keep a check on your bone density.
 - **Headaches and dizziness** – these can be the result of raised blood pressure. Your medical team should check your blood pressure regularly while you are on steroids.
 - **Blurred or reduced vision** – if you take steroids for a long time, you could develop cataracts (cloudy patches in the lens of your eye) or glaucoma (build-up of pressure in the eye). Both of these conditions affect vision. If you notice changes in your sight, consult an optometrist (optician) or your GP.
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What precautions should I take when I am on steroids?

There are some simple steps you can take to help you stay well when you are on steroid medication.

Talk to your doctor before taking other medicines

Speak to your doctor about the safety of taking other medications. This includes those that you can buy without a prescription, such as pain relief medication and herbal remedies.

Some medicines could interact with your steroid medication and change the effect of both. Examples are those used to manage:

- inflammation, such as ibuprofen
- indigestion, such as antacids
- high blood pressure
- heart problems
- tuberculosis
- diabetes
- seizures
- blood clotting, for example blood thinning drugs such as warfarin.

Prevent pregnancy and avoid breastfeeding

It is not advisable to become pregnant, or to father a child, while on steroids or for a few months afterwards. This is because steroids can harm the development of an unborn baby. It is therefore important to use reliable contraception during this time. If you do become pregnant while taking steroids, you may be at an increased risk of developing **gestational diabetes**. Speak to a member of your medical team for advice about this.

If you already have a baby, take care to avoid people who are infected with **chicken pox** or **shingles**. If you are breastfeeding, speak to a member of your medical team for advice specific to your type and dose of steroids. The general advice is to avoid breastfeeding for around 3 to 4 hours after each dose of steroids, to allow time for the steroids crossing into the breast milk to reduce minimal levels. This is with the exception of topical steroids, when there is no need to wait before breastfeeding.

Take care not to get chicken pox or shingles

Avoid contact with people who have chicken pox or shingles, even if you have had these infections in the past – they could be serious if you have lymphoma and are on steroids. Tell your doctor straightaway if you think you could have chicken pox or shingles.

Vaccinations

Be aware of which **vaccinations** are safe for you to have, including **travel vaccinations**. You shouldn't have live vaccines (which contain weakened, live bacteria or viruses) while you are on steroids or for 6 months afterwards.

Live vaccines include those given to protect against:

- chickenpox
- measles, mumps and rubella (MMR)
- polio
- shingles
- tuberculosis (BCG vaccine)
- typhoid
- yellow fever.

You can have **inactivated (non-live) vaccines**, for example, the winter flu jab; however these might not be as effective as usual – speak to your doctor for advice.

Be aware of signs of infection

Contact your medical team straightaway if you have any **signs of infection** or if you feel generally unwell. This is especially important if you have **neutropenia** (low neutrophil count), a common side effect of **chemotherapy**. Remember that shivering can be a sign of infection even if you do not have a fever. This is more likely if you are taking steroids.

Problems are usually easier to treat if you seek medical assistance as soon as possible. You should have been given a number to call if you feel unwell. If not, ask for it.

Carry a steroid warning card

You are usually given a steroid warning card if you are on steroids for 3 weeks or longer. In the case of an emergency, the card lets doctors know that you are on, or have recently had, steroid medication. It tells them the dose and, if applicable, that you need to keep taking the steroids

Keep the warning card with you while you are taking steroids and for 2 years after your treatment ends. People often carry them in their purse, wallet or bag.

If you experience adrenal suppression, it can take a long time to fully recover from, particularly after high-dose steroid treatment.

Steroids are important in the recovery from surgery or injury. If you have any dental work or an operation in the future, show your steroid warning card to your dentist or anaesthetist. He or she can take any necessary precautions to ensure that you recover well.

We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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