

## Steroids

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

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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](mailto:information@lymphoma-action.org.uk).

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## What are steroids?

Steroids are chemical messengers (hormones) that are made naturally in your body. The type of steroids most commonly used in the **treatment of lymphoma** are corticosteroids.

### Corticosteroids

Corticosteroids are a type of steroid that your body makes in the adrenal glands, which lie just above the kidneys.

Corticosteroids have an important role in:

- balancing the water and salt in your body
- controlling your blood pressure
- controlling your metabolism (breaking down food to get energy from it)
- fighting infections (**immunity**)
- your body's response to allergic reactions and helping to reduce swelling (inflammation) that can happen as a result of **fluid retention**
- your body's response to **stress**
- regulating your mood.

Corticosteroid medication is made in a laboratory. The types of corticosteroids most often used to treat lymphoma are **dexamethasone**, **methylprednisolone** and **prednisolone**. A group of steroids called mineralocorticoids (including **fludrocortisone** and **hydrocortisone**) are sometimes used to treat **adrenal crisis**.

Other types of steroids are sex steroids (oestrogen, progesterone and testosterone) and anabolic steroids. Neither type is used in the treatment of lymphoma.

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## Steroids in the treatment of lymphoma

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', before other treatment such as **chemotherapy**.
- **Increase your appetite** – steroids can help you to eat more in order to boost your energy levels. Sometimes, this is part of prephase treatment for a few days before you start **chemotherapy**, or if you are very unwell or physically weak.
- **Make chemotherapy more effective** – you might have a drug combination (**regimen**) that is made up of steroids **and** chemotherapy.
- **Reduce side effects of chemotherapy**, such as **nausea** (feeling sick)
- **Treat an allergic reaction to another lymphoma drug**, for example, to **rituximab** (an **antibody therapy**).

Steroids can be taken in different ways:

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

Depending on your type of steroid medication and how long you are taking it for, you might be given a **steroid treatment card** or a **steroid emergency card**, or both. You should carry these with you for all the time you are on steroids and for some time after completing treatment with them – this is usually 12 months, but seek advice from your medical team.

If you have an operation or any dental work in the future, let the anaesthetist or dentist know beforehand that you've had steroid treatment. They can then take any necessary precautions to ensure that you recover well.

### Steroid treatment card

A steroid treatment card reminds you that you should not stop taking steroids suddenly, and what to do if you become unwell. It also tells health professionals the details of the steroids prescribed to you.

You are given a steroid treatment card at the beginning of treatment with steroids if you are taking them:

- in tablet or liquid form (orally)
- for more than 4 weeks.

Your doctor might also give you a steroid warning card in other situations. For example, this could include if you have four or more short courses of oral steroids a year.

## Steroid emergency card

If you take steroids for a long time, your body can start to get used to the changed hormone levels and having steroids provided. You then make fewer of your own natural steroids. If this happens and you stop taking steroids suddenly, it can lead to a lack of the steroid hormone cortisol within your body. This is known as adrenal crisis, or secondary adrenal insufficiency. It is more likely to happen with steroids taken by mouth (orally) than with other types of steroids.

The purpose of a steroid emergency card is to help support the early recognition of adrenal crisis.

If you experience adrenal crisis, it is important that you **do not stop taking steroid medication suddenly** – withdrawal symptoms can be severe. Your consultant can help you to safely and gradually reduce your steroid medication.

Symptoms of adrenal crisis include:

- increased **risk of infection**
- headache
- light-headedness or dizziness
- confusion
- extreme tiredness (fatigue)
- rapid and unexpected weight loss
- feeling or being sick (nausea or vomiting)
- tummy pain
- mild (low-grade) fever, where your body temperature is just a little over normal temperature.

Your steroid medication is adjusted to help lower this risk if you are at an increased risk of developing adrenal crisis. For example, if you are unwell or admitted to hospital for surgery.

If you develop adrenal crisis, your doctors give you an injection of extra steroid medication, to help bring the steroid level within your body back up to a safe level.

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## Side effects of steroids

Below, we outline some of the most **common side effects** and some of the **less common side effects** of steroids. Most are heightened forms of the natural effects of your body's own corticosteroid hormones.

Not everyone gets side effects. The risk of developing them is affected by factors such as:

- the dose of steroid
- how long you take steroids for
- your age – children and older people have a higher likelihood of developing side effects
- having certain other medical conditions
- taking certain other medications.

Any side effects of steroids are usually short-term and gradually improve once you stop taking them.

Tell your medical team if you experience side effects so that they can help you to manage them. It's important that you do not just stop taking steroids without seeking advice as this can lead to **adrenal crisis**.

## Common side effects of steroids

Common side effects of steroid medication include:

- muscle weakness and aches (**myopathy**)
- **increased risk of infection**
- **indigestion or heartburn**
- **water (fluid) retention** (lymphoedema)
- **changes in metabolism** (how your body gets energy from food)
- **changes in blood-sugar (glucose) levels**
- **changes in mood**
- **difficulties sleeping.**

Steroid creams and ointments (topical steroids) can cause side effects in the areas where they are applied. These can include:

- thinning of the skin, making bruising in this area more likely
- changes in skin colour
- spots (acne)
- increased hair growth.

It is also possible that a topical steroid could irritate your skin or cause an allergic reaction. This is known as **contact dermatitis**. If this happens, you will be given a different type of topical steroid treatment.

### **Myopathy**

Steroids can affect the fibres in your muscles. This is known as myopathy. Myopathy can lead to muscle weakness, often in your hips and shoulders. If this happens, your legs and arms might feel weaker than usual, making some tasks difficult – for example, climbing steps, getting up from a chair, reaching to hang washing, and getting dressed. Symptoms can also include muscle cramps and stiffness.

Myopathy is more common with higher-dose steroids taken over a long time. Older age can also increase the risk of myopathy.

Usually, myopathy usually gradually improves once you reduce your dose or stop taking steroids. However, it can take weeks or months to build muscle strength back up.

### **Increased risk of infection**

Taking steroids for longer than a few weeks can affect your ability to fight infection (**immunity**).

The type of infections you are more at risk of depends on the type and dose of steroid medication you take. For example, steroid tablets and steroids given intravenously (into a vein) can make you more prone to developing infections such as colds, **chickenpox, shingles** and **measles**.

Steroid medication can also cause **oral thrush** (an infection in your mouth), or **thrush in the vagina or penis**.

Be aware of any **signs of infection** and seek medical advice straightaway if you notice any.

## Indigestion or heartburn

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

Seek advice from a member of your medical team if you experience indigestion or heartburn. It is important not to take any medicines (including those available without a prescription, such as antacids) without checking with your doctor; some can interact with steroids and cause unwanted effects.

## Changes in metabolism

Steroids can affect the speed at which your body breaks down food to get energy from it (your metabolism). This can increase your hunger levels, leading you to eat more and to gain weight. If your metabolism slows down, you might gain weight, even if your appetite doesn't increase.

The change in metabolism can also temporarily affect your body's storage of fat. It might build up in your face, giving your face a more rounded or puffy appearance. You might lose some of the weight in your arms and legs. This can happen with or without an increase in appetite.

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

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**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)

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## Water (fluid) retention

Steroids play an important role in balancing 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, swelling in your ankles, hands and/or feet (**lymphoedema**), and puffiness around your eyes.

Avoid standing for long amounts of time to help ease fluid retention. You might also be interested in our information about **coping with lymphoedema**.

## Changes in blood-sugar (glucose) levels

Steroids and insulin are hormones made by your body that work together to balance your blood-glucose levels. Steroids cause a rise in the level of sugar in your blood, and insulin lowers the level.

Taking steroid medication can disrupt this balance and lead to high blood-sugar levels. Usually, this is short-term and the balance is restored once you stop taking steroids. While your blood sugar levels are disrupted, avoid sugary foods and drinks.

Occasionally, if you take steroids for a long time, it leads to type two **diabetes**, or can uncover diabetes that has gone undiagnosed up until this time. It is important to recognise symptoms of diabetes, in case you need treatment to help control your blood-sugar levels.

The main symptoms of diabetes to look out for are:

- feeling very thirsty
- needing to wee more often than is usual for you, especially at night
- feeling very tired
- losing weight (including muscle) without trying to
- itching around the penis or vagina
- **thrush**, a yeast infection
- blurred vision.

Tell your doctor straightaway if you experience any of these symptoms, and let them know that you are on steroid medication:

If you had diabetes before you started steroid treatment, your lymphoma medical team and your diabetes medical team work together to manage your treatment and blood sugar levels.

## Changes in mood

Steroids regulate emotions such as excitement and nervousness. Taking steroid medication can therefore affect your mood. Some people feel happier than usual while others feel, low in mood, short-tempered and irritable. Very rarely, steroids cause confusion. Some people feel low or flat for several days to weeks after they stop taking steroids, as it takes a while for your body to begin making its own steroids naturally again.



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**At the start of his treatment, my son felt on edge due to the steroids. His younger brother got the brunt of it. It was an exhausting and difficult time, but now treatment is over and we feel like we can breathe again.**

Nichola, whose son was 16 when he was diagnosed with Hodgkin lymphoma

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Effects on your mood can happen quite suddenly and improve once you stop taking steroids. Nonetheless, it can be unsettling to experience changes in mood. Let your medical team know how you are feeling so that they can help to manage these side effects of steroids. If your side effects are severe, they might lower your dose of steroids.

Changes in mood can also impact your **relationships with family and friends**. You can **contact us** if you'd like **support** with any aspect of **living with lymphoma**. You might also be interested in our information about **communicating with the people around you**, which includes tips to help you let others know how you're feeling.

### Difficulty sleeping

Steroids can disrupt the natural sleep cycle. You might feel alert when you would like to be sleeping. Speak to your doctor or clinical nurse specialist for advice. They might recommend that you take your steroids first thing in the morning and can offer **suggestions to help you get restful sleep**.

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**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)

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### Less common side effects

We list some of the less common side effects of steroids below. These are more likely if you take steroids for a long time. However, they can also happen with steroids taken at a lower dose for a long time.

- **changes to your skin**
- **changes to your bones**
- **raised blood pressure**
- **eye problems.**

## Changes to your skin

Steroids can cause thinning of the skin, which can make you bruise more easily than usual – this is further increased if you have thrombocytopenia. They can also make your skin more oily, which can cause spots (acne) – this is more common on the face, back and chest, and in younger people.

## Changes to your bones

You might experience aches and weakness in your bones. If you take steroids for a long time, you might be at risk of **osteoporosis**, where your bones become thin and weak. This can make them more fragile and likely to fracture or break.

Osteoporosis is very 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 bones in the spine (vertebrae). If you are at an increased risk of osteoporosis, your doctors might suggest a **dual energy X-ray absorptiometry (DEXA) scan** to keep a check on your bone density. You might also be prescribed medicines to help protect you from developing osteoporosis.

There are some lifestyle factors that can help to reduce the risk of developing osteoporosis, including:

- taking regular **exercise**, particularly **strengthening activities** such as walking up stairs and carrying shopping bags.
- eating a **healthy, balanced diet** that includes enough **calcium** and **vitamin D** to support good bone health. Your doctor might also recommend taking a vitamin D supplement
- having some daily exposure to sunlight – this helps you to produce vitamin D, which helps your body to absorb calcium
- **not smoking**
- limiting your **intake of alcohol**.

You can find out more about **preventing osteoporosis** on the NHS website.

## Raised blood pressure

Steroids can increase your blood pressure (**hypertension**), which can lead to headaches and dizziness. You should have regular blood pressure checks while you are taking steroids – ask your medical team for advice.

To help reduce your risk of developing high blood pressure, the NHS recommends that you:

- take **regular exercise**
- eat a **healthy, balanced diet**, limiting the amount of salt you eat
- limit your **alcohol** and caffeine intake
- keep to a **healthy weight**
- **don't smoke.**

You can read more about **hypertension (high blood pressure)** on the NHS website.

## Eye problems

Taking steroids can cause a temporary blurring of vision. If you take them for a long time or at a high dose, they can cause side effects including reduced vision, cloudy patches in the lens of your eye (cataracts) and a build-up of pressure in the eye (**glaucoma**).

If you notice any changes in your vision, ask your GP or optometrist (optician) for an eye health check.

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## Safety precautions while you are taking steroids

There are some simple steps you can take to help lower the risk of developing problems while you are on steroid medication.

### Be aware of signs of infection

Let a member of your medical team know straightaway if you notice any **signs of infection**. Early action can help stop problems from developing into more serious difficulties.

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.

## Talk to your doctor before taking other medicines

Speak to your doctor about the safety of taking other medications. This applies to medicines that are available without a prescription, such as pain relief medication and herbal treatments. Some medicines could interact with your steroid medication and change the effect of both. Examples are medicines used to manage:

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

## Check which vaccinations you should and shouldn't have

Ask a member of **your medical team** or your GP about which **vaccinations** are safe and advisable for you to have; this includes **travel vaccinations** if you are planning a trip to another country, and the **COVID-19 vaccination**.

### Live vaccines

Live vaccines are made using weakened, live bacteria or viruses. In general, you shouldn't have live vaccines while you are on steroid medication and for 6 months afterwards. This is likely to be longer (at least 24 months) if you have had a **stem cell transplant**.

Live vaccines include those given to protect against chicken pox, measles, mumps and rubella (MMR), polio, some brands of the shingles vaccines, BCG vaccine (to protect against tuberculosis), typhoid, yellow fever.

### Non-live (inactivated) vaccines

Inactivated vaccines (such as the winter flu vaccination) are considered safe for people with lymphoma; however, they might not be as effective – speak to your doctor for advice.

## Frequently asked questions

Below, we answer some frequently asked questions about steroids in the treatment of lymphoma.

### How long will I take steroids for?

Your treatment plan is tailored specifically to you and your individual situation. Your medical team will give you advice about how and when to take your steroid medication.

With **non-Hodgkin lymphoma**, you might have steroids for a few days or a week during each cycle of chemotherapy. This can help to reduce the side effects of chemotherapy.

If you have steroids as part of treatment for **Hodgkin lymphoma**, you might be given them intravenously, at the same time as your chemotherapy.

### Will I have side effects from steroids?

Not everyone experiences **side effects**. Whether you develop them depends on factors including the dose and how long you take them for. Age can also be a factor with young children and older people more commonly experiencing side effects.

### Why is it important that I do not stop taking steroids without medical advice to do so?

It's important to seek medical advice before stopping or making any changes to your medication. Usually, you need to stop taking them gradually in order to reduce the risk of **adrenal crisis**, which can be serious.

### Is it OK to breastfeed if I am taking steroids?

The amount of steroid medication in breast milk is unlikely to harm an infant. However, speak to your medical team for advice.

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## References

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

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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