

Steroids for children with Duchenne Muscular Dystrophy (DMD)

Children's Hospital
Information for Patients

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Introduction

This leaflet is for parents and carers of children with Duchenne Muscular Dystrophy (DMD). It explains why steroid medicine may be offered, how it can help, and what side effects to look out for.

We know this can feel like a lot of information. You do not need to remember everything all at once. You can come back to this leaflet at any time, and you can always ask us questions.

Why might steroids be offered?

Steroids are medicines that can help keep muscles working for longer in boys with DMD.

We usually talk about starting steroids when your child's walking has stopped improving but has not yet started to get worse. This is sometimes called the "plateau phase". Every child is different, so the timing is always decided with you, based on what feels right for your child and family.

How might steroids help my child?

Many parents tell us that steroids help their child feel less tired and more able to join in with everyday activities. Possible benefits of taking steroids for DMD include:

- Staying walking for longer. Research suggests that on average children who take steroids may stay walking 3 years longer than those who do not. This varies from child to child.
- Increased energy and stamina.
- Better ability to take part in some physical activities.
- A reduced chance of needing spinal surgery.
- Can help maintain heart and breathing function.
- Keeping arm function for longer which can make a big difference for daily activities such as eating, washing, using a phone, or playing games.

Which steroids are used for DMD?

- **Prednisolone** comes as a tablet or a liquid. Some children gain more weight on this medicine and may have changes in behaviour, such as being more restless or irritable.
- **Deflazacort** comes as a tablet. It can affect growth and bone strength and may increase the chance of cataracts (clouding of the lens in the eye). Some studies suggest it may slow loss of strength compared to Prednisolone.
- **Vamorolone** is a newer steroid that comes as a liquid. It was approved by National Institute for Health and Care Excellence (NICE) in January 2025. Early studies suggest that it may be less likely to slow growth or weaken bones and may cause fewer behaviour changes, but we are still learning more about it.

Some steroids are taken every day. Others are taken in cycles, such as 10 days on and 10 days off. Taking steroids every day often gives more benefit, but side effects can be stronger. We will talk through the options with you and review things regularly.

Taking steroids long term

Many boys with DMD benefit from taking steroids for a long time. Not every child gets side effects. If they do have side effects they are often manageable.

If side effects become a problem, we can adjust the dose, change the type of steroid, or slowly stop the medicine if needed. We always try to balance how well the steroid is working with how your child is feeling day to day.

Possible side effects

Changes in appetite and weight

Steroids can make your child feel hungrier. This makes them put on weight more easily.

- Extra weight can make moving harder. Losing weight is very difficult in DMD.
- We may suggest support from a Dietitian to help with food choices and portion sizes.
- If weight gain starts to affect your child, we will review the steroid treatment with you.

Mood, behaviour and sleep

Some children have changes in mood or behaviour, especially in the first 6 weeks after starting steroids.

- Your child may seem more irritable, restless, or have trouble sleeping. These changes often settle with time.
- If your child already has behaviour or sleep difficulties, it helps to manage these before starting steroids.
- Changing the time of day you give medicine can sometimes help. We can talk about this with you.

Growth and puberty

Steroids can slow growth and delay puberty. Puberty is important for bone strength.

- If you notice your child's growth has slowed, or there are no signs of puberty by around age 14, please tell us.
- We may refer your child to a hormone specialist (Endocrinologist) to see if treatment like testosterone can help.

Changes to face shape

- You may notice fullness in the face and cheeks. This is linked to weight gain.
- Healthy eating can help reduce this.

Bone health

Steroids can weaken bones over time.

- This already happens in many children with DMD because they put less weight through their bones.
- We will give advice about foods that contain calcium and Vitamin D. Some children will need Vitamin D supplements.
- Bone scans (DEXA scans) are offered to children taking steroids.
- If your child has a fracture after a small injury, or complains of back pain, please contact us. Your child may need more checks.

Stomach problems

Steroids can irritate the stomach.

- Always give the medicine with food, usually in the morning.
- If your child has on-going stomach pain, let us know. We may prescribe medicine to protect the stomach.
- Your child should not take ibuprofen or similar medicines (NSAIDs) while taking steroids.
- You need to get medical advice if your child has sudden stomach pain.

Blood pressure and diabetes

Steroids can raise blood pressure and increase the chance of diabetes.

- Tell us if your child seems much thirstier than usual or is peeing more than normal.
- We will ask your GP to check your child's blood pressure and pee (urine) in the first few months after starting steroids.

Eye health

- After some years on steroids, some children develop cataracts. This means the lens of the eye becomes cloudy.
- We advise a yearly eye test with your local optician.

Body hair

- You may notice extra body hair growth. This is often mild and does not need treatment.

Infections and vaccines

Steroids make it harder for the body to fight infections. You must act quickly if your child becomes unwell. Even minor infections should be taken seriously.

While your child is taking steroids:

- **You should not give them live vaccines** (such as nasal flu or MMR) as these can make them very unwell.
- Your child can get injected vaccines, such as the flu jab. These are safe.

Chickenpox can be serious in children taking steroids. Before starting treatment, we check if your child is immune. If not, they may need vaccination. If your child is taking steroids and has contact with chickenpox or shingles or gets a chickenpox-like rash, contact your neuromuscular team or get medical advice the same day.

Important safety information

Adrenal insufficiency means that the body cannot make its own steroids. This can happen if your child has been taking steroid medication for a long time. The body gets used to the medicine and stops making its own natural steroids.

It is very important to remember:

- do not stop steroids suddenly.
- do not miss doses for more than 24 hours (1 day).
- always tell healthcare staff that your child takes steroids.

Missing doses can lead to a serious problem called an **adrenal crisis**.

If your child cannot take their steroid medicine (for example, because of diarrhoea or vomiting) they can become very unwell because their body is no longer making steroids naturally.

Your child's Emergency Steroid Care Plan

Your consultant will give an **Emergency Steroid Care Plan** for sick days and emergencies. It explains adrenal insufficiency and tells you exactly what to do.

This leaflet will help you to:

- notice warning signs,
- know when extra ("stress dose") steroids are needed,
- know what action to take,

Children taking steroids for a long time may need extra doses during illness or stress.

Important: This leaflet does not replace your child's **Emergency Steroid Care Plan**.

- Always keep the plan with you.
- Show it to doctors, nurses or ambulance staff.
- Follow the plan carefully.

Warning signs to look out for:

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| • very sleepy or weak, | • vomiting, |
| • dizzy or confused, | • fainting, |
| • pale, | • seeming much more unwell than expected, |
| • clammy, | |

These can be signs of adrenal insufficiency and can quickly become serious.

What to do if you are worried:

- get urgent medical help,
- go to the Emergency department,

Always tell staff that your child takes steroid medication.

Your child may need steroids given in a different way, such as an injection directly into a vein (intravenously).

Who needs to know that my son is taking or has taken steroids?

Always tell doctors, nurses, dentists, and pharmacists that your child is taking or has taken steroids, even up to 1 year after stopping.

Your child may wish to wear a MedicAlert bracelet (www.medicalert.org.uk)

Or a DMD Care UK Steroid Dependent Wristband (www.duchenneuk.org/dmd-emergency-support/).

This is so that people know that your child is taking or has taken steroids.

Stopping steroids

The decision to stop steroids is always made together with you and your consultant. Some children continue steroids even after they stop walking.

If steroids are stopped, we reduce the dose slowly so the body can start making its own steroids again. Tests may be needed before stopping completely.

Where can I find more support?

Scan the QR code or visit the website to get more information.



Muscular Dystrophy UK

<http://www.musculardystrophyuk.org/>



Action Duchenne

<http://www.actionduchenne.org/>



Parent Project Muscular Dystrophy

<http://www.parentprojectmd.org/care/care-guidelines/by-area/steroids/>



DMD Care UK

<http://www.dmdcareuk.org/>

