



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

# Corticosteroids for children with neuromuscular disorders

This information sheet is one of a series produced for children attending the Dubowitz Children's Neuromuscular Centre at Great Ormond Street Hospital (GOSH). It has been provided to help answer some of the questions you may have about your child's corticosteroid (steroid) medication.



## When should my child take his or her steroid medication?

The body normally produces its highest levels of steroids in the morning, so the best time to take steroid medication is in the morning. Your child should take it after breakfast because steroids can irritate the lining of the stomach and cause pain, so taking medication after having something to eat will help to prevent tummy ache.

## How steroids might affect your child

### Infections

Taking steroid medication can affect how vigorously your child's body responds to infections. If your child becomes unwell, please seek medical advice early. Always tell the doctor that your child is taking steroids, whether this is every day or intermittently on a '10 days on 10 days off' regime.

### Stomach pain

One of the possible side effects of steroids is irritation of the stomach lining and ulceration of the stomach. Steroids should be taken after food to help minimise the effects on the stomach. It is very rare for ulceration to lead to a perforation of the stomach. If your child is on steroids and experiences a sudden stomach pain, even if it not severe, he or she should see a doctor, either your family doctor (GP) or at your local Accident and Emergency (A+E) department. Always tell them that your child is taking steroids.

If your child has stomach pain while taking steroids, your local paediatrician should prescribe medicine

to protect the stomach. Please tell us if this (or any other medicine) is prescribed locally.

### Weight gain

Steroid medication may stimulate your child's appetite so that he or she will want to eat more. We will talk to you about healthy eating before your child starts taking steroid medication and discuss ways of coping with increased appetite. In children with neuromuscular disorders, excessive weight gain can make it harder to move around.

Losing weight is very difficult for boys with Duchenne Muscular Dystrophy so it is preferable to prevent weight gain. If your child does put on weight too quickly, we recommend referral to a dietitian who can help you make changes to the amount or types of food that your child eats.

### Raised (high) blood pressure and diabetes

A side effect of steroid medicine is that it may cause a rise in blood pressure. There is also a risk of developing diabetes. We will ask your family doctor (GP) to check your child's blood pressure and test his or her urine for glucose regularly. For the first year of treatment, we ask for these tests every month when taking daily steroids. After the first year, the checks will need to be carried out every three months. If your child is taking steroid intermittently, for instance, on the '10 days on 10 days off' regime, checks will need to be carried out every three months. You will need to make an appointment with your family doctor (GP) for these tests.

### Cataracts

Children can develop cataracts (clouding of the lens in the eye) after some years on steroid medication. Your

child will need to have an eye test once a year so that an optician can check for any sign of cataracts.

### **Bone thinning**

Another side effect of long term steroid medication is that they lead to some thinning of the bones. This already happens in most children with neuromuscular disorders to some extent, as they often walk less than other children and therefore do not put sufficient stress through their bones. We will give you and your child information about which foods maintain bone strength by containing calcium and vitamin D. However, if your child has low levels of vitamin D, we will advise that he or she takes a supplement. DEXA scans to monitor bone density are now offered to all children taking steroid medication.

If your child has a broken bone that was caused by a minor injury, please contact us and we will advise your local paediatrician about any action needed.

Compression fractures of the vertebral bones (which make up the spine) can occur in a small number of children on steroid medication. If your child complains of pain in his or her back, please contact your family doctor (GP) or local paediatrician. Your child should have an x-ray to rule out the possibility of a compression vertebral fracture.

### **Immunisations**

Children taking steroid medications either daily or intermittently should not be given live vaccines, as they could make them seriously unwell. This applies to holiday immunisations too. Your child can receive inactivated immunisations when they are taking steroid medication. Your family doctor (GP) will advise about the choice and caution regarding steroids and immunisation.

### **Chicken pox**

Chicken pox can be more severe in children taking corticosteroid medicines. We will arrange for a blood test to check whether your child has antibodies to the chicken pox virus before starting steroids. They may need an immunisation to the virus

## **Who needs to know that my child is taking or has taken steroids?**

If your child receives treatment from anyone such as a doctor, nurse, dentist or pharmacist, you should always tell them that your child is taking or has taken steroids, for up to a year after stopping the medication.

Your child should carry a steroid card and/or wear a MedicAlert bracelet at all times, so that people know that he or she is taking or has taken steroids. Application forms are available from the Dubowitz Children's Neuromuscular Centre or online at [www.medicalert.org.uk](http://www.medicalert.org.uk) or by telephoning 0800 581 420.

## **'Fast track' access**

We will write to your local hospital paediatric consultant to request that they arrange direct access or 'fast track' to either the children's ward or children's accident and emergency department once your child starts steroids.

## **What if my child is unwell or cannot take the steroid medication for some reason?**

Steroids are produced naturally in the body by the adrenal gland. If your child is taking steroid medication every day, this gland gradually stops producing steroids naturally for the body. This is not a problem as long as the steroid medication is taken every day.

If, for any reason, your child cannot take his or her steroid medication, for instance due to diarrhoea and vomiting, he or she can become very unwell because the body is not producing steroids naturally.

You should seek urgent medical advice for your child, either at your local Accident and Emergency (A+E) department or use your 'fast track' arrangement with your local hospital children's department. Your child may need to be given the steroid medication through another route, for instance, intravenously (into a vein).

## **What if I want to stop my child's daily steroids?**

Always discuss this first – either your paediatrician or a member of the Dubowitz Children's Neuromuscular Centre at GOSH.

If your child is on daily steroids, his or her body needs time to adjust to not having steroids every day. Do not suddenly stop giving the steroid medication, as your child could become very unwell. The steroid doses need to be reduced gradually to allow your child's body to start producing them naturally again.

If you have any more questions, please ring the Clinical Nurse Specialists for the Dubowitz Children's Neuromuscular Centre on 020 7405 9200 ext 1195. Out of hours, please ring 020 7405 9200 and ask for the On Call Neurology Registrar.