The Children & Young People's Cancer Association

# Prednisolone for children and young people

An information guide for parents, carers and young adult patients

**The purpose of this guide is to give information about the use of prednisolone to parents, carers and young people undergoing treatment for cancer. It also offers help for managing the behaviour of children who need to take regular steroids as part of their treatment.**

Please read this guide carefully alongside any patient information provided by the manufacturer. We have written this guide to give you more information about the use of this medicine in children and young people. Keep it somewhere safe so you can read it again.

## What is prednisolone?

Prednisolone is a steroid medicine used to treat a number of conditions, including lymphomas, such as Hodgkin lymphoma and non-Hodgkin Lymphoma (NHL), Langerhans cell histiocytosis (LCH) and some leukaemias.

### What preparations of prednisolone are available?

Prednisolone is available in tablets of 1mg, 5mg and 25mg strengths. It is also available as a soluble 5mg tablet. Not all hospitals may keep all the different strengths of prednisolone. Your medical team will explain which strength of tablet is needed.

### Where can I get prednisolone from?

It is best to obtain all prednisolone from your treating hospital, as the supply made will always be for the correct length of time needed, especially if it is for a fixed number of days or weeks. Please remember to bring all medication with you at each hospital visit.

## How is prednisolone given?

Prednisolone is given by mouth. It may be given once, twice or three times a day, depending on the treatment plan. How prednisolone is given will depend on why it is being used. Instructions will be on the label or on the patient dosing information chart. It should be given with food or immediately after food or milk. If nasogastric (NG) feeds are in place, it can be timed around these. Your medical team will be able to advise you on this.

Follow the instructions on how to give the tablets very carefully. The instructions may differ if the dose is to change during the course of treatment. The details of how many tablets are to be given will be clearly written on the label or on the patient dosing information chart. Please check with your medical team if you are unsure. In some situations the dose may be reduced towards the end of the course.

If the required dose needs to be made up using more than one strength of prednisolone tablet, this will be explained clearly on the labels or patient dosing information chart.

Sometimes prednisolone soluble tablets will be used if a portion of a tablet is needed. This will be done by dissolving the tablet(s) in water and measuring the liquid dose using an oral syringe. Your medical team will explain how to measure this.

## Are there any side effects?

It is important to remember that everyone reacts differently to medicines. Some will have very few side effects, whilst others will have more. The side effects listed below will not affect everyone who is given prednisolone and may be different if more than one medicine is given.

When prednisolone is being given instead of dexamethasone for the treatment of leukaemia, the side effects are listed as the same, but they are usually less severe with prednisolone.

**Stomach irritation**

If prednisolone is taken at high doses or over a long period of time, another medicine may be given to take with it that will help prevent tummy ache or indigestion. If tummy ache develops, contact your team for advice.

**Weight gain**

When taking prednisolone, it is common to feel more hungry and want to eat more than usual. Appetite will return to normal once prednisolone has stopped. Prednisolone may also cause the body to retain water which may contribute to weight gain. If there is a lot of weight gain this can cause stretch marks, especially on the tummy and thighs. If you are concerned, talk to your nurse or dietitian about how to safely control weight.

**High blood pressure**

Blood pressure will be monitored regularly. Contact your team for advice if headaches or dizziness develop.

**Changes in blood sugar level**

Prednisolone may cause a temporary increase in blood sugar levels. If it is taken for more than a few days, blood sugar levels or testing for sugar in the urine will be done regularly. Feeling more tired or thirsty than normal or having to wee much more often than usual could be signs of this, so contact your team for advice.

**Effect on growth and thinning of the bones**

This may happen if prednisolone is taken at high doses or over a long period of time. Monitoring for this will continue throughout treatment.

**Increased risk of infection**

This is more likely to happen if prednisolone is taken at high doses or over a long period of time. If there are any signs of infection such as redness, soreness or a temperature, or if a cut takes longer than usual to heal, contact your medical team for advice.

**Build-up of fluid**

It is usual to put on weight whilst taking prednisolone. Fluid build-up can cause fingers, feet and ankles to swell and the face to look more round than usual. This is more common if prednisolone is taken for a long time. Swelling gets better after treatment ends.

## Is there anything else I should know about or do?

Contact your treating hospital if:

- a dose of prednisolone is forgotten
- vomiting occurs after taking the dose
- too much prednisolone is given

Any prednisolone that has not been given, or is out of date, must be returned to your treating hospital. **Do not throw away at home.**

### How should the medicine be handled and stored?

- always handle medicines with care
- keep in a safe place, out of reach and sight of children
- store the tablets at room temperature
- keep out of direct sunlight

### Does prednisolone interact with any other medicines?

Some medicines can affect how well prednisolone works, so always tell your doctor about any other medication being taken. Check with your doctor or pharmacist before starting any other medicines. This includes supplements, herbal and complementary medicines.

## Changes in behaviour in children

These may include sleep disturbance, mood swings, anxiety or irritability, bed wetting, and tantrums.

The following are typical of children when the effect of prednisolone is at its peak. Children may:

- be quick-tempered or easily upset, which can make getting along with other children challenging
- feel irritable or impatient, which can affect taking turns and tolerance of other people
- need more guidance and support to manage frustration or behave appropriately
- feel restless or anxious
- seem withdrawn or quieter than usual
- be tearful and need more reassurance and affection than normal
- have disturbed sleep, changes in energy levels, or feel tired during the day
- want to stay home from school or nursery
- have short-term difficulties with attention and memory, leading to frustration or confusion
- feel self-conscious about changes in their appearance





Not all children experience these problems all of the time. The effects of prednisolone are usually short lived and most children will go back to their usual way of behaving once their medication wears off, but it can last for several days after the prednisolone stops.

## Practical suggestions

Managing a child while they receive prednisolone is sometimes difficult, not only for the parents but also for brothers and sisters. The practical suggestions below might be helpful.

**Try to plan fewer family activities** when you know your child will be taking prednisolone (or for a few days after). Do not expect them to fit in with a busy household schedule but do not exclude them either.

**Give positive attention** to your child, for example, praise or rewards for good behaviour.

**It might be useful to make a note of mood swings** to see if there is a pattern that you can work around and schedule outings for when they are least affected.

**Allow your child to run about** in the house or garden to burn off any extra energy. Some parents find taking long walks with their child outside helps as well.

**You might enlist a helper**, for example a grandparent or babysitter, to provide one-to-one attention for your child. It can be exhausting looking after a 'grumpy' child; an extra helper can give you time to recover.

**To control weight gain, offer low calorie and low fat snacks and limit sugary food and drinks.** Tackle increased appetite with sensible eating. For example, you may find giving small portions more often rather than big meals may help to keep your child's tummy feeling full and reduce the constant demand for food.

**Create rest periods** for your child by reading stories, watching relaxing television or DVDs, or listening to music that helps them to feel calm.

**Support brothers and sisters** who may take the brunt of the ill child's aggression. Explain and prepare them for changes in mood and the reasons for this. This can be a very hard time for brothers and sisters. They also need praise for their good behaviour. You may need to find ways to keep your ill child apart from siblings.

**Teach your child about the effects of prednisolone** and explain it is not their fault, but it is because of the medicine they are having. Also explain this to their brothers and sisters.

**Use a baby listening device** so you know when they wake in the night and leave their bed. Re-settle them by sitting by their bedside to offer reassurance so they will fall back to sleep. By doing this you can help stop your child from coming into your bed and prevent a sleep problem from developing.

**Discuss timing of doses** with your medical team if your child has problems at night.

**Tell your child's school or nursery** how prednisolone affects them. Preparing school staff and notifying them when your child is on prednisolone will help them to plan and support in a consistent way. Share with the school how you would like them to manage difficult or challenging behaviour and increased appetite. Your specialist nurse, key worker or social worker may be able to help by talking to the school on your behalf.

**Maintaining routines, boundaries and being consistent about acceptable behaviour** while your child is taking prednisolone will help prevent mixed messages being given to them. Routines and sticking to family rules will allow them to have a sense of stability and security.

This list may help to provide you with new ideas or will reinforce what you are doing already. In addition, the following tips on rewarding behaviour may help.

## Rewarding behaviour

One way of trying to help manage your child's behviour is to use praise or rewards. All children are different, and what works for one may not work for another. Making a reward chart together can be fun and helps to involve the child in the process. This can then be used with small rewards. If your child loses interest, try changing the reward. Below are ideas you could try:

- **tell them how good they are** for being patient or well behaved
- **give cuddles and attention**, or mention how well they have done
- **spend special time together**, for example reading a book, going for a walk, baking a cake or drawing
- **allow them to stay up later** or have an extra bedtime story
- **allow your child to choose a small reward** at a shop
- **take a trip** to a restaurant or cinema
- **allow your child to choose a special DVD** for the weekend
- **have a friend for tea**
- **give small amounts of money** to save up for something

**Remember,** your care and attention are the most important rewards of all.

Strategies to guide positive behaviour work best when they are consistent. Try to reward positive behaviour as often as possible and always offer praise when giving rewards. Remember that cuddles, smiles, or verbal praise are as effective as toys, sweets and gifts and use these strategies often. Try to ignore the behaviour that you wish to reduce where possible. This helps to not reinforce the unwanted behaviour.

Finally, remember to inform your medical team if you notice any change in your child's behaviour or if you need help in any way. Often parents can think this is not something to bother the doctor with, and it is their problem or failing. Dealing with the effects of prednisolone are challenging and can add to the difficulties parents face. They can make you feel very angry and frustrated with your child, which you then feel guilty about. Remember you are not alone. Do talk to a member of your medical team about any of these issues.

If you have any questions about prednisolone, please contact your treating hospital. This guide only gives general information.

Always discuss individual treatment with your medical team. Do not rely on this guide alone for information about treatment.

## Useful information

**CCLG: The Children & Young People's Cancer Association** publishes a variety of free resources to order or download at **www.cclg.org.uk/publications**

Scan to order or download this factsheet or any other CCLG publications FREE of charge.

**Young Lives vs Cancer** provides practical support and advice for children and young people affected by cancer, and their families.
**www.younglivesvscancer.org.uk**

**Macmillan Cancer Support** offers support and advice to those affected by cancer.
**www.macmillan.org.uk**

**EMC (Electronic Medicines Compendium)** offers up to date, approved and regulated information for licensed medicines.
**www.medicines.org.uk**

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**We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.**

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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