

Dexamethasone 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 dexamethasone 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 dexamethasone?

Dexamethasone is a steroid medicine used to treat a number of conditions. It can be used to help treat acute lymphoblastic leukaemia (ALL) and lymphoma, to reduce swelling on the brain for patients with brain tumours and as an anti-sickness medicine

What preparations of dexamethasone are available?

Dexamethasone is available as an oral liquid, tablets or injection. Not all hospitals may keep all the different strengths of the injection and liquid. The tablets are available in 500 microgram and 2mg strengths. Your medical team will explain the strength of dose needed.

Where can I get dexamethasone from?

It is best to obtain all dexamethasone 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 dexamethasone given?

Dexamethasone is given by mouth. It may be given once, twice or three times a day, depending on the treatment plan. How dexamethasone is given, and

for how long, 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 dexamethasone tablet, this will be explained clearly on the labels or patient dosing information chart

Liquid medicine should be measured in an oral syringe through a bung or stopper in the neck of the bottle. This will be supplied by the pharmacy. Your pharmacy team will explain how to measure liquid medicine using a syringe.

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 dexamethasone and may be different if more than one medicine is given.

Stomach irritation

If dexamethasone 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 dexamethasone, it is common to feel more hungry and want to eat more than usual. Appetite will return to normal once dexamethasone has stopped. Dexamethasone 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

Dexamethasone 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 dexamethasone 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 dexamethasone 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 gain weight whilst taking dexamethasone. 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 dexamethasone 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 dexamethasone is forgotten
- vomiting occurs after taking the dose
- too much dexamethasone is given

Any dexamethasone 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 and liquid at room temperature
- dexamethasone liquid has a short expiry once opened, so make sure you write the date opened on the bottle
- keep out of direct sunlight

Does dexamethasone interact with any other medicines?

Some medicines can affect how well dexamethasone 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 dexamethasone 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 dexamethasone 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 dexamethasone stops.

Practical suggestions

Managing a child while they are on dexamethasone 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 dexamethasone (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 dexamethasone 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 dexamethasone affects them. Preparing school staff and notifying them when your child is on dexamethasone 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 will help prevent mixed messages being given to your child. 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 behaviour 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 dexamethasone 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 dexamethasone, 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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CCLG and The Children & Young People's Cancer Association are operating names of The Children's Cancer and Leukaemia Group, registered charity in England and Wales (1182637) and Scotland (SC049948).

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This edition: July 2026

Next review date: July 2029



This factsheet was reviewed by Rachel Greer, Paediatric Oncology Pharmacist, Leeds and Laura Mattis, Paediatric Oncology Pharmacist, London in conjunction with the Neonatal and Paediatric Pharmacists Group (NPPG) Paediatric Oncology Pharmacists Steering Committee alongside Dr Sarah-Jane Verity, Paediatric Neuropsychologist, Newcastle on behalf of the CCLG Information Advisory Group, comprising parents, survivors and multiprofessional experts in the field of children and young people's cancer.

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.

Our work is funded by donations. If you would like to help, visit www.cclg.org.uk/donate or text 'CCLG' to 70085 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.



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