



Dexamethasone for children and young people

An information guide for patients, parents and carers

The purpose of this guide is to give information on the use of dexamethasone in children and young people with cancer. It also offers help for managing the behaviour of children who need regular steroids.

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 many different conditions.

It can be used:

- to help treat acute lymphoblastic leukaemia (ALL) and lymphoma
- to help reduce swelling on the brain for patients with brain tumours
- as an anti-sickness medicine

What preparations of dexamethasone are available?

Dexamethasone is available as an injection, oral liquid or tablets. The strength of the injection and liquid may vary from centre to centre. The tablets are available in 500 microgram and 2mg strength.

Where can I get dexamethasone from?

Dexamethasone may be obtained from the hospital at which you/your child is being treated or from your community pharmacy. Please remember to bring all medication with you at each hospital visit.

How is dexamethasone given?

How dexamethasone is given will depend on why it is being used. Instructions will be on the label or on the patient dosing information chart. If it is being given by mouth it should be given with food or immediately after food or milk. If your child is having nasogastric (NG) feeds, it can be timed around their feeds. Your hospital team will be able to advise you on this.

Liquid medicine should be measured in an oral syringe through a bung/stopper in the neck of the bottle (supplied by the pharmacy). The hospital or shared care centre will explain how to measure liquid medicine using a syringe.

Are there any possible 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. If you experience any of the following side effects, contact your team for advice.

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 to help prevent tummy ache or indigestion. If tummy ache develops, contact your team for advice.

Weight gain

When taking dexamethasone, you/your child may feel hungrier than usual and may want to eat more. Their appetite will return to normal once dexamethasone has stopped. Dexamethasone may also cause the body to retain water which may contribute to weight gain.

High blood pressure

Blood pressure will be monitored regularly. If headaches or dizziness develop, contact your team for advice.

Alteration 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 and/or testing for sugar in the urine, will be done regularly. If you/your child feels more tired than usual, is more thirsty than normal or is passing much more urine than normal 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. You/your child will be monitored 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 you notice signs of infection such as redness, soreness or a temperature, or if a cut takes longer than usual to heal, contact your team for advice.

Build-up of fluid

You/your child may put on weight while you are taking dexamethasone and fingers, feet and ankles may swell because of fluid build-up. This is more common if you/your child is taking this medication for a long time. The swelling gets better after treatment ends.

How should the medicine be handled and stored?

- keep out of reach and sight of children
- store the tablets and liquid at room temperature
- keep out of direct sunlight
- dexamethasone liquid has a short expiry once opened so make sure you write the date opened on the bottle
- always handle medicines with care

Is there anything else I should know about or do?

Contact the hospital at which you/your child is being treated 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 the hospital at which you/your child is being treated. **Do not throw away at home.**

Does dexamethasone interact with any other medicines?

Some medicines can affect how well dexamethasone works. Always tell the prescriber about any other medication that is being taken. Make sure and check with the doctor or pharmacist before taking any other medicines. This includes supplements, herbal and complementary medicines.

Changes in behaviour

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:

- less likely to socialise and may have difficulties getting along with other children
- more hyperactive
- more emotional
- in need of more reassurance and affection than usual
- more likely to misbehave
- more likely to want to stay home from school or nursery
- more likely to have nightmares or sleep disturbances
- more tired and want to rest more, and could have attention and memory problems because they are tired

Of course not all children experience these problems all of the time. The effects of dexamethasone can be short lived and most children will revert back to their pre-dexamethasone or 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 receive dexamethasone is sometimes difficult not only for the parents but also for brothers and sisters. The following list of practical suggestions might be helpful.

Try to plan fewer family activities when you know your child will be taking dexamethasone (or for a few days after). Give positive attention to your child, for example, praise or rewards for good behaviour. Do not expect them to fit in with a busy household schedule but do not exclude them either.

It might be worth keeping a record of your child's mood swings to see if there is a pattern that you can work around and schedule outings 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 in a park or country area 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 some time to recover.

To keep weight down offer low calorie and low fat snacks and limit sugary food and drinks.

Children usually have an increased appetite and gain weight while taking dexamethasone, so tackle this 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 or watching relaxing television or DVDs or listening to music to help 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 brothers and sisters.

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 to catch your child when they wake in the night and leave their bed. Re-settle them by sitting by the bedside to offer reassurance so they will fall back to sleep. In this way you can help stop your child from coming into your bed to 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 them in a consistent way. Share with the school how you would like them to manage difficult or challenging behaviour and increased appetite when at school. 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 whilst your child is taking dexamethasone will help prevent mixed messages from 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 plan of rewarding good behaviour may help.

Rewarding good behaviour

If you would like to **improve your child's behaviour, one way of doing so is to use praise or rewards.** The following list may give you some ideas.

- **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
- **occasionally allow the privilege of staying up later** or having an extra bedtime story

- **allow your child to choose a small reward** at a shop after earning so many stars on a star/sticker chart that you make together
- **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

There are two things to remember about rewards:

- your care and attention are the most important rewards of all for your child
- do not reward them when they are naughty or showing problem behaviour and try to ignore unacceptable behaviour if possible

To achieve success, be creative and get your child involved in the planning of rewards. You will know when to change a reward because your child will lose interest, so you can begin again with something new. Also always offer praise when giving rewards.

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. Too often parents think this is not something to bother the doctor with, and it is their problem/failings. The problems with 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.

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

If you have any questions about dexamethasone, please contact the hospital at which you/your child is being treated. This guide only gives general information.

i USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG)

publishes a variety of free resources to order or download
www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to 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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Leukaemia
Group

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Patient Information Forum

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70300 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

We are grateful to all those who have contributed to this publication. We make every effort to ensure that this information is accurate and up to date at the time of printing. CCLG does not accept any responsibility for information provided by third parties including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

If you have any comments on this factsheet, please contact us at publications@cclg.org.uk CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.