



Dexamethasone

A SELF HELP GUIDE FOR PARENTS



This leaflet offers help to parents in managing the behaviour of children with cancer, requiring regular steroids.

Children's Cancer and Leukaemia Group - www.cclg.org.uk

ABOUT DEXAMETHASONE

Dexamethasone is a steroid – it is especially good at killing leukaemic cells and has been shown to be essential when used as part of the treatment of acute lymphoblastic leukaemia (ALL). It is also used to reduce swelling on the brain for children with brain tumours.

Like most medicines, dexamethasone has side effects that produce physical and behavioural changes. Some of the physical changes include fluid retention, puffiness, increased appetite and increased chance of infection. The changes to behaviour include sleep disturbance, mood swings, anxiety or irritability, bed wetting and temper tantrums.



BEHAVIOUR SEEN DURING DEXAMETHASONE TREATMENT

The following are typical of children when the effect of dexamethasone is at its peak.

Children are:

- 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, want to rest more and can 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 the medication wears off but it can last for several days after the dexamethasone stops.

PRACTICAL SUGGESTIONS

Managing a child while he/she is receiving dexamethasone is sometimes difficult not only for parents but also for brothers and sisters. The following list of practical suggestions might be helpful.

- 1) **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 him/her to fit in with a busy household schedule but also do not exclude them.
- 2) **It might be worth keeping a record of your child's mood swings** to see if there is a pattern that you can work round – scheduling outings when they are least affected.
- 3) **Allow your child to run about** in the garden, bedroom, etc. to burn off any extra energy. Some parents find taking long walks with their child in a park or country area helps as well.
- 4) **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.
- 5) **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 that 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.
- 6) **Create rest periods** for your child by reading stories or by watching relaxing television or DVDs or listening to music to help them to feel calm.
- 7) **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.
- 8) **Teach your child about the effects of dexamethasone** and explain it is not their fault, it is their “grumpy tablets”. Also explain this to their brothers and sisters.
- 9) **Use a baby listening device** to catch your child when he/she wakes in the night and leaves their bed. Re-settle them by sitting by the bedside to offer reassurance so they will fall back to sleep. In this way you will stop your child from coming into your bed and will prevent a sleep problem from developing.
- 10) **Discuss timing of doses** with your medical team if your child has problems at night.
- 11) **Tell your child's school or nursery** how dexamethasone affects them. Preparing schools 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.
- 12) **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 as well.

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.

- 1) **Tell him/her how good he/she** is for being patient or well behaved, etc.
- 2) **Give cuddles, a pat on the back** or mention how well he/she has done.
- 3) **Spend special time together**, for example reading a book, going for a walk, baking a cake or doing a drawing.
- 4) **Occasionally allow the privilege of staying up later** or having an extra bedtime story.
- 5) **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.
- 6) **Take a trip to a restaurant or cinema**.
- 7) **Allow your child to choose a special DVD** for the weekend.
- 8) **Have a friend to tea**.
- 9) **Give small amounts of money** to save up for something.

There are two things to remember about rewards:

- 1) **Your care and attention are the most important rewards of all for your child.**
- 2) **DON'T reward him/her when he/she is naughty or showing problem behaviour but reward good or acceptable behaviour and try to ignore unacceptable behaviour if possible.**

To achieve success use your imagination 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 that this is not something to bother the doctor with, and that 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.



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