

Siblings may also struggle, as they see their sister or brother getting away with things that they wouldn't.

“For Ella’s sister Jen, we would remind her of the steroid week approaching, and that Ella’s behaviour was associated with the steroid and never her. We would praise Jen for how well she was doing, and Ella often relied on Jen for reassurance and cuddles.”

Clearly it seems very unfair, but what can you do about it? The main thing is that everyone in the family knows that it is the medicine that is making your child feel horrible. A home environment that is understanding and sympathetic, will be an enormous relief to your child, and will help reduce tensions within the family.

Similarly with friendships at school and elsewhere – if people understand what is happening, they are more likely to make allowances for what otherwise would be unacceptable behaviour. Don't forget, a nurse can come and talk to the school to explain.

A few final words

If you are struggling with any aspect of your child's treatment for cancer, including the behavioural impacts on your family, you must speak to your paediatric oncology nurse, either in the hospital or in the community team. There is likely to be help available for families who are finding it really tough to deal with, so don't be afraid to ask.

- **Be positive and hopeful**, and believe in the treatment as a means to an end - resulting in your child being well again
- **Your reaction will influence** how your child reacts
- Each child's reaction to individual drugs will vary considerably.
- **Children are incredibly resilient**, and the majority do cope
- **Speak to your paediatric oncology nurse** if you are struggling.



Dexamethasone

A guide for parents



Dexamethasone - an introduction

Steroids are a crucial part of your child's treatment for leukaemia. Research over many years has shown that using the steroid dexamethasone gives your child the best chance of being cured. However, it is important to know that there may be difficult side effects and your medical team will discuss the potential side effects with you.

This leaflet is designed to help prepare you for those side effects that parents often find most difficult to cope with, especially in the initial phase of treatment (during the first month), namely:

- **Mood swings**
- **Increased appetite**
- **Feeling tired**
- **Changes in appearance**



School, friendships and relationships

Such changes can potentially have an impact on school life and friendships.

"I felt completely out of control, starving and a mess when I took it! I would cry at anything. My mum was very supportive but at the same time made me get up and try and stop freaking out. I think the word I would use is being totally irrational."

An out-of-control, hungry and irrational child is likely to fall out with a lot of people! If you are sending your child to school when on steroids, you may want to:

- Tell the school about the steroids and the possible effects on your child
- Arrange for a place at school where your child can go to for some rest during the school day
- Prepare snacks to last throughout the day and inform the school, so that arrangements can be made if he/she needs to be excused from classes
- Think about assigning a mentor – possibly a good friend, or a teacher, who will recognise if your child is beginning to struggle, and will be able to take him/her to a quiet room at school for a rest

If you feel unable to do any of that, for whatever reason, speak to your nurse because they will be able to talk to the school on your behalf and make any necessary arrangements. That is what they are there for.

Consider your child talking to your community play specialist or a psychologist- they may find it helpful to talk to someone independent. These issues can be made to appear more normal by a professional, which may be more believable for the child, as opposed to mum or dad just saying things to make them feel better. Your paediatric oncology nurse is there to help with issues such as this.

"Our daughter saw a psychologist, as she herself identified she may need help in the transition back to school. I know body image was discussed relating to steroids. This was incredibly helpful for her at the time."

Increased appetite

Your child is likely to have an appetite unlike any you may have witnessed before. However, remember that at different points in the treatment, the opposite will be true, when they may feel nauseous from the chemotherapy.

Here is a quote from a parent blog (of a 4 year old child):

“Tonight for dinner, she had 4 slices of pizza, a few pieces of carrot, 1/2 an apple, a jammy dodger, a marshmallow, 2 plates of chicken, 5 chicken nuggets, and 2 helpings of risotto. That's what the dexamethasone does.”

So how do you deal with such an appetite? It is almost impossible to refuse their demands because it is a physical craving caused by the medication. Here are some suggestions:

- Give them what they want but try to give them small portions at a time if you can
- Try to eliminate calories where possible. For example, give them lots of water to drink and low fat versions of food they want. Don't butter the sandwiches, and grill the bacon/sausages. Try to avoid sweets and crisps
- You may find they want the same food over and over again so if that pattern emerges, don't fight it because it won't work! Just make sure it is as nutritious and as low in calories as you can get away with



It is not unusual for a child to wake up in the middle of the night and demand food. Before you go to bed, be prepared for having to get up and give your child some food. This way, it is less likely to wake up the household and you can plan for something nutritious to be on hand.

“He ate 40 sausage rolls in one day. He put on so much weight he couldn't walk after midday because his legs couldn't carry him”

Feeling tired

Generally children are more tired when they are on steroids, and may also have difficulty in falling asleep. In addition dexamethasone may cause aches, pains and muscle weakness. All of this can contribute to their potentially grumpy mood, but if they say they can't walk out to the car, they probably can't. Their back or legs may ache, or they just may not have any energy. Just being aware of this and realising they aren't necessarily just being difficult, might prevent one or two arguments. Also, do speak to your medical team if the aches and pains persist. They will be able to help with pain relief, but will also be monitoring persistent bony pain for a condition called avascular necrosis which can sometimes develop.

Children are encouraged to remain as mobile as possible but if you have a pushchair or wheelchair for your child, you may find you will use it more frequently during steroid blocks of treatment. If you don't



have either and he/she is clearly struggling, speak to your nurse who can order one for you. Some children may find they require help from a physiotherapist and will need to do some exercises to build up their strength again.

Changes in appearance

The likely result of the increase in appetite is that your child may gain weight quite rapidly. As with everything, each child will be different in the extent to which this affects them. Ultimately, any weight gained will almost certainly be lost again, as there may be periods when your child will neither want, nor be able to, eat. However, the change in both your child's appearance and behaviour can be difficult for the whole family.

“My daughter gained a huge amount of weight during the steroid part of her treatment. She became so fat that she couldn't stand up from a sitting position without help, and she couldn't walk from one end of the room to the other without toppling over. Her neck totally disappeared, and I lost my beautiful little girl. People stared at us when we were out and I knew they were thinking, 'look at what those awful people have done to that little girl', especially if she was munching away in the pushchair because she just could not stop eating. This period was one of the worst parts of her treatment, worse than her losing her hair. I'm not really sure why, and it feels awful to admit it, but it's true. Perhaps it was because we were so unprepared for the dramatic and rapid changes.”

Remember, your child will start to lose the weight again when the steroid treatment is finished.

Other changes will be apparent, too. Most commonly, a 'moon' face, and perhaps dark circles around the eyes. Increased facial hair may also occur. With these physical changes, your child may struggle with body image which can add to the behavioural stresses also caused by this medicine. These are all temporary issues, but issues which cause anxiety at the time.

Mood Swings

Children on dexamethasone tend to become very demanding. They can become very angry for no apparent reason and may appear obsessive, angry, tearful, and inconsolable when they don't get what they want. It can happen even to the most placid of children. It is important to realise that your child cannot help feeling as they do. It is temporary, and your child's normal character will return when they have finished their course of dexamethasone.

“We had absolutely no idea the way it was going to change his personality. As he was so young he couldn't control the way it was making him feel. Some older children and adults can control their emotions better I think, but he lashed out.”

'Coping strategy' suggestions

- **Maintain a discipline structure**
It isn't necessarily easier or fair for the rest of the family to give in all the time. Just because they are on steroids and feel the way they do as a result, is no excuse for *really* bad behaviour. Make sure they know what the boundaries are, and be consistent. This is really important and it will help the rest of the family know how to deal with the situation too.
- **Keep them occupied but away from other influences**
For example, think about not having friends round to play (younger children) and maybe for older children, just let them shut themselves away if that's what they want. They are probably happier on their own.

“Her moods are very fragile, and you can see the insistent, anxious, slightly compulsive edge to her. We had to cancel a few outings over the weekend, because she didn't want to see anyone. Hopefully we have dealt with it in a way which has eased her stress.”