

8 BEING THE PARENT OF A CHILD WITH ADDISON'S

a) MONITORING YOUR CHILD'S CONDITION

As the parent of a child with Addison's, there are practical and emotional issues surrounding their care, which you will need to address. At the practical level, you need to be able to monitor their condition and be alert to any need to adjust their medication.

This means becoming as well informed as you can about the disease, its signs and symptoms, the circumstances which might trigger the need for an increased dosage of medication and how much extra might be needed. It also means being trained so you can give an emergency injection if you have to.

The more you can discuss these practical issues with your child's endocrinologist, the better equipped you will be. You may find it helpful to give them a written list of your questions and the issues you would like to be educated about in advance of your appointment, so they have time to collect the appropriate information.

The amount of steroid medication to prescribe for children and teenagers is a fine balance and is likely to require some experimentation to get it right. Too much can stunt their growth. Too little can leave them lethargic and unable to concentrate on their schoolwork. In general, hydrocortisone is preferable to prednisone or dexamethasone, as it is less likely to interfere with their growth.

In turn, you will have to help your child learn to manage their health as far as possible. Some of the things they will need to be aware of are:

- *Remembering to drink plenty of fluids so they stay hydrated (especially on school trips and sports days).*
- *Remembering to take their pills at the right time of day, so they do not run low on steroid cover.*
- *Being alert to the early warning signs that they are running low on steroid cover, such as a headache, stomach ache or wobbly knees.*
- *Remembering to carry their 'emergency' pack with extra hydrocortisone and their injection kit when they go on school trips.*

Some schools have a trained nurse who is able to give injections. You will need to talk to the staff at your child's school and establish what level of first aid care they are able to give for your child's condition, should it ever be necessary.

At the emotional level, you need to be aware of your own emotional needs and the anxieties that surround being the parent of a child with a chronic illness. You need to find ways to get personal and practical support from your circle of family and friends, so that you can stay calm and caring towards your Addisonian child and their siblings.

There is a helpful publication on caring for your Addisonian child, "Our Addisonian Kids" listed in section 11.

"It's hard for a parent to see their child go through this disease. We can take them to the doctor, do what they say, but we can't make it go away. Since my son has been sick with Addison's my life has been so stressful: going to all different kinds of doctors, holding down a job, and a household with three other kids who need me as well. I feel like I am running all the time. I am so tired. With my son, I do a lot of joking around to make him smile. When he smiles, it makes me feel good." KAREN

b) SUPPORTING YOUR TEENAGER

Developing a chronic illness during the teenage years can be doubly challenging for both the teenager and their parents. Particularly where the teenager has been severely ill before diagnosis, they will have experienced anxieties and emotions, which are difficult for them to describe or resolve. Recognising this fact can make it easier to move on. It may help your teenager if you are able to explain your own emotions in a straightforward way.

A teenager is preparing to become an adult and take full responsibility for managing their own health, but they have not yet become that adult person. As a parent, you need to be able to step back where appropriate and move in again when they need more practical help from you.

- *Encourage your teenager to educate themselves as fully as possible about the disease.*
- *Make sure they understand the potential consequences of skipping doses.*
- *Help them become competent to give themselves an emergency injection.*

During their growth spurt, your teenager's medication may need to be adjusted more frequently. Again, you need to be alert to the early warning signs that they are running low on steroid cover and raise any important changes in the general health with their endocrinologist.

"I am a 17 year old girl who has recently been diagnosed with Addison's. I also have several other autoimmune complications. I have some advice for you on how to handle your children's illnesses. Please be as strong as you can for them and make sure you talk about it. My mother tried hard but I ended up having to be the strong one and 'protect' my parents when I was very ill. I never felt I could talk about it with my family because they would cry uncontrollably. And please make sure your children know that you don't think they're doing it to themselves when they are ill. Because after a while of people telling you it's all in your head you start to believe them." KATIE