Common Reactions in Children to Chronic Illness

The long term process of adjusting to having a chronic illness and managing the demands of the illness and its treatment can be a challenge for any child. Children all respond in different ways depending on their personality, on the illness itself, and the support they are given. But most children experience some kind of difficulty.

This leaflet outlines some common reactions and makes some suggestions about strategies to try to help them.

There is no single reason for changes in the way children respond to a serious illness. However, below are some common themes:

**How Children Understand**

Children learn about illness in the same way they learn about the world around them – through a combination of their own experience, watching other people’s experiences/reactions, and by trying to make sense of all these impressions and information to form their own ideas and beliefs. Children’s thinking develops in stages starting with fairly simple ideas and getting gradually more complex as they get older. When very young they tend not to think “logically” and can take things very literally, based in the here-and-now. As they get older they become more able to tolerate delay, understand things more widely, and can see other people’s point of view. When children become ill their understanding of what happens to them will depend on their development. Sometimes mis-understanding can leave them feeling worried, upset or confused and this affects how they react and behave.

There is no evidence that there is a connection between the seriousness of a child’s illness and their reactions to it. Much will depend on how the child understands and feels about their illness and its treatment. Therefore how other people talk about it, and support them, will have a big effect on how they cope.

**Understanding of Illness and the Body**

Very young children are curious about their bodies but have little understanding of how the different parts are connected. They might know there are things inside them but worry about how they work. As they grow they will develop new ideas about the body, and what the different parts do. Ill children tend to have more awareness of the part of their body that is not working well, but it is important to keep re-visiting the explanations they are given so they can update their understanding as they get older. Using pictures and drawings can be a really helpful way to find out what children understand and help them get more accurate information.

**Keeping Things “Normal”**

There is some evidence that children cope better with illness if they are able to carry on with as normal a life as possible – keeping to the same routines, having the same rules and boundaries, and doing the same kind of activities if possible, including education and joining in with their family as usual.

**Procedural Distress & Adherence**

Many children find having procedures done difficult. But there are ways to help children cope better with these situations, particularly by helping them develop coping strategies between procedures and preparing them in advance. If you need more information about this some advice can be found by following the link: [www.shropscommunityhealth.nhs.uk](http://www.shropscommunityhealth.nhs.uk)

**Communication & Information**

Children often get frightened or worried when they don’t understand what is happening and have not had a chance to prepare. It is important to think about what a child needs to know, how they might react, and thinking about when is a good time to talk. Children need time to think and ask questions, but the information they are given needs to be suitable for their age. It is also important not to leave them with unanswered worries – they will draw their own conclusions which may not be helpful. They need to know that they can ask questions and get honest answers, and that their views will be listened to. When giving information try to include specific facts but also ideas about how things will look, feel and sound. Use of drawings can help and will help the child remember what they have been told. If possible, it can also be useful to ask children how much preparation time they would like, and to plan with them how they want to cope. Too much advance warning might make them worry too much ahead of time, but practicing coping strategies will help with this. Another useful tactic is to build up some shared names for things, including the illness/condition, the medicines, the equipment, and so on.
**Behavioural Reactions:** Nearly all children will respond to illness by behaving differently. Sometimes they act younger than their age, for example by crying more, wetting their bed, or becoming more clingy. They might become anxious or panicked, or they might become more irritable and annoyed about things. These are all common reactions. Children might feel sad, angry, or frightened, or they might have sudden changes in mood which are hard to predict. They may express their feelings by being angry or aggressive, or they might withdraw and not want to join in anything any more. They may refuse or find it hard to go to school, have trouble sleeping and become very tired. Others react by getting too active and find it hard to relax. All these reactions can be a result of the child expressing their feelings, especially if they cannot understand what is happening to them or find words to describe how they feel. Remember, your child’s behaviour may be hard to deal with but it is always important to think about how they are feeling – not just respond to the behaviour it leads to. Changes in routine, boredom and frustration, being separated from family and friends, feeling worried, and dealing with hospitals and lots of new people, will all affect how a child reacts. Although it can be hard to decide how firm to be, try to find a balance between keeping the “rules” for behaviour the same while making sure you also have time to listen, to and talk with your child. Try not to excuse behaviour that you would have previously not allowed – even ill children need to know what is OK and what is not acceptable.

**Social Effects:** Being ill usually means relationships with other people change. Other people might be curious and ask lots of questions, or they might be anxious about the illness and avoid the child because they don’t know what to say. Children often need help to think about these changes and to plan how they deal with them. They might like you to talk with their school and get teachers to help with explanations in class, or they might like to keep things more private but work out ways to answer difficult questions or comments. It usually helps to plan ahead and think of solutions together, and to work out what things often sets off getting upset so you can avoid them if possible. You may need to plan things ahead more so that you don’t have too many events going on or too many visitors at once, as that can get tiring and overwhelming.

**Treatment Effects:** Some treatments will leave children feeling tired, sick, with aches and pains, or upset and anxious. It is always important to try and find out what side-effects are normal and expected, and try to notice how your child tends to respond. You can then prepare ahead and try to plan ways to cope with those more difficult times.

**Coping Strategies and Things to Try:**

- Talk to your child so that they know they are being listened to and understood. Help them give names to their feelings and experiences and try to help them make links between what they feel/think and how they are reacting.

- Have things available to keep them busy and occupied. It can help to have some games and small activities ready for difficult times – especially if there are periods of waiting or delay. Ask the hospital play specialists and ward staff if they can give you ideas or help.

- Try to identify when things are especially tricky and plan ahead if you can. Think about possible solutions together and talk about what your child might like to help make things more manageable. Practice coping tactics at home – using distraction, relaxation or breathing techniques. Every time your child practices make sure you reward them with a small treat so that they learn to get better at these coping strategies – it will help.

- Talk with the medical team about how your child is feeling and reacting, and ask about any choices they can make to make things easier or more comfortable. For example, having less people in a room, less noise, or choices about who does a procedure.

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