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Helping Your Child Cope with Neurofibromatosis

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When a child is diagnosed with neurofibromatosis, parents have numerous questions to which they need answers. While they are learning all the medical intricacies of NF, they inevitably stop and ask themselves, "How will I explain NF to my child?"

To answer that question requires parents to consider their own ability to cope with the diagnosis and their child's age and ability to understand a variety of concepts.

Why NF Is So Difficult To Explain

NF is a variable disorder that has no predictable course, no certain prognosis, and can vary in severity. In addition, NF has a whole host of seemingly unrelated symptoms that make it a complicated disorder to unravel.

So, parents often find themselves playing detective to figure out whether what is happening with their child's health and behavior is connected to NF or has a separate cause. For example, children might struggle in school or have social problems, and parents must try to sort out how much of these difficulties might be related to the NF. Understanding all the aspects of NF may be difficult for you, and even harder to explain to your child.

When you are sorting all this out, it is hard to keep your own fears in check and talk with your children in ways that keep optimism alive. Your greatest challenge communicating with your child will be to minimize his fear and not transmit your apprehension and anxiety.

Understanding Your Own Ability To Cope

The feelings of sadness, anger, guilt and anxiety you may feel are completely normal for a parent whose child has NF. Therefore, it is important to understand your own feelings before you approach your child.

A great deal you are experiencing comes from the sense of loss parents feel when a child is born with a health issue like NF. Parents' expectations of the child they are going to raise become radically altered with such a diagnosis. In a sense, parents go through a grieving process over this loss that is similar to the death of a loved one.

It is important to remember that you do not go through the grieving process in a prescribed step-by-step fashion once and then you are done. In fact, you will move fluidly back and forth between these phases from time to time. So, it is important to be aware of your reactions and be sensitive to what your current state of mind allows you to handle.

Psychologist Elizabeth Kubler-Ross outlined this process in her landmark work on grief. I have provided examples for each stage that relate to NF.

Stage I: DENIAL

- "He just has some birthmarks, otherwise he's fine."
- "There cannot be anything wrong, she looks and acts perfectly healthy."

Stage II: ANGER

- "What have we done to deserve this?"
- "Why my child?"

Stage III: BARGAINING

- Promises to God like, "I'll quit smoking if you make this go away."
- "I'll be OK if the NF amounts to just café-au-lait spots and learning disabilities."

Stage IV: DEPRESSION

- "What will become of my child?"
- "I've failed as a parent."

Stage V: ACCEPTANCE

- "My son may have NF, but he's like any other child."
- "I accept that my daughter has NF. Now, what can I do to help her and others?"

Understanding Your Child's World

Children pass through stages that shape their ability to understand their world. To properly consider what and when to tell your child about NF, you need to be aware of what explanations make sense to children at different ages.

Keep in mind, every child's development is unique, and no child ever develops all key areas -- cognitive, social, behavioral, motor skills -- simultaneously. Children may develop more quickly in one area and slower in another. For example, a one year old may begin to speak but have trouble standing.

It also is important to make sure your child knows he is part of the treatment team. When kids feel included, they feel empowered to affect their destiny, which will help them feel better about themselves and develop a sense of independence and self-sufficiency. With these feelings, they will be better able to handle doctor visits, uncomfortable exams, and procedures.

2 to 4 Years of Age

Before the age of two, children are beginning to develop their language skills and understand their place in the world around them. From ages two to four years, children become more actively involved in their world.

However, preschool age children cannot really understand what causes something or how their behavior may cause something else to happen. They deal with events in their lives as they happen. Preschoolers begin to think in ideas and realize that their thoughts can be separate from their actions. For example, just thinking about eating a cookie versus actually going over to the cookie jar and taking one.

In addition, children at this age cannot understand something they cannot see, and their thoughts are tied to concrete, observable, and tangible things. Therefore, children cannot grasp the idea that NF is caused by an genetic disorder or an underlying process.

Children between the ages of two and four can really only think of one idea at a time. So a child with multiple manifestation of NF can only think about and wrestle with one symptom at a time.

The practical application to these developmental factors are that it is best to deal with one issue at a time, and to stick with specific, concrete issues you are trying to address. Also, because kids gradually become aware of NF, it is helpful to begin to use the terms neurofibromatosis and NF. It may be easiest to refer to NF in conjunction with the specific symptoms, so that your child begins to group these disparate issues under the umbrella of neurofibromatosis. This is also an age when your child can be introduced to the NF community to understand that others are experiencing the same things.

The manner in which all this information is delivered is crucial. Your explanations should convey there is a distinction between the NF and your child. For example, NF is a difficult disorder to handle but your child is not difficult. If this is not made clear, your child may experience a sense of being flawed or somehow defective as a person. To counteract this negative feeling, you will also want to emphasize to your child the positives about him child and his life.

At this stage your child can and should become an active participant in her care and treatment, so it is important to find ways for her to participate in doctor visits. For example, ask your child what time of day she prefers to go, what she wants to wear for the appointment or give him a choice as to the route to take to the office. Establishing rituals is another way to instill a sense of predictability, and thereby some control, to doctor visits. For example, you may decide with your child that after every appointment you stop for a snack, a new book, or at a nearby park to play.

4 to 6 Years of Age

Between the ages of four to six years, children begin to take one idea and relate it to another, and they begin to understand something about cause and effect. They also can understand a little bit about things that are not visible to them. For example, they begin to understand something about genetic issues and the idea that there is something inside that leads to something showing outside. So you can begin to discuss underlying causes of NF and how what is inside may show up in different ways externally.

Kids at this stage are very active in their efforts to make sense out of their experiences. You probably have examples from your growing up when you came up with an inaccurate conclusion about something based on bits of information from a variety of situations. For your child with NF, you can try to explain about genes, and five years from now you will hear that your child thought that he has NF because he wore the wrong color blue jeans.

It is best to continue to tackle one NF-related subject at a time during this age span. Moreover, when you discuss a subject, you will want to ask your child to explain back to you what you have just discussed.

At this stage, your child may begin to express anger about having NF. Allow her to have and express feelings about what is happening. This is an important time to reinforce that your child is separate from the disorder. Remind her that NF is just one aspect of who she is, like having brown eyes or being able to throw a ball. Use NF as a reason to explain to your child that life is often imperfect and unpredictable, and some people have more to deal with than other people.

Role play with your child to say out loud the words that they might use to explain NF in social situations. Since kids this age are action-oriented, if they do not practice the words, it is not going to become second nature. They can be in control by practicing with you, actually using the words, doing role playing, imagining different situations that could come up. Your child should also hear how you talk about NF to other people, so you can be a role model.

With all this exposure, when kids have to think fast on their feet, they will have phrases to use and can stand up for themselves to other children. It is important at this juncture to help your child deal with any sense of being different from his peers. This will depend on the involvement and the severity of the manifestations. You will have to arm your child with words that he can use to explain his situation to other children and teachers. The child has to be able to say, "I have NF -- it is not contagious. I am used to it and you will get used to it too." Saying this will help your child maintain his self-worth and dignity.

6 to 10 Years of Age

Between the ages of six and ten years, kids they are able to think in systematic ways and really appreciate the complexity of their world. Children now can think in terms of abstract concepts like the future and its possibilities.

So it is at this point children are going to start to have a lot more questions about what is going to happen -- "If I am like this now, if I am having this struggle right now, what is it going to be like in the future?" They also can make comparisons between people. They will be able to think, "Well, I know that I have NF and Bobby has NF, but he has bumps on his arms and I don't."

Kids can understand at this age that there are a range of things that we cannot predict, and not always know what is going to happen next. It may not be a comfortable thought, but as they start to wrestle with that they may need to discuss it often.

At this age, your discussions of the genetic aspects of NF may include an explanation, such as, "The body has a map or a plan inside that tells your hair and eyes what color to be. That same plan can sometimes create these brown spots and the bumps. When that happens, it is something that we have to make sure we take care of, look at, learn about and visit the doctor and deal with. It is going to affect us in different ways, but we will be understanding and help you deal with the situation."

Those kinds of explanations provide a beginning. When your child has specific questions, that is the time to elaborate, but never far beyond what the child has asked and can understand. Stick with what is going on today and talk about it in real, present, and concrete terms.

Adolescence

Adolescence brings more serious questions about the future. Some of the concerns are going to be, "What is this going to mean for my relationships with the opposite sex? What does it mean in terms of how I define who I am?"

In addition, adolescence is always a time when family dynamics become complicated because the teenager is developing an identity distinct from his family. Whenever a child has to come to terms with something that is difficult and has mixed feelings associated with it, a child often deals with these issues by taking the pieces that he doesn't like and puts them "outside." For example, he may accept that he's not a great tennis player, but will blame you for all the unwanted attention that NF brings to him.

So rather than have these feelings, teens will give the feelings they don't like to someone else. Instead of having a struggle with themselves or being mad at themselves for making a mistake, they often set up a fight with you. They are in effect saying, "I am going to create a fight between us so I do not have to face what I do not like." By focusing outside of themselves and blaming others for their troubles, teens defend against painful self-doubt and anxiety.

That is an example of hating something that is an internal conflict and putting a piece of it outside to create an external conflict. We all pick fights with somebody with words, not wanting to face things inside of ourselves.

One thing that parents have to do is gently give back to the child the pieces that the child is trying to put on the parent or the health care professional. For example, saying things like, "Right now I know you are really mad at me for making you go to the doctor again. Did you consider that your anger may be because you have NF and you are tired of having to deal with it all the time? NF is hard to deal with and you have reasons to be mad." Comments like this move the struggle from NF being interpersonal to being an internal struggle.

Staying Positive

Throughout all of the stages described above the key to helping you and your child cope with the unpredictable road of NF is to stay optimistic. Optimism is not a way to simply sugar coat the issues by saying, "Everything is going to turn out wonderfully." Optimism is understanding that there is always something you can do to better the situation -- attend a support group, learn about the latest research advances, focus on what is going well in your child's life. As long as you have something you can do to cope, you can avoid the hopelessness and helplessness that can sometimes overcome you.

You can be instrumental in helping your child gain self-esteem and a positive attitude about her life. You can show her that there is always some way to be effective and to cope. Most importantly, you can give your child hope.