

Sharing the Diagnosis

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When you get a diagnosis of any sort, others want to know details, often when you are trying to come to terms with the diagnosis yourself. There is no right or wrong way to share information, but learning tips from others might be able to give you some ideas.

Make sure you have some “default” responses for how to answer questions. Think of your own very quick and simple way to answer basic questions. Some ideas and suggestions are included below.

Explain to children that everyone’s bodies are different and unique, and that just the way you did not choose your hair color or height, you cannot choose how your body works. Everyone works differently and learns and experiences the world in different ways.

With others...	With your affected child...	With siblings...
<ul style="list-style-type: none"> • Anticipate questions! You will get them. • Before you get questions, consider how you will answer and what you are willing to share with people. • Some families find it helpful to write out a short description of the diagnosis on cards to give away. • Give people the resources to look up information on their own; you are not responsible for explaining everything! • Have a few resources ready to share with others. You can carry a copy of materials from the National MPS Society or just give them a simple explanation and then empower them to learn about it themselves. 	<ul style="list-style-type: none"> • Use <i>developmentally</i> appropriate language, which may not always correspond to the biological age • Using words to describe MPS as “being sick” or “a disease” may make the child feel like something is wrong with them and may tie it in with an illness like a cold or the flu that they will recover from in a short time; give them a name for the condition (e.g., “I have MPS”) and a very simple way to explain it to others when they are asked. • Answer their questions and encourage the child to come and talk to you at any time. • It is always okay to say “I don’t know” when the child asks you a question. You do not have to have all the answers! 	<ul style="list-style-type: none"> • Use age-appropriate language and clear, straightforward information. • Remain available for questions, and encourage your child to come to you over time. • Use real terminology, as much as possible. • Be honest. It is not easy, but it is harder to “reverse” inaccurate information later on. • Children do best processing pieces of information, rather than long explanations. Answer their questions at the time, but do not feel as though you have to provide extensive answers all at once. • Look at some resources available that explain how children understand illness at different ages for more ideas on talking to siblings.

Ideas for Answering Common Questions

These are questions that you may get, with some ideas to help you respond to them. Think of your own answers and how much information you are willing and ready to share. It is a good idea to consider family counseling, even for a brief period of time, to have the support of professionals trained in answering difficult questions like these.

“What is MPS?”

How you respond to this question depends on the person asking, but a simple response is something like: “Our bodies are made up of cells, and the cells have lots of jobs. One of the jobs is to get rid of waste, kind of like trashcans. With MPS, the trashcans in the cells overflow with cell waste, and this makes it build up in the body. This causes problems throughout the whole body, and they are different in every person.”

“Why does my sibling hit me and it is okay, but I get in trouble when I hit other people?”

Explain to the child that you do different things to respond to behaviors, and that you have different consequences for each child. You can have the same rules, but the things that happen if you break the rules are different. They may be things like losing TV time, moving away from the child who is being aggressive or firmly and calmly saying “no,” but all those things are types of consequences. Make sure to praise your children for good, appropriate behaviors!

“Am I going to die from MPS?”

This is probably the scariest question, and one that you may have yourself in worrying about your child. It will help if you look at a description of how children understand death (some of the links in the “resources” section below can help) and consider what the child understands. It is fine to say something like: “We are all going to die, and none of us knows when that will happen” and to include some thoughts about your spiritual or religious beliefs, if you have them. There is no right or wrong way to answer this, but it is one of the most difficult for parents to process themselves, which makes it very hard to try and answer for others.

Resources

National MPS Society

- <http://www.mpsociety.org>

Wonders & Worries: Developmental Stages for Children Facing the Illness of a Family Member

- <http://www.wondersandworries.org/developmental-stages-for-children/>

Talking with Children and Youth about Serious Illness

- http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication/Talking+with+Children+and+Youth.aspx