Let's talk about...

Ideas for Explaining a Child's Genetic Condition

There are many unknowns when a child is diagnosed with a genetic condition. This can make it hard to explain to children. Keeping information clear, simple, and accurate is helpful.

What is a genetic condition?

■ The body is made up of millions of tiny cells. There are many kinds of cells in the body: brain cells, skin cells, hair cells. . . Cells are everywhere.

■ When a baby is growing, the cells that are making their many parts sometimes change, or "mutate." The cells that mutate cause the genetic condition. This may lead to a different type of life for the child than what was expected.

Tips for explaining your child's genetic condition:

■ Begin by sharing what you know about your child's case. Share the name of the genetic condition and common words they might hear. Share that it is not a condition that a child can "catch," from someone else like a cold.

■ Share what parts may be different about your child. For example, does your child have physical differences?

■ Talk about the medical needs your child has. When children know the purpose of medical devices, such as tubes or lines, it can make them seem less scary. Consider showing pictures while you talk about this.

■ Discuss in simple terms how the inside of your child is different. If the brain grew differently, describe how your child may do things differently now (need help with eating, for example) or in the future (may not walk or talk, for example), including if the child's life might be shortened.

■ Remember to also share positive information. Be sure to focus on what your child can do, or what the family can do with your child (like cuddle, feed, dress, and love).

■ It is okay to say, "I do not know right now." Remind the child that when you do know the answer, you will share it.

For more information or to connect with a Child Life Specialist, please visit: http://ucdavis.health/childlife

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