UNIQUE

UNDERSTANDING GENES
& CHROMOSOMES

Telling your child or their sibling(s) about a rare genetic diagnosis

www.rarechromo.org

We are all different and how you tell your child and/or their siblings about a rare genetic diagnosis will be unique to you, your child and your family. However, we hope this guide provides some tips and ideas to help pass on information to your children.

It may be helpful to provide children information about a genetic condition slowly over time in a way they understand.

Getting ready to talk to children about a genetic condition

The first conversation opens the door to an ongoing conversation about your child's condition. It is important that you feel ready to start this conversation. Often there is no hurry to start talking to your child and/or their sibling(s), and getting used to the idea yourself can be helpful.

Taking time to talk to friends and family or seeking counselling or psychological support may be beneficial.

You may also like to engage with support groups or charities specific to your child's condition for ongoing support. Many charities understand the questions and needs of families with a new diagnosis and are able to offer support tailored to the condition. Although not all genetic conditions have a support group, Unique would be happy to be contacted to offer support to families who have received a new genetic diagnosis.

Children will be guided by how you tell them about the condition, and your emotions, so giving it time for the diagnosis to somewhat settle with you may make you feel more ready.

On the day

Often, after the initial conversation, there may be follow-up questions over the following few days. It may help to choose a time when you will be around for the rest of the day, and the next few days, so you are available to answer any questions.

Children, in general, like to have conversations when they are doing something else, as opposed to a face-to-face sit-down chat, so think about when would be a good time to start the conversation. For example, while you are both carrying out activities around the home or having a snack together.

Make sure you feel ready on the day. Families have up-days and down-days while adjusting to diagnoses. If it doesn't feel right that day, or you are feeling upset, you can give yourself more time and postpone it until another day.

Find out what they know already

It may be worth asking what a child knows already. Many families worry about giving information to children, but what they know already, or may be worried about, shouldn't be underestimated. Sometimes children may be worried about something unnecessarily, for example thinking they need an operation or that their sibling has cancer. Therefore, for some children, giving the diagnosis can be somewhat reassuring. Some children, especially siblings, will have pieced things together and listened hard to conversations and may know about the diagnosis already.

Also by finding out what a child knows already means you may be giving a name to something they already know, which may be less daunting than new information.

Starting a conversation

You could start the conversation with an open question, for example:

"You have had quite a few hospital appointments recently, do you know what they have been for?"

"We have taken your brother/sister to a few hospital appointments recently, do you know what they have been for?"

You could then use the child's own language to take this forward, or words you use at home.

Most of the time a genetic condition is an explanation for a child's difficulties.

"The doctors have found a reason why you find learning hard at school."

"The doctors have found out why your brother/sister is not as tall as the other children in their class."

In terms of giving the name of the condition, it is worth planning how you are going to name it for them. If your child has learning difficulties, a short memorable name would be easier to remember.

Instead of using the conditions full name, some people prefer to use an acronym. For example, in the case of the genetic condition Wiedemann-Steiner syndrome, many families refer to it as WSS.

You might like to look at support groups and how they refer to the condition.
You might want to find your own name that works.
You might prefer just to say, 'change in a gene', or 'change to a chromosome'.

You don't have to go into complex genetic explanations. The doctors may have explained the genetic diagnosis to you in quite a lot of detail, but you don't need to go into this level of detail with your child(ren). Just telling then that the reason why they have health or learning challenges has been found, may be enough. If you feel it is appropriate, you could mention a simple explanation about genes or chromosomes. For example:

"We all have instructions in our bodies called genes. Genes tell our bodies how to grow and function. You have a change in one of your genes. This is why you have difficulties at school with learning."

"We all carry instructions in our bodies called genes. Genes tell our bodies how to grow and function. These genes are found in packages called chromosomes. Your brother/sister has a missing/extra piece of chromosome. This is why they have difficulties at school with learning."

It is important to emphasise that this is not your child's fault (or anyone's fault). We are all unique and we all have changes in our genes/chromosomes. As well as reassuring your child that they (or their sibling(s)) are not alone, let them know that there are other children and adults with the condition, who live all over the world.

Children might worry about how the condition will affect them or their sibling. It is important to reassure them that many things are not going to change on a day-to-day basis and that you will all learn how to best support your child as you continue through your rare gene/chromosome journey:

"We can still do all the things we do as a family; we can still go to the park and eat pizza and enjoy the music we listen to."

"It might mean that your brother/sister needs extra help at school or maybe they might do best if they go to a special needs school. We can all help him/her as a family too. You already help him/her a lot at home."

Ask your child(ren) if they have any questions

Be prepared for your child(ren) to quickly start thinking/talking about something else, perhaps before you even think the conversation has finished. For example, “can we go outside now?”, “what’s for dinner?”. This is a completely normal response from children, and this conversation is just the beginning of many.

Be ready for questions over the next few days

Some people find the spontaneous questions over the following days more challenging as they might come when you least expect them. If your child(ren) does ask questions, give yourself time to pause before answering if necessary. If the questions catch you off guard and make you feel upset, you could try and answer as best you can in the moment or come back to them later if you need to. If the question seems ambiguous or potentially overwhelming, perhaps explore why your child(ren) is asking what they are asking or consider whether they are simply asking for reassurance.

For example, if you child asks: “mummy is it serious?”, you could respond with “what do you mean by that?”. It may mean that they are simply asking for reassurance and you can reassure them that this is new information, but together as a family you can take this on board and try to help as much as you can.

Remember this is an ongoing conversation and you might find you get upset after some of these conversations. Take time to yourself and/or seek support from friends and family around this time. You could also ask for support from your local Clinical Genetics team, clinical nurse specialist or request a referral to the local clinical psychology service.

Remember that a genetic diagnosis is only part of the story. You still have your own unique family identity with the music you listen to, the games you play and the things you enjoy together.

Perhaps you might want to look for more resources about genetic conditions to show your children. Some people find it helpful to have these at the time they first talk about the diagnosis or in the days and weeks after this. Resources, in various formats, that may be of help, are listed at the end of this guide.

Future conversations

There’s no right or wrong age to start discussions with your child(ren) about a genetic diagnosis. You will need to decide what you feel best fits your current circumstances, but talking to children can help them feel valued and respected and can help them cope better with the information.

It is important not to keep secrets from children. Knowing ‘for as long as you can remember’ that you or your sibling have/has a genetic condition is far less likely to cause psychological difficulties later than being faced with a ‘new’ diagnosis when you are older.

Children will observe differences in their family and family behaviours, and this could lead to confusion and unnecessary worrying if they are not aware of what is happening and are not helped to distinguish misinformation from facts.

Talking to children about genetic diagnoses is a continuous process. As children age, they may be able to understand more, and gradually build up their knowledge over time, and this will depend on their intellectual abilities. Children tend to ask questions when they feel ready to hear the answers, and you may find their questions explore different aspects of their condition over time.

Repeating information over time or asking a child if they have any new questions, or would like anything explained further/again, might help a child to solidify their knowledge. Siblings may also

need reassurance that they are not/will not be affected, and what the possibilities are of their children having the same genetic change. Children, just like adults, need time to process information and think things through.

Families say …

"In our experience, before I talked to my 8-year-old about the genetic difference, I started sharing books with her about bodies and differences (e.g. the book 'bodies are cool'). This led on to a conversation about a blood test she had had which told the doctors that they wanted to check up on a few things to check everything was working well. I also told her that it explained why it was hard for her to learn some things. It was a huge relief to be able to medicalise things and have language in which I could talk openly with her about it. And also a way that I could talk openly with doctors when she was present."

Unique resources

Unique has a selection of 'Chromosome Story' and 'Gene Story' picture booklets for children, that help explain specific and general rare genetic diagnoses. This collection is constantly expanding so please check back if your child's condition is not currently included.

Children's booklets for general diagnoses currently include:

Single gene disorders
Deletions and microdeletions
Duplications and microduplications
Balanced translocations

Condition specific children's booklets are found here, under the 'My chromosome story booklets' tab.

An illustrated poem 'What can we say about microarray' is also available.

Unique also has an expanding collection of general and condition-specific EasyRead guides for adults with intellectual disability that are found here, under the 'Easy Read Guides' tab.

Unique has a selection of condition specific disclosing guides for parent's considering telling their children about their diagnosis. General information in these guides may be very helpful for other conditions:

Talking to Children and Young People about Balanced Translocations
Disclosing about XXX for girls
Disclosing about XXX for parents
Disclosing about XYY for boys
Disclosing about XYY for parents

Other resources

Animations

GOSH My Genome Sequence part 1 and part 2.

Rare Revolution Youth has developed a series of videos for, and made by, young people about various genetic topics (not targeted at people with learning disabilities) that can be found here.

Resources to help young people and their families prepare for other people's reactions in the situation where an individual has visible differences can be found here.

Inform Network Support

Rare Chromosome Disorder Support Group
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Join Unique for family links, information and support.

https://rarechromo.org/join-us/

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at: https://rarechromo.org/donate/ Please help us to help you!

This information guide is not a substitute for personal medical advice. Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health. Information on genetic changes is a very fast-moving field and while the information in this guide is believed to be the best available at the time of publication, some facts may later change.

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