



Understanding Chromosome & Gene Disorders

Talking to Children and Young People about Balanced Translocations

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Talking to children and young people about balanced translocations

Many parents find it difficult to know what and when they should tell their children about balanced translocations, the risks involved and the possible consequences.

Studies show that for many parents, their first instinct is to protect their children from knowing.

Many parents can feel a sense of guilt that their children are affected by - or have a chance of being affected by - the balanced translocation.

They should be reassured: it's no-one's fault and is a natural occurrence that happens in genetics.

Balanced translocations have no health or developmental implications for the person in which they occur. There are, however, implications for their reproductive health, making it harder for them to have their own children.

What helps children and young people learn about balanced translocations?

In most cases, children cope better when the parents are more willing to discuss what is happening to different family members. Talking to children helps them feel valued and respected and helps them cope better with the information. This is because they can openly discuss with the people they trust most – their parents.

When the balanced translocation isn't openly discussed in the family, they might be left feeling confused and unsure how or what to ask. Most children from an early age will observe differences in their family and family behaviours. Not having the opportunity to discuss what is happening can leave them feeling isolated and confused, and sometimes blaming themselves.

Children get information from many places including school, television, friends, the Internet and overheard conversations, even from a young age. By talking to them you can help them sort out what is happening in their family and what is accurate compared with inaccurate information. You can clarify things they are not sure about.

Children are likely to already have some knowledge about genes and heredity, but this will vary. They will need explanations appropriate to their age or developmental stage about the potential effects of the translocation on them or their sibling. Different ages need different levels of explanation, and it is good to check in with each child individually to see what they know and if they have further questions. The unaffected child will need reassurance that they are not affected, and those who are affected or who

have a chance of carrying a translocation can have a gene test when they reach 16 years of age to find out.

You may have to explain repeatedly over a period because it can sometimes take children and young people several explanations before they begin to understand, even though they may have asked the same questions previously. Similar to adults, children need time to process the information and think it through.

Younger children do not have the experience to recognise and anticipate the fuller implications; therefore, there is a gradual realisation if you talk to your child as they develop. Finding out when older can be a shock to young people and they can ask difficult questions when they are not emotionally prepared for the answers. For these reasons, gradually learning more about balanced translocations as they grow up is the most helpful way to find out.

Explanations about Balanced Translocations are provided in the second part of this leaflet.

Unique also publishes a separate guide to [Balanced Translocations](#).

When is a good time to tell your children?

There is no 'right' age but try not to keep secrets. Children place great emphasis on trust and honesty from parents. Children often observe changes in their parents' behaviour and may try asking questions or be waiting for you to discuss what is happening. Watch for any changes in your child's behaviour, at home or school; it may indicate that they are worried or concerned about what they have observed or overheard.

By the age of 8 years, children learn not to ask difficult questions unless their parent(s) gives them permission because they fear upsetting their parents. Therefore, you may have to prompt your child and let them know you are willing to talk with them about what is happening in the family and about the translocation, and explain what it means. This applies to older children, including teenagers, too.

What information do you tell children?

Try to respond to children's questions using language appropriate to their age. Providing small amounts of information gradually is likely to help children understand and cope best. Check on the question being asked so that you find out what your child actually wants to know.

Explain and provide the name 'Balanced Translocation': Children cope better because knowing the name allows them to discuss it with you, and this knowledge also gives them a sense of control.

Where there are screening options, parents can explain the positive emphasis on the importance of knowing about the balanced translocation.

Communication Tips

- Children and young people think it is most important that it is their parents who discuss the balanced translocation with them first. They then might wish to speak to health professionals or other family members after their parents have told them.
- If you want to start a discussion, try to take naturally occurring opportunities, for example a TV programme or something your child has told you.
- Try not to use emotive or dramatic language in explaining the balanced translocation.
- Children and young people prefer informal discussion about the translocation often whilst doing other things together e.g. driving, cooking, or gardening.
- Check their understanding because children and young people worry about upsetting their parents and so may not always ask.
- Talking about the balanced translocation is an on-going discussion rather than a one-off conversation. Like adults, children probably need information given to them more than once. They may need time to digest information and then want to come back and discuss it with you.
- Discuss information young people find on the Internet or in newspapers.
- Discuss emotions – provide reassurance they are not alone in how they might feel.
- Explain parents behaviour if they are anxious or upset.
- Being with peers e.g. cousins in similar circumstances, might be helpful – if there are other family members affected by a similar experience, ask them to talk to your child or teenager.
- Support and guide decision-making, especially with young people, who usually like to make their own decisions but with advice from parents.
- If you do not know the answer, explain that you will try to find out for your child or that some questions do not have answers.
- Agree appropriate times to discuss the balanced translocation if your child asks questions at inopportune moments. For example, explain its appropriate to discuss personal family things at home but not in the supermarket.
- Try not to let the balanced translocation or concerns about it dominate your lives; recognise there are many other aspects to family life. The balanced translocation is part of, but not central, to it.

What are children likely to know about genes and inheritance?

8-11 years: They have a very basic understanding of genetics and inheritance and that they share characteristics with parents such as eye or hair colour. They may talk about genes but not fully understand what they are because they are taught the basics in school science.

Often children of this age cope with simple explanations in response to their questions and are not easily upset, although you may have to reassure them that having a balanced translocation is not the same as having an illness or disease and explain the difference.

Children and young people can easily confuse this, so it often needs repeating throughout development into adulthood.

12 – 14 years: Beginning to develop more insight about genetics and inheritance of traits, young people will begin to recognise that having the balanced translocation may have implications for them. They will usually cope well if you explain there is only 50% chance (1 in 2) of them carrying the gene translocation and that they can have a gene test when they are 16 years old, to find out for sure.

15 – 17 years: Young people recognise the implication to themselves and their future children and can begin to consider genetic testing. By this age young people will be learning about genetics and inheritance in school and will need to know that gene translocations can have implications for their reproductive health. They should therefore go to a genetic counselling service to learn more and consider having a genetic test to see if they have a balanced translocation, as they might have difficulty having their own children.

Most children are quite pragmatic in response to the implications for families affected by balanced translocations. Most children and young people are often focused on living their lives; developing friendships, schoolwork, and their personal interests, and these should be encouraged so that they do not dwell on the gene translocation or its implications. The more pragmatic and calm you are as a parent when talking about the balanced translocation in the family the better - your children and teenagers' reactions will often mirror your response.

What helped parents talk to their children?

It has been observed that the following points helped parents talk to their children:

- Children and young people feel valued when parents talk to them about what is happening in the family.

- Belief in a child's right to know.
- Not feeling pressurised to talk by an impending event e.g. a school science lesson or a genetic test. Try not to set yourself deadlines.
- Parents can be the role model for young people – giving them insight into how to cope with the balanced translocation.
- Do not be afraid to discuss your own feelings and emotions about the balanced translocation; talk to your children about how you cope with the emotions so that they can learn from your or another parent's example.
- Recognising siblings may all have different needs; try to find out what each understands at different times in their development.
- Talking was a relief for parents and ultimately easier than secrets.
- Ensure children and young people understand a positive genetic test is not always a diagnosis of an illness – some get quite confused about this.
- Support from other family members, friends and health professionals.
- Attendance at support groups gave focus to regular discussions with children and young people, with parents explaining where they were going and what had been discussed at the meeting when they returned.

Preparing to talk to your children

It might be worth considering the benefits and drawbacks in preparing to talk to your child but do try to take naturally occurring opportunities where possible.

Benefits	Drawbacks
<ul style="list-style-type: none"> ■ Makes family closer. ■ Support for children. ■ Gives insight and helps them realise that parent's being upset about the balanced translocation is not down to them or their behaviour i.e. 'no fault' of theirs. ■ Confidence to talk to close friends. ■ Children and young people feel valued by parent(s). ■ Allows discussion of the balanced translocation and its implications without centralising it to life. ■ A shared reality and understanding helps children and young people cope. ■ Reduces risk of children getting inaccurate information from elsewhere. 	<ul style="list-style-type: none"> ■ It can be emotionally taxing dealing with questions. ■ Children and young people can remind you about the balanced translocation, when you do not want to be reminded. ■ Questions can arise at inopportune moments – explain when it is appropriate to discuss it. ■ Wanting to talk to peers but networks can be limited. ■ Can affect schoolwork for a short time (but so can worrying about what's happening in their family if there is secrecy).

Providing Reassurance

Provide children and teenagers with reassurance that there's no one to blame for a translocation, it's something that just happens in nature.

It is up to you how much you tell your child about your own experience of the translocation. For example, if you have had miscarriages or difficulties getting pregnant. Sharing experiences as your child get older can help them cope with the implications for them.

However, do not feel you have to share lots of personal information and judge the most appropriate age to share personal information with your child. It's important not to give too much information all in one go but make it clear you are willing to answer your child's questions.

Knowing other family members have a balanced translocation can provide reassurance for your child, especially where they have had children.

Finally, encourage your child to express and talk about their feelings about a balanced translocation as this will give them a chance to express how they feel and find ways of coping with information. Try not to assume a child knows or understands everything that's happening in the family just because they are part of the family.

How to explain balanced translocations to different age groups

■ Explaining to 15-17 year olds

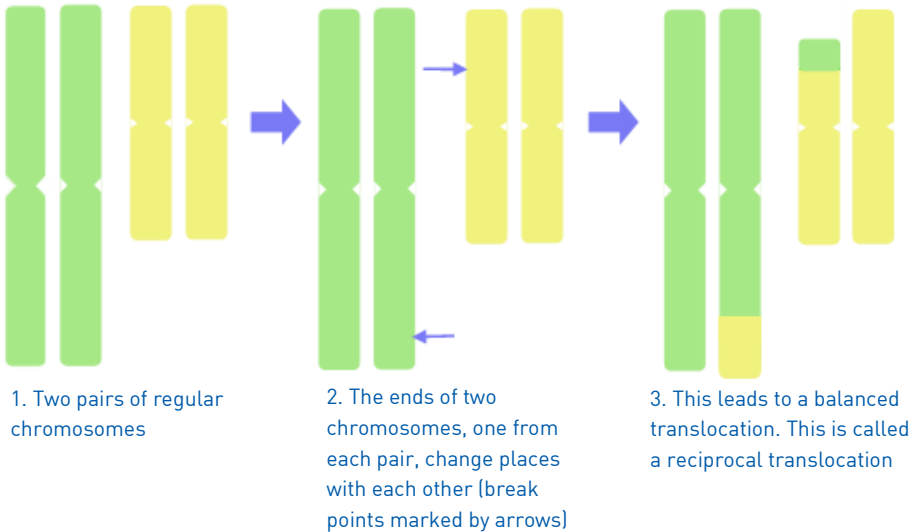
This might depend on if our teenager studies science. Here we provide a basic explanation for the non-scientist.

Genes are the building blocks of life – they tell our bodies how to grow and develop and transmit the information to make sure our bodies function properly. There are many thousands of different genes, and these are all packaged together to form chromosomes.

There are 23 pairs of chromosomes, and one chromosome from each pair is inherited from each of our biological parents – figure 1 (next page).

Sometimes a piece of one end of a chromosome changes places with a piece from the end of another chromosome – see figure 2.

Providing there is no loss of chromosome material, and no genes are lost or interrupted, there are no health or development problems for the person – see figure 3. Scientists call it a “reciprocal balanced translocation” or ‘balanced translocation’ for ease.



How to find out if you have a translocation?

To find out if you have a balanced translocation, you need a genetic test, which you can usually request when you are 16 years or older, unless you were tested as a young child. You can ask your family doctor to refer you to the genetics clinic.

The genetic counsellor will explain more about the test and its implications to allow you to decide. The actual test is a simple blood test, and the result is usually returned to you in a few weeks or months depending on where you live. You can decide if you have the test, or you might decide to wait until you're older.

If the genetic test shows you have the translocation, you are called a 'carrier'. Usually there are no health or development concerns for a carrier. However, there are sometimes difficulties having your own children and when you do you might pass on the balanced translocation to them.

What causes Balanced Translocations?

They simply occur quite naturally - in all animals and plants including humans. Once they have happened there is 50% (1 in 2) possibility of passing on the translocation to each of your own children. This should not cause your children health or development concerns but might have implications if they decide to have children of their own.

Balanced translocations are unusual but not rare.

■ Explaining to 12-14 year olds

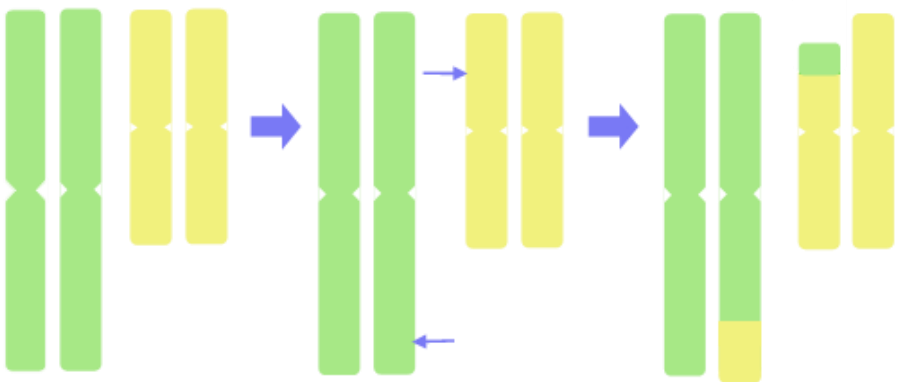
Explain that genes are the building blocks of our bodies and the genes are packaged together to form chromosomes. You could use Lego as an analogy or to help explain.

There are 46 chromosomes in every cell of our bodies, 23 chromosomes from a child's biological mother and 23 chromosomes from the child's biological father.

There are 23 pairs of chromosomes, and one chromosome from each pair is inherited from each of our biological parents – figure 1 below.

Sometimes a piece of one end of a chromosome changes places with a piece from the end of another chromosome – it just happens – see figure 2.

Providing there is no loss of chromosome material, and no genes are lost or disrupted, there are no health or development problems for the person – see figure 3. Scientists call this a "reciprocal balanced translocation" or 'balanced translocation' for ease.



1. Two pairs of regular chromosomes

2. The ends of two chromosomes, one from each pair, change places with each other (break points marked by arrows)

3. This leads to a balanced translocation. This is called a reciprocal translocation

How to find out if you have a translocation

To find out if you have a balanced translocation, you need a genetic test, usually when you are 16 years old, unless you were tested as a young child.

If the genetic test that shows you have the translocation, you are called a 'carrier'. Usually there are no health or development concerns. However, there are sometimes difficulties having your own children and when you do you might pass on the balanced translocation to them. Therefore, your children might need a genetic test too.

What causes Balanced Translocations?

They simply occur quite naturally - in all animals and plants including humans. Once they have happened there is 50% (1 in 2) possibility of passing on the translocation to each of their own children. This should not cause your children health or development problems.

Balanced translocations are unusual but not rare. Some people will have a balanced translocation and won't know it. Having a balanced translocation does not mean you are ill.

Important messages to introduce gradually:

- Keep messages positive. Normalise your child's life.
- This should make no difference to your or to your child's own health and development.
- This should only affect your child if they want to have children.
- The translocation means that your child may have more difficulties when they want to have children.
- It would be advisable for your child to tell their partner about the translocation before they start trying for a pregnancy.
- It's a good idea for your child to ask their GP for a referral to their local genetics centre before starting a family.
- There are usually four possible outcomes when a couple with a balanced translocation tries for a baby. These are:
 1. A pregnancy with a baby with regular chromosomes
 2. A pregnancy with a baby with the same balanced translocation as the parent
 3. Fertility problems or pregnancy loss
 4. Pregnancy with a baby with an unbalanced translocation, causing special needs and sometimes health concerns.

These outcomes will be more likely or less likely, depending on the specific translocation.

The geneticist or genetic counsellor may be able to provide the most likely outcomes for their individual translocation.

The genetics specialist can tell them about their choices. These can include trying for a natural pregnancy and in some countries the option of pre-implantation genetic testing (PGT).

In Summary

- Telling you child about a balanced translocation isn't a single episode, it's a process. Come back to the subject as there can be misunderstandings.
- Gradually build up knowledge over time, give small amounts of information.
- Repeat the message as your child's understanding matures. Check what your child has understood. What questions (if any) are they asking? Be ready to answer questions. Encourage your child to ask questions. Your child may not want to upset you by asking questions.
- You may tell your child but be unsure that they have taken it in. People remember things best when they are relevant. Knowing about the balanced translocation may only become meaningful once they are in a stable relationship.
- It can be helpful for them to have someone else to talk to about it with. For example, an older brother or sister, another adult relative, a parent of one of their friends, or a teacher.

Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group,

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Join Unique for family links, information and support.

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

There is a closed Facebook group for families affected by balanced chromosome translocations at www.facebook.com/groups/35507179052

Unique lists external message boards and websites in order to be helpful to families looking for information and support. This does not imply that we endorse their content or have any responsibility for it.

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. This guide was written by Alison Metcalfe PhD BSc RN PG Cert. Family Therapy. Director of LOHA Health Ltd.

2024 Version 1 (CA)

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