



unique

UNDERSTANDING GENES
& CHROMOSOMES

Easy read guide

17q12 deletions

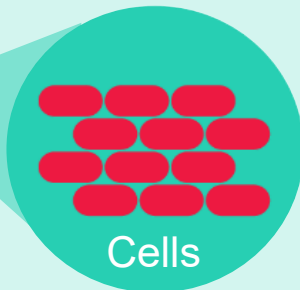
rarechromo.org

17q12 deletions

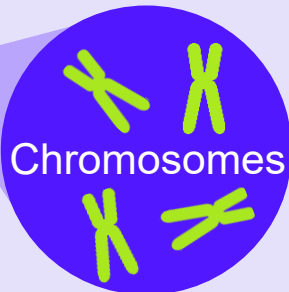
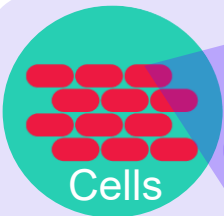
This is an easy read guide about a type of chromosome change, called a 17q12 deletion.



Before we learn about 17q12 deletions first let us learn a little bit about chromosomes and our bodies.



Our bodies are made from millions of tiny building blocks called cells.



Inside our cells are chromosomes.



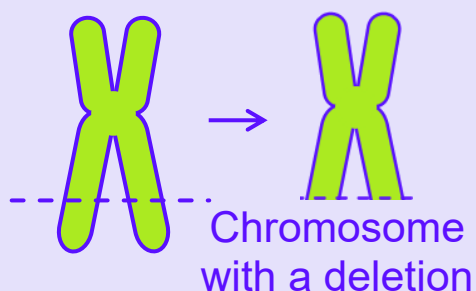
Inside our chromosomes are genes.



Genes tell our bodies how to grow and work.



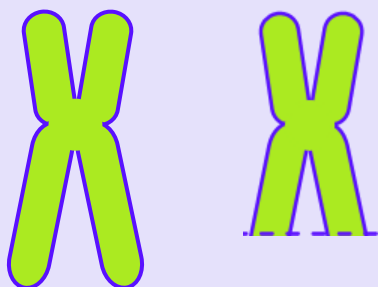
What is a 17q12 deletion?



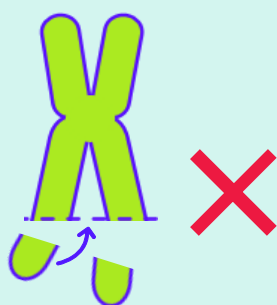
A 17q12 deletion means there is a small missing piece of a chromosome, called chromosome 17.



When a piece of chromosome is missing, some genes are lost, and this can affect how our bodies grow and work.



Chromosomes come in pairs. Even if one chromosome has a small part missing, the other matching chromosome still has all its genes.



If a piece of chromosome 17 is missing, it cannot be replaced.



You can only find out if you have a 17q12 deletion by having a genetic test.



How can a 17q12 deletion affect my learning?

You might only experience some of these challenges or none of them at all!



You might find learning a bit harder than other people.



You might take a little longer to learn new skills.



You might need extra time to understand information.



You might need things explained in a clear and simple way.



You might have difficulties with memory, attention or problem-solving.



How can a 17q12 deletion affect how I talk and communicate?

You might only experience some of these challenges or none of them at all!



You might have started talking later than other children when you were younger.



You might find it hard to say words clearly.



You might find it difficult to explain what you are thinking or feeling.



You might use different ways to help you communicate.



You might see a speech and language therapist. They can help with talking, understanding words or communicating.

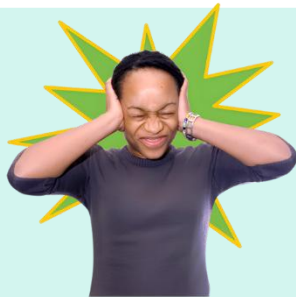


How can a 17q12 deletion affect my feelings and behaviour?

You might only experience some of these challenges or none of them at all!



You might notice that your brain can get confused and make it harder to know what is real and what is not real.



You might be sensitive to noise, light, clothing or certain food textures.



You might prefer routines and feel upset when things change.



You might feel anxious or very sad more often. Strong feelings can sometimes be hard to manage.



A psychologist or mental health professional can also help you manage strong feelings or thoughts.

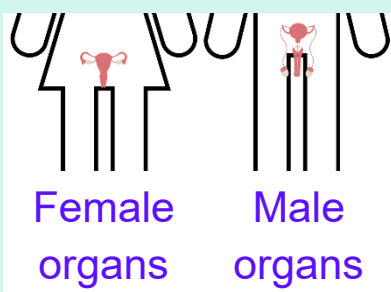


How can a 17q12 deletion affect my body and health?

You might only experience some of these challenges or none of them at all!



You might find it harder to control your movements, making tasks such as writing, catching a ball, using tools, or keeping your balance more difficult.



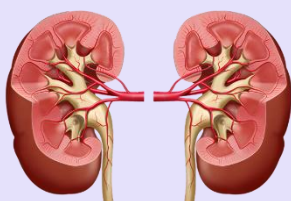
You might have reproductive organs that have developed differently and you may have differences in how your genitals look.



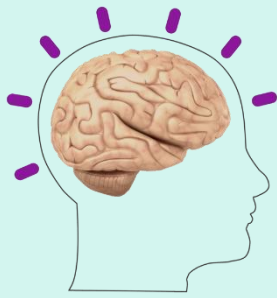
You may look similar to others with the same deletion, even though you are not related.



You might develop diabetes, which means the amount of sugar in your blood can become too high or too low.



You might have some kidney problems. Regular kidney check-ups are important throughout your life.



You might have seizures. This means your brain might act differently for a short time and your body might shake.



You may be a bit shorter than other people.



You might see doctors regularly to check your health.



You might see a physiotherapist. They can help make your muscles stronger and show you stretches if you have pain or tight muscles.



You might see an occupational therapist. They can help you learn new skills to do more things on your own.



You might see a dietician. They can help you make healthy food choices and to stay active.



What will my future be like?



With the right support, many adults with a 17q12 deletion live happy and healthy lives.



Many adults with a 17q12 deletion develop their own strengths, skills and interests.



Adults with a 17q12 deletion can live by themselves, sometimes with a little support, live with family or in supported housing.



Some adults with a 17q12 deletion work in jobs if they are able to. Adults can have extra support in jobs if they need it.



Some adults with a 17q12 deletion choose to volunteer and help out in their communities if they are able to.



It is good to know about your 17q12 deletion so you can get extra support if you need it.



If you would like to know more about your 17q12 deletion, you can talk to your doctor.



Or you can talk to a genetics specialist. They are doctors who know a lot about genes and chromosomes.



You can contact a 17q12 deletion support group.



You can contact a charity, like Unique.



Unique has other easy read guides that you might find helpful. You can find these on our [website](https://trachrom.org).



How can I contact Unique?



You can call us on the phone.

+44(0)1883 723356



You can email us.

help@rarechromo.org



You can go to our website.

<https://rarechromo.org/>



You can send a letter to our office.

The Stables, Station Road West,
Oxted, Surrey, RH8 9EE, UK.

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