



unique

UNDERSTANDING GENES
& CHROMOSOMES

Easy read guide

1q21.1 microdeletions

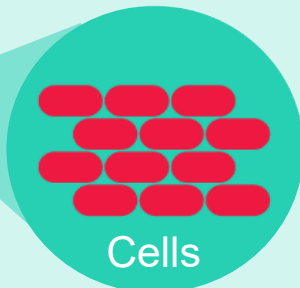
rarechromo.org

1q21.1 microdeletions

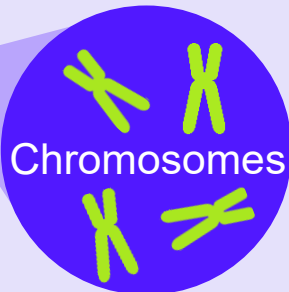
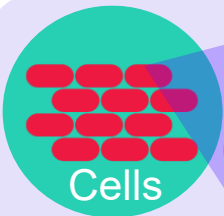
This is an easy read guide about a type of chromosome change, called a 1q21.1 microdeletion.



Before we learn about 1q21.1 microdeletions, 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.



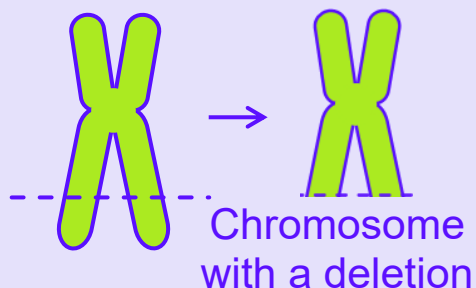
Inside our chromosomes are genes.



Genes tell our bodies how to grow and work.



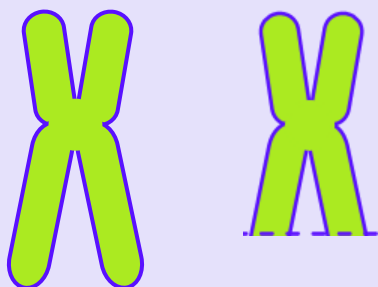
What is a 1q21.1 microdeletion?



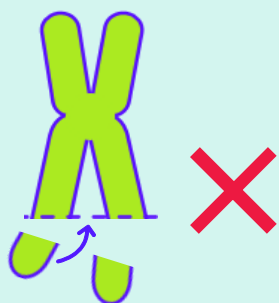
A 1q21.1 microdeletion means a small piece of a chromosome, called chromosome 1, is missing.



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 1 is missing, it cannot be replaced.



You can only find out if you have a 1q21.1 microdeletion by having a genetic test.



How can a 1q21.1 microdeletion 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 1q21.1 microdeletion 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 1q21.1 microdeletion affect my feelings and behaviour?

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



You might find it hard to sit still or concentrate for a long time. This is sometimes called ADHD.



You might have very strong mood swings. You might feel very happy one moment and very upset the next.



You might feel anxious more easily or feel very sad. There are people who can help if you feel anxious or sad.



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



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



How can a 1q21.1 microdeletion affect my body and health?

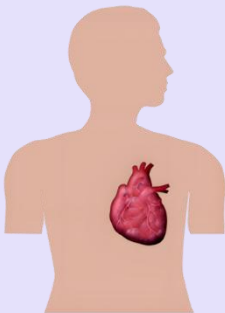
You might only experience some of these challenges or none of them at all!



Some of your muscles may not be very strong. This is called low muscle tone.



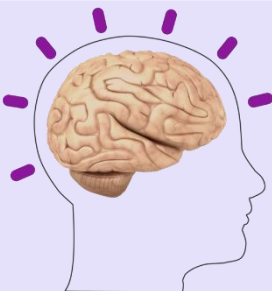
Some parts of your body may be extra stretchy and bendy. This is called hypermobility.



You may have minor differences in your heart that doctors can check.



You might have a smaller head than other people your age.



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



You might need to wear glasses and have appointments to check your eyes.



You might have hearing difficulties, and you might need some help so you can hear better.



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 1q21.1 microdeletion live happy and healthy lives.



Many adults with a 1q21.1 microdeletion develop their own strengths, skills and interests.



Adults with a 1q21.1 microdeletion can live by themselves, sometimes with a little support, live with family or in supported housing.



Some adults with a 1q21.1 microdeletion work in jobs if they are able to. Adults can have extra support in jobs if they need it.



Some adults with a 1q21.1 microdeletion choose to volunteer and help out in their communities if they are able to.



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



If you would like to know more about your 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 1q21.1 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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We are very grateful to The Baily Thomas Charitable Fund for very kindly funding the research, writing and publication of this guide.

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Version 1 [NM] 2026

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