

# Why am I small?



Information about achondroplasia



This booklet is about achondroplasia

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# What is achondroplasia?

Imagine your body is like a house, and your genes are the instructions that tell your body how to grow and develop. Sometimes, there is a little change in those instructions, and that's what happens with achondroplasia.

Achondroplasia is a special word that describes a condition that affects the way people grow. It's like having a special blueprint for your body. When someone has achondroplasia, their bones don't grow as much as other people's, and they will end up being shorter than other people.

You know how some houses have high ceilings and some have low ceilings? Well, in people with achondroplasia, their bones are like the low ceilings. This happens because of a small change in the genes that control how their bones grow.

People with achondroplasia often have shorter arms and legs compared to other people their age. They might also have a bigger head and some other features that make them unique.

The word achondroplasia is a Greek word. It means 'without cartilage formation'. Cartilage is the special material which protects your bones and joints. Cartilage stops your bones rubbing together and has other jobs too, like helping people grow.

The main cause of achondroplasia is when the cartilage in the body doesn't work in the same way. This slows down growth and means that a person has shorter bones.

People with achondroplasia most often have parents of typical height, however some may have one or both parents with achondroplasia.

Achondroplasia affects 1 in 20,000 babies.

# What do people call achondroplasia?

Achondroplasia is a specific medical term. Some people might call it achondroplasia or people with achondroplasia. You might hear it called:

- people with restricted growth
- dwarfism
- small stature
- short people

Sometimes, people like to be called different things. It's important to be kind and use the words that make them feel happy. Just like you have a special name, some people with achondroplasia might like to be called specific words too.

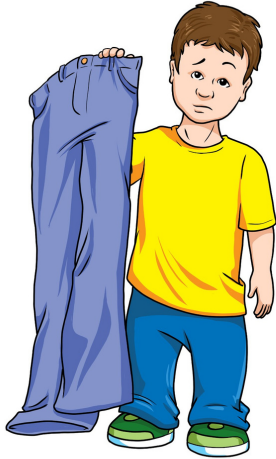
If you're not sure how to talk about achondroplasia, it's okay to ask them or listen to how they talk about themselves. They know best! By using the words they like, we show them respect and kindness.

Remember, everyone is unique, and we should use words that are kind and don't make people feel bad about themselves.





# How does achondroplasia affect people?



## Clothing

Clothing is often made in factories and made in large numbers. This means they are made for people with average body sizes.

People who have shorter legs, or arms might have to get their clothes specially made or altered.

Some shops sell clothes for people of all shapes and sizes.

You might buy clothes in a shop and need them changed a bit to make sure they fit.

## Wheelchair

People with achondroplasia might need or want to use a wheelchair. A wheelchair might be helpful if you are finding it difficult to walk far. You might get tired quickly, or you might have more pain if you have to walk or do other activities.

The wheelchair might help prevent being in pain or mean you are able to do more things.

Other people might use a scooter or stop to rest.



## Pain

Some people with achondroplasia don't have enough space for some of their nerves. This means the nerves can get squashed (compressed) and can cause pain. It might also cause weakness and numbness in different parts of the body.



## Hearing

Some people might have hearing problems and use hearing aids or have grommets to help them hear

# Questions you might ask

## Can I grow taller if I have achondroplasia?

As you grow older, your bones will continue to grow, but they will not grow as much as other people's bones. So, while you might get a bit taller, you may still be shorter than many others. It's important to remember that being a bit shorter doesn't stop you from doing amazing things and being happy.

## Why are some people shorter than others?

Just like how people have different eye colors or hair types, some people have genes that make their bones grow differently, resulting in shorter height. Achondroplasia is a condition that affects how bones grow, making some people shorter than others.

## What makes my arms and legs shorter than my friends?

People with achondroplasia have a specific change in their genes that affects the growth of their bones. This change makes their arms and legs not grow as long as other people's, which is why they may be shorter.

## Will I always have achondroplasia, or can it go away?

Achondroplasia is something you are born with, and it stays with you throughout your life. It doesn't go away on its own.

## Do other parts of my body grow differently too?

Yes, some other parts of the body can also be affected by achondroplasia. For example, people with achondroplasia often have a larger head, shorter fingers, or a curved lower back.

## How can I explain achondroplasia to my friends or classmates?

You can tell them that achondroplasia is a condition that affects the way your bones grow, making you shorter than others. Explain that it's just one part of who you are and doesn't change the amazing person you are inside. If you feel happy talking about it more, encourage them to ask questions if they're curious, and remind them that kindness and understanding are important.

## Is it something I did to have achondroplasia?

No, achondroplasia is not something you did or caused. It's something you are born with because of a change in your genes.

# What might be helpful at school?

## How does your school help you?

Have a look at some of things that other children have said helps them.

Do you think some of these things would be helpful?

Put a tick in the box if your school already does this.



We have left a box for you to write your own ideas about what your school can do to help you



It's important for me to have a seat and desk that fit me perfectly. When everything is just the right size, I feel comfortable and can reach all my things easily.

Sometimes, I need a little help reaching things that are high up A step can help with this

I've got special tools that help me write, like pencils or grips. These tools make it easier for me to hold and write, so I can do my work easier.



When we have PE or playtime, my teachers make sure I can join in too. They can adapt games or exercises so that I can participate and have a blast with my friends. It's all about having fun together!

# My body parts

## Bones

**Bones:** Achondroplasia affects the bones, particularly the long bones of the arms and legs. It can result in shorter limbs compared to individuals without the condition.

## Spines

The spine is commonly affected in achondroplasia. It can lead to a condition called "lordosis," where the lower back curves inward more than usual. It can also cause a "kyphosis" or rounding of the upper back.

## Head and face

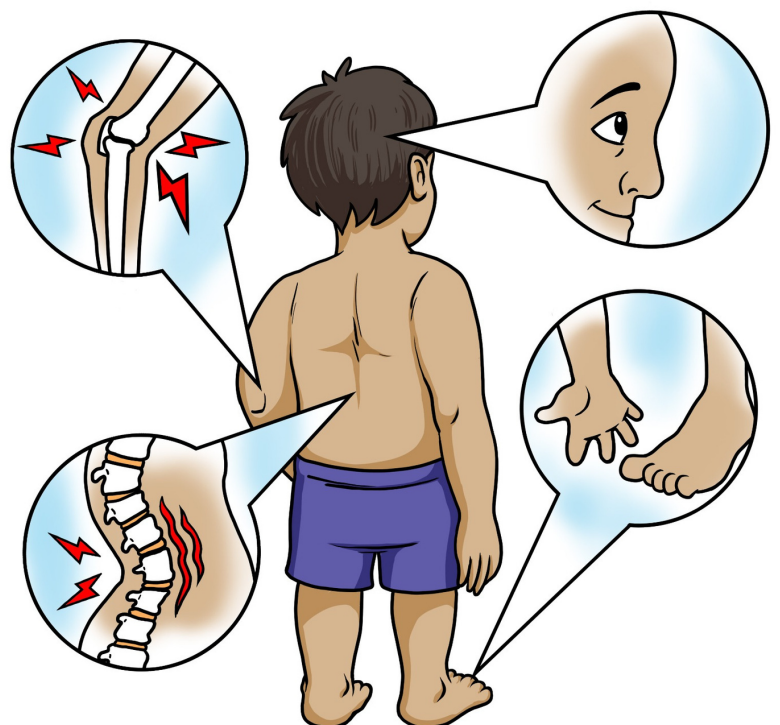
**Head and Face:** Individuals with achondroplasia often have distinctive facial features, including a prominent forehead, a flattened nasal bridge, and a small midface. The head may also be larger in proportion to the body.

## Hands and feet

The hands and feet in individuals with achondroplasia may have specific characteristics. They can be shorter and broader, with stubby fingers and a larger space between the middle and ring fingers. The feet may be flatter and have a wider shape.

## Joints

Joints, such as the elbows and knees, may have limited mobility or stiffness due to achondroplasia. This can make certain movements or activities more challenging.



# Pain scale

Sometimes, our bodies can feel different sensations, like when we have pain. It's important to let grown-ups know when we're feeling pain, so they can help us feel better. To help them understand how much pain we're feeling, we can use a special tool called a pain scale.

This pain scale is like a chart that helps us describe how much something hurts. It uses numbers and words to show the different levels of pain. Let's learn about it together:

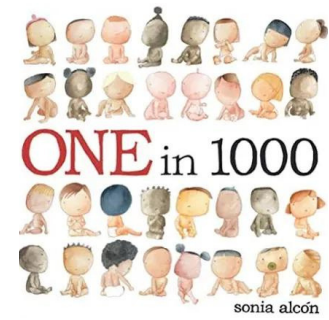
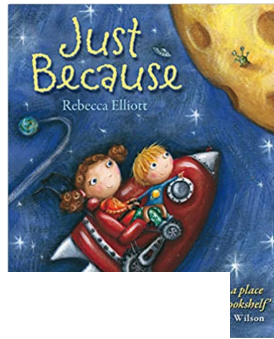
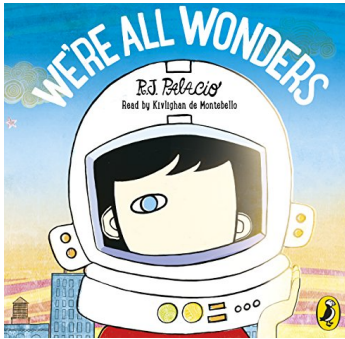
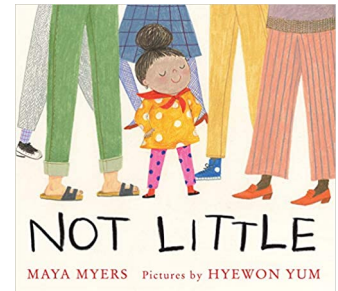
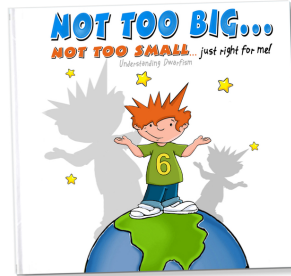
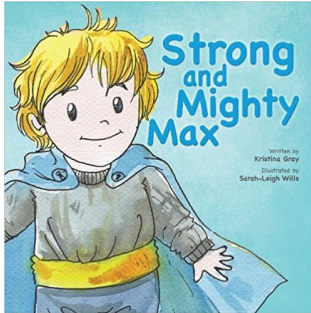
- Number 1 means it feels like little tickles, just barely noticeable.
- Number 3 means it hurts and you might need to take a break from what you're doing.
- Number 5 means the pain is very strong, and you definitely need help from a grown-up or a doctor.

Remember, it's okay to talk about your pain and ask for help. Grown-ups want to make sure you're comfortable and happy. So, let's use the pain scale together and communicate how we're feeling. That way, we can get the right help at the right time!





# Books that you might like



# Websites that you might find helpful



**Little People UK**

<https://littlepeopleuk.org/>



**Dwarfism Sports Association UK**

<https://www.dsauk.org>



**Restricted Growth Association**

<https://www.dsauk.org>



