

All About Alopecia – A Guide for 7-11 year olds

This guide helps you understand what alopecia is. It will answer some questions you may have or may be asked by others.

We hope it will help you with any worries you might have about alopecia. Perhaps read through it with a parent or adult so you can talk to them about any further questions you may have.

What is alopecia?

Alopecia sounds like this - "al-o-pee-sha". The full name is 'alopecia areata' but that's a bit of a mouthful! Most of us call it alopecia for short.

It is perfectly normal to lose a little hair every day. But when you have alopecia, more hair than usual falls out and the hair becomes thin.

Bald patches sometimes appear where the hair has fallen out. Some children lose more hair than others. Some boys and girls are able to cover their patches with their remaining hair. Others may lose all or the majority of their hair.

Does having alopecia mean I am poorly?

The good news is that having alopecia doesn't mean you are poorly. You can carry on playing with your friends, going to school, playing sports, going to parties and having fun!

Sometimes when hair is falling out there might be a little bit of itchiness but this is nothing to worry about.

Why do I have alopecia?

This is a difficult question to answer as doctors and scientists don't know exactly why some children get alopecia and others don't. Children of all ages from all over the world can get alopecia. People are born with all sorts of different conditions, or they can develop them later. It is important to remember that everyone is different and how you look is only one part of who are.

Will I lose all my hair?

Alopecia doesn't follow any rules so this is another difficult question to answer. If you have had one or two patches, which have grown back in the past, it is likely that they will grow back again and it may never get worse.

Most people with alopecia fall into this category, sometimes experiencing hair loss for just a few months, sometimes longer, but always only a small number of patches.

Some of us have patches that spread so that we lose larger areas of hair.

In some cases, all hair is lost from the scalp. This is sometimes known as 'alopecia totalis'.

In rarer cases, all hair is lost from all over the body, including eyebrows and eyelashes. This is sometimes known as 'alopecia universalis'.

Will my hair grow back?

You may have guessed it – another difficult question! Nobody knows for certain the course that alopecia will take or how severe it might become because it is so unpredictable. Some of us experience regrowth and others do not.

If you have lost a few small patches you have a good chance of the hair completely re-growing and no further patches developing.

Lots of people with alopecia experience a pattern of their hair falling out and re-growing over a period of time. Even though the body's immune system attacks the hair follicles, these follicles remain healthy and hair can re-grow normally at any time even after long periods of having no hair.

Re-growth hair can be any texture of colour, soft and white to thick and dark, or just like it was before it fell out.

Some of us with alopecia do not experience any regrowth at all.

Will my alopecia go away?

It's hard to know what will happen when someone has alopecia. Your hair might grow back soon, or in a long while or, it might not grow back at all. Lots of us who have alopecia wish we knew what was going to happen but it's not possible to tell.

What can I do if I think other children are looking at me because I have alopecia?

The first thing to do is remember that someone might be looking at you for another reason. They may be talking to you or just looking in your direction.

However, some people do look more if a person appears different in some way. Often when people look for this reason, it's because they are curious. They might not be being unkind or meaning to make you feel uncomfortable. They just might not have seen someone with alopecia before.

Tell yourself, it's OK for people to look for a moment or two especially if they give you a friendly smile.

Looking is OK but staring is rude. However some people, especially young children, may stare without even realising they're doing it! Have you ever been caught staring at something or someone? Sometimes we don't even know we're doing it!

If you think someone is staring at you, try giving them a quick smile. This lets them know that you've seen they are staring. Most people will feel a little embarrassed and stop staring at once.

Tips on how to explain your alopecia to others.

When you look a bit different, people may ask you questions about your appearance. You may find it tricky to know how to answer questions. If someone asks you a question about your alopecia, and you feel like answering, here are some tips:

You could say:

"I have alopecia. It means my hair falls out" OR, "I'm not poorly. Alopecia only affects my hair." OR, "I have an autoimmune condition called alopecia which makes my hair fall out, I'm not sick though."

If someone is worried about whether it hurts:

"It's just a condition that affects my hair. Don't worry, it doesn't hurt me"

If someone is worried if alopecia is something they can catch from you:

"I have alopecia. It's not contagious. You can't catch it from me".

If you do not feel like answering questions, you don't have to:

"I don't really want to talk about my alopecia today. Perhaps I can answer your questions another day"

What if other children are unkind to me because I have alopecia?

Most people you meet will not make any problems for you. Unfortunately you might meet children who are unkind to you. Please remember that these children are probably unkind to other children that don't have alopecia too. Children who bully other children often pick out those who have something different about them. Perhaps someone who is shorter than everyone else, or taller than everyone else, or someone who doesn't wear the same clothes as everyone else.

It is **NEVER OK** to bully others for any reason and if you do have a problem with someone making unkind comments to you, or about you to others, make sure you tell an adult what is happening.

But remember, the majority of children are not bullies so don't assume you will get picked on because you have alopecia. Often bullies are children who are feeling sad about themselves for some reason and they decide to take it out on others.

What can I do if I am bullied?

Always tell an adult. It's VERY IMPORTANT to tell an adult what is happening as they can help put a stop to it. Tell someone who you're comfortable talking to – your parents, your teacher, your classroom assistant, your PE teacher, your grandparent, aunt/uncle – it doesn't matter who you tell, just make sure you tell someone.

Try to stay in a group. Bullies often pick on children who are on their own a lot. It's easier for them to target you if you're alone. If you can, surround yourself with others. You'll not be as easy to pick on and there will be others around to help.

Try to stand up to the bully – only if it feels safe to do so. If the person who is bullying you thinks you won't do anything to stop it, they will more than likely continue. This doesn't mean you should start a fight or bully them back. Instead tell them to stop. Keep the message simple. Perhaps "Stop doing this, Sarah" or "Cut it out, Jack". And walk away. Try to keep your voice calm. Bullies like to see people upset. If they don't see that they're upsetting you, they're more likely to give up.

If the bullying is taking place online, don't reply. Replying can actually mean it continues and gets worse. Save evidence of the message you've received and tell an adult. If possible, block the person from sending further communications.

Important things to remember if you are being bullied

It's not your fault. This is the most important thing to remember. *Nobody* deserves to be bullied. It's nothing you've done.

Don't fight or bully back. It's very unlikely to make things better and it could get you into trouble if you hurt the bully. Try to act better than the bully at all times.

Don't keep it to yourself. Tell an adult what is happening. This is so important. You are not a tattletale for telling someone. It's the right thing to do.

Don't skip school or avoid clubs/activities because of a bully. Missing out isn't the answer. You have a right to be there and have fun. If it's got to the point where you want to skip activities, you need to tell an adult why you're not wanting to take part.

(The above is adapted from information taken from Childline. Further information is available on their website: www.childline.org.uk)

What can I do if I feel sad because of my alopecia?

We all feel sad sometimes. It's perfectly normal to feel sad from time to time. We all deal with things differently. Some of us like to talk to others, some of us prefer some time on our own.

It is usually best to share your feelings with others. Perhaps a friend, a parent, a teacher, a grandparent. Remember, a problem shared is a problem halved.

Develop a motto to say to yourself when you're feeling sad

"I am ok just the way I am"

"I have alopecia. Alopecia doesn't have me"

"Alopecia doesn't change who I am"

"I can deal with what alopecia throws at me because I am strong"

We are all different

Everybody is different. None of us are the same as someone else. We are all unique. It's what makes the world a fun and interesting place. Think about your friends, family and classmates. They will all be different sizes and shapes. They will have different coloured hair

and eyes. Having alopecia is just one thing that makes us different. But your personality and your talents make you different too. Difference isn't a bad thing.

Your alopecia is just a little part of you

Your alopecia isn't what makes you you! You have a personality. You have skills. You have family. You have friends. You have favourite things. You have not-so favourite things! You have good jokes. You have bad jokes! There are so much things that make you who you are! Alopecia is just a small part of who you are.

Alopecia won't stop you doing ANYTHING!

People with alopecia can do anything they want to do. Alopecia UK is in touch with lots of adults and children with alopecia.

The adults with alopecia have lots of different jobs (authors, pilots, soldiers, teachers, nurses to name a few). Alopecia doesn't stop them from getting married and having families.

The children with alopecia have different talents. Some are good at maths, some are good at swimming, some are great dancers, some are great footballers. Alopecia doesn't change what we are good at!

Did you know that people with alopecia have won Olympic gold medals?

Duncan Goodhew won an Olympic Gold medal for swimming in 1980. He has had alopecia since he was very young.

Joanna Rowsell-Shand won Olympic Gold medals for cycling in 2012 and 2016. She has had alopecia since she was a child.

Did you know that some sports stars with alopecia have played for their country?

Jonjo Shelvey is a professional footballer who has alopecia. He has played for a number of Premiership teams as well as representing England.

Heather Fisher is a professional rugby player who has alopecia. She was part of the rugby team that won the 2014 World Cup. Prior to her rugby-playing career, Heather represented Great Britain in the bobsleigh too!

Did you know that some people with alopecia end up in a job they love?

Tom Spencer, also known as Tomohawk, is now a professional YouTuber doing a job that he LOVES.

Sue Hampton is an author who writes books for young people for a living and she LOVES her work.

John Altman is a composer and saxophonist who has played with some of the best musicians in the world – a job he LOVES.

Joelle is our 'Young Person's Ambassador' and is a singer. She LOVES what she does.

(Take a look at our website for more information about some of these people:
<http://www alopeciaonline.org.uk/ambassadors.asp>)

You are not alone!

There are millions of people all over the world with alopecia. Lots of people understand what it's like to have alopecia and you are not alone.