

All About Alopecia – A Guide for 12- 16 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 deal with any difficulties you may face.

What is alopecia?

Alopecia areata is understood to be an autoimmune condition that causes hair to fall out. It basically means your body attacks the hair on your body. This can be a small bald patch on the head, a couple of bald patches or the total loss of all hair. People generally shorten the name to simply 'alopecia'.

Can anyone get alopecia?

Boys, girls, women and men of all ages and races can get alopecia. The exact number of people with alopecia is unknown but it's thought that between 1% and 2% of the population will have alopecia areata at some point in their lifetime. This could mean around 1 million people just in the UK! You are definitely not the only one with alopecia although it can sometimes feel that way if you've not met anyone else with alopecia before.

What is the cause of alopecia?

This is a difficult question to answer as we don't know exactly why some people get alopecia and others do not. With alopecia areata the body's immune system, which usually protects the body from diseases like measles, attacks some of the hair follicles causing hair to fall out.

Scientists don't know exactly what causes alopecia yet but they believe something 'triggers' the immune system to mistakenly attack the hair follicles. Many people with alopecia have theories as to what could have 'triggered' their alopecia but nobody knows for sure. One thing that we do know is that those with alopecia are not to blame for having the condition. It's not your fault that you have alopecia.

Alopecia is more common in people who have, or have family members with, asthma, eczema or other autoimmune conditions such as type 1 diabetes, rheumatoid arthritis, vitiligo or coeliac disease.

Is alopecia contagious?

Absolutely not. You cannot pass your alopecia to another person by any means. Although there are many 'unknowns' about alopecia, we do know that it is not a contagious condition.

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 areata 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 50p-sized 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 or colour, from downy white to thick and dark, or just like it was before it fell out.

Some of us with alopecia do not experience regrowth.

How will alopecia affect me?

Alopecia will not make you sick or tired. People with alopecia are generally otherwise healthy. So keep doing what you do!

Occasionally whilst hair is falling out, or re-growing, people can feel some itchiness or aching sensations on the scalp. This is perfectly normal and nothing to worry about. It normally doesn't last very long.

You might struggle initially to deal with the emotional effects of alopecia. It can be challenging to deal with other people's reactions to your hair loss and you may feel quite

down from time to time. This is perfectly natural as coming to terms with a change in our appearance is a big thing.

Dealing with alopecia

Talking to other people with alopecia can help. It can be really comforting to know you're not alone. Alopecia UK is always happy to hear from young people with alopecia. The charity even has support groups that you can attend to meet others and even national events, such as the annual trip to Alton Towers.

Talk to your family and friends about how your alopecia makes you feel. Try not to keep feelings bottled up. If you feel uncomfortable talking to those closest to you, consider confiding in a teacher or school counsellor. The key thing is to talk to someone if you are finding things difficult. You'd be amazed at how helpful others can be. They may not have experienced alopecia but they may have gone through other challenging experiences and might be able to offer good advice based on this.

If you feel very down talk to your doctor. They may be able to refer you to a professional counsellor who may be able to help you cope with your feelings.

Exercise and fresh air are good for relieving tension and proven to release endorphins which cheer us up.

What can I do if I think others 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. Remember, humans are naturally inquisitive and curious creatures! We will tend to linger our glances slightly longer on something or someone that is slightly different to 'the norm'. To some people, you may be the first person with alopecia that they see and they may take a few seconds longer to process what they are seeing. They may not even know what alopecia is and be concerned for you. Most people will not stare at you.

Tell yourself, it's OK for people to look especially if they are being friendly.

Looking is OK but staring is rude. However some people, especially young children, may stare without even realising they'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 straight away.

What can I do if I want to cover up my alopecia?

Disguising patchy hair loss

If you have patchy hair loss, you can often disguise this simply by the way you wear your hair. A simple change of parting can often help.

If you have long hair, tying it back in different ways or accessorising with headbands, grips or slides can help. Hairdressers are often good at suggesting options for covering alopecia patches.

Please don't be embarrassed to ask a hairdresser or barber. It's likely you won't be the first person they've seen with alopecia.

Options for re-styling may be limited if you have shorter hair. However, there are volumising sprays that have the effect of thickening remaining hair, which might help to conceal patchy hair loss. Using a camouflage powder a bit like to an eyeshadow, or a coloured spray, similar in colour to your hair, on the bald patches can help to conceal the patches. Such products can be purchased online or from most wig companies.

Covering more extensive hair loss

If you have more extensive areas of hair loss and you would prefer to cover these up, you might want to consider wearing hats, headscarves/bandanas or wigs.

Hats

There are LOADS of hat options. Anything from beanies to berets to baseball caps and Fedoras. Try on different styles and find one that works for you. Bear in mind some hats will work better with some outfits than others and some will be more suitable for cold or hot weather.

Headscarves/Bandanas/Tube Scarves (one brand name is Buff)

These might be less familiar to you than hats but again there are plenty of options. You can pick them up from high street stores or there are lots of online shops. Similar to hats, it's about finding a style that works for you. There are different ways you can wear these products with lots of tying options. Some you can style to incorporate any remaining hair. There are lots of tutorial videos to be found on YouTube which might provide you with some inspiration as to how you can wear this type of head-covering.

Wigs

There are lots of different types of wigs available in all different types of style and colour. You might be able to get a wig from your dermatologist. You would need to ask your parent/guardian to make an appointment.

Wigs generally fall into two categories; synthetic and human hair. It's not the case that one is better than the other. There are positives and negatives to both. If you visit Alopecia UK's website, you will find LOTS of information about the different kind of wigs.

As well as the possibility of getting a wig on a prescription from your dermatologist, wigs can also be purchased directly from wig shops. There are lots of wig shops in the UK and the staff who work in these shops can be very helpful in finding you a style and fit that works for you. It's so important that a wig fits right or you won't be comfortable in it and it won't look quite right. If possible, make an appointment to ensure you have enough time and assistance when choosing.

Prices for wigs vary considerably so you would need to speak to your parent/guardian about what your options are. It's also worth bearing in mind that wigs don't last forever and will need replacing. Following the care instructions provided with your wig will hopefully mean you get lots of wear out of it.

Wig options for boys can be very limited and this is perhaps one of the reasons why many young men with alopecia choose not to wear them.

Uncovered Heads

Remember, it's up to you to choose whether or not you cover up. It should be **YOUR CHOICE**.

Deciding not to cover up can be a really positive choice for some people and lots of children and adults with alopecia prefer not to cover their heads.

Although it can be a bit scary the first time, the good side is that taking the plunge may actually give your confidence a big boost. Some people who go uncovered for the first time tell us that they feel proud, brave, liberated and unique!

However, going uncovered might not be right for you. At Alopecia UK we don't suggest one way is better than another. The important thing is that YOU make YOUR choice and you're happy with that.

If the first time you go without a head covering feels a bit scary and daunting, give yourself a treat of some kind afterward. The first time might be easy! Or it might be difficult. Having some kind of treat to look forward to is always a good way to get through anything you feel a bit nervous about.

School uniform policy

If you think your school's uniform policy won't allow you to wear the choices you wish to wear to manage your alopecia, ask your parent to speak to your headteacher to get permission so you don't have any problems at school.

Mix it up!

You don't have to choose just one option and stick to that. You can mix up different options. Perhaps one day you want to wear a hat. Another day you might want to wear a wig. Other days you might want to go without anything. We might select different options for different activities or different weather! On hot days, it can be really nice to not have anything covering our heads. But remember if you are going out in the sun uncovered, put a high-factor sun cream on your scalp. A sunburned head is VERY painful – take care!

Eyebrows and eyelashes

Many people with alopecia will keep their eyebrows and eyelashes. Some people with alopecia can lose their eyebrows or eyelashes – some people lose both.

People are sometimes concerned that if they don't have eyelashes things will get in their eyes, as they don't have the lashes to protect them. Most people with alopecia have found this isn't a problem. Or it might be for a short term whilst your eyes adjust to suddenly not having any eyelashes. You may find it beneficial to wear glasses outside, particularly on a windy day.

Some people with alopecia who lose their eyebrows and/or eyelashes are happy with their look and like to stay as they are. Others prefer to recreate eyebrows and eyelashes using make up and other products.

Eyebrow pencils can be used to draw brows. It can be really tricky to get it right and lots of practice might be needed. Tutorial videos can be found on YouTube. Or the staff on make up counters in department stores can be really helpful. Boots (the chemist) have special assistants who are trained in providing make up guidance to people with hair loss. These staff members are called "Boots Macmillan Beauty Advisors".

Eyebrow stencils are an option. These will help you get a natural shape. There are also eyebrow temporary tattoos or you can even buy brows made with hair that you can stick on with glue.

A little eyeliner can create some definition around the eyes and give the illusion of still having eyelashes. Again, experimentation and practice is key.

False eyelashes are also an option. These can be tricky to apply at first but it does get easier with practice.

Permanent make-up (micro-pigmentation)

It is possible to have eyebrows created by cosmetic tattooing, by applying hair like strokes of pigment in the shape of an eyebrow. This is something you could consider and discuss with your parents as a possible option as you get older – you need to be 18 years old. The reason there is a minimum age of 18 is that up to this age, your face is still developing.

Practitioners can be found on the Suppliers Directory on Alopecia UK's website or in your local Yellow Pages. The tattoo will fade over time and generally lasts approximately three years. It is sometimes necessary to have additional treatment on a yearly basis to refresh the eyebrow.

Dealing with other people's reaction

Some people might not know that you have alopecia or what alopecia is and therefore might not know how to react. It helps to have an answer ready for any questions, you could try, "I have alopecia, a condition that causes my hair to fall out".

Use whatever you feel comfortable with and that fits the situation. Be yourself, and be proud of who you are.

As a wise person once said,

"Only a few heads are perfect, the rest are covered with hair to stop people noticing!"

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 have alopecia. It's an autoimmune condition that makes my hair fall out"

"I'm not ill. Alopecia affects only my hair. I am otherwise as healthy as you"

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."

If you feel like the same person wants to talk about your alopecia too much:

"There is more to me than just having alopecia. Please can we talk about something else?"

What can I do if I am bullied?

Always tell an adult. It's so 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. Schools have anti-bullying policies in place to ensure bullying doesn't continue – but you need to let an adult know what is happening.

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 target 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 fight back or bully them back. Instead tell them to stop. Keep the message simple. Perhaps "Stop doing this, Emily" 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. 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 section has been adapted from information taken from Childline. Further information can be found on their website: www.childline.org.uk)

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

It's perfectly normal to feel upset from time to time. Many of us feel sad at times because of our alopecia. 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. Bottling up how we're feeling can be exhausting. It can really help to get our feelings and thoughts out. Writing a diary or journal can be a good idea.

It can help to develop a motto or mantra to remind ourselves on bad days. Here are some suggestions:

"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 stronger than I think"

Alopecia UK Support Groups and Events

You might find it helpful to come along to a local Alopecia UK support group or national event and meet others with alopecia.

Here are some things that children and teens have said about our support groups:

"You know you're not alone"

"It's easy to talk to others because they understand how you feel"

"It's useful to have an adult with alopecia to talk to and know that having alopecia isn't all bad"

Personal experiences of alopecia

It can help to hear the experiences of others with alopecia.

Emily, age 13, tells us a little about her experience with alopecia:

"From my experience it has been tough but I have taken each day as it comes. I also try to be as open as I can, trying not to keep my problems inside me and making me worry. I try to find solutions and things that can help me. I have met others with alopecia at the support group that I go to and it really helps and can give me lots of information. I haven't told my school about my alopecia as I want to avoid any attention but I'm sure people would be supportive if I told them. For any other kids I would say, try not to worry about it and look for solutions that might work for you such as hats or wigs or make up.

I haven't ever had any really bad experiences during my alopecia but for anyone who has said something to me (for example, someone commented about my eyebrow falling out), I try make a joke out of it or just act like it's ok and doesn't bother me. It is much harder as a kid or teen with alopecia as you see your friends every day and it's natural to feel insecure that your appearance is changing so fast and they might notice. PE is challenging as I have to wear my hair up but I luckily get away with wearing mine down. Alopecia does get better once you talk to people and find out tips that can help."

You can find lots of further examples of personal experiences from young people with alopecia on the Healthtalk.org website: <http://www.healthtalk.org/young-peoples-experiences/alopecia/topics>

Important things to remember

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. Difference isn't a bad thing! Yet many, particularly those in teenage years, are critical of their appearance and compare themselves to others.

Your alopecia is just a little part of you

Your alopecia isn't what makes you you! You have a personality. You have talents. How we look is just a small part of you we are. How we communicate with others it what is important. If we are friendly, interesting and fun, others will respond to that.

Don't believe everything you see in magazines!

Comparing ourselves to celebrities and models found on the pages of magazines can be unhelpful. Remember, most of the images you are seeing have been airbrushed to make people appear more attractive than they actually are. It adds to the pressure on young people, not just those of us with alopecia, to look a certain way.

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. One of things that many young people with alopecia worry about, is that they won't have boyfriends or girlfriends. Alopecia doesn't stop people from finding us attractive. If a potential boyfriend or girlfriend has a problem with our alopecia, they are definitely not the right one for us! But there are lots of people who won't care that you have alopecia – it just won't be an issue.

Adults with alopecia have relationships. They get married. They have families. They have successful careers. They have JUST THE SAME CHOICES as everyone else.

Alopecia shouldn't stop you doing anything that you want to do. Be confident. Be happy and live your life to the full!

Did you know

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

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

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! She has had alopecia since she was a teenager.

Tom Spencer, a.k.a Tomohawk, is a professional YouTuber who has a very successful YouTube channel. In addition, he also has a channel dedicated to raising awareness of alopecia. He has had alopecia since he was 14.

Joelle is our 'Young Person's Ambassador' and is a singer. Her 'Big In LA' music video has received over 200,000 hits on YouTube.

Matt Lucas is a successful comedian and actor. He co-wrote 'Little Britain' with David Walliams and has appeared in movies such as 'Shaun of the Dead' and 'Bridesmaids'. He has had alopecia since he was 6.

Sue Hampton is an author who has written books for children, teens and adults. Sue has had alopecia since the age of 24 and two of her stories, The Waterhouse Girl and Crazy Daise, feature characters with alopecia.

John Altman is an award-winning composer who has had a glittering career. He has worked with so many music stars including Amy Winehouse and Jessie J. He lost his hair suddenly at the age of 50 but that didn't stop him winning an Emmy Award.

And finally, and this is REALLY important to remember; 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. If we've not met someone else, it can be easy to think we're the only one with alopecia but it couldn't be further from the truth. It's actually more common than you might think. You just need to look at the [photos from Alopecia UK events](#), to know that there are lots of others with alopecia out there!