

Parents Pack

This guide is designed to help parents of children with alopecia.

We have three guides designed for your child to help explain alopecia to them (these guides will also help you understand about alopecia):

- Factsheet for children aged 6 and under
- Guide for 7 to 11 year olds
- Guide for 12 to 16 year olds

This Parents Pack is more to help you with ways you can help your child thrive and be happy.

“The hardest part of being a parent is watching a child go through something really tough and not being able to fix it for them.”

Nobody ever claimed that parenting was easy. Some say it’s the hardest job in the world. Throwing something as frustratingly unpredictable and emotionally challenging as alopecia into the mix can make things a little more difficult.

Tips for helping your child to cope with their alopecia

There are a number of things you can do to help your child to manage with their alopecia.

- **Explain alopecia in simple terms to your child.** Our guides designed for the different age groups explain alopecia using age appropriate language.
- **Ensure that your child knows it's ok to feel bad or even cry.** Alopecia throws a lot of different emotions at us and it's important for your child to understand that their feelings are valid. Try to remind them that negative feelings will pass. If your child struggles to move beyond these feelings and experiences long periods of sadness, extreme mood swings or behavioural changes, you may wish to consider exploring the option of counselling.
- **Ensure your child knows that they are not alone.** It will be easy for them to think that they are the only child in the world that has experienced hair loss but it couldn't be further from the truth. There are many other children and adults both in the UK and further afield that have alopecia. It's important for your child to understand they are not the only one. Alopecia UK can help connect you with other families, whether that be attending one of our support groups where your child can meet others, coming along to one of our larger national events or chatting to other parents in our Facebook group.
- **Encourage your child to continue to be engaged in the activities they enjoy.** Sports, dance, arts, social groups – continuing with what they love doing will help with confidence, self esteem and building strong bonds with peers. Withdrawal from the activities they enjoy may seem like a good option at the time for your child (easier to stay at home than face others) but it can be so hard to get back involved once they've stepped away from activities, leading to further withdrawal.
- **Talk with your child's school and activity organisations** (Scouts/Brownies/Sports Clubs/Dance Schools etc) to discuss the possibility of adapting any rules they may have about hair styles or head coverings. Most organisations should be flexible in enforcing rules about headwear to cater for a child with alopecia. If you experience any difficulty, Alopecia UK may be able to help. Please get in touch if you need any advice: info@alopecia.org.uk
- **Remember that there is no set rule book for how to deal with alopecia. We're all individuals with different personalities.** What works for one person might not work for another. Be sure that any decisions around telling others about your child's alopecia or decisions about head coverings are led by your child. It can be important to provide choices but try not to push your own choices onto your child. Remember,

what you think might be the best option might differ from what your child thinks is the best option.

- **Consider whether it's even something you need to mention to your child.** If your child has one or two small patches that are easily covered with their remaining hair, you might not wish to draw their attention to the patches. However, if the hair loss becomes visible to others we would suggest that your child needs to understand what is going on. How alopecia is explained to your child will depend on their age. Some parents believe they are sparing their child distress by not discussing their hair loss but often this creates greater anxiety by avoiding conversation. Our guides for children can help children to understand their alopecia.
- **Try to avoid comparisons with other conditions or diseases.** Try to avoid statements that compare alopecia with other things such as, "At least it's nothing worse", "Thank goodness it's just your hair" or "Let's be glad it's not cancer". Although it's very important to provide reassurance to your child that alopecia only affects the hair and doesn't make them poorly (again our guides for children are good for explaining this), it is equally important not to use statements that can result in the child feeling guilty or bad in any way.
- **Explain to your child that staring is inappropriate** but explain to them that it's common for people to linger their glances a little longer on people or things that appear a bit different to the 'norm'. At some point your own child will have stared at someone or something they found interesting or unusual and you may have pulled them up on it. Perhaps use this as an example. It's important to boost your child's confidence and explain that they may encounter the occasional 'starer'. Develop ways to deal with staring should it happen- smiling is often the best option. It's amazing how just making eye contact and giving a smile to the person doing the staring will stop it happening.
- **Don't blame yourself!** Over the years, Alopecia UK has heard from a huge number of parents who feel guilty and blame themselves for their child having alopecia. It's a natural feeling given that as parent you are chief protector of your child. However, you are not to blame for your child having alopecia. It is just 'one of those things'. There are a lot of unknowns about alopecia but one thing is clear, it's not something that is simply 'passed on'. Genetics play a role but it's not the sole factor. Blaming yourself will not help you or your child come to terms with the situation.
- **Be as strong as you can be around your child.** It can be very upsetting for a parent to watch their child lose their hair. However, your child will be looking to you for reassurance and strength. If you can, save your 'wobbles' for when they're not around. If your child sees you are upset, they might be less willing to talk to you when they are struggling and this can lead to further upset.

- **Be positive!** – Initially it might be scary, particularly if your child is very upset or there is a lot of hair loss. If your child is wanting to cover their hair loss, come up with positive new looks. Perhaps have a day out shopping for new hats, scarves or wigs. Find items to accessorise and keep it fun and positive. Make sure you allow your child to lead as this will help them gain confidence.

Tips for interacting with your child's school

Good communication is key! We would always recommend early engagement with a school. In our experience, a little education and awareness goes a long way. Some children have found communication via a whole school assembly, with or without being present, or a note to home to parents can be effective. It is important to listen to your child/teen; in particular, older children and teenagers may not feel comfortable with any alopecia awareness being done within the school/classroom environment.

Remember, children and teens almost always have their own ideas on how they wish to handle a situation. If possible, follow through with their desires. If not, it's important to explain why and look for alternative options.

An important point to note, if your child is adamant about keeping their alopecia secret from other classmates by concealing their hair loss under a wig, be aware that this can add to feelings of anxiety and pressure. The fear of their hair loss being revealed can in some cases cause greater anxiety and distress as the original hair loss. Being open about having alopecia can remove any fear of being discovered as a child who has no/little/missing hair. Just because your child/teens opts for 'openness' about their alopecia, doesn't mean they need to talk about it all the time with classmates. Many children with alopecia insist on their alopecia being a very private thing and may only feel comfortable telling close family. Privacy and secrecy about alopecia is understandable but it's important that having alopecia doesn't mean your child misses out on experiences and activities that many kids love, such as sports, swimming and sleepovers. If it reaches a point where their hair loss is stopping them from taking part in any activities, you may wish to consider reaching out for professional psychological support.

If your child/teen is as relaxed as possible about their alopecia and adopts an attitude of "Yes, I have alopecia. It's not a big deal. Lots of people have alopecia. I'm still just a regular kid/teen. I'd prefer not to talk about it all the time" etc, it's likely they'll have a more positive experience at school. The separate guides we have developed for children/teens may help your child develop confidence around their hair loss. Attending an Alopecia UK event or support group can help with this too.

Nursery Age

Very young children are often not as affected by having alopecia as older kids. Little ones tend to adjust more readily to whatever is going on. Young children are simply more accepting. Hair doesn't hold the same significance and meaning that it does for older children, teens and adults. Therefore, the approach taken by the adults and older children around your little one (yourself, older siblings, teachers, grandparents etc) will have a big impact in influencing the child's thoughts about their hair loss. The more relaxed and comfortable you are about your little one's alopecia, the more laidback and confident they will be about their hair loss. At nursery age, inform your child's caregiver about alopecia and be open with other parents about the condition. It's unlikely you will encounter any problems if there is open dialogue about why your child looks different. If alopecia is not explained to others, this may lead to misunderstandings and confusion.

Early Primary

As your child reaches primary school, they are more likely to face comments from their peers who are a curious age group – just think about the number of times your 4-6 year old has blurted out a question/comment to a stranger that's left you feeling embarrassed. This age group are still finding out about the world and will likely comment on things, and people, around them.

Try to ensure that hair loss is not a major focus of your child's life and the way to do this is to ensure it's not a major focus of *your* life. Your child's alopecia should not be a source of anxiety for them or you. If you are struggling to come to terms with your child's alopecia, you may wish to seek professional psychological support from your GP. They may be able to put you in touch with counselling services. Alternatively, the charity Changing Faces offers professional counsellors and also has some great self-help resources on its website too.

Be honest with the school/nursery. Perhaps have a standard answer or explanation your child can use if asked by others why they don't have hair. For example "I'm not sick, I have alopecia and that means I don't have hair."

Older Children and Teens

As children become older, they become more aware of their own appearance. Older children begin to judge themselves and, as they approach teen years, awareness of physical appearance can be at its strongest. During these years, children can be very tough on themselves. Where previously they may have not been critical of their alopecia, it can become something they become more focused on.

They might change the way they manage their alopecia. Children who have never worn hats, scarves or wigs in early years may decide to wear a head covering as they enter their adolescent years. Or vice versa. Feelings can change.

There are lots of ways to support teenagers. The key thing is to consult with them how they wish to handle any challenge or problem. If it's possible, follow through with what they want. If it's not possible, explain why not and seek alternative options. Putting them in touch with others with alopecia can really help, whether that be in person at an Alopecia UK event or support group, or chatting to others online.

Encourage your child to receive support from classmates and teachers. Encourage your child to have someone to confide in. That might be you or it might be someone else. Sometimes it can be easier to talk to someone other than a parent.

Be supportive of your child, these can be tricky years and they need all the love and support they can get. Be aware of warning signs if your child is slipping into anxiety or depression. Make sure you reach out and get help from your child's school or GP.

Uniform Policies and Head Coverings

Many schools have very strict uniform policies and this often includes a rule about no head coverings, with the exception of when it is for religious reasons. Very occasionally 'medical reasons' are cited but this tends to be quite rare.

We believe that schools should make allowances for children with alopecia. If your child struggles with their alopecia being visible, they should be able to wear a head covering that they're comfortable with. We would hope most schools would be obliging however we would recommend early engagement with the school to discuss options. Also bear in mind that your child may need to compromise on their choice of headwear. For instance, a school is unlikely to be happy with fashion-branded baseball caps but may allow a more discreet beanie hat. Colours of hats or scarves may need to be kept in line with school uniform colours. Similarly, wigs may need to be natural shades as the school may not allow bold hair colours such as pink or blue.

We strongly recommend reaching an agreement with the school's headteacher to avoid your child being challenged about their head covering. They may also wish to carry a hat/scarf 'pass' (see the tools section of this guide).

Similarly, if your child wishes to wear make up to replace lost eyebrows, you may need to seek approval for this if the school has a strict 'no make-up' policy.

From other parents

It can help share experiences with other parents. Our support groups and events provide the opportunity to meet other families coping with alopecia. The following quotes have been provided by parents of children and teens with alopecia:

"Two things to remember: Firstly, it is not easy to watch your child lose their hair. Secondly, it's ok to admit this."

"I found honesty was the best way to deal with it. Suggest to your child that they be open about having alopecia. From our experience, we have found this openness helped my daughter to come to terms with her hair loss. Also, encourage your child to join a sports team. Team sports are a great way to get your child integrated with others, understand about working as a team and teammates become a fantastic support network."

"When your child is diagnosed with alopecia, eventually you need to find a way to block it out of your head for some of the day otherwise it can be all consuming. It's important to look after your own mental well-being as well as your child's."

"We found Buff scarves to be a godsend. And cheap hats with changeable accessories."

"We didn't try to hide her hair loss from our daughter. If she asked a question, we answered it as best we could. We kept reaffirming that she was beautiful, with or without hair. We allowed her to cover her head when she wanted to and only show her alopecia if she felt able to."

"We went to our first Alopecia UK support meeting and it was great for our own emotional support as well as our son's. It really helps to meet others on a similar journey. We felt less alone. Our son did not want to go to the first meeting but we met the organiser, Stu, and his 13 year old son Ben. We were not sure if we should encourage our son to shave his head and Ben told us that no matter how much or how little hair our son had, we had to let him decide. We have used this advice on numerous occasions and it has really empowered our son. I should add that he and Ben are now great friends."

"Don't automatically assume there will be problems at school. I answered any questions from my daughter's friends, put to me openly and simply. Other parents were known to stare occasionally. We smile back!"

"Simply ignore stupid comments from family and friends. We had 'You're not feeding her properly', 'She's not getting enough sleep', 'You tie her hair back too much' and others. Don't let ignorant comments get you down. Brush them off".



"I'd recommend attending an alopecia support group. Meeting other parents can be really helpful- sharing tips, advice and just speaking to others who 'get it' can be such a relief."

"My son's confidence was boosted so much by meeting others with alopecia, both kids and adults. By meeting others his own age, he realised he wasn't the only one and by meeting adults with alopecia, he was able to see that it doesn't stop you doing anything you want to."

"My advice to other parents would be to focus on maintaining their personality not their hair. Alopecia takes our children's hair but it shouldn't take their spirit. I tell Lucy that she should be proud of who she is, not what she is not. From a more practical point of view, it's shocking to begin with but it does get easier. I never wanted Lucy to feel like she had to cover up. If she'd wanted to then of course we would have supported her. We've always tried to keep things fun. In the early days we used all sorts of hair bands then as it got colder I called upon friends and family and got her a big bag full of funky hats to choose from, and now that she's got no hair we have fun with face paints and glitter!"

"My son is 7 and has lost about 70% of his hair. I've been totally led by him; his feelings, his decisions. I am in awe of how brave he is and how he faces things every day. He is in complete control and says "I may have alopecia but I've still got so many friends". One piece of advice I'd share with other parents is to write a letter to parents at school, explaining that your child has alopecia, what that is and asking them to talk to their own children about it. We even had something included in the school's newsletter. We found this incredibly helpful as it stopped any assumptions or gossip at the school gates."

"Focus on the positives; no head lice, no getting hair tangled, no rushing around in the morning getting hair styled. I tell my daughter that she's beautiful every day, whether she has no hair or a million hairs on her head. She has always been the one to make the choice about wigs etc. She prefers to go without; she's never found a wig that she's truly comfortable in. She covers up in summer and winter but most of the time just shows her beautiful bald head."

"Try and find support from other parents of children with alopecia. If you don't get along to a face to face support group, consider chatting online in Alopecia UK's Facebook group. There's so much reassurance when you're not going it alone. Most of us would swap places with our children in an instant to stop them suffering, and most of the times us parents can fix things, but not alopecia. It helps to hang out with those who know how that feels. It helps with the journey so much."

From adults looking back on their childhood alopecia

“Take your child’s lead. If they’re not bothered (I wasn’t), then try to accept that. If they want to cover up with wigs, hats or scarves, help them to make choices. If they don’t want to cover up, then help them to be comfortable in their skin. The only thing which has changed is hair. You may well be struggling with this more than your child (that is normal). Try to reach out through Alopecia UK to other parents of children with alopecia. You are not alone.”

“My mum was supportive but wasn’t ever keen on me going out without a wig. She was only trying to protect me but I would have preferred it if she has said I looked beautiful and strode about with me looking proud.”

Useful Tools

You might find the following tools are helpful templates. You may wish to amend them to fit your own child’s circumstances. We hope they will assist with your own communications.

Sample letter for starting secondary school (or perhaps entering a new year group)

We recommend you add, amend or delete sections as appropriate. This sample is meant to act as a guide and should be tailored to your own child’s requirements, dependent on the nature of their hair loss and how they choose to manage it eg wigs, hats, scarves etc.

Dear Teacher,

I am writing this letter to inform you of the special circumstances regarding Ben Jones who will be in your class this term.

Ben has alopecia areata. This is a medical condition that results in hair loss, in varying degrees, to the scalp and body. For some, it can present as a few small, round bald patches on the scalp. Others may lose all their scalp hair or all their body hair, including eyebrows, eyelashes and nasal hair.

Ben has recently lost all his hair, after a year of having patches. He is still coming to terms with his new appearance and is most comfortable with his scalp covered.

Alopecia Areata is understood to be an autoimmune condition. It is not contagious and can occur in males and females of any age. Approximately 2% of the population will experience alopecia areata at some point in their lifetime.



The condition is extremely unpredictable and hair can regrow spontaneously. However, it often falls out again.

Alopecia areata causes no physical harm but it can be an emotionally challenging condition to have. It can be difficult to look and feel different to your peers. For this reason, we ask you to be aware of Ben's circumstances.

Ben normally wears a beanie hat and he should be allowed to wear this both inside and outside of classes. If you believe another teacher may ask Ben to remove their head covering, please can I ask you pass this letter to them to read, to avoid any awkward and uncomfortable situations for Ben. We are aware of the school's uniform policy and recognise that hats are not allowed. However, we have consulted with the headteacher and it has been agreed that Ben can wear a smart black beanie and we have bought him a couple that he is comfortable with. Ben is prepared that other pupils may question his hat and he is happy to explain that he has alopecia and what that means.

At the moment, Ben does not wish to engage in wider classroom discussion about his alopecia so I would be grateful for your sensitivity and discretion. Please do not bring up Ben's alopecia unless he does first. We hope as Ben's confidence grows, he may be comfortable to go without a hat and talk more openly about his alopecia, but we feel it is important that he is not pushed into anything he feels uncomfortable with.

Please be aware of any bullying or teasing from other pupils. I would be grateful if you could make me aware of any problems and how they have been dealt with in school.

If you have any questions, please let me know. I am hopeful that Ben's secondary school experience will be a positive one and his alopecia will not impact on his learning or friendships.

If you would like to do your own reading about alopecia, there is lots of information on Alopecia UK's website: [www.alopecia.org.uk](http://www alopecia.org.uk)

Thank you for your understanding.

Kate Jones (Ben's mum)

Sample letter for primary school parents (to perhaps be included in classmates' book bags, with teacher permission)

You may wish to tailor a similar letter for your own child.

Information about Lucy Smith – Reception Class 1A

Dear Parents and Carers,

We are writing to let you know about our daughter Lucy who will be in your own child's class. Lucy has no hair and it's likely that your child may have some questions about Lucy's appearance and we would like you to be in a position to answer them as openly as possible.

Why does Lucy have no hair?

Lucy has a condition called alopecia areata, commonly known as simply 'alopecia'. It is understood to be an autoimmune condition, whereby Lucy's immune system attacks the hair follicles causing the hair to fall out. Some people with alopecia lose only a small amount of hair and others like Lucy have more extensive hair loss.

Does she have any other health problems?

No, Lucy is otherwise very healthy. She is not on any medication. It is just her hair that is affected. Having no eyelashes and eyebrows means that her eyes are more sensitive but other than that she is as fit as a fiddle!

Is alopecia contagious?

Alopecia is not contagious. There is no way that your child can catch it from Lucy. We think this is an important question to address as this might be something your own child is wondering. Our children are aware of chicken pox. It's important that they know alopecia is not like this.

Will Lucy's hair grow back?

That's something we just don't know. Lots of people with alopecia do experience spontaneous regrowth. This might happen for Lucy or she might be without hair for the rest of her life.



More about Lucy

Lucy is a happy and active girl. She is getting on with life regardless of her hair loss. She likes playing football with her big brother. Her favourite food is spaghetti and her favourite colour is purple. She is just like any other nearly five year old. Just minus the hair.

We have been advised that questions should be answered honestly. We expect your child will have questions. It's only natural when someone looks different. We want to be open and honest but equally we want Lucy to have the same school experience as all her classmates.

If there is anything you would like to ask, please feel free to come and speak to us in the playground.

Many thanks,

Jenny and Dave (Lucy's Mum and Dad)

Sample head-covering 'pass' for your child to have in their school bag

Please ensure you have received permission from the headteacher for your child to wear the head covering they need to wear before creating this 'pass'. If you have any trouble in getting a school to agree to a head covering, please contact Alopecia UK and we'll see what we can do to help.

A 'pass' can be a particularly good idea if your child is in a big school with lots of different teachers/supply teachers/lunchtime supervisors.

HAT/SCARF/BANDANA PASS

To whom it may concern,

Please note, I have permission to wear a hat/scarf/beanie in school. I have alopecia. Please do not insist I remove my head covering. I am not comfortable doing this.

It has been agreed by <Insert name of headteacher> that I can wear my hat/scarf/beanie. Please speak to them about my head covering.

Many thanks.