

Supplementary File 1 - Alopecia UK Facebook Group Rules and Guidance

Alopecia UK is a registered charity. This group is for members living in the UK only. If you live outside the UK and are looking for support, you may wish to join the 'Alopecia Areata' Facebook Group which is a worldwide online community.

Further information about the charity can be found at www.alopecia.org.uk

General Rules and Guidance:

The aim of this group is to provide valuable peer support and share information about alopecia and Alopecia UK.

This is a 'closed' group. Anyone can find the group and see who is in it, but only current members can view the posts made within the group.

We also have three associated groups:

AUK Wigs, Headwear, Make Up & More Chat Group – for discussions about wigs and other products related to alopecia.

Alopecia UK Parents Chat – a private space for parents of children with alopecia to chat

AUK Men's Chat – a private space for men with alopecia to chat

Please DO NOT SHARE any member posts from this group. There is no 'share' setting within our closed group (apart from on external links) for the reason that posts are to remain in the group. Anyone found lifting any posts or photos from the group without permission from the post's owner will be deleted from the group with immediate effect.

Before your post is published in the group, it will need to be approved by one of our Admin team. The approval of posts improves the group experience for everyone, meaning any unsuitable posts are deleted prior to being seen by other group members. Admins work hard to approve posts in a timely manner but your post might take a short while to appear.

If your post does not appear in the group, please check whether it goes against any of the following rules:

Please keep all posts and threads relevant to the topic of alopecia (hair loss). If your post does not relate to alopecia, please consider whether the group is the place for the post or if it would be more appropriate for your own personal Facebook profile. We want the posts in the Alopecia UK group to remain on the topic of alopecia and support. We are trying to direct many of the post about wigs to the AUK Wigs, Headwear, Make Up & More Chat Group. If your post relates to questions about wigs, headwear, makeup and other products, please consider posting in the separate group which has been designed for more of the product chat.

NO SWEARING. Please refrain from swearing in posts. Please be aware that posts including swear words may not be approved. This can be a shame as sometimes the rest of the post is really good. Occasionally we will private message members asking for their pending post to be edited or reposted in order for it to be approved. But please remember, we are a small and busy Admin team. We won't always have time for this. To avoid your post being deleted, please keep your language clean. We recognise that you may need to vent but please make use of 'fluffing' or 'flipping'! (We know not everyone will agree with our firm stance on swearing but we do believe that keeping the group free from swearing makes it a much nicer place for everyone to be).

We do not allow posts highlighting petitions, campaigns or self-promoting businesses or webpages (see below for further details relating to business mentions/posts).

Any members found sending unsolicited messages (private messages without invitation) to other group members will be removed from the group.

Please do not recruit for media, casting, photography or research study opportunities in this group. If you are looking to recruit participants for any such project, you must get in touch with Alopecia UK: info@alopecia.org.uk Any recruitment adverts for participants posted without permission will be deleted.

Posts alluding to thoughts of suicide or self-harm might not be approved. Alopecia UK's Facebook group is not moderated by any professional counsellors and we are worried that anyone who may be in urgent need of help may not get the type of support they need from the replies in our group. If other mental health issues are also impacting on your life, please consider reaching out for support for these too. We want every member of this group to feel supported but we would ask you to consider if the Alopecia UK Facebook Group is the best place to get the support you might need. If we do not approve a post because we are concerned about the nature of it, an Alopecia UK admin will send you a private message signposting you to additional support organisations which can also be found here.

Posts that include links to fundraising pages for charities other than Alopecia UK or crowdfunding pages, including 'Go Fund Me' pages, will not be approved. If you are fundraising for Alopecia UK, we are happy for you to post a link to your fundraising page but it will only be approved the once. If you do wish to post about your fundraising efforts, please do a short post letting people know what you're doing. Please don't just post a link to your page without an introduction (it will just look spammy and most members will ignore).

Group members wishing to sell, swap or giveaway wigs/headwear are only permitted to do so in the AUK Wigs, Headwear, Make Up & More Chat Group, each Monday on

'Members' Market Mondays'. Any sales posts in the main group will not be approved.

Please note, 'Members' Market Mondays' are strictly for individuals and not business owners.

Posts promoting other Facebook groups will not be approved and comments including links to other Facebook groups may be deleted by admin.

Only Alopecia UK events or Alopecia UK support groups can be set up as Facebook events within our Facebook group.

Please consider carefully prior to posting 'jokes' & 'memes' in the group. Not everyone shares the same sense of humour and if admins believe a joke may cause offence to some group members, your post may not be approved.

If you share an alopecia news story or video in the group that has already appeared recently, the Admin team may choose not to approve your own post. Instead, they may tag you in the original post in the group – thus bumping it back up the page and also meaning there are not then lots of posts about the same news story in the group.

Posts that discuss, ask about or recommend shampoos and supplements which claim to stop hair loss or help hair growth will not be approved into the group, unless the manufacturers have provided clinical research to validate their claims. We appreciate that some people may feel these products have been beneficial for them and would then want to share with others. But we don't want to risk giving false hope to others who may try them and then feel they have wasted money.

Alopecia UK does not endorse the products or services of any one supplier. Any recommendations made in the group are not endorsed by Alopecia UK. Please see

below for further information prior to posting about products and suppliers.
Please be respectful to all members with your interactions within the group. Any offensive/rude/aggressive comments will be deleted and members may be removed. Alopecia UK reserves the right to remove any content from the group that it deems inappropriate.

Our public Facebook page can be found here: <https://www.facebook.com/AlopeciaUK>
Please visit our website: www.alopecia.org.uk to sign up to our mailing list.

Posts regarding businesses/products related to alopecia – Additional Info:
Businesses should not advertise any companies, products or services within this group.

Posts including adverts/external links to businesses will not be approved by an Admin. An exception to this rule is our weekly, 'Free to Promote Fridays' over in our AUK Wigs, Headwear, Make Up & More Chat Group. Each Friday in our separate wigs/products group, business owners are permitted to advertise their services to group members. Otherwise, business owners can answer queries and questions about products and services.

We're sure other members may be able to benefit from the expertise shared in the group*. But business owners should not send private messages to members with details of products and services, unless THEY request you to do so. The comments in which business owners share their expertise should not be used as an opportunity to tell the original poster that you have a business and can help. If an Admin believes a comment to be self-promotion by someone connected to a business, it will be deleted.

'Free to Promote Fridays' in the AUKWigs, Headwear, Make Up & More Chat Group is the only time that promotion of businesses can be done.

*This will be monitored and AUK reserves the right to amend the rules at any time and delete posts if they deem them inappropriate.

If any group members have a business relationship with any companies or brands, they should refrain from any promotion within the Alopecia UK groups and keep any such posts to their own social media pages.

If any group members receive a product free from a supplier or manufacturer, we would ask that you refrain from posting photos or discussing it in the group as this could be viewed as paid promotion.

Members should not create a post which appears to just be giving a shout out or thank you to a business or tagging a business owner in it after they have bought something from them. We know some people want to show their appreciation, but this is not appropriate for the group and is inadvertently advertising. If you want to thank a business owner, please thank them directly and not in the Alopecia UK Facebook Groups.

Where can businesses advertise?

Each Friday in the AUK Wigs, Headwear, Make Up & More Chat Group we have 'Free to Promote Fridays', allowing businesses to advertise their services to group members. You may also promote your business to those with alopecia through joining Alopecia UK's Suppliers Directory (an annual fee applies).

Issues & Complaints

Should you have any issues or complaints with the Alopecia UK Facebook Group please do approach a group admin and see if your issue can be resolved that way.

If your issue or complaint with the Alopecia UK Facebook Group cannot be resolved by an admin, or you have an issue or complaint about Alopecia UK generally, then please see the following web link for next steps: <http://www.alopeciaonline.org.uk/complaints.asp>

Supplementary File 2 - Instructions sent to participants for creating screenshots

Before your interview we would like you to find an example of your activity within the Alopecia UK Facebook group that was meaningful to you in a positive way. These can include posts with or without photos and either with or without comments. Please take care when doing this, allowing yourself some time

to reflect on your example and remember how you were feeling before and after publishing the post, as well as how it felt to receive any comments from others within the group.

Special permission given re screen shot posts in the Facebook Group:

You may be aware that the Alopecia UK Facebook Group Rules state that group members are not allowed to screenshot any posts and share elsewhere. We are giving special permission to participants of this study as you will be asked to screenshot posts that you have found helpful. We ask that you only share these for the purposes of the study and follow guidelines given regards deleting your conversation once it is complete. Sheffield University have been given guidelines to employ when using these screenshots and while they may quote wording from screenshots in their final paper they will not use any identifying data, names or imagery in their final report or any resulting published work.

(Jen Chambers, Charity Development Manager)

Once you have found your example/s we would like you to take a screenshot and send them over on Facebook messenger to be used during your interview. This can be done in several ways depending on what device you are using, instructions can be found for each device below. Once your example is visible on your screen, use one of the instructions below to take a screenshot.

You are also able to send screenshots from your phone, please email me if you need instructions on how to do this.

Windows PC or Laptop

You want the “Print Screen” key (or “PrtScn”) which is usually at the top right of your keyboard.

To take a screenshot try pressing one of:

- 1) “Alt” + “Printscreen”
- 2) “Fn” + “Printscreen”

3) Windows key + Printscreen



This will save a screenshot to the pictures folder on your computer, where you will be able to open the file and send over messenger.

Mac

To get a screenshot on a Mac press:

“Command” + “Shift” + “3”

This will save your screenshot to your clipboard where you can open and send the file over messenger.

Chromebook

You want the “Switch Window” key, located on the top row between the “Full-screen” and “Brightness Down” keys.



Take a screenshot by pressing:

“Ctrl” + “Switch Window key”

This will save directly to your Chromebook’s download folder where you can open and send the file over messenger.

Supplementary File 3 - Tables with summary and supplementary information for each theme found within data.

Gradual Healing: Subordinate Themes, Supporting Quotes and Screenshots within Theme

Subordinate	Description	Supporting Quotes	Screenshots
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Theme			
<p>Expressing emotions</p>	<p>Within this theme participants describe the use of the group for expressing emotions both good and bad. The group is a place to let go of feelings.</p>	<p>Poppy - “I think I would still be very depressed”</p> <p>Amber - “ I no that if I do have a bad day someone will be there and guide me or just be there”</p> <p>Merida - “It’s a great resource to have.”</p> <p>Lily - “It’s a way of off loading at times instead of moaning to my hubby all the time!”</p> <p>Merida - “My husband (Who is amazing) was the only person I could talk to about it and I didn’t want to dump it all on him”</p> <p>Claire - “Every time I write a response it’s a reminder to me of how far I’ve come, and how I’m doing OK.”</p>	<hr/> <p>Am feeling so great! My first time in public without anything to cover my head and feel so happy....it may have been only in the gym but it’s a start yes some people stared but you know what I don’t care, I have my family and friends who love me for who I am and I don’t care what anyone else thinks. Enjoy the weekend xo — 😊</p> <hr/>

		<p>Claire - “The history bubbles up to the surface every so often, and rather than keep it in, I shared it.”</p> <p>Merida - “I'd come to terms with what was happening but it helps to reinforce your attitude”</p>	<p>Having a bad few days and feeling very disheartened!! Recently been diagnosed with scarring alopecia & have lost considerable amount of hair on one side of my head. The last 2 weeks I am now losing handfuls of hair & it is very very thin in places, with more larger bald patches appearing. This week Hubby had to unblock the outside drain & pulled out the most enormous ball of my hair!!!! 😞😞</p> <p>Have started to lose eyebrows now & eye lashes have gotten thinner too 😞😞 hair on my arms has almost vanished too!!</p> <p>Am feeling really low & peed off about it all!!!! 😞😞😞😞</p> <p>Have managed to keep it hidden with buffs up to now, but don't think I will be able to for much longer.</p> <p>It's the discomfort on my scalp that annoys me the most! Burning & itching sensation!!</p> <p>Bloody alopecia!!!!</p> <p>👍👍👍👍👍👍</p> <p>👍 Like 💬 Comment</p>
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Image concern: Subordinate themes, supporting quotes, and screenshots.

Subordinate Themes	Description	Supporting Quotes	Screenshots
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Practical Support	Participants use the group to gain practical and up to date advice for coping with alopecia, including wig use and makeup techniques.	Evie - "I found out you could get 50% off eyelure eyelashes which has helped massively in feeling I can afford to try a new pair at £2.50 against £5." Carla - "I've learnt a lot about good realistic wigs too that don't cost an arm and a leg" Penny - "Yeah there was one a while ago about sealing the knots on wigs with concealer this is a lifesaver" Evie - "Yes at present but things change & again the group keeps me up to date with new ideas and more comfortable hair pieces"	
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<p>Tips on coping</p>	<p>This theme highlights the individual choices available when coping with alopecia. Some chose to cover up whilst others choose to shave their hair. Whichever coping method is chosen there is always support found within the group.</p>	<p>Alice - “I am publicly bald now, and speaking to others on the group has inspired and encouraged me to do that ”</p> <p>Leah - “I think once I started to see that there were lots of solutions, and practical things to do, I could focus more on practicalities rather than [daughter’s] hair loss”</p> <p>Amber - “People putting up pictures/selfies of themselves bald or patchy or with wigs or scarves out in public, gives u a sense of feeling well they can do it y can’t I”</p> <p>Amber - “So scared when I heard the sound from the shaver and watching what was left of my hair fall around me but I felt so so so much better and actually liked it.....I felt liberated”</p>	<p>Thank you so much to everyone for their lovely comments today on my first ever 'selfie'!! I'm touched by your kind remarks 😊😊😊 I have added another photo as so many of you said I needed to add a smile....</p>  <p>A whole year has gone by since I shaved the rest of my hair off supported by my lovely hubby!! Best thing I ever did!!! Taking control of a negative situation relieved the stress and anxiety. My life has changed so much since I joined this amazing group and I have made some wonderful friends along the way 😊 I have accepted how I look and now just get on with my life.</p> <p>Alopecia UK rocks 💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙</p> <p>Thank you all for the strength and support I have gained since joining this group xxxxxx</p>  <p>Iv done it I have shaved my head.....AND I feel so liberated. I can now hopefully watch my hair grow instead of watch it fall out.....I am channeling Demi Moore in GI JANE but with “duck lips selfie” 🤪 I am embracing it day by day</p>
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		<p>Olivia - “Maybe one day i would be able to wear a different wig everyday and not worry what people think!”</p> <p>Olivia - “Well i see people on there and they look so gorgeous with or without hair. I suppose i worry that if i told people of my alopecia they would think less of me. I don’t know why! It matters more what a person is like ie personality etc not how they look.”</p>	
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Belonging: Subordinate themes, supporting quotes, and screenshots.

Subordinate Themes	Description	Supporting quotes	<u>Screenshots</u>
Connecting	<p>Connecting with similar others reduces loneliness and allows group</p>	<p>Lily - “Scarring Alopecia is rare so it was even more important that I found someone else with the same type.”</p>	

	<p>members to support each other.</p>	<p>Amber - “just getting the kind remarks made me feel even more happy and confident and felt like I did do the right thing and was glad that I did, I felt liberated.”</p> <p>Lily - “I did a charity raffle last September which was supported by AUK and they were amazing! They promoted it for me and helped me with resources etc. I felt very proud when they posted the story on their main charity page”</p> <p>Amber - “I wanted to post it and share it with the group and maybe inspire someone else who is thinking of the same thing”</p>	
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		<p>Claire - “helping others, helps me too.”</p> <p>Leah - “Just how brilliant the administrators are. [Administrator] was very helpful and supported me through the difficult times.”</p> <p>Carla - “Just that there is a well established community spirit of support”</p> <p>Lily - “When the comments and advice started coming I was overwhelmed by the support and kindness of everyone.”</p> <p>Poppy - “I felt like that post might help other people which also made me happy”</p>	
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<p>Shared Experience</p>	<p>Sharing experiences within the group creates a feeling of normality, appearing to reduce the shame associated with alopecia.</p>	<p>Evie - “helped me to see not the only one and not just me.....before this would blame myself but able to see actually it can happen to anyone and the fact that she’s able to tell others on the site just makes it less scary and so what if it does happen”</p> <p>Merida - “The first one [screenshot] is really inspiring that we can just go about our lives and no one is really paying that much attention which is basically what you're worried about.”</p> <p>Amber - “The support group was different as you would get comments like I</p>	 <p>Note to self- before jumping in a packed swimming pool and in front of your new boyfriends family, make sure to take your wig off 😂😂 came back up to the surface and my wig was floating away from me 😂😂</p> <p>👍👍👍 52 11 comments</p> <p>👍 Like 💬 Comment</p> <hr/> <p>Been a member for a while now and haven't posted anything. I thought I would let u in to my journey so far....From about 2015 I started loosing hair I had hair well past my shoulders and it really was my pride and joy being able to do all sorts of styles. I didn't realise at first what was happening, I was in denial. It got to the point where my pony tail was no thicker than the thickness of my baby finger 🙄. The doctor told me it was areata alopecia but what they didn't tell me was that the tablets they so desperately wanted me on for my exzema could cause hair loss! So for the next two years I battled with my hair falling out in patches and hair growing back WHICH I was VERY VERY thankful for but once it got to a certain length BAM hair all over my pillow chunks coming out when washing it patches reoccurring and lots lots of tears 😭.</p> <p>📄 👤 🏠 🔔 ☰</p>

		<p>no how u feel.....it was a different kind of support mentally and family and friends would b more physically like the hugs”</p>	<p>While talking to a friend the other day I mentioned how kids staring really hurts. Of course I get they are kids. But, when I’m walking through a park at lunch time and there is a camp of 50 kids having lunch...they all stop talking and eating and just stare. What a horrible feeling.</p> <p>   9</p> <p>11 comments</p> <p> Like  Comment</p>
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New Identity and Self Acceptance: Subordinate themes, supporting quotes, and screenshots

Subordinate Themes	Description	Supporting Quotes	<u>Screenshots</u>
Internal Changes	Participants describe acceptance with their alopecia, as well as developing compassion for others and themselves.	Evie - “ Now I can look at myself and think ok not what I would have chosen but it’s ok” Alice - “I have accepted that after 30 years nothing will make my hair grow back!” Amber - “Now I love my hair reminds me of GI JANE lol” Penny - “Yeah i don’t feel like i want it to come back i honestly prefer the way i am now. I couldn’t go through it coming back and having patches again” Carla - “Iv met up with a few people who live nearby and my husband came with me to meet	

		<p>another couple, and it was nice for the men to talk about how it affected them us having it”</p> <p>Claire - “I feel more peaceful, I describe it as me and alopecia having called a truce, a respectful let’s not bother each other.”</p> <p>Merida - “I think I think more about judging people. You never know what’s going on with them. Like I try not to but when I do, I stop and think about how I would feel.”</p> <p>Evie - “That particular post I related to as I had been in similar position where wig has come off in public and you feel like you want to die at the time but by making light of it helps to not focus on it and puts it into perspective”</p>	<p>A whole year has gone by since I shaved the rest of my hair off supported by my lovely hubby!! Best thing I ever did!!! Taking control of a negative situation relieved the stress and anxiety. My life has changed so much since I joined this amazing group and I have made some wonderful friends along the way 😊 I have accepted how I look and now just get on with my life.</p> <p>Alopecia UK rocks </p> <p>Thank you all for the strength and support I have gained since joining this group xxxxxx</p> <hr/> <p>—</p> <p>feeling good. i have a life i love. i still miss my hair but would i trade it to lose any part of what i have the answer is no im happy and i am loved what more could u want.</p>
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		<p>Evie - "I was in the car with my daughter and said I wasn't going on a night out as it was a wig theme & that wasn't my thing & she laughed. If this had happened pre this group I would have felt low for weeks & embarrassed as her friend was in the car but I laughed with her at the irony of my comment"</p>	
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Social Life and Openness

Within this theme participants describe better coping on a social level, returning to work, hobbies and being more open to others about their alopecia.

Carla - “I went to an alopecia uk big weekend and because i won a free head henna i didn't wear a wig all weekend there and went by myself to Birmingham to meet new ppl”

Merida - “There’s pretty much no fear. I'll go bald at the gym, playing football, walking about, going to the pub of an afternoon”

Claire - “I believe more I have as much right as anyone else to be in a restaurant, to attend an event.”

Am feeling proud of myself today 😊 I have visited my first primary school to do a short talk about Alopecia in their reception class and it went really well. The children were amazing and loved Ella so much that they wanted her to stay!
The little book 'Ben's first day' was a hit!

Spreading Alopecia awareness 💙💙💙💙💙💙💙💙💙💙
💙💙💙💙💙💙💙💙💙💙 — 😊 feeling proud.



Write a comment... GIF 😊

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		<p>Amber - “I even went back to work afterwards I felt ready to take on the world”</p> <p>Penny - “I don’t feel ashamed tell people like i used too”</p> <p>Alice - “I am able to express my feelings to others about how I’m feeling,which for me being able to verbalise has been invaluable”</p> <p>Lily - “The information about the support group should be put up in all dermatology departments”</p> <p>Lily - “I did this with the support and help from the group. It was a big thing to tell the world about it”</p>	<p>Am feeling so great! My first time in public without anything to cover my head and feel so happy....it may have been only in the gym but it’s a start yes some people stared but you know what I don’t care, I have my family and friends who love me for who I am and I don’t care what anyone else thinks. Enjoy the weekend xo — 😊 feeling fantastic.</p> <hr/>
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		<p>Penny - "I now model for that brand of wig get taken away to do a fashion show and promote their wigs they will often send me them to review for them"</p>	
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