A little bit of everything about Alopecia



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Part 1 What is Alopecia? - the science bit!

'Alopecia' simply means hair loss.

There are many types of alopecia, ranging from thinning hair to complete hair loss. In this booklet we explain a few of the most common types of hair loss. More information can be found on our website.

Alopecia Areata

-including Alopecia Totalis and Alopecia Universalis

Alopecia Areata typically starts as one or more bald, smooth patches on the scalp about the size of a coin, which are not inflamed or scalu. It tends to affect the pigmented hair so there may be some white hairs left within the bald area in older people. Sometimes the hair loss is diffused rather than defined patches. Short, tapered hairs, known as 'exclamation mark hairs' that are characteristic of Alopecia Areata, may be seen at the edge of the bald patch. Regrowth usually starts at the centre of the bald patch with fine white hair that thickens with time and usually regains its colour. In many cases, the condition does not extend beyond a few bald patches. In some people hair loss is more extensive and can progress to cause total loss of hair on the scalp (referred to as Alopecia Totalis) or complete loss of hair on the scalp, face and body (Alopecia Universalis).

What causes Alopecia Areata?

Alopecia areata is considered an autoimmune condition in which the immune system, which is designed to protect the body from foreign invaders such as viruses and bacteria, mistakenly attacks the hair follicles, the structures from which the hairs grow. This is what leads to hair loss on the scalp and elsewhere. The hair is lost because it is affected by inflammation. Why the immune system might attack the hair follicle in this way is not fully understood, nor is it known why only localised areas are affected and why the hair usually regrows again. Someone with Alopecia Areata is slightly more likely than a person without the condition to develop other autoimmune conditions such as thyroid disease, diabetes, lupus and vitiligo although the risk of having other conditions is still very low.

Androgenetic Alopecia

-sometimes called Male or Female Patterned Hair Loss

Androgenetic Alopecia is the most common type of progressive hair loss. It affects about 50% of men over the age of 50, and about 50% of women over the age of 65, although it can start at any age. In women the severity varies, it may present as widespread hair thinning but in some cases it can lead to complete hair loss. The progression of this condition in both men and women tends to be very slow, spanning several years to decades. An earlier age of onset may predict a quicker rate of progression.

What causes Androgenetic Alopecia?

Androgenetic Alopecia is caused by a combination of genetic and hormonal factors. With this type of hair loss the problem is not the level of male hormone but the sensitivity of the testosterone receptor on the hair follicle inducing a change in the hair follicles on the scalp. The hairs produced by the affected follicles become progressively smaller in diameter; shorter in length and lighter in colour until eventually the follicles shrink completely and stop producing hair.





alonecia uk

"I have Lichen Planopilaris and, through the help and support of Alopecia UK, I have come to terms with my hair loss."

lopecia uk



I HAVE LOPECIA

Scarring Alopecias

Scarring Alopecias, also known as Cicatricial Alopecias, refers to a group of rare disorders that destroy hair follicles. The follicles are replaced with scar tissue, causing permanent hair loss. In some cases, hair loss is gradual without symptoms, and is unnoticed for long periods. In other cases, hair loss is associated with severe itching, burning and pain and is rapidly progressive. The inflammation that destroys the follicle is below the skin surface but there is no scarring as such seen on the scalp. Affected areas of the scalp may show little signs of inflammation, or have redness, scaling and increased or decreased pigmentation. Scarring Alopecias occur in all ages although are much less common in children. Frontal Fibrosing Alopecia, Lichen Planopilaris and Folliculitis Decaluans are three of the more well-known types of Scarring Alopecias.

What causes Scarring Alopecias?

The cause of Scarring Alopecias is not well understood. What is known is that redness, heat, pain or swelling occurs in the upper part of the hair follicle. This is the place where stem cells and sebaceous (oil) glands are located. If the stem cells and oil glands are destroyed, the hair follicle cannot regrow, and hair is permanently lost. From a dermatological point of view it is important to identify scarring alopecia because this permanently destroys hair follicles and the disease process may be slowed down or stopped by topical or systemic treatment. There is no scarring as such but a complete loss of visible follicles in the affected area.

Telogen Effluvium

Telogen Effluvium refers to increased shedding of hair from the scalp. This is a greater than normal level of hair loss and can be most noticeable when you brush or wash your hair. However, your scalp and the remaining hair look healthy. You will not have patches of hair loss (bald patches) but rather a generalised thinning. Telogen Effluvium tends to affect older hairs, which are brought to an end of their life cycle earlier than the usual three years or so. Many more hairs than usual are then ready to fall out at one time, resulting in a decrease in hair volume.

What causes Telogen Effluvium?

Telogen effluvium occurs due to a disturbance in the normal hair cycle, usually about 1–3 months after a major stress to the body. The most common time it occurs is in women about 1–3 months after childbirth. Other common triggers include major operations, accidents, illnesses, stressful life events, significant weight loss or medication changes.

Chemoinduced Alopecia

Hair loss is one of the most well-known side effects of cancer treatment. Generally, chemotherapy is the type of cancer drug treatment most likely to cause hair loss. If your hair is going to fall out, it usually begins within 2 to 3 weeks after treatment starts. It is usually a gradual loss rather than a sudden one. For the majority of individuals, hair will grow back once chemotherapy treatment has finished. In very rare cases the hair does not grow back but usually this only happens with very high doses of particular drugs.





Diagnosis of alopecia

It is important that you seek professional medical advice from your GP. If there is any doubt about which type of hair loss you are experiencing ask to be referred to a Dermatologist for a diagnosis. If you have other symptoms then you should discuss these with your doctor. Your doctor may suggest a blood test to check for other possible causes of hair loss.

What are the symptoms?

There may be a tingling sensation on the scalp. If alopecia affects the eyelashes, then the eyes may become sore due to dust, particularly in dry and windy conditions. In some cases of Scarring Alopecias, hair loss happens quickly, and there is severe itching, pain and burning. In other cases, hair loss is gradual and there are no other symptoms. Similarly in Alopecia Areata, while in most cases it is not painful some people report feelings of itchiness, soreness or irritation at times of shedding or regrowth. Some people with Alopecia Areata also develop small pits on their nails, similar to the dimples seen on a thimble.

Androgenetic Alopecia looks different in males and females. Hairs in the affected areas are initially smaller in diameter, and shorter compared to hairs in unaffected areas, before they become absent. In men, the usual pattern of hair loss is a receding hairline, and loss of hair from the top and the front of the head. In women, hair loss or thinning typically occurs at the crown of the scalp, with complete or nearly complete preservation of the frontal hairline. Chemotherapy induced alopecia can develop by mild thinning of your hair, partial hair loss, or loss of patches of hair, or complete hair loss.

Is alopecia contagious?

No, none of the types of alopecia are contagious.

Is alopecia hereditary?

There can be a genetic predisposition, so there can be an increased likelihood of developing Androgenetic Alopecia and Alopecia Areata if family members are affected. Scarring Alopecia usually affects only one family member.

Treatments for Alopecia

Unfortunately, there is currently no known cure for alopecia and no universally proven therapy to induce hair regrowth and sustain remission. However, there are treatments that you can discuss with your GP or dermatologist. It is worth noting, that the effectiveness of treatments tends to vary and something that works well for one person may not for another. Please review the Patient Information Leaflet for your type of alopecia, produced by the British Association of Dermatologists (BAD). You can find links to BAD leaflets at the end of each alopecia type within the 'About Alopecia' section of our website.

Points to consider

- Everyone is different
- What works for one person may not work for another
- Be mindful of treatments that say they 'cure' hair loss – there is currently no known cure
- There are different types of hair loss check that the treatment is suitable for your type
- Do your research. There are many weird and wonderful 'treatments' and remedies out there for hair loss. Be careful how you spend your money!
- The media is awash with success stories and miracle cures, but remember, if these treatments were really as effective as the stories claim – every doctor would be prescribing them!
- Be realistic. As much as you can wish your hair to grow sadly this may not happen and it's important to manage your expectations so you are not too disappointed.

Always seek medical advice as the effectiveness of treatments can depend on your type of alopecia and how advanced your hair loss has become.



Is regrowth possible?

-it depends...

Alopecia Areata

People may experience some degree of regrowth over a period of months or sometimes years, but it cannot be guaranteed. The chances of the hair re-growing are greater if the initial hair loss is patchy. 80% of people with only a few small patches experience full regrowth within a year but further episodes of hair loss may be experienced in the future. If more than half the hair is lost then the chance of full recovery is less likely but not impossible. Regrowth can often appear in a different colour to the hair that was lost, with white pigment-free hair being quite common.

Alopecia Totalis and Alopecia Universalis

The likelihood of total regrowth is less likely than in cases of patchy Alopecia Areata but not completely unheard of. Some people with Alopecia Totalis and Alopecia Universalis do experience full regrowth.

Androgenetic Alopecia

Regrowth does not occur. There are treatments available to slow the effects but they are not guaranteed to work in each case.

Scarring Alopecias

Unfortunately the hair loss experienced in cases of Scarring Alopecias is permanent and hair does not regrow in the affected areas.

Telogen Effluvium

This type of hair loss should correct itself over time without treatment and in a short time new hairs grow from hair follicles as usual. A normal pattern and thickness of hair returns within a few months once these new hairs are established.

Chemotherapy Induced Alopecia

Unless you have had very high doses of particular chemotherapy drugs, your hair will grow back once the course of treatment is over. After chemotherapy, this may take several months and your hair is likely to be softer. It may come back a different colour and may be more curly than before. It will probably grow back at the same rate as it grew before chemotherapy, within 4 to 6 months after your treatment ends.

With any type of hair loss, we understand that it can be emotionally difficult. Part 2 of this booklet explains how Alopecia UK can help.

"I choose to keep my patchy hair shaved back. It all comes down to what we're most comfortable with; there's no right or wrong way."

www.alopecia.org.uk



Part 2

Alopecia UK: Who are we and how can we help?

Regardless of which type of alopecia you may be experiencing; we understand all types of hair loss can cause emotional distress. At Alopecia UK we have a deep understanding of the psychological impact of hair loss. Many of the staff team working at the charity have personal experience of alopecia. Alopecia UK works to improve the lives of those affected by alopecia through our aims of Support, Awareness and Research.

Our vision is to create a world without alopecia, or a world in which people with alopecia can live the life they want with confidence.

When you are first diagnosed with alopecia you may feel that your world has turned upside down. It might affect your relationships, work and social life. You may experience feelings of loss, perhaps a loss of your sense of who you are due to a change in your appearance. Feelings of grief can be very common for people with alopecia. Seeking support to help you upon diagnosis and/or later down the line can help enormously. Alopecia UK can support you at this difficult time. We want to help people diagnosed with alopecia to overcome or move beyond their condition and experience.

We offer information, advice and support in the following ways:

- A website full of up-to-date information and advice
- A network of support groups nationwide where you can meet others with alopecia
- The opportunity to connect with other people affected by hair loss online via private Facebook groups
- One to one email and telephone support
- Fun and informative annual events run throughout the UK
- A monthly e-newsletter sent to our mailing list
- Awareness campaigns, including Alopecia Awareness Month, and social media (Facebook, Instagram, Twitter and YouTube)
- Service Directory providing an online search facility and offering discounts on products
- Support and fund alopecia research projects



"Alopecia UK makes me feel part of a community – a community of people who know what it feels like."



Alopecia UK Support Groups

Adjusting to your changed appearance and dealing with the reactions of others to your hair loss can be hard to deal with. Practical and honest information along with support and friendship of others can really help. Our group leaders are not professional counsellors but they have experience of alopecia themselves and can help to give insight and advice on living and dealing with alopecia on a day-to-day basis.

Our support groups aim to help you:

- Feel less lonely, isolated or judged
- Gain a sense of empowerment and control
- Improve your coping skills and sense of adjustment
- Talk openly and honestly about your feelings
- Reduce distress, depression or anxiety
- Develop a clearer understanding of what to expect with your situation
- Get practical advice or information about treatment options
- Compare notes about resources, such as doctors and alternative options, such as wigs, head scarves or holistic therapies

Meetings are designed to be informal, fun and friendly. Friends and family are all welcome. Anyone under the age of 16 who wishes to attend a support group meeting needs to be accompanied by someone aged 18 or over or check to see if an Alopecia UK Children's Group is an option.

Support groups usually meet between 4 and 6 times a year, depending on the support lead. To find the nearest group to you, check our list of support groups currently running across the UK on our website under the 'Support and Advice' section. "She was visibly shaking with nerves and had been pacing outside, scared to come into the room. But she did come in and she talked to us about her experience of alopecia and how, up until that point, she had never spoken to anyone about it. We chatted about all sorts of things, including coping, confidence and wigs. At our next meeting she carried herself with a confident smile, wearing a new wig. For the first time in 16 years of suffering with alopecia (I use the word suffer because I feel this lady had suffered for years) she is now being open about her hair loss. It was amazing to see."

Gwennan Thomas (Cardiff Support Group Lead), recalling a story of a new group member to one of her meetings.

Supporting men with alopecia

Sadly, there is still a misconception that hair loss is easier for men to deal with than women. This is not the case! Everyone is different. While it may be true that some men find hair loss easier to manage than some women, the reverse is also true. Lots of things affect how we cope, including how much support we have, how important our hair is to us and our individual personalities.

Men can often feel self-conscious and embarrassed about their hair loss, and if it affects different areas of the body these feelings can be worse in the Summer or when doing some sports. For men it is much more difficult to disguise hair loss which can make them feel down about how they look. Men can often feel isolated due to the assumption that 'it's more acceptable for men to lose their hair' and this can lead it to being harder for men to talk about their feelings about hair loss.

At Alopecia UK we know that men can understandably struggle with losing their hair, and that it can be hard to ask for help. We recognise that no matter who you are, losing your hair can be distressing and we want to support anyone who is affected by hair loss.

Supporting children with alopecia

At Alopecia UK we are in touch with lots of children, young people and families who are affected by hair loss. It can be a very challenging time for families. as you are helping a child to adjust to hair loss whilst also dealing with your own emotions about your child losing their hair. For many children, young people and families there can be fears around being bullied, and not being accepted by their peers. At Alopecia UK we have a network of childrens and teens groups that you can attend as a family to meet others with alopecia. The groups can help children and teens to see they are not the only one with alopecia. Our groups can be a great place to share tips on managing alopecia - both practically and emotionally.

As well as our groups we also have annual events and activities, including our trip to Alton Towers which is a big hit with younger people. For more information on support for children, young people and families please visit the **'Children and Young People'** section of our website.





Living well with Alopecia

It is OK to feel upset or angry (or both) about losing your hair. 'I won't feel better unless I get my hair back' is something we often hear at Alopecia UK, but sadly there is no way of knowing when hair will grow back, and in some cases hair may not grow back. There are some very difficult emotions to manage; however, in time, you can live well with alopecia.

If you are feeling down, or stressed, or upset because of your hair loss here are some things to remember:

1. You are your own worst critic

Thoughts are not facts; they are opinions based on your own experiences. Try and see beyond your thoughts, ask others what they think. Try the following: imagine what you would say to a loved one who was having the same negative thoughts as you or perhaps ask a loved one for their opinion.

Have a look at our wellbeing tips for advice on managing negative thoughts.

2. How you think affects how you feel and how you act

If you have negative thoughts it's likely you will feel down and be less likely to do things you used to enjoy. For example, you might not want to go and see friends because you think you look 'strange'. However, by not seeing friends and not doing things you enjoy you are more likely to feel down. It becomes a vicious cycle, but we can make changes.

3. Motivation will not come to you... go find it

It might seem like you need to wait until you 'feel better' for your motivation to come back, but it doesn't work this way. If you have been avoiding seeing friends and socialising, it can feel difficult at first to do it again. But over time you may start to notice that you are laughing and having fun again. This will give you the motivation to see friends again. Don't delay; make the call/send the text!

4. You can't compare yourself to others, everyone is unique

People tell us that having alopecia can feel very isolating. You might not know anyone else with hair loss and you might see everyone around you with hair and feel different. The media doesn't help by promoting unrealistic body ideals. Many of us are guilty of comparing ourselves to others, but we are all unique and it can be damaging to your self-esteem to make these comparisons. It is important to remember that what you see in the media is only one part of the story – and images are often altered anyway! If you compare yourself to someone in the street, remember – they may have their own body image struggles that no one knows about.

5. Adversity can lead to personal growth

Dealing with alopecia can bring unexpected benefits. The inner strength you start to develop can help you to learn new ways of dealing with problems and new ways of looking at the world. Many people get in touch with the charity to tell us that their experience has helped them feel like a better person. People find they become less quick to judge others on their appearance and are more accepting of the differences of others.



Top tips for wellbeing

It's OK to not be OK... you are allowed to feel sad, upset, anxious or any other emotions over losing your hair. You may find that other people don't understand what you are going through and they may say things that are insensitive or unhelpful. It's OK to feel upset about this but try not to take it personally. It can be hard to understand something if you have not experienced it for yourself.

It can help to write down how you feel to get your feelings out. You might want to write a diary or a blog, or even a letter to someone (you don't have to send it).

Writing your thoughts down can help in a number of ways:

- Help to explore your feelings
- See if there are any patterns to your moods, any times when you seem to feel better or worse?
- Help explain how you feel to others
- Help to express how you feel and get those difficult emotions 'out'

You might prefer to try more creative ways of expressing your feelings, for example through art. Some people find physical activity a helpful way to manage some of their difficult feelings, particularly high energy activities, for example running or boxing.

Accept support

Most of us rely on our friends and family to help us when we have problems, Alopecia should be no exception. Friends and family will most likely want to be there to support you. If your friends and family are struggling to know how to help you, let them know that they can also contact Alopecia UK for support and advice.

Schedule in some 'you time'

It is important to prioritise yourself! Don't forget about the little things. Even just doing the little things that you enjoy can help you feel better, improve your mood and relieve feelings of stress and tension. For example you might enjoy a relaxing bath, a long walk, treating yourself to something indulgent or watching your favourite film. Whatever you do, be kind to yourself!

Develop healthy routines

Think about what you do now when you are feeling down or stressed. You might feel tired and sleep more, or you might drink alcohol or smoke more. Try and think about how you can develop some healthy routines to help manage your mood.

Exercise can help release your feelings in a positive way and reduce stress. Some kinds of exercise are particularly good for expressing anger or upset, such as running or a gym workout, others are more calming such as Yoga or Tai Chi.

Believe it or not, the types of foods you eat can affect your mood. A balanced diet including vegetables and non-processed foods not only keeps you healthy but also keeps the mind healthy and happy. If you feel physically better this will help your mood.

Everyday life can bring unexpected challenges but its important to have a routine that works for you (most of the time). You might find it helpful to ask yourself the following questions:

- Is my to do list achievable?
- Is there a good balance in my week of things I have to do and things I like to do?
- How much time do I have to do things for myself?
- Does my routine look how I want it to?

Try relaxation

When you are stressed, stress hormones are released which lead to a range of responses in the body which include:

- Heart beating faster
- Tension in the muscles
- Sweating
- Upset stomach
- Increased blood pressure

All of these things can feel uncomfortable and sometimes frightening but relaxation can help to reduce the levels of stress hormones and relax the body.

Here is a quick and simple relaxation exercise you can try:

- Sitting or standing, whichever is most comfortable for you, place both feet flat on the ground, hip width apart
- * Let your breath flow as deep down into your belly as is comfortable
- * Try breathing in through your nose and out through your mouth
- Now, breathing in gently count steadily to five and then without a pause or holding your breath breathe out slowly to the count of five
- * Gently breathe in through your nose to the count of five and out of your mouth to the count of five
- * Keep doing this for around three to five minutes.

Acknowledge your positives

You are so much more than how you look but alopecia can make it very difficult to focus on anything else. Try and take some time to think about all the things you can do well, all the things that people say are your good qualities. If it helps, why not ask people you trust what your best qualities are.



Speaking to others who 'get it' can be really helpful

If you don't know anyone with alopecia it can feel quite isolating. Speaking to other people affected by alopecia can help. Meeting others is also a great way to get practical advice and support on your options for managing hair loss.

Alopecia can present challenges and at some stage it may be necessary to share your feelings and concerns and to get some support to boost your self-esteem once again. You may therefore find it helpful to try some form of psychological therapy, e.g. counselling, or art therapy. If you do, talk to your GP about the possibility of a referral on the NHS. Alternatively, you can find an accredited therapist on the **British Association for Counselling and Psychotherapy: www.bacp.co.uk**

We hope the wellbeing tips are helpful. REMEMBER, it can take different people different amounts of time to start to feel more positive. Try not to feel bad for feeling bad as it's perfectly normal to feel down. Don't compare yourself to others who you feel are coping better or worse. We are all very different human beings!





Part 4

Appearance tips for managing hair loss

Some people with alopecia are comfortable accepting their appearance without any desire or need to enhance existing features or cover up. Others feel more comfortable disguising or covering their hair loss and for these people the following tips and hints may be useful.

Eyebrows

If you have lost your eyebrows, you could consider trying one of the following:

Make Up

- 1. Find an eyeliner or eyebrow pencil in a similar colour to your head hair or wig. Make sure the pencil is sharp to ensure a fine line.
- 2. Place the eyebrow pencil vertically across the tear duct on your eye to measure up with your eyebrow bone, this is where your eyebrows should start from. Mark this with your pencil.
- 3. To find the end of where your eyebrows should be, place your eyebrow pencil at the edge of your nostril, lining up with the corner of your eye on onto your brow bone. Mark this as the end.
- 4. The next part is to find the arch of your brow, to do this line the pencil up again with the outside of your nostril, this time slightly more vertical so it passes by the iris of your eye. This should be your highest point of the brow, again mark this area.
- 5. Begin to draw in short soft lines where your eyebrow used to be to give the appearance of natural hair. Don't draw just one line use little strokes to imitate eyebrow hairs.

Stencils & Temporary Eyebrows

Egebrow stencils can provide you with a guide for pencilling in egebrows or applying powder in your desired shape. Alternatively, you can purchase temporary tattoos (sometimes known as transfers) which are available in a range of colours, shapes and styles. These are temporary, lasting two or three days and can be removed easily with baby oil. There are also stick-on eyebrows available, made from real or synthetic hair. Both stencils and temporary eyebrows can be purchased online.

Permanent Make-Up (PMU)

Permanent make-up is a method of inserting small amounts of pigment into the dermal layer of the skin using very fine and accurate probes to enhance or recreate features. This can produce a natural finish as the technique can create the appearance of individual eyebrow hairs. Permanent make-up is also referred to as semi-permanent make-up (confusing we know), cosmetic tattooing or microblading. Although the technique can be a little sore, good practitioners use local anaesthetic to help numb the area.

The benefits of PMU are:

- It can last 2–3 years (no need to worry about your eye brows every day)
- It is smudge free and waterproof

However, it is important to remember that PMU does last a long time and therefore you need to be happy with the result. To get the best outcome you need to do your research.

Here are some top tips on PMU:

- Always use a qualified technician. Ideally one who specialises in working with people with hair loss
- Ask to see the technician's portfolio to see examples of their previous work
- Make sure the technician performs an allergy test on you before the procedure to reduce the risk of an allergic reaction to the PMU
- Agree the shape and colour before you have it done; most technicians will draw brows on your face using pencil to agree the shape and size

For more information on PMU please visit the 'Appearance Tips' section of our website under 'Support & Advice'.



Eyelashes

Eyeliner and False Eyelashes

If you have lost your eyelashes, applying eyeliner pencil or liquid eyeliner creates definition around your eyes. Experiment with different colours to see what suits you.

False eyelashes made of both synthetic and real hair are widely available in most large chemists, high street stores and online. Eyelashes are applied with glue, which is usually supplied with the eyelashes (although glue can be bought separately). Pre-glued eyelashes are also available.

Applying False Eyelashes:

- Measure the size of the false eyelashes against your eyes as the eyelashes may need to be trimmed to fit if too big.
- 2. Apply a thin layer of glue to the seam of the eyelash, leave this for around 30 seconds to go tacky before applying to your eye.
- Use tweezers or eyelash grippers to place the strip of lashes on your eyelid, as close to your natural eyeline as possible
- 4. Allow the glue to dry, try not to press or flutter your eyes until they feel stuck
- 5. If you wanted you can now apply mascara or eyeliner to fill in any gaps



Disguising patchy hair loss

If you have patchy hair loss changing the way you wear your hair can help disguise this. Try experimenting by wearing your hair differently such as changing the parting or tying it back in various ways. A different hair style could help to make patches look less obvious. Your hairdresser may be able to give you some ideas

Camouflage products

If you have just a few patches of hair loss you could try coloured hair root touch up spray or dry shampoo to reduce the colour contrast between your skin and hair, making the patches less obvious. You could also use a keratin microfibre product which is sprinkled on the scalp and binds to each hair fibre to give more natural weight and density.

Head wear: Hats, Bandanas and Scarves

One option to cover more extensive hair loss is a scarf or bandana. There is an endless range of options available in high street shops and online. There are different colours, styles, fabrics and seasonal options. Some manufacturers use very soft materials with no seam, which helps to reduce possible irritation. A popular option is using scarves which you circle round your head and then clip or tie into place. This may take some practice but it opens up a range of colours and styles. There are many demonstration videos available online.

Another option would be to buy a design of headwear that is specifically designed for those with medical hair loss. These are often hats, turbans or bandanas that fit snugly to the head and come in a range of styles.

Wigs and Hairpieces

Synthetic Wigs

Synthetic wigs are lighter than real hair and can look extremely natural. There are many styles to choose from. They come pre-styled and the hairstyle stays in shape after washing. Although this does not mean you cannot take them for a trim. Synthetic wigs can be obtained quickly as they are affordable and readily stocked in wig salons. If worn daily, synthetic wigs can wear out quickly. Wigs may need replacing after 3-4 months. This can pose difficulties if a prescription only allows you two a year.

Human Hair Wigs

As with synthetic wigs there is a lot of choice with human hair wigs too. They are generally more expensive than synthetic wigs but will also generally last longer. It can be more difficult to get assistance with human hair wigs from the NHS. Some can be bought in a standard style, others will be custom made and may take a few weeks/months (depending on the type) to be ready.

Practical Considerations

Most wig wearers have two at any one time – one to wear and one to wash. A wellfitted wig should feel secure and snug to your scalp. Comfort is important so be sure to try on different ones for size and style. It is recommended you visit a salon so they can measure you for your first one. A good wig supplier should be able to make any adjustments to wigs to ensure they fit as well as they can.

The guidance on wigs is different depending if it is synthetic or human hair so if you have different types of wig don't care for them in the same way; follow individual instructions!

For those with total hair loss on the scalp, you can buy special adhesive tape or grip bands to stop the wig slipping.

Can I get a wig on the NHS?

This is a question we get asked a lot and our response is – it depends.

In some areas of the UK the NHS makes provision for the supply of wigs to dermatology patients who need them. Unfortunately, in other areas there is no provision and the cost has to be met entirely by the individual.

Your dermatologist will decide if you qualify for a wig prescription. If you qualify, you will be given a prescription and be advised which wig suppliers you can take your prescription to. Some NHS Trusts give you a choice of supplier and some only give you one option.

For further information, please see our 'Guide to Wigs' within the Appearance Tips pages of our website in the 'Support & Advice' section.

Wigs and VAT

If you wear a wig for medical reasons, including any type of alopecia, you should not pay VAT on your wig. Your wig supplier should be aware of this and provide you with a form to complete (or incorporate it into their online checkout for website purchases) in order to obtain the VAT relief. If they don't, be sure to ask them!

Finding Products and Services

Alopecia UK's Service Directory lists details of businesses across the UK that provide products and services such as wigs, headwear and PMU that can help those with alopecia. If you are looking for products and services it is worth checking out the Service Directory to see what is available locally or from national online suppliers. Please note that some businesses listed on the Service Directory offer discounts to Alopecia UK VIP Cardholders. You can find details on our website on how to become an AUK VIP Cardholder.

There is so much information on wigs that it would be impossible to cover it all here. We have included some of the main information you need to consider, for more information on wigs please visit the 'Appearance tips' section of our website under 'Support & Advice'.





Part 5

How to get involved

We support thousands of people every year, reach millions through awareness projects and look to the future by investing funds into alopecia research. But we can't do any of that without your support.

There are lots of ways you can get involved with Alopecia UK!

Donations and Fundraising

Alopecia UK can only continue to do the work we do with the ongoing support of individual donors and fundraisers. Donations make a really huge difference. You can donate via our website or social media channels (or get in touch for more ways to donate).

Fundraising can be lots of fun – lots of our fundraisers do team-based activities which means you are having fun while raising money! If you don't fancy doing something active why not do something like host a bake sale or coffee morning? You might want to get your family or colleagues involved in some way too. We have lots of fundraising support and resources available on our website under the 'Get Involved' section.

Volunteering

Alopecia UK is always looking for willing and enthusiastic volunteers. By donating your time and/or skills, there is lots you can get involved with. If you would like to donate some of your time we would love to hear from you. We have a volunteer sign-up form on our website under the 'Get Involved' section.

Sign up to our mailing list

Make sure you sign up to our mailing list to receive our monthly newsletter by email to ensure you stay up to date with all the latest activity from Alopecia UK, including support group and event dates.

Become an AUK VIP

Our VIP Scheme is a very simple way for people to support the charity. The cost of your AUK VIP card helps to support Alopecia UK and the work we do. In return, not only do you get the warm fuzzy feelings from helping a small charity but you also get discounts on products and services from participating Service Directory members plus free entry into AUK VIP prize draws.

There are lots of ways to get involved! The more you support us, the more we can continue to work towards and develop our aims of Support, Awareness and Research. For further information, please visit the 'Get Involved' section of the website.



Part 6

Further support available

www.alopecia.org.uk

For further information about alopecia, including details of research projects, ways of managing visibility of hair loss, local support groups, online peer support, national events, products and services (via our Service Directory) and much more, visit our website.

www.mind.org

MIND is a charity that provides advice and support to empower anyone experiencing a mental health problem. You can call them on **0300 123 3393** or text **86463** for support.

www.samaritans.org

The Samaritans are available 24 hours a day, 365 days a year. They offer emotional support and a listening ear. Call **116 123**. It's a freephone number, which can even be called from a mobile that has no credit, and the call will not appear on your phone bill. The service is totally confidential.

www.nspcc.org.uk

If you are under 19 you can find support from the NSPCC. You can speak to someone on the phone by calling **0800 1111** or you can visit their website which provides support information. The NSPCC supports young people with any issue they may be experiencing.

www.changingfaces.org.uk

Changing Faces is a charity that provides support to those living with a visible difference. On their website you can find self-help guides, and information on managing your visible difference at work.

www.bad.org.uk

You can visit the British Association of Dermatologists website for information and support on different skin conditions, including alopecia. This information has been written by Dermatologists. The British Association of Dermatologists has also developed a website **www.skinsupport.org.uk** which has support information on managing your well-being.

www.nhs.uk

The NHS website has lots of information on mental health and well-being. You can do your own mood self-assessment, listen to mental health audio guides, read information on managing anxiety and depression, and also find out more about local support.

Acknowledgements and thanks

In order to compile the information in this booklet we used the following resources, which you may find useful for your own further reading.

- 1. Alopecia UK: www.alopecia.org.uk
- 2. British Association of Dermatologists Patient Information Leaflets: <u>www.bad.org.uk</u>
- 3. Hunt, N & McHale, S. 2004. Coping with Alopecia. London: Sheldon Press.
- 4. Messenger A.G. et al. 2012. Guidelines for the management of alopecia areata, British Journal of Dermatology 166, pp.916–926.





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