

Dermatology Department

Frontal Fibrosing Alopecia

Information for patients



What is Frontal Fibrosing Alopecia (FFA)?

FFA is a condition which causes hair loss, mainly over the hairline at the front of your head. It is a type of alopecia known as 'scarring alopecia' or 'cicatricial alopecia'. It is thought to be related to another condition called lichen planus which, when it affects the scalp, is called 'lichen planopilaris'. FFA causes inflammation which destroys the hair follicle, replacing it with permanent scarring. It mainly affects post-menopausal women.

What causes FFA?

FFA is a condition that has only relatively recently been recognised and the number of reported cases is increasing. The cause of FFA is unknown. It is thought that hormones may be partially responsible, as it typically affects post-menopausal women and can occur alongside genetic hair loss (also known as androgenetic or female pattern hair loss). However, blood tests for hormone levels don't usually show any abnormalities.

We do know that in lichen planopilaris the body's immune system is affected, especially T-lymphocytes, a type of white blood cell. White blood cells form part of the body's immune system and are involved in fighting infection. When the body mounts an immune response this causes inflammation, which eventually destroys the hair follicles.

The possible role of environmental factors contributing to FFA is still being investigated.

Is FFA inherited?

FFA is not thought to be inherited but some patients have reported family members developing the same condition. Research is being carried out into whether a particular gene or combination of genes (set of instructions made from DNA) could make a person more likely to develop FFA, but the answer is not yet known.

What are the symptoms of FFA?

Usually FFA causes very few symptoms. Unlike lichen planopilaris and other forms of lichen planus you probably won't notice much or any itching. The most common complaint is loss of hair at the front of the head, which slowly moves backwards, and loss of eyebrow hairs.

What does FFA look like?

FFA will cause you to lose hair along the front of your hairline and this will slowly move backwards. There will be scarring along the front and sometimes the sides of your scalp. You may notice some redness and scaly skin around your hair follicles. The area that is affected usually progresses slowly over several years, although occasionally this process can happen more quickly. You might also notice that you are losing your eyebrow hairs and hairs elsewhere on your body. There is also a rare chance that you may develop lichen planus. This can cause a rash on your skin, in your mouth and on your genitals, as well as nail abnormalities.

How is FFA diagnosed?

Your dermatologist will usually be able to diagnose FFA by performing a medical examination. They may also need to carry out a biopsy to confirm the diagnosis. This involves removing two small samples of your affected scalp skin under local anaesthetic, so that they can be studied under a microscope.

Can FFA be cured?

When the hair follicles are destroyed and replaced by scar tissue they cannot regrow. This means that your hair won't grow back. The condition can become inactive and your hair loss may stop after several years, but slow progression over many years is common. Treatment aims to prevent further destruction of your hair follicles but will not be able to make hair grow back that has already been lost.

How can FFA be treated?

FFA can be treated with topical scalp treatments such as creams, lotions and gels. It can also be treated with tablets. However, the evidence for any of the treatments for FFA is poor and success rates can be very variable. Unfortunately there is no single proven effective treatment and despite trying many treatments some people still continue to notice hair loss. Some people choose to have no treatment at all and decide to wait to see if the condition will stop on its own.

Topical treatments

Topical steroid preparations – Potent topical steroids in the form of lotions, gels or mousses can help treat specific areas and can improve symptoms. Although scalp skin is quite thick and can withstand steroid application relatively well, there is a chance that your skin can become thin if the topical steroids are used incorrectly.

Steroid injections (known as intralesional steroids) – Injection of a steroid may be an option if only a small area of your scalp is affected. However, injections are often painful or uncomfortable and carry a risk of causing side effects such as skin atrophy (thinning) or dimpling.

Topical calcineurin inhibitor ointments – These topical treatments are not usually prescribed for FFA but can help to settle inflammation and in certain cases may be useful.

Tablet treatments

Corticosteroids – A short course of steroid tablets can be used to try and switch off the inflammation. However, they can cause side effects such as weight gain, high blood pressure, diabetes and osteoporosis (thinning of the bones) if they are used long-term.

Tetracycline antibiotics (e.g. doxycycline or lymecycline) – This family of antibiotics are commonly used as anti-inflammatory treatments. They have few side effects, require little monitoring and can often be used for long periods of time (6 months or more).

Hydroxychloroquine – This is an anti-malarial tablet which, although slow to start working, can be useful in this condition. Very rarely it may cause eye problems and so it is recommended that you have an annual eye check. It can also affect your liver, so you will also need to have six monthly blood tests to check your liver is working properly.

Mycophenolate mofetil – This is a strong “immunosuppressive” drug most commonly used in patients after a kidney transplant. It works by suppressing the immune system so your body is less likely to react and cause inflammation. It also makes your body less able to fight off germs, so care must be taken to avoid catching an infection. Common side effects include nausea, vomiting and diarrhoea, and you will need to have regular blood tests.

5 α reductase inhibitors (Finasteride and Dutasteride) –

These are anti-androgen (anti-male hormone) medications which are licenced and normally prescribed for men with prostate disease. Dermatologists with an interest in hair and scalp disorders sometimes use them 'off licence' to see whether they can also treat FFA. Strict monitoring is required if you are prescribed these medications, to check for side effects and make sure there are no complications.

Other options

Often people wear hats, hair bands or scarfs to hide their hair loss. Some individuals who have extensive hair loss choose to wear a wig or hairpiece. These can either be bought privately or obtained through the NHS (although you may still need to make a small contribution).

Semi-permanent makeup and medical tattooing can be helpful, especially if you have eyebrow hair loss, but these are not currently available on the NHS.

Hair transplantation may be an option once the condition has been stable for a number of years. This is not available on the NHS and isn't always successful, especially if the condition is still progressing or it reactivates.

Where can I get more information?

New Zealand based Trust with good information about different skin problems, including FFA.

Website:

www.dermnetnz.org/hair-nails-sweat/frontal-fibrosing-alopecia.html

Patient support groups:

Cicatricial Alopecia Research Foundation (US)

Website: <http://www.carfintl.org/>

Alopecia UK (focuses on alopecia areata but useful advice on hair loss generally)

Website: <http://www.alopeciaonline.org.uk/>

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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