



Jeff Donovan MD PhD FRCPC

Dermatologist, specializing in hair loss

750 West Broadway Suite 905 - Vancouver BC V5Z 1H8

Phone: 604.283.9299 Fax: 604.648.9003

Email: vancouveroffice@donovanmedical.com Web: www.donovanmedical.com

25 Frequently Asked Questions about Scarring Alopecia

Scarring alopecia (also called cicatricial alopecia) is a type of hair loss whereby the affected patient develops permanent areas of hair loss. This is usually on the scalp but can include the eyebrows, eyelashes and body hair. There are well over 50 types of scarring alopecia. However, the most commonly seen scarring alopecias can be summarized in a short list, including lichen planopilaris (LPP), frontal fibrosing alopecia (FFA), central centrifugal cicatricial alopecia (CCCA), discoid lupus (DLE), and dissecting cellulitis (DSC).

Individuals with newly diagnosed scarring alopecias have many questions. They want to know if they have the right diagnosis, what treatment to start and what the future holds.

Below, I've summarized the most commonly asked questions I get about scarring alopecia.

FREQUENTLY ASKED QUESTIONS

1. Do I have the right diagnosis?

Many patients with scarring alopecia remain unsure if they have the right diagnosis. Some look on google for verification. Some seek a second opinion from another physician (or third opinion).

Determining the right diagnosis is absolutely essential. If one is not sure they have the right diagnosis, getting a second opinion could prove worthwhile. This is especially true if the patient feels their hair loss does not quite follow what they heard from another source or read online.

If one is not sure if the first diagnosis they were given is correct, they may consider getting a second opinion from a dermatologist. If at all possible, getting an opinion from a dermatologist who specializes in hair loss is a good idea.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 2

2. Do I need a scalp biopsy?

Dermatologists have a lot of different views as to whether every patient with potential scarring alopecia needs a scalp biopsy or not. These views fall in three main categories:

- 1) There are some hair loss centers/clinics/physicians whereby every single patient with hair loss (scarring or non-scarring) gets a biopsy. Period.
- 2) There are some physicians who perform a scalp biopsy in every single patient with scarring alopecia. Period.
- 3) There are some physicians who perform a biopsy if the diagnosis is not certain and there is even the slightest ambiguity in the diagnosis.

I fall in the third category. My decision on whether a patient needs a biopsy comes during the final steps of a typical patient evaluation. First (step 1), I listen to the patient's story about their hair loss (we call this a history). Second (step 2), I examine the scalp using a dermatoscope. Third (step 3) I review blood tests. Fourth, I decide whether a biopsy is needed given all the information I have collected during steps 1-3. If the diagnosis is clear and there simply can't be another diagnosis possible, I don't do a biopsy.

Here's an example. Suppose a 56 year old female patient comes to see me. She started losing her eyebrows at age 51. At age 54 she started losing hair along her frontal hairline and it's receded now about ½ inch. She's lost her arm hair, pubic hair and leg hair. Examination shows a scarring alopecia along the frontal hairline. Her blood tests are normal. Based on steps 1-3 I'm confident in the diagnosis of a condition known as frontal fibrosing alopecia.

Will I do a biopsy? No. I will not recommend doing a biopsy in this situation. If the biopsy returns showing scarring alopecia, it's true that I will have confirmed the diagnosis. Not a bad thing of course. But I will have caused the patient an unnecessary scar. Also, there is always the potential that biopsies (or any trauma) can further activate scarring alopecias, so I'd like to stay away from that.

But suppose the biopsy returns showing something else – such as androgenetic alopecia or alopecia areata. Biopsies are not 100 % accurate so once in a while a scenario like this does occur. In a situation like this, I won't believe the biopsy results. I'll simply put the biopsy results aside and move on with discussing treatment. In other words, I'd simply have to explain to the patient that biopsies are not perfect. The reality is that I have caused an unnecessary scar. There may also have been unnecessary expense for getting the biopsy done. There may have even been some pain and discomfort for a few days.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 3

Suppose in the above example, we change things a bit. Suppose the patient is a 56 year old female patient like in the above example. She started losing her eyebrows at age 51. At age 54 she started losing hair along her frontal hairline and it's receded now about ½ inch. She's lost her arm hair, pubic hair and leg hair. She has joint pain in her wrists and ankles, unusual rashes, extreme fatigue and prominent lymph nodes enlarged in her neck. She is troubled by headaches and has had 2 seizures this year that nobody can figure out why. She has dry mouth and dry eyes. Examination shows a scarring alopecia along the frontal hairline. Her blood tests are abnormal with low white cells, abnormal kidney function tests, as elevated liver enzymes. Her ANA is borderline positive at 1:160. When I examine her scalp, I have the impression this is a scarring alopecia – resembling very close frontal fibrosing alopecia.

Here's a good example of where I will do a scalp biopsy. Even though it seems the patient has frontal fibrosing alopecia, I want to rule out other conditions such as cutaneous lupus, discoid lupus, lymphomas, various infiltrative conditions, including some rare cancers.

3. I had a biopsy already but it was said to be 'inconclusive.' Do I need another biopsy?

This scenario is not so uncommon. It's not uncommon for a biopsy to return inconclusive. However, whether or not a patient needs a rebiopsy depends on a number of factors. Sometimes a patient comes to see me and they have already had a biopsy (and it's inconclusive). However, after gathering the patient's story, examining their scalp and reviewing their blood tests, I determine that a biopsy is not needed because the diagnosis is clear. In this case I won't recommend a repeat biopsy.

However, if there is any uncertainty I will recommend a repeat biopsy.

The decision as to whether one needs a repeat biopsy comes from reviewing the patient's story and details.

4. What treatment should I start?

There is quite a bit of variation as to how physicians approach this question. The treatments that are available will depend on the diagnosis and generally include topical, oral and injection based treatments. Some physicians start with topical treatments and considering adding steroid injections or pills to the overall plan if things get worse. Other physicians tend to start with topical, injection AND oral treatments first.

I'm in the second group. Provided the patient is in agreement, I generally believe in trying hard to stop the disease. I'd rather be a bit more aggressive first and then remove various treatments quickly once we know the disease is calming down than start slowly and add treatments once the patients gets worse and worse. There's no right or wrong answer but one must remember that most of the time hairs that are lost in scarring alopecia are gone forever.

Consider these two scenarios as illustrative purposes. They shed further light on the importance of this topic.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 4

SCENARIO 1. The patient is a 45-year old female with lichen planopilaris affecting her central scalp. Her hair loss is fairly significant but with styling and hair products, she can cover the area fairly well. Her dermatologist recommends she start with topical clobetasol and she does so. It helps reduce her itching a bit but 6 months later she finds she has lost a lot more hair. The dermatologist now recommends she start steroid injections and schedules her for injection every 6 weeks for the next 6 months. After 6 more months, it's clear that she's still losing hair and the area on the central scalp is much bigger. It's difficult to hide the area now. The dermatologist start doxycycline 100 mg daily. It proves helpful and together the clobetasol and steroid injections, the doxycycline helps stop hair loss. The patient finds that the hair loss has stopped at the next 6 month visit.

18 months result: Marked hair loss compared to starting appointment; but finally stable now

SCENARIO 2. The patient is a 45-year old female with lichen planopilaris affecting her central scalp. Her hair loss is fairly significant but with styling and hair products, she can cover the area fairly well. Her dermatologist recommends she start with topical clobetasol and recommends beginning oral doxycycline and steroid injections as well. The patient agrees. It helps reduce her itching considerably and 6 months later she finds she has halted her hair loss. The dermatologist continues the same plan for the next 6 months and photos show that again the patient is stable. The frequency of steroid injections are reduced but doxycycline is continued. Minoxidil is added at this visit as there is an appreciation that a bit of genetic hair loss might also be present. After 6 more months, the patient finds that things are still pretty stable (and maybe even improved a little bit) and steroid injections are stopped altogether. The patient is kept on doxycycline and topical clobetasol for a while longer.

18 month result: no further hair loss compared to starting appointment; continues stable

As much as possible, I like my patients to have stories that fit in this second category. Provided a patient is agreeable, I like to err on the side of being a bit more aggressive to try to save hair.

5. How do I know if my scarring alopecia is “active” or not?

This is a very common question but surprisingly a fairly easy question to answer much of the time. A patient's scarring alopecia is active if a photograph shows the hair loss getting worse over time. In other words, the patient themselves can determine if a scarring alopecia is active by looking at their photos from time to time. If the hair loss is getting worse, it's probably active. If the hair has not changed a bit over a period of a few years, it's probably stable.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 5

A physician can also determine if the scarring alopecia is active by looking up close at the scalp. The appearance of redness and/or scaling around hairs may be one tip off that things are active. Hearing from the patient that there is ongoing itching burning or pain are important signs that things are active.

However, there is a really important point that physicians often get wrong. Even though one can determine if a scarring alopecia is active by looking at the scalp. One can not determine if a scarring alopecia is quiet by looking at the scalp. The only way that one can confidently know that a scarring alopecia is quiet is by following with repeat photography over time. Some scarring alopecias can come to look very quiet and one would be tempted to say that it is quiet (inactive) only to find that the patient has still lost hair when followed over time.

6. Is my treatment working?

There are many things that one must look at before determining if a treatment is helping or “working.” If one has a lot of itching, burning or pain and finds that the treatment is helping to reduce that itching, burning or pain, then the treatment is likely “working.”

One must be careful to use this as the sole criteria because the ultimate test as to whether a treatment is working is the determination at a time point 6 months and 12 months after starting the treatment as to whether there has been more hair loss or not. If there has been more hair loss, the treatment is not working well. If there has been no further hair loss, the treatment is working well.

7. Should I be doing steroid injections or not?

Steroid injections are helpful for some types of scarring alopecias. The decision as to whether one should be using steroid injections or not really needs to be taken on a case by case basis. Often it’s reasonable to begin with steroid injections at some point early on in the disease course to see if these injections can help stop the disease. However, not all patients need steroid injections if their current treatment plan is successfully stopping the disease.

8. What caused my scarring alopecias?

We’re still learning a lot the causes of scarring alopecias and still don’t have all the answers. At present, it would appear that scarring alopecias are caused by a variety of processes that destroy hair follicle stem cells and oil glands (sebaceous glands). For some conditions, such as lichen planopilaris, it would appear that the production of abnormal (pro-inflammatory, toxic) lipids by the hair follicle, has a very important role. In scarring alopecias like folliculitis decalvans, it would appear that bacteria such as *Staphylococcus aureus* have an important role.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 6

9. Am I at risk for other diseases because I have scarring alopecia?

Most patients with scarring alopecia are healthy. Various research studies have shown that a small proportion of those with scarring alopecia may have other health issues. For example, we know that individuals with lichen planopilaris may have a higher chance of having thyroid disease. Rarely issues such as high cholesterol may be present as well. The risk of low vitamin D appears to be increased as well.

Rarely, patients with discoid lupus are at increased risk for developing systemic lupus a disease that affects many organs in the body. Fortunately, this is uncommon. Patients with dissecting cellulitis may have acne, boils in the armpits and groin, and pilonidal cysts.

10. Can my scarring alopecia stop on its own?

Yes, scarring alopecias can stop on their own. We call this spontaneous remission or spontaneous burning out of the disease. However, not everyone's scarring alopecia will burn out spontaneously. For those that do burn out spontaneously, the timing is highly variable and time course for spontaneous burning out can range from 1 year to 20+ years.

11. What blood tests should I be getting?

The precise blood tests that are ordered will vary from doctor to doctor. Some physicians don't order any tests and simply let the patient's story guide them as to what they should be ordering. Some order complete panels of blood tests on everyone.

Generally, I order CBC, TSH, ferritin and vitamin D on all patients with hair loss. Other blood tests may be ordered on a case by case basis including ANA, zinc, ESR, CRP, ENA, creatinine (kidney function tests), and liver function tests.

12. How often should I be seeing my dermatologist?

The interval between appointments will depend on a variety of factors including the type of disease and the treatments being used. For patients with active disease who are just starting on new treatments, follow up every 4-6 months is reasonable at minimum. Patients receiving steroid injections may be seen every 4-6 weeks as well

13. How often should I be taking photos of my scalp?

One should take photos every 3 months.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 7

14. I think my disease has become stable. Should I get a biopsy again to check?

No, this would not be my recommendation. If one has not lost hair over an extended period of observation (ie 3-5 years), the patient's disease is stable (inactive) by definition. The results of the biopsy will not sway this in any way.

15. Can I have a hair transplant?

A hair transplant may be possible for some scarring alopecias. For other scarring alopecias, it's usually not such a good idea. Scarring alopecias such as lichen planopilaris, frontal fibrosing alopecia and central centrifugal cicatricial alopecia can be transplanted provided they have been completely quiet (inactive) for 2 + years. Scarring alopecias such as discoid lupus and folliculitis decalvans can be transplanted provided they are quiet but tend to be more challenging. Success rates are lower in the later two conditions.

16. How long will I need to be on my treatment?

Generally speaking, most patients are on some type of treatment for several years. Initially, one may use a few treatments simultaneously such as topical steroids, and perhaps steroid injections and some type of oral medication. Over time, as the disease stabilizes, treatments will be slowly removed. Oral treatments might be removed first while continuing steroid injections. Over time s further improvement occurs, the interval between steroid injection appointments might be increased (i.e. from every 6 weeks to every 4 months). Eventually, these too may be stopped but the patient will continue on periodic topical steroid for some extended period of time. Some of my patients with very stable disease use a topical steroid once every two weeks.

17. Are there patient support groups nearby?

There may be support groups nearby. I always recommend that patients contact the Cicatricial Alopecia Research Foundation (CARF) at www.carfintl.org to enquire about support groups that may existing in one's geographical area. If there are no support groups, consider speaking to CARF about your interest in starting one!

18. Will I pass this condition on to my children?

Most scarring alopecias don't seem to have a strong genetic component. For example, we don't typically see lichen planopilaris or frontal fibrosing alopecia run in families (there are exceptions of course).

The one scarring alopecia that may have a strong genetic component is central centrifugal cicatricial alopecia (CCCA). This may be more likely to be passed down in families.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 8

19. If I don't treat my disease and just let it run its course, am I harming myself in anyway?

We don't believe so. We have no evidence at present to suggest that by not treating the disease that one is placing themselves at any type of increased risk for other health issues.

20. Besides taking medications, are changes in my diet or addressing things like stress likely to help me?

These are important questions and we don't know these answers yet. Reducing stress in those that have high levels of stress could play an important role in improving one's quality of life and sometimes even reducing symptoms like itching, burning or pain. Whether this actually helps stop the disease is unknown.

The role of diet continues to be explored. Certainly, diets rich in fruit and vegetables give the highest chance of providing anti-oxidant and anti-inflammatory benefits. However, whether avoiding certain foods (ie nightshade vegetables) or whether following certain other types of diets is helpful is still undetermined.

21. Is it okay to dye my hair?

For most people with scarring alopecia, the hair can continue to be dyed. If there is any evidence of irritation from visits to the salon this should be carefully reviewed with a dermatologist.

22. Should I change how often I shampoo my hair?

The frequency of shampooing does not need to be changed unless specifically advised by the dermatologist.

23. Are there any shampoos you recommend?

Dr. Donovan will review if there are any changes need in your shampoo. For the most part, the shampoo that you were using in the past can be continued. If there is any evidence of seborrheic dermatitis on the scalp, this should be treated.

24. What supplements should I be using?

The key supplements are those that replace any deficiencies. If one is deficient in iron or vitamin D, these should be replaced. There is no great evidence for a role of other supplements at this time. If one is using prescription medications such as doxycycline to treat the scarring alopecia, one should speak with the dermatologist as to whether probiotics should be used as well.

FREQUENTLY ASKED QUESTIONS ABOUT SCARRING ALOPECIA - 9

25. Can I continue to use TOPPIK and similar camouflaging fibers?

These are generally safe and can be continued. They should be washed out if topical medicines are going to be applied to the scalp.