Resource Sheet #16
June 2022

How to Tell if Your Disease is in Remission or Burned Out

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Scalp hair is an important component of body self-image in humans. Hair loss can have a marked impact on a person's psychological status, quality of life, and social interaction, in cicatricial alopecias, the situation is aggravated by the usually irreversible and often progressive nature of the condition. Cicatricial alopecias are a rare, but important, group of disorders that cause irreversible damage to hair follicles resulting in scarring and permanent hair loss. Hair regeneration is prevented because of the destruction of stem cells located in the hair follicles. Cicatricial alopecia should be considered a "trichologic emergency".

The disease course in cicatricial alopecias is progressive and chronic with temporary improvement and multiple relapses. Patients should always know that hair re-growth cannot be expected in the scarring areas and the primary goal of the treatment is just to arrest any further hair loss. Treatment of cicatricial alopecias is difficult and challenging. The best outcome at present is induction of remission with the arrest of symptoms and signs, although the progression of hair loss may continue slowly and insidiously. In many cases, remission is not permanent and clinical activity may resume, even after several years.

Scarring alopecias can stop on their own. We call this spontaneous remission or spontaneous burning out of the disease. The principal difference between remission and burning out of the disease is that the latter is a final stage of the disease where it has spread at a certain point that it is impossible to continue spreading, because there is no longer hair available to be affected. Differentiating between these two is difficult and should always be assessed by

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your dermatologist. 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.

If one has not lost hair over an extended period of observation (i.e. 3-5 years), the patient's disease is stable (inactive) by definition.

A physician can 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. Affected areas of the scalp are inflamed and feel thickened and indurated. With time it can produce large, irregularly shaped, flesh-colored or ivory white patches of cicatricial alopecia.

Ongoing itching, burning or pain are important signs that things are active. For example, scalp itching is a typical early sign of lichen planopilaris (LPP) and may be associated with minimal signs of scarring at disease onset. Patient symptoms can often be used to guide the clinician to active areas of disease that may otherwise have been overlooked and often represent a particularly fruitful area to biopsy

Unfortunately, the absence of symptoms and of any sign of inflammation on physical examination for a prolonged period of time does not necessarily imply the disease is in remission as hair loss may still be taking place insidiously. Even if patients agree to be biopsied and re-biopsied, sampling one or even a few areas of the scalp, although very informative, may not be representative of the overall situation.

The only way that one can confidently know that 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.

Dermatoscopy performed by a dermatologist can be profitably used for clinical diagnosis to see if your disease is in remission/burned out, the search for loss of follicular ostia is an important clinical hallmark.

Generally speaking, most patients with scarring alopecia 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

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stabilizes, treatments will be slowly removed. Oral treatments might be removed first while continuing steroid injections. Over time 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 patients with very stable disease use a topical steroid once every two weeks. Your doctor will let you know whether you might be suitable for surgical procedures such as hair transplant or remotion/reduction in size of permanent areas of hair loss.

Unger et al. advised contemplating surgical correction only after having confirmed at least 1 year of quiescence. That is because if the disease is active, the transplanted follicles will be the target of the same inflammatory reaction as the follicles they are replacing and may suffer the same fate. However, monitoring disease activity in patients with scarring alopecia is not as straightforward as one would hope. The patient should be put on maintenance therapy to try to avoid a recurrence of the inflammatory disease.

If undertaking a transplant procedure, it is a good idea to keep the cases small in terms of number of grafts. A session of 500 or so grafts at a time might allow the physician to see how the grafts will take without jeopardizing a large number of valuable donor hairs.

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 latter two conditions.

To make the situation even more complex, it is well known that lichen planopilaris (LPP) and other scarring alopecias can go through periods of activity and remission for many years and that in pseudopelade of Brocq, the hair loss is not associated with any apparent inflammation.

Therefore, if the surgeon cannot reliably depend on his clinical examination, or on the results of scalp biopsies, to decide whether the scarring alopecia is burned-out or smoldering, and if relapses may occur after years of quiescence, the recommendation of waiting for 1 year of remission before attempting transplant becomes irrelevant.

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That said, conditions such as central centrifugal alopecia that tend to burn out with time and in which triggering factors are known, hair transplant can be carried out successfully when selecting patients committed to avoid practices such as hot combing.

In conclusion, despite using specific outcome measures, the unclear natural course of the diseases can make it difficult to determine if the disease has responded to a specific treatment or if it is in “remission”, or burnt out, different factors affect the prognosis especially the type of scarring alopecia. Follow-up with your dermatologist through photographs and a careful clinical and dermatoscopic evaluation can be useful regarding the state of your disease in order to choose the most appropriate treatment and further decissions in management.

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