## Hair in Ectodermal Dysplasia - don't forget that you can get normal problems too

by

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Ectodermal Dysplasia is such a broad term that it is not possible to try to address the wide range of problems suffered by all the members of the Society. However, when there are problems, one common feature is that the hair is not as thick or full as normal. It may be sparse, fragile, and wiry or in a pattern that gives the impression of being older than is the case. In this article I am going to run through the kind of advice I give to people without ED who come to see me with hair problems. Many people have trouble with hair shedding or sparse hair and although there may not always be cures, there can be ways of helping explain why these problems come about and what you can do to try to improve the situation.

Hair shedding can be a sign of general medical problems. One pattern of hair loss is where 2 to 3 months after a bad illness your hair starts to fall out. This is sufficiently long after the illness that many people will not make the connection. When the hair starts blocking the plug or coming out in clumps, there appears to be no explanation. However, what has happened is that the hair follicle has a delayed response to severe illness. A bad fever or giving birth can turn you upside down - but your hair roots may not show their response for several months. The loss may be just a bit above normal - or go as far as losing all your hair. The bad news is that there is nothing that you can do about it. The good news is that it gets better by itself. Nearly always, the hair will re-grow to be as it was before.

But you may not want to sit back and accept this possibility without checking out some other possibilities. The 2 main other options are that you have developed a hormonal problem or that you are short of iron. Most hormonal problems will be reflected by altered menstrual periods. They may become irregular, cease or become very heavy. The 2 main hormones to be assessed are testosterone and thyroxine. Testosterone is present in normal men and women and a blood test can detect whether it is within the normal range for your gender. If you are a woman with an increased level of testosterone, you will usually have other problems in addition to hair loss. The hair loss will typically be "patterned" - that is in the pattern of male pattern baldness. A woman may also develop additional hair on the body and face. Sometimes this is associated with weight gain and a broader problem known as polycystic ovary syndrome.

Disorders of the thyroid gland can lead to excess or lack of thyroxine. When there is an excess, you may shed hair and weight at the same time. In extreme cases, you may be hyperactive, prone to sweating, have a big appetite, loose bowels and become irritable. If it goes the other way and you lack thyroxine, the hair becomes more dry and coarse and

again may be shed. At the same time you may put on weight, develop dry skin, and become constipated and low on energy. A blood test will give the answer.

The last test that can help is to check on iron levels. This is usually measured as Ferritin. Ferritin is a protein in the blood that binds iron. When Ferritin is low, it corresponds to low iron. Iron is necessary for many biological processes. The most obvious of these is maintaining your haemoglobin. Lack of haemoglobin means you are anaemic and in turn means that your blood does not carry oxygen as well as it should. Poor oxygen supply to the tissues mean that they do not thrive and grow in the normal way. This can affect hair follicles. Low Ferritin is rarely a problem for men, but is occasionally seen in women where menstruation is a source of blood loss which can contribute to iron loss. Vegan vegetarians can have a similar problem due to lack of iron in their diet. In ED you may also have other causes for iron loss, such as loss of blood or protein from troublesome skin. When your doctor checks the Ferritin level, the normal range varies for different laboratories, but is typically between 20 and 300ng/dl. However in the realms of hair growth, it is believed that hair growth can be compromised when the Ferritin is below 70ng/dl. A Ferritin between 20 and 70 rarely warrants a formal course of iron tablets which can be indigestible and cause constipation. But it may be worth taking multivitamins with added iron to cover that angle.

Some women ask about hormone replacement therapy and the oral contraceptive - can they play a part in keeping or losing hair? The general rule for both of these is the drug Norethisterone is best avoided - at least on theoretical grounds. Both HRT and the oral contraceptive are usually made up from an oestrogen and progestogen. The latter is related to testosterone and Norethisterone is a version that may carry some side effects related to testosterone. Accordingly it is recommended to ask your GP if there is a version that contains a "synthetic progestogen" in which testosterone-like effects are likely to be avoided.

There is a list of other medications that can be connected with hair problems (Table 1). It should be noted that for many of these the evidence that they play a significant role is slim and it should always be borne in mind that they may be important for serious medical reasons. Some ED patients will be taking Acitretin and whilst this may make hair more wiry and sparse, it can also be the main way of achieving a comfortable skin. In some instances, the draw backs for the hair may be more than compensated for by the improvement in the skin on the scalp - where a sore scalp will cause hair loss.

As part of the normal hair loss assessment I would expect to examine the scalp and determine whether there is any inflammation or scaling. A rash in the scalp can upset the hair roots, which may then contribute to hair shedding. This may not be a permanent effect, but is likely to continue for as long as the scalp is inflamed. This can usually be addressed by a range of treatments, in ED and non ED people. One factor that is seldom appreciated is that shampoo may be making the problem worse. This is not to say that there is anything wrong with your shampoo, but there is a tendency to wash our scalp and hair more frequently than is good for it. Shampoo is not that different from washing up liquid and although it may be gentler, it will still dry out your scalp. When it is

vulnerable, this may contribute to soreness and itch. So reduce the amount you use and how often you use it. Try spacing it out so that sometimes you use conditioner alone. Washing the hair with conditioner will rinse out most dirt, but it will not remove oils in the same way. When the scalp is dry and itchy this can be useful. During periods of scalp irritation, it is also best to avoid hair styling products that might have similar problems - such as bleaching or perming agents or heat processes such as hood dryers.

Finally, many people with natural and not reversible causes of hair loss will accept that there is no clear disease of their scalp, but they would still like to know if there is anything medical that can be offered to help. In a long term sense I would say probably not. In the short term some people like to try Minoxidil. This is a lotion that comes as a 2% (for women) or 5% (for men) solution, applied to the affected area of scalp twice a day. Technically, we know that in a small number of people this will make some difference in age-related causes of hair loss in both men and women. However, it will take 6 months to be certain one way or another and whilst counting hairs will confirm that it can help, the cosmetic effects are not usually impressive. This means that although on a scientific level it can be said to work, on a personal cosmetic level, you may not notice the difference when you look in the mirror. Minoxidil is also not a good option if you have scalp irritation. The medication is dissolved in a solvent, which can be an irritant. As an alternative or supplement to Minoxidil, very occasionally, people will take hormonal medication. This is not a good long term option in my view as there are side effects and complications that can arise from taking these medications.

Although this check list is a general list for all comers - don't forget that you are a normal person also and could also have factors beyond just the ED contributing to hair loss. This is particularly the case if it changes after being stable for a long time, or if you become unwell.

## TABLE 1: Examples of drugs that may cause or contribute to hair loss in some people (1)

Drug Group(Drug Name)

Anticoagulants (Warfarin)
Anticonvulsants (Sodium valproate, Phenytoin, Carbamazepine)
Drugs for heart disease (Amiodarone, Captopril, Enalapril, Propranolol)
Chemotherapy (Treatment for internal cancers)
Arthritis drugs (Allopurinol, Antimalarials)
Skin treatment drugs (Retinoids: Acitretin; Methotrexate)

(1) It is important to remember that many drugs will be necessary for your health and their role in hair loss is not always certain. Any changes in medication should be done through consultation with your doctor.

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