

Treating Hair Problems in Ectodermal Dysplasias

Unfortunately, there are no treatments that can change the structure of the hair. Care is directed toward preventing damage to the hair shafts.

- Gentle shampoos, such as Neutrogena or Purpose, are good for washing hair.
- Mild dandruff shampoos, containing selenium sulfide (e.g., Sebulex), salicylic acid (e.g., T-Sal), or pyrithione zinc (e.g., Head & Shoulders) may help excessive scaling of the scalp. In some people, however, these shampoos may increase the dryness.
- Protein-coating shampoos such as Daragen may give extra body to the hair shafts.
- Cream rinses, such as DHS Cream Rinse or Ionil Cream Rinse, may increase manageability.
- A gentle body wave permanent may be tried but cannot be tolerated by everyone.

Careful cutting and styling of the hair improves appearance, but if the hair is sparse, a well-fitting, age-appropriate wig may be used. Remember that wigs do not look natural until they are thinned and styled. Information about where such wigs may be purchased is available from dermatologists or the NFED.

Improving Appearance

Hair Styling

A few simple grooming techniques can improve the appearance of sparse hair.

- Keeping the hair short is usually a good idea, since long strands tend to emphasize the thinness of the hair.
- Gentle shampoos that contain protein and conditioners that discourage drying and breaking can make the hair appear somewhat thicker.
- Use of a conditioner after every shampoo is also a good idea.
- Thickeners and sprays can improve appearance and protect hair from

breakage.

- Pomade and mousse may also be helpful.

Hair Transplants

People with ectodermal dysplasia are not candidates for hair transplantation because there is not enough “donor” hair to cover the thin areas. Individuals also should avoid hair implants. The artificial fibers used in implants can cause allergic reaction, severe skin irritation, and scarring.

Hair Growth Products

Among products designed to promote hair growth, minoxidil (Rogaine in the United States and Regaine in Canada) is a topical medication that has been used with variable success in people with a type of hair abnormality. Minoxidil use has not been studied in people with ectodermal dysplasia.

Many other products on the market claim to stimulate hair growth. There is no scientific evidence of their safety or effectiveness. Before considering the use of minoxidil or any other hair growth product, consult a physician who has expertise in hair problems.

Wigs

Some people are comfortable with their appearance and may find a wig unnecessary. Others choose to wear wigs to improve self-image and increase self-confidence in social situations. The decision to wear a wig is, and should be, a personal choice. A child should not be forced to wear a wig. Providing the option to wear one will permit the child to feel more empowered.

There are many types of wigs. The hair used to make them may be real or synthetic. Caps may be made of netting or plastic. These factors help

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to determine the price of a wig, which can range from several hundred to several thousand dollars.

One type of wig is designed to stay on during swimming, bathing, and active play, and also in high-wind conditions. This type of wig has a custom-molded cap that is held in place by suction. Predictably, it falls into the more expensive range (approximately \$2,000 - \$3,000). It also has the disadvantage of requiring a hairless scalp for optimal fit. For most people with ectodermal dysplasia, this means shaving.



Tips for Purchasing a Wig

- Purchase wigs only from a reputable maker. The supplier should be able to provide information about the materials used, as well as details about anticipated durability and the cost of repairs and replacements.
- The supplier or the stylist working under the supplier's supervision should provide initial cutting and styling, necessary with any hairpiece.
- Some families recommend buying an inexpensive wig for a trial period before investing in a more expensive wig. During vacation from work or school the wig can be worn on a daily basis so the individual can experience wearing and caring for it. Then, it's easier to make a well-informed decision about the value of a wig, and whether or not greater expense is justified.
- Expect comments from classmates or co-workers the first day a wig is worn to school or work. After a few days, the wig should draw little or no attention.



Some insurers will cover the cost of a wig if a letter of medical necessity is provided. Discuss this with your physician.

Locks of Love (<http://www.locksoflove.org>) is a support organization that provides financial assistance based on the need for wigs for children with hair loss due to any medical condition.

Special Note

Information on treatment in this article is given as a guide to what might be expected or recommended by physicians who are consulted by our families. It is important for you to understand that the statements are generalizations about a large number of the ectodermal dysplasias, and no absolute recommendations are made or implied. Trust the physicians whom you consult to do the right things, but also be an advocate for yourself or your child. The mention of any "brand name" drug is presented as an example only and must not be interpreted as endorsement of a specific product or brand by the National Foundation for Ectodermal Dysplasias or its Scientific Advisory Council.