

Explaining Ectodermal Dysplasia to my child

I have been asked many times “when is the best time to tell my child that they have ED? Should I wait until my child is older?”

I believe that it is better to talk to your child about ED as early as possible. However, every family is different, and every child is too. Therefore, you are the best person to judge when the time is right, what level of ability your child has to understand and at what level you aim your conversation.



I was once told of a little boy who asked his mum where he came from. After she had gone to great lengths to explain about the “birds and the bees”, he pointed out that he merely wanted to know which town he was born in! Explaining to a child about ED is very similar in that they will probably only want to know the basics of why they are different.

As your child grows so will their need to cope with the outside world. If ED is explained from a very early age in a positive straightforward manner, they will be more equipped to deal with problems ahead of them. It is important to encourage their strengths to help build a positive self-image. Don't be dishonest or evasive, answer their questions simply, openly and most importantly, honestly.

Every person is different, and nobody is perfect, but each is very special to someone.

Supporting a normal lifestyle

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