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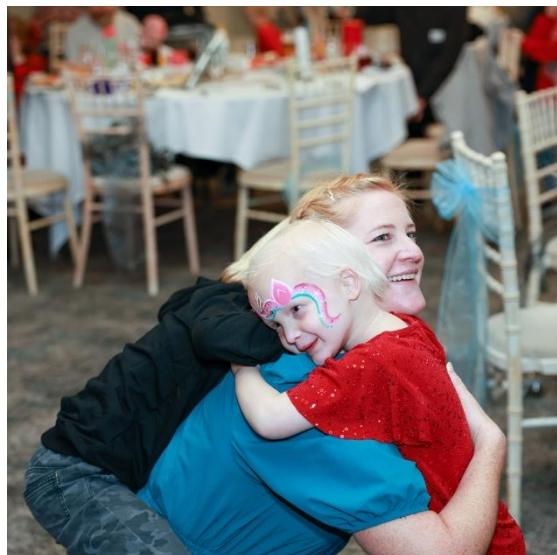
Patron: Francesca Jones

Explaining Ectodermal Dysplasia to my Child

CEO Diana Perry

I am often asked, “When is the best time to tell my child that they have ED? Should I wait until my child is older?” I believe it is best to talk to your child about ED as early as possible.

That said, every family is different, and every child is different too. You are the best person to judge when the time is right, how much your child can understand, and the level at which to pitch the conversation.



I was once told a story about a young boy who asked his mum where he came from. After she went to great lengths explaining the “birds and the bees,” he pointed out that he simply wanted to know which town he was born in! Talking to a child about ED can be very similar — they often just want to understand the basics of why they are different.

As your child grows, so will their need to cope with the outside world. When ED is explained from an early age in a positive and straightforward way, children are better equipped to handle challenges as they arise. It is important to encourage their strengths to help build a positive self-image. Avoid being dishonest or evasive; answer their questions simply, openly, and most importantly, honestly.

Every person is different, and nobody is perfect — but everyone is special to someone.