

Growing up with Ectodermal Dysplasia

I am writing this article in the hope that my experiences of growing up and dealing with all aspects of Ectodermal Dysplasia may help some of you who are going through the same process.

Whilst I know that having ED places a number of limitations on what I can do with my life (for example, playing rugby in the height of summer in Australia was never going to happen), for me, ED has never been a limitation in itself but more of a challenge. Watching your friends go off and do activities in the sun soon makes you realise that you do not want to miss out, and so I have always strived to push myself, and to not let ED determine what I can and cannot do. The perfect example I have of this is that I love history and have always been interested in Greek and Roman history in particular. In 2016 I went travelling around Europe during the summer, and one of the places I visited was Rome. The temperature was roughly 40-42 degrees, and we had two days to visit every site we wanted in Rome; I was not going to miss this opportunity and sit inside by a fan all day. Somehow, I managed to walk 18 miles across two days around the city in order to see everything (thankfully they have a lot of taps on the streets).

What has annoyed me most about ED is the fact that you have to push yourself or take precautions in order to do things which most other people would find easy. For me, the fact that you have to take a spray bottle, or wet your T-shirt, or even wear dentures, is annoying. It is easy to sit there and go "why do I have to do this, this is so unfair, why can't I be like everyone else," but sadly, complaining isn't going to do anything except put you down. I have never let ED dictate what I can and cannot do and neither should you, if you want to go and do something then get out and do it.

I'd like to talk about bullying, because I know that most children, and even teenagers and adults, who have ED have at some point in their life have been bullied or are currently. I'm afraid to say that bullying is just something you will have to deal with.

Usually it is children or teenagers that bully, because they don't know any better and find taking the micky out of someone to be a cheap laugh. On countless times I have walked past a group of kids or teenagers and heard them all whisper and laugh quietly. I was bullied a lot in school when I was younger, but I stood up for myself and never let bullying get the better of me. I know for some of you this may be harder, but just think, why let someone put you down just because you look slightly different to them? I have always been of the mind-set that, they can laugh now, but I guarantee that I will be better than them; if I work harder and push myself further then I will be the one laughing in 20 years. I remember once there was this one boy in junior school who just would not leave me alone, he had been annoying me all day and I was fed up, so I tricked him and locked him in a shed. I got in trouble, but I didn't care because he had been bullying me and I had stood up for myself, and from then on, he didn't bully me anymore. Now, I'm not saying you should go around locking people in sheds, but certainly stand up for yourself. ED does not make you any bigger or smaller, dumber or smarter, stronger or weaker than anyone else, so why let other people bully you just for the way you look.

Even as an adult you will experience bullying. It has happened numerous times in bars or clubs where some drunken fool will say some passing comment to me, but I will always say something back and stand up for myself. When they turn around and ask if I want to fight, the simple answer is usually no; I'm quite small and will probably lose so why would I fight you? I have been very fortunate in that I have a group of friends who are non-judgmental, very understanding and will stand up for me if anyone ever makes a passing comment to me, which is nice. Surround yourself with people who don't care what you look like or whether you can run a marathon in a desert, but like you for who you are. Ultimately, I am quite a positive person and so have never really been affected by bullying; every bully has just made my skin that little bit thicker. Having ED will let you see the worst in some people, but also the best in others, an insight which many people may not get to experience.

Supporting a normal lifestyle

Finally, I'd just like to touch on dentures and teeth briefly because I am certain that many people will feel extremely self-conscious about their teeth. I got called a vampire hundreds of times when I was younger for having pointy teeth, and some of you may have been on the brunt end of the same unoriginal joke. I'm sure you will realise that once you have dentures, no one will notice your teeth. I am currently in the process of having a bone graft and dental implants, but this is not because I am self-conscious about the way my teeth look. I am having them done because I am sick to death of having to clean three sets of teeth every night. I have a close friend who I have known for 10 years who did not even realise I wore dentures until a couple of months ago; it makes you realise that as you grow up people start looking less at your appearance and pay more attention to who you are as a person.

Having Ectodermal Dysplasia is extremely unfortunate and there is not a day that goes by that I wish I did not have it. When I have children, I do not want to have girls as I do not want to pass ED on any further in my family. But, whilst I wish I did not have it, I have not let it affect the way I live my life. There is no use in moaning and complaining about having ED. Instead, use it as a positive influence. Think of it as a unique insight into the difficulties of life that most people will never understand or experience. Use it as motivation to achieve things you might not otherwise, and to push yourself that little bit further.

Jack Perry

Supporting a normal lifestyle

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