

# Difficulties = Courage

by  
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I have two sons who have Hypohidrotic Ectodermal Dysplasia. When Peter, my oldest boy, was first diagnosed I wondered how we would cope. It felt like our world came crashing in around us. My fourteen month old toddler with all these odds stacked against him. Will he ever have friends? Will other children laugh at him? How could a child wear dentures? Will he be able to play sports if he cannot sweat? These were some of the questions I worried about. If you are parents who have just discovered your child has ED I would like to share Peter and Michael's story. I hope it brings some hope to you.

Peter is now thirteen years old, and already is nearly six feet tall!! He had his first dentures when he was two and is waiting until his mouth has fully grown to have implants. Even now he seems to have no shortage of girlfriends, and is a happy well adjusted young person in school. Sports are his big thing and he came first for his county in the 800 meters race this year, and second in the 1000 meters for all Ulster. He loves the stage and doing drama. At present he thinks he would like to do law, but I expect that may change a few times before he does A levels. He does have added difficulties, 1000m is a long way to run on a hot day, even for people who sweat, but there is a solution to everything. Peter wears a wet t-shirt and plenty of sun-block to keep his skin cool. The lights on the stage are very hot and uncomfortable at times, but once his teachers are aware they can be flexible.

Michael, his little brother, was born with a second and unrelated condition Myotonic Dystrophy, so as well as having ED to cope with, he also has muscle weakness, learning difficulties, speech problems, etc. But he is a wonderful person. Full of the joys of life. He too has lots of ambitions, hopes and dreams. He has lots of friends in school and recently won The Ironside Perpetual Cup for "Children of Courage". Michael does not let his difficulties get him down. Recently he was pleading with me to take part in the Mummy's race in school, I said 'No Michael I don't want to, I always come last'. To which he responded 'I always come last, but it doesn't stop me trying'. So my little child taught me a profound lesson.

We want everything to be perfect for our children, but as I grow older and watch my boys cope with life I think they have more depth and inner strength in them, developed because of their difficulties. They are not all grown up yet, we may have difficulties ahead, but they have given me a reason to come from a place where I felt hopeless despair, to a place where I feel much hope and pride in my boys. I have seen the beauty of the human spirit as it rises to the challenge of life's difficulties. When they were born I wanted everything to be perfect for them, so they would have all the ace cards as it were, to live in a difficult world. God in His wisdom allowed them to have difficulties so He could mould courageous strong young men. For how can you have courage if you never faced a difficulty? Or strength of character if you never faced a single problem?

(Well done Michael on your wonderful achievement - your strength and determination is a blessing and will enable you to fulfil your ambitions. Editor)

Some names and locations have been changed in order to preserve confidentiality.

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