He never sheds a tear

The following article appeared in the Teeside Evening Gazette in July 2003 about one of our members

Michael Flanagan was the baby who could never cry. He was born without tear ducts because of an illness which also stopped his teeth and hair growing. Now aged 18, he tells Marie Turbill what it's like to live with his rare condition.

A tiny set of dentures little bigger than a 2GBP coin were a milestone for Michael Flanagan. Unlike most children, he loved the idea of going to the dentist - and getting the set of teeth nature had denied him. Pictures record the significant day when Michael was fitted with his new teeth. And, like the Tooth Fairy, mum has kept the tiny set of dentures to remind her of that landmark day.

Michael's life has been without the other milestones that mark the development of so-called 'normal' children. His hair never grew and he couldn't cry like other babies because his tear ducts weren't formed. All this because he was born with a rare condition called Ectodermal Dysplasia.

Now he's 18 and has learned to live with the condition which has significantly affected his life. Sometimes people stare at him in the street. "I am used to it", he says with a resigned smile. "It happens all the time." That's something the 18 year old is determined not to let get to him. A brave face covers any hurt that may have been inflicted during the last 18 years.

Michael has never looked like other people his age, even when he was a baby because of the ED. "It is a group of different genetic disorders," he explains. For Michael it means he has no sweat glands, his tear ducts do not work, he has asthma, his hair doesn't grow properly, his skin is very pale and he has no teeth. He is also susceptible to chest infections. The thing that bothers him most is not being able to sweat, something most of us take for granted. "My body has no way of cooling down. In the heat, I just get hotter and hotter." To ease the problem, there is a fan on constantly in his Marske home and when out and about on a sunny day, he will frequently dowse himself in water.

At 18 he enjoys nights out with his friends but with all the smoke and heat, pubs and clubs are uncomfortable places. It doesn't stop him from having a good time. Dealing with such difficulties is second nature to Michael. "I have just accepted that I have this condition," he says. "People stare and sometimes say things but I am used to it."

Mum Gill Simpson, however, sees past the brave face and looks concerned as she says: "I think that it affects him more than he lets on. Michael is the sort of person who keeps that sort of thing to himself." She has had to watch her son deal with a rare condition since he was a tiny baby. Michael was diagnosed at six months but his parents, Gill and Stephen, knew that

something wasn't quite right before that. "He was just generally unwell as a baby," says Gill. "He always cried when we took him outside."

The couple, who were living in London at the time, talked to doctors about their concerns and were referred to St George's Hospital where a skin biopsy identified the condition. "We just didn't believe it was happening to us," says mum. "You are going into the unknown and we just didn't know what to expect. There was a point, when he was about ten months old, when he was admitted to hospital with an infection. He got five or six different infections while he was in there and was really quite ill. I thought we wouldn't be bringing him home again but he pulled through."

Coping was made even harder by the sheer rarity of the condition, affecting only 800 in the UK. Gill says they have been into hospitals where staff haven't even heard of it. Despite everything, Michael was a happy child and a support group, in the early years, was also a great help to the family. Gill found out about the condition at a series of conferences attended by other sufferers and their families. She says it was reassuring to meet others going through the same experiences. "When you got the children together, they all looked the same," she said. "You would think they were all brothers and sisters."

Unfortunately, because the condition is so rare, the gatherings offering support gradually stopped. Now Michael's only contact with other sufferers is through occasional articles he reads in magazines. He also searches the Internet for websites about the condition. Every article the family have ever found is carefully filed away for safe-keeping. "I like reading them because I can really relate to what they say," says Michael. He just wishes more people were aware of the condition so maybe they would understand more.

His own life has been peppered with harsh comments from people living in ignorance. Every time he goes somewhere new he must accept the stares and even name calling. Fortunately, through school, he had a close group of friends who saw beyond his physical differences.

He says: "I had a good group of friends and while I did get names and looks from other people I just let it pass over me."

This attitude is what has allowed Michael to live a "normal life."

He has just had his 18th birthday, is studying A levels at Prior Pursglove College and hopes to work in the travel industry.

Though his mum and dad have split up, he has stayed very close to both, and he now has a younger stepbrother, Craig, and two stepsisters, Katie and Abigail.

"When they were younger Michael used to take his teeth out and pull faces at them," says Gill. Michael laughs at the memory, saying his life is happy despite the discomfort of his condition. What he really wants is: "For people to be aware of Ectodermal Dysplasia and what it means.

Anyone with ED who wants to get in touch with Michael can do so via email to features@eveninggazette.co.uk.

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