

Alone For So Long

by
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My name is Liz and I have lived with ED all my life. I have two children who also have ED. It is not an easy complaint to live with because no one seems to know an awful lot about it. Although these last few months I have learnt a lot, from the NFED in America and our own support group Diana Perry to the both I am most grateful.

I am fifty years old and my children are twenty-nine and twenty, boy and girl. Through David's life he was ill quite a lot, but I never knew it could have been part of ED, he always had infections of the lungs, ulcers in the throat and mouth, and still has bad ulcers to the present day.

My daughter Charlotte spent most of her young life poorly. She went from one illness into another, she did not have much hair, so from the age of three when she went to school she wore a wig and she hated it. She had a milk allergy, but the doctor could not find anything wrong for the first eighteen months of her life and it was hell, as she cried all the time and lost weight so much it looked as if we were starving her. She also had pains in the legs the same as her brother, I had been told they were growing pains and not to worry. I told the doctors that I had suffered with these pains and I still do. At one time my legs came out in bruises so bad the pain was awful. My GP did not know why this was happening, so I paid to have a specialist to the house and was told that it was stress because my daughter had the same ED as myself.

Well the stress has lasted a long time, through my life I have felt very alone, I didn't even know that anyone else had this complaint. I thought it was just something that was part of my family, crazy but true, no one ever told me anything different.

This past week my daughter's tooth has started to crumble and I am so afraid that the same thing that happened to mine is starting with hers. I paid for her first teeth to be painted with a substance to stop the first ones going to soon, but I just don't know if there is anything to help with her second teeth and no one to go to for help. When I went to one dental hospital years ago with my son because his teeth started crumbling, I was told that I was giving him too many sweets, they just would not listen to me. If anyone has had this problem I would be grateful to know.

I have felt angry the past few months because such a lot of our lives could have been different. The strange thing is you get on with your life no matter what, but are these little ones going to go through what us older ones have gone through, with no one taking notice. It would make life so much better for us all if doctors would listen to the people that have got the complaint, and realize that we are not hypochondriacs or parents that are mollycoddling their

children. We are people that need some answers and maybe just a little support along the way. I am glad to say that my anger was short lived, but I think it is alright for us to feel this way for a little while, after all we are only human. We need our doctors to understand this complaint because different things happen at different stages of our lives, so if they don't understand how are we to know what is happening to our bodies.

The doctors may not know an awful lot about this complaint, but they might learn a lot more if they would just take the time to hear what we have to say, there is so much that goes on in our lives you can't put it in one letter, but I will say this, it makes you a little bit stronger along the way.

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

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