

Living with ED for 93 Years!

When Diana asked me to write a bit about older times I thought 'where to start?' it's like a history, so I have started at the beginning.

I was born in 1920 when nothing was known of ED; I am the eldest of eight children and all the others are ok. I had normal hair, slightly misshapen teeth, very bad circulation, chilblains and catarrh; I used to get spots a lot which the doctors said were German measles – mother used to say “how many times can you have German measles!”

During the war I was in the Land Army; the other girls used to think I was lucky as they would be wet with sweat and I was always bone dry, although I often felt ill. In later years we found out about ED and then I understood a lot of things about myself. I still regularly have itchy skin and nose trouble, together with really bad arthritis and now have to use a wheelchair.

My first child, Michael, was born in hospital in 1945 weighing 8lb 4oz after a normal pregnancy. Sadly he lived for just 4 days. After my other children were born I realised that my first baby had ED as he had the same transparent skin and cotton wool hair.

My second child, Glenys was born at home in 1947 weighing 8lbs. She was a lovely healthy baby with normal skin and hair.

When Glenys grew up and wanted to get married, we all went to the hospital to have tests carried out to see which of my children had inherited ED; my own mother was ok, Glenys was normal, I am a carrier and have fairly mild symptoms, Margaret is a carrier and has symptoms more severe than I and Allan has full blown ED. The test was to see if we sweated by putting our hands on a piece of paper. Glenys then got married and went on to have 2 children, a boy and a girl, and are now grandparents of 2 children, all of whom are ok.

My third child, Margaret, was born in 1952 and looked quite healthy. However, when she started teething she began having high temperatures, ear ache, vomited, wasn't eating properly, but did drink a lot. She would cough all day and night, spots would come out anywhere on her body, her temperature would rise rapidly, but no one knew what was wrong. When Margaret was about 3/4 years old I took her to the dental school to see Professor Jackson; he was wonderful with her and gave us the first idea of what was wrong. She had a perfect set of teeth except for her two front ones which were missing. Over a period of time Prof. Jackson moved her teeth around to close the gaps and also sent us to a doctor who explained more about the condition, but said nothing could be done about it. I was now pregnant with my next child. As Margaret got older we learned how to cope with her temperatures; her hair was very thin which gave her lots of problems, she always suffered with colds, rashes and ear problems. She got married to David when she was 18 years old, but decided not to have children as she didn't want to pass ED on. When Margaret was 22 they adopted a 6 week old baby girl and are now grandparents to 3 year old little Holly. Margaret and David have had 40+ years of very happy marriage and are now both retired.

My fourth child, Alan, was born at home in 1961 weighing 10lbs. I had quite a difficult pregnancy and as soon as he was born I knew he had ED as he had the same skin and hair as

Michael and Margaret. When he was 2 weeks old the weather was very cold so I wrapped him up well, put him in his cot and watched him. He began to look really ill later so we called the doctor who took us straight to the hospital. Alan's temperature was very high! They didn't think he would last the night; they put him in a cot in the duty doctor's room and began testing for all sorts of things. Later they moved him to Seacroft Hospital into a room of his own; the Sister was very good and looked after him really well; she told me they had put a dry sponge on his back and put a hot water bottle on him to test his ability to sweat, his temperature rose to well over 100f but he was bone dry and very poorly. When we arrived to see him he was a mass of tubes and pipes, but then began to get better and once he was normal again we then had another fight as Alan would pull the feeding tubes out and struggled to feed. They tried giving him salt water one hour and then milk the next hour, but nothing worked. The Sister felt he would be better at home, but Dr. Alibone was in against this. However, he allowed us to take him home at 12 weeks weighing just 7lb. The doctor came to see him twice a day; after 2 weeks Alan had put on over a 1lb.

The next few years were a nightmare, his temperature would shoot up without any warning, the mucus from his nose made him choke, he would go off his food, would often be sick if he went near our food, such as fruit and salad, etc., as he couldn't stand the smell; even now he won't touch them. He doesn't eat bread, eggs, beans, bacon, but thankfully does like a good dinner with lots of vegetables.

Up to about 9 years old Alan was happy to attend all Dr. Alibone's lectures/classes and made films for other doctors at the dental school, but then Dr. Alibone retired, so Alan stopped going. Alan had a lot of trouble at school. He had false teeth at the age of 3, but couldn't wear the bottom set as there was no gum; I am sure this is why he can't eat many things and his indigestion is a real problem.

Margaret will talk about ED, but Alan wont, he just wants to get on with his life.

We all get a dry cough around December time that goes on until Easter! It is not a chesty cough, more a throat irritation which is difficult for Alan as he works with the public. Alan gets very tired when he is hot and coughing doesn't help as this makes him hotter. He has had his own flat for about 20 years now and has worked in public offices since being 16 years old; he is now senior manager and gets on well with his work colleagues. He still has friends from when he was at school which is wonderful as they are very supportive. Since my husband died Alan has taken great care of me and rings me every morning to make sure I am ok.

We are all very proud of Alan and how he has coped over the years.

Nell Bedford