

By Elizabeth Trapani
Mother of Chey-Anne aged 17

Chey-Anne first developed hyperhidrosis when she was around 3 years old. Her hands and feet would be constantly damp, book pages would curl up and it was no end of frustration for her. We found that only costly leather shoes helped with the foot odour and that there was precious little we as parents could do about it.

When Chey-Anne was approximately seven there was some information on the current affairs programs about this condition and so we sought medical advice. It was then that we were informed by our GP that they would not even look at treatment until our daughter had stopped growing. Around sixteen to seventeen years of age.

As Chey-Anne advanced into puberty the hyperhidrosis then became extremely prevalent in her armpits. She would always smell of very bad body odour even just after showering. Her clothes became stained and required replacing much more often due to the excessive sweating. She became a fan of wearing many layers so that the sweat marks would not show. Even in summer she pushes her body to the point of heat stroke so that the sweat stains are hidden. From the age of 13 years this has been the nature of Chey-Anne's life. As a mother I have found it almost crushing to watch my daughter suffer so.

It has been hard for her to deal with the ignorance of people who call her dirty, tell her to take a shower and think of her as a grubby person. No matter how many times she showers in a day by the time she has towelled off she smells again. Other students have been especially cruel with taunts and bullying but fortunately Chey-Anne has a fabulous support group of close friends and family who help her through these rough patches. That being said there has been many tears and it has been a battle to keep full blown depression at bay. Being a teenager in this day and age, as we all know and accept, is hard enough without the terrible burden of hyperhidrosis.

She went for a few job interviews when she became of an age to work part time and was knocked back on all occasions. At a local store where I knew the interviewer I made inquiries as to why. Chey-Anne despite this horrendous condition is a confident, vivacious, articulate and attractive young woman. I was told that her body odour was the only reason that she was not hired. This, as you may well imagine, was a huge blow to her and she has point blank refused to try to find work due to the embarrassment.

Chey-Anne has suffered this condition with no hope of treatment due to our financial circumstances. It broke my heart seeing her suffer but as a single parent it was hard enough keeping a roof over the girls' heads. The day came when my father unwittingly complained about Chey-Anne's body odour. It was then I managed to sit my parents down and explain hyperhidrosis to them and about the operation needed to rectify the problem. Prior to that Chey-Anne forbade me speaking of it outside of ourselves. Fortunately for us and Chey-Anne in particular, they decided to pay whatever was needed to fix this condition.

It was then, after an appointment with our GP, that we discovered how little was known about this condition. The GP had no idea where to refer us. After some research she got back to us with a referral to the Monash Medical Centre Out Patients Endocrinology. At the Monash appointment they didn't have a clue why Chey-Anne was sent to them as this did not involve their area of expertise. One of the Doctors we saw that day did have the brilliant idea that a dermatologist may know how to deal with this condition and they were able to find one for a consult immediately as we live so far away. (We live in Bairnsdale in rural Victoria some 4 hours driveway from Melbourne. This Doctor was aware of the condition and where Chey-Anne could get the treatment she needed. She offered to write a referral to the Skin and Cancer Clinic's Hyperhidrosis Clinic and after a wait of 6 months Chey-Anne had her first appointment and her first treatment of Botox. It took us 13 years to get to this place and there

were many tears. Not due to the pain of the injections, and they were painful, but because finally, something was being done.

That day she had 35mls injected into each arm pit and was prescribed a lotion for her hands and feet at a further cost of \$80 for a small bottle. There was some success with the initial injections however on month later after a sweat test another 30mls was required overall for which Chey-Anne happily took the next lot of injections in her stride. Such is the relief that comes with treatment for a condition such as this. The lotion for the hands and feet worked well in regards to the sweating but where ever it was applied Chey-Anne broke out in hives. We are now trying another lotion at \$174 per 20mls.

Having nurtured a child through this condition I am very aware of the impact it has on her life. There is very little information and knowledge available to sufferers and their families.

Chey-Anne has become, what I call, a defensive dresser. There are many bad days and little a parent can do to change the situation until they are of an age to commence treatment. That being the operation, as I have believed for many years. To find out about Botox was just incredible. I had always thought Botox a beauty treatment for the rich. It never occurred to me that it had a medical application that could change Chey-Anne's life.

Had I been aware of Botox before, Chey-Anne may have been able to be treated from the age of 12 onwards. Even so, for me, this treatment would have simply been unobtainable. I am aware that we are very blessed to have my mother and father paying for this treatment. I wonder about people who are in desperate need of this treatment find the cost puts it far and away out of their financial capacity.

Today with travel, consultation, other medicines and the Botox itself I can safely say that our expenses after 2 treatments (essentially one treatment over two visits) would be in the area of \$1500 over two months. It brings to my mind the question, again. How many people are out there living a half life because this treatment is not in their financial capabilities? To put Botox for the treatment of hyperhidrosis on the PBS would have an undeniable impact. A treatment such as this has the capacity to set stalled lives in motion. To reinvigorate those hiding, ashamed in the shadows and bring them into the light. Hyperhidrosis may not be life threatening but it is life halting, this I have seen firsthand.

At this point it would be prudent to point out that this condition requires ongoing administering of Botox. The repeat procedure may be as little as 6 monthly or as much at 18 monthly, depending on the severity of the condition. Hyperhidrosis has no cure. There has been some success with surgical procedures but the opposite is a very real risk. Increased sweating in the affected or other areas, palsy of the face, collapsed lung leaving this as an absolute last resort for sufferers who have no joy with other modes of treatment.

Understanding the desperation that hyperhidrosis sufferer's feel will only come with education. This is not an issue of cleanliness. It is not, as some people think, just a little sweat problem that isn't life threatening. It is life altering to the extreme. I have nurtured my daughter through this condition. I have watched her take a battering from ignorant people. Her confidence and self esteem are often shaken and require mine and all our family's love and support to keep her on an even keel.

The impact is huge and to find that such a simple process can alleviate so much of this grief is amazing. To discover its cost is disheartening. Worst of all, to hear it touted in the media by our Federal Health Minister as an unimportant condition is shattering. I wonder how many hyperhidrosis victims and carers Ms Roxon has had the pleasure of consulting? How many nights has she rocked her baby while she cries herself to sleep because of hyperhidrosis? For me it has been many and this is why my beautiful daughter and I have chosen to stand up and be counted.