

SO, THIS IS LIPOEDEMA

Sarah Spratt

I find it hard to remember when I first began to realise that my legs looked different to others. Being obese from the age of six hid the fact that my body was showing signs of other problems. I have always been singled out as being different, and when my knee-high nylon school socks only came up to my mid-calves, they just got shoved down to bunch around my ankles. I had to wear skirts in schools and for over four years I had only one skirt I would wear, as this went down to my ankles hiding my legs.

Numerous times over the years I wondered why my legs were so different from other fat people. From the end of my teenage years I was limited to only fitting into clothes from Evans (Plus Size Clothing). Trousers would pull up round my legs, so full-length looked cropped, particularly on my left leg which was larger than my right. Other fat people would wear shorts in the summer, but I was too ashamed of my legs to put them on display and, although I loved swimming, I did not have the courage to walk from the changing rooms to the pool.

Hindsight is a wonderful thing; at the age of 25 I cut my left leg on a piece of glass. The 10- and 9-inch wounds were stitched and left for the usual fortnight to heal. The stitches were removed and a day later the scars tore apart. My wound was then only dressed as it could not be re-stitched. I was put on a dose of penicillin, as the conclusion was that it had reopened due to infection. Looking back, it was probably the lipoedema that made it reopen, as the original wound was full of fluid and very little blood: the strain

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from the size of the legs probably did not help. However, more than that was my reaction to the penicillin, as it turned out that like my mother I was allergic to it, and it presented itself on the inside of my right knee by swelling into a lump and oozing fluid. The penicillin was stopped and so did the oozing after a few weeks, but the swelling on the side of the knee still remains.

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Years of going to the GP and being told that the swelling in your legs is due to oedema because you are so obese stops you asking for help, and so my leg swelling, eczema patches and fungal infections were all self-managed. I was lucky enough to be working for Huntleigh Healthcare at this time and would often use the intermittent pneumatic compression (IPC) machines to keep the extra swelling off my legs, and I would swim as much as I could bear in public. I was, however, losing my battle with obesity and, in 2002, I started my long journey to weight loss surgery. This took place on the 8th November 2005.

On 24th March 2006 my life changed for the second time. I was four and a half months out of weight loss surgery and had lost around six stone. I was back at work and exhibiting at the Leg Ulcer Forum event at Ashford Hospital in Middlesex. Lynfa Edwards had asked if they could use me in the clinic workshop

for clinicians to examine real patients' legs in the afternoon and I had agreed. With my legs exposed in the leg ulcer clinic, explaining about my obesity and weight loss surgery and my weight-bearing oedema in my legs, Professor Christine Moffatt from Thames Valley University came over to take a look. She said that I did not have oedema, but lipoedema, and that it was going up into my belly too. I know what lipoedema is, it is not a foreign language to me working with lymphoedema and tissue viability nurse specialists. I was stunned, at last I had a reason as to why there was up to four sizes difference in clothes between my top and bottom half; this was why my legs were the shape they were, why the swelling stopped at my ankles, why it was uncomfortable to wear tight clothes (something common in lipoedema sufferers). You cannot imagine what it felt like to be told that it was not just your fault for being obese that your legs looked like that. Professor Moffatt recommended that I see Professor Peter Mortimer at St George's Hospital, London. She e-mailed her recommendation so that I could give it to my GP.

Armed with my e-mail, I went to see my GP in Worksop, and this is where it got hard: Worksop does not fall into the catchment area for London and, even by speaking to the heads of the primary care trust (PCT), my GP could not get anywhere for trying — so much for patient choice!

I am not an only child, I have an older sister (Anna) who is fairly identical (only not so obese) to me, especially in the leg department. This is important as lipoedema appears to be genetic on the female side of the family, appearing with the onset of puberty. Anna's condition also stood no chance of referral from

her PCT. The frustration of knowing you have a condition but cannot get to see anyone about it makes you a little angry. I started searching the internet and came up with a solution: Dr Anne Child from St George's was looking for families with lipoedema for genetic research. My sister and I got to see her in June 2006. Looking back at old family photographs the signs of this condition were there. I believe that the generation before my sister and I may have kept their condition controlled by the tights that they wore: being firmer and thicker than today's tights they offered more support. Sadly, Dr Child's funding is small and she needs three generations to do the genetic research. Our mother and grandmother have passed away and so the line stops, although we are watching Anna's two girls for any signs as they start to go through puberty. If we can help them now, perhaps they will not suffer as we have. The good news is that Dr Anne Child has our DNA on file and has referred us to Professor Mortimer for assessment.

My sister and I attended St George's Hospital together in November 2006. Lymphography scans were taken to establish how bad our lymphatic systems were damaged and if we had lymphoedema as well as lipoedema. Anna's was as expected with her right thigh showing lymphoedema. I was lucky, despite all the swelling in my legs and varicose veins, I had no signs of lymphoedema.

My lipoedema is bad and has most likely been exacerbated by my extreme obesity. My sister's is not as bad as she has controlled her weight far better than I have. Anna has an additional problem in that her lymphoedema is spreading from her groin down her right leg. The result of our visit was that we were fitted for compression hosiery. We did not know how well this would work. Lipoedema cannot be drained back into the lymphatic system, our only hope of success was to drain the excess fluid around the condition, and hopefully some of Anna's lymphoedema too.

It is a long journey that my sister and I have started and there may be no hope for our generation, but if my nieces are carrying the genes maybe we can help them.

The shape of my legs and my under cuts of skin left me with only the first choice of flat-knit hosiery (which, unfortunately, on a subsequent visit was found not to fit correctly). I both expected and dreaded this, as I don't like tight clothing and wasn't at all sure how I was going to cope with class 2 flat-knit tights. Jenny at the clinic measured me, and wanted to go a whole centimetre smaller than my leg size to bring in all the loose skin.

Once my tights arrived we followed the advice on washing them and prepping for wear. The comedy routine then began. I won't describe it, I'll let your imaginations wonder. After two hours of fighting, my husband and I still couldn't get the garment up to sit correctly at the groin, concluding that it was falling two inches short. My knuckles were bleeding from friction burns, and there were blisters on the ends of my fingers. We went back to the clinic who decided that by bringing me in so much some of the length was being lost. I was reluctant to go wider, so they reordered going longer. The next pair we did get on, although not without a fight. I have found small-sized gardening gloves, which have a good grip help application. Jenny has also given me an easy slide to help me get into the tights. There are two things I would like invented. One is a spray compression system (like fake tan); you spray it on, as it dries it compresses and then you peel it off at the end of the day. Or, secondly, an expander system that stretches the garment for you to slide into it; a bit like the dressing system Wallace has in Wallace & Gromit. I can now understand the problems with getting someone into compression. I would not put a frail old lady into class 2 flat-knit compression garments.

Getting into compression is not without a fight. However, I had not realised that I had been living in pain, probably for a very long time. Once my compression was on, the pain in my legs, especially my calves, disappeared. This was brought home to me when I was with a company exhibiting at the European Wound Management Association (EWMA) conference in May 2007 in Glasgow, and wore the compression while on the stand. Long hours on my feet on a concrete floor would normally



Figure 1. Even with the excess weight, the classic asymmetrical shape and cut-in points of lipoedema at the ankles are still clearly visible.

have left me in agony, with extra swelling. However, it was my colleagues who were suffering not me, the most trouble I had was with aching feet.

There is no current standard of treatment for lipoedema; it cannot even be managed in the same way as lymphoedema, as manual lymphatic drainage (MLD) can only clear the excess fluid that builds around the lipids. There are new types of liposuction being tried in Europe that do not cause the lymphatic damage that standard liposuction can bring about. The complications with fitting hosiery have been a problem for me. Even after all my weight loss, the apron belly (holding lipoedema) has so far prevented garments from fitting correctly. The recommendation from St George's for an apronectomy was put forward to my PCT and, although my GP supported me, my PCT refused. Experts are trying to find the gene that causes lipoedema to hopefully prevent the condition in future generations. If patients are caught early enough, they can hopefully be prevented from ending up with grotesque shaped legs and pendulum bellies as I have done. All it takes is a little closer look and asking about family history to pick up the differences between oedema and lipoedema that could make a major difference to someone's quality of life. JL