

Lipoedema — a family story

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Lipoedema is an adipose tissue disorder, commonly confused with lymphoedema, which affects around 300 million women worldwide (Fonder et al, 2007). The causes of the condition, which leaves people with a large build up of fatty tissue in their limbs, especially the lower ones, are still largely unknown, the symptoms often misunderstood and dismissed, and the psychological effects unnoticed or ignored. There is no treatment or cure. I know all of this because am one of the 300 million women who has lipoedema. Here, I will tell the story of a family living with the reality of lipoedema.

The condition is congenital and often affects many generations of the same family. Pamela, 60, Michaela, 39, and Poppy Dawe, 15, mother, daughter and granddaughter respectively, all suffer from lipoedema. Pamela was diagnosed around 6 years ago when she was 54, but has had lipoedema for as long as she can remember. She described her legs as always looking like 'tree trunks' with no knees. The last time she can remember seeing her knees was at the age of nine. She says that even as a child, clothes didn't fit her and long socks would only reach just above her thick ankles. Her legs were constantly covered in bruises, always cold, and her joints would ache non-stop. She also had sore, dry skin, which rubbed and chapped.

For a while, Pamela thought feeling this way was normal and everyone felt constantly tired and sore. She didn't realise she had a medical problem and put up with the internal turmoil, as well as everyone's jibes and comments. Pamela thought that having big legs was just a part of who she was, and that nothing would change them. Even day-to-day tasks were difficult, but Pamela dusted herself off every time she fell and just got on with things.

Instead of questioning why she was this

way, and what might be done to help, she went out of her way to disguise herself and blend in, never showing her legs. Pamela developed a phobia of going to the doctors and the thought of anything medical.

It was not until a group of small ulcers she developed on her legs 6 years ago started to grow and weep continuously, that she realised she needed to seek medical attention. Eventually, the blister became one large one with the ulcer underneath. The wetness continued for months and the hole in the leg got deeper, leaving a scar.

This was the first time Pamela had ever shown her legs to a doctor. She was referred to a lymphoedema clinic, and to a nurse, to whom she told her story. This was an incredibly big deal for Pamela. As a child, she felt nobody recognised her health needs or the fact she had a problem. She learned to keep quiet about the pain she was going through and felt her family would continue to dismiss her needs throughout her life, as they had failed to acknowledge her difficulties, pain or discomfort except to make comments about her size. Because she was ignored as a child, she felt like she didn't matter. This was a feeling she carried with her throughout her life, and was why her condition was so bad before she did eventually visit her GP.

Pamela was diagnosed with lipo-lymphoedema and was treated for the ulcer, cellulitis and other infections for over a year with bandaging and compression therapy. She described the diagnosis as a 'light bulb moment.' For once, someone looked at her without judgement, and believed that she wasn't just overweight through any fault of her own. She felt a range of emotions; shock, sadness, disbelief, and guilt. She grieved for the duration of her treatment; for all the years she had lost and because so much damage had been done to her body.

Pamela has doubted her diagnosis at times. This is common for most women with lipoedema, who are often in denial, and do not want to accept that they do have a medical

condition. In the same way that there is an explanation for all of the things that are wrong with your body, a diagnosis is bittersweet because it may mean that there is not much that can medically be done. What is also common is the lack of information and support women with lipoedema are given. Pamela was told to stay as active as possible, manage her weight and wear compression. Although no amount of diet or exercise can remove the stubborn adipose fat and tissue, keeping weight in check can mean lipoedema is kept a little more under control. This, however, does not solve the root cause of lipoedema.

Despite the overall apathy towards lipoedema, there are a few members of the medical profession who seem to be taking an interest. Dr Karen Herbst is an American doctor known as one of the pioneers of lipoedema research and works as a Specialist at the University of Arizona, Tucson. Pamela and Michaela were lucky enough to meet this 'inspirational' woman in May 2014. Here in the UK, Dr Peter Mortimer, a Professor of dermatological medicine at St George's Hospital in London has a clinical interest in lymphovascular medicine. Pamela had a consultation with Dr Mortimer in November 2012, when he confirmed her diagnosis and explained that gastric bypass surgery might help reduce her weight from 26 stone, lessen her pain and increase mobility she had lost.

By the time of her consultation with Dr Mortimer, Pamela could not get out of a chair unassisted, navigate stairs, or walk without excruciating pain. The notion of surgery was a real shock to her, and making the decision to have it was difficult. But, at that stage, it seemed it was either surgery or ending up wheelchair-bound.

Pamela has lost 15 stone since the gastric bypass surgery, and her leg pain has improved, along with some mobility. However, life is still difficult and her days are based around concerns of what to eat, what to wear, and what stresses the day will bring. Simple tasks are complicated; putting on compression

Patient perspective

hosiery and clothes is painful as the pain in her arms has not reduced even after the surgery, housework is impossible, and making a cup of tea is difficult. Pamela says lipoedema has infiltrated every part of her life.

On top of having to look after herself, Pamela cares for four autistic people who live with her. She has busied herself with looking after others in order to distract herself from her own condition. This includes her children, whom she has tried to prevent from experiencing lipoedema as she has. But lipoedema is congenital, which means unfortunately there is nothing anyone can do to prevent it and Michaela, Pamela's daughter, was diagnosed with lipoedema just a few weeks after she was.

Michaela had previously recognised she was overweight with large legs, but never imagined there was something medically wrong with her. It wasn't until Pamela explained her diagnosis at the lymphoedema clinic, and they spent time searching on the internet for images of lipoedema, that she realised they both looked like the women on the screen. She then visited the lymphoedema clinic again with Pamela to receive her diagnosis.

Being there to support each other through their diagnoses was some comfort for both women, but Michaela was angry, upset, and disheartened at her diagnosis. She felt that she had been left for 33 years thinking and believing she was fat and lazy. Her weight had always been an issue, and she went through many phases of gaining and losing weight, and even became bulimic for a period of time.

Like Pamela, Michaela was in denial at first, and didn't want to actively manage her condition. Treating it means you have to accept it, which can be difficult. It didn't help that she wasn't given much support with managing her condition. Michaela was left to find out information about lipoedema on her own by carrying out research online and joining a support group. Once she felt like she was equipped with the information she needed, she then felt confident enough to return to the doctors to ask for support, which she said, she had to beg for. For Michaela, the limitations of lipoedema means it is difficult to stand for longer than a minute (although she can walk for miles), and drive. Brushing her daughter Poppy's hair is also hard work sometimes because of the strain on her arms.

Pamela and Michaela always suspected that Poppy would have lipoedema too, and that signs would start to show. Poppy, who is now 15, noticed her legs grow suddenly and that none of her jeans would fit over her legs.

She was taken to the lymphoedema clinic in May this year, and given a positive diagnosis for lipoedema. She described the diagnosis as being a horrible moment that made her very upset. She is angry she has lipoedema, and said she fears she will end up with legs that look like her mother's. But Poppy also feels lucky that she is aware of the lipoedema, and said her grandmother and mother have been able to provide her with all of the help and support she needs after going through the same experiences themselves.

All three women now wear compression daily (although Poppy cannot wear prescribed medical grade compression until she turns 16), and try to eat as well as possible, excluding carbohydrates and processed foods from their diets. But this isn't always easy, especially for Poppy. They also try to manage their pain by exercising in water when they can.

Although the limitations are different for Pamela, Michaela and Poppy, they have all struggled to get help from doctors and have had to find their own ways of managing lipoedema, which is not kept in check by doctors like other medical conditions. When considering the advancements made in other areas of medicine though, it seems quite surprising that healthcare professionals in the UK are not learning more about lipoedema.

It is bad enough that doctors don't recognise how debilitating the physical side of lipoedema can be, but much worse, the psychological side is often totally ignored. The mental and emotional side effects of lipoedema are severe for most women. Sufferers don't only live with physical restrictions. Many also feel an immense amount of shame, guilt and hurt.

Pamela said she is sickened by the fact that she has passed lipoedema on to Michaela and Poppy, and believes it is her fault they have the condition as it started with her. She feels an overwhelming guilt for putting 'her girls' in the situation they are in, and knows that the vicious cycle of lipoedema will never end. Michaela also said she is heartbroken for Poppy, who she feels has a life of struggles ahead of her. Poppy has not told her friends about having lipoedema as she is embarrassed by it. She also thinks they will not be able to understand what the condition is, or how it will affect her throughout her life.

Finding Talk Lipoedema has been a 'life saving' experience for Pamela. She believes she has found true friends within the Talk Lipoedema support group, and said without them, her life would still be dark. She has rarely had friends throughout her life, and has



always been guarded. Michaela doesn't talk about her condition with her friends either. She doesn't want them to think she is trying to make excuses for being fat. But the outlet of the support group means that everyone can share their thoughts and fears in a safe space.

Along with Pamela, Michaela and Poppy, this author has realised how, in the absence of any real and valid support from GPs, consultants and specialists, just how important it is to get some. Some people might get their support from their family, some from friends, and some from a group like Talk Lipoedema.

Talk Lipoedema is leading the way to raise awareness of our condition, something that the medical industry should be doing, but we feel, choose to ignore. So we are helping ourselves to get through this. We are educating, advocating, and supporting. One day, we hope this condition will be taken seriously, and that doctors will be able to recognise lipoedema and educate us. We hope that no woman will feel alone, blame herself, or be ridiculed for her size. We hope that no woman will have to beg for the treatment she so badly needs.

References

Fonder MA, Loveless JW, Lazarus GS (2007) Lipoedema, a frequently unrecognized problem. *J Am Acad Dermatol* 57(2 Suppl):S1-3

Talk Lipoedema is a not-for-profit UK organisation that provides support to sufferers of lipoedema and their carers. Visit the website at www.talklipoedema.org.