the DISEASE THEY CALL FAT

LIPEDEMA LADY
SHARIE FETZER

Transcript of Lipedema Lady Video Episode 22

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Lipedema Advocacy in the UK

(note: the European spelling is lipoedema and used interchangeably in this transcript)

My personal story is I'm now sixty-two. I've had lipedema since I was fifteen. I have two daughters, three grandsons, and one granddaughter. My granddaughter's the reason I'm standing up here talking to you. She's two and a half and I don't want her finding out she's got lipedema when she's fifteen and there's no hope, no treatment, nothing. So I want to bang some drums and I don't want it to pass down the generations of my family.

I think I'm very lucky. I could have died when I was twenty-three, and I've lived in some nice places and I've got a lovely family. But life has always been a struggle and I always knew I wasn't as well as I should be and that something was dragging me down. Sometimes I could barely get out of bed. My legs ached and I was always, always covered in bruises. Why me? Why these blue legs? Clothes never seemed to fit me the same as everyone else. Boots were a complete nightmare.

In 1995, when I was forty-five, I found out I had lipedema. So it took me thirty years to work out what it was. I'd already discovered MLD and I have to say that was thanks to the *Daily Mail.* So there are a few journalists out there doing a few good stories. I was lucky enough to have a therapist nearby who could do home visits and she was one of the top ones working with Professor Mortimer, and I had bandaging and home visits as and when I could afford it. It was not cheap, but somehow I just knew I had no option. I must have had about twenty or thirty sessions, always in my own home, and I actually think that is very, very beneficial to have it at home, not travel, not be sitting in waiting rooms et cetera.

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I would waddle around my house full of teenagers with my lower half looking like an Egyptian mummy, and always in a long, flowing, black skirt. Being teenagers, they barely noticed, so I didn't make much of an impact. Then a miracle happened. One morning, I unwrapped the bandages, and there they were. I touched. I gasped. I was really thrilled. I could actually see and feel my anklebones. That was like, there is something under there, underneath all this fat. Since then, I've found lots of things that have helped me personally. I keep to a very, very careful diet. I avoid a lot of common foods. I don't [walk] very far in heat. I put my legs up high at every possible opportunity, sometimes in very public places. I cycle and whenever possible, I walk in cold water, and I swim, and I swim, and I swim.

So that's me. That's what helped me. But none of these things have been suggested by the NHS and none of them are being paid for or provided on the NHS. It has been up to me to find that they work for me. I think one of the problems is we've all been on our own. We've all been shy. We've all been hidden away. And that is the real issue. Nobody knows how many people are out there. And that's what we want to try and change. Statistics do actually count in the medical profession. So that's when I come on to the survey. Hopefully I will. I'm just a person who's got up and done something. I'm just another person who's trying.

Lipoedema UK's Research Survey

One day when I was swimming, I hit upon the idea of an internet questionnaire. I decided to go and see Professor Mortimer and the wonderful LSN. I went to see them on the thirtieth of April this year. I met with Anita Wallace and Karen, who's here today.

They were charming and they were encouraging. They both liked the idea and the LSN said they would back the questionnaire if I went off and did the work. This keeps coming back folks. It's up to us. It really is up to us.

Lipoedema UK's big survey. I hope everybody has heard of it in the room. Lipoedema Ladies did a nice plug for us and I know a lot of you have done it. All the comments will be read, as together they make a really moving and powerful case. The more people say things, the better our case and it is humbling to find out how torturous some people's experiences have been.

People have all been very positive. As somebody wrote, "It feels good to be able to write down the ups and downs of living with lipedema." People are complementing Lipoedema Ladies. There's lots of information there. You have got the opportunity in the survey to have your say. Bring up anything you think about because we are going to St. George's with this. I had the most wonderful comment in the meeting from Sandy Ella. She said, "I think this will end up in the House of Commons." I hardly dare repeat it because it's too big an aspiration. But who knows? We suspect there are a mass of people out there. We want to reach them and we just want some good statistics because if you know medical people, they need statistics to start listening. So thank you very much for listening to me. Thank you very much.

About Sharie Fetzer

Sharie Fetzer is Chair at Lipoedema UK, a member of Lipoedema Ladies, mother of two daughters and grandmother of four. Sharie co-organized and co-hosted the Lipedema Solutions Forum at the 1st International Symposium on Lipedema in New York City in April 2015. As a passionate advocate for lipoedema, she has been instrumental in raising awareness and supporting treatment for lipoedema ladies in the UK.

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