

Lipoedema: the first UK patient survey

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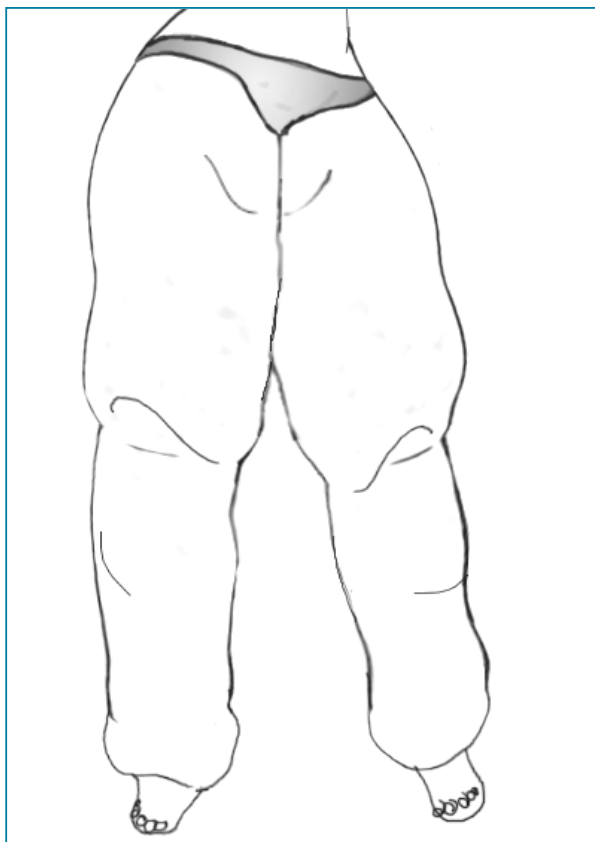
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Lipoedema is a debilitating and disfiguring disease. Despite the fact the condition was first identified in 1940, it is not taught to student doctors in medical schools and it would be unlikely that reference is made to the condition in medical text books.

Lack of awareness of lipoedema means the majority of sufferers are denied access to expert services.

The condition strikes without warning and it strikes quickly (I watched my own daughter transform from a skinny, probably underweight child, into one who clearly had 'a weight problem' in the space of just 3 weeks, below her still tiny waist at least).

In my family lipoedema has affected five generations of women that we know of, although it can skip a generation and not all women in a family are necessarily affected (my sister does not have it, for instance). Research (Wold and Allen, 1951; Chen et al, 2004) suggests that while men only rarely manifest symptoms – there are only rare and isolated reports of presentation in males who have severe hormonal disorders – it can be passed down the male line.



The amount of lipoedema a woman has and the way it is distributed on her legs and hips, varies between sufferers; some women may just have small pockets of fat above the ankles, for example, while in others there is a dramatic and obvious discrepancy in size between their upper and lower body. Typically, in the early stages, there is a bulge below the waist on the hips, bulges on the thighs, knees, calves and perhaps an 'elastic band' effect at the ankles. With each subsequent hormonal event, pregnancy or use of hormonal contraception for example, the fat deposits may increase and can become pendulous (*Figure 1*).

Although maintaining a healthy body weight is important for lipoedema management, overeating does not cause lipoedema and dieting cannot cure it. However, it can and does co-exist with obesity in patients, although it should be remembered that BMI measurements can be skewed by lipoedema. This needs to be taken into consideration when assessing what actually constitutes a 'healthy body weight' in women with lipoedema. Exactly what does cause lipoedema is unknown, but what is known is that the condition is connected to female hormones because it usually appears first at puberty and then worsens with any subsequent hormonal change. There is no gene testing available at present.

Because they are usually considered to be obese, the advice women are given before their diagnosis is often harmful. For example, a woman may be told to reduce her calorie intake when she is not overeating (and may already be undereating), or start a high-impact exercise regime, which is unsuitable for lipoedema sufferers whose joints appear to be liable to injury.

At present, women are usually diagnosed only when health has deteriorated due to comorbidities such as lymphoedema (lipo-lymphoedema), varicose veins, osteoarthritis and adipositas delorosa. Poor understanding of the condition in the medical and care professions can also exacerbate psychological problems such as low self-esteem, poor self-image and lack of social confidence.

In response, a key aim of Lipoedema UK is to raise awareness of the condition so women can be diagnosed earlier and deterioration can be prevented (*Box 1*).

In August 2012, Lipoedema UK launched the first national patient survey on lipoedema. The survey seeks to broaden understanding of the condition and its symptoms (See *Box 2*) and to assess the physical and psychological impact on sufferers. It is already proving extremely useful in identifying future research strategies and potential new symptoms, and has been a positive initiative.

At present, it is difficult to know how many women in the population are affected, because the condition

Figure 1. As lipoedema develops the fat deposits on the hips, thighs, knees and calves may increase and can become pendulous

goes so hugely undiagnosed. One study has suggested 11% of women may be affected (Foldi and Foldi, 2006). Other studies suggest between 8-17% of women with lymphoedema may also have lipoedema (Meier-Vollrath et al, 2005). However, until the condition is more firmly on the radar of health professionals these figures are open to debate. I personally do not believe lipoedema is rare; once a health professional knows what to look for, it is not difficult to spot women who may have the condition, even while out and about in a public place.

Only diagnosed lipoedema sufferers living in the UK have been invited to participate in Lipoedema UK's survey. So far, 136 women have taken part. The questions have been developed by lipoedema specialists, including lymphoedema nurses, working with patients. In addition to questions about physical manifestation and symptoms of lipoedema, the survey asks lifestyle questions such as how easy it is to buy clothes and take exercise; whether participants have eating disorders; whether it affects their ability to work and such like. The charity is also asking for anecdotal evidence about any treatments that have helped improve the physical appearance or ease the pain of the condition with a view to conducting further research should any positive threads emerge.

To date, all those completing the survey have been women. Participants range currently from age 19 to 79 and, for more than half, their initial symptoms presented with the onset of puberty. Although the majority of survey respondents have been prescribed compression hosiery, which supports the soft tissues and helps prevent the onset of lymphoedema, less than half reported that they actually wear it every day as advised; this highlights the fact that the pain in lipoedema tissues makes the process of using compression garments very difficult for many women.

We have had very positive feedback from survey participants. They are delighted someone is listening to them, feeling they have had little or no sympathy from doctors, dieticians or physical therapists when raising concerns about their inability to lose weight below their waists. They feel they have been written off as 'fat' or 'lazy' and that few doctors have been able to see beyond their 'fat bias' to take them seriously.

The following are the words of women who have taken part in the survey:

'Doctors and other health professionals REALLY need to be made aware of lipoedema. Too many are completely ignorant of the condition so people aren't being diagnosed, and lives are being made more difficult than necessary.'

'Thanks very much for beginning to find out more about this debilitating condition. Let's hope that mainstream healthcare professionals hear about it soon and we are not just told we are fat and to eat less and exercise more!'

Box 1. About Lipoedema UK

Lipoedema UK was founded in 2012 by women with lipoedema and clinicians working in the Lymphoedema Service at St George's Hospital in London. Its patron is Professor Peter Mortimer, the UK's leading Lipoedema expert, and its nurse consultant is Sandy Ellis, who diagnoses and treats many women with Lipoedema in the UK and is also the nurse consultant in the St George's team. The charity's objectives are to educate doctors, health professionals and the public about lipoedema and its symptoms, so it may be diagnosed and treated earlier.

Because lipoedema is frequently mistaken for obesity or lymphoedema, women do not get appropriate advice or treatment – a state of affairs the charity is on a mission to change. Lipoedema UK's key aims are to raise awareness, tackle misdiagnosis and help women get the treatment they need. Its hope is that with earlier diagnosis and treatment women can be spared at least some of the many complications of lipoedema. It can also provide information about lipoedema to members and health professionals, report on research findings and commission its own research.

There is info on the website (www.lipoedema.co.uk) which will eventually be a research resource and nurses can support the charity through membership. There is also an AGM/information day on 18th May, with lipoedema experts and patient views, which will be a good 'learning day' for nurses.

The charity has deemed 11 June to be National Lipoedema Day.

Box 2. Lipoedema symptoms

- ◆ Disproportionately larger/fatter legs and hips compared to the upper body
- ◆ Swelling is symmetrical
- ◆ Hands and feet are not affected
- ◆ Loose, floppy connective tissues around the knee joints
- ◆ Fat that looks like cellulite and feels soft
- ◆ Tenderness/pain and easy or spontaneous bruising to affected areas
- ◆ Skin of affected areas may be pale and cold
- ◆ Upper arms may also be affected and be disproportionately fatter
- ◆ Patients may report increased swelling in hot weather

'It has been so liberating to know that I am not just fat and on my own.'

The survey is still ongoing. Lipoedema UK can send out posters advertising the survey to put in clinics, or provide 'About Lipoedema UK' leaflets, free of charge, for distribution. **BJCN**

Anyone who wants to take the survey must live in the UK and have a formal diagnosis. To take part nurses just have to send an email to info@lipoedema.co.uk, which is also the main contact for the charity.

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