

Nursing Practice

COMMENT

“I have lipoedema. So please don’t blame me or call me fat”

If I am fat, then it must be my fault, right? This is what I believed too until, after a lifetime of failed diet and exercise regimens, I was diagnosed with lipoedema, a genetic condition countless doctors, nurses, diet experts and physical trainers I consulted seemed not to have heard of.

Thin as a child, at 15 my legs got fatter than those of the other girls at school, even though some of them had tummies clearly tubbier than my still skinny waist. My thighs rubbed together and red rashes developed between them. Slow on my feet, I was last to be picked for team games and I became acutely conscious of my fat wobbly legs in PE.

The social stigma lay heavily on me. I was bulimic by age 19, taking laxatives after every meal, alternately starving and then bingeing, beating myself up mentally for not being able to make myself sick. Nothing, but nothing made my legs thinner.

Then I put on a lot of weight when I was pregnant and then my ankles disappeared altogether. By then, I had stopped the laxatives but was still alternately dieting, fasting, bingeing and compulsively over-exercising.

Six years ago, I discovered Overeaters Anonymous and started eating normally and healthily for the first time since I can remember.

Previously, I had never had much sympathy from anyone, especially not from doctors. I used to dread the three-monthly visit to renew my prescription for the contraceptive pill, knowing what would follow once I stepped off the scales – a comment

that my BMI meant I was “obese” and I should lose weight. Protestations that I was trying were met with a look that said simply: “Here’s another fatty in denial.”

I was diagnosed with lipoedema only by chance, when a consultant who was treating the osteoarthritis in my knees noticed my swollen ankles and referred me to a colleague who explained that this genetic condition was the cause of my large and painful legs.

At her words, everything tumbled into place: runs in families... makes women fat below the waist... symptoms begin at puberty then get worse with further hormonal changes such as using hormonal contraception, pregnancy... the fat is often painful to the touch... many women also have enlarged upper arms... frequent knee problems. Then she said the magic words: the fat wasn’t my fault, because it’s not caused by overeating, diet and exercise is pointless as neither will shift it. Oh to be believed!

Founding Lipoedema UK to raise awareness, provide information and promote research into lipoedema is my way of doing what I can to help prevent other women from suffering and instead help ensure they get as early a diagnosis as possible.

So please, the next time you meet a woman whose BMI belies a relatively small upper body and/or slim face, and whose bottom half is out of proportion with her torso, don’t simply suggest she loses weight. Believe her when she says she has tried and ask: could this be lipoedema?

Suzanne Evans is chair, Lipoedema UK, www.lipoedema.co.uk

SPOTLIGHT



Kathryn Godfrey is practice and learning editor of Nursing Times. kathryn.godfrey@emap.com [@GodfreyKathryn](https://twitter.com/GodfreyKathryn). Don't miss the practice blog, go to nursingtimes.net/practiceblog