



My legs

Ipswich woman Casey Whiting despaired of ever being able to exercise enough to shift the fat from her legs but then, after years of discomfort and self-consciousness, she was eventually diagnosed with lipoedema. Casey talks to **LYNNE MORTIMER** about this little-known condition

Your legs hurt – all the time and they appear so big compared to the rest of you – and they look different, paler than the rest of you.

The doctor recommends exercise, so you walk miles and you swim, even though you are embarrassed about the appearance of your legs. But they don't get any thinner and they don't stop hurting. Why?

This is what was happening to Ipswich woman Casey Whiting until she discovered she was suffering from a condition that accounted for all her symptoms. She has lipoedema. If you've never heard of it you're not alone, nor have most people which is why Casey, a young woman who is not keen to be thrust into the spotlight, decided she had to talk about it. So determined is she to raise awareness that she is going to a lipoedema conference, next March.

She doesn't want anyone else to suffer the distress, discomfort and embarrassment that she has endured because of this rarely-

spoken-of condition.

In a world where body image seems to dominate the media, having over-sized legs when there isn't a thing you can do about it, can impact on your self-esteem but, as Casey, says, getting the diagnosis confirmed is massively important in restoring confidence.

The condition manifests itself through a "fatty cuff" just above

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the foot, fatty bulge below the knee, bulges on the inner and outer thigh and a hip cushion. The feet are unaffected.

Casey, who is in her mid-20s, says: "Since my early teens my legs have always been bigger. There were comments from other people.

"When I was at school, I put it down to being overweight – I just



■ Lipoedema can cause distress, discomfort and embarrassment to sufferers.

Pictures:
TALKLIPOEDEMA



were so embarrassing

Lipoedema: 'Misdiagnosis is common'

The Royal College of General Practitioners defines lipoedema, an adipose tissue disorder, as: "A progressive, inherited condition characterised by abnormal fat deposition of the lower limbs. It affects women from puberty onwards and can be extremely distressing and debilitating."

It says very few doctors (just 5% in a 2014 survey) or health care professionals are trained to recognise lipoedema.

"Misdiagnosis is common and patients are labelled as being obese or having

lymphoedema. This can result in decades of unnecessary dieting and significant psychological damage."

One woman who had been undiagnosed for many years before her lipoedema was recognised said: "To be helped to manage the condition made me look at my own body in a different way for the first time in possibly 45 years."

■ More information can be found at www.lipoedema.co.uk and www.talklipoedema.org



thought my legs were bigger and that was it. A few years ago I got into running, cycling etc and I could lose weight off my stomach and shoulders but not off my legs. They stayed the same. I couldn't seem to shift any weight off my legs.

"Over the last two years I have also been in pain. It's a heavy, constant, achy pain. I thought it might be caused by the amount of exercise. So, around a year ago, I went to the doctor and explained that I was doing all this exercise but couldn't seem to lose weight off my legs. They were still big and heavy.

"The doctor had a look at my legs and concluded they were fine and said I needed to lose weight."

More often than not, this is what happens when a lipoedema sufferer goes to the doctor, says Casey, because there is so little awareness of the condition.

"There are lots of other people this has happened to and they go away thinking they have got to do more exercise. You can walk away from the doctor's surgery feeling foolish.

"I thought I wasn't doing enough. But when I tried to run I got this real pressure; this pain... like my legs were going to burst and it kept happening. And it was getting worse to the point where I couldn't run any more.

"I walk home up a hill every day and it was getting harder. The heaviness wakes me up in the night and it's difficult to get back to sleep."

Casey suspected there was something behind her problem... surely it couldn't just be down to lack of exercise? "I kept questioning it. When I walked into town with my sister I asked if her legs were hurting and she said no.

"I Googled 'weight on legs' and came across the website Lipoedema UK... and another website Talk Lipoedema. All the symptoms they listed – such as walking along and feeling pain – were exactly what I have got."

Is this a rare condition then?

Casey shakes her head. "It's not very much heard of, but it's not rare."

"I went back to the doctor and I had armed myself with information from the internet. I

“If I can help one person get a diagnosis, then talking about it today has got to be worth it

took it all in with me and asked to be referred. I had to do some persuading because the doctor was unsure if it would help."

She thinks this is because many GPs are not aware of the condition although, she adds, there is an online course doctors can take which will give them the information they need.

"In July, this year, I went to the hospital and talked to the (female) doctor about my history and lifestyle. She looked at me and measured every centimetre of my legs and she said there was no doubt that I had lipoedema."

But there is no cure.

"I have now been prescribed compression garments. They help me feel supported but they are uncomfortable to wear each day... and to put on each day."

"The condition is caused by stubborn fat on the lower limbs. They can do liposuction but it has

to be a procedure that doesn't affect the lymph nodes... and it's not available on the NHS."

As a result, Casey will fund it privately. It seems the health service can only offer special garments to wear. These may alleviate symptoms but they do not make it better."

As we sit in Costa, Casey says her legs are aching now, even as we chat.

"When I was diagnosed it was bitter-sweet. I was so glad there was a reason for what was happening to me."

But at the same time:

"Lipoedema is a progressive condition so it will get worse; my mobility will get worse. If they could do something about it now it would help me in the future."

"The reason for surgery is to try and stop (lipoedema) in its tracks, to increase mobility and reduce the pain."

Casey hopes the op will go ahead in January, next year.

"Women on social media have said it was the best thing they have done."

Will it come back? Casey acknowledges it could but in the meanwhile: "It would be brilliant to fit into trousers properly. But if the size doesn't change just to be pain-free would make it worthwhile."

She will also be continuing to increase awareness: "If I can help one person get a diagnosis, then talking about it today has got to be worth it."

■ Images have kindly been provided by talklipoedema



■ Casey Whiting, who suffers from lipoedema

Picture: CONTRIBUTED

