

Turning into a pear shape? Then you could have 'painful fat' syndrome

by JILL FOSTER • AUG. 1, 2011

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Louise Farquharson was gaining weight, but it only seemed to affect her from the waist down

Like many women who have dieted, Louise Farquharson blamed herself for putting on weight.

The 44-year-old office manager noticed the pounds creeping on around the age of 35.

Oddly, the weight only seemed to affect her from the waist down.

'I noticed my ankles swelling up, but I thought it was just fluid retention and it would sort itself out,' says Louise, a mother-of-three from Edinburgh.

'But gradually my calves, knees and thighs all began to get bigger.

'I thought it was weight gain, but it didn't matter how much I cut calories or how much exercise I did, I was piling on pounds.'

By her late 30s, she was a size 16.

She says: 'I visited my GP, who said if I stuck to the diet, the weight would come off.

'I'd been inactive for the previous three years because I had ME, so I thought the weight gain may have been something to do with that. But nothing helped.'

Over the next eight years, Louise tried to diet to no avail. By the time she went back to her GP again last October, she weighed 18st and her legs were so swollen she needed a walking stick.

'I called my legs "tree trunks" because they had taken on a strange column shape,' she says.

'I was wearing size 24 trousers, even though my waist and top half was only size 18.'

Despite what Louise and her GP thought, she was actually suffering from lipoedema. It's a condition that affects only women and despite being common, is often missed.

As consultant vascular surgeon Constantinos Kyriakides, of The Private Clinic and Bath and London NHS trust, explains: 'Lipoedema was first discovered in the Forties, but there has been so little research into it that few medical professionals even know that it exists.'



With lipoedema, the swelling is caused by a deposition of fat cells underneath the skin as well as the build-up of fluid in those fat cells

'Many doctors confuse it with weight gain or it can be confused with lymphoedema, another condition that causes swelling in the body.'

While lymphoedema is caused when the body's lymphatic drainage system is damaged, resulting in lymphatic fluid builds up in the tissues of the legs, waist, arms and sometimes the face, with lipoedema, the lymphatic system can be healthy.

Here the swelling is caused by a deposition of fat cells underneath the skin as well as the build-up of fluid in those fat cells.

No one knows what triggers it and there is no cure.

Women can be born with these excess fat cells or it's thought

they may multiply when hormones spike such as during puberty or the menopause.

‘Lipoedema tends to concentrate in the calves, knees, thighs and lower girth, whereas lymphoedema can affect other parts of the body,’ says Mr Kyriakides.

‘Your weight seems to have no bearing on it, so you have a very slim upper body, but very heavy buttocks, thighs and lower leg.

‘Also, your feet are not affected — with lymphoedema, your feet and toes tend to swell up, too.’

‘The problem is that it’s possible for lipoedema patients also to have an element of lymphoedema, which adds to the confusion.’

Anita Wallace, of the Lymphoedema Support Network, adds: ‘Lipoedema can be a very frustrating and depressing condition to have — especially if it has been misdiagnosed.’

Mr Kyriakides adds: ‘I’ve seen many women who have put up with this condition for years thanks to never being diagnosed.

‘Most doctors are not aware of it and because the treatments are not great, there’s little interest in it from the medical profession.

From the first time she noticed her ankles swelling in her mid-30s, it took more than eight years for Louise to get a correct diagnosis.

‘When I went back to my GP last October, he said it looked like a build up of lymphatic fluid and gave me some diuretics which didn’t work at all,’ she says.

‘He then referred me to a vascular surgeon for further tests.

‘The surgeon told me it was probably chronic lymphoedema in both legs. He sent me for an ultrasound test to rule out vascular damage as well — that was one of the most painful experiences of my life.

‘A technician had to pinch the flesh to cut off the blood supply so she could monitor how the blood was travelling.

‘I screamed with the pain and the technician seemed very surprised. She also noted that I had a nodule — a cluster of fat cells — in the back of my calf.’



'I cried with relief. Not only had I been blaming myself for a condition that wasn't my fault, it meant I could now have the right treatment,' said Louise

She adds: 'I've since found out that lipoedema is also called "painful fat syndrome" and that nodules and pain are classic symptoms.

'Today I have dozens of nodules — which feel like small polystyrene balls — in my calves, thighs and buttocks. But none of this was even mentioned by the surgeon at my later appointment.'

Louise was prescribed compression garments, which she wore all day every day for two months, even though they were excruciating to wear.

‘It was like being in a vice,’ she says. ‘The garments were always rolling down and creating a tourniquet around my ankles.

‘I would be in tears as I put them on or took them off. I couldn’t bear the thought that I would be in this much pain for the rest of my life.’

In desperation, Louise turned to the internet, where she came across a treatment that others found helpful. Manual lymphatic drainage is a gentle massage that stimulates the lymph glands to relieve the swelling. Louise had several treatments.

She says: ‘The therapist couldn’t work properly on my legs at first because they were too painful, but the rest of the massage was very relaxing.

‘Afterwards I felt nauseous, but after several sessions, my legs were feeling lighter so I knew it would be doing some good.’

When Louise went to the specialist lymphoedema clinic in February, her diagnosis was confirmed: it was lipoedema.

‘I cried with relief. Not only had I been blaming myself for a condition that wasn’t my fault, it meant I could now have the right treatment: special types of compression garments that didn’t cause me as much pain. They have made a huge difference.’

Mr Kyriakides explains that compression garments help by supporting the tissues and encouraging the lymph system to drain.

‘But they can be very uncomfortable if not fitted correctly for the lipoedema patient,’ he says.

‘There are different types of compression garment — a bulky knit is often used for lymphoedema patients but these have a habit of rolling down and forming a tourniquet on the leg, which can be incredibly painful for a patient with lipoedema.

‘They need instead flat-knit garments which are measured to the individual and sewn up the back.‘In extreme circumstances, surgery is an option, but it’s not perfect. It involves cutting out big islands of

skin and fat. I'd only operate in very extreme cases.

'More recently, surgeons have been venturing into liposuction as a treatment and there's anecdotal evidence around the world that there are some good results.

'But overall, it's a short to medium-term solution because in the longer term, the fat tends to come back. And also, in the longer-term there's the worry that you may make the condition worse.'

Louise now manages her condition with proper garments and weekly manual lymphatic drainage — which she pays £40 for privately.

She has also recently set up her own support group which can be contacted through the Lymphoedema Support Network.

'I'm not angry about what's happened, but I do feel cheated by the NHS and annoyed that more research has not been done,' she says.

'It seems to me that if it was a condition that did more than make women fat, something would have been done about it.'

LYMPHOEDEMA Support Network, 020 7351 4480, lymphoedema.org

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<http://www.dailymail.co.uk/health/article-2021263/Turning-pear-shape-Then-painful-fat-syndrome.html>