

"I had painful fat syndrome for a decade and didn't know"

More than 1 in 9 Australian women have lipoedema, but for some, like Jen Matsas, it can take years to diagnose

Gaining weight in your teens and early 20s can often be explained away as a result of changing hormones and lifestyle. But what if that weight doesn't shift with a good diet and exercise regimen? And what if that weight starts to become painful — literally?

Lipoedema is a condition affecting thousands of women, but it's hardly spoken about. In fact, sufferers can live with it for years before getting diagnosis and help.

For Jen Matsas, 31, it was only last year that she first put a name to what had been going on in her body for more than a decade.

"I was having intense flesh pain down the side of my left leg and when I looked up my symptoms, lipoedema came up as a possible diagnosis," Jen says. "I printed out the information and took it to my doctor. She'd never heard of it either!"

Jen, who is now a member of the Lipoedema Australia board, says a lot of doctors don't know about the condition, which is why so many women live with it for years without realising.

Lipoedema is an abnormal build-up of fatty tissue — typically in the thighs, bum and lower legs — that in many cases leads to swelling and pain, to the point that it can even affect mobility. It's a genetic disease that's thought to be triggered or made worse by hormonal changes, particularly puberty, pregnancy and menopause.

Now that she's researched it, Jen realises that her lipoedema began in her teens and escalated when she started taking the contraceptive pill at the age of 24, and began putting on extra weight in the area from her hips to her knees.

"As a teenager, I used to be a dancer and when I'd do concerts, I'd have saddle bags hanging out of the sides of my leotard. I was a size 10 to 12, but the fat was disproportionate between my waist and my hips," she explains.

"Finding a school uniform was also hard. I had to buy a size 16 to 18 skirt

and a 10 to 12 top, and I always felt self-conscious about that. And it really sucked when I had a special event and couldn't find anything that fitted. Those were some of my lowest moments."

She couldn't understand why she couldn't shift the weight, despite all the dancing and exercise she did, and the fad diets she tried.

Then in her 20s, when she went on the pill, she gained 15kg in just two months. Again, Jen thought it was just her body shape, but this time she also started experiencing pain in her leg.

"It started off feeling tender — it was a little uncomfortable, but it would come and go, and often appear from nowhere. But over the years that pain gradually got worse and worse until it became very intense. And it didn't feel like normal joint or muscle pain — it was in my flesh."

She also noticed that the extra 'fat' felt different. "The texture was initially like cellulite, but now if you run your fingers up my leg, you can feel the fat — it feels like little peas under my skin," says Jen.

Having a diagnosis has helped her find the physical and emotional support she needs to manage her symptoms and stop its progression.



Physically, depending on the combination of symptoms, there are many ways to manage lipoedema, but, unfortunately, the usual weight-loss methods will have little impact – although it's still important to maintain a healthy lifestyle to reduce the risk of any more complications.

Jen eats a Paleo and Mediterranean-style diet to reduce inflammation in her body and has a monthly lymphatic-drainage treatment to help move excess fluid from the affected tissues.

She also spends up to 90 minutes a day having compression therapy, where she wears compression pants connected to a pump that applies pressure to the affected

areas and keeps lymph fluid moving from the tissues. "I wear the pants when I'm watching TV. I joke that it gets me out of the housework, but it's a big time commitment," she says.

On the days Jen knows she'll be on her feet a lot, or when she flies, she wears compression pantyhose. "They're not that attractive. I'm 31 – not 80 – but I do wear them when I need to."

The treatments have eased her pain, and her improved lymphatic system has also boosted her immune system. "I used to get lots of coughs and colds, but rarely get sick now. I had a small cold recently and it was my first one in nine months," she says.

Liposuction is a longer-term treatment option, although not a cure, but surgery costs around \$20,000 and is not supported by Medicare.

Aside from the physical effects of the condition, the psychological impact can be just as debilitating. Reduced mobility impairs sufferers' ability to perform daily tasks and can also impact their social life. And the

lack of awareness – coupled with the stigma attached to being overweight – can have a major impact on emotional wellbeing.

"Women with lipoedema aren't just fat – we don't look this way because we're sneaking snacks in the middle of the night," Jen says. "But people think it's your lifestyle and they judge. I once went to a GP who wasn't my usual doctor, who

assumed it was caused by my eating and wanted to put me on diet pills. And I once had a stranger call me fat, but I brushed it off."

She admits that while she's coped well emotionally in general, there are still times when it gets to her. "I recently went shopping for a wedding dress and at one store the assistant showed me size-20 dresses. I was swimming in them, but she'd looked at my legs and assumed that was my size," she says.

"And sometimes it upsets me when I can't do things because my condition prevents it, like when friends suggested we do a sunset hike before our wedding – I definitely wouldn't be able to do that, but I would have liked to."

Now that she finally has a diagnosis, Jen's made peace with her condition and is determined to remain positive. "I enjoy my life, and I have plenty of friends and lots to look forward to."

Jen is keen to have children, even though she knows the pregnancy hormones could worsen her lipoedema. "I'm happy to take that risk. Some women decide not to have kids because they don't want to get worse. It's daunting to know there's no magic cure for my condition, but I'm determined to live my life well."

"We aren't fat – we don't look this way because we're sneaking snacks"

Lipoedema explained

SIGNS AND SYMPTOMS

Lipoedema is a build-up of abnormal fatty tissue, typically in the thighs, bum and lower legs, and sometimes in the arms. The feet are not affected. It can lead to swelling and pain, and can affect mobility.

WHY IT OCCURS

It is still unclear why some women develop lipoedema, but it's believed to be a result of genetics and hormonal changes that occur during puberty, pregnancy and menopause.

WHO HAS IT?

It's estimated that 11 per cent of Australian women are affected in some way by lipoedema. It rarely affects men. A lack of awareness

means diagnosis can be slow – while lipoedema begins in puberty, the average age of diagnosis is 44.

WHAT'S THE IMPACT?

Women with lipoedema commonly report difficulty buying clothes as sizes can vary greatly between their top and bottom halves, low self-esteem, lack of energy, restricted mobility and also restricted social life, and feelings of hopelessness.

For information and support, go to lipoedemaaustralia.com.au

