

By JO WATERS

Women whose legs keep getting bigger... no matter how much they diet

HITTING puberty, what troubled Laura Childs was not her skin, but her legs, which began to balloon completely out of proportion with the rest of her body.

'It was much more exaggerated than just being pear-shaped,' recalls Laura, 37, a local authority administrative officer, who lives in Dover with her husband, Dean, 42, a trainee teacher, and their two children Leah, 13, and Oliver, ten.

'I'd previously been very slim, but over two to three years my legs became up to two dress sizes bigger than my top half.'

'It was weird because I had slim ankles and feet — the fat formed a cuff above the knee and the ankle. The skin on my legs would bruise really easily, too — even if I just scratched an itch, my whole leg would bruise. My legs also swelled up in the heat and could be quite achy and painful.'

'I couldn't understand it because I wasn't eating any more than usual. I dreaded having to wear shorts for PE lessons, and I would cover my legs up as much as I could with long skirts and wide-legged trousers.'

Her elder sister, Emma, and their mother, Janice, had exactly the same problem. 'We just thought it was our family body shape and we had to live with it. We all tried dieting, but could only lose weight from our top halves.'

But when she was pregnant with Leah, Laura's legs — particularly her calves — got even larger and more painful. 'After Leah was born, my GP prescribed me pills for water retention, but they did nothing,' she says.

She discovered the cause only after sister Emma lost 3st, but none from her legs — that's when her doctor diagnosed Emma and then Laura with lipoedema.

This is a common condition that affects only women and which causes abnormal amounts of fat to accumulate on the lower body (the legs, buttocks and hips although it sometimes also affects the arms).

The feet and hands are not affected, so the excess fat forms a distinctive 'bracelet', with fat overhanging the ankle, elbow or wrist.

It is a painful, often disabling, condition thought to affect up to one in ten women.

WHILE the cause is not clear, it's likely to be linked to hormones; in most cases the fat accumulation starts after puberty or other times of hormonal upheaval such as pregnancy or the menopause, and generally becomes progressively worse over time, causing increased pain and mobility problems. Women affected can lose weight only from their upper bodies — it's not known why the fat does not respond to dieting.

As the condition tends to run in families, experts believe it has a genetic element, although some women don't have a family history.

'The classic hallmarks of lipoedema are that the lower limbs are enlarged and the fat that accumulates there is painful — we don't really know why,' explains Vasu Karri, a plastic surgeon who runs a private clinic in Hull where he treats the condition.

'Patients often say they feel as though they're wearing a fat suit from the waist down. Some women are acutely sensitive to any type of pressure on their legs and can't even stand a duvet over them, as it's so painful.'

'As the disease progresses, these women may have difficulty walking because of pressure on their joints from the weight, and may even need joint replacements.'

Despite the number of women affected, the condition is poorly

recognised. A survey in 2014 by the charity Lipoedema UK found the average age of diagnosis was 44, although 46 per cent of respondents said their symptoms started at puberty and only 5 per cent were diagnosed by their GP — patients are usually told they are just fat or have been lying about what they eat.

The main treatments available on the NHS are compression tights to reduce the fluid build-up which sometimes accompanies lipoedema, and manual lymphatic massage, a specialised type of massage which helps to drain fluid out of affected areas. However, neither treatment can reduce the fat, as Laura and Emma discovered.

'At first, we were both relieved that there was a medical cause for our fat legs, but when we realised the treatment options were very limited, that quickly wore off,' says Laura. 'I found the NHS compression tights too uncomfortable

to wear, and the manual lymphatic massage reduced only the swelling, not the fat.'

The only other treatment for lipoedema is a form of liposuction known as tumescent liposuction — a specialised technique which must be carried out by surgeons who have specialist knowledge about the lymphatic system, so that it is not damaged during the procedure.

BUT the treatment is expensive and many local health authorities refuse to fund it, arguing that lipoedema is purely a cosmetic problem for which liposuction is not proven to work. And yet in other countries, including Germany, the treatment is routinely offered to lipoedema patients.

Furthermore, research published last year in the British Journal of Dermatology showed it was

effective; doctors at the University of Luebeck followed up lipoedema patients eight years after they were treated with liposuction, and found that the effects had lasted.

'Liposuction is a permanent solution for lipoedema. Provided all the abnormal fat cells are removed, research shows that it recurs in only 2 per cent of cases,' says Anne Dancy, a plastic surgeon at Spire Park Way Clinic in Birmingham who uses the technique.

But Sharie Fetzter, chair of Lipoedema UK, says women who apply for treatment with liposuction on the NHS face a struggle to get funding. 'These women have usually spent their lives hiding away. Some of them have been told by their doctors, and even their friends and family, that they must be lying about what they eat or the amount of exercise they do.'

'Then, when they eventually get a diagnosis, they are denied the

treatment they need.' It's often wrongly assumed that these women are overeating and lazy, adds Ms Dancy. 'Often they'll get stared at in public and people will make horrible remarks.'

'This is frustrating and upsetting because lipoedema is a recognised medical condition, which causes pain and mobility problems.'

She says the National Institute for Health and Care Excellence (NICE) hasn't looked at liposuction as a treatment for lipoedema because it's not seen as a priority.

'Consequently, some women will even remortgage their homes because they are so desperate to get the fat removed.'

'In most cases, it's the pain and the fear of their immobility getting worse or needing a joint replacement that drives them to this, and not what their legs look like.'

Susan Acton, 64, a retired nursery nurse from Forton, near Lancaster, was diagnosed with lipoedema only three years ago despite having had symptoms since her 20s.

Susan, who is married to Ian, 68, a semi-retired joiner, has been turned down for NHS funding and is now considering travelling to Germany and paying £20,000 for the treatment with retirement savings.

'It's the pain and lack of mobility I find hardest to deal with,' she says. 'I can cover up my big legs with wide trousers and long tops, but the pain is something else. It's becoming unbearable.'

'I really don't want to end up in a wheelchair because my legs have got so big I can't walk.'

LAURA CHILDS has applied for NHS funding for liposuction, but isn't hopeful. She's been to see a private consultant, but has been told she needs four to five liposuction operations at a cost of £32,000. 'I just don't know how we would find the money for this,' she says.

'I feel it's very wrong we're being denied NHS treatment and told it's just cosmetic when lipoedema is a real medical problem.'

'Now my daughter is starting to get the same symptoms as me, and I'm really worried that she will have to face the same battle to get treatment.'

Dr Vaughan Keeley, a consultant at the Royal Derby Hospital who treats the condition, says part of the problem is that while it is an accepted medical condition, lipoedema is not yet officially recognised in the World Health Organisation's International Classification of Diseases.

There is also no good diagnostic test — 'we do sometimes use ultrasound for confirming it, but that's not a proven test as yet'.

Diagnosis is via clinical assessment and sometimes it's not easy to distinguish lipoedema, especially in women who are also overweight, he says. However, one of the key characteristics is an inability to lose weight from the legs even after successfully dieting and losing weight elsewhere in the body.

Other signs include easy bruising (even from just scratching, or patients wake up with bruises not knowing what has caused them) and painful fat.

'But until we get a diagnostic test or set of diagnostic criteria that are universally agreed, it's going to be difficult to persuade a body like NICE to look at this,' adds Dr Keeley.

■ lipoedema.co.uk

Painful problem: Laura Childs

Picture: PAUL WEBB

MISGUIDED MISTAKES

THE 'HEALTHY' things we do that are actually unhealthy. This week: Brushing teeth after breakfast

IT MAY seem the right thing to do, but you could be damaging your teeth. Acids and sugars in food temporarily weaken the protective tooth enamel, so if you clean your teeth too soon after eating, you're actually brushing away the enamel before it hardens again, leaving teeth vulnerable to sensitivity and decay.

'The best routine is to brush your teeth before meals, then freshen

up after eating using an alcohol-free mouthwash,' says Dr Phil Stemmer, a dentist at The Fresh Breath Centre in London. Alternatively, wait for half an hour after eating before brushing, as by then the enamel should have hardened again.

Don't use mouthwash after brushing because this washes away the protective fluoride coating left by the toothpaste, which would add hours of protection.

'I don't even wet my toothbrush, as this can dilute the effect of the toothpaste,' adds Dr Stemmer.



SPECIAL DELIVERY

INNOVATIVE ways to deliver drugs. This week, an ibuprofen inhaler

U.S. RESEARCHERS are working on an ibuprofen inhaler for people with cystic fibrosis (CF), which could also be used more generally for faster pain relief.

CF causes breathing difficulties, as the lungs are permanently clogged with mucus and patients pick up infections easily.

Research shows that high doses of the drug ibuprofen can slow the disease's progression by reducing inflammatory changes in the lung. But it is not routinely prescribed in such high doses, as it can cause stomach bleeding and kidney failure. Inhaling the drug directly into the

lungs would avoid these side-effects, and researchers at Texas A&M University are developing a way to make ibuprofen particles smaller to make them easier to inhale.

With studies in animals ongoing, 'the nanoparticle ibuprofen delivered in a small inhaler like those used in asthma could be available to patients in two to five years,' says lead researcher Carolyn Cannon, an associate professor in the department of microbial pathogenesis and immunology.

Professor Cannon says that her inhaler could also be used for fast pain relief in other conditions, such as osteoarthritis or headaches.

