Hot Topic

Hidden in plain sight: recognising lipoedema in maternity care

Mary Warrilow

ORIGINAL

Lipoedema UK is a well-established charity supporting individuals living with lipoedema, and we are delighted to collaborate with *MIDIRS Midwifery Digest* and the midwifery community with a call to action and a lipoedema awareness campaign aimed at midwifery services.

Lipoedema is a chronic, often under-recognised adipose tissue condition that predominantly affects those assigned female at birth (Child et al 2010), and is frequently misunderstood and misdiagnosed (Lipoedema UK 2021, Faerber et al 2024).

It has been estimated that 10 per cent of women may develop lipoedema (Kruppa et al 2020), with onset occurring at puberty, around the time of pregnancy or menopause. Evidence suggests that lipoedema is poorly recognised and may be misdiagnosed as obesity or lymphoedema, leaving many women struggling to get an accurate diagnosis, treatment and care.

Midwives are uniquely placed to notice early signs of lipoedema, as they build trusted relationships with women during pregnancy, birth and the postnatal period. Pregnancy and the postnatal period can provide an opportunity for midwifery services to recognise the condition, thereby increasing the likelihood of earlier diagnosis and management of the condition.

What is lipoedema?

Lipoedema, also known as lipedema, is characterised by a symmetrical and disproportionate build up of abnormal, excessive adipose tissue that develops on the hips, buttocks, lower limbs and, sometimes, the arms. The waist, in patients who are not pregnant, is relatively slim. Many patients struggle to find clothing that fits and report wearing much larger dress sizes for the lower body, in comparison to the slimmer upper body. The cause of lipoedema is uncertain, but inflammation plays a key role (Kruppa 2023) and it is thought to be hereditary, and associated with periods of hormonal fluctuations, with many women reporting the onset of the condition at puberty, around pregnancy or the menopause, with oestrogen thought to play a major role (Katzer et al 2021).

Symptoms of lipoedema

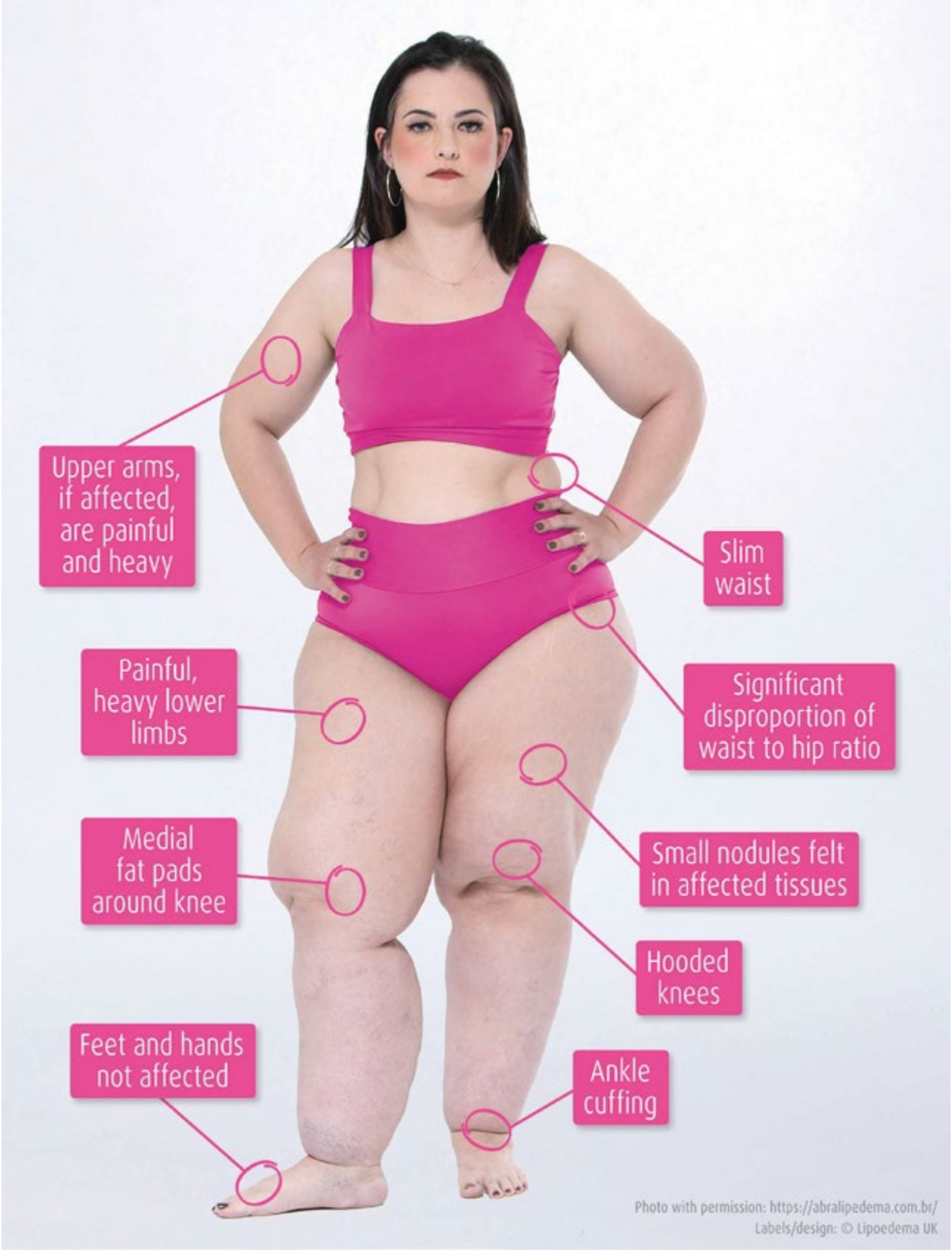
The condition manifests with a myriad of physical, socio-psychological and emotional symptoms that can have a negative impact on quality of life and everyday living for patients, often leading to low self-esteem and social isolation, and potentially resulting in job loss, financial hardship and severe disability in later stages.

Pain and heaviness in the legs/arms are a common symptom, and lipoedema can affect mobility, gait, range of movement and balance, as well as having an impact on joints. A ‘cuffing’ or ‘bracelet’ effect can also often be seen around the ankle and can affect the arms. Another feature sometimes seen in lipoedema is easy bruising without trauma. Many with lipoedema describe their skin as soft and doughy in texture, rather than firm (as in lymphoedema), and spider or varicose veins may be present. Subcutaneous tissues are uneven, with sometimes a ‘mattress’ appearance to the skin. On palpating, small nodules are sometimes felt under the surface of the skin and skin folds over the lower limbs may be present in later stages. A fat pad can often be seen bilaterally over the medial knee. The feet/hands are not affected in lipoedema, a key characteristic to note that aids differential diagnosis.

Lipoedema and obesity can co-exist and secondary lymphoedema may develop with later stages of

the condition. However, the condition is often mistaken and misdiagnosed as obesity, leading to feelings of embarrassment, shame, low self-esteem and frustration of being told, but being unable, to lose the excess and abnormal adipose tissue and weight from the lower body, because of the nature of the condition. The abnormal fat associated with lipoedema is usually resistant to diet modification and exercise.

However, weight management is relevant and adopting a healthy lifestyle is important.



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Waist-to-height ratio (WHtR) rather than BMI will be more accurate when assessing between obesity and lipoedema. In a study in 2025, Melican & Pfeffer found that the WHtR biometric diagnosed 50 per cent fewer individuals with lipoedema as obese than when BMI was used as a biometric.

There are currently no specific diagnostic investigations or tools for identifying lipoedema and clinical diagnosis relies on taking a previous medical history along with a family history, physical examination, and a holistic assessment to gain differential diagnosis (Forner-Cordero et al 2012).

Managing lipoedema in perinatal care

The management of lipoedema generally falls into conservative and surgical options. Self-management is a key aspect of lipoedema care and includes conservative treatments such as good skincare, wearing supportive or compression garments, good nutrition (which involves avoiding processed foods), and looking after general health and wellbeing through exercise and movement.

A surgical approach is through specialist liposuction, which is currently not available to patients via the NHS. Many women are forced to travel to Europe for this treatment, which evidence suggests can improve tissue bulk, pain, function and other symptoms, and other quality of life outcomes (Kirstein et al 2023).

Midwifery services are ideally placed to recognise the condition in women under their care and to give advice on self-management or if undiagnosed make prior to a referral to their GP or specialist services. The aim is to empower women and to act as their advocate by supplying correct information on the condition, and signposting them to Lipoedema UK or referring to other appropriate services. This might include pain management or weight management if coexisting obesity is present.

Simple considerations could be included in perinatal care, such as:

- Undertaking pain scores using a VAS scoring system, which can be helpful in assessing and addressing the pain in areas affected, usually in the lower and upper limbs
- Asking individuals if lipoedema is affecting their arms, in which case having a blood pressure cuff inflated on the upper arm could be excruciatingly painful
- This condition contributes to a distorted body image, low self-esteem and embarrassment for some living with the condition. Having an empathetic approach, whilst building a therapeutic relationship, asking for any preferences such as exposure of limbs, should be part of holistic care. Taking this approach can help reduce the stigma often associated with visible differences
- Advocacy, signposting and referral to their GP and or local lymphoedema/lipoedema services
- Referral to other services such as pain management or psychological/talking therapies can be useful in some cases of lipoedema. Often, living with undiagnosed lipoedema can bring years of not just physical pain but also psychological anguish.

Midwives are often the first professionals to provide long-term, holistic care to women, and they may be able to identify the key characteristics and symptoms of lipoedema during routine perinatal care. It is also important to avoid diagnostic overshadowing, particularly in relation to co-existing conditions such as mental health issues, lymphoedema, obesity and, of course, recognising red flags such as pre-eclampsia or deep vein thrombosis.

By playing a crucial role in identifying this condition earlier, midwives can help ensure that concerns and symptoms are managed following an empathetic and supportive approach. This has the potential to be hugely transformative to the patient experience.

The 2022 Women's Health Strategy highlighted the need for health care professionals (HCPs) to receive better education and training on women's health conditions, to enable the best health and care possible. All HCPs can access the Royal College of General Practitioners (RCGP) eLearning **lipoedema module** (https://elearning.rcgp.org.uk/course/info.php?id=146), which was developed by Lipoedema UK. The charity regularly participates in a range of learning events and membership allows access to a variety of international webinars on the topic. Lipoedema UK has recently updated its health information leaflet *How to distinguish between lipoedema, obesity and lymphoedema* (see pp.330-331). This leaflet is a useful tool for health professionals in differentiating between these conditions and with diagnosing lipoedema. You can find it on the Lipoedema UK website: www.lipoedema.co.uk/lipoedema-uk-research-publications/.

By raising awareness in the midwifery profession, we can help ensure women receive appropriate care, referral and compassionate support. Increased understanding can also reduce the stigma associated with lipoedema, improve physical and maternal wellbeing, and empower women to advocate for their health.

Also, given that more than three-quarters of the 1.3 million members of NHS staff are women, many HCPs are also likely to recognise an undiagnosed condition in their colleagues — or in themselves (Warrilow 2023).

Lipoedema UK is issuing a call to action for better awareness and understanding of the condition within perinatal services, and hopes to continue its collaborative work with the Royal College

of Nurses, Royal College of Midwives, and the MIDIRS community.

Further Resource

Lipoedema UK was delighted to collaborate with the Royal Society of Medicine as part of the *Medicine and me* programme to raise further awareness of Lipoedema. This major joint initiative brought together patient voices and clinical experts to produce an informative and educational webinar for anyone wishing to learn more about Lipoedema: https://youtu.be/B8JSuAFkxu8

Lipoedema UK is also supporting a new international research study, led by SWPS University in Poland and Jönköping University in Sweden, to understand the physical, emotional and social experiences of women with lipoedema before, during and after pregnancy. Further information and the survey link is on Lipoedema UK's website: https://lipoedema.co.uk/take-part-in-a-new-international-research-study-on-lipedema-and-pregnancy/.

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Permission statement

Permission gained from https://abralipedema.com.br and Lipoedema UK to share the image within this article. Also, permission gained from Lipoedema UK for sharing the 'How to distinguish between lipoedema, obesity and lymphoedema' leaflet.

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AWARENESS, DIAGNOSIS, TREATMENT & RESEARCH

How to distinguish between:

a) **lipoedema**
b) **obesity**
c) **lymphoedema**

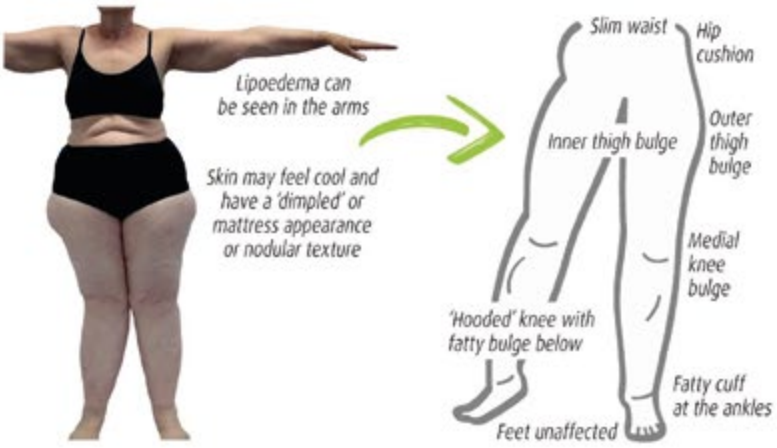
Differential diagnosis is vital in lipoedema

- **Lipoedema is an adipose tissue disorder mainly affecting females and characterised by abnormal, symmetrical fat deposition affecting the arms, legs, hips and buttocks.**
- Hormonal and genetic factors are linked to lipoedema.[1] It often presents around puberty, pregnancy or menopause.
- Lipoedema can have a severe impact on quality of life (QoL) and physical and psychosocial well-being.[2]
- Left untreated, the condition can be debilitating and is a massive cost burden to the NHS, as well as other public services.
- Early diagnosis and treatment are vital for lipoedema patients. Yet service provision is varied and often non-existent.

There is no diagnostic tool for lipoedema and identifying the condition relies on key clinical indicators based on history taking, clinical assessment, examination and differential diagnosis.

Because lipoedema can appear alongside obesity, clinicians may not always distinguish between the two. But lipoedema is NOT the same as obesity.

Women with lipoedema are often incorrectly diagnosed and treated as obese by their primary healthcare professionals



DIFFERENTIATING LIPOEDEMA FROM LYMPHOEDEMA & OBESITY

CHARACTERISTIC	LIPOEDEMA	LYMPHOEDEMA	OBESITY
Gender	• Almost exclusively female	• Male or female	• Male or female
Age at onset	• Most commonly presents at puberty, pregnancy or menopause – times of hormonal change	• Childhood (mainly primary); adult (primary or secondary)	• Childhood onwards
Family history	• Common	• Only for primary lymphoedema	• Very common
Areas affected	• Bilateral • Usually symmetrical • Most frequently affects legs, hips and buttocks; may affect arms • Slim waist and disproportionately larger body size below waist • Feet/hands spared	• Can affect any area of the body • Can be bilateral but usually unilateral limbs affected • Feet usually affected in lower limb lymphoedema	• All parts of the body • Usually symmetrical
Psychological impact	• High psychological burden • Can lead to low self-esteem, eating disorders, anxiety, depression	• High psychological burden – reminder of disease in some cases – leading to anxiety and depression	• High psychological burden
Effect of dieting on condition	• Lipoedema fat unresponsive to dietary intervention	• Proportionate loss from trunk and affected limbs	• Weight reduction with uniform weight loss
Effect of limb elevation	• No effect	• Initially effective in reducing swelling; may become less effective as disease progresses	• No effect
Pitting oedema	• Absent in early stages of the disease	• Usually present but pitting may cease as the disease progresses and tissues fibrose	• No
Bruises easily	• Yes	• Not usually	• No
Pain/discomfort in affected areas	• Often • May be hypersensitive to touch and pressure	• May be uncomfortable • No hypersensitivity to touch	• No
Skin consistency	• Normal or softer/looser	• Thickened and firmer	• Normal
History of cellulitis	• Unusual	• Often	• Unusual
Stemmer sign*	• Usually negative	• Usually positive	• Usually negative

Table based on *Best Practice Guidelines: The Management of Lipoedema*. London: Wounds UK, 2017. Photo © Lipoedema UK 2022. Illustration © Lucinda Evans & Lipoedema UK. All rights reserved

*A positive Stemmer sign represents failure to pinch a fold of skin at base of second toe – this will be negative in a patient with lipoedema. A positive stemmer may be seen in associated secondary lymphoedema

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Signs and symptoms

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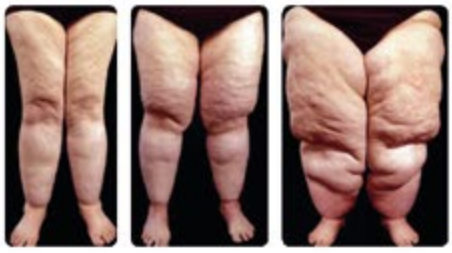
There are different types and stages of lipoedema



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4 STAGES OF LIPOEDEMA

1. Skin appears smooth. On palpation, the thickened subcutaneous tissue may contain small nodules.
2. Skin has an irregular texture that resembles the skin of an orange ('peau d'orange') or a mattress. Subcutaneous nodules occur that vary from the size of a walnut to that of an apple in size.
3. The indurations are larger and more prominent than in Stage 2. Deformed lobular fat deposits form, especially around thighs and knees, and may cause considerable distortion of limb profile.
4. Lipoedema with secondary lymphoedema

KEY CHARACTERISTICS

Individual patients may present with all or some of these signs and symptoms

- Onset of symptoms is usually during puberty, during/after pregnancy or menopause.
- Symmetrical presentation involving both legs. Significant disproportion of hip-to-waist ratio.
- Arms may be affected.
- **Early stages:** the upper body may remain slender as the lower body enlarges and fat accumulates in the hips, thighs and legs.
- **Later stages:** mobility is restricted and the condition becomes more with joint problems and skin changes that can be seen. A secondary lymphoedema may also develop. Can lead to disability and poor QoL.
- Feet and hands are generally unaffected with a 'cuffing' or 'bracelet' effect seen to the ankles or wrists.
- Likely psychological distress, low self-esteem, anxiety and depression.
- Fatigue and pain/heaviness in tissues, may have hypersensitivity to touch. Easily bruised.
- Weight-loss diets have little/no effect on lipoedemic fat.
- Fat pads above, inside and below knees and in outer regions of upper thighs.
- Gait can be affected, and patients may have fallen arches.
- Skin may feel cool and have a 'dimpled' or mattress appearance or nodular texture.

TYPES OF LIPOEDEMA

TYPE I	Pelvis, buttocks and hips (saddle bag phenomenon)
TYPE II	Buttocks to knees, with formation of folds of fat around the inner side of the knees
TYPE III	Buttocks to ankles
TYPE IV	Arms
TYPE V	Lower legs
	DESCRIPTION ACCORDING TO THE SHAPE OF TISSUE ENLARGEMENT
COLUMNAR	Enlargement of the lower limbs which become column-shaped or cylindrical
LOBAR	Presence of large bulges or lobes of fat overlying enlarged lower extremities, hips or upper arms

Table based on *Best Practice Guidelines: The Management of Lipoedema*. London: Wounds UK, 2017

Information for clinicians

Early diagnosis and treatment are vital

Despite lipoedema first being described in 1940, until recently there has been poor awareness of the condition in the medical community. As a result, lipoedema has been widely misunderstood and misdiagnosed, with many people waiting 30–40 years to receive a diagnosis. Most patients report the onset of symptoms in their teens, while their body is still slender. In the later stages, the social isolation, pain and lack of mobility associated with lipoedema may be complicated by obesity.

For patients with coexisting obesity, weight-loss drugs such as GLP-1 receptor agonists may offer benefits. The MHRA has advised healthcare professionals to remind patients undergoing procedures requiring an anaesthesia or deep sedation, such as non-cosmetic liposuction, to inform their healthcare providers if they are on GLP-1 or dual GIP/GLP-1 receptor agonists. Currently, NICE recommends that non-cosmetic liposuction should only be used in the UK in the context of research, but in July 2025, the German Joint Federal Committee for Healthcare Services (G-BA) recommended that liposuction for lipoedema should be funded by the health insurance system in Germany, recognising the clear benefits of surgery in the treatment of lipoedema.

FURTHER INFORMATION:

Lipoedema UK

Visit: lipoedema.co.uk

... to find more information for health professionals & patients

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