

## Information on Lipoedema for Health Care Professionals

### What is lipoedema?




Lipoedema is a type of fat and connective tissue swelling that predominately affects women, usually triggered around puberty and influenced by hormonal change. Aetiology is unclear, although there is growing evidence of genetic and epigenetic factors (Grigoriadis et al. 2021).

### Pathophysiology of lipoedema

The characteristic pattern of fat deposition in lipoedema leads to distinct changes in body shape (Wounds UK, 2017). Adipocyte hypertrophy and/or hyperplasia, low grade inflammatory processes and tissue hypoxia contribute to lipoedema signs and symptoms (Bertsch and Erbacher, 2020). People with lipoedema who experience progressive generalised weight gain may be more likely to develop secondary lymphoedema (Bertsch and Erbacher, 2020).

### Stages of lipoedema

There are various classification systems. Lipoedema is not necessarily progressive but can change over time.

<b>Table 1: A guide to typical lipoedema staging (this can vary)</b>		
<b>Mild: Stage 1</b>	<b>Moderate: Stage 2/3</b>	<b>Severe: Stage 3/4</b>
		
<p><b>'Mild' lipoedema:</b></p> <ul style="list-style-type: none"> <li>• Fat deposition with disproportion between upper and lower body.</li> <li>• Ankle shape is often lost, but feet are spared.</li> <li>• Tissues may be sensitive to pressure.</li> <li>• Bruising or varicosity may be evident.</li> </ul>	<p><b>'Moderate' lipoedema:</b></p> <ul style="list-style-type: none"> <li>• Fat lobes are more obvious at the knees and may influence gait.</li> <li>• Arms and abdomen may be affected.</li> <li>• Lipomas may be palpated in the adipose tissues.</li> <li>• Chronic pain may develop.</li> <li>• Problems with hip and/or knee joints.</li> </ul>	<p><b>'Severe' lipoedema:</b></p> <ul style="list-style-type: none"> <li>• Increased weight gain has complicated the lipoedema.</li> <li>• Secondary lymphoedema may be present.</li> <li>• Chronic pain may be more problematic.</li> <li>• Changes to walking gait.</li> </ul>

## Consider lipoedema diagnosis

This is based on history and clinical examination as currently there are no diagnostic tests or biomarkers for lipoedema.

<b>Table 2: Does the person have any of the following that may indicate lipoedema?</b>	<b>✓</b>
Changes in body shape due to fat deposition, with lack of ankle shape (ankle 'cuffing') and/or fat lobes or bulges at the knees	
Bilateral, symmetrical enlargement of legs, buttocks ('shelving'), hips and/or arms; feet may not be affected	
Disproportion between upper and lower body, with limited success from dieting	
Pain or tenderness particularly when pressure is applied to the enlarged area	
Tendency to bruising or varicosities	
Tissues feel soft and may be cold to the touch	
Secondary weight gain may show as more generalized increase in fat tissue that is also evident in the upper body, neck and face	
Secondary lymphoedema may show as more persistent swelling of the lower limbs and/or buttocks with fibrotic changes and tendency to cellulitis.	

### Differential diagnosis:

- General obesity which is more evenly distributed without body disproportion
- Lymphoedema which may have an obvious primary or secondary cause, although lipoedema can also lead to secondary lymphoedema
- Oedema related to cardiac, renal, hepatic causes
- Pre-menstrual oedema; drug-induced swelling
- Madelung's disease
- Lipodystrophy/ lipohypertrophy.

**Exclude/red flags:** Deep venous thrombosis; cellulitis.

### References

Bertsch, T., Erbacher, G. (2020) *Lipoedema: a paradigm shift and consensus*. Journal of Wound Care. Consensus Document, Vol. 29 Sup 2. (11) p. 1-53

Grigoriadis, D et al (2021) *[Preprint] Investigation of clinical characteristics and genome associations in the 'UK Lipoedema' cohort* (p. 2021.06.15.21258988).

<https://doi.org/10.1101/2021.06.15.21258988>

Wounds UK (2017) *Best practice guidelines. The management of lipoedema*. Wounds UK, London.

## **Taking a history from someone with lipoedema**

- Age of onset
- Possible triggers including hormonal or weight changes
- Type and duration of symptoms including pain
- Co-morbidities and medications that may influence/cause oedema
- Family history
- Impact on personal, home and work life
- Psychological vulnerability or mental health challenges (depression, disordered eating, anxiety, isolation)
- Effect of dietary restrictions or physical activity
- Their understanding of the condition, and expectations.

## **Observe**

- Symmetrical pattern of fat distribution
- Body shape and disproportion (upper body out of proportion with lower)
- Overpronation of feet, and associated problems
- Mobility and gait influenced by shape change and fat lobes at the knees.

## **Examination/palpation of tissues**

- Characteristic shape changes with enlarged lower body, loss of ankle shape, sparing of feet
- Fat lobes at knees
- Extent of lipoedema may include abdomen, hips, arms
- Tissues may feel very soft; or cold
- Lipomas may be palpated in the adipose tissue
- Signs of varicosity
- Easy bruising
- Pain or hypersensitivity on pressure
- Negative Stemmer's sign (unless complicated by lymphoedema)
- Signs of lymphoedema including pitting or non-pitting tissues
- Signs of secondary weight gain
- Signs of knee or hip joints problems; possible hypermobility.

## Plan of care and support

Diagnosis by the general health care professional; consider exacerbating factors or medications (calcium channel blocking agents that exacerbate lymphoedema); avoid diuretics

Provide information from Talk Lipoedema

Referral to NHS lymphoedema clinic for advice on self-management and measurement for compression therapy

Consider additional investigations to exclude other conditions (see below)

Consider additional support/discuss with patient if relevant:

- Referral to local NHS weight management services
- Referral to physical activity support
- Referral to physiotherapy, podiatry, occupational therapy
- Referral to psychology or mental health services

Some patients may be considering surgery for lipoedema, as this is commonly discussed in the media. There is limited research into the long-term outcomes of surgery although improvements in pain, mobility and quality of life have been evidenced. Previously, referral to Mr Alex Munnoch at NHS Tayside has been possible in Scotland.

## Possible investigations/measurements to consider

To consider	Comment
Weight, height, BMI and waist to hip ratio	BMI has limited value and waist-to-hip ratio may be more useful; waist-to-height may also provide an indication of the distribution of body fat.
Circumferential measurements of limb/s and limb volume	Mainly required if compression is being ordered or treatment outcome measured
Blood tests	U & Es, full blood count, thyroid function, liver function, brain natriuretic peptide to exclude cardiac function, C-reactive protein may be useful only in acute inflammation
Lymphoscintigraphy	May provide indication of extent of lymphatic insufficiency but unlikely to influence treatment plan
Ultrasound	Helps indicate dermal thickness to differentiate lymphoedema and lipoedema
MRI	May provide differential diagnosis but not routinely required
Venous duplex scanning	May be indicated to exclude venous insufficiency
Ankle brachial pressure index (ABPI)	May be required if the person is to have compression therapy.

## Information for People with Lipoedema

### What is lipoedema?

Lipoedema is a condition of the fat and connective tissue. It mainly affects women, and often develops around puberty or times of hormonal change.

Some possible signs of lipoedema:

- Fat tissue changes affecting the legs, buttocks, hip, tummy (abdomen) and/or upper arms
- Fat 'bulges' developing around the knees or at the hips for example
- Body may look out of proportion; the upper body is smaller than the lower body
- Waistline may be narrow in comparison to hips
- Feet and hands may not be affected
- The area may bruise easily, with broken blood vessels, and/or varicose veins.

What might lipoedema feel like?

- The skin and tissues can feel very soft and may be cold to touch
- Some people feel small lumps (called lipomas) in the enlarged tissues
- There may be pain in the affected areas, especially when pressure is applied
- The legs (and arms) may feel heavy, tired, and aching.

### What help is available if I have lipoedema?

Once you have a diagnosis of lipoedema you may have mixed feelings. You now know there is a medical reason for symptoms that may have affected your life. It can be difficult to hear that there is no quick fix.

You may be referred to an NHS Lymphoedema clinic where they can provide further information and measure you for compression garments such as stockings or tights that help improve symptoms.

Talk to your doctor about other available support that may be relevant to you such as physiotherapy, weight management services, or mental health support.

### About Talk Lipoedema

Talk Lipoedema was set up in 2013 by people with lipoedema. We provide friendly online peer support, also run regular local roadshows, and offer a self-management support programme called 'Living Well with Lipoedema'.

For more information please do not hesitate to contact us.

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