

**Lipoedema is a chronic disorder of disproportionate increase in adipose tissue (fat cells) in the legs and occasionally in the arms, almost exclusively affecting women. It was first described by Allen & Hines in 1940 as a 'symmetrical accumulation of fat in the subcutaneous tissue'. In recognition that there is no 'oedema' in lipoedema, there is an ongoing discussion on what may be a more appropriate term. Lipalgia or lipalgia syndrome have been suggested to reflect that those with the condition often experience pain. However, there is no consensus as yet.**

## Awareness

There is limited awareness and poor understanding of the condition amongst health care professionals resulting in:

- lack of recognition,
- misdiagnosis - it is often confused with obesity and lymphoedema,
- inconsistent & inappropriate care,
- lack of research,
- negative attitudes and lack of support for those with the condition.

In 2020, an international document on lipoedema and its management was published (Bersch & Erbacher 2020) with the aim of challenging unsubstantiated facts (myths) and to encourage debate, which would enhance understanding of this distressing condition. BLS acknowledge the work involved in this first effort to create a consensus among stakeholders. Indeed, the topic was debated at the 2020 BLS conference. As in any year, concurrent research and practice reviews continue to be published, and these have been reviewed alongside the 2020 international document by an independent BLS subcommittee. This fact sheet reflects our weighing of the evidence and current best understanding in this developing field. For further up to date evidence about lipoedema please refer to: [www.lipedema.org/](http://www.lipedema.org/)

## Diagnosis

Lipoedema may be recognised within primary care however diagnosing lipoedema is usually the result of a clinical assessment by an experienced lymphoedema practitioner or consultant. There are currently no diagnostic tests for lipoedema and the main reason for investigations will be to exclude/identify contributing or exacerbating features – especially if weight gain and lethargy are present. Although hormonal factors are thought to contribute to the disease, there is no evidence that endocrinological/

hormone tests will detect any abnormalities. However, multiple research studies are ongoing and may provide further robust evidence in the future.

## Clinical features of lipoedema

**Body shape:** assessment of 'weight' needs to be a combination of BMI, history of weight increase over years (where applicable) and waist-to-hip ratio (WHR), in order to exclude central obesity as a cause of a high BMI. A WHR value of  $\geq 0.85$  cm is suggestive of obesity in women (World Health Organization, 2011) therefore a value of  $< 0.75$  suggests disproportionate fat deposition below the waist which supports a diagnosis of lipoedema. Waist to height measurement is also used to clarify abdominal obesity.

It is the 'disproportionate' aspect of the condition that is a key factor in assessment. There is symmetrical and pronounced increase of non-pitting subcutaneous fatty tissue, usually on the legs, hips and buttocks. Feet/hands are usually unaffected leading to a 'bracelet' effect at the ankle/wrist. There tends to be shape disproportion, particularly apparent in those with a normal sized torso, the torso appearing small in comparison to the lower half of the body (hip/waist ratio is high). However, this can be masked if obesity coexists.

**Pain** – most suffer tenderness in the tissues, thought to be a consequence of low-grade inflammatory processes and hypoxia within the adipose tissue. Others report limb pain and heaviness with some reporting significant knee pain, likely due to joint alignment changes.

**Altered skin appearance:** The affected areas may appear cooler than unaffected areas, and the skin may have a floppy, dimpled appearance referred to as 'mattressing'.

**Bruising** – Although clinical experience suggests that some people with lipoedema do bruise easily, there is no known physiological explanation for this as yet.

**Impaired mobility** – Performing activities of daily living can prove troublesome as a result of pain in the tissues. Where there are joint problems, the effect can be amplified if superimposed with obesity.

## References

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## Differences between lipoedema & lymphoedema

Lipoedema can sometimes be confused with lymphoedema, which is accumulation of fluid in the tissues. There are however differences between the two conditions as outlined in the table below. Lipoedema may often be complicated by obesity or lymphoedema and therefore it is imperative that historical symptoms are considered together with examination of findings.

Characteristics	Lipoedema	Lymphoedema
<b>Distribution</b>	Symmetrical increase in size due to fat deposition, usually affecting the lower limbs, hips and buttocks.	Swelling affects one or both limbs which may be asymmetrical.
<b>Shape</b>	Body shape disproportion – normal sized torso with large hips/legs.	There may be shape distortion within the affected limb.
<b>Feet /hands</b>	Never affected.	Frequently affected.
<b>Stemmer Sign</b>	Negative.	Generally positive.
<b>Pitting of tissues</b>	No.	Yes, in early stages, but less obvious in later stages.
<b>Skin and tissues</b>	Skin in affected areas is usually soft with loose, floppy connective tissues. There is no skin thickening.	Skin and subcutaneous tissues in affected areas are often thickened and fibrous.
<b>Pain</b>	Tissues are painful to palpation.	Tissues are generally not painful.
<b>Risk of cellulitis</b>	No greater than normal.	Increased risk in affected areas.
<b>Who may be affected</b>	Females, correlation (not causal) with hormonal changes such as puberty, pregnancy, menopause. (Extremely rare cases reported in men).	Males and females.
<b>Response to weight loss</b>	If there is obesity, i.e. fatty tissue distributed more generally, weight loss is beneficial.	Achieving and maintaining a healthy body weight usually has a beneficial effect on the swelling.

- A study by Fetzer and Fetzer (2016) surveyed women on the lived experience of lipoedema (n=250).
- 95% reported difficulty in buying clothes,
- 86% reported low self-esteem,
- 60% reported restricted social life,
- 60% reported feelings of hopelessness,
- 50% reported restricted sex life,
- 47% reported feelings of self-blame,
- 45% reported eating disorders.

### Principles of lipoedema management

- As with all chronic, long term conditions, the management of lipoedema requires a holistic, multi-disciplinary team approach which should include individualised care plans according to need and person-centred treatment goals.
- This approach should include:
  - management of symptoms including pain, impaired mobility and psychosocial issues.
  - facilitating, encouraging, and enhancing the person's ability to self-care. This will include education, and a healthy lifestyle such as appropriate activity, exercise and weight management.

### Components of lipoedema management

Obesity appears to complicate the clinical picture for many women with lipoedema (and weight gain may be implicated in progression of lipoedema), so it is important to address this. The psychological impact of the condition must also not be underestimated.

The following components of care need to be tailored to the individual's need – taking into account the severity of symptoms, the degree and complexity of tissue enlargement and whether there is a secondary lymphoedema.

Management components should include:

- **education** – advice and a person-centred approach to foster confidence and ability to take control of their own condition.
- **psychosocial support** and the management of expectations.
- **weight management** including healthy eating.
- **exercise and ways** to maintain physical activity which avoid joint pain or harm (swimming is particularly beneficial).
- **compression therapy** – patients report that their main reasons for wearing compression garments were to feel supported, reduce pain and improve mobility. Compression therapy for lower limbs will not decrease excess adipose tissue, but may have an anti-inflammatory and oxygenating effect on the tissues that can reduce associated pain. Compression may be compressive sportswear, Lycra-style leggings or healthcare provided garments.

- **skin care** and protection.

- **liposuction** – NICE reviewed liposuction for chronic lipoedema in March 2022, the recommendations were:

- 1) Evidence on the safety of liposuction for chronic lipoedema is inadequate, therefore this procedure should only be used in the context of research.
- 2) Further research should report patient selection, details of the procedures and technique, long term outcomes, and patient reported outcomes including quality of life.

If a person with lipoedema is considering liposuction overseas, it is recommended that the following steps are considered:

- 1) Read the NICE Guidance (NICE, 2022) to ensure the reasons why liposuction is currently not available in the UK unless part of a research study for lipoedema is understood.
- 2) Research the surgeon/surgical team.
- 3) Look at **Lipoedema UK** website [www.lipoedema.co.uk/](http://www.lipoedema.co.uk/)
- 4) Consider the practicalities of the decision with regard to travel post surgery, and the risk of complications such as DVT or wound healing.
- 5) Consider what follow-up care your patient may require and how they will access this.

- **Manual Lymphatic Drainage**, there is no evidence to support a benefit of manual lymphatic drainage for limb size reduction in lipoedema, however pain and discomfort may be helped by complementary therapies e.g. massage or acupuncture.

## Key points of current understanding:

1. There is no oedema (excess extravascular fluid) in early stage lipoedema. There is some evidence for oedema developing in later stages when there may be coexistence of other oedema-forming pathology, such as lymphoedema, chronic venous insufficiency or obesity.
2. Weight gain in those genetically predisposed to lipoedema may be the trigger for worsening symptoms.
3. Weight loss for coexisting obesity is important and improves the symptoms of lipoedema. For those people without obesity, maintaining a healthy body weight is equally important.
4. Lipoedema is not progressive for everyone. Early identification and advice on self-management including healthy eating and exercise can reduce the risk of the additional burden of obesity. Nor does lipoedema need to lead to obesity.
5. Lipoedema does not seem to cause lymphoedema. Where this co-exists, consider whether obesity is causing the lymphoedema and address this where possible.

## Summary

Lipoedema is a chronic condition of disproportionate adipose tissue mostly affecting the lower limbs and mostly in women. Self-reported evidence shows that people living with lipoedema can feel ignored and rejected by healthcare services as their condition is often misdiagnosed as obesity or lymphoedema. Challenges relating to lipoedema treatment and support in the UK include: poor awareness of the condition amongst health professionals, lack of diagnostic tools and limited access to services. Mental health issues such as depression, anxiety or psychological distress are common and may compromise the ability to self-manage. A multidisciplinary approach is recommended, focussing on facilitation and enhancement of the individual's ability to self-care and management of symptoms.

## Contributing literature

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## About Lymph Facts

Lymph Facts are a series of documents produced, reviewed, and monitored by BLS members. Please feel free to use these to support your education/patient care and awareness raising activities.

Every effort is made to ensure the content is accurate, up-to-date, and appropriately referenced and any feedback is gratefully received. Please see the website for the full range of Lymph Facts available.

## About the British Lymphology Society (BLS)

The BLS actively promotes professional standards and the study, understanding, and treatment of lymphoedema/chronic oedema.

The BLS seeks to achieve high standards of care and equitable access to treatment across the UK, raise awareness of the condition, and promote early detection and intervention with supported self-management. BLS works with other stakeholders, and advises government, NHS and other professional bodies and organisations to effect change and influence practice.

See [www.thebls.com](http://www.thebls.com) for helpful resources and the benefits of membership.

## Lipoedema UK

Lipoedema UK is a national charity supporting patients with lipoedema and informing health care professionals.

Goals of the charity include to:

- raise awareness of the disease within the medical profession throughout the UK
- achieve early diagnosis so women get the help and treatment they require
- encourage new research into treatments, which ultimately find a cure.

They have been pivotal in improving the awareness of the condition – not least through an e-Learning module for GPs and HCPs through the Royal College of General Practitioners

<http://elearning.rcgp.org.uk/course/search.php?search=lipoedema>

See <http://www.lipoedema.co.uk/> for more information.

British Lymphology Society trustees and members of the Scientific Committee have contributed to the development of this Lymph Fact Sheet.

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## Best Practice, Leadership, Support

For more information see [www.thebls.com](http://www.thebls.com) admin@thebls.com



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The British Lymphology Society

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