

Pathophysiology

Lipoedema appears to be an autosomal dominant condition with no known cure.^{5,8} The ever-growing body of global research now describes a biomarker⁹ and numerous genetic variances^{10,11} involved with lipoedema; however, there is more to discover, and we have yet to see findings translated into clinical testing at a general population level.

Hormones appear to play a major role, as symptoms often onset during significant hormone fluctuations, such as puberty (most commonly), hormonal contraception, IVF treatment, pregnancy, perimenopause, menopause, post-menopause, emotional and/or physical trauma, and insulin resistance.^{5,12}

In lipoedema, vascular and lymphatic challenges are common.^{5,8} This can lead to excessive interstitial fluid and extracellular matrix remodelling resulting in inflammation, metabolic dysregulation, and growth of diseased fatty tissue.^{4,5,8} Early degenerative articular disease and obesity are also common comorbidities.^{4,5,8,13} Other comorbidities include anaemia, lymphoedema, hypothyroidism, PCOS, hypermobility, and Ehlers-Danlos syndrome.^{14,16}



Lipoedema Australia is a patient-led charity with a board-appointed healthcare professional advisory board. We advocate for lipoedema awareness and research, provide educational tools, resources, and support for the general public and health professionals.

We aim to improve awareness of lipoedema as a distinct disease entity to reduce misdiagnosis as general obesity or lymphoedema and improve access to treatment plans for this chronic disease.



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Please refer to Praxhub and NLPR (National Lymphoedema Practitioner Register*) for further training and information.

Lipoedema LIE-poh-dee-muh

First detailed in 1940^{1a} by the Mayo Clinic, USA, lipoedema was recognised as a disease by the WHO in 2017 and listed in 2019 on the ICD 11th edition.² Lipoedema is a loose connective tissue disorder resulting in excessive diseased adipose tissue growth, predominantly affecting women.^{3,4,5}

Lipoedema often goes undiagnosed until the latter stages, when mobility and psycho-social wellbeing are compromised and the risk of comorbidities increases.^{5,6,16}

Reference list can be found here:



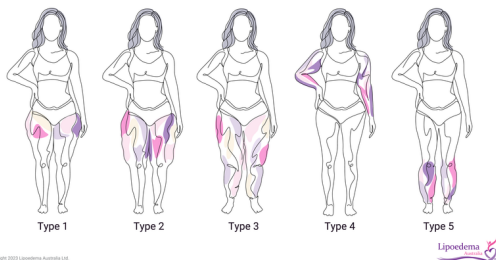
LIPOEDEMA

A Guide for Health Professionals

Recognising Lipoedema

Lipoedema can be present in any combination of the following types:

Types of lipoedema



Women with lipoedema can experience combinations of the following symptoms:

- Symmetrical, disproportionate accumulation of fatty tissue (See graphic above)
- Texture of fatty tissue may feel granular and/or fibrotic
- Cuffs or bulges may develop around joints (e.g. ankles, knees, elbows, wrists). Feet remain unaffected unless lymphoedema is a comorbidity
- The waist may be small in proportion to thighs, buttocks, and legs
- Legs are often hypersensitive to touch and pressure and may feel cold
- Affected areas may bruise easily with minimal trauma
- Patients describe affected areas as sore, painful, heavy, swollen and tired
- Symptoms can worsen in hot weather, during or after exercise, standing or sitting for long periods
- Fat pads, which can be tender or painful, accumulate on the upper outer thighs, inner thighs, and around the knee area, can cause abnormal gait, and contribute to joint pain
- Filling of the retromalleolar sulcus
- Hypermobility
- Soft, thin skin with loss of elasticity. Skin can have a lumpy appearance.
- Non-pitting oedema and negative Stemmer's sign on feet and hands in the absence of coexisting lymphoedema
- Difficulty losing weight from affected areas despite exercise, modified diet or bariatric surgery. If well-directed, these measures may help reduce inflammation and co-existing obesity if present
- Abnormal nerve sensations
- Pain on blood pressure check (larger cuff may be required)
- Relatives with similar body shape or fat distribution

Adapted from 1, 4, 5, 6, 7, 8, 9, 12, 13,14[1], 16, 18

Later Stages

Lymphatic insufficiency is often observed, leading to oedema in feet and/or hands. There is a significant risk of cellulitis if secondary lymphoedema is present. Mobility is severely impacted and can lead to forced early retirement. There is also a high incidence of chronic comorbidities. ^{15,16,17}



Diagnosis & Treatments

A shift of focus from weight to health is recommended. The waist-to-height ratio biometric is recommended to replace BMI for lipoedema patients. ¹⁹

Early diagnosis and treatment are paramount in slowing progression and improving patient outcomes.^{5,16} Conservative treatment can include compression therapy, manual lymphatic drainage, exercise prescription and nutritional support.⁵ Surgical intervention may be an option by an appropriately qualified surgeon after conservative treatment has been undertaken.⁵ Lipoedema specific surgical treatment is currently not covered by Medicare.



Triaging & Referring for Specialist Care

A lymphoedema therapist experienced in managing lipoedema (via the NLPR) is recommended for all lipoedema patients.

- Thyroid, menstrual or other hormonal issues - **endocrinologist**
- Venous disease/varicosities or spider veins - **vascular specialist** and **physiotherapist, lymphoedema therapist**
- Joint or limb pain - **physiotherapist, rheumatologist, clinical nutritionist, dietitian**
- Mobility issues - **physiotherapist, exercise physiologist, clinical nutritionist, dietitian**
- Heaviness or pain in legs - **vascular specialist, lymphoedema therapist, clinical nutritionist/dietician**
- Excess weight at waist - **clinical nutritionist, dietician, endocrinologist, exercise physiologist**
- Foot issues - **podiatrist**
- Psychological distress/anxiety/depression - **psychologist, counsellor**
- Patient has tried everything, and symptoms still significantly impact QOL- **surgeon**

Note: Cellulitis, caused by secondary lymphoedema, requires urgent medical treatment and administration of antibiotics.¹⁷