

## Patient information

# Lipoedema: information and advice

## What is lipoedema?

Lipoedema is a chronic medical condition characterised by a symmetric build up (both sides of the body) of adipose (fatty) tissue in the legs and arms. A common but under-recognised disorder, lipoedema may cause pain, swelling and easy bruising. It also may be accompanied by unusual texture that can feel like rice, peas or walnuts beneath the surface of the skin.

The intensity of pain may range from none to severe and its frequency may be constant, come and go, or only occur when the tissue is pressed on. Limited public awareness of lipoedema, coupled with few research-backed treatments, can lead to exacerbation of symptoms as well as physical and emotional distress. Common symptoms include fatigue, muscle pain or easy bruising.

## What causes lipoedema

The causes of lipoedema are not well understood. It is reported to start or worsen during puberty and other periods of hormonal changes, such as pregnancy and menopause. Research is underway to determine the biological role of hormones, genetics, inflammation and metabolism in the condition's development.

## Who gets lipoedema?

Lipoedema mainly occurs in women but a small percentage of men have been known to have the condition.

## Diagnosis

Many people with lipoedema find it difficult and embarrassing to discuss their symptoms with their doctor, but as lipoedema is often a progressive condition it is

important to obtain an early diagnosis and reduce the risk of symptoms getting any worse.

Symptoms are often mis-diagnosed for lymphoedema or obesity and if left undiagnosed lipoedema can develop into lipo-lymphoedema.

A number of factors are taken into consideration when making a diagnosis of lipoedema:

- Disproportionately larger/fatter legs and hips compared to the upper body
- Swelling is symmetrical (both sides of the body are affected equally)
- Hands and feet are not affected
- Loose, floppy connective tissues around the knee joints
- Tissue that looks like cellulite and feels soft
- Tenderness/pain and easy or spontaneous bruising to affected areas
- Skin of affected areas may be pale and cold
- Upper arms may also be disproportionately bigger
- Patients may report increased swelling in hot weather

## **Lipoedema treatments**

Patients with lipoedema are normally seen by a local lymphoedema service which will clinically assess and provide appropriate treatment. These can include:

- Compression therapy
- Simple lymphatic drainage (massage)
- Daily skin care
- Exercise and movement
- Attendance to a self-management workshop
- Regular reviews and support

The only treatment that appears to be effective in reducing the build-up of adipose tissue associated with lipoedema is a procedure called tumescent liposuction.

The procedure can be effective and have good results but several operations may be needed to remove the adipose tissue from different parts of your body. Increased adipose tissue in the legs may return after having the procedure if you gain weight.

It's difficult to get NHS funding for liposuction to treat lipoedema, but your GP can try to apply for funding through your local Clinical Commissioning Group.

## **Guidance and support**

Dealing with lipoedema can be a lonely and confusing journey.

Compliance with the above treatment methods can help to reduce the symptoms and help you self-manage the condition. Patients are encouraged to:

- Improve lymphatic flow by being active
- Reduce inflammation
- Manage pain
- Get emotional support

## **Quality of life**

Alongside the physical pain symptoms, lipoedema can impact an individual's mental health and quality of life, leading to lack of energy, feelings of hopelessness, low self-esteem or eating disorders. Affected individuals are encouraged to speak with their healthcare provider about their mental health. Support groups where patients can share their experiences may also be found through social media. To find these groups search **lipedema** or **lipoedema**

## **Nutrition**

Although the adipose tissue caused by lipoedema cannot be lost by just reducing calories and exercising, being overweight and sedentary can have a negative impact on your condition.

Eating a well-balanced diet, including five-a-day fruit and vegetables, and participating in regular low impact exercise, can reduce the risk of the condition worsening and even help to reduce the symptoms.

## Useful information and websites

### Lipoedema UK

<https://www.lipoedema.co.uk/>

[Info@lipoedema.co.uk](mailto:Info@lipoedema.co.uk)

### Lymphoedema Support Network (LSN)

St Luke's Crypt, Sydney Street, London, SW3 6NH

020 7351 0990

[www.lymphoedema.org](http://www.lymphoedema.org)

### NHS website

<https://www.nhs.uk/conditions/lipoedema/>

### Lipedema Foundation

[www.lipedema.org](http://www.lipedema.org) | [info@lipedema.org](mailto:info@lipedema.org) [www.lipedema.org/registry](http://www.lipedema.org/registry)

### Talk Lipoedema

16 Milton Bridge, Penicuik, Midlothian, EH26 ORD

[contact@talklipoedema.org](mailto:contact@talklipoedema.org)

## Contact details

If you have any queries, please contact:

**Lymphoedema Service** on telephone: 01284 712732

Email: [wsh-tr.wslymphoedemaservice@nhs.net](mailto:wsh-tr.wslymphoedemaservice@nhs.net)

**Integrated Therapies** on telephone: 01284713300

West Suffolk NHS Foundation Trust is actively involved in clinical research. Your doctor, clinical team or the research and development department may contact you regarding specific clinical research studies that you might be interested in participating in. If you do not wish to be contacted for these purposes, please email [info.gov@wsh.nsh.uk](mailto:info.gov@wsh.nsh.uk). This will in no way affect the care or treatment you receive.

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