About us here at TALK LIPOEDEMA

Talk Lipoedema is a Scottish registered charity that is active across the UK. We provide information and support to people with lipoedema, their families and carers through our social media channels and our website. We also provide local roadshows and national conferences to bring together people affected by lipoedema.

We believe that education is key to empowering people with lipoedema and improving treatment and care. Talk Lipoedema also initiates and participates in various projects to increase awareness of the condition and improve research evidence.

We have a vision for the future that everyone with lipoedema will be given an accurate diagnosis with access to an appropriate range of services and support with self-management.

For support and information:-

contact@talklipoedema.org
talklipoedema.org
What is LIPOEDEMA?

Lipoedema is a chronic disorder of the connective and fat tissue that mainly affects women.

It usually presents in the lower half of the body, leading to a disproportionate waist to hip ratio, but may also be found in the arms and other areas of the body.

Lipoedema is often not recognised by health care professionals and may be misdiagnosed as lymphoedema or obesity. Frustratingly, there is often limited support and available treatments for lipoedema from the NHS.

Lipoedema frequently worsens at times of hormonal changes in a woman’s life, such as pregnancy and menopause. It is believed that the disease may be genetic and inherited, although it can miss a generation.

What are the CAUSES?

The exact causes of lipoedema are not well understood, but it is thought that hormonal factors play a role as the onset of the disease is often at puberty.

Lipoedema may not respond to traditional approaches to long term dieting and exercise. Some people with lipoedema experience physical and psychological distress that affects their daily living and work activities.

What are the typical SIGNS OF LIPOEDEMA?

- Lower body is often out of proportion with the upper body.
- Legs, buttocks and/or hips increase in size, with loss of ankle shape.
- Hands and feet are usually not affected.
- Bruising occurs spontaneously and is often unexplained.
- Enlarged areas are sensitive to touch and pressure; sometimes there is deeper throbbing pain in affected areas.
- Legs may feel heavy and swell throughout the day.
- Affected areas can look dimpled like “orange peel”.

What can I do to HELP myself?

Firstly, it is important to get an accurate diagnosis either by a doctor or specialist such as a lymphoedema practitioner. Ask your GP to refer you to a lymphoedema service who may provide treatments and advice on self-management.

Your GP may not be familiar with lipoedema so:

- Consider taking them information from Talk Lipoedema.
- Tell them to check out our website as it has information for health care professionals and a diagnosis video too.

I think I have LIPOEDEMA, what should I do?

- Keep your skin well moisturized and protect from cuts and injuries that could lead to infections.
- Consider your eating habits: being overweight can make the symptoms worse; eating foods that are anti-inflammatory and low in carbohydrates may be beneficial.
- Exercise in low impact ways such as swimming, Nordic walking, cycling, yoga, Pilates, Tripudio, and general strengthening exercises; rebounding and vibration plates can improve lymphatic drainage without putting strain on the joints; find something that feels right for you.
- If you think your mental health may be affected, ask your doctor if you think you would benefit from professional help.

What can TREATMENTS be available?

- Compression garments: a variety of garments are available through NHS lymphoedema clinics or on prescription from your GP. These should be measured accurately for comfort. When worn regularly they provide support to the affected areas, improving lymph drainage, and reducing symptoms such as swelling and pain.
- Manual Lymphatic Drainage (MLD) is a type of gentle massage used to manage problems such as pain and oedema. Check with your NHS clinic or private MLD therapist at: www.mlduk.org.uk.
- Liposuction may also be an effective treatment for managing the symptoms of lipoedema but is not a cure.