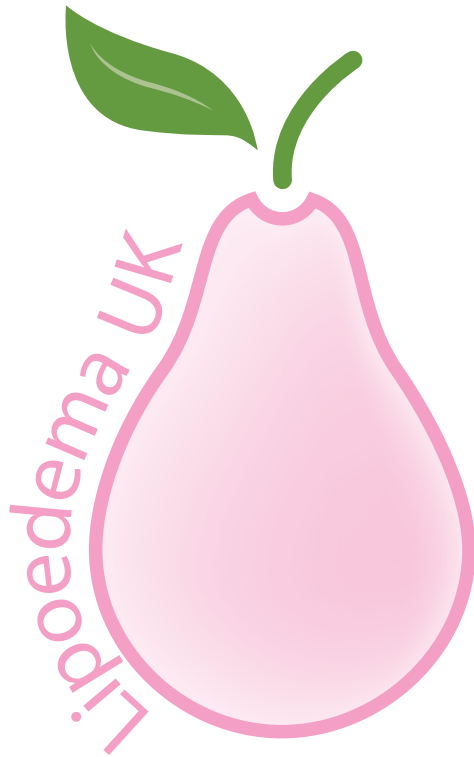


INFORMATION FOR WOMEN

and Health Care Professionals

Lipoedema UK

AWARENESS, DIAGNOSIS, TREATMENT, RESEARCH



www.lipoedema.co.uk

Registered Charity No 1157716
Ref: LUKW&HCP002

ABOUT LIPOEDEMA UK

Registered Charity No 1157716

Who we are:

Lipoedema UK is the UK's leading charity for lipoedema. It was started by women who have lipoedema and the Lymphoedema Department at St Georges Hospital, London. We raise awareness of the disease within the medical profession and throughout the UK. Our main goals are to achieve early diagnosis, so that women get the help and the treatments they need, and to encourage new research into treatments which will ultimately find a cure. Lipoedema UK undertake our own research and hold conferences for members and health care professionals.

The charity's patrons, Professor Peter Mortimer, and Dr Kristiana Gordon, from St Georges Hospital, London, are leading lipoedema experts. Our Nurse Consultants are Denise Hardy and Christine Wise, both of whom who have many years' experience of treating women with Lipoedema.

Recent collaboration with the Royal College of GPs (RCGP) has resulted in the first ever elearning course on Lipoedema. Work continues with the RCGP to spread awareness of lipoedema to GPs and all health care professionals, nationally and internationally.

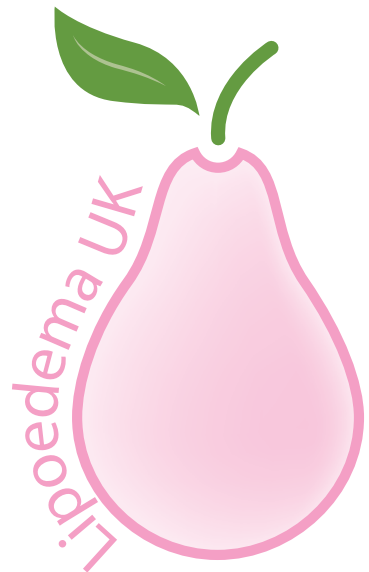
Lipoedema UK members range from 18 - 80+. By becoming a member, you will be part of a special group of women and supporters working to bring about improved awareness, treatment and change whilst encouraging new avenues of research.

Lipoedema UK relies solely on membership subscriptions and donations to continue this vital work.

Join Lipoedema UK to change the future for people living with lipoedema.

For more information,

visit: www.lipoedema.co.uk



eLearning course for GPs, nurses & health care practitioners



Royal College of
General Practitioners

Prior to the launch of the Lipoedema UK and the Royal College of GP's (RCGP) elearning course in 2014, only 5%⁽¹⁾ of UK GPs recognised and diagnosed lipoedema. It could take several decades before women were able to obtain a correct diagnosis, by which time, for many, the disease had progressed to lipo-lymphoedema, alongside other associated conditions such as obesity.

Lipoedema is an adipose tissue disorder causing bilateral symmetrical enlargement of the lower, and in some cases the upper, extremities in women leading to significant disproportion of the waist to hip ratio. Affecting mainly women, Lipoedema is commonly misunderstood and sadly rarely recognised, leading to misdiagnosis in primary care.

The RCGP eLearning course addresses these issues by describing the presentation, pathophysiology, diagnosis and management of lipoedema in primary care. This free course has been developed in partnership with Lipoedema UK and endorsed by the Royal College of Nursing. (There is a fee of £25 for non RCGP members based outside the UK).



Royal College
of Nursing

The voice of nursing in the UK

“Truly eye-opening. We all have misdiagnosed this condition and it is important to educate the health professionals about lipoedema. The course is an excellent resource to understand the condition.”
GP comment after completing the course.

Course available at: www.elearning.rcgp.org.uk/lipoedema

Lipoedema UK were able to undertake the development of this course due to the generous contributions we received from our sponsors and members.

Reference:

(1) Lipoedema UK Big Survey 2014

What is Lipoedema?

Lipoedema predominately affects females and is exceptionally rare in males. Current research supports genetic links and it can often affect more than one family member. In 78%⁽¹⁾ of women, lipoedema first appears during puberty when sufferers become aware of the differences between their body shape and that of their peers. It becomes increasingly apparent that the lower part of the body is disproportionate to the upper, which remains normal from the waist upwards.

Areas such as knees, hips, thighs and buttocks develop distinctive pads of fatty tissue which becomes noticeably bigger than the rest of the body. These differences in size can cause distress when shopping for clothes, and finding boots and trousers to fit can be especially difficult. The tissues in affected areas can appear to be very loose and floppy and there is often pain and tenderness in the limbs. The affected skin may be pale and cool to the touch, bruising can occur easily and spontaneously without apparent cause. The feet are hardly ever affected, often creating a 'bracelet' appearance at the ankles. Lipoedema can develop in the arms but rarely affects the hands. The knees and hips can also become painful. Lipoedema develops symmetrically on both sides, unlike lymphoedema which usually affects only one side.



One sister with and one without lipoedema. Difference in leg size apparent despite only 2" difference in waist measurements.

Reference:

(1) Lipoedema UK Big Survey 2014

Treatments for lipoedema

When patients receive a diagnosis, it can be very frustrating to discover that, as yet, there is no proven cure for lipoedema. However much can be done to help improve symptoms and prevent progression. Significant improvements can be achieved by following a sensible, healthy eating programme designed to lose any excess weight and prevent further weight gain. Following an appropriate exercise schedule to build muscle tone, and wearing compression garments to support the tissues and reduce oedema (fluid build up), will help maintain an active lifestyle.

Lipoedema and dieting

95%⁽¹⁾ of people with lipoedema report that they fail to lose weight in areas affected by lipoedema, despite losing weight successfully from other areas. However, it is vital that people with lipoedema learn to manage their weight as lipoedema is exacerbated by obesity. Choosing healthy foods and avoiding over or under-eating out of frustration with the situation is extremely important, as is eating a well-balanced diet, with normal-sized portions. Although there is no proven connection, many people find that certain food such as wine, wheat and processed foods seem to affect their symptoms and that avoiding certain foods can help control swelling and discomfort.

Lipoedema and exercise

Exercise is very important as it helps maintain a healthy weight, and leads to a feeling of wellbeing. However, it is very important that people with lipoedema learn to distinguish between high and low impact exercises, and choose sporting activities that will help, as opposed to aggravate, the condition. Swimming or aqua exercise walking and cycling are low impact and amongst the most beneficial exercises for reducing and controlling areas with lipoedema. Exercise in water is especially good for controlling lipoedema and many people who do this regularly report reductions in pain and size⁽¹⁾, with marked improvements to the loose, often floppy, tissues of their legs and arms.

High impact exercises such as running and aerobics classes may not be tolerated because the extra weight can damage joints and can lead to a worsening of the condition. This risk of damage is increased by high impact sports such as football, hockey and netball which should be avoided as they can cause bruising and exacerbate pain.

Reference:

(1) Lipoedema UK Big Survey 2014

Remedial exercises such as those recommended by physiotherapists to strengthen and improve muscle tone in the legs and around the knees are very beneficial as knees are often under strain from additional weight on the lower limbs. Sitting or standing for long periods without a break should be avoided as it will lead to a build up of fluid.

Lack of confidence and embarrassment about their appearance may prevent some women with lipoedema participating in sporting activities, but it is very important to keep as active as possible. Options such as joining 'women only' exercise classes/ gyms or taking along a friend or relative for support can be a good way to try new activities or sports facilities.

Psychological support

After the initial relief at receiving a diagnosis, many people find the news that there is currently no cure for lipoedema difficult to accept and may need to talk through their feelings and receive emotional support.

Lack of knowledge about lipoedema and the fact that the condition is often mistaken for obesity means many women experience self-doubt and feel stigmatised. Referral to clinical psychologists is an option, but can prove difficult to access in the present healthcare climate. However, appropriate support from health care professionals with a knowledge of lipoedema and its management, can be of great benefit to many patients.

Tumescent Liposuction

Tumescent liposuction has been proved to be of benefit for patients with lipoedema and, to date, is the only method where results on patients with lipoedema have been fully evaluated and results published⁽³⁾. Liposuction is a surgical intervention that aims to reduce the overall size of the limb (or part of the limb) thereby improving mobility/function and reducing pain. It is important to realize that it is not a cure for lipoedema and that liposuction can only be undertaken for lipoedema if morbid obesity weight is fully controlled. Traditional liposuction is NOT recommended as it results in surgical traumatisation, especially to the lymph vessels, which can lead to lipo-lymphoedema and a worsening of the symptoms. Inappropriate liposuction or plastic surgery can be very damaging and lead to complications and deterioration of the disease.

Lipoedema services at lymphoedema clinics

Lymphoedema therapists are appropriately trained to assess, diagnose and advise patients about the best possible treatment to manage and prevent further progression.

As Lymphoedema service provisions vary from area to area, Lipoedema UK are currently compiling a register of UK NHS and private clinics that treat lipoedema. For more information, contact www.lipoedema.co.uk,

Compression garments and hosiery

Compression garments, such as stockings, tights, leggings and capri pants are important to reduce fluid (oedema) in the tissues by promoting venous and lymphatic drainage. However, they also support the limbs, lifting and streamlining uneven appearance, as well as helping to reduce pain and discomfort. Garments should be worn for as much of the day as possible. Applying them first thing in the morning when the legs are at their smallest is often easiest. It is vital that garments are correctly prescribed (most garments are now available on GP prescription), which includes taking specific measurements to ensure a good fit so that they are comfortable to wear.

Lymphoedema nurses are trained to advise on the type, strength and style of compression garments that will be the most beneficial. Depending on the severity of the condition, compression garments can be off-the-shelf or made-to-measure.



Assessment of the circulatory system is vital to avoid other problems before garments are prescribed, so finding a clinic to advise is important.

Manual Lymphatic Drainage (MLD)

MLD is a specific type of gentle massage that is used to stimulate lymphatic flow thus helping reduce oedema (fluid build up) and pain and discomfort. It is most effective when combined with other treatments such as compression bandaging and/or compression garments. Unfortunately, provision of MLD is a postcode lottery and it is not widely available within the NHS. MLD is performed by specially trained therapists and it is essential that qualifications are checked before embarking on a course of treatment that can be expensive if done privately. To find practitioners and for further information, visit: Manual Lymphatic Drainage (MLD) UK: www.mlduk.org.uk

Self-Lymphatic Drainage (SLD)

Many patients find that performing SLD on themselves helps to reduce swelling and relieve discomfort. The Lymphoedema Support Network (LSN) provides support and information on managing lymphoedema and produces videos demonstrating Self Lymphatic Drainage (SLD). www.lymphoedema.org

Intermittent Pneumatic Compression Therapy (IPC)

IPC provides a mechanical massage using air driven pumps and comfortable, inflatable garments that are used over affected areas/swollen limbs. They complement other conservative treatments such as compression and MLD and are not used in isolation. Patients may purchase their own device to use at home under careful supervision - but caution is required before they are issued and careful assessment should be carried out before they are initiated to prevent further problems. Not all lipoedema patients can tolerate them, especially if pain/tenderness is a problem, but pressures in the new multi-chamber systems can be sufficiently lowered to ensure comfort as well as improvements in symptoms.

Obesity and Eating Disorders

Lipoedema is often misdiagnosed as obesity and as consequently many lipoedema patients are given inappropriate diagnosis and information. It is also possible to have lipoedema alongside an eating disorder such as anorexia nervosa as undiagnosed women who receive inappropriate advice are susceptible to embarking on extreme diet and exercise regimes. Misdiagnosis can lead to self-blame and prevent patients from being given the right advice and treatments to help control disease progression.

How to distinguish between lipoedema and obesity

- In lipoedema, excessive fat distribution occurs predominantly from the waist down, resulting in the lower limbs becoming disproportionately larger than the upper torso. In generalised obesity, excessive fat distribution occurs all over the body.
- Lipoedema fat often responds very poorly to diet and exercise, and weight loss may occur only in areas of the body not affected by lipoedema. In some cases, excessive weight loss may exacerbate the difference between a slender upper and larger lower torso. Obesity, on the other hand, is known to respond well to diet and exercise, and weight loss is experienced from all parts of the body.
- In lipoedema, the lower limbs are tender and bruise easily. Pain may occur in the limbs and can often worsen as the day progresses. This phenomenon is not experienced in obesity, as the limbs are not tender and there is no increased tendency to bruising.
- Unlike normal adipose tissue, in lipoedema, the excess fat, particularly in the thighs, often feels soft and floppy and sometimes painful nodules can be palpated under the surface of the skin particularly at the lateral aspect of the thigh.

(3) Br J Dermatol. 2012 Jan;166(1):161-8.
Tumescent liposuction in lipoedema yields good long-term results.
Schmeller W, Hueppe M, Meier-Vollrath I.
J Dtsch Dermatol Ges. 2011 Jan;9(1):33-40.

Liposuction is an effective treatment for lipoedema—results of a study with 25 patients.
[Article in English, German]
Rapprich S, Dingler A, Podda M.

Pregnancy

Although lipoedema can progress at times of hormonal change, many women have no problems during or after pregnancy and child-birth, and have children who do not develop lipoedema. However, some women report that their condition worsened during pregnancy and so it is important to take particular care to avoid oedema (fluid build up) and take frequent rests. Manual Lymphatic Drainage can help prevent or reduce swelling and wearing maternity compression hosiery is advisable.

Lipo-lymphoedema

Lymphoedema is swelling that occurs when the lymphatic system stops draining the tissues adequately. Although there are many reasons why this happens, with lipoedema it seems that body shape distortion – around the ankles for example – means the lymph system struggles to cope in that area and fails to drain the area of excess fluid efficiently. If fluid builds up in the tissues alongside the fatty deposits caused by lipoedema, the condition of lipoedema is re-classified as lipo-lymphoedema.

Research

St Georges Hospital, London are undertaking a long term study into the genetics of lipoedema. The research team is studying families where there are several generations with the disease. The team have made great strides in identifying genes in similar conditions, and are hopeful that they will discover the genetic predisposition that leads to lipoedema before too long.

Lipoedema UK Research

Lipoedema UK's Big Survey 2014 was completed by 250 women who had been diagnosed with lipoedema and revealed just how difficult many women found getting a diagnosis, even after many years or even decades of consulting their GPs and other health care professionals. It provides invaluable data on symptoms and the impact of living with lipoedema much of which was included in the design of the Lipoedema UK and the Royal College of GPs elearning course for GPs.

Play your part - Get involved in research

Lipoedema UK survey into treatments & exercises for lipoedema

Lipoedema UK have launched a new survey for sufferers of lipoedema. We want to hear from as many women as possible about the treatments and exercises they find most beneficial as well as identify any difficulties experienced in complying with advice and treatments.

To take part visit: www.lipoedema.co.uk or email: exercise@lipoedema.co.uk

Lipoedema UK

Registered charity No 1157716

Application for Membership/Donation



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I have lipoedema

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GP's Name & Post Code

Yes, I am a UK Taxpayer and I would like Lipoedema UK to reclaim the tax on all qualifying donations I have made as well as any future donations until I notify them otherwise. I understand that I must have paid income / capital gains tax that is at least equal to the amount of tax that all the charities and Community Amateur Sports Clubs I donate to will reclaim on my Gift Aid donations in the tax year which they are received and that Council Tax and VAT do not count for this purpose.

Thank you so much - your support is vital and will enable us to improve the lives of people affected by Lipoedema.

Return to:

Foxfield House, Chichester Road, West Wittering, Chichester, West Sussex. PO20 8QB UK



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www.lipoedema.co.uk