

LIVING WITH Lipoedema

JUNE 2023



THE DRUG OZEMPIC

Is this drug effective for those with lipoedema? **p2**



DESIGNS FOR YOUR LIFE!

Products to improve your daily life and mobility **p6**

CELEBRATING SUCCESS!

Member Pai completes fund-raising marathon **p12**

Lipoedema: a neglected area of women's health

A new article in the *British Journal of Community Nursing* shines a light on lipoedema and the role that community and primary care nurses can play in identifying it...

Everyone at Lipoedema UK was delighted to see our Nurse Consultant Mary Warrilow's article, "Lipoedema: a neglected area of women's health", published in the *British Journal of Community Nursing*. In her article, Mary highlights the "chronic and debilitating" features of the condition, which for so long has been – and remains – poorly recognised and often misdiagnosed as obesity or lymphoedema. The article outlines the symptoms of lipoedema (lipedema in the US), and the impact this condition can have on those living with it, as well as the importance of early diagnosis.

When it comes to diagnosing lipoedema, Mary's article notes that the timing of the onset of symptoms can be helpful, because lipoedema usually presents at times of hormonal fluctuation – many women report that their symptoms appeared around the time of puberty, pregnancy and menopause. The symptoms include abnormal distribution of fat on the buttocks, lower limbs, hips and occasionally the arms, with the result that women with lipoedema often need to wear different dress sizes to accommodate their shape below the waist.

Frequent bruising (due to capillary fragility) is another symptom widely reported. Mary adds, "Skin is soft and doughy in texture, rather than firm as in lymphoedema, and spider or varicose veins can be present." Feet, however, are not affected, which can be key for diagnosing the condition.

Facts and figures

Many people with lipoedema comment on the psychological impact it has on their lives. Mary (pictured left) quotes Lipoedema UK's own research of 2021 to state that **97%** of women report low self-esteem and confidence and a further **86%** experience anxiety and depression.



However, she goes on to identify ways to manage the condition, which include conservative and surgical options. Conservative management includes compression therapy, whereas surgical management targets liposuction, which removes the abnormal build up of fatty tissue.

CONTINUED ON PAGE 11 ...



AT A GLANCE:

What are the key lipoedema symptoms and characteristics

Some of the key signs, symptoms and characteristics are:

- Disproportionate distribution of abnormal subcutaneous adipose tissue (SAT) to below the waist, affecting buttocks, hips and both legs and sometimes upper limbs
- Significant disproportion of hip to waist ratio – distorted shape to the lower body
- Little or no effect on abnormal SAT from weight loss diets/exercise/bariatric surgery
- Likely psychological distress, anxiety and depression
- Low self-esteem and sometimes eating disorders
- Pain to areas affected (but not always) – especially sensitive and increased pain on pressure
- Fatigue and tiredness
- Easy bruising
- Feet are spared with 'cuffing' or 'bracelet' effect seen in the ankle or wrist
- Fatty deposits medially to knees and lateral thighs
- Skin folds to upper legs and knees

THE UK'S LEADING CHARITY FOR LIPOEDEMA

Founded in 2012, our mission is to raise awareness of lipoedema, for all women to receive early diagnosis, treatment and support, and to find a cure for this debilitating condition.



Ozempic, lipoedema and me

The new weight loss drug semaglutide (brandnames Ozempic and Wegovy) is all over the news. NICE has approved it to treat obesity in people with a BMI of over 35, but they limit treatment to two years and it will only be available in specialist NHS clinics. It is available privately to people without an NHS referral, with a lower BMI. There's no doubt it works for weight loss, but is this drug effective for those of us with lipoedema?

Well, my experience has been a resounding YES! Not only did I lose a whopping 25% of my starting weight over 16 months on this weekly injected medication but the invisible symptoms of lipoedema – pain, fatigue and brain fog – reduced almost from the start. Living in a society so obsessed with thinness means that friends have complemented me on my weight loss rather than my renewed energy but for me, the invisible changes are those I value most. These effects may relate to semaglutide's less talked about impact on chronic inflammation. Research into semaglutide as a lipoedema treatment is urgently needed.

What is semaglutide?

Semaglutide is a synthetic hormone, a GLP-1 agonist. It mimics a natural hormone that is produced in our digestive system.

Unlike our sex and thyroid hormones, our GLP-1 levels are not routinely tested. This hormone has a role in moderating glucose and insulin levels, and it can be low in diabetes patients. The drug was therefore originally trialled then released as a diabetes treatment, under the brand name Ozempic in the US in 2017, and in the UK in 2019.

Some diabetics taking it unexpectedly lost weight. Drug trials with non-diabetics swiftly followed, with Ozempic repackaged for weight-loss as Wegovy, with a maximum weekly dose of 2.4mg instead of Ozempic's 1mg. The results were astounding. In a British trial, people lost an average of 18% of their body weight over 68 weeks. It was approved for weight loss in the US in 2021, and by NICE in Britain in 2022, with the final guidance issued on 8 March 2023.

My story

I was told about semaglutide when I was diagnosed with lipoedema in 2021, aged 62 and 40 years after first seeking a diagnosis for my symptoms. By this stage, I also had lipo-lymphedema and was obese. The specialist told me that it wasn't my fault that I couldn't lose weight, but that I needed to anyway. Desperate, I seized the chance to try out semaglutide, paying out of pocket because it was not available on the NHS.

My weight loss was steady and gradual, around a pound a week, then stopped after around 16 months, which is typical. I can't tell whether I've lost any lipoedema fat, but the lymphoedema nurse (who measured me for compression garments) calculated that my legs had shrunk in volume by 25% by the time I'd been taking it for 9 months. I am continuing to take it weekly and, in due course, my dose will probably be reduced, but I do not intend to stop taking it.

How does it work?

Semaglutide works for weight loss by suppressing the appetite in three ways. It regulates insulin secretion, keeping blood glucose levels more stable. I no longer get afternoon energy dips that sometimes made me really "hangry". It also affects neural pathways. It's easy now to resist tempting food when I'm not hungry. This, friends tell me, is their "normal". Thirdly, it slows down the digestive system. Small portions leave me feeling full. However, this effect causes unpleasant but short-term side-effects for some people. I experienced a lot of nausea and constipation during the initial months while my body adjusted to the medication. Others vomit. There was 20% drop-out rate in the original medical trials, but there are ways to avoid the worst of this. I found a daily glass of prune juice, drinking a lot of water, and an anti-nausea wrist device (Reliefband has long straps!) all helped. And it did get better.



Semaglutide is a GLP-1 agonist. It mimics a natural hormone that is produced in our digestive system

25% drop in my weight and much less pain and fatigue

18% loss of body weight over 68 weeks in a British trial

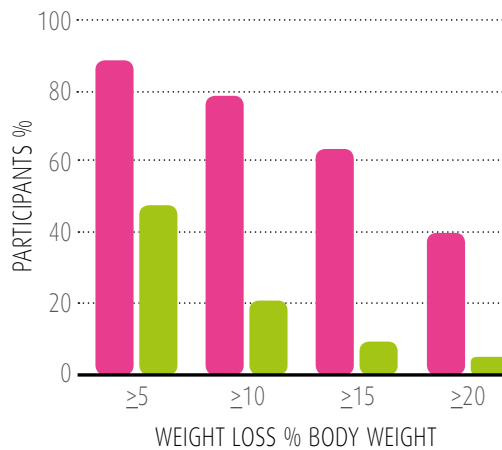
Semaglutide has been life-changing in ways that extend well beyond my more youthful face, my slimmer body, and my lovely new wardrobe. This, I think, is primarily down to its anti-inflammatory properties. These have been mentioned less in the media but, for people with lipoedema, this may be as important as its weight-loss effects: our tissue is inflamed, and experts have suggested that this inflammation may be the cause of our pain. There is a growing body of research about semaglutide's helpful anti-inflammatory effects in diseases such as atherosclerosis, dementia, asthma and psoriasis. Are these anti-inflammatory effects the reason why I have felt so much better, virtually from the start, well before significant weight-loss? We need to persuade someone to research this.

I'm not greedy!

The NICE guidelines reflect the usual fat-shaming story that people who are overweight eat too much of the wrong food, and don't move enough. They say that the semaglutide needs to be accompanied by changes in diet and exercise. This may be true for some people, but not for me. My diet was already healthy with few starchy carbs or ultra-processed foods, and I exercised regularly already. The pounds disappeared without me changing what I ate or my exercise regime. I ate less, not because I applied will-power, but because the effects of the drug meant that my body craved for less. I finally accept that I'm not greedy, but that my natural hormones and physiology are (for some reason) out of whack. I expect that if I stop taking semaglutide, my appetite will surge back up, and I will put on weight.

Semaglutide is a treatment, not a cure. All the follow-up studies have shown that – like with just about every other weight-loss method – people rapidly regain weight

PROPORTION OF PARTICIPANTS ACHIEVING THRESHOLDS OF WEIGHT LOSS DURING THE ENTIRE TRIAL (WEEKS 0-68; OBSERVED IN-TRIAL DATA)



- 20 weeks of semaglutide run-in + 48 weeks of continued semaglutide, 2.4mg/wk (n = 520)
- 20 weeks of semaglutide run-in + 48 weeks of placebo (n = 250)

Rubino, Domenica et al. Effect of Continued Weekly Subcutaneous Semaglutide. JAMA. 2021; 325(14):1414-25. doi:10.1001/jama.2021.3224

once they come off it. Some experts have suggested that it works for people whose natural levels of the hormone are, for some

reason, too low. If that's the case, it's unsurprising that the weight piles back on if they stop taking it. NICE is aware of the rebound effect, and they may well revise their edict that this is a 2-year time-limited treatment, once more evidence is available. Personally, I expect to be on this treatment for life, and I hope that, eventually, my GP will be able to prescribe it for me.

Semaglutide is not a miracle cure for lipoedema. My legs and arms are much smaller but they are still disproportionately large and lumpy though dressed in something flattering, I just look curvy and a bit plump. It is not an alternative to wearing compression or avoiding inflammatory foods. It does not replace liposuction, though it would mean far fewer and far less traumatic procedures if I chose to go down that road. I anticipate that it will become a welcome new option for lipoedema sufferers, and is therefore a reason for optimism.

I certainly expect my life to continue to be healthier and more fun thanks to taking it.



Can you help with our future research?

I've written this article in my personal capacity as someone with lipoedema, and all opinions are my own. I am, however, quietly simmering about the state of diagnosis and treatment for lipoedema.

Accordingly, I've welcomed the opportunity to join Lipoedema UK as Head of Research. I plan to use some of my new-found energy to stimulate research into all aspects of our condition, including semaglutide. Ultimately, we hope to help establish a formal trial into semaglutide and lipoedema. In the meantime, some Lipoedema UK members who are taking semaglutide are sharing their experiences, confidentially, with me.

The aim is to gain insights into the drug's effects on our symptoms, and therefore to refine the questions that medical researchers can investigate in a formal trial.

If you are taking semaglutide, please get in touch by emailing me at lesley@lipoedema.co.uk



Centre for Appearance Research explores Lipoedema patients' concerns and feelings over their appearance

The Centre for Appearance Research (CAR) at the University of the West of England, Bristol uses research to improve the lives of people affected by appearance-related concerns. Established in 1993, we are now the world's largest group of psychology researchers specialising in appearance and body image.

Our work sets out to explore how people feel about their appearance, identify if there are any problems or concerns and, if so, who's affected by them. We then develop new evidence-based ways to help young people, adults, and family members who might be adversely affected, and evaluate whether these interventions have been helpful.

We do all of this by working closely with support organisations and charities, health professionals, schools, industry, policy makers and, most importantly, people with lived experience of the issues we are studying. A major programme of research at CAR is being conducted by a team of researchers led by Professor Diana Harcourt and Dr Amy Slater, who are working with the Appearance Collective – a group of charities, including

Lipoedema UK, that support people who have conditions or injuries that alter their appearance in some way. The work we are doing has been driven by priorities that were set by the Appearance Collective charities in 2017, and then updated in 2021. Taking part in our research could involve being interviewed, or completing a questionnaire, or maybe using a new kind of supportive intervention that we are evaluating.

Recent online survey response

We are immensely grateful to everyone associated with Lipoedema UK who is interested in our work and particularly to those who took part in a recent online survey, exploring the support preferences of people with conditions that impact on appearance. A total of 318 adults with lipoedema and 3

parents/guardians of young people with the condition completed our survey. Of the 318 adults, 308 (97%) were women and ages ranged from 18-82 years. Most (91.2%) of the respondents who had lipoedema wanted more information about possible treatments and 59.7% wanted to know about causes. Almost two-thirds (62.6%) wanted support with pain management, and more than half (53.8%) wanted support with mental health, and confidence and self esteem (28.8%). Many would like help with issues related to appearance – more than 60% wanted help with accepting their appearance and body image. More than a third (37.7%) wanted help with how to talk to other people about their appearance, and a quarter (26.1%) would like support with how to respond to questions and manage other people's reactions to how they look. The most popular ways that people wanted to receive support were via websites (65%), information in physical formats such as booklets and self-help books, support groups, in-person counselling, apps and podcasts. When asked what they would take into consideration when accessing support, the most important

318 adults with Lipoedema completed the online study and **97%** were women

60% wanted help with accepting their appearance and body image

65% preferred to receive support via websites

thing was that it was specific to their condition, that it was based on scientific evidence and has been tested, and that it was provided by a reputable organisation or health professional, followed by cost, geographical location, format and accessibility. This information will help us as we take our work forwards, and we hope it will be useful to Lipoedema UK too. One of the next steps is to examine people's support needs in greater detail and to find ways to make it easier for people's needs to be identified so that they can be directed to appropriate help – this is the focus of a new PhD being conducted by Clare Clement Clare.Clement@uwe.ac.uk

Other studies by the team:

Loving ACTION podcasts

Since there has been a lack of evidence-based support for adults with a visible difference who have concerns about romantic relationships, we have created materials to help individuals manage difficult thoughts and feelings related to relationships or intimacy.

Dr Maia Thornton worked with a group of adults to develop a series of podcasts, known as *Loving ACTION*, focussing specifically on these issues, and in 2023 she will be launching a study to evaluate this resource. If the results of this trial show that it can make a real difference, it will be made freely available through organisations such as Lipoedema UK.

For more information about this aspect of our work, please contact Maia.Thornton@uwe.ac.uk

The Parenting Toolkit e-book

Maia is also leading a trial of a new e-book, known as *The Parenting Toolkit*, which is intended to support parents and carers of children and young people with conditions that impact on appearance.

This study will be launched in the Spring of 2023 and we will be asking parents to complete some questionnaires before and after using the toolkit.

Again, please contact Maia if you are interested in this study or look out for further details through CAR's social media (details below).

Developing the Acceptance and Commitment Therapy (ACT) app

People with lived experiences of a range of appearance-altering conditions and specialist clinicians have worked with Dr Fabio Zucchelli to design a prototype mobile phone app to support adults with any sort of visible difference and who report distress related to their appearance.

Both the intimacy intervention and this prototype app are based on a psychological approach known as ACT (Acceptance and Commitment Therapy). The development of the app has built on research conducted by Fabio on how ACT can help people with appearance concerns.

Fabio's work has shown that the app has promising proof of concept and we are now developing a full app, which will be available to people served by charities like Lipoedema UK in due course. Fabio will be leading a study to evaluate the app.

For more information about this study, please contact Fabio.Zucchelli@uwe.ac.uk

Everybody's Different – a board game

As well as developing resources to support people whose lives are impacted by appearance-related issues, we also work to promote inclusion and positive attitudes towards diversity of appearance across society.

One of the ways we've done this is through developing a board game, *Everybody's Different*, which aims to help children understand and respect the differences in

people's appearance and promote their own body confidence. In a randomised controlled trial involving 259 young people aged 9-11 years, we found that playing the game within a classroom setting increased knowledge of appearance-related issues.

The game is available from www.appearancegame.com

Social media plays a major part

Social media is a major part of many people's lives, particularly young people. Research by Ella Guest, Amy Slater and Abbi Matthews is exploring the role of social media in the lives of individuals with appearance-altering conditions and expanding knowledge on how social media can be used to reduce stigma towards those with a visible difference.

Ella and Amy are carrying out interviews with adults and adolescents about how they, and other people with visible differences, portray themselves online, their overall experiences, and how social media could be best used to reduce stigma. Abbi is carrying out experimental research for her PhD to understand how social media can be used to educate the general population about visible differences and reduce appearance-related stigma and discrimination.

We hope this has given you a taster of some of our work at the Centre for Appearance Research. We would like to say a very big "Thank you" to everyone who has taken part in our studies to date and is helping us to make a difference to the support that is available for people who are troubled by appearance-related issues – we really couldn't do our work without you.



Interested in taking part in future research

You can join the CAR Participant Pool by going to www.uwe.ac.uk/car or find out more about the broad portfolio of CAR's work at the website, or by following us on Facebook [@AppearanceResearch](https://www.facebook.com/AppearanceResearch) – Twitter [@CAR_UWE](https://twitter.com/CAR_UWE) or Instagram [@car_uwe](https://www.instagram.com/car_uwe)

CAR also produces *Appearance Matters: The Podcast* and there are now more than 75 episodes, all freely available through i-tunes, Spotify and SoundCloud.

Products designed to improve your life!

Lipoedema UK is very fortunate to be supported by companies who have a professional and clinical understanding of lipoedema, accompanied by a keen desire to provide products that improve the lives of patients...

Many products, including made-to-measure compression garments, are available on prescription through a lymphoedema clinic or GP surgery. Should you encounter any issues with choosing a style or size, or need advice on the comfort and fit of a garment, these companies provide excellent customer care.

- **Compressiontherapy UK**

Naomi Northen-Ellis is the director/owner of Compression Therapy UK Ltd and as a patient herself with lipo-lymphoedema she has first-hand knowledge about the benefits and the efficacy in regular use of the *Lympha Press* products.

- The massage is based on the Vodder method of MLD massage.
- The 12 and 24 chamber garments have cells that are exactly the same size as bandages used in multi-layer bandaging techniques popular with MLD therapists to reduce limb size.

Definitely a product to consider saving up for if you want to enjoy the benefits of a MLD style treatment in the comfort of your home.

Visit: www.lymphapress.co.uk

- **medi uk ltd**

As a global leader, medi has over 70 years of experience leading the way in compression therapy. We are proud to develop innovations for a better quality of life and are committed to investing in technology to simplify everyday solutions for patients and clinicians alike. Our

mediven® cosy compression tights are specially designed for people living with lipoedema. Available in a range of colours and patterns, *mediven*® cosy is made-to-measure for a perfect fit, with a soft and gentle feel whilst giving freedom of movement. With our extensive range of products to suit individual needs, people feel better with medi.

Monica Smith, medi's Lymphoedema Training Manager, is an expert in compression for lipoedema and she and the team are able to provide advice on your best size and fit.

Visit: www.mediuk.co.uk

- **SIGVARIS GROUP Britain**

Sigvaris are renowned for making exceptional products that combine advanced technology and quality craftsmanship with diverse styles that fit modern lives and our *Essential Comfortable*, *Semi Transparent* and *Style Opaque* ranges have been popular for many years with lipoedema patients, and with the new *Style Patterns* range this is no exception.

Smooth seams help to reduce the friction against the limb and the lower compression offers containment of tissues to reduce oedema and helps to reduce the pain in legs, thereby easing discomfort, which in turn improves mobility.

Style Patterns offers contemporary, comfortable hosiery for everyday wear for mild to moderate lipoedema. With a choice of three patterns, Mosaic, Chequered and Polka Dot in below knee, thigh high and tights.

Call our customer services on **01264 326 666** or email customerservices@sigvaris.com



Chequered tights – Just one of the new Style Patterns range available from Sigvaris

to find out more about *Style Patterns* or any of our other products.

At Sigvaris we realise that for some people it can be very difficult to access clinical advice regarding compression. That is why we have an award-winning specialist as our Clinical Manager. Tracy can offer support regarding compression and the condition of lipoedema. Contact her at clinical.advisor@sigvaris.com Visit: www.sigvaris.com



• **Haddenham Healthcare**

How Comfiwave helps in self-management of lipoedema

NATALIE PHILLIPS MSc

Clinical Manager
Haddenham Healthcare Ltd

KAREN COOPER

Clinical Advisor
Haddenham Healthcare Ltd

Finding compression garments suitable for lipoedema patients is a challenge at the best of times – not only for you, the patient, but also for us, the clinicians. Clinical decision-making in compression for lipoedema tends to depend on the stage and type of lipoedema, as well as individual symptoms, and a patient's experience of, and ability to use, compression garments. Finding garments that fit comfortably, and which manage symptoms (such as pain and swelling) but are also easy to get on and off, is a careful balancing act and can be quite stressful.

Recently we have had reports of people with lipoedema using Haddenham *Comfiwave* as part of their management. *Comfiwave* was originally intended for night-time/resting compression. A seamless, 'breathable' garment made from 100 per cent organic cotton, *Comfiwave* has a wave patterning that creates a massaging effect on the tissues. The whole-knitting technology results in a highly elastic knit, meaning it is easy to stretch (making it simpler to get on), but powerful enough to limit the stretch in response to oedema fluctuations.

Comfiwave comes in a variety of sizes, with a newly added larger size which may suit those with more severe stages of lipoedema. It is also available in a variety of styles for various body parts.



Comfiwave compression is easy to pull on and comfortable to wear around the house

"Improved mobility and quality of life"

The case study below demonstrates how *Comfiwave* has benefitted this patient. (Permission was gained from the patient to use her case study, and details remain anonymous to maintain confidentiality.)

Case Study: MRS H

Mrs H first came to me in 2021 aged 57. She was presenting with lipoedema stage 3, Type III & IV, with secondary lymphoedema and moderate lymphorrhea in her lower legs. She had been diagnosed with lipoedema in 2016 and was measured for CCL2 below-knee

hosiery, but this had been poorly managed since then due to a house move followed by Covid restrictions. Long-standing lipoedema had taken its toll, and consequently she was struggling with general mobility and low self-esteem. Symptoms of severe neuropathy and burning in her feet, heavy lower legs and ankles, plus bilateral knee pain with hypermobility were also contributing to her flexibility issues. Her thighs were bruising easily with soft adipose tissue and weight-gain issues.

Treatment: Mrs H began with a short course of Complex Decongestive Therapy/manual lymphatic drainage (CDT/MLD) with multilayer bandaging of lower legs and feet to control the lymphorrhea and stop the leakage.

Intermittent Pneumatic Compression was

"Since wearing Comfiwave, I'm not experiencing the 'stinging' sensation or the feeling of heaviness in my legs each morning"

used regularly on bilateral legs at 40mmHg. We issued CCL2 flat-knit MTM below-knee stockings and made to measure (MTM) Bermuda shorts.

In 2022, we supplied Haddenham *Comfiwave* thigh-high stockings

for evenings and night-time (the product only became available on prescription that year). They were a rapid game changer, because we found they reduced Mrs H's limb sizes – the massaging effect of the ribbing in the garments softened the fibrotic band of tight cuffing in her ankles and lower legs. This resulted in her skin becoming more pliable and responding better to MLD/IPC, which further facilitated her ankle mobility.

The *Comfiwave* garments helped reshape Mrs H's lower legs, in particular her knee

CONTINUED ON PAGE 8 ...

... CONTINUED FROM PAGE 7

Products designed to *improve your life!*

areas, which were prone to soreness. She finds the stockings easy to don/doff and very comfortable to wear. Overall, these changes have improved her mobility and quality of life, allowing her to do more activities.

“Comfiwave has also helped to stop the build-up of fluid which previously reduced flexibility and movement in my ankles each morning”

In the patient’s own words

I asked Mrs H to describe in her own words how she feels *Comfiwave* has helped her. She said, “Before wearing *Comfiwave* garments, I always had a ‘stinging’ sensation in my legs each morning; my legs felt heavy, and my ankles looked bigger despite having had my legs elevated all night. As I wear compression garments during the day, it feels normal for me to wear garments at night. I find these ones easy to pull on and comfortable – they do not restrict me in any way. Since wearing *Comfiwave*, I’m not experiencing the ‘stinging’ sensation or the feeling of heaviness in my legs each morning. *Comfiwave* has also helped to stop the build-up of fluid which previously reduced flexibility and movement in my ankles each morning. I feel that *Comfiwave* is helping me to control my lipoedema and secondary lymphoedema.”

Therapist comment: “Overall, I feel confident that *Comfiwave* has allowed women to manage lipoedema and its complications with minimum effort. *Comfiwave* gives rapid results and softens stubborn heavy skin folds, and its restrictive nature allows better range of motion and quality of life.”

For further information on these products, speak to your therapist or visit www.lymphshop.com or hadhealth.com



Introducing new styles with **JOBST® Confidence**

Innovative knitting method allows for high ability to **conform to individual body shapes**



Contour Fit

Advanced moisture management system with double-layer construction for **optimal wearing comfort**



Moisture Management

Made with a supple conforming fabric that also gives the reassurance of **firm support**



Soft & Firm

Flexible, conforming fabric designed to make putting on and taking off easier



Easy Donning

Get started with JOBST Confidence, contact your local UK Essity Account Manager or email: concierge.service@essity.com



JOBST®, an Essity brand



www.jobst.co.uk
Tel: 01482 670100 • Fax: 01482 670111
E-mail: compression.uk@jobst.com

HEALTHCARE PROFESSIONAL EVENT

LIPPEDEMA WORLD CONGRESS
OCTOBER 5 – 7, 2023 | POTSDAM/BERLIN



SAVE THE DATE!

CONGRESS CHAIRS



Mojibba Ghods MD, PhD (Germany)



Karen L. Herbst MD, PhD (United States)



Sandro Michelini MD (Italy)



CONGRESS ORGANIZATION
congress@gb-mc.com
www.gb-mc.com



More information

Donating in memory of your loved one



It has become common to donate to charity in memory of a loved one at the time of the funeral...

Giving to charity in memory is a favourite way to commemorate a special person and continue their values and wishes.

Created in 2010 by fifth-generation funeral directors Julian and Matthew Walker, Memory Giving provides a service to allow donors easier access to giving and the ability to leave messages in tribute. It is a secure online website specialising in donations to honour the life of a loved one.

Families are able to create and manage their own pages, to share details about the funeral and if required, provide links for live-streaming of the service.

The site is simple, respectful and efficient allowing friends and family to create messages and share memories to accompany their donation.

Memory Giving also enables charities to increase the amount received 'in memory' as it is registered with the Charity Commission to claim back Gift Aid and pay the total contribution directly to the chosen charity.

It all helps to reduce overall administration tasks and costs to the receiving charities. Sharie Fetzer, Lipoedema UK Chair said:

"Since working with Memory Giving we are pleased to find that donations come through quickly and directly to our bank account and we're grateful to have the additional Gift Aid contribution. Families choosing to commemorate their loved ones by supporting the work of Lipoedema UK always have a special place in our hearts"

Brother Sean donates to Lipoedema UK in memory of beloved sister Carmen

Members of our Health & Wellbeing meetings were deeply touched by Sean's devotion to his beloved sister Carmen and shared his grief and heartbreak when we heard of her tragic early death at the age of 55. Thank you Sean to you and your family for collecting over £300 for Lipoedema UK through Memory Giving.

Create your dedicated page in memory of your loved one, by visiting www.memorygiving.com and nominate Lipoedema UK as your chosen charity

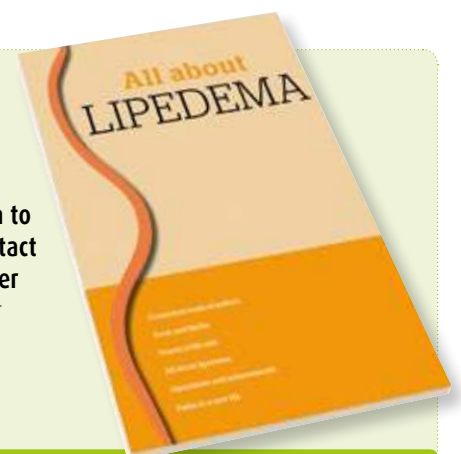
ALL ABOUT LIPEDEMA

A really informative book written by a patient and her family to help others navigate the many aspects of lipoedema.

Over 270 pages, including photos, practical advice on diagnosis, diet, liposuction, compression, lymphatic drainage... and much more.

"Lipedema was completely unknown to us when my daughter came into contact with this disease after the birth of her two children." Bernd Degen, Publisher

Lipoedema UK PROUD TO BE THE OFFICIAL UK DISTRIBUTOR



AVAILABLE NOW FOR ONLY **£25** INCL. UK P&P

Order today at: www.lipoedema.co.uk/new-book-all-about-lipedema/

Shape, swimming and surviving!



It's not as if I dislike swimming but I don't love it. I am told it's a necessary function for anyone overweight and with mobility issues. Well, two hits there!

I've been conscious of my body shape since I was young, from primary school through to now, almost 77. Looking back, I was not the fat person I believed myself to be, but more a fit young girl following on to a nicely-shaped teenager, through to an attractive woman – depending on your ideas on that, of course.

Fitness was important to me too, so you can imagine just how low I felt when, three years ago, I was taken home by my husband following a collapse in a tea tent halfway through a 24-mile charity bike ride, feeling my health crumbling around me.

I hadn't been right for some time – pain burning through my body. My doc diagnosed lipoedema and retrospectively this explained such a lot... the usual lipoedema story.

Following a kind of recovery and facing all that we know about this malicious beastly, I began to rebuild my fitness. Long-standing back problems – lumber & cervical – troubled eyes, tin knee, weakness, arthritis, tiredness,

depression (lifetime sufferer) and old age adding to this pot of confusion surrounding lipoedema, had me running for a safe place to hide. There is no such place of course, other than in our heads or in our survival instincts. Mine are high, I know of old.

Swimming, walking (no!) and biking were advised, so I researched big girls' bike-riding and swimming gear. Once kitted out, with great difficulty due to my shape, I hit the 'go' button and cycled round the village (with the odd tumble) and joined a gym with a pool. Therein lay the biggest challenge.

I could barely motivate myself to appear alongside the posing men, checking-out their movements in mirrors as they pummelled those machines at speed whilst I cringed, walking slowly along the moving rubber track, hanging on to the rails for fear of falling.

If I thought the gym was hard, I hadn't bargained on my discomfort in the pool. Well, not 'in' the pool exactly but en-route the pool.

Lipoedema and the costume drama

Having changed shape dramatically within a short space of time, I hadn't realised how wide my beam-end had become, nor how batty my batwings were. All this was a shock to me, believe it or not, when, thanks to the many mirrors, I had no choice but to see myself, to say nothing of the sight of me in towels which barely covered me.

To get myself into the pool was a major fight within. I tried every day (in my head) but in the beginning the event happened once a week, if that. It involved me dragging out my swim bag which I stocked the night before, so no

excuses: getting up early for diuretics, so the toilet-rush was over before getting to the pool, so I didn't have to come out and get back in more than once. Important!

Next obstacle, getting through the cossie struggle at home so that I could disrobe at the gym without the faff of changing room indignity. So there I was, at home – fully dressed with cossie half-on, bra part-hanging below my sweatshirt so prior to leaving home, it was an easy last trip to the loo. Note to self – don't answer the door without tucking in the cossie!

Avoiding the enemy

To cope with the biggest hurdle of getting into the pool, I developed a cat-and-mouse peek into the shared corridor. Waiting, hidden, to spot any males wandering up or down, I make a slow sort of dash with towel over shoulder, soap bag under armpit and walking stick to ensure I don't tumble. Head high I make it to the poolside where I deposit all my stuff, checking no males were swimming towards the ladder, which I had to go down bum first, slowly and gently to avoid a tsunami.

Getting out has become a bigger challenge since I keep growing, and feel so huge and ungainly – in fact my legs feel heavier with each step as I climb out up the ladder, pulling hard on the rails hoping I don't slip and cause that tsunami I have, so far, managed to avoid.

Ordeal over, I feel virtuous and happy about my few lengths, pedalling and exercising after each with my next visit in the back of my mind.



97% of women report low self-esteem and confidence

86% experience anxiety and depression

The longest walk

I decided last year to try for a fundraiser for LUK whilst holidaying on the Isle of Harris. A public showing of my body beautiful on the world-renowned Luskentyre Bay.

We were desperate for a break after many journeys up and down the dreaded A9, dealing with settling my 96-year-old dad into a nursing home*, clearing and selling his house. It was an emotional and physical challenge with a five-hour journey to Inverness and I don't travel well, followed by days of bending, sorting boxes, memories and dust with daily dad visits.

I'd decided to raise funds through a swim in Luskentyre Bay where Harris meets the Atlantic. Great idea, but during the journey there, we were feeling a bit unwell. On May 3rd as we arrived, Brian tested positive for Covid and I had a pink test line, so decided I wouldn't take my next test until after my swim.

We felt rubbish, but I was determined, and Brian was a wonderful sherpa, so I managed what felt like a long naked walk over the wet sand for what was a token swim on the 6th, my birthday and 25th wedding anniversary. This followed by a test confirming I had Covid. I was so ill I couldn't finish my champagne, nor my dairy-free truffles. Then an unwelcome 14-hour journey home, one week earlier than planned. BUT! I had done my fundraiser - stubborn or an idiot? Take your pick.

Our recovery looked set to be a normal seven-day run, but mine turned into months of 'Covid cough' and other complications.

Appreciating the 'now'

On a positive note, I'm beginning to accept my shape. I've had some serious health issues and more readily appreciate the curtailed abilities I do have. I've graduated to wearing tops and trousers with no cover-ups whilst friends visit, but am yet to allow a public view of me as I am.

Finding an acceptance of this condition and its complications is a must, and I'm even less caring at the pool. I'll know tomorrow when I go back again it'll be a bit easier, but with some of the same ol' routine... my Poirot walk!

CONTINUED FROM PAGE 1 ...

Mary highlights the UK government's Women's Health Strategy for England (2022) which concluded that not enough focus is placed on women-specific issues; and that access to services can be poor and fragmented.

She notes, "This is very relatable when considering the long-term condition of lipoedema, which affects an estimated 10% of women in the UK and worldwide."

Community and primary care nurses (as well as teachers, school nurses and GPs) are identified as being key to early diagnosis - Lipoedema UK's own research of 2021 (quoted in the article) concludes that although **48%** of participants reported symptoms started at puberty (age 11-18), **61%** only received a diagnosis after the age of 40 (and **32%** of these were not diagnosed until after the age of 50).

You can read Mary's article, "Lipoedema: a neglected area of women's health" published in the *British Journal of Community Nursing*, in full online at: bit.ly/3AX6gAq

Lipoedema UK's mission for an early diagnosis

Our fact-packed leaflet has all you need to know...

Lipoedema UK's newest leaflet, *How to distinguish between lipoedema, obesity and lymphoedema*, is getting the thumbs-up from healthcare professional and patients alike.

Full of information on symptoms, illustrations and references to aid a diagnosis, plus a differential diagnosis chart - it is all neatly presented in a compact handbag-sized A5 leaflet.

All Lip UK members will receive a copy in their membership pack. Bulk orders for clinics or HCPs are available on request. If you would like a quote for additional copies to be supplied, email info@lipoedema.co.uk



*His choice when he experienced a local convalescence two week stay and is very happy at now aged 97

Living with lipoedema



BY SHARIE FETZER, CHAIR, LIPOEDEMA UK

Too many people with lipoedema face daily ignorance and disinterest in their condition from the healthcare professionals they turn to for a diagnosis and support.

This can often lead to a fear of sharing the physical and emotional difficulties associated with lipoedema with

their family and friends.

Is it a coincidence that lipoedema affects mainly females, or another example of how women's health has been under-resourced and underfunded for generations?

Lipoedema UK is proud of our pioneering work highlighting the difficulties in obtaining a diagnosis and treatments, and now very proud to be a Founder Patient Association member of the Lipoedema World Alliance (LWA). We believe that many of the issues and mysteries surrounding lipoedema (spelt lipedema in many parts of the world including the USA) can only be solved by international co-operation at the highest level.

Lipedema research

The LWA will be taking part in the prestigious healthcare professionals event, Lipedema World Congress in Berlin, Germany in October 2023, hosted by Dr Ghods, and congress chairs Dr Karen Herbst and Dr S Michelini.

Dr Ghods surgical team are especially important to UK patients as they are undertaking the lipedema research project which, when the results are published, will trigger the next NICE review of liposuction for lipoedema in the UK.

If you are a healthcare professional, we hope to see you in Berlin. If you are a patient, we're ready to make your case with the best in the world, and will keep you posted on Dr Ghods' research in our membership newsletters.

Membership of Lipoedema UK is open to all healthcare professionals and patients interested in creating a world where...

"together we will beat lipoedema"

FUN & FUNDRAISING

Pai's London Marathon

Pai Masendu did it! She completed the London marathon, raising £595 so far to bust her target!



Pai Masendu says the marathon is an experience she'll never forget. Will she do it again? "If I manage to get liposuction, then I'll consider another marathon," she said. "But for now, I'll stick to half marathons."

Pai was recently diagnosed with lipoedema after many years of being told she was obese. "I hated my legs being disproportionately larger than my upper body," she said. "Losing weight is always a battle, but when I do, it's from my upper body, with very little change to my legs and upper arms."

"I suffered with tenderness and bruising, and for many years GPs told me that I was 'knocking myself'. Since finding Lipoedema UK, I've learned there are other women like me, including many who've received a diagnosis so late that mobility is an issue. Lipoedema UK guided me towards getting a diagnosis and the support I need to manage my condition."

Pai ran the marathon for Lipoedema UK for two reasons. "My experience is that many GPs are unfamiliar with lipoedema and frequently misdiagnose it. I wanted to raise awareness. I also wanted to raise money for research, leading to the treatment and management of this debilitating, chronic condition."

Pai's friends and family found donating through JustGiving simple and fast. Payment details are secure and JustGiving never sends unwanted emails. Once donated, money raised is sent directly to the charity, making it an efficient way to help Lipoedema UK cut costs.

One kind giver on Pai's page wrote: "You are an inspiration Pai. I am so pleased that Lipoedema UK has helped you find a diagnosis and how you are helping us help more people struggling with lipoedema. Love your energy, too!"

On completing her marathon task, Pai joked, "So I went and did the London marathon. Was it hard? Hell yes! Did I finish? It was never an option not to."

