

LIVING WITH Lipoedema

MAY 2022



CAN DIET HELP?

We reveal encouraging science and research p2



DESIGNS FOR YOUR LIFE!

A round-up of products to improve your daily life and mobility p4

AWARENESS MONTH...

Save these important dates for your diary p8

NICE Liposuction for Lipoedema Review – not such a nice outcome?

Whilst Lipoedema UK is disappointed that NICE are not yet in a position to fully recommend the provision of liposuction for lipoedema by the NHS, we have been really heartened by the recognition that the committee gave to the impact that lipoedema has on peoples' quality of life...

Our thanks go to all our members and those who responded to our survey with their stories, which enabled us to help the NICE committee understand the need for better treatment options than the current highly-limited provision. Those personal stories led NICE to conclude that lipoedema is still under-recognised and can be “*extremely debilitating*”.

NICE has published cautious recommendations that do not endorse widespread UK NHS access to liposuction for lipoedema at this time. NICE want to see more published evidence first into longer term improvements to quality of life, how different patients' outcomes vary etc. NICE have recognised and reinforced that lipoedema is different to obesity and lymphoedema, and that limited NHS treatments are currently available. The people we have worked with at NICE appreciate the need for better NHS lipoedema treatment.

Our surveys and case studies tell us how hard it has been for some people to fund their surgeries, and how much they can

BY KATE FORSTER · TRUSTEE · LIPOEDEMA UK

improve quality of life, so we continue to campaign for NHS liposuction provision. NICE has agreed it will review its guidance again after the publication of a current German lipoedema liposuction study in the next couple of years.

As we write this, some doctors in the UK are in discussions with their insurers and/or the clinics where they perform liposuction, to understand the impact of the NICE review on their practices and if they will need to make any changes; at the time we are writing, this is still being worked out and we are in communication with them.

What exactly did NICE say?

NICE classifies its recommendations into four types, based on risk reduction:

- **Standard Arrangements:** NICE consider there to be enough evidence for doctors to offer this procedure.

- **Special Arrangements:** NICE consider there to be uncertainties about the safety and effectiveness about a procedure, resulting in an increased focus on informed consent and collecting data on surgical outcomes.

- **Only In Research:** NICE consider there to be unresolved uncertainties or that a procedure is still considered experimental, so it recommends clinicians only carry out the procedure in formal research studies

which were approved by ethics committees.

- **Do Not Use:** Where NICE think there is either evidence that a procedure does not work well or has unacceptable safety risks.

“...doctors in the UK are in discussions with their insurers and/or the clinics where they perform liposuction”

The guidelines on liposuction for lipoedema have been classified by NICE as **Only In Research**. NICE want to see more research into patient selection and outcomes (e.g. age and severity of lipoedema before surgery), longer term improvements to quality of life and measurable outcomes including changes to weight.

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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.

Lipoedema UK

Emerging evidence indicates that diet may help lipoedema

Can lipoedema symptoms be improved by eating certain foods and avoiding others? Lipoedema UK members at our Conference last November heard encouraging evidence from scientists as well as via feedback from our own research...

One of the frustrations for lipoedema patients is that, until recently, diet and exercise were not believed to be effective in reducing or preventing lipoedema fat. However, Lipoedema UK members at our Conference heard encouraging evidence that certain diets which focus on wholefoods, good quality protein and avoiding processed foods might work.

This provides much-needed hope for many lipoedema patients. Until now, the medical consensus has been that diets don't help to shift 'lipoedema fat'. If patients do lose weight or reduce their limb size, it's by reducing 'normal' excess weight, rather than 'lipoedema weight'.

Typical weight loss diets tend to be low fat – high carb. However, the research presented by Dr Gabriele Faerber and Dr Jessica Jin at the conference showed that some patients have experienced dramatic improvements in their symptoms after eating diets which favour vegetables, fruits, wholegrains, lean proteins, and omega 3 fatty acids.



ABOVE: Diets rich in vegetables, fruits, wholegrains, lean proteins, and omega 3 fatty acids could help

Nutrition, Deputy Programmer, De Montfort University. 95% were classified as either overweight or obese according to their BMI.

The first phase of the ongoing study found that following an anti-inflammatory diet was effective at improving one or more lipoedema symptoms. Anti-inflammatory diets favour wholefoods, and avoid processed foods (see box below). Ketogenic and rare adipose disorder diets were also effective for some patients.

Research presented

Dr. med. Gabriele Faerber, Head of Department, from the Centre for Vascular Medicine,

Hamburg, Germany, also presented her research at the Conference. Based on 14 years of research and treatment of lipoedema patients, Dr Faerber shared case histories of patients experiencing dramatic improvements following the keto diet. Many lost large



In ongoing research by Lipoedema UK and De Montfort University, one in five participants (20%) who tried weight loss experienced improvement in their lipoedema symptoms. 257 women participated in the study led by Dr Jessica (Yunnan) Jin, Senior Lecturer in



What are anti-inflammatory and keto diets

WHOLEFOOD FOCUS

Both anti-inflammatory and keto diets focus on wholefoods and avoiding processed foods. Wholefoods are one-ingredient foods that you find in nature – like an apple, orange, cucumber, fish or wholegrains such as brown rice or brown wheat. Foods, like hummus, that have more than one ingredient can be wholefoods if they are made up of wholefood ingredients with minimal processing and preserving.

AVOID PROCESSED FOODS

Both diets recommend avoiding processed foods – especially those with lots of sugar, salt, and ingredients you don't recognise. That's snacks like crisps, commercially baked goods, ready meals, fried foods like chips and sugary/artificially sweetened drinks.

KETO: PROTEIN FOCUS

The big difference between the two diets is that whilst the anti-inflammatory diet takes a Mediterranean approach focused on fresh vegetables, pulses, grains and meat, the keto diet is high-fat, low carb with plenty of protein and vegetables, but with only a very small amount of carbs a day. Faerber's patients were restricted to 50g. This typically means eating lots of unprocessed meats and vegetables with few grains such as bread, pasta, rice and pizza – whether they're wholegrains or not.

257 women participated in the Lipoedema UK /De Montfort University study

20% who tried weight loss experienced improvement in their symptoms

83% had improved symptoms after 3 years (in Faerber's research)

amounts of weight, with accompanying reductions in thigh and calf circumferences. They also reported reductions in other symptoms, such as pain and restricted mobility. 83% reported an improvement in symptoms three years later. However, the diet's restrictive nature can make it very hard to maintain and it is not recommended for all patients.

One 52-year-old lost 19kg in 14 weeks following a 600-calorie a day keto diet with omega 3 supplements. Her lipoedema had led her to retire early due to pain and sensitivity, but after the weight loss diet, she was pain free and able to re-join her table tennis team again. Another 118kg patient lost 50kg in 32 weeks, losing 18-21cm around each thigh. This means she lost 42% of her total original body weight. For many of Dr Faerber's patients, pre-diabetes markers, such as insulin resistance, were also improved.

Other studies have also shown that lipoedema patients are less likely to suffer from diabetes than patients who are also

considered overweight. This adds to the case that lipoedema fat is different to the typical excess weight associated with obesity.

According to Dr Faerber, the majority – 62-88% – of lipoedema patients are obese. But many are diagnosed with obesity using their Body Mass Index (BMI). This is based on weight-height ratio, and does not take into account unhealthy abdominal (tummy) fat.

Abdominal fat is linked to cardiovascular disease, Type 2 diabetes, breast cancer in women, dementia and shorter life spans.

Dr Faerber joins the increasing consensus in the medical community that a waist-

height ratio is much more reliable measure of obesity, noting that some of her patients' small waists show that they are not obese, but suffering from lipoedema. Waist-height ratios (WHtR), are calculated by dividing your waist by your height. For women, a result over 0.49 indicates being overweight, over 0.58 indicates obesity. Using this measurement might help women with lipoedema demonstrate that their weight is due to their condition, de-stigmatising lipoedema and improving access to treatment.

These findings provide hope, but more research is now needed to identify exactly which diets are effective so that women can have the guidance they need to manage their lipoedema.

"One 52-year-old lost 19kg in 14 weeks following a 600-calorie a day keto diet with omega 3 supplements"

Please help us recruit a candidate for this fabulous opportunity

Can you help us find a candidate? Lipoedema UK and De Montfort University are recruiting a full time PhD student to help answer the urgent question of whether the inflammatory properties of diet affect the severity of lipoedema. The position is full time for three-four years, based in the UK. By sharing this job ad with your networks, or apply yourself via this link: <https://www.findaphd.com/phds/project/dietary-intervention-and-efficacy-in-improving-lipoedema-symptoms-among-patients-in-the-uk/?p133563>

Become a regular giver

Regular and reliable support has never been more important than now. Regular donations via standing order/direct debit provide valuable income to help Lipoedema UK create the legacy of a better future for future generations.

We are all frustrated and angry by the way that it can take an average of 30 years from the onset of lipoedema to a diagnosis. We want to eliminate the pain, struggling, feelings of isolation and despair this delay can bring.

Lipoedema UK works tirelessly to help ensure the medical community is equipped to diagnose and support lipoedema.



But this costs money. For example Lipoedema UK paid over £14,000 for the Royal College of GPs e-learning course on Lipoedema. If you could kindly contribute a set amount each month, we can target more medical institutions, the government and influential research organisations, to create the Legacy we all want – and future generations deserve!

To donate or set up regular payments direct, please visit <https://bit.ly/3NrtQJX>

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 of their products, including made-to-measure compression garments, are available on prescription through a lymphoedema clinic or GP surgery. Should you encounter any issues with a repeat prescription or the fit of a garment, they all provide excellent customer care.

Many prescriptions can be provided directly through a specialist mail order pharmacy which may provide a speedier service than a local pharmacy.

Haddenham Healthcare

Haddenham Healthcare are a family-owned UK based company, who for over 20 years have specialised in products and services for managing lymphoedema, lipoedema, wound care and breast care. We pride ourselves in being innovative, responsive and are often told we stand out by being problem solvers.

We designed our *Eto Grace* compression tights specifically for people living with lipoedema. *Eto Grace* tights are:

- Supportive and breathable
- Easy to put on
- Machine washable
- Cost-effective
- Suitable post surgery
- hadhealth.com

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



Compression garments enable many people to enjoy everyday activities

Photo courtesy of Sigvaris

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.

- www.mediuk.co.uk

Sigvaris

At Sigvaris, we care about people. For 155 years, our products including compression, have offered effective and reliable solutions – anywhere, anytime, and for anyone.

Sigvaris understands that people aim to be their best – everywhere, every day. So, we strive to offer:

- medical effectiveness and reliable relief
- best-in-class quality, craftsmanship and durability
- freedom of movement, comfort and fit.

Our shared passion for helping people is what got us here, and we're excited to take our next step towards wellness together.

- www.sigvaris.com

Jobst/Essity

JOBST® is an Essity brand. Essity is a leading global hygiene and health company dedicated to improving well-being through providing excellent products and services in the wound care, compression therapy,



orthopaedics and incontinence areas. Together with JOBST®, Essity's key brands include TENA®, Leukoplast®, Cutimed®, Actimove® and Delta-Cast®.

• www.jobst.co.uk

Thuasne

Founded in 1847, Thuasne imagines, develops and manufactures medical devices allowing everyone to become actors in their own health.

For six generations, the Group offers concrete, adaptive and innovative health solutions including Mobiderm for lymphoedema and lipoedema sufferers. Mobiderm technology consists of foam cubes within pads, bandages and garments which promote lymphatic circulation and assist in the softening of fibrotic tissue.

• www.thuasne.co.uk

Human Med

As an innovator in water-jet assisted technology, HUMAN MED® is the leader and the world's largest manufacturer of water-jet assisted medical devices for aesthetic and plastic-reconstructive surgery as well as regenerative medicine. Based on many years of success in the areas of general surgery, urology and neurosurgery, in 2004 HUMAN MED® dedicated to aesthetic and plastic-reconstructive surgery as well as regenerative medicine.

• www.humanmed.com

PhysioPod UK LTD

PhysioPod® UK Ltd are the exclusive distributors of DEEP OSCILLATION® therapy, an internationally patented and effective treatment option used to manage pain, the oedema element of lipoedema and to reduce the 'heavy leg feeling' in lipoedema.

The gentle non-invasive electrostatic impulses of Deep Oscillation are delivered via vinyl gloved hands as a massage which permeates a tissue depth of 8cm. PhysioPod have a small number of units which can be hired for pre- and post-liposuction to

enhance the recovery process; reducing pain, bruising and oedema.

PhysioPod is run by sisters, Julie Soroczyn and Mary Fickling who are advocates for ladies living with Lipoedema.

• www.physiopod.co.uk

"All of these companies provide excellent customer care, should you encounter any issues with repeat prescription or the fit of a garment"

Compression Therapy 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 Lympa 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.

• www.compressiontherapyuk.com



Compression tights worn by a mother and her daughters after liposuction on their legs. Compression garments are recommended to maintain the beneficial effects of surgery

Photo courtesy of Haddenham





Lipoedema
UK

AWARENESS, DIAGNOSIS, TREATMENT & RESEARCH

Lipoedema patients have been badly let down by all governments and medical institutions. It is scandalous, that in the 21st century, patients are left responsible for funding and researching their own illness.

Lipoedema has the potential to change young, healthy, active teenagers, (almost exclusively girls) into adults suffering **unbearable pain and disfigurement** that blight their career prospects, family life and ultimately their independence.

National Institute for Health & Care Excellence (NICE)'s acknowledgement of the need for research into treatments, means healthcare and government policy makers must make it their priority to remove the **disgraceful and discriminatory inequality** of treatments currently experienced by all lipoedema patients.

NICE's ruling will not keep patients safe. It has effectively closed down all UK surgery, both NHS and private. This potentially increases the risk to lives by forcing patients overseas, without adequate safeguards or support.

NICE's caution also leaves patients in great **economic hardship** as they are forced to fund their own treatments by taking out huge loans, mortgaging their homes, or cashing in pensions. Without access to treatment, many patients find their future bleak.

Hundreds of thousands of families currently suffer the devastating effects of lipoedema. Many have already chosen to pay for private surgery from dedicated and experienced surgeons and as a result enjoy a better quality of life, free of many of lipoedema's painful and debilitating symptoms.

Create a Legacy, by fundraising and donating to Lipoedema UK, to help us campaign for fairness and NHS treatment for all lipoedema patients.

Lipoedema is genetic and can strike any family at any time.

Sharie Fetzer

Sharie Fetzer
Lipoedema UK

Visit Lipoedema UK to find out about diagnosis, treatment options and our pioneering work to help change the future for people living with lipoedema

lipoedema.co.uk info@lipoedema.co.uk

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

Become a member
of Lipoedema UK

We are committed to creating a brighter future for our members and their families.

Join our caring community of people who understand your fears and frustrations. Benefits include:

- Leaflets and info to share with your GP and healthcare professionals
- Email newsletters with updates on Lipoedema UK activities and latest developments
- Invites to exclusive Health and Wellbeing online/'zoom' sessions
- Access our nurse consultants team
- Presentations from experts
- Opportunity to share experiences in a safe environment
- Invitations to lipoedema events and conferences
- Opportunity to participate in research projects
- Lipoedema UK Awareness/ Fundraising posters, badges and postcards
- **Individual Membership - only £25 p.a.**
- **Healthcare Professional Membership - only £25 p.a.**

To join us, simply visit:

www.lipoedema.co.uk/membership/

A new lipoedema book...

ALL ABOUT LIPOEDEMA

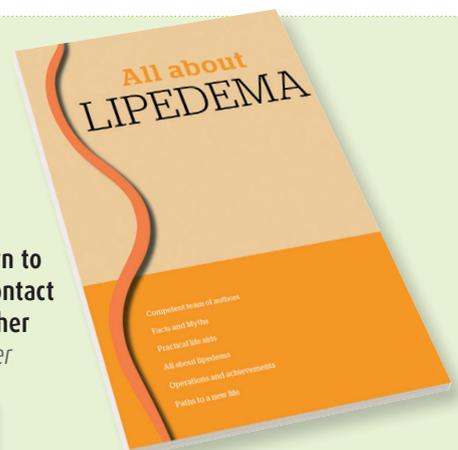
A really informative book written by a patient and her family to help others navigate the many aspects of lipoedema.

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

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Why wasn't the recommendation more positive?

NICE require a high standard of evidence before it places the treatment into its Standard Arrangements category, so it often takes quite some time from people benefiting from self-funded care to NICE endorsement. The intention of its guidance is to help patients to "receive care that is based on the best available clinical evidence". NICE's four types of classification show that it is very focussed on making cautious and deeply evidence based assessments.

As some patients in the UK have experienced problems after liposuction, the aim of NICE guidelines is to reduce the risk of adverse outcomes for future patients by setting out a basis on which the treatment should or should not be provided.

NICE recognises that it is very difficult to have "gold standard" randomised trials into liposuction, and that who funds research is a big challenge. However, NICE is focussed on rigorous assessment and evaluation of research, so not all the current research meets NICE's specific requirements. We are aware of other conditions and treatments where despite positive patient feedback and self-funding, the NICE endorsement process and encouragement of routine NHS funding has taken years of evidence gathering and engagement.

What is the good news in the NICE guidance?

NICE very clearly and repeatedly stated that lipoedema is different to obesity and lymphoedema. That distinction, and its acknowledgement that the emerging evidence into bariatric surgery and lipoedema relates to people who have lipoedema and obesity, not just lipoedema, is helpful to educate NHS service providers and to look at the recommendations around bariatric surgery and lipoedema in the future.

The NICE reviewers developed a good understanding of the challenges that living with lipoedema can present, and this was stated by them during NICE's public consultation meetings online. NICE was also positive about the number of respondents



Photos courtesy of the patient

ABOVE: 30 year old UK patient, diagnosed by a leading UK consultant and told that her condition would deteriorate to the point that she would need to use a wheelchair within 15 years. Despite her being accepted as an ideal candidate for NHS surgery, NHS funding was denied. Her family fund-raised the £15,000 needed for 3 surgeries in Germany. She now leads a normal life, no longer needs pain medication, and is successfully managing her lipoedema with compression garments. Top photos immediately before first surgery (age 30), bottom photos 12 months later after third surgery (age 31)

in our survey and how many patients made contact throughout the consultation. We showed that we are an engaged community, and are determined to improve patient experiences.

NICE's awareness of our needs and the necessity to improve NHS lipoedema treatment in general, will help us as we continue to work to broaden the lipoedema services in the UK. We can refer to NICE's statements such as:

"The size and shape of legs and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life and physical and mental health."

What can I do now?

- **Keep sharing your stories with us**, so we can continue to build our case studies. A picture is worth a thousand words too!
- **You can write to NICE** to express your feelings at nice@nice.org.uk.

- **You can write to your MP** to ask them to engage with us to address the wider issues around NHS lipoedema treatment and tell them how you feel about the challenges of self-funding care, where appropriate.
- **Keep spreading the word about membership.** The more people who join us, the stronger our voice is with authorities and institutions.
- **Access our materials for healthcare professionals** or take your GP information pack to your next appointment. We have some great healthcare professional engagement and want to grow and grow this.

We've come a long way in a few years, and have a long way still to go, but...

"Together we will beat lipoedema"

Lipoedema Awareness month

Don't miss out on these important webinars - save these key dates:

8th June
20th June
23rd June
1st July...

Starting on 8th June with an update on the latest news by Dr Karen Herbst and Dr Thomas Wright, Lipoedema UK will be co-hosting a series of webinars featuring prominent researchers. International experts will present on liposuction, bariatric surgery, diet and inflammation – plus a special Lip UK feature on early stage Lipoedema.



What's going on in lipoedema?

RESEARCH UPDATE

8TH JUNE 2022

with Karen Herbst, PhD, MD
& Thomas Wright, MD

Watch out for more information in our newsletters, website and social media...

FUN & FUNDRAISING

Congratulations to Zoe Blyth on raising £675 for Lipoedema UK by walking 5K. Zoe, from Dorset, completed the fundraising walk after registering her charity challenge on the Lipoedema UK Just Giving website.



"It was a gorgeous route with spectacular scenery... and we received some lovely supportive comments regarding Lipoedema," shares Zoe who was

accompanied by her dog and friend Jane. "Jane is very supportive and also very funny so we had a good laugh during the walk."

We hope Zoe and will inspire you to complete your own challenge. Don't forget, challenges like sponsored walks can always be completed in several stages if you don't feel you can walk the whole distance in one go it in one go.

The money raised by you and Zoe will help Lipoedema UK's constant fight for better awareness and treatment for lipoedema. Thank you Zoe, you always inspire us all.



To take part, or for more info, please scan the QR code or visit www.justgiving.com/lipoedemaUK



Get involved in June's Lipoedema Awareness Month

June is Lipoedema Awareness Month and we need your help to make it a massive success! Organisations from around the world are coming together to raise awareness of lipoedema and the importance of ensuring patients have better access to treatments, and the need for more research into the condition.

You can help too by organising your own Lipoedema UK fundraiser, such as a coffee morning sponsored cycle ride, swim or walk. We take our hats off to Pia one of our members who is currently in training for the London Marathon.

Congratulations to members who completed our Lipoedema UK Ambassador Expert Patient Day on May 7th, do keep us posted on your progress.

Everyone can make June the month you raise awareness of lipoedema, such as by giving your GP practice, hospital or leisure centre some Lip UK leaflets. Why not ask your local supermarket, village fete, etc, if you can have a stand!

"Together we will beat lipoedema"

Lipoedema
Charity No 1181312
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