

WOMEN'S HEALTH – LET'S TALK ABOUT IT

DEPARTMENT
OF HEALTH
AND SOCIAL
CARE

RESPONSE FROM LIPOEDEMA UK

Submitted by Suzanne Evans,
Founder and Trustee

Revised & updated May 2024

Lipoedema UK was pleased to have the opportunity to respond to the government's call for evidence to address inequalities in women's health. We recognise from our work with both women and the health professionals who treat them that there is most certainly a 'gender health gap' and one that is especially visible when it comes to the treatment of lipoedema, a condition suffered almost exclusively by women.



Executive summary of the main points made in our submission

- Women with lipoedema are unlikely to receive a diagnosis of their condition until middle age, despite symptoms usually first coinciding with puberty. Greater awareness is needed within the medical community and the general public, so women can be diagnosed and supported earlier.
- A failure to adequately fund and support nationwide lymphoedema services, where lipoedema is most likely to be diagnosed, or standalone lipoedema services, means women in dire need of treatment are refused help. Integrated Care Boards (ICBs) should allocate resources and funding for lipoedema patients to prevent higher long-term NHS costs and an unacceptable quality-of-life cost to women patients.
- Lipoedema UK challenges the current NHS philosophy that specialist liposuction for lipoedema is 'cosmetic' surgery and therefore should not be funded. We believe this misrepresents the facts and is clear evidence of women's health inequality, given the life-changing potential of such surgery.
- Women with lipoedema regularly experience prejudice within the public health service. Lipoedema UK suggests this can be explained by a strong implicit and explicit anti-fat bias that evidence suggests is as pervasive among medical doctors as it is among the general public.
- If the healthcare system is to work for everyone, the ingrained anti-fat bias within the medical profession must be tackled. Public health is not well served when it discriminates against women with non-normative bodies who are wrongly labelled 'obese'.

- Lipoedema UK research suggests the existing workplace gender pay gap is exacerbated for women with lipoedema. They are doubly discriminated against by being prevented from advancing in their careers because of ill health, and therefore not having sufficient funds to pay for private treatment which could enable them to get their lives and careers back on track.

A woman should not be treated as a small man

Lipoedema is a chronic, genetic condition, the main symptom of which is disproportionate adipose (fat) tissue that affects any or all of the hips, buttocks, lower limbs and arms. It usually first manifests at puberty. The condition may worsen with later hormonal changes, such as birth control use, pregnancy and menopause. Unlike the normal fat caused by obesity, fat that accumulates with lipoedema is often painful, and does not reduce in response to diet and exercise. The condition is not well recognised within the medical profession, making it difficult to assess with any accuracy the numbers of women affected, although estimates have been made.¹ Part of the reason that lipoedema may be under-diagnosed is that it may be mistaken for other conditions that cause subcutaneous tissue enlargement/swelling or fat deposition. The two most frequent misdiagnoses are generalised obesity and lymphoedema. Lipoedema almost exclusively affects women with only a few cases reported in men.

For more information visit www.lipoedema.co.uk or www.nhs.uk/conditions/lipoedema/

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LEFT: In the early stages, signs and symptoms may be mild but may worsen as the disease progresses

How lipoedema impacts women

Women with lipoedema may experience various physical impairments, including painful knee joints; heavy, aching legs; limbs that may be agonisingly painful if squeezed even gently; easy bruising; chafing skin between the thighs and/or knees; itching or flaky skin; foot pain; gait impairment; tiredness; problems going to the toilet; and the development of lymphoedema.

If allowed to advance untreated or if it manifests

in a severe form, lipoedema can lead to a severe loss of mobility as both the weight and location of excess fat cells restricts, distorts, and puts considerable pressure on joint movements.

For many women, the psychological impact of lipoedema is as bad as, if not worse than, the physical. They may face considerable prejudice because of their misshapen bodies and experience mental health trauma, which in turn fuels self-imposed restrictions upon, or difficulties with, aspects of life such as eating habits, socialising, relationships, sport and exercise.

A study conducted by Lipoedema UK between 2012 and 2014 surveyed 250 women with a medical diagnosis of lipoedema about their lived experiences. The study found:

- **95%** reported difficulty buying clothes
- **86%** reported low self-esteem
- **83%** avoided having their photograph taken
- **60%** reported a restricted social life
- **60%** reported feelings of hopelessness
- **50%** reported a restricted sex life
- **47%** reported feelings of self-blame
- **45%** reported eating disorders
- **19%** reported being on state benefits as a result of debilitating lipoedema symptoms.²

Subsequent research and our practical experiences running Lipoedema UK, taking phone calls and emails, and hosting conferences and events for patients, regularly confirms these statistics.

The lived experiences we hear about daily chime with international academic research into lipoedema and quality of life. For example, a Polish study of women with lipoedema found participants reported low quality of life and displayed a high severity of depressive symptoms.³

About Lipoedema UK

Lipoedema UK was set up as a national patient charity in 2011 by women with lipoedema and clinical staff in the Lymphoedema Service at St George's University Hospitals NHS Foundation Trust in London. We continue to work with St George's Hospital and other specialist clinics and organisations focusing on lipoedema, both nationally and internationally.

We contributed to the NHS Website's 'Lipoedema' page; put together the expert working group to inform publication of the *Best Practice Guidelines for the Management of Lipoedema*, and commissioned an eLearning course in lipoedema with the Royal College of General Practitioners, which is also endorsed by the Royal College of Nursing.

We support women with lipoedema through our network of specialist health professionals, informal social and focus groups, host regular webinar presentations and discussions, and hold regular conferences and exhibitions for patients, medical professionals and relevant medical device manufacturers to attend in person.

¹ For example: "Specialists estimate that the disease affects 7 to 11% of adult women in western countries" *Quality of Life, its factors, sociodemographic characteristics of Polish women with lipoedema*: Joanna E Dudek, Wojciech Białaszek and Marcin Gabriel. *BMC Women's Health* 2021 <https://bmcmenshealth.biomedcentral.com/articles/10.1186/s12905-021-01174-y>

² *Lipoedema UK Big Survey 2014 research report* <https://lipoedema.co.uk/wp-content/uploads/2024/03/LATEST-LUK000-UK-Big-Survey16-Mar24-web.pdf>

³ Dudek, J.E., Białaszek, W. & Gabriel, M. *Quality of life, its factors, and sociodemographic characteristics of Polish women with lipoedema*. *BMC Women's Health* 21, 27 (2021). <https://doi.org/10.1186/s12905-021-01174-y>

Lipoedema is commonly misdiagnosed and untreated

We would like to be able to point to clinical examples of outstanding practice in the treatment of lipoedema but although the work we have done in raising awareness of the condition means these do occur on occasion, most women with lipoedema feel they are being badly let down by the NHS system.

They suffer unnecessary physical and mental health traumas, firstly because their condition is not well recognised within the medical profession – hence it is often misdiagnosed, misunderstood and mistreated – and secondly due to a lack of access to effective treatments.

In the aforementioned Lipoedema UK Big Survey 2014, **only 9%** of respondents reported that their health professional diagnosed lipoedema when they first reported their symptoms, and **only 5%** were diagnosed by their GP.

Despite initial lipoedema symptoms usually presenting at puberty, the average age of diagnosis for our survey respondents was 44 years of age.

The failure to diagnose lipoedema is not only based on a lack of medical training but also, we believe, on social expectations of what a woman's body fat content should be, and an assumption that all women should be able to control their body fat content through diet or exercise (something that is impossible with the excess fat caused by lipoedema). This would explain why the overwhelming majority of women with lipoedema, when presenting with symptoms to their primary healthcare professional, will be misdiagnosed as simply 'fat'.

There is an urgent need for better awareness of lipoedema throughout the medical community and the general public, so that women can be diagnosed as early as possible to enable management to help prevent progression and improve quality of life. There is also considerable need for research into both treatments and, ultimately, finding a cure.

A call to commission lipoedema services

Lymphoedema services have been supportive and are able to provide diagnosis and compression garments, but there is a postcode lottery regarding referral to these services, which are overwhelmed. As a result, some patients have been declined referral for lipoedema, and/or there is a BMI limit on referrals. This means that lipoedema patients have no access to compression garments (both measurement and supply). This is the absolute minimum that should be available to reduce pain and improve mobility.

Furthermore, lymphoedema clinics are not able to provide the other specialist services required by patients to enable them to self-manage their condition and prevent further deterioration.

Many lipoedema patients, especially those who have been misdiagnosed as obese for many years, require psychological services, diet and lifestyle advice and specialist weight management support. They will also require physiotherapy to help manage the physical strain of a disproportionate weight distribution on their joints and they may require specialist pain management. It is unacceptable that women in dire need of treatment have nowhere to turn; unless they can afford to pay privately for diagnosis and treatment, they are nearly always refused help. They feel not only let down by the NHS system – they feel actively dismissed by it.

Lipoedema UK believes it is imperative that ICBs allocate resources and specific funding for lipoedema patients. If this does not happen, the long-term economic cost of not treating women will lead ultimately to higher NHS costs, and an unacceptable social and quality-of-life cost to the women themselves.

A call for access to specialist liposuction for lipoedema

A second area in which women with lipoedema are failed by health services is in the area of specialist liposuction for lipoedema. Numerous surgeons throughout Europe specialise in the surgical management of lipoedema and have been able to demonstrate the benefits of such surgery. This surgical approach differs from liposuction used for purely cosmetic reasons, because it uses a different technique to remove abnormal adipose lipoedema tissue, resulting in improved quality of life. Many of our members who have been able to afford it have travelled overseas to access this specialist liposuction, and consequently, Lipoedema UK has amassed



ABOVE: A Lipoedema UK survey asked questions about post-operative symptoms such as bruising, pain, swelling and inflammation which were commonly experienced up to 12 weeks post-operatively

a considerable body of evidence showing that liposuction for lipoedema does have a significant, positive effect on the physical mobility and mental health of those women who undergo such surgery.⁴

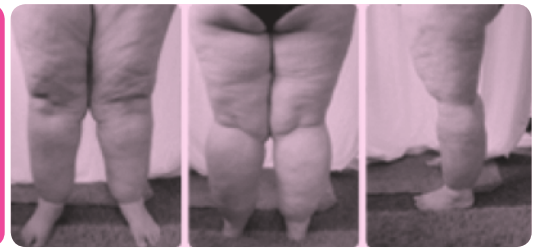
Specialist liposuction can also help with mobility impairment, chronic pain and mechanical issues. Evidence from Thomas Stutz (2011) and Thomas Wright (2023) indicates that the abnormal accumulation of fat seen in lipoedema can result in gait and mechanical issues which can lead to orthopaedic abnormalities. Knee joint abnormalities, for example, are often seen in lipoedema patients and can lead to mobility problems and disability. Many individuals living with lipoedema have approached Lipoedema UK for advice from our clinical advisors regarding questions over knee replacement surgery – for many, this is denied by some orthopaedic surgeons because of concerns over the 'swelling' or fat accumulation.

Evidence by Thomas Wright (2023) indicates that liposuction in lipoedema can improve knee range of movement by 8°, as well as improvement in valgus rotation, and that it can be more cost effective than a total knee replacement surgery. Their evidence found that liposuction will improve patients' movement, gait (seen in 84%) and pain levels, promoting independence and an improved quality of life.

Other medical studies confirm the following:

- a 'Patients showed significant reductions in spontaneous pain, sensitivity to pressure, feeling of tension, bruising, cosmetic impairment, and general impairment to quality of life from the preoperative period to the first postoperative follow-up, and these results remained consistent until the second postoperative follow up... Liposuction is effective in the treatment of lipoedema [sic] and leads to an improvement in quality of life and a decrease in the need for conservative therapy.'⁵
- b '106 patients who underwent a total of 298 liposuction procedures were included in this study... Multiple comorbidities were observed in the assessed collective. The prevalence for obesity, hypothyroidism, migraine, and depression were markedly increased in relation to comparable non-lipoedema populations... After surgical treatment, a significant reduction of lipoedema-associated symptoms was demonstrated.'⁶

In 2021, Lipoedema UK was heavily involved in a consultation process with the National Institute for Health and Care Excellence (NICE), providing evidence for the NICE review on guidance for Non-Cosmetic Liposuction (NCL) as a proposed interventional procedure for chronic



ABOVE: This 30-year-old UK patient was 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 being accepted as an ideal candidate for NHS surgery, she was denied NHS funding. Her family raised the funds needed for three surgeries in Germany. She is shown here, top, immediately before surgery (age 30). The post-operative pictures below were taken 12 months after her third surgery (age 31).

lipoedema. NICE did a rapid review of the published literature on the efficacy and safety of this procedure.

'The committee recognised that there were currently limited treatment options for this condition and that there was a need to define the most safe and effective treatment for it. The committee also recognised that there needs to be more research into patient selection, to understand who would benefit most from this procedure. These factors underpinned the recommendation for further research. The committee noted that this condition is distinct from obesity and lymphoedema.'⁷

NICE concluded that lipoedema is still under-recognised and can be extremely debilitating, but wants to see more published evidence into longer-term improvements to patients' quality of life and safety. NICE also wants to see more research into patient selection and outcomes – for example, patients' age and the severity of their lipoedema before surgery, as well as outcomes including changes to patients' weight.

The NICE recommendations have stifled all existing liposuction in the UK and exacerbated the shortage of trained plastic surgeons able to perform liposuction operations on women with lipoedema in the UK, and increased the reluctance of the NHS to fund such surgery. At the same time, the longer-term effects of Covid and financial crisis within the NHS have restricted even further access to both lymphoedema and multi-disciplinary services required to holistically manage lipoedema.

⁴ *Life after liposuction: the life-changing impact of surgery on lipoedema patients' lives*, A Lipoedema UK Focus Group Report, Series no:3. Amy Fetzer BA (Hons-Psychology) MSc (Distinction); Mary Warrillow RGN, BSc (Hons), QN, Joint Founder, LymphCare UK, Independent Nurse Consultant. See: <https://lipoedema.co.uk/wp-content/uploads/2024/04/LUK-FGR-Liposuction-Web-ne.pdf>

⁵ *Liposuction in the Treatment of Lipoedema: A Longitudinal Study*: Mehran Dadras, Peter Joachim Mallinger, Cord Christian Corterier, Sotiria Theodosiadi, Mojtaba Ghods; published in the Archives of Plastic Surgery, Vol 44, No 4, July 2017

⁶ *Disease progression and comorbidities in lipoedema patients: A 10-year retrospective analysis*. Ghods, Georgiou, Schmidt and Kruppa. Dermatologic Therapy. 6th November 2020 <https://doi.org/10.1111/dth.14534>

THE ANATOMY OF LIPOEDEMA



Lipoedema UK welcomes NICE’s commitment to review its decision as and when any emerging relevant evidence on the benefits of liposuction as a safe and effective treatment for lipoedema is published. NICE stated that it undertook a ‘rapid review of the published literature on the efficacy and safety of this procedure’ back in 2022.⁷

Many consider liposuction to be merely cosmetic, but evidence indicates that in lipoedema management, liposuction is a cost-effective way to manage symptoms – improving pain levels, movement and gait, reducing bruising and preventing orthopaedic conditions and disability, as well as preventing/addressing psychological problems around body image, eating disorders, anxiety and depression.

Although conjecture, as men only very rarely contract lipoedema, we do question whether a man walking into his GP surgery complaining of increased weight and bulbous fatty pads, which are completely at odds with the rest of his slim body, along with pain and reduced mobility, would not be taken seriously.

However, such is the perception of women’s ‘obsession’ with their body shape and size, and the myth that ‘fat’ is always the fault of the individual and their eating habits, that the overwhelming majority of women who report such symptoms are all quickly dismissed with diet and exercise advice.

Lipoedema UK continues to advocate for the choice of early liposuction for women with lipoedema. We have numerous personal testimonials and experience of patients for whom this surgery has been life-changing. The benefit to the NHS of this surgery is that it can prevent a vicious cycle of depression, frustration, eating disorders, pain, immobility, disability, isolation and financial insecurity, as highlighted above.

Lipoedema UK suggests that withholding potentially life-changing surgery from women is evidence of a clear inequality in women’s health. At the root of this discrimination is medical anti-fat bias; the myth that women are wholly responsible for their body weight; and that those who are not slim are ‘greedy’ and deserve punishment and social ostracisation, rather than help.

In line with other conditions that affect health and quality of life, people with lipoedema should be given the opportunity to access funding for remedial specialist liposuction on an IFR (individual funding request), and have a specialism that they can be referred to for conservative and surgical management when necessary.

Evidence of medical ‘anti-fat bias’

Lipoedema and lipodystrophy disorders should be incorporated into the medical and nursing curriculum as part of undergraduate and postgraduate training. The only formal training currently available on lipoedema is online via the RCGP website, but this doesn’t get universal footfall. The widespread failure on the part of health professionals to recognise and treat lipoedema is due to lack of awareness of the condition, but it is leading to significant numbers of diminished and missed life-chances for women. It is a failure at odds with the Hippocratic oath to ‘do no harm or injustice’ to patients and the National Health Service’s constitutional commitment to ‘everyone counts’.

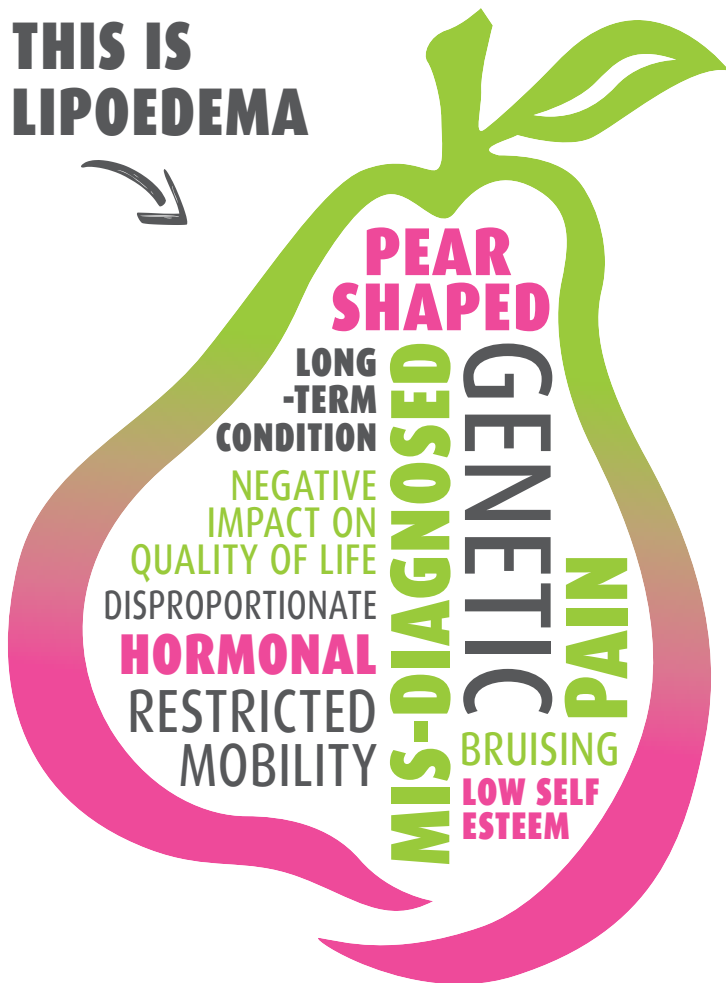
Lipoedema UK believes that the prejudice experienced by women with lipoedema can be explained by a strong implicit and explicit anti-fat bias that is sadly as pervasive among medical doctors as it is among the general public. Numerous studies have established that overweight patients face weight discrimination in healthcare settings and consequently receive a sub-standard level of care.⁸

⁷ www.nice.org.uk/guidance/ipg721/chapter/3-Committee-considerations

⁸ See for example: (1) *Medical fat bias: Implicit and explicit anti-fat bias among a large sample of medical doctors by BMI, race/ethnicity and gender*. Janice A Sabin, Maddalena Marini, Brian A Nosek. Department of Medical Education and Biomedical Informatics, University of Washington, Seattle, WA, USA. See: <https://pubmed.ncbi.nlm.nih.gov/23144885/> (2) *Implicit and explicit weight bias in a national sample of 4,732 medical students: the medical student CHANGES study*. Sean M Phelan, John F Dovidio, Rebecca M Puhl, Diana J Burgess, David B Nelson, Mark W Yeazel, Rachel Hardeman, Sylvia Perry, Michelle van Ryn. Division of Health Care Policy and Research, Mayo Clinic, Rochester, Minnesota, USA. See: <https://pubmed.ncbi.nlm.nih.gov/24375989/>

For people with Lipoedema, BMI can be misleading and has limited value due to the falsely high values in the areas affected by lipoedema. Waist-to-height ratio (WHR) is increasingly considered a more accurate assessment of the disproportionate fat distribution associated with lipoedema.

THIS IS LIPOEDEMA



As lipoedema is a fat disorder, women with lipoedema face the full impact of this discrimination. Indeed, the stigma against them is exacerbated, we believe, by the additional social and media expectations placed on women in particular to be slim.

Lipoedema is not caused by overeating, nor a lack of exercise, and so neither dieting nor exercising more can shift the excess fat caused by it. It is a genetic, currently incurable condition. Unfortunately, though, because the condition is so poorly understood by primary healthcare service providers, when women present with symptoms, they frequently find themselves being judged, shamed and blamed, either implicitly or explicitly. They are nearly always initially labelled 'obese' and told the only thing wrong with them is that they need to lose weight.⁹

Patients who protest they are not overeating are met with allegations that they are 'in denial' about their food consumption. They are considered to be telling untruths when they claim honestly that despite attempts to diet and lose weight, their legs/hips/arms either do not reduce or keep getting bigger. Women then develop a sense of hopelessness in the face of anti-fat and humiliation that lessens their ability to advocate for themselves in healthcare situations, and they can feel abandoned by primary care providers.

By the time lipoedema is diagnosed (if it ever is), decades may have passed and severe damage may have been done to women's mental and physical health. Ironically, by this time, women may have become obese as, having been assured eating less will solve the problem, when it doesn't, lack of tangible results from conventional diets can lead to developing an eating disorder such as restrictive eating (anorexia) or binge eating.

These examples from our case files are typical of the stories we hear again and again:¹⁰

"Some days I feel so angry. My whole life I've struggled with the way I look. I developed an eating disorder and became morbidly obese. Every doctor and nurse I ever spoke to always had something negative or unpleasant to say about my weight and it completely takes over your life."

"Over the years I had become convinced by the medical professionals that the way my legs were was my responsibility. I was too fat, they were made that way, put up with it, be grateful they still work etc. So, I just accepted it and made the best of it."

⁹ The extent of this problem, and the damage this misdiagnosis does, cannot be underestimated. Our case files have many examples of women who are clearly very underweight still being told to diet when they present with excess fat on their legs, hips and arms. We know cases of anorexia nervosa that have been missed by GPs as a consequence.

¹⁰ These women's full stories are on our website: See <https://lipoedema.co.uk/member-stories/>

Medical professionals have been told to tackle obesity in consultations to enable patients to get support. However, these professionals aren't taught how to approach this, and very often services may not be available for referrals. The lack of education in lipoedema and fat dystrophy disorders for clinicians throughout their careers leads to lipoedema patients feeling misunderstood, unsupported and judged.



Lipoedema and the gender pay gap

Finally, we wanted to draw the inquiry's attention to evidence of a vicious circle that appears to plague women with lipoedema, one that makes it much more difficult to find and/or hold down a job and achieve financial stability and security.

We have made the case that women with lipoedema suffer prejudice from both the general population and the medical profession because of their size and non-normative body shape, meaning they are more likely than the wider female population to develop mental health problems and suffer from low self-esteem.

They may also find it more difficult to establish healthy, supportive relationships.

These factors alone make it more likely from the outset that

women with lipoedema are 'on the back foot' as it were when it comes to securing well-paid, secure work. Over time, as the physical toll that lipoedema takes on the body increases with worsening symptoms, many women find that their career fails to progress. The severity of both physical and mental health symptoms might even be career-ending: **51%** of women completing the Lipoedema UK Big Survey 2014 agreed that lipoedema had an impact on their ability to carry out their chosen career. They cited a lack of mobility, discomfort and inability to stand as key reasons for this.

Additionally, **39%** felt lipoedema had actively restricted their career choices. Two examples from our files:

"I lost my career as I didn't know what was wrong with me and I couldn't physically do the work anymore. So we got into debt. We're now in rented accommodation, with nothing to show for our careers."

"My lack of mobility cost me my career and 25 years of mortgage payments because I was prevented from earning an income."

Our research suggests the existing workplace gender pay gap is exacerbated for women with lipoedema who may experience financial hardship because their ill health prevents them advancing in their careers. Many are also doubly victimised as they are unlikely to have the means to pay for private treatment which could enable them to get their lives and careers back on track.

Conclusion

Lipoedema UK has made great strides in raising awareness of lipoedema since our inception in 2011. However, this success has created a situation whereby more women realise what is wrong with them, and therefore seek support and treatment, but because many healthcare providers remain unfamiliar with lipoedema or unable or unwilling to treat it, women continue to experience the frustration of being excluded and let down.

Our pioneering work with the Royal College of General Practitioners has led to 4,000 downloads of completed eLearning courses, so awareness of lipoedema is growing, but the NHS is not keeping pace.

We hope that this document highlights the difficulties and prejudices faced by a specific female population, and we continue to support the Department of Health and Social Care's project which is dedicated to tackling the gender health gap.

LIPOEDEMA

IS PAINFUL, DEBILITATING & LONG-TERM

Lipoedema UK  IS ON A MISSION...

Charity No 1181312

OUR VOICE TO ACTION

OUR CAMPAIGNING

- **Providing education and knowledge** to patients and healthcare practitioners (HCP)
- **Advocating better access** for diagnosis and treatment
- **Offering advice** to patients and HCPs on the management of lipoedema
- **Empowering women** to self-manage their condition and obtain appropriate treatments
- **Generating awareness** at a wide range of HCP events
- **Networking and collaborating** with key national and international organisations
- **Listening to women's experiences** of lipoedema through surveys, focus groups and conferences
- **Encouraging more research** and evidence-based reports
- **Founder patient organisation** of Lipedema World Alliance



OUR IMPACT

- **Improved awareness**, knowledge and skills for GPs, nurse specialists and other medical professionals
- **Specialist nursing advice** for Lipoedema UK members via webinars
- **Empowering women to fight back** against ignorance and lack of empathy
- **Providing medically approved information**, links and patient stories on our website
- **Collaborating with the NHS** and other reputable websites
- **Contributing expertise and data** to the NICE review into non-cosmetic liposuction for lipoedema

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