

Women's Health - Let's Talk About It: Department of Health and Social Care

A Response from Lipoedema UK submitted by Suzanne Evans, Founder and Trustee

Lipoedema UK is 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 this 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. CCGs 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 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.

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 e-learning 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, regular webinar presentations and discussions, and in normal times hold an annual conference and exhibition for patients, medical professionals and relevant medical device manufacturers to attend in person.

About Lipoedema

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, and onset can be very sudden, occurring in a matter of weeks, if not days. The condition may worsen with later hormonal changes such as hormonal birth control use, pregnancy and the menopause. Unlike the normal fat caused by obesity, fat that accumulates with lipoedema is often painful as well as unsightly; will be totally absent in some regions of the body; and does not reduce as normal fat does 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

For more information visit www.lipoedema.co.uk, or <https://www.nhs.uk/conditions/lipoedema/>

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 lipedema*: Joanna E Dudek, Wojciech Bialaszek and Marcin Gabriel. BMC Women's Health 2021 <https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-021-01174-y>

NB: 'Lipedema' and 'lipodema' are alternative spellings of lipoedema.

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 even gently squeezed; easy bruising; chaffing 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 manifest 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

² Lipoedema UK Big Survey 2014 research report <https://www.lipoedema.co.uk/wp-content/uploads/2016/04/UK-Big-Survey-version-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 because of 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

Although a well-run and well-funded lymphoedema clinic may provide an accurate diagnosis and compression garments for women with lipoedema, most women are unable to access such services. 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 CCGs 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 in practice on the continent have been able to demonstrate the benefits of such surgery, and many of our members who have been able to afford it, have travelled overseas to access this specialist liposuction. Consequentially, Lipoedema UK has amassed a considerably body of evidence showing that liposuction for lipoedema does in general have a significant, positive effect on the quality of life, physical mobility, and mental health of those women who undergo such surgery.⁴

Several medical studies confirm our own findings and experiences. For example:

- 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 lipedema (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-*

⁴ *Life after liposuction: the life-changing impact of surgery on lipoedema patients' lives*, A Lipoedema UK Focus Group Report, Series no:3. Amy Fetzter BA (Hons-Psychology) MSc (Distinction); Mary Warrilow RGN, BSc (Hons), QN, Joint Founder, LymphCare UK, Independent Nurse Consultant. See: <https://www.lipoedema.co.uk/wp-content/uploads/2019/10/LUK-FGR-Liposuction-Web-3.pdf>

⁵ *Liposuction in the Treatment of Lipedema: 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 2017b

lipedema populations....After surgical treatment, a significant reduction of lipedema-associated symptoms was demonstrated.⁶

There is, however, a shortage of trained plastic surgeons able to perform liposuction operations on women with lipoedema in the UK. The NHS is also reluctant to fund such surgery, despite the evidence-based advantages to patients. In England and Wales liposuction for lipoedema is deemed 'cosmetic' meaning funding is nearly always withheld by CCGs.

Lipoedema UK challenges the labelling of liposuction for lipoedema as 'cosmetic' surgery. We believe this misrepresents the facts and belittles the impact of surgery. Women with lipoedema are not seeking prettier legs, they seek relief from a potentially debilitating disease that impairs mobility, and which may ultimately consign them to a wheelchair. They want to stop feeling like a 'freak' and become 'normal,' free of appearance-based shame and stigma. They want to be able to find clothes to fit, take part in sports, and not suffer pain on a daily basis.

Although conjecture, as men only very rarely contract lipoedema, we do question whether a man walking into his GP surgery complaining of very suddenly bloated ankles and bulbous fatty pads on the inside of his knees, completely at odds with the rest of his slim body, would not be taken seriously. Such however 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 advocates the choice of early liposuction for women with lipoedema. This surgery can be life-changing and of benefit to the NHS by preventing a vicious circle of self-hate, 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 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.

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>

We note the NHS patient guidelines for breast reduction surgery state that:

Generally speaking, you might be considered for breast reduction on the NHS if you have problems caused by having very large breasts, such as:

- *backache*
- *shoulder or neck pain*
- *skin irritation*
- *rashes and skin infections under the breasts*
- *grooves on the shoulders from bra straps*
- *psychological distress, such as low self-esteem or depression*
- *an inability to exercise or take part in sports.*⁷

There are clear parallels here with lipoedema, albeit in different parts of the body. Women with lipoedema can no more 'cure' themselves of lipoedema than can a woman cure herself of excessively large breasts.

However, we welcome the fact that NICE has authorised its Interventional Procedures Advisory Committee to look at liposuction for lipoedema as part of its work programme. We have been approached to provide an organisational submission to share our views on the procedure and comment on draft guidance. The consultation covers two key areas: the safety of the procedure and whether it works well enough for use within the NHS. This is an important step; any inclusion of non-cosmetic liposuction being funded on the NHS could be life-changing for many women.⁸

Evidence of Medical 'Anti-Fat Bias'

The widespread failure and apparent reluctance on the part of health professionals to recognise and treat lipoedema is leading to significant numbers of diminished and missed life-chances for women. How can this failure be explained, given the Hippocratic oath to 'do no harm or injustice' to patients and the National Health Service's constitutional commitment to 'everyone counts'?

⁷ Taken from: <https://www.nhs.uk/conditions/breast-reduction-on-the-nhs/>

⁸ Liposuction for chronic lipoedema. In development [GID-IPG10190]. Expected publication date: TBC. See <https://www.nice.org.uk/guidance/indevelopment/gid-ipg10190>

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 as sadly as pervasive among medical doctors as it is among the general public. Numerous studies have established that overweight patients face weight discrimination in health care settings and consequently receive a sub-standard level of care.⁹

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.¹⁰ 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 tend to learn a sense of powerlessness in the face of this anti-fat bias. The humiliation they feel lessens their ability to advocate for themselves in healthcare situations, and they subsequently avoid routine preventative healthcare.

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, they give up on healthy eating out of pure frustration. There are examples of women who purposely overeat and intentionally put on weight to 'normalise' their shape, because they find they are more acceptable both socially and medically as an obese person.

⁹ 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/>

¹⁰ 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.

These examples from our case files are typical of the stories we hear again and again: ¹¹

"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."

If the healthcare system is to ensure 'everyone counts' and if women with lipoedema are to access the treatment and services they need, free from harm and injustice, the ingrained fat-bias within the medical profession must be tackled. Public health is not well served when it actively – and legally – discriminates against women with non-normative bodies who are wrongly labelled 'obese.'

Lipoedema and the Gender Pay Gap

We would finally like 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 lipoedema takes on the body increases as symptoms worsen, career progression may be prevented. 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:

¹¹ These women's full stories are on our website: See <https://www.lipoedema.co.uk/lipoedema-uk-posts/>

"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 nearly ten years ago. However, our successes have created a situation where more women realise what is wrong with them and seek support and treatment but, because health services are either not aware of the problem or, if they are aware, they are unable or unwilling to meet demand, women continue to experience the frustration of being 'let down.'

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

We trust this submission, in highlighting the difficulties and prejudices faced by a specific female population, will serve as a case study to illustrate women's health inequalities and support the Department for Health and Social Care inquiry. We wish the inquiry all the best and look forward to the final report.

-ENDS-

This report was completed with input from:

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