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## Women in dire need denied surgery and treatments:

Preview results of 2019 Lipoedema UK survey report

### Compression Garments and Liposuction as Treatments to Manage Lipoedema

A survey by charity Lipoedema UK highlights that a bleak future could await UK women with a debilitating condition called Lipoedema because life-changing treatments and surgery are not available on the NHS. Many risk their future and that of their family by taking out loans and spending savings to finance private treatments.

Lipoedema UK's recent survey ***Compression Garments and Liposuction as Treatments to Manage Lipoedema*** found that out of 236 women in the UK, 33% (78) had undergone or were booked in have surgery to treat lipoedema. Over 80% of those who had had surgery said it had been effective or very effective at improving their quality of life.

Out of 236 UK respondents, 88% (22 of 25) of those who had applied for NHS funding were turned down.

Lipoedema UK relies on donations, membership and volunteers to continue our work. Membership is open to individuals, patients, clinics and all healthcare professionals.

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## BACKGROUND: WHAT IS LIPOEDEMA?

Lipoedema is a medical condition which can cause great distress and pain and significantly impact on a patient's mobility, wellbeing and ability to work.

Lipoedema fat is genetic and hormonal, most often appearing in young girls at puberty when they are vulnerable and self-conscious of their appearance. What starts as a few extra pounds can grow into large, heavy, painful fat, which disfigures the body and can leave patients reliant on walking sticks or wheelchairs.

Legs, hips, ankles and arms grow disproportionately until they are several sizes larger than other parts of the body. The waist remains small, as do wrists, hands and feet. This is different to 'normal' fat, which is evenly distributed over all the body making all body parts, including fingers and feet, podgy.

### Debilitating disease

Lipoedema fat is heavy and painful. A patient with advanced lipoedema cannot often walk easily, stand for any length of time or fit into normal-sized chairs. The majority of women become the target of cruel jokes about their size and shape and find it difficult to physically and emotionally cope with life.

Many find themselves physically unable to carry on with their career or look after their families and become too embarrassed about their appearance to socialise and take part in sport or everyday activities.

As normal dieting and exercise appear to have little effect on the areas affected by lipoedema fat, many women then 'give up' and become overweight in other areas too. However, exercising in water or other low impact exercise do show promising results in being able to help manage disease progression.

*"It feels like I am being held down by a lead weight," noted one respondent to the survey **Compression Garments and Liposuction as Treatments to Manage Lipoedema**. "I constantly feel exhausted and in pain. Climbing stairs is a complete effort for me and I am afraid that things will only get worse. I am progressing [in my lipoedema] even though... I watch my diet... and exercise regularly."*

Another respondent explained: *"If I try to walk faster than a snail's pace my 'lipoedema lumps' swing about and I fall over. I will be costing the NHS a fortune in the future!"*

**Lipoedema predominately affects women, and is a chronic fat and connective tissue disorder that typically affects the thighs, buttocks, lower legs and/or arms (with sparing of the feet/hands). It leads to tissue enlargement, swelling and pain that may severely impact on mobility, daily living activities, and psychosocial wellbeing. It appears to be unresponsive to diet or exercise.**

## Not well known in the medical community

Few doctors and health care professionals are trained to diagnose lipoedema. This means countless women are undiagnosed and un/mistreated. Lipoedema UK Chair Sharie Fetzer states:

*"It is absolutely astonishing that something that is so obviously 'abnormal' has been ignored and misdiagnosed by the entire worldwide medical communities for centuries.*

*"Once you recognise the symptoms, you will notice huge numbers of women walking around without a diagnosis. Women who have been told that a poor diet and laziness are the cause of their heavy, tree-trunk like legs and fatty lumps that don't go away, no matter how good their diet or how hard they exercise."*

*"These women are completely desperate for help and treatments that will mean they can lead a normal life and reduce pain."*

## LIFE-CHANGING SURGERY

Many, but not all, lipoedema patients can be helped by a life-changing form of specialised surgery: tumescent liposuction. Yet, despite the name, liposuction surgery for lipoedema is not cosmetic surgery – it is a medical necessity for many women.

However, such surgery is complex and only successful if the surgeon is very experienced and has an empathy for the lymphatic system. Depending on the patient's individual health, including weight/height (BMI), and clinical need; up to five to seven litres of fat are removed from an area of the body at a time, (more may be removed in certain circumstances). Most women need several separate operations to remove the litres of unwanted fat. Recovery can be painful and requires time off work, which can also be costly.

There are variations to the type of liposuction procedures suitable for lipoedema and different clinical factors are considered by doctors in selecting the methods they prefer to use on individual patients. The type offered is influenced by the amount of lipoedema tissue to be removed and the general health of the patient. Aftercare is also very important: almost all patients have to commit to wearing compression garments for a period following surgery and some require compression garments 12 - 24 hours a day for the foreseeable future.

Lipoedema UK conducted the survey on compression garments and liposuction as these are the two main treatment pathways for lipoedema at present.

This report focuses on some of the select findings relating to liposuction.

## OUTCOMES

The survey found that liposuction surgery can improve lipoedema patient's lives in the following ways:

### 1. Mobility, social confidence and ability to continue careers

Mobility is of great concern to lipoedema patients when their increasing size and shape impacts on their everyday movement, posture, balance and gait as well as their ability to function in a normal way, often to the detriment of their career and family life. Social confidence also becomes an increasing problem as they find their shape and size becoming an unwelcome focus of attention. After surgery:

- 53% reported a dramatic improvement in their mobility.
- 36% reported a dramatic improvement in their ability to continue their career.
- 60% reported a dramatic improvement in their social confidence.

**This indicates a huge potential saving for the NHS and social healthcare, as well as a vastly improved personal quality of life.**

### 2. Pain

Pain can be a significant, negative feature in the life of a lipoedema patient. Many find the skin and underlying tissues tend to be extremely tender/painful while others have considerable pain in their joints - particularly their knees.

Following surgery, respondents said liposuction had been effective, or very effective at reducing pain in the following parts of the body:

- Thighs 69%
- Knees 58%
- Calves 62%
- Hips 61%
- Ankles 68%
- Arms 50%

### 3. Reduction of size

Unlike similar conditions, the size of lipoedema tissue is unresponsive to many treatments offered and the resulting, abnormal body shape causes considerable psychological distress. This in turn leads to clothing limitations (finding clothes/boots etc to fit can be very difficult/expensive).

Respondents said liposuction had been effective or very effective at reducing size in the following parts of the body:

- Thighs 83%
- Knees 83%
- Calves 80%
- Hips 76%
- Ankles 69%
- Arms 78%

## 4. Quality of Life (QOL)

Clinics treating lipoedema patients struggle to improve overall quality of life for lipoedema patients as they are unable to remove the abnormal fatty tissue. Clinicians can help, advise and support women - but as lipoedema is a long term, chronic condition, there is generally very little chance of improving quality of life with conservative treatment methods like compression, particularly in those with more severe swelling. Liposuction however demonstrates a huge improvement:

- Over 80% said the surgery had been effective or very effective at improving their quality of life.

### Comments on the outcomes of surgery

Respondents who had undergone surgery were keen to comment on the way it had changed their ability to enjoy life and improvement in their symptoms.

Comments on the outcomes of the surgery included:

*"Outcomes have been better than I could ever have imagined. Life is totally different now. Mentally and physically I feel in far better shape. It has been truly life-changing."*

*"I can walk to the school hall for assemblies, not be pushed in my wheelchair."*

*"Liposuction is not an easy option, as it is painful and there is a lot of aftercare. I have also been left with some loose skin, although all of the above made very clear to me before the operation. It's not a magic wand to all the problems that Lipoedema brings, but surgery has helped a great deal, and I feel very lucky, and happy that I had it done."*

*"Please diagnose others at an earlier age. Don't let them lose years of their life to embarrassment and dreadful lack of mobility. Have liposuction at a young age and live life!"*

### Focus group findings

These findings are supported by new focus group research **Life after Liposuction** by Lipoedema UK with lipoedema patients which concluded that:

- Liposuction had improved patients' quality of life and pain.
- Liposuction had helped with pain relief.
- Liposuction had positive mental impacts.

## OTHER KEY LIPOSUCTION FACTS FROM THE SURVEY

Other key data points from the survey *Compression Garments and Liposuction as Treatments to Manage Lipoedema Survey*:

- Out of the 236 women in the UK, 88% who had applied for NHS funding were turned down. (25 women applied, 22 were turned down. All lived in England. The three who were approved lived in Scotland.)
- Of the 22 who were turned down for NHS funding, 65% (15 patients) still chose to go ahead and pay for private surgery
- 33% (78) of the 236 UK respondents had undergone or were booked in to have surgery to treat liposuction
- 27% (64) had already undergone liposuction surgery
- Age groups undergoing liposuction

Ages 19 – 40 years	24%
Ages 41- 60 years	49%
Ages 61 -70 years	21%
Ages 71 + years	6%
- 61% of those who had had surgery (41), had had it in the last one - two years
- 17 respondents reported they had gone abroad for their surgery
- 53 respondents reported they had surgery in the UK.

## DIGGING INTO THE DETAIL

### Denied life-changing treatment

The research indicates that it is almost impossible for people with lipoedema to receive treatment or surgery on the NHS. Even when GPs recognise that treatment is essential and go to great lengths to help their patients apply for funding for treatment, very few have managed to get their applications approved by the NHS.

As described above the *Compression Garments and Liposuction as Treatments to Manage Lipoedema Survey* found that:

- Not one respondent in England had had their application for NHS funding approved
- Scotland was the only place where funding applications had ever received approval: the three respondents who had been granted funding were based in Scotland.

**Feedback indicates applications are turned down because the funding bodies consider the treatments cosmetic and do not recognise the severe physical and emotional impacts of the condition.**

## Denied funding

Despite support from their GPs, the research highlighted how women find the process and uncertainty around funding extremely stressful, with comments on how they felt the system was unjust when other operations, such as bariatric surgery, appeared to be easily available. Many of the women are desperate because they have tried all other methods with only limited success.

*“The application for funding, then being turned down was mentally exhausting.”*

*“I am desperate for liposuction to reduce pain and improve my mobility and reduce leg size so I can have a normal life instead of hiding away.”*

*“It makes me distraught knowing there is a treatment that would significantly improve the quality of my life that I simply can’t afford. I get angry and frustrated at being offered other treatments (e.g. bariatric surgery) that are costly.”*

*“I can’t save quickly enough due to not being able to work. I feel like that by the time I have enough money I’ll be too old for the operation to be any benefit.”*

*“Many tears and humiliation in applying for funding fighting decisions. 2 week wait for Dr to find out funding decisions after the meet was horrendous, I couldn’t sleep or understand if they made the choice and why they wouldn’t tell even the GP.”*

*“Until the NHS in England is willing to fund liposuction, there will be an even greater cost to the NHS. I have worked really hard to do everything recommended to improve my own mobility and have gone from needing a wheelchair most days to being able to walk with a stick, but I cannot make any further improvement myself.”*

## Force to self-fund

This means most patients have to fund the treatment they need, themselves. Operations to remove lipoedema-related fatty deposits cost between £5,000-80,000. As surgeons competent in treating lipoedema are scarce, women often have to travel abroad. The research found that many desperate UK families are being forced to spend their savings, retirement funds, sell their homes or go into debt to fund treatments.

Our survey and focus groups reveal that women are becoming better informed through organisations such as Lipoedema UK, joining forums on the internet, sharing their frustrations and experiences and learning about the benefits of specialist liposuction. As a result, patients are queuing up for surgery and the most reputable surgeons can be booked up to a year or more in advance.

**When people cannot fund treatments themselves, they become desperate. Many lose their jobs or retire early because their size prevents them leading a normal life. Whole families are affected when a mother is too embarrassed or in too much pain to take part in normal activities, and her ability to work is impacted.**

## The impacts of paying privately

Many resorted to multiple ways to fund their surgery, including funding it themselves, taking out loans, borrowing from family and friends, selling property and taking money out of pension schemes.

*"We don't have this sort of money available. I am self-employed and have lost income through having to recover from surgery"*

*"I will not be able to retire when I would like to... Suffered with Lipoedema since puberty, just diagnosed at 51... want to regain some of my life back... lost due to this crippling/debilitating disease!!"*

*"we had to give up trying for a family this year and all travel plans have been put on hold."*

*"...I've spent £45,000 so far on 4 ops and feel differently now but ....my pre-surgery experience was dreadful and I was often suicidal."*

*"I'm retired and so had to take £10,400 from my pension for the 1st op and a loan for the 2nd. You don't want to lumber yourself with debts once retired!"*

## Guilt

Even after finding funding and going ahead with the surgery, the majority felt a huge amount of guilt about the effects of spending significant sums of money on their treatment on their families.

*"feel a huge amount of guilt as there are many things my kids will now go without due to this and we have had to delay a much-needed house move."*

*"...it is coming out of years of savings for a comfortable retirement and being able to support my children. I feel guilty and angry at having to use this money."*

*"eroded all savings so feel very vulnerable"*

*"Very stressful, meant my whole family has had to make sacrifices. Make me feel very depressed, guilty and a burden"*

30 year old UK patient, 'Cassie', 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 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 as her only NHS support.

Top photos immediately before first surgery (age 30), bottom photo 12 months later after third surgery (age 31).

## Worth the hardship

Yet despite all the hardship, the majority of patients were enthusiastic about the results. A few who had been treated by surgeons who were not trained in the right techniques for Lipoedema had had disappointing results but the overwhelming majority were thrilled with the results and the huge improvement in their lives.

*"I am in a great deal of debt and more to come but feel it is worth it for the health benefits. Feel fantastic since surgery and worth every penny."*

*"Amazing, incredible! People do not recognise me. My arms reduced by 43%! 45 pints of fat removed from legs!"*

*"Family and friends wept with delight. Many describe it as miraculous!"*

*"They can't believe it, one friend said you now actually look like what you eat, I always thought you were a secret eater, my husband says the difference is amazing. I have tons more energy and excitement for life. I have a amazing body it looks and feels strong and beautiful, after spending 25 years hating myself, I feel sad for the lost years"*

*"Loads more energy - I used to sleep every chance I got. No more chaffing from walks! Less pain! Very pleased :)"*

*"No more joint pain, I got up the day of my surgery and realised my knees worked and didn't hurt, it's so liberating!!!"*

*"They have all thought me very brave and amazed at the results and the change it has made to my life."*

*"I had the wrong type of liposuction. The Dr didn't know what they doing or treating, they assumed it was normal fat."*



## CASE STUDY: Michele's story

One of our Lipoedema UK members, Michele, found her lifestyle slipping away as her body became heavy and painful with lipoedema. She applied for, and was awarded money for one round of surgery but still had to fund several follow up operations herself. Despite the cost she is overjoyed to get her life back and several years later still feels emotional about how surgery has changed her life.

### Before surgery:

*"I was using a wheelchair frequently as mobility was so challenging, I couldn't fit into chairs or cinema seats. I couldn't fit my arms into coats... I couldn't dance... and could hardly walk..."*

*"My family and I were all so desperate as I was repeatedly told by medical practitioners to go home and be bed ridden..."*

### After surgery:

*"Surgery cost a fortune! But I am a different person now!"*

*"I am crying as I write this! I can eat in public as I feel people aren't staring and blaming me for being fat. Improved mobility, confidence... Sitting on trains, in pubs, in cinema or any public seat is possible."*

*"I can fit into chairs and cinema seats. I can fit my arms into coats... I don't feel an embarrassment to my family, I can dance... at my daughter's wedding."*

## CASE STUDY: Kate's story

Kate's mother has been bed bound for many years due to her advanced condition, size, and the pain and impaired mobility exacerbated by the delay in obtaining accurate diagnosis and support. She can only leave home in an ambulance. Kate is in the early stages, reporting that her lipoedema is 'mild'. However, because she was afraid that lipoedema might take over her life like her mother, she paid for her own tumescent liposuction surgery in Germany in 2016. She had one operation over several areas of her upper legs from her outer thighs and inner thighs down to her knees.

Kate reports that her surgery has been very effective at reducing pain in her knees and thighs and very effective at improving her quality of life.

### After surgery:

*"I thought I was clumsy... had balance issues for years. This resolved within six weeks of surgery. I used to fall over playing badminton in every game. Within 6 weeks of surgery (and still now) I do not fall over in several hours. I think the impact of lipoedema fat on distorted posture affects knees, balance, mobility. A massive issue that was totally unexpected! I had knee pain issues for years... gone now! No need for a knee support for exercising!"*

*"I am more confident. I do not have big thighs that look odd compared to my tiny waist. My brother asked me 'what is wrong with you' when he saw me in jeans and a top before... not now! I look a normal pear shape not an abnormal one. I do not have pain outdoors in the cold. I have improved exercise effectiveness through my improved balance."*

Following a diagnosis by a leading UK consultant, 36-year-old 'Andrea' and her family raised £15,000 for three surgeries in Germany.

Andrea said her surgeries have dramatically improved her social confidence and ability to continue her work and career. She feels so much happier and has gained in confidence; in her own words "I just feel free".



## LIPOSUCTION TECHNIQUES AND FACTS CONCLUSION

The **UK Best Practice Guidelines for the Management of Lipoedema** (1) advise that surgical options may be appropriate for some patients with lipoedema. These include liposuction (to treat the tissue enlargement) and bariatric surgery (to treat obesity). However, while both types of surgery may help with symptoms, neither has been shown to cure lipoedema itself and it will remain a long-term condition requiring careful lifestyle management.

Patients considering liposuction should research clinics carefully to ensure they provide adequate standards of care, and to establish that the procedures they offer are appropriate for their individual needs. Patients should also be aware that liposuction procedures are not without risk in the immediate post-operative period and **may** cause long-term complications (Stutz & Krahl, 2009; Rappich et al 2015). Age, condition of skin and tissues will also impact on results, as too will further weight gain post operatively.

However, overall, liposuction in patients with lipoedema has been found to reduce tissue bulk, pain, bruising, improve mobility, functioning and quality of life (Reich-Schupke et al, 2012; Peled & Kappos, 2016).

There is also evidence of longer term benefits of liposuction surgery. For example, in a study of 112 patients who had undergone tumescent liposuction between 5 and 11 years previously, positive changes over time were found in seven parameters. These include pain, bruising, oedema (swelling), mobility and quality of life and contributed to an overall improvement (Schmeller et al, 2012; Baumgartner et al; 2016).

Patients with lipoedema considering liposuction should carefully assess their own situation, and be aware that carrying additional weight from non-lipoedema fat could affect the complexities and long-term results from liposuction. The **UK Best Practice Guidelines** also recommend that patients undertake non-surgical (conservative) treatment for at least six months before surgery.

Pre-operative counselling is also recommended to ensure that each person has a realistic expectation of what can be achieved, understands the procedure and the importance of post-operative care (including compression therapy). Post operative pain and swelling is inevitable – and may take several months to resolve. There may be a longer recovery period if such recommendations/information are not taken on board.

In conclusion, more reliable long-term research and evidence is desperately needed by the growing community of lipoedema patients and clinicians, to guide them and help them understand and manage this long-term, chronic condition. Until this happens countless women suffering from lipoedema and their families will continue to feel ignored and in dire need of help.

Lipoedema UK's survey **Compression Garments and Liposuction as Treatments to Manage Lipoedema** starkly highlights the failings in the healthcare system to fund a promising treatment for a recognised medical condition, and the pain, anguish, suffering and financial hardship this can cause.

The survey also provides data on the effectiveness of liposuction as a treatment, as evaluated by patients themselves, providing a strong case for the liposuction to be included as an approved treatment by NHS Clinical Commissioning Groups.

With 85% of respondents undertaking surgery in the last 1-2 years, ongoing longitudinal research which compliments existing medical studies, such as those by Schmeller et al, 2012 and Baumgartner et al, 2016 is needed to understand the long-term impact and implications of liposuction for lipoedema. But in the meantime, the survey provides some much need data, which can, and must, be used to challenge and change the way the healthcare system is providing for lipoedema patients in the UK.

## RESEARCH DESCRIPTION

### **Compression Garments and Liposuction as Treatments to Manage Lipoedema.**

Online survey of lipoedema patients undertaken by 428 respondents internationally between 16th February and 11th May 2018. This report focusses on the 236 UK respondents to the liposuction section of the survey.

#### **Definition of liposuction**

**Liposuction is the removal of subcutaneous adipose deposits via a cannula attached to a suction device that is inserted through small incisions in the skin. Large volumes of fatty tissue can be removed from areas such as the legs, hips and arms. There are numerous types of liposuction, including tumescent and water-jet assisted. The type used in the treatment of lipoedema may relate to the preferences of the individual surgeon and overall health of the patient.**

(1) Wounds UK Best Practice Guidelines, The management of lipoedema (2017)

# Lipoedema UK

AWARENESS, DIAGNOSIS, TREATMENT, RESEARCH

Charity No 1181312

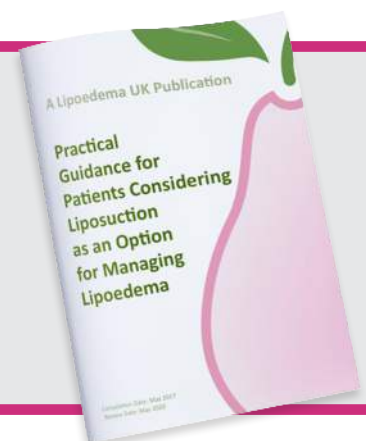
## About charity Lipoedema UK:

### Lipoedema UK is working hard to:

- Ensure lipoedema is taught/accepted as a condition in all medical schools, throughout NHS and entire medical profession.
- Drive acceptance and understanding that the lack of treatment leads to unacceptable physical, social, lifestyle and career limitations leading to psychological issues.
- Ensure the medical community – and patients – understand and research the potential for surgery and other treatments to be life changing, restore mobility, improve self-esteem and social confidence and ability to lead a normal life.
  - Stimulate funding for research into a cure and better treatments.
- Improve the management and provision of services for this chronic condition.

Lipoedema patients considering liposuction should read Lipoedema UK's publication:

**Practical Guidance for Patients Considering Liposuction as an Option for Managing Lipoedema**



Lipoedema UK relies on donations, membership and volunteers to continue our work. Membership is open to individuals, patients, clinics and all healthcare professionals.

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