

WOMEN IN DIRE NEED

A Lipoedema UK Focus Group Report

Series no:3

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Life after liposuction: the life-changing impact of surgery on lipoedema patients' lives

Lipoedema UK conducted a focus group with patients to explore how they felt liposuction surgery had impacted on their lipoedema and their lives.

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 as her only NHS support. Top photos immediately before first surgery (age 30), bottom photos 12 months later after third surgery (age 31)

Patients ranged from 19 to 53-years-old, from stage 1 to stage 4 lipoedema. Patients had had between one and five surgical procedures. Most had more procedures planned – between an additional one to five operations – to complete their treatment.

The discussion highlighted that whilst almost all the women agreed that liposuction surgery had improved their symptoms and quality of life, it was not a silver bullet, and challenges remained. The women also experienced new challenges as a result of the procedure, such as guilt over spending so much money on themselves.

KEY FINDINGS

- Liposuction surgery had improved quality of life and pain
- Liposuction surgery was not seen as an 'easy option'
- Liposuction surgery had helped with pain relief
- Liposuction surgery had positive mental impacts
- Feelings of guilt were common and substantial
- Feelings of frustration and anger were common
- Feelings of disappointment in how much liposuction could achieve were acknowledged
- Compression was still important, but less of a priority
- Lipoedema UK was cited as a catalyst

Life after Liposuction Focus Group

THE FINDINGS

● Liposuction surgery had improved quality of life and pain

All bar one of the women agreed that liposuction surgery had vastly improved the quality of her life.

When asked, "what is your opinion of liposuction surgery as a treatment for lipoedema?", responses were overwhelmingly positive, with patients largely saying the procedure had improved their:

- quality of life
- mobility
- experience of pain
- confidence
- size
- visual appearance
- puffiness and swelling
- the sensation of heavy, hard-to-lift legs, especially when going upstairs at the end of the day
- sensitivity to pressure

The one ambiguous response ("Not sure yet. Smaller but still hurts") came from a 41-year-old Stage 1 patient who was four months post-operative (indicated with an * when referenced later). The other patients were keen to reassure her that she would be likely to experience greater benefits when she had had more time to fully heal.

"It has helped my life greatly – reduced pain and improved quality of life."

19-year-old Stage 1 patient

"Necessary." 25-year-old Stage 1 patient

"Best thing ever. Changed my life."

38-year-old Stage 4 patient

"Happy with what I have had done so far."

53-year-old Stage 2-3 patient

"100% best treatment for mobility."

46-year-old, unspecified stage

"It's definitely improved my quality of life – it's made me more confident as I felt like I looked like a freak with bulky bulbous legs." 38-year-old Stage 1-2 patient

● Liposuction surgery was not seen as an 'easy option'

Women talked about recovery being "a long hard road" and "tough going" but that it was worth it to "get my life back" as the initial procedures had already "made a huge difference". Areas that had been operated on could remain tender for up to year. Patients also reported an "electric shock" style tingle post-operatively that had replaced pain in their legs. Those who had had longer post-operative periods advised that this sensation would lessen as the nerve endings healed.

"I'm still processing. It's been my life since the age of 10 with the condition – so I'm still physically, mentally and emotionally recovering." 52-year-old Stage 2/3 patient

"It's been a long hard journey, but I'm really pleased I've had it done for myself and my kids."

38-year-old Stage 4 patient

"Even though it is tough going, I feel for me, it's worth it. I'm getting my life back – walking again – that is the most important. To enjoy time with family."

52-year-old Stage 4 patient

● Liposuction surgery had helped with pain relief

The group agreed that pain, whilst not eliminated entirely, was lessened after liposuction surgery. This was agreed across age groups and stages with young stage 1 patients also reporting that surgery reduced their pain.

"When I was 12-13, I got suddenly got really big legs – I put on two stone out of nowhere. I had to stop all the activities I wanted to do... I was given compression, but the pain was still there... the weight of my legs pushing on my joints. But since surgery, all that seems to have gone. I no longer have pain when I walk and I can enjoy activities."

19-year-old Stage 1 patient

"I didn't think I had pain but after surgery but realised I did have pain as I didn't really have it anymore."

25-year-old Stage 1 patient

Photos courtesy of the patient



Top photos: 17 year old patient showing clear disproportion between waist and lower body along with chafing between upper legs.



Lower photos: Aged 19, following three sessions of liposuction. Patient reported a massive impact on her freedom to choose clothes, no restrictions on exercise or joining in activities with her friends and feeling happier and able to enjoy life. "The surgery has made me feel like me again, before lipoedema changed my life, reduced my self esteem, confidence and ability to enjoy life"

● Lipoedema surgery had positive mental impacts

The women discussed a range of positive mental impacts as result of the surgery.

- **Improved outlook, confidence and body image.** These were some major side effects of surgery for all bar one of the patients*. This included improved confidence, body image and self-esteem, which in some cases had also led improved relationships with food and the cessation of eating disorders. Having access to a wider choice of clothing and fashion styles was also a source of enjoyment, pleasure and self-confidence.
- **Pride.** The women also expressed pride in themselves – for their bravery and resilience in finding a pathway to treatment, and in undertaking surgery when many were petrified at the prospect.

"Unexpectedly, the main outcome from surgery was the impact on my mental health and my eating disorders. I still have to work [at it], but it was only after surgery that I was able to go into recovery from eating disorders. I've been in recovery for three years. It gave me ability to look in a mirror without hating what I saw which helped. I'm less self-conscious: of exercising, eating in front of other people, etc." 25-year-old Stage 1 patient

"It's made me a totally different person. Now I can wear what I want. I can now try and keep up with the trends, the same as my friends. I was wearing the same clothes as my mum! That makes you feel so drained. But now I have so many more skirts and dresses. Now I can have fun." 19-year-old Stage 1 patient

"I still wear the same clothes all the time but after surgery I'm wearing ... shorter skirts more – I do actually feel great. I've suffered with my confidence but now I'm feeling good... It's been a long journey but I don't regret it one bit." 53-year-old Stage 2 patient

"I was in a right old state [about the liposuction]. I was having panic attacks – I had to take tablets to even get me in to surgery. My husband told them, 'she's not coming in'. It was a frozen moment... I was so nervous. It's a massive deal – to get over that panic attack to do something positive. It's a big thing for me to say we're brave – I'm not confident – but we've all had to dig deep to do this. It is no mean achievement doing this [having liposuction]... We have all done really well." 53-year-old, Stage 2 patient

● Feelings of guilt were common and substantial

All bar one of the patients had to fund surgery privately. This led to substantial amounts of guilt which the women agreed was a major component of post-operative life. The women felt guilty about:

- investing significant sums of money in themselves
- using money that could have been spent on other important things or borrowing money to fund the operation
- "putting their families through it"
- the support needed during recuperation

"I'd always put other people first. To think about investing a large sum of the family's money in me... my biggest question to myself was: 'am I worth it?'" 52-year-old stage 2-3 patient

"Do I deserve it? I don't deserve this – I still have that belief: 'I'm a fat, ugly overeating cow.'... That's the guilt: what have I done?" 38-year-old stage 4 patient

● Feelings of frustration and anger were common

Several of the women noted how their post-operative experience made them realise how lipoedema has shaped their life and held them back.

In some cases, this frustration and anger appeared to be very deep-rooted. One young woman said she had to sacrifice continuing her studies as she needed to use the money to fund her operations instead. She felt these sacrifices "poisoned it [the success of the liposuction] because of other things I could have done with my life" if she hadn't had to fund treatment for her lipoedema.

Some of the women felt angry that so many other women are born with "normal" legs, and did not need to make hard choices just to have what many other people take for granted.

The value in seeing a psychologist/counsellor before and after surgery was also viewed very positively to help deal with the psychological issues that surgery raises.

● Feelings of disappointment in how much liposuction surgery could achieve were acknowledged

Quite a few patients expressed disappointment that they didn't have "beautiful" legs after surgery, or that they still had pain. Bumpy, saggy skin was still an issue.

Patients acknowledged although they may have thought surgery "was going to be a magic wand and I wouldn't have lipoedema anymore and I'd have beautiful legs," there was a need to be "be realistic - because even though surgery significantly improves it - we're always going to have lipoedema. But we can have it - and it won't be so uncomfortable, and we can try and stop progression."

● Compression was still important, but less of a priority

Whilst many women still wore compression, and some still indicated a reliance on it, several noted they could do without it more easily. For example, if the weather was hot, or if they felt their schedule did not require it. Alternatively, some reported that compression had been too painful to put on pre-operatively, but that they were now able to wear it because their leg size and sensitivity had reduced.

● Lipoedema UK cited as a catalyst

Some patients explicitly mentioned Lipoedema UK, in particular its annual conference, as a source of finding treatment information, surgeons and support/inspiration from other members.

"I was diagnosed in August last year [2017]. I came to the Lipoedema UK Conference in Sheffield and met [my surgeon] and had surgery 9 weeks ago. Which I feel already has made a huge difference. I'm really pleased I did it."
46-year-old Stage 2 patient

"I was diagnosed at the beginning of last year. I came to the [Lipoedema UK] conference and met [another patient - the patient quoted above]... We live in same town. And I met [my surgeon]. I've had one surgery so far... I've noticed a massive difference around my ankles as I had significant cuffs. It's made me feel much more confident."
38-year-old, Stage 1-2 patient

Research description: A focus group was held on 30 June 2018. It comprised of 14 people: 12 lipoedema patients (11 of whom who had had liposuction surgery and one who wanted to learn about liposuction surgery) one therapist and one researcher. Topics/talking points included:

- The outcome of their liposuction surgery and their opinion of liposuction surgery as a treatment for lipoedema
- What lipoedema-related symptoms/pain they still experience
- The surprises and challenges of life for post-liposuction surgery lipoedema patients.



Lipoedema UK was founded in 2012 and is the UK's leading charity for lipoedema. Our mission is to raise awareness of lipoedema, for all women to receive an early diagnosis, the treatment and support they need and to find a cure for this debilitating condition.

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

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