

INTRODUCTION

Lipoedema is a chronic long-term condition affecting mostly women, presents as a symmetrical, abnormal build-up of fatty connective tissue affecting the buttocks, thighs and lower legs and in some cases the upper limbs, hands and feet and trunk are not affected and remain slim. Lipoedema usually presents around the time of puberty but can also occur at other times of hormonal changes such as pregnancy or menopause. There is sometimes a familial pattern and its cause is still unclear, although it is thought that there is a genetic and hormonal link to the condition.

Lipoedema UK were approached by the National Institute for Health and Care Excellence (NICE) to contribute as a patient organisation to the development of national guidelines - *Interventional Procedures Guidance: Non-Cosmetic Liposuction in the treatment of Chronic Lipoedema IP1843*.

A survey was launched in May 2021 to gather the views and experiences of women living with lipoedema and focusing on those women that had undergone non-cosmetic liposuction (NCL) treatment.

Survey methodology

The survey was launched in May 2021 with a strict 2-week window to respond. The survey was advertised via social media and in newsletters to Lipoedema UK membership. The survey consisted of informed consent and 104 multiple questions, divided into subgroups. There were two main 'pathways' depending on whether the respondent had undergone non-cosmetic liposuction (NCL) or not, this was to make comparisons between the two groups on QOL indicators and Pre- and Post-visual analogue scores (VAS) 0-10 were used. Respondents were able to give comments in order to gain further detailed information on certain questions. Data was collated using Survey Monkey and analysed by the authors. External analysts were used to also review the results.

RESULTS

There was an overwhelming response with 933 respondents taking part. This included respondents overseas also, however, for the purpose of the NICE report, only responses from the 756 participants from England, Wales, Scotland and Northern Ireland were used. The age range was 18yrs to over 81yrs. Ethnicity of respondents was mostly white with only 3% being of Asian, Black or other ethnicity.

Themes included diagnosis and service provision, symptoms and impact on quality of life, motivation, pre- and post-liposuction, treatment effectiveness/outcomes and non-cosmetic liposuction complications.

Diagnosis and service provision

The results highlight the massive gap from first symptoms of lipoedema to actually having a diagnosis. Almost half of the respondents, 48% of stated that their first symptoms started around puberty, between 11-18. However, the delay in diagnosis is evident with 31% of women being diagnosed between 26-40yrs, 29% being diagnosed between 41-50yrs and 32% having a diagnosis after the age of 50yrs.

Figure 1: Wrong heading for figure 1, should be 'Living with Lipoedema - VAS Scores - 2021 Survey'

Score	0	1	2	3	4	5	6	7	8	9	10	N=756
	None	Mild	Moderate	Severe	Very severe - Worst possible	Mod - very severe tots						
PAIN	7%	23%	40%	27%	3%	70%						
SWELLING	3%	13%	32%	42%	10%	74%						
DISCOMFORT	3%	14%	29%	45%	9%	83%						
HEAVINESS	2%	9%	21%	52%	16%	89%						

Other QOL questions were asked and participants were asked how Lipoedema impacted on several aspects and activities affecting of QOL

When asked "Have you found that the services provided by your lymphoedema clinic help improve your symptoms?" 15% were unsure, 27% said no and 22% thought that the services provided had helped symptoms, with many finding the compression garments helpful with supporting lower limbs and helping with discomfort.

The survey asked women with lipoedema how they would rate the care and support provided by their NHS lipoedema clinic, although it was apparent that not all respondents had access to a lymphoedema clinic. From those that had been seen at an NHS clinic, a total of 33% of women stated that care had been either good, very good or excellent, with 31% stating care and support had been poor-fair. Several respondents commented on the over stretched resources and staff at clinics. Many respondents had tried several treatments such as medical lymphatic drainage (MLD), and pneumatic compression but the majority, 72% had used compression garments, wraps or bandages.

Pain and lipoedema

All participants in our survey, including those that had undergone NCL, were asked about the pain experienced on the day of completing the survey. A visual analogue scale (VAS) was used to rate this pain on a score of 0-10. This was correlated with a verbal descriptive scale, no pain, mild (1-3) moderate (4-6) severe (7-9) and very severe or worst possible pain (10). The British Pain Society (2019) states that VAS can be modified to measure other variables and functions and was also used for rating other symptoms of swelling, discomfort and heaviness. A large number of respondents experienced moderate-severe pain, swelling, heaviness and discomfort. Figure 1, below/left, highlights those results.

Our Survey showed that living with lipoedema resulted in many negative aspects to everyday health and activities that many of us may take for granted as illustrated in Figure 2, below.

Figure 2 Living with Lipoedema - Quality of Life - 2021 survey



Non-cosmetic liposuction - motivations

91 women in the survey stated that they had undergone either water assisted liposuction (WAL) or tumescent NCL.

- 87% wanting to reduce heaviness in their limbs and 80% to improve overall quality of life and to prevent lipoedema symptoms from deteriorating and disease progression
- 70% of respondents stating the other main reasons were to reduce pain, improve the condition and symptoms such as mobility, fatigue, reduce tissue bulk and the size of the limb, to improve their mental health and to avoid lipoedema related health conditions such as joint problems
- 40% stated they wanted to reduce their need for care
- 100% of respondents (n=933) in the survey stated that NCL should be available on the NHS

Pre- & post-operative advice

Our survey found that information, advice and support given was reported to be good with 82% of respondents stating that they were given adequate pre- and post-operative advice, 86% were informed about what to expect before, during and after the procedure, and 95% were informed of the risks associated with the procedure.

84% of respondents stated that they were given advice by their surgeon as to when to seek medical advice following their discharge.

23% of women underwent NCL as a day case, 44% stayed overnight and 28% between 2-4 days. Interestingly vitamins or other supplements were suggested pre-operatively for 52% of the respondents.

Post-operative complications

The survey asked questions about post-operative symptoms such as bruising, pain, swelling and inflammation which were commonly experienced up to 12 weeks post-operatively. The majority of patients experienced no post-operative complications. However, 21% stated that post-op numbness was still experienced 12 months post-op, and 46% of respondents still had scars.

14% on women experienced a wound infection and 1% reported developing sepsis post-operatively. 27% of respondents stated 'other' and this included blood transfusion, anaemia and seroma. 16% reported a non-healing wound that required dressing, however the survey did not specify the criteria for length of time to qualify to be classed as non-healing.

Benefits of non-cosmetic liposuction

When comparing QOL indicators pre- and post-NCL for lipoedema it was evident there were a number of significant improvements in symptoms indicated by the VAS scores reported by respondents following the procedure. We asked respondents who had undergone NCL procedure to complete pain scores based on today (post-NCL) and retrospectively pre-liposuction, although we realise this is subjective, the results indicate that there were significant improvements in pain, swelling, discomfort and heaviness scores and improved QOL outcomes when comparing both sets of data.

Other questions relating to the effectiveness of NCL were asked which highlighted significantly high numbers reporting that NCL had been quite or very effective in improving a range of QOL indicators. Also care needs had been reduced due the massive improvement in management of symptoms. Disability had been reversed in some cases with drastic improvements in mobility, pain and heaviness in limbs - see Figure 3, below.

Figure 3 Reported benefits of non-cosmetic liposuction - improved QOL outcomes



CONCLUSION

- The survey provides valuable information about the experiences of living with lipoedema and how it has a negative impact on the individual and carers and family members. The lower quality of life with regard to physical, emotional, psychological and social aspects of daily life and living with the condition was evident. The 100s of freehand comments given by respondents were a very powerful testimony to the devastating impact of this disease.
- The NHS is currently failing women with lipoedema. This life-limiting, debilitating disease is almost completely ignored by GPs and Health Care professionals. Lack of awareness and training throughout almost the entire medical community, means women are routinely neglected and misdiagnosed, meaning they suffer unnecessary physical, mental, and psycho-social health and disability trauma. A lack of NHS service provision, any clear pathways for conservative treatments such as compression therapy and a refusal to fund surgical interventions, inevitably leaves women in dire need at risk of worsening health outcomes.
- Non-cosmetic liposuction for lipoedema can dramatically and positively transform women's health and lives. Lipoedema UK's 'Living with Lipoedema' 2021 survey provides clear evidence of Improved Quality of Life outcomes for women who have undergone the procedure. There has usually been a permanent reduction in symptoms and severity and the need for conservative treatments. Significant long-term improvements are seen in patients' physical, mental and psycho-social wellbeing. These positive effects are mirrored in numerous international studies and publications.
- Liposuction for lipoedema is a necessary medical intervention: it is NOT cosmetic. Women with lipoedema do not want 'perfect legs or arms,' they want to be able to live without pain, fear of disability, or worsening disability. They want to protect their mobility, to be able to live 'a normal life.' Not become a burden to their family or dependant on the state. NCL surgery can prevent worsening health and therefore plays an important preventative role, reducing and potentially removing longer-term costs to the NHS. The wider benefits of the surgery, not just to a patient's life, but to their family life, career prospects and long-term prosperity and independence are incalculable.
- Women are being put at greater risk by being forced to self-fund surgery, often overseas. The risk of greater post-operative complications in this context is obvious, as is the inability of women to be sure surgeons are adequately qualified. Currently, women are seeking out surgeons based on personal recommendations, and may well opt for cheaper options. Lack of UK specialists, regulation and treatment mean that women are often left without proper guidance and access to appropriate aftercare.
- Non-cosmetic liposuction for lipoedema should be available on the NHS. NCL for lipoedema surgery is currently the only known, effective intervention to manage lipoedema symptoms, as evidenced by numerous studies. As a relatively simple, safe and effective procedure with minimal risks to the individual, it is hoped that the *Interventional Procedures Guidance: Non-Cosmetic Liposuction in the treatment of Chronic Lipoedema IP1843* will start a process to make NCL more accessible on the NHS and improve service provision for those living with lipoedema.

