

LIPOEDEMA UK BIG SURVEY 2014 RESEARCH REPORT

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In 2012-2014, Lipoedema UK conducted the first research of its kind on lipoedema. The survey's objective was to provide data and statistics on how people are diagnosed and treated by the medical profession; the range of symptoms; the efficacy of interventions and to scope out the experience of living with lipoedema from a patient's perspective.

The survey demonstrated for the first time the issues faced by patients with lipoedema.

It revealed:

- How challenging it is to receive an accurate diagnosis.
- How people with lipoedema are treated by the medical profession, with interactions characterised as dismissive, negative and hurtful, with lipoedema commonly misdiagnosed as excess weight or obesity due to a lack of medical understanding about the condition.
- How living with lipoedema has a significant, sustained, negative impact on peoples' lives, careers, and relationships.
- The emotional anguish experienced by lipoedema patients, from the guilt that the fat is their fault, to humiliation, anger and depression that there is no cure, and only limited treatments.
- The range of debilitating physical symptoms of the disease, including discomfort, pain, tenderness, bruising and restricted mobility.
- The huge impact that lipoedema has on patients' lives, from restricting their work options and social life to negatively impacting on personal and sexual relationships.
- The urgent need for better awareness of lipoedema throughout the medical community and general public so that patients can be diagnosed as early as possible to enable management to help prevent progression and improve quality of life.
- The urgent need for research into treatments and ultimately, a cure.

Survey impact:

The survey has had tremendous impact. It has been instrumental in creating the impetus for better awareness and has led to concrete change.

- The survey led to the creation of an elearning course on the diagnosis and management of Lipoedema, produced by the Royal College of General Practitioners (RCGP), in partnership with Lipoedema UK. This enables GPs and other health professionals to learn about lipoedema as part of their ongoing professional development.
- The survey raised awareness of the condition, the experience of patients and the validity of certain treatments through the presentation of its findings at conferences, dissemination amongst practitioners, and being used as source material for journal articles on lipoedema. Such events have sparked interest throughout the medical community and helped to create and drive the impetus for action internationally, including working groups, symposiums and conferences.
- The benefits of aqua exercise are now recognised, and it is now being recommended by health practitioners and other information sources such as Lipoedema UK. Many lipoedema patients have begun or increased the volume of their aqua exercise with positive results reported, identifying this as another key area for future research.
- The survey continues to help Lipoedema UK, St George's Hospital and others to drive the agenda for further research into lipoedema and treatments by providing a vital evidence base.

Study details:

- 250 female respondents completed a 74 question online survey.
 - Survey was fielded between Sept 2012 and Feb 2014.
 - It was launched at the 2012 BLS Conference. UK-based respondents were recruited through their local lymphoedema clinics, lipoedema websites and social networks. Respondents had to request the link to access the survey to try and ensure that only people who had been medically diagnosed with lipoedema completed the survey.
 - Respondents were mainly white British. Other ethnicities represented included white South African, Hispanic and African American.
 - Respondents were female and aged between 21-79. Their average age was 59.
 - The survey combined multiple choice with a large proportion of free text questions designed to give people the chance to share the detail and the complex issues associated with the condition.
 - The survey was compiled by Sharie Fetzer and Suzanne Evans of Lipoedema UK, and Sandy Ellis, former Nurse Consultant and Head of Therapies at St George's NHS Trust Lymphoedema Service.
- Lipoedema is prevalent in arms – 48% of respondents reported having lipoedema in their arms.
 - 98% of lipoedema patients had tried to lose weight, but only 5% had lost weight evenly across their body.
 - 33% had another family member who had been diagnosed with lipoedema, but 74% suspect other members of their family have/had lipoedema without being diagnosed.
 - Lipoedema has significant negative emotional impacts. 87% reported that “Overall my Lipoedema has had a negative effect on my quality of life”.
 - When asked “Has your body shape lead to any of the following?”
 - » 95% reported difficulty in buying clothes
 - » 86% reported low self esteem
 - » 60% reported restricted social life
 - » 60% reported feelings of hopelessness
 - » 50% reported restricted sex life
 - » 47% reported feelings of self blame
 - » 45% reported eating disorders
 - Compression hosiery was the most common treatment, with 79% of respondents reporting being prescribed compression hosiery.
 - Discomfort is a major barrier to patients wearing compression - 55% said they wore compression “most days” or “every day”. The majority cited the discomfort and difficulty in putting compression on as the main barriers to wearing it.
 - Exercising in water is an effective treatment for lipoedema. 79% answered yes when asked if “exercising in water helps your lipoedema?”
 - Aqua aerobics/swimming was reported as being an effective treatment for both size reduction and pain relief. Of those who had tried it, 63% reported it as somewhat effective, effective or very effective at reducing size. 90% reported it as somewhat effective, effective or very effective for helping with pain relief.
 - The majority found clothes shopping immensely difficult, with all categories of lower clothing difficult for over 70%, but 98% of respondents said boots were difficult or impossible.

All respondent identities remain confidential. Data is reported in aggregate.

Key findings

- Lipoedema has been poorly understood by the medical community. Only 9% of respondents reported that their health professional diagnosed lipoedema the first time they reported their symptoms. Only 5% were diagnosed by their GP.
- 46% of respondents reported that the start of their lipoedema coincided with puberty.
- The average age of diagnosis was 44 years old.
- The majority of respondents reported that medical professionals were dismissive of the condition and misdiagnosed their lipoedema as excess weight/bad diet/lack of exercise.
- The most commonly reported response to diagnosis was relief. Respondents also felt angry and frustrated that diagnosis had taken so long, and felt scared about a future with no cure and little that can be done to ameliorate symptoms.
- Lipoedema impacts on careers. 51% reported that lipoedema has an impact on “your ability to carry out your chosen career”, commonly citing a lack of mobility, discomfort and inability to stand. 39% felt their lipoedema had restricted their career choices.

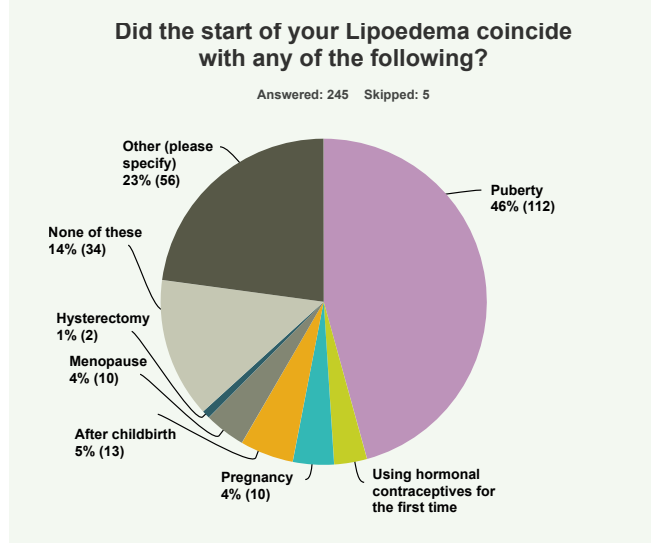


SURVEY FINDINGS

Lipoedema: presentation

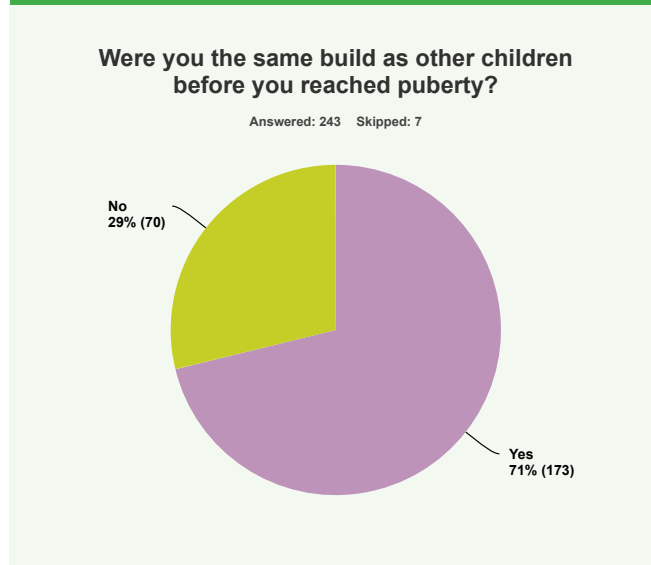
- 46% of respondents reported that the start of their lipoedema coincided with puberty (see figure 1).

Figure 1 QUESTION 9



- 71% reported that they were the same build as other children before puberty (see figure 2).

Figure 2 QUESTION 21

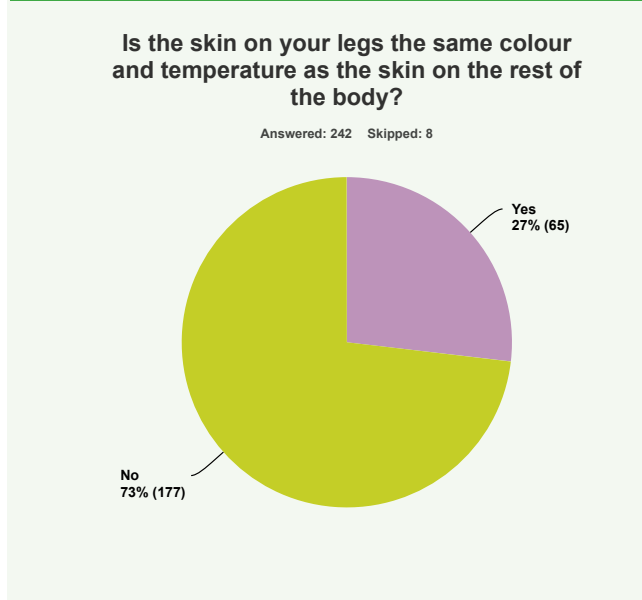


- The most common symptoms described to the diagnosing health professional were:
 - » Feelings of heaviness in legs (79%)
 - » Painful legs (77%)
 - » Difficulty in losing weight (76%)
 - » Thick 'swollen' legs (70%)
 - » Bruised legs (66%)
 - » Tiredness, lack of energy (56%)
 - » Knee problems (51%)
 - » Cold skin (41%)

- » Swollen arms (31%)
- » Varicose veins (29%)
- » Skin problems (28%)

- 48% of respondents reported having lipoedema in their arms.
- 73% said the skin on their legs was NOT the same colour and temperature as the rest of their body (see figure 3).

Figure 3 QUESTION 31



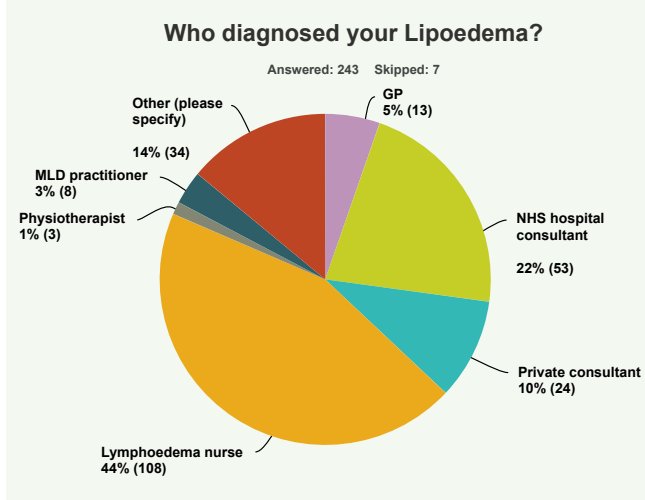
- 43% reported flaking skin; 50% reported itchy skin on their legs.
- 98% had tried to lose weight by dieting, 82% were able to lose weight, but only 5% lost weight evenly from their body.
- The most common areas respondents found it difficult to lose weight from were their:
 - » Thighs (92%)
 - » Calves (90%)
 - » Knees (85%)
 - » Buttocks (73%)
 - » Ankles (71%)
 - » Hips (69%)
 - » Upper arms (61%)
- 33% had another family member who had been diagnosed with lipoedema, but 74% suspect other members of their family have/had lipoedema without being diagnosed.
- When asked about associated conditions, 46% had lymphoedema, 35% varicose veins, 23% painful fat syndrome, 46% knee problems, 24% flat feet/fallen arches, all as diagnosed by a doctor.
- 81% said their hands and feet were NOT affected by lipoedema. Of the 19% who said they were affected, the majority said they were swollen and painful.



Lipoedema: the difficulties in obtaining diagnosis

- Only 9% reported that their doctor diagnosed lipoedema the first time they reported their symptoms.
- Only 5% were diagnosed by their GP (see figure 4).

Figure 4 QUESTION 17



- When asked to describe their doctor's response to their condition when they described their symptoms, the majority of respondents reported that doctors were dismissive, unhelpful and misdiagnosed obesity. A sample of responses are below.

- » "I had repeatedly told my doctor of symptoms and he repeatedly told me he had no idea what was wrong with my legs, without looking at them."
- » "Derisory, hostile and refused to refer me as he said it was incurable."
- » "Totally dismissive. Suggested diet and exercise."
- » "That I was just obese and this problem did not exist."
- » "That I was delusional about my eating habits and was accused of lying about my food diary. Generally each doctor I saw thought it was food and laziness related."
- » "Took many appointments over a number of years. GP mentioned Oedema and said no facilities in our area for Lymphoedema"
- » "Did not understand what the problem was and felt very 'fobbed' off for years."

- When asked how their GPs response had made them feel, there were two clear categories of answers. Those whose doctors failed to diagnose lipoedema or take their concerns seriously had very negative responses. The minority who received a diagnosis or whose concerns were taken seriously felt positive. A selection of responses are below.

- » "Gutted, demoralised, depressed"
- » "Very angry, bereft and isolated. But made of strong stuff so told him I would make my own enquiries regarding the condition and referral!"

- » "Incredibly depressed."
- » "Angry, annoyed that he didn't have the integrity to admit he hadn't known about lipoedema and that he still didn't want to know about it. Frustrated that even when presented with the facts he had no desire whatsoever to help. Overwhelmed with feelings after waiting 50 yrs for an explanation and thinking I'd finally found one, there was no will to help or support me or refer me on whatsoever."
- » "Was so relieved to finally get a diagnosis and feel understood by a kind GP. He arranged for me to have care from the practice nurse as I had varicose veins by this time"
- » "I was pleased that there was a reason why I was so misshapen and couldn't lose weight"

- 67% had discussed their symptoms with another health professional, such as a nurse (27%) or massage therapists (16%), before their diagnosis.
- Before being diagnosed with having lipoedema, 65% were told go on a diet, 60% were told to do more exercise.

- The majority of respondents felt negatively about the advice they had been given before diagnosis. Typical judgements on the advice given included:

- » "Poor and unsympathetic"
- » "Useless"
- » "It was uninformative"
- » "Did not help at all. Made me feel I was to blame."
- » "That I must not be trying hard enough or doing something wrong"
- » "Naively, I would say raise awareness of lipoedema with GPs but with GPs so busy, few are going to spend time differentiating between a genuinely obese patient and one suffering from lipoedema."
- » "I just hope GPs soon look beyond a persons weight and consider could it be Lipoedema"

- When asked "How did you feel when you were diagnosed with Lipoedema?", the common response to this question was "relieved", but respondents also felt angry and frustrated that diagnosis had taken so long, and scared about a future with no cure and little that can be done to ameliorate symptoms. Responses included:

- » "Relieved that at last someone knew what was going on for me. at last I felt safe in the hands of an expert who would know how to help me."
- » "Let down by the doctors because they had not listened to me and just said I was fat."
- » "Relieved initially until I read up on it and then felt frightened"
- » "Annoyed because so many years had passed despite trying to get diagnosis and relieved that the problems I had endured all the years actually had a name."
- » "A mixture of relief and despair. It was great to finally have a name to put to my symptoms. It all



fell into place and I didn't feel like I was going mad anymore. Also happy that my fats legs weren't "my fault". I felt awful though when I found out that because it had been left for so long without intervention, that the most they could now do was prevent further deterioration."

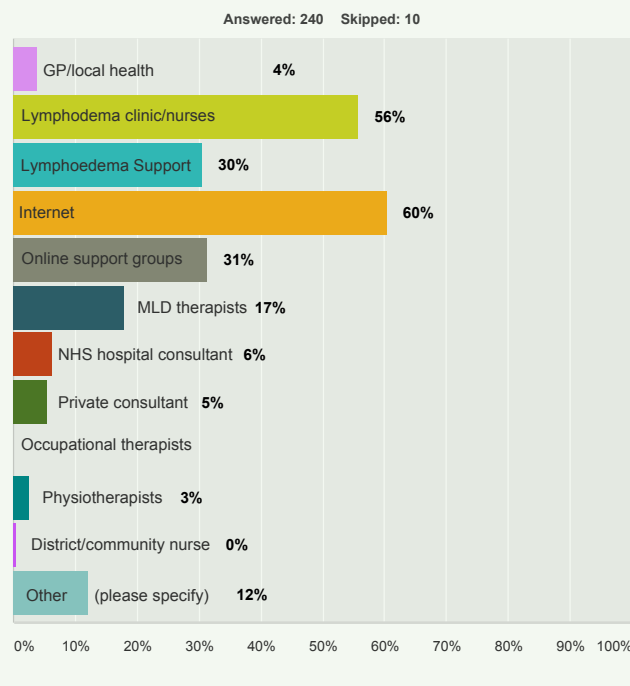
- Diagnosis appears to bring respondents relief but also frustration and a desire for more research into treatments and ultimately a cure, as this selection of comments to the question "If there is anything else you would like to tell us about your diagnosis" show:

- » "It was wonderful to be listened to and be taken seriously and to be treated with compassion, caring and dignity after being ignored and dismissed for fifty years. Even writing this is making me tearful"
- » "I feel like the Lipoedema nurse has thrown me a life line and was so understanding and supportive."
- » "wish more medical people knew about it - only this week I have been to the vascular clinic at Manchester Royal Infirmary to find that neither the doctor or specialist vascular nurse even knew what it was"
- » "To be spoken to as a patient with an illness made a huge difference and to be helped to manage the condition made me look at my own body in a different way for the first time in possibly 45 years. The nurse I saw was excellent and she told me to love my legs because they were my legs. This was life changing for me."
- » "the nurse said if i had help sooner i my not be in the state i am in now"
- » "I wish that there was more research into reasons why this disease occurs, and financial support to find better treatment and perhaps a cure. No-one seems to care and this website etc is the first time someone seems to be doing something positive. I wish I could see a specialist who could recommend further treatment that would help, but it is never really an option. no one knows anything about lipoedema. The attitude appears to be, 'you've got it so live with it.' It is a very hard thing to live with and it is time that people recognise how much people with this disease suffer, and do some thing about it."
- » "The psychological damage of this condition is just as painful to deal with as the physical elements. Feeling alone and most people, including most doctors assuming I am lazy, greedy and fat. I'd had food addiction problems prior to the diagnosis but my Lipoedema diagnosis plunged me into a 10 year binge eating spiral."
- » "It sounds silly too say that fat legs can stop you from doing things in life but we are brought up seeing the ideal body image. When you can't change your shape through diet or exercise it can be upsetting and out of your control."
- » "Since diagnosis it's helped because now I am empowered and trying to find out all I can to change."

- Lymphoedema nurses/clinics (56%) and the internet (60%) were credited as being the most useful sources of information on how to manage lipoedema. (see figure 5).

Figure 5 QUESTION 50

What have you found to be the most useful sources of information on how to manage your Lipoedema? (Tick all that apply)



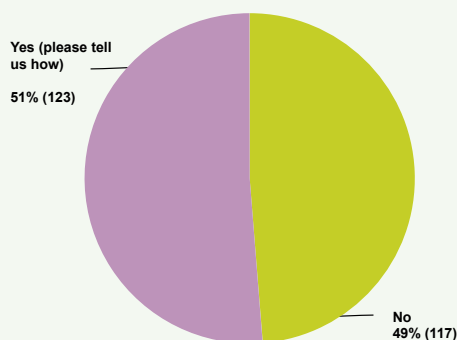
Lipodema: career impacts

- 51% reported that lipoedema has an impact on "your ability to carry out your chosen career", commonly citing a lack of mobility, discomfort and inability to stand (see figure 6). Comments included:

Figure 6 QUESTION 39

If you work, does Lipoedema have any impact on your ability to carry out your chosen career?

Answered: 240 Skipped: 10



- » “I work in a steelworks and find it difficult to get safety shoes/boots and standard boilersuits/workwear doesn’t fit my legs.”
- » “I work in a furniture shop and have trouble getting around the shop to display items as I can’t get through the gaps without usually banging my legs and causing pain.”
- » “I no longer work due to the severe pain in my legs so it has stopped me progressing in my career.”
- » “I’m a part time florist and there is no way now that I could do it all day every day. its a standing job with no sitting down, with lots of bending and carrying heavy objects.”
- 39% felt their lipoedema had restricted their career choices. Comments included:
 - » “I wanted to be a teacher, but gave up as I couldn’t stand all day, I wanted to act but I couldn’t stand up long enough, and I wanted to dance, but I was ridiculed at class for not wanting to wear the correct dance attire as a teen, so I gave up”
 - » “I can’t do any work that involves standing for any length of time. I worked at a hotel at front desk for a summer when I was 20 and was in agony.”
- Nearly 1/5th (19%) reported receiving disability benefit as a result of their lipoedema.

Lipoedema: emotional impacts

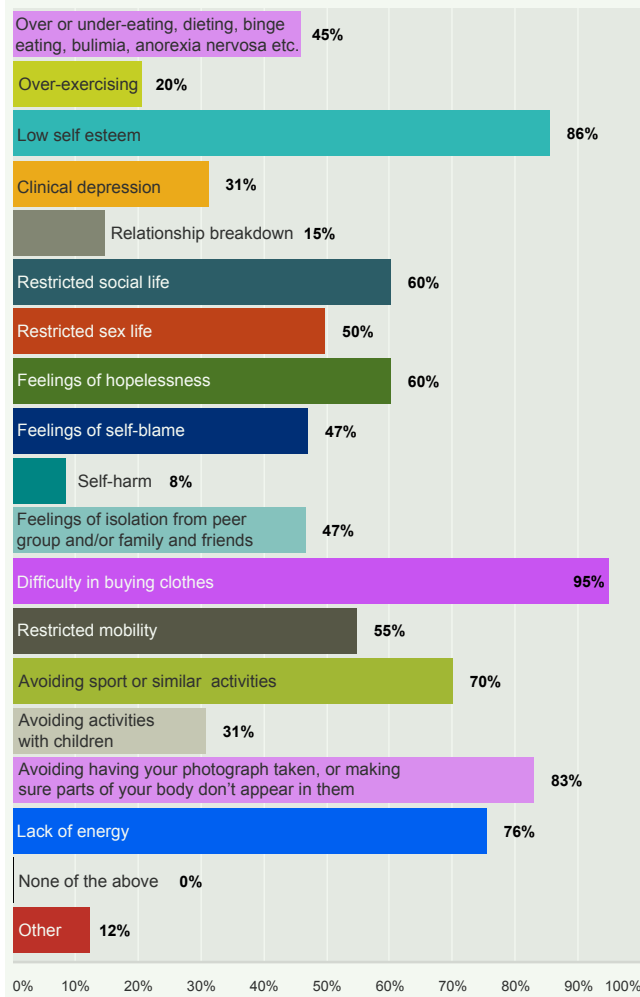
The emotional impacts for lipoedema patients are significant. Embarrassment and shame about the size, shape and look of the areas affected by lipoedema is a huge issue. This negatively impacts on confidence, body image and self esteem, often leading to other issues such as depression.

- 78% reported that people made comments about their legs which made them embarrassed by them. Many gave additional comments such as those below:
 - » “My ex used to call the[m] trotters. My brother once said “You look like you have elephantitus!”
 - » “Look at the size of your legs, you should go on a diet fatty.”
 - » “I had a terrible time at senior school because of my legs. I was laughed at and called ‘Tree Trunks’”
 - » “Peole said it was odd to be slim with fat legs, my answer was fat legs ran in the family.”
 - » “Why are your legs so big is the common one I get. Or bloody hell look at the size of her.”
 - » “Always teased at school and by doctors who thought I was just obese.”
- When asked “Has your body shape lead to any of the following?” (see figure 7).
 - » 95% reported difficulty in buying clothes
 - » 86% reported low self esteem
 - » 60% restricted social life
 - » 60% feelings of hopelessness
 - » 50% restricted sex life

- » 47% feelings of self blame
- » 45% eating disorders

Figure 7 QUESTION 33

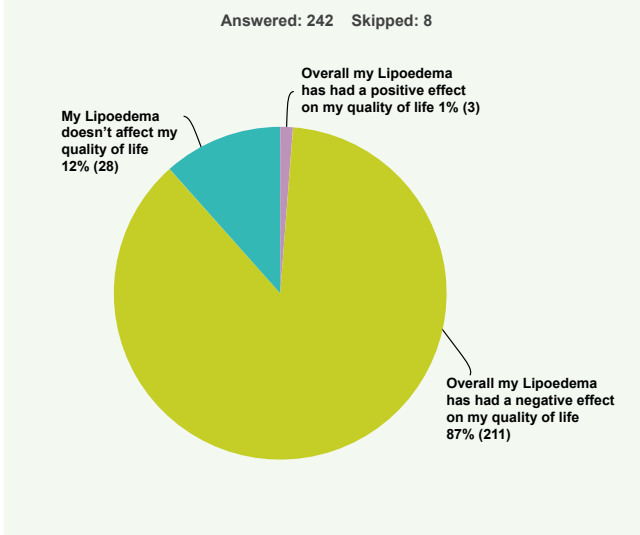
Has your body shape led to any of the following



- 87% reported that “Overall my Lipoedema has had a negative effect on my quality of life” (see figure 8).

Figure 8 QUESTION 34

How would you describe the effect Lipoedema has had on your quality of life overall?



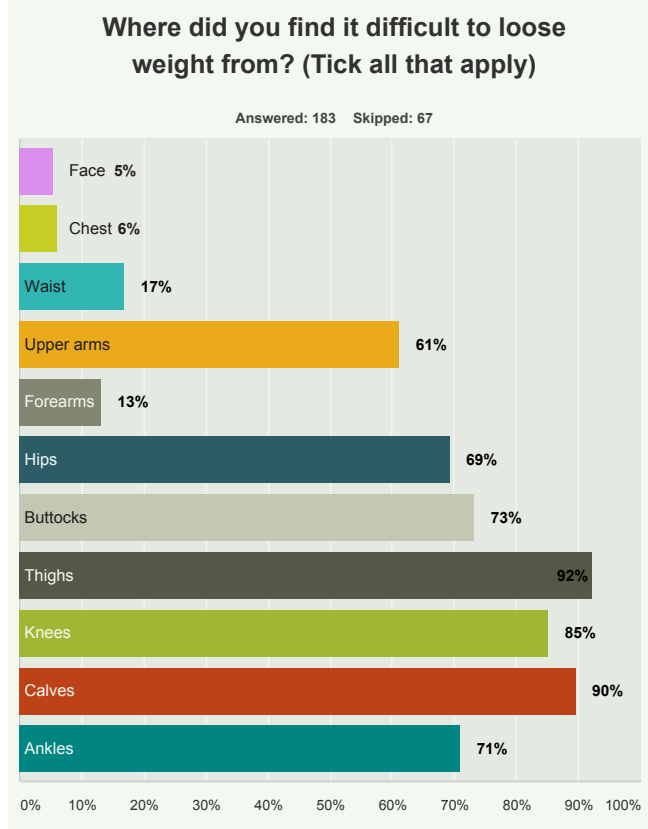
- 40% said they had been discriminated against because of their lipoedema.
- The majority found clothes shopping immensely difficult, with all categories of lower clothing difficult for over 70% but 98% of respondents said boots were difficult or impossible.

Lipoedema: treatments

The lack of advice over treatments, the difficulty in accessing appropriate treatment and the lack of research into effective treatments and a cure were major themes in the report.

- Compression hosiery was the most common treatment, with 79% of respondents reporting being prescribed compression hosiery but only 26% being prescribed Manual Lymphatic Drainage (MLD).
- Compression and MLD were the most commonly used treatments.
- 55% said they wore compression “most days” or “every day”. The majority cited the discomfort and difficulty in putting it on as the main barriers to wearing compression.
- 82% lost weight by dieting but 95% said they did not lose weight evenly from their body (see figure 9). No diets stand out as being particularly helpful – the diet that was reported to have the most success (18%) was low carb.

Figure 9 QUESTION 44

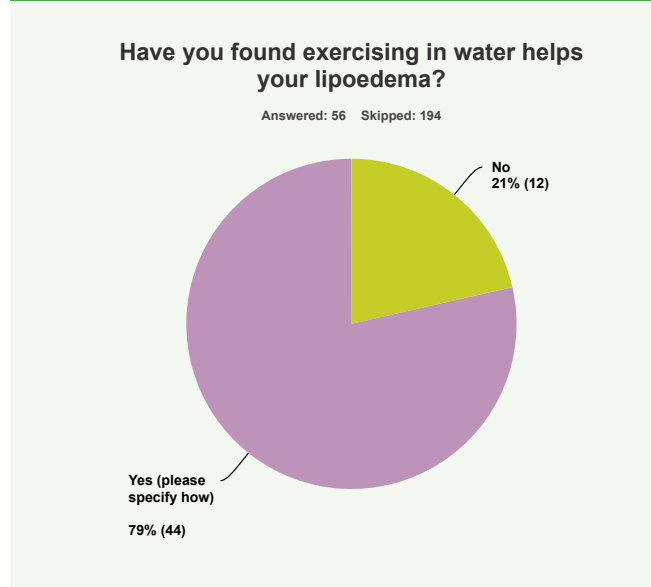


- When asked “Does anything influence the size of your legs,” certain influencing factors emerge, such as: limbs being less swollen in morning; wheat; alcohol: standing; sitting.
- Health issues, pain and mobility were the most commonly cited reasons for not taking regular exercise.

Aqua exercise

- Exercising in water is an effective treatment for lipoedema. Aqua aerobics/swimming was reported as being an effective treatments for both size reduction and pain relief.
- 23% said they regularly exercised in water. Of these, 79% said they found exercising in water helps their lipoedema (see figure 10). Some themes that came up in the answers:

Figure 10 Q55



- » “legs feel less heavy afterwards”
- » “increase in mobility”
- » “eases pain and swelling”
- » “has improved the shape of my butt, hips and legs”
- » “REGULAR SWIMMING HAS REDUCED LEGS DRAMATICALLY”
- » “swimming seems to reduce my leg size and the aching goes away temporarily”
- » “I have found exercising in water helpfull even when I did not know what was wrong with me.I have less pain than other types of exercise and can exercise for longer periods.”

- Of those who had tried it, 63% reported aqua aerobics/swimming as somewhat effective, effective or very effective at reducing size. 90% reported it as somewhat effective, effective or very effective for helping with pain relief.
- When asked “If you don’t exercise in water, but would like to, what is preventing you?” 59% said embarrassment.
- Apart from water exercises, 64% said they took “any other form of regular exercise”.



Other treatments

- When asked to “tick any treatments you have had and tell us how effective you found them to be for REDUCING THE SIZE of the parts of your body affected by lipoedema”
 - » of the 19 people who ticked liposuction, 74% said it was somewhat effective, effective or very effective
 - » of the 81 people who ticked MLD, 75% said it was somewhat to very effective
 - » of the 41 people who ticked multi-layer bandaging, 76% said it was somewhat to very effective
 - » of the 23 people who ticked multi-layer bandaging with MLD, 83% said it was somewhat to very effective
 - » of the 14 people who ticked weight loss surgery, 71% said it was somewhat to very effective.
 - » of the 28 people who ticked dietician, 75% said this was NOT effective
 - » of the 21 people who ticked physiotherapy, 76% said this was NOT effective
- When asked to “tick any treatments you have had and tell us how effective you found them to be for helping with PAIN RELIEF”
 - » of the 13 people who ticked liposuction, 69% said it was somewhat effective, effective or very effective
 - » of the 61 people who ticked MLD, 85% said it was somewhat to very effective
 - » of the 23 people who ticked multi-layer bandaging, 52% said it was somewhat to very effective
 - » of the 19 people who ticked multi-layer bandaging with MLD, 58% said it was somewhat to very effective
 - » of the 12 people who ticked weight loss surgery, 50% said it was somewhat to very effective
 - » of the 18 people who ticked dietician, 67% said this was NOT effective
 - » of the 14 people who ticked physiotherapy, 64% said this was NOT effective

Representative comments include:

- “Thank you for conducting this survey. It has been sorely needed”
- “Hopefully a better understanding of Lipoedema by the medical profession will be achieved.”
- “Thank you for your support. I’m so glad you’re here.”
- “WOULD LIKE TO FIND A CURE !!!!!!!!!!!!!!!”
- “It would be good to have this condition recognised more by medical people. No-one seems to treat it seriously, and they don’t understand the distress it can cause.”
- “I am delighted to be able to take part in this survey and feel that until the medical profession know about the condition the people with lipoedema will feel fat and self conscious and doctors and nurses could lessen that by giving patients knowledge but that means doctors need to know”
- “Thank you for doing this - so many young girls need to know about this so they don’t throw their lives away hating and blaming themselves.”
- “Look forward to the findings of the survey, hopefully a better understanding of Lipoedema by the medical profession will be achieved one day and more help will be available to people who suffer from Lipoedema”
- “Thankful that I am able to at last voice my opinion on this crap genetic disease. Glad that someone may just listen to me and people like me...happy to at last been diagnosed after many many years of suffering comments and wrong “treatment” from (in those days) unkind, uncaring medics. (Apologies to those who may not have been.... 1% ?)”
- “Thanks for caring!”
- “I am very thankful that I have at long last found out what my “illness” is and just pray and hope that a cure will be found very soon. Also grateful that I managed to find Lipoedema UK.”
- “Thank you for what you are doing! :-)”

The value of the survey

When asked for final comments, common themes emerged. Many respondents expressed gratitude at the effort to research lipoedema, and the desire to drive awareness about and further research into the condition.

For further information on lipoedema and Lipoedema UK visit:

www.lipoedema.co.uk

The Royal College of GPs’ elearning course is available at:

<http://www.elearning.rcgp.org.uk/lipoedema>

