



WOMEN IN DIRE NEED

A Lipoedema UK Focus Group Report

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Lipoedema and me: the damaging impacts of lipoedema on everyday life

Lipoedema has far-reaching impacts on womens' lives. This includes significant effects on mobility, careers, relationships, mental health, social interactions and the ability to participate in daily activities.

To explore the impacts, challenges and perhaps surprising effects that lipoedema can have on everyday life in more depth, Lipoedema UK conducted a focus group with patients in June 2018. Patients ranged from 22 to 67 years old, from stage 1 to stage 4.

RIGHT: These images highlight some of the different stages and types of lipoedema. The condition may present at puberty, during pregnancy or around the menopause. All stages have a negative impact on the quality of life for an individual. Early recognition and treatment are vital to prevent progression and deterioration



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KEY FINDINGS

The women reported that lipoedema had substantial, negative effects in the following areas:

EVERY DAY ACTIVITIES These are severely impacted and/or restricted as a result of factors which include:

- Mobility constraints, including the challenges of finding accessible toilets and getting in and out of vehicles
- Size constraints, including finding clothing and footwear that fits
- Psychological constraints

POOR MENTAL HEALTH (ANGUISH) As a result of factors including:

- Lack of understanding and control of their bodies
- Frustration, guilt and blame
- Poor body image, self-esteem and self-confidence

PAINFUL LEGS AND BRUISING

FOOD RELATIONSHIPS AND EATING DISORDERS

ROMANTIC AND SEXUAL RELATIONSHIPS

ABILITY TO EXERCISE Exercise was a challenge for several reasons:

- Challenges in wearing suitable kit
- Embarrassment about wearing swimwear
- Access
- Having to remove compression
- Floatation issues
- Conflicting advice over suitable exercise
- Gait complications

CAREER PATH AND JOB PROSPECTS

THE NECESSITY TO "PLAN EVERY MINUTE"

Lipoedema and Me Focus Group

THE FINDINGS

● Every day activities

These are severely impacted and/or restricted. Examples given of activities that had been severely impact included:

- playing with their children/grandchildren
- working
- shopping
- social occasions
- exercise
- going on holiday
- sleep

The list of everyday activities that the women found challenging, found themselves excluded from or chose to exclude themselves from because of lipoedema was comprehensive. This was because of the way the condition manifests itself in three main areas.

Mobility constraints: Mobility is a major issue for women with lipoedema as the condition progresses. The physical challenges, and often pain, related to doing everyday things such as walking, standing and getting in and out of seats/cars/using public transport restricts all areas of life. This includes work (jobs that require standing, or bending/moving are not sustainable), everyday requirements such as shopping and getting out and about, and relationships. The excess body weight that resulted from lipoedema was also felt to contribute to increased falls.

The women reported that getting to toilets when out and about was also a challenge and fear of finding and accessing toilets could prevent them from doing things.

Patients reported that getting in and out of cars was a frequent problem because when a car was parked next to them, this can mean there is not enough room to get in or out. This sometimes led to the women attempting to clamber out of the passenger door, a mammoth challenge in itself. One patient reported that when someone parked too close to her driver's door, she had to wait 40 minutes for him/her to return.

Disability cards or doctors' letters were agreed to be very helpful as the women reported that members of the public often responded negatively to women with lipoedema accessing disabled facilities.

Size constraints: Size issues also precluded women from being able to participate in certain activities, such as being unable to fit into a fun fair ride when going out with their children. Size constraints also have a massive impact on:

- **Finding clothes that fit.** All of the women – including stage 1 patients – found clothes shopping a major challenge because their body shape made it extremely hard to find clothes that fit. For the younger women, being unable to keep up with fashion trends (such as skinny jeans because jeans would be baggy at the waist but not fit around their ankles) was frustrating, depressing and alienating, especially in a social media age.
- **Finding footwear that fits.** The lack of fitting footwear has a massively restrictive impact on everyday life. Universally, the women expressed frustration that “no shoes fit me properly”. From running around with their children, to gardening and going out, even the young women in earlier stages of lipoedema had issues finding footwear. The women felt immense frustration that their lipoedema made many types of footwear unwearable. This was a particular issue for activities that require boots including wellington, walking, skating and skiing boots. Everyday fashion or winter boots were also noted as being totally unwearable because of a persistent inability to fit around the ankle/lower leg.

“Footwear has affected my hobbies. Orthotics are needed. I have to go for men's shoes with orthotics.”

“I'd previously gone ice skating with the kids, and last year, I couldn't get them on. A bloke let me try his on, but I still couldn't do it. I felt I suddenly can't do stuff.”

“I used to love skiing. But last time, there were no ski boots that would fit me. I was still in kid's sizes. I went through all the different boots and makes and models. It was so embarrassing.”

Psychological constraint: In some instances, although an activity was physically possible, it was felt to be psychologically impossible. This is the case for many types of social occasions, especially special social events such as celebrations and parties. Patients reported that this was because of the problems in finding suitable and flattering clothing. Being invited to a wedding or a social occasion was “the end of the world” because of the need to wear a party dress. A common response was to “stop going to the things” because, as another patient confessed, “I never dress up smart.”

“My lack of mobility cost me my career and 25 years of mortgage payments because my lack of mobility prevented me from earning an income.”

“I can't stand for very long. People don't understand. I take a folding stool with me because I know I won't be able to cope with the day.”

“I can't stand in shopping queues; my legs start burning and itching. I feel like I'm always moving.”

● Poor mental health (anguish)

Lipoedema is characterised by mental anguish. Patient responses indicated that negative feelings were a near-constant feature of their lives. This is as a result of factors including:

- **Lack of understanding and control.** Patients described their anguish at having a body shape they can't control or understand (and which often causes them pain and restricts their mobility and everyday life) for many years until they finally achieve a diagnosis.
- **Frustration, guilt and blame.** The women described frustration, guilt and blame experienced over many years as a result of other people – often mothers or other family members, friends, peers and partners – appearing to blame them for their body size. This is often followed by huge relief when they achieve diagnosis to understand that their size is no longer “their fault”. The acceptance and greater sympathy they then feel they receive in place of previous judgements is significant. However, their frustration with their condition tends to remain unabated after diagnosis.
- **Poor body image, self-esteem and self-confidence.** All of the women agreed that lipoedema has had an enormous impact on their self-esteem and confidence. The women also indicated that negative body image can be a permanent distraction, seeping into virtually all aspects of life. For example, one reported that when she was pregnant, it was not the fear of labour that worried her, but the fear of having to show her legs during labour. The younger women (in their early twenties) also noted the impact of social media and how impossible they felt it was to live up to the images they saw online of slender legs.

“You’re constantly comparing yourself with social media. It tells you legs should be like this and mine just aren’t.”

“My mum said: ‘Why can’t you get rid of it?’ ... When she found out about Lipoedema, she said ‘This is you!’ The relief that it’s not my fault was tremendous. I took mum last year to the Lipoedema UK Conference and it opened her eyes and made her realise it’s not my fault.”

● Painful legs and bruising

The majority of the women reported that their legs were extremely painful, especially when touched or brushed. This was often the result of incidental everyday contact, like being brushed up against or knocked. The women also reported that their legs bruised very easily. Other routine activities could also cause considerable pain. For example, two women reported that having a smear was agonizing and brought them to tears or near collapse because of the position of their legs.

The women also indicated that they received a lack of understanding and sympathy regarding their leg pain. Having it acknowledged by

other patients and Lipoedema UK as a genuine symptom of the condition helped the women to feel vindicated and helped them to demonstrate to family and friends that the pain was real and significant.

“I looked in mirror at the hotel for this conference – I didn’t realise I had so much bruising.”

● Food relationships and eating disorders

Many women reported that they had or had had eating disorders as a direct result of their lipoedema and the challenges of losing and maintaining a normal weight. For some women, the eating disorders themselves were perceived as “take[ing] over every aspect of my life” and having a permanent impact.

The women reported that they felt that having a normal relationship with food was deemed near impossible when what they ate appeared to in no way correlate with how much weight they put on.

Certain foods – such as bread, alcohol and processed foods – were also noted as having negative consequences, such as increasing pain, making their knees hurt or making them feel “toxic and foggy.”

“Food is never enjoyable. I’m always thinking: ‘are my legs going to get bigger afterwards?’”

● Romantic and sexual relationships

The women reported that low self-esteem and body image made it harder for them to enter into romantic and sexual relationships. One woman confessed she was single for 20 years because of her lipoedema. Another, a 19-year-old woman with early stage lipoedema said, “We hate them [our legs] so much, we can’t imagine anyone that doesn’t.” However, it was noted that being in a relationship could be confidence boosting because it helped the women to realise that other people did not really notice or care about their legs in the same way that they did.

Sexual intimacy was also a problem, with self-consciousness about their legs dominating and “ruining it”. The challenges of having painful legs also means that some partners worried about intimacy causing pain. One woman recounted that her partner told her: “when you go ‘oh, ah’, I don’t know whether it’s from pleasure or pain”. Another noted that a lipoedema-related mound above her pubic area made full penetration challenging.

For one 25-year-old young woman, her bulimia had led to infertility, so she felt her lipoedema was indirectly preventing her from having a family in the future. She also felt it was a barrier to starting relationships, because she felt she had to disclose her infertility early on to be fair to a potential partner who may wish to have his own family in the future.

● Ability to exercise

Whilst the women agreed on the importance of exercise, exercise was a challenge for several reasons:

- **Challenges in wearing suitable kit.** For example, when arm and leg support was needed to be comfortable, long-sleeve sports clothing could make doing exercise unbearably hot.
- **Embarrassment about wearing swimwear.** Swimming was seen as a really positive exercise to take part in which brought relief and helped to manage symptoms but getting into the water was a big hurdle. This was largely because of issues around wearing swimwear and being seen in public. Swimming leggings and full body suits were highly rated as helpful tools in combatting this.
- **Access.** The practicalities of getting in and out of pools with restricted mobility.
- **Having to remove compression.** Doing activities, even something as simple as walking to a poolside without compression was also a barrier as it could cause pain and discomfort. One woman reported that walking without compression to get in and out of the pool, caused "my legs to scrape and get sores."
- **Flotation issues.** A couple of the women reported that they found it unsafe to swim as the areas with lipoedema "floated". This made their bums and thighs go up, making it a struggle to get their feet back down again.
- **Conflicting advice over suitable exercise.** As lipoedema affects muscle strength, patients were advised to be cautious over exercise which often led to fear and a reluctance to do any. Finding supportive trainers who could recommend appropriate programs was noted to be very helpful and confidence building. Swimming was also agreed to be helpful.
- **Gait complications.** One woman had been referred to a podiatrist for gait analysis because the shape of her legs had affected the shape of foot and hip so "everything was out of alignment".

● Career path and prospects

The women reported that their lipoedema had a significant impact on their working lives. Many reported that mobility issues (such as trouble standing) had led to them having to give up certain careers or work altogether. Particularly physical roles such as nursing or teaching were examples given.

The difficulties in finding uniforms that fit was a common theme, and in some instances, actually prevented women from certain careers because of the need to wear support. For example, for hygiene reasons, nurses need to be bare below the elbow and this was not feasible for women who needed arm compression. The necessity of having uniform made-to-measure was also noted.

● The necessity to "plan every minute"

There was agreement that lipoedema had such wide-ranging impacts that it required patients to "plan every minute". This was attributed to several factors:

- Compression is hugely time consuming to put on (and take off – for bathroom breaks for example).
- The inability to sit, stand or walk for long periods.
- The need to manage pain and fatigue.
- Physical restraints. From choosing restaurants/leisure facilities on the basis of their access and seat dimensions to planning trips – such as shopping or travel – with frequent, suitable rest stops.

Research description: A focus group was held on 30 June 2018. It comprised of 11 people: nine lipoedema patients, one clinical nurse specialist and one researcher.

Questions and discussion topics included: • The biggest impact lipoedema has on everyday life • Mobility • Clothes shopping & shoes • Relationships & sex • Careers • Exercise



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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