

## WOMEN IN DIRE NEED

## A Lipoedema UK Focus Group Report

Series no:1

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# Debilitating and distressing: the unique challenges facing late-stage lipoedema patients

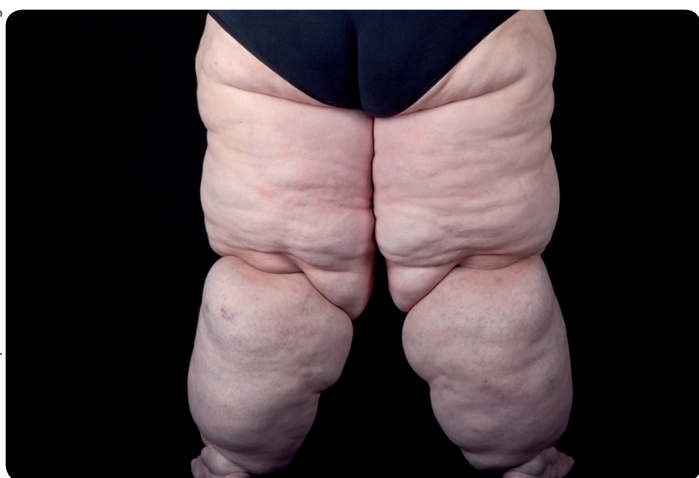
**A focus group conducted by leading UK charity, Lipoedema UK, set out to investigate the huge challenges faced by women with late-stage lipoedema.**

It gives them a unique set of needs, from significant mobility issues, to ill-health related debt and discrimination. Lipoedema UK set up the focus group with late-stage lipoedema patients, garment manufacturers and practitioners to identify some of these specific issues.

Focus group patients categorised themselves as having late-stage lipoedema. This definition was assumed to encompass stage 3 severe lipoedema and stage 4 lymphoedema secondary to lipoedema (lipo-lymphoedema).

### KEY FINDINGS

- Lipoedema restricts all areas of life and mobility is a primary concern
- Toileting can be seriously problematic
- Discrimination and public judgements can be as debilitating as some physical symptoms
- Lipoedema is an invisible, unrecognised disability. Establishing lipoedema as a known condition would be helpful in accessing treatment and in improving public perception for patients
- Financial health and debt are major issues
- Retirement is a looming concern
- Compression is a help as well as a hindrance
- Swimming can be hugely effective at managing pain and in reducing size
- Pain management treatments can improve symptoms and quality of life
- Access to treatment is problematic
- Guidance on filling in medical paperwork would be hugely helpful



**ABOVE:** Late stage Lipoedema - showing classic skin changes, fat pads and skin folds resulting in gait changes and joint complications. Body image issues and restrictions in mobility can lead to social isolation and mental anguish - all having a negative impact on a patient's quality of life

# Late-stage Focus Group

## THE FINDINGS

### ● Lipoedema restricts all areas of life and mobility is a primary concern

For women with late-stage lipoedema, mobility issues impacted on every part of their lives. Several used mobility aids (such as walking sticks) and most found movement uncomfortable. Navigating simple elements of everyday life, such as working, shopping and going out to a café, could be prohibitively hard.

“I have to plan everything – if I don’t walk enough, my legs get sore. If I walk too much, I get sore.”

“I can’t just go shopping. I need to know which shops I will be going to, where the toilets will be, where I will be able to park so I can manage the distances, etc.”

### ● Toileting seriously problematic

Going to the toilet is extremely difficult for women with late-stage lipoedema. This is primarily because of compression and access issues around public toilets.

**Compression:** Because compression requires a typical minimum investment of 20 minutes to put on – a process the women described as a struggle best done at home – there is great reluctance to take compression off/down to use the toilet. This leads women to restrict their fluid intake to reduce bathroom visits, which can lead to other negative health impacts such as dehydration. If manufacturers were able to incorporate features which make going to the toilet quicker and easier, this could be transformative.

**Access:** Using a public toilet cubicle where doors usually open inwards and spaces are cramped can make them inaccessible. Yet women reported being challenged or receiving rude remarks when they mustered up the courage to request access to disabled facilities or used their own radar key (keys which open over 9,000 accessible toilets in the UK). There was agreement that patients should acquire radar keys, which can be ordered for a small charge online. Awareness should also be raised with GPs and health professionals so they can advise relevant late-stage patients to organise radar keys.

“I’m often challenged when I’ve tried to use a disabled toilet.”

“Tiny cubicles and compression are terrible.”

### ● Discrimination and public judgements can be as debilitating as some physical symptoms

The women shared stories of negative comments they had received from friends, family and members of the public. Public judgments – from stares, comments and hostility – were common and had a very detrimental impact on the women.

These responses, and the fear of such responses, affected women’s confidence, self-esteem, self-worth, social lives, working lives and made them reluctant to go out and about. Being challenged about their right to use disabled services, such as parking spaces and toilets, was also a common theme that caused a lot of pain and embarrassment. Late-stage patients also feel isolated from, and judged by, early-stage patients. They felt that patients with early-stage lipoedema had no idea of the challenges and difficulties facing late-stage patients.

“People are really aggressive about you using disabled toilets/parking spaces. I’ve been told to go away and die. That I’m fat and lazy. I have had so many rude comments.”

“A lot of people challenge you if you use disabled space or disabled toilet.”

“I always park at the furthest disabled bay away because I’m so conscious of using them. But I have to use disabled bays because otherwise I can’t get in and out of the car. If I clip my legs squeezing in and out, I get open wounds and cellulitis.”

“I can only get in on the driver’s side.”

### ● Lipoedema is an invisible, unrecognised disability

Establishing lipoedema as a known condition would be helpful in accessing treatment and in improving public perception for patients. Having a debilitating condition that is not widely recognized as a disability creates multiple problems. Lipoedema UK links and material were viewed as invaluable resources to demonstrate how lipoedema could limit movement and its impacts on everyday life when registering for services, such as disabled identify cards, or interacting with health professionals as well as friends and family.

“It’s a struggle enough to get people to believe it’s not just fat. Friends or whatever. I try and explain it is an adipose tissue disorder.”

“I lost 7 stone, but only lost half a centimetre around my legs, but people still don’t get it.”

## ● Financial health and debt are major issues

The potent combination of mobility issues, pain, co-morbidities, low self-esteem, low confidence and other issues dramatically impact on late-stage patients' financial health, limiting previous and current income and their prospects. Most reported periods out of work due to ill health. Many acknowledged the limits the condition put on the types of work they could undertake, or how challenging it made their working life.

"I lost my career as I didn't know what was wrong with me and I couldn't physically do the work anymore. So we got into debt. We're now in rented accommodation, with nothing to show for our careers. Lots of older ladies are almost homeless – and their condition makes them housebound."

## ● Retirement a looming concern

There were serious worries and concerns about retirement as most women had already used up savings during periods of ill health, or to pay for treatments such as liposuction. The prospect of retirement, with no prospect of earning and when women felt their condition was only likely to have worsened, filled the women with fear and dread.

## ● Compression a help and a hindrance

Compression evoked strong responses. When measured correctly and well fitting, it was seen as a life-saving tool for late-stage patients. But the challenges in obtaining well-fitting garments, putting compression on and the discomfort it caused were often seen as a near insurmountable barriers.

### The positives:

- All patients agreed that compression was helpful for pain management.
- A majority said it helped with mobility.
- Compression improves feelings of security and reduces feelings of vulnerability – from feeling better visually to being less worried about being knocked.

"My knees hurt without compression."

"I feel insecure and vulnerable without compression. It holds you in, and keeps everything up. Compression also stop things hitting or catching your legs. You can be quite vulnerable without. Stockings help protect them."

"The sensation in my legs is lots better when wearing it."

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**ABOVE:** Marked Lipoedema showing bracelet effect around the ankle with minimal swelling to foot. Subcutaneous tissues can feel firm and thickened as secondary Lymphoedema may be present along with a risk of developing fungal or bacterial infection of the skin to the lower limbs. Symptoms of pain, heaviness and restricted mobility are common, finding footwear and clothing are very problematic

### The negatives:

- Several of the women reported negative consequences from wearing ill-fitting compression. These included cutting off circulation, creating bands around the ankle or cutting the skin.
- Compression itself caused pain – six patients reported compression hurt at the end of the day.
- Compression takes a huge time commitment to put on and take off.
- Colour palettes for late-stage compression were seen as being "medical" and "boring". Manufactures are tied to using functional fabrics that will provide the right pressure, and these fabrics do not usually take dye well, limiting colour palettes. Investment in R&D in this area could potentially increase the uptake and usage of compression.
- The prescription process makes patients reluctant to try new garments/styles because if a new garment does not work out, they feel they are stuck with it until their next prescription allocation.
- Stockings make legs dry, though moisturising cream is not recommended as it causes the elastic fibres to deteriorate more quickly.

"It's really important that compression fits at the beginning otherwise you give up. I've got scars from ill-fitting compression. You know your body. Therapists need to listen."

"Putting it on makes your fingers sore and breaks your nails."

Getting ready in the morning takes ages."

"The problem is you can't try things. Most of the time, I've only got two garments. A trial so you can try things would be amazing."

### ● Swimming hugely effective at managing pain and in reducing size

The six women who swam said it was “amazing” and that they “loved it”. The rest would love to swim if they could get in or out of the pool – this was a mobility issue as well as a confidence issue.

“Swimming helps massively. It’s the only time I’m genuinely pain free. For my birthday, I hired a hot tub for a week. Purely for pain relief. I lived in it for the whole time we had it.”

“I’ve parked outside twice but not made it inside.”

### ● Pain management treatments can improve symptoms and quality of life

Patients mentioned a range of interventions that helped to reduce pain, alleviate feelings of heaviness, aid mobility and reduce swelling, especially towards the end of the day. These included:

- Skin brushing
- MLD
- Physiopod
- Vibration plate
- Intermittent pneumatic compression

However, the high price of the majority of these treatments (bar skin brushing) made them prohibitive for many patients for whom money was typically tight, often in part because of the impact their lipoedema had had on their income and earning potential.

“Some nights it feels like my legs are going to explode. But the Lymph Flow machine [intermittent pneumatic compression] really helps. My legs feel a lot lighter afterwards. It helps to get rid of the fluid throughout the day – they build up so much, and feel really heavy.”

### ● Access to treatment is problematic

Many patients mentioned the difficulties they had in accessing treatment, especially NHS treatments via lymphoedema clinics. Two said they were no longer accepted at lymphoedema clinics because the clinic’s referral criteria had changed (for example, they only accepted cancer patients).

Many would like to undergo liposuction surgery, but the lack of provision on the NHS and the high cost of funding it privately made it impossible, though people were trying to find ways to save up to fund their own treatment. Patients wished payment plans were available to make surgery more accessible.

There were positive stories of GPs who had responded proactively and helpfully when the patient had explained about the condition and what services they required. Several of the women noted how despite being confident in everyday life, they were “apologetic” when asking GPs for help and when explaining lipoedema if the GP was not familiar with the condition.

“I had to drive 18 miles and get my legs bandaged one by one because I didn’t fit the demographic for a home visit.”

### ● Guidance on filling in medical paperwork would be hugely helpful

Patients found filling in reports and referrals in order to access treatment and apply for funding for liposuction surgery or other treatments on the NHS a challenge. The funding for every procedure had to be fought for.

Patients said that a guide or template that outlines how to write reports and referrals and what steps need to be taken in order to give patients the best chance of being approved would be immensely beneficial.

**Research description:** A focus group was held on 14 October 2017. It comprised of 13 people: 11 lipoedema patients, one health care professional and one researcher. Report author: Amy Fetzer MSc (distinction) © Lipoedema UK 2017. Published: May 2018. This reprint published September 2019.



**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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