

WOMEN IN DIRE NEED

A Lipoedema UK Focus Group Report

Series no:2

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The system is broken: the challenges facing lipoedema patients in obtaining well-fitting compression garments

Lipoedema UK conducted a focus group with lipoedema patients, garment manufacturers and practitioners to understand patients' experiences with compression garments.

It revealed the serious challenges faced by patients in getting the correct fitting garments on prescription. Discussion topics included:

- The process of getting garments on prescription, including who measured, recommended and prescribed them - and whether the correct garments were prescribed and received - and that they fit
- What would make the process easier and less open to errors
- Patients' experiences of wearing compression garments including fit, ease of application and the challenges of the prescription process
- What health care professionals and garment manufacturers can do to improve the process and garments

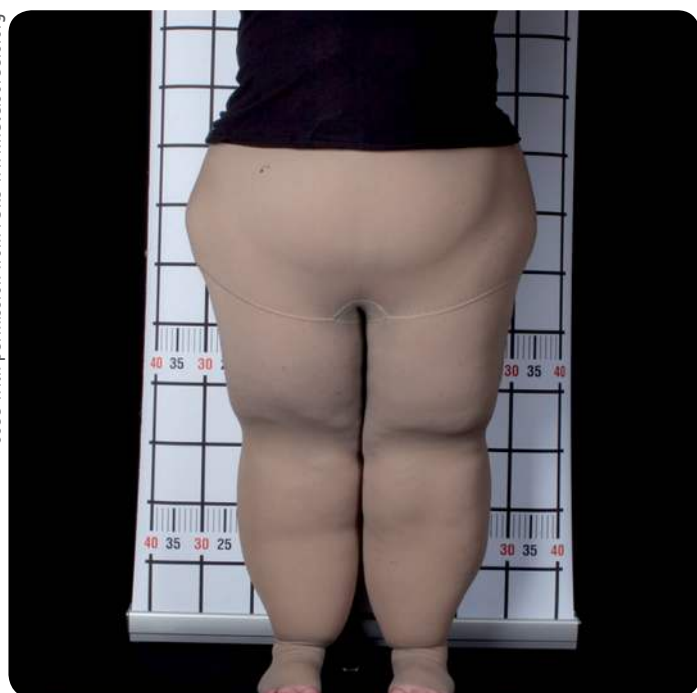
KEY FINDINGS & RECOMMENDATIONS

• PATIENTS STRUGGLE TO GET THE CORRECT GARMENTS

Very few women were successful in getting well-fitting garments on prescription. They reported that compression recommendations from practitioners were often not reflected in the products received. Commonly, made-to-measure recommendations were not followed, with patients given off-the-shelf products in their place.

THE SOLUTION: Patients should request that GPs **handwrite prescriptions** to ensure accuracy and that practitioner recommendations are followed, and that they receive what they have been prescribed from the pharmacy.

...(CONTINUED OVERLEAF)



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Compression Therapy is a main treatment for all stages of Lipoedema but it is important that it fits well and that it is correctly prescribed

...KEY FINDINGS & RECOMMENDATIONS (CONTINUED)

- **PATIENTS NOT ROUTINELY TAUGHT HOW TO USE GARMENTS AND IDENTIFY A GOOD FIT**
THE SOLUTIONS: Lipoedema UK and manufacturers to run education programmes for therapists, practitioners to train patients in garment use, patients to request guidance from therapists.
- **PATIENTS WAIT A LONG TIME FOR THEIR GARMENTS**
THE SOLUTION: Patients to contact their prescriber (usually their GP) to ensure their garments (once correct) are put on repeat prescription.
- **WELL-FITTING GARMENTS CAN VASTLY IMPROVE QUALITY OF LIFE**
THE SOLUTION: Patients, practitioners and manufacturers: Ensure all women are measured correctly and receive the correct garments.
- **OFF-THE-SHELF PRODUCTS HAVE LIMITED EFFECTIVENESS FOR MODERATE TO SEVERE PATIENTS**
THE SOLUTIONS: Patients must be guided by the practitioner on finding the best possible garment, including being open to trying new garment types. Manufacturers must invest in Research & Design (R&D) to improve off-the-shelf ranges.
- **INCONSISTENT MEASUREMENT TECHNIQUES**
THE SOLUTION: Lipoedema UK and manufacturers to run practitioner education programs on measurement. Practitioners to ensure they are up-to-date with the appropriate measurement techniques.
- **WEARABILITY A BIG BARRIER TO USE**
THE SOLUTION: Lipoedema UK and manufacturers to invest more in R&D to create more comfortable and easier to put on garments that are specifically designed for lipoedema patients.
- **PATIENTS HAVE TO BE PROACTIVE TO GET THE GARMENTS AND ADVICE THEY NEED**
THE SOLUTION: Lipoedema UK and manufacturers: Create a checklist that explains what patients are entitled to regarding compression and which includes advice and tips on the prescription system and identifying if a garment is the correct fit.

“You know if your garments are OK when you are experienced, but if you are new to compression, you need to be fitted by therapists.” Patient

“Education is key – we must make sure people aren’t throwing garments away. There has to be a focus on the initial consultation and hosiery fit – patients must demand that. Even if that means saying, I will wait until you fit it on me.” Nurse practitioner

Compression for Lipoedema

THE CHALLENGE

Obtaining well-fitting compression garments on prescription can be a major headache for lipoedema patients. Compression garments – from getting ones that fit to getting them on – can be time consuming, challenging and hugely personal. This is the consistent patient, practitioner and industry feedback received and noted by Lipoedema UK. Compression garments are the most readily available effective treatment for the management of lipoedema. It is vitally important that women receive the correct garments as quickly as possible in order to prevent disease progression and in ongoing condition management. This research is aimed to understand the processes and the challenges from the patients’ perspective regarding the process of measurement, prescription and the fulfilment of their prescription for their compression garments. It also aimed to explore the degree of comfort, functionality and fit of garments and whether patient expectations were met. Its goal was to identify potential solutions for patients, manufacturers and practitioners to improve the processes and products available.

Compression Focus Group

THE FINDINGS

- **Patients struggle to get the recommended garments**
Patients tend to receive compression recommendations from specialist nurse practitioners or other lipoedema/lymphoedema therapists. These have to be taken to a GP and a prescription requested. However, focus group attendees reported that GPs tend to create prescriptions that differ from therapist recommendations. This was attributed to three issues.
 - **Cost.** If a patient is mild-to-moderate, they often fit well into off-the-shelf garments. However, moderate-to-severe patients often do need made-to-measure items. However, made-to-measure items are more expensive (typically two to three times more) than off-the-shelf compression garments. Cost-conscious GPs therefore often switch to an off-the-shelf product when writing prescriptions to save costs.
 - **The difficulties of filling in the prescription form.** Often computerised, industry insiders noted how the prescription software was not designed for complicated items such as compression garments. If the codes given are correct, they will be found on the relevant prescribing system but it can still be time consuming and challenging for GPs/surgery staff to fill out prescription forms correctly. In some cases, this leads to errors and a bias towards ordering off-the-shelf, simpler products.

- **Pharmacy fulfillment issues.** Even when a prescription is written according to a recommendation, pharmacies can fail to provide the garment as described because of the constraints of their systems and product ranges. However, it is illegal to dispense a different product to what has actually been prescribed.

SOLUTIONS: Patients can request that GPs handwrite prescriptions to ensure accuracy and that practitioner recommendations are followed, especially for more complex made-to-measure garment prescriptions.

Patients must check they receive what they have been prescribed from the pharmacy, and should refuse to accept an incorrect product and insist on a replacement if an order has been fulfilled incorrectly. This is because once it has been accepted, it cannot be taken back. Online pharmacies, such as Daylong and Patient Direct among others, who specialise in compression, have a better reputation for fulfilling orders accurately so these types of services are worth considering where appropriate.

“He [the GP] is given a prescription [recommendation] for made-to-measure, but he will give me a prescription for off-the-shelf.”

- **Patients not routinely taught how to use garments and how to identify a good fit**

None of the nine patients attending the focus group had been told how to put their garments on, which aids to use or how to know if garments did not fit correctly. Whilst good practitioners do teach patients how to put on compression and what constitutes a correct fit, and in some cases even book patients in for a fitting appointment, the research highlights that this best practice is in no way standard practice.

“I’m on my own – I screamed in pain trying to get them on. So I’ve not managed to get my compression garments on yet. So I haven’t even got to the stage of managing my lipoedema using compression.”

SOLUTIONS: Lipoedema UK and manufacturers should run education programs for practitioners which highlight the importance of patient education and which describe how to train patients in compression usage and identifying a good fit.

Practitioners have a responsibility to their patients to ensure garments fit well and appropriately. They should also be ensuring there is no vascular impairment; or severe consequences can ensue. Practitioners must routinely train patients in how to put garments on and how to assess garment fit.

Patients must request guidance from practitioners on how to put on garments and how to identify problems if guidance is not forthcoming.

- **Patients wait a long time for their garments**

One patient said it took three and a half months from being measured to receiving her first garments. This means that patients are going without garments or are wearing old garments that have lost their functional properties for long periods.

Clinic waiting times also heavily contribute to how often patients wait for garments. One patient explained that her clinic was so oversubscribed she had to wait 18 months for each new measurement.

“If it’s the right fit – you are walking on air. When it becomes ill-fitting, it goes backwards. To be effective, your garments have to be really well-fitting.”

SOLUTION: Patients. Once the fit is correct, the patient should arrange with their GPs surgery, or relevant hosiery prescriber, that the garments are put on repeat prescription (like other medication).

- **Well-fitting garments can vastly improve quality of life**

The women who had managed to get well-fitting garments reported that they are hugely beneficial. This included improving mobility, relieving pain and reducing oedema.

“I wear compression 24/7. I couldn’t function without it.”

SOLUTION: Patients, practitioners and manufacturers: Ensure all women are measured correctly and receive the correct garments.

- **Off-the-shelf products have limited effectiveness for moderate to severe patients**

Many mild to moderate lipoedema patients fit very well into the off-the-shelf range. However, patients and practitioners felt strongly that off-the-shelf products are not generally appropriate for moderate to severe lipoedema patients. This is because ranges have not been primarily designed for lipoedema patients; different companies have different measuring systems; each patient’s needs are unique; and off-the-shelf product ranges do not have a wide enough range. Patients reported being given ‘the best fit’ when no existing band actually matched their measurements. Patients suggested that half sizes and petite sizes could help.

“There needs to be a half size. My off-the-shelf garments dropped off me.”

SOLUTIONS: Patients must be guided by the practitioner on finding the best possible garment, including being open to trying new garment styles such as tights, for example.

Manufacturers must invest in R&D to improve/increase off-the-shelf ranges so they address the needs of lipoedema patients more readily, for example, by increasing circumference size.

● Measurement techniques and conclusions are inconsistent

The women noted that how they were measured and the results differed depending on which practitioner had measured them. This is often because each company has different products and so measuring can vary from company to company and clinic to clinic depending on which products they use.

SOLUTION: Lipoedema UK and manufacturers to run practitioner education programs on measurement.

Practitioners to ensure they keep up-to-date with appropriate measuring techniques.

● Practicability: barriers to use

Comfort, ease of putting on and off and heat were all cited as barriers to wearing compression. Very few women reported wearing compression every day because many found it so hard to put on and so uncomfortable to wear. Wearing it was likened to wearing a wetsuit. This is particularly relevant for those with lipoedema in their arms. Cutting in around the knees was also an issue – patients suggested silk pockets for the backs of the knees to counter this.

“Even when the garments fit well, putting them on is an excruciating experience. And when they’re on, OK, but how do you go to the loo?”

“They don’t tell you it will hurt – and how uncomfortable it can be. And that can lead to other things – like dehydration. No one told me I needed to drink more – but now I actually drink less as I dread going to the loo.”

SOLUTION: Manufacturers to sponsor more patient focus groups and to invest more in R&D to create more comfortable and easier to put on garments that are specifically designed for lipoedema patients.

● Patients have to be proactive and lobby to get what they need

Patients have to drive the process themselves. There was consensus that patients had to understand and drive the process both in accessing a practitioner to be measured in the first place, and then in getting their prescription processed accurately once a compression recommendation had been received.

This included activities such as arranging repeat garment prescriptions and being persistent in securing a fitting appointment to ensure new garments fit and that they are able to put them on.

This can be a huge challenge for newly diagnosed patients who do not yet understand the process and how to assess whether their garments are correct.

SOLUTION: Lipoedema UK: Create a checklist that explains what patients are entitled to regarding compression including advice and tips, such as getting GPs to hand write prescriptions to ensure accuracy; contacting GPs/clinics for repeat prescriptions and how to identify a correct garment fit. Such a leaflet could potentially be sponsored by the garment manufacturers and issued to patients at clinics. It could also be available online via Lipoedema UK.

Research description: A focus group was held on 14 October 2017. It comprised of 15 people: nine lipoedema patients, two representatives from garment manufacturers (one of whom was also a healthcare practitioner and a patient themselves), one lipoedema-specialised physiotherapist, one carer, one health care professional and one researcher.



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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