



Prescription challenges for people with lipoedema

In October 2017, Lipoedema UK conducted a focus group to understand the experiences of compression wearers with lipoedema. The group included women with lipoedema, garment manufacturers and clinicians. Here, some of the key findings and recommendations relating to obtaining the correct hosiery on prescription are presented.



Lipoedema is a chronic condition that mainly affects women. It is characterised by an accumulation of fat below the waist in the hips, legs and buttocks, creating a pear-shaped figure in which the bottom half is significantly larger than the upper part of the body. The legs can be heavy and painful, and can bruise very easily. For people with lipoedema, compression garments are a key component of the long-term management of the condition.

When a compression garment is recommended it is vitally important that the correct product is received promptly to alleviate the discomfort of the wearer as soon as possible, and to ensure the lipoedema is being managed effectively. However, obtaining well-fitting compression garments on prescription can be problematic.

The focus group carried out by Lipoedema UK asked nine women with



lipoedema about their experiences of getting the correct fitting garments on prescription. The results highlighted a number of challenges.

It is difficult to get the correct garment

Very few people with lipoedema were successful in obtaining well-fitting garments on prescription.

The group revealed that compression recommendations from their practitioners did not translate into the garments that they received.

Usually in practice a compression recommendation is given to the patient by a specialist nurse or therapist, with the patient then taking this to the GP to obtain a prescription. Commonly, made-to-measure recommendations were not followed, with off-the-shelf products prescribed in their place.

The participants of the focus group also reported that their GPs tended to write a prescription that differed from the therapist's recommendations. This was thought to be a result of cost, with off-the-shelf products costing less than made-to-measure so budget-savvy GPs were possibly opting for what seemed like the cheaper option. However, this cost-saving decision failed to appreciate the importance of a made-to-measure garment for the patient, and the fact that prescribing the incorrect garment would ultimately result in a waste and create the need for another prescription. It was also

thought that difficulties in completing the electronic prescription may have accounted for the prescribing of the incorrect garment.

One patient said: 'the amount of problems I've had where the GP has written the prescription wrong — what was on the prescription is not what the nurse has recommended. And what is dispensed doesn't agree with what is prescribed'.

It was also noted that even when a prescription is written correctly according to a specialist recommendation, the pharmacy can fail to provide the garment because of the constraints of their systems and the product ranges available.

Recommendations

Together the focus group decided that patients with lipoedema should take a more pro-active role to overcome these issues. For example, they could ask their GP to generate a handwritten prescription following specialist recommendations to ensure accuracy, especially for complex made-to-measure garment prescriptions. When their garment is dispensed, the patient should check what they have been given and should refuse to accept incorrect garments; insist on a replacement if an order has been fulfilled incorrectly. It is important to do this in the pharmacy, because once the product has been accepted, it can't be returned.

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Another option would be to use an alternative dispenser, such as Daylong, who specialise in compression and have a good reputation for fulfilling accurately and promptly.

Patients have to wait a long time for their garments

One patient said it had taken approximately three and a half months from being measured to receiving her first garments. If this is reflected across the patient group, as anecdotal evidence suggests it is, then patients are waiting for long periods of time in which their condition can decline further, or are

having to continue wearing old, ineffective garments until receipt of the new one. Whatever the scenario, such a lengthy wait is not ideal.

Clinic waiting times were also blamed for lengthy delays in remeasuring. As one of the clinicians participating in the focus group advised 'With lipoedema there has to be an element of self-management and patients have to take some ownership; our clinic has 8–900 patients and one clinician. If you need more hosiery, phone, ask, leave messages until you get what you need. We do react to the patients who shout the loudest'. 

Sharie Fetzer, Chair, Lipoedema UK comments:



Lipoedema patients come in many shapes and sizes, so measuring and prescribing garments is challenging for even the most experienced clinician. Another complication is that most available garments are designed for lymphoedema, not the sensitive, painful, floppy skin of lipoedema, and are usually for one limb rather than both limbs as needed for lipoedema.

The good news is that manufacturers are heeding feedback from Lipoedema UK and are beginning to provide training on lipoedema and are actively looking for new fabrics and ways to improve the range and comfort of garments specifically for lipoedema.

In the meantime, GPs and pharmacies must realise that prescribing alternative garments is counter productive and stressful for the patient. Patients should always check their garment against the original prescription and highlight any issues before wearing, plus seek advice if a garment is uncomfortable to wear. Getting the best fit usually requires determination and patience from patients.

Clinicians, manufacturers, GPs, and pharmacies should also improve their knowledge, skills, creativity and empathy and work with their patients until every prescription results in a well-fitting comfortable garment and a happy patient!