Compression Garments for Lipoedema Patients. Friend or Foe?

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Compression for Lipoedema - Introduction

Definition of Lipoedema
Lipoedema is an abnormal accumulation of subcutaneous fat, mainly affecting the lower extremities and almost exclusively affecting women. It is often compounded by obesity, sometimes oedema and presents with obvious disproportion between the upper/lower parts of the body. Pain (tenderness of the tissues) and bruising are common.

Use of Compression for Lipoedema
Compression for lipoedema patients is a very contentious – there is very little evidence/research to support its use and patients (and HCP’s) frequently describe the difficulties/frustrations they have obtaining/using/fitting garments.
Q51 Please tell us about any treatments you have been prescribed for your Lipoedema. (Tick all that apply).

Answered: 240  Skipped: 10

- Compression hosiery: 78.75%
- Skin care regime: 39.17%
- MLD: 26.25%
- Exercise: 26.67%
- Healthy Eating programme: 16.25%
- Weight loss diet: 10.00%
- Weight loss surgery: 5.83%
- I've not been prescribed: 16.67%
- Other (please specify): 27.08%
Q52 If you have been prescribed compression hosiery, do you wear it:

Answered: 240   Skipped: 10

- Every day: 37.92%
- Most days: 16.67%
- Sometimes: 13.33%
- Rarely: 9.58%
- Never: 22.50%
The Lipoedema UK Survey 2018 (The Use of Compression & Liposuction in the Management of Lipoedema)

Questions included the demographics/background of patients and how lipoedema had affected them in general – as well as specifics around:
Who prescribed/measured the garments
The types of garments recommended
How easy it was to get them dispensed
Information given on fitting them
How the compression was used
How effective it was
How quality of life was affected

The types of garment used after Liposuction (if applicable) was also explored, as well as comments, suggestions, and challenges.
The Lipoedema UK Survey 2018

Demographics:
328 (76%) from the UK
41 (10%) from the USA
18 (4%) from Australia
18 (4%) from Netherlands
23 (6%) Other countries

428 Respondents worldwide; 250 within 48 hours

Age at Diagnosis:
11-18yrs 1%
19 – 25 yrs 5%
26 - 40yrs 26%
41-50 27%
51-60 25%
61+ 16%
Who prescribed the garments?

Diagnosis was made predominantly by:
- Lymphoedema Clinics (29%)
- Private Consultant (20%)
- GP’s (10%)
- Also by surgeons, vascular consultants, dermatologist
- 17% admitted self diagnosis

Who Actually Measured For them?
- 68% were measured by the lymphoedema clinic
- 15% by LipUK Nurse Consultants
- 11% by MLD Therapists
- 5% were measured by a practice nurse
Stage of Disease

Most patients (93%) described their Lipoedema as Moderate to Severe.

Further questioning determined that 32% had been diagnosed with lymphoedema secondary to lipoedema (often known as lipo-lymphoedema) and the group most likely to reduce/improve with compression garments.
Impact Lipoedema Has on Quality of Life

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<tr>
<th>Confidence in social situations</th>
<th>8.94%</th>
<th>9.76%</th>
<th>19.51%</th>
<th>17.88%</th>
<th>43.90%</th>
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<td>24</td>
<td>22</td>
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<tr>
<th>Your long term career prospects</th>
<th>24.14%</th>
<th>11.21%</th>
<th>18.97%</th>
<th>9.48%</th>
<th>36.21%</th>
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As predicted, the lipoedema had a significant impact on quality of life and activities of daily living.
The types and class of garments recommended

Q12 Are your current prescription compression garments an off the shelf size or made to measure for you.

Answered: 107  Skipped: 16

- Off the shelf standard size
- Made to measure bespoke
- I don't know
- Other (please specify)

Q13 What class of compression garments have you been prescribed by your healthcare professional, GP or clinic?

Answered: 106  Skipped: 17

- Class 1
- Class 2
- Class 3
- Don't know
- Other (please specify) De ...

Range of styles offered – predominantly tights/leggings for those with made to measure garments
Problems patient experience with garments

The lymphedema clinic wants me in class 3 garments - I can barely cope with class 2 and they're uncomfortable as hell - I feel like a sausage stuffed into too little skin :/

Languishing at the bottom of the wardrobe!

It took over a year and several different failed attempts before compression garments that fit me properly were achieved. I persisted, and my young/inexperienced lymphoedema clinic practitioner listened to me (& took advice from the company that makes the garments) Thank goodness - I am very grateful for that.

I use a set of braces to keep them up and I still can't keep them from falling down.

First item felt good. Subsequent orders were not the same (though my nurse asked for them to be so.) They were re-ordered several times and out of five garments, two were good, one OK and two completely unsuitable - completely the wrong size! Apparently due to manufacturer reorder problems. Five times to get 3 wearable pairs!
How easy it was to get them dispensed?

Although a number said they had no problems, over 44% of respondents commented on:
• The length of time to receive the garments (weeks to months on occasions)
• Incorrect style, strengths, colours etc dispensed
• Long wait to get errors sorted
• Garment not as prescribed – e.g. bands missing; open rather than closed toe; thigh-highs not tights
• Problems with confusing codes – pharmacy/surgery struggling to find correct garments required
• Received garments not fitting correctly (e.g. too tight, unable to get on, rolling down)
Information given on fitting them

88% of patients seen in lymphoedema clinics were given instructions on how to use/apply/remove or care for the garments.

The remaining 12% used the manufacturers instructions, the internet, friends/family.
How the compression was used

A great improvement over the first Big Survey where only 37% of patients wore garments everyday. Once patients are able to get the garments on, many find the garments actually improve the pain they experience.
How effective the compression was (Size reduction)

Compression is only likely to improve the size (volume) of the limbs, if there is a fluid component to the swelling (those patients with lymphoedema secondary to lipoedema and/or obesity)

**However they can help to:**
- To improve blood and lymphatic flow and prevent fluid retention
- Help **support** the loose connective tissue (less ‘floppy/pendulous’) and thereby enhances mobility
- **Reduce** discomfort, pain and tenderness
- **Protect** the limbs
- **Improve** the cosmetic appearance of the limbs – helps to define/reshape/streamline

*Many quotes from the survey support the above comments*
Has Compression Therapy Helped Improve Overall Quality Of Life?

Q27 Please rate how effective wearing compression garments has been in improving your overall Quality Of Life (QOL)

78% of respondents felt that QoL had improved:
- 39% felt it was effective/very effective
- 39% felt it had been slightly effective

Answered: 101  Skipped: 22
Many negative comments about compression, but many positive too

“My legs feel lighter and do not swell up. It’s hard to describe. I’m so used to wearing them all the time now, that they feel normal, and NOT wearing them is easier to describe. Without them my legs feel heavy, swollen, tender, painful, ‘loose’, ugly, vulnerable, and above all TIRED. I could not carry out my usual walking and day to day pursuits without wearing the tights"

78% of respondents felt that QoL had improved
The types of garment used after Liposuction (if applicable) was also explored.

A selection of garments were used post liposuction ranging from ‘below knee’ to tights with full compression, to wraps.

27% were prescribed by the surgeon
27% by the surgeons nurse
5% sourced their own garments
5% not prescribed at all

13% of patients seen in clinics had surgery, 11% were awaiting surgery,
10% had pursued funding – but were refused
The Challenges Patients Face – and the Patient Wish List (Q23/24)

CHALLENGES:
• Toileting – pulling up tights – especially in hot weather
• Keeping garments up
• Stop them rolling/slipping/creasing – especially at the knee/ankle joints which is so painful

WISH LIST
• For fabric to be breathable – especially during exercise/hot weather
• Smooth fitting
• To be given more supplies – and the chance to try new products without using up NHS allocation
• Ease of application/removal
• Larger sizes - and shorter slengths off the shelf (RtW)
• Larger/better fitting leggings with smaller, shorter waist
• More choice of colour/styles/fabrics
What have we learnt from this Survey?

In the 5 years since the initial Big Survey – there appear to have been substantial improvements in the provision and use of compression garments for lipoedema patients.

If it is worn more often, it seems to help relieve the pain associated with the condition (IF THEY ARE A GOOD FIT), and can help to improve activities of daily living and quality of life considerably (particularly in the earlier stages of the disease)

Patients require support, encouragement (physical/psychological) to use compression appropriately & effectively & need encouragement/peer support to commit to using/wearing it on a daily basis

Majority of patients use a variety of flat/circular knitted products (MtM and RtW) in classes I & II – and achieve reduction in size (and improved shape) if there is a secondary oedema present

This presentation focussed on the patients of the survey who were seen in a lymphoedema service or by an experienced practitioner - however, there are many patients who are unable to access such help – and as a result are unable to obtain good fitting garments leading to regression of the disease and a poor quality of life
Further suggestions/recommendations

A gap in terms of products and technologies?
• Sizing for this group of patients is very difficult with the products available (e.g. far too small in the RtW range)
• The current products are adapted from those within the venous/lymphology field – the need to develop condition specific garments fit for purpose is required
• Improved yarns/fabrics – the fabrics used in sport/outdoor is an option – durable, long-lasting, consistent, and breathable ‘support’ – particularly for early stage lipoedema
• Comfortable to wear
• More fashionable
• Lighter-weight fabric offering flexibility and facilitating movement

Plus Further Education:
• For HCP’s in measuring/adapting compression currently available
• For dispensing surgeries/pharmacies on prescribing compression garments
Thank You For Your Attention *********
And to Sharie Fetzer and LipoedemaUK for their on-going work/dedication to improve the care and support offered to this group of patients so often neglected/ignored.