

# Compression Garments for Lipoedema Patients. Friend or Foe?

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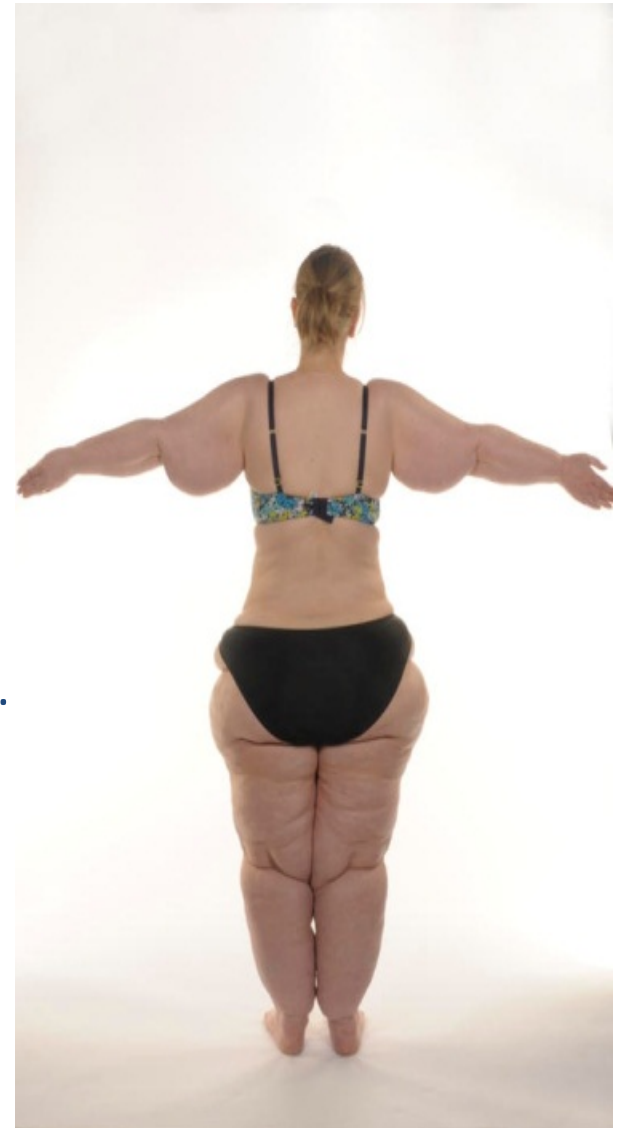
# Compression for Lipoedema - Introduction

## 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

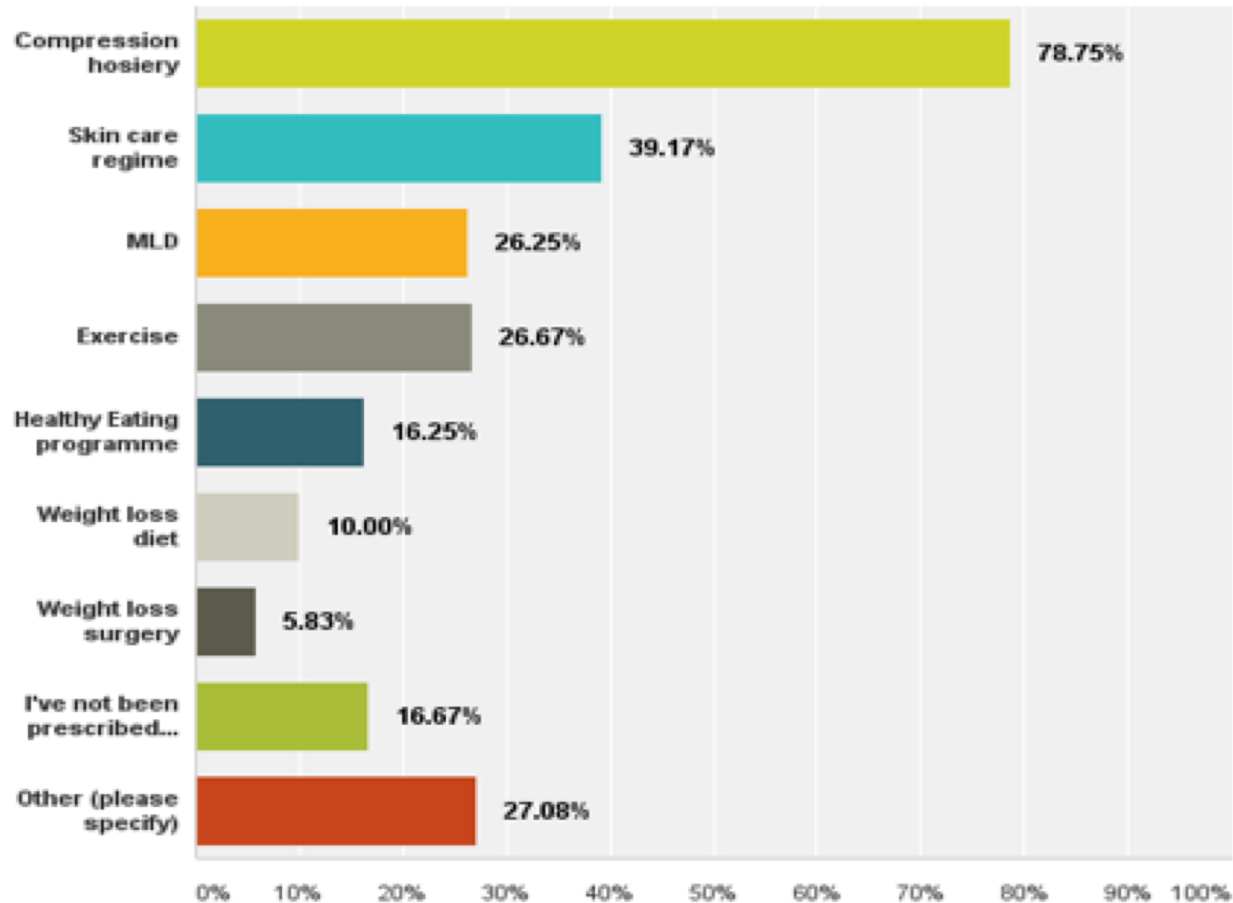
Compression for lipoedema patients is a very contentious – there is very little evidence/research to support its use and patients (and HCP's) frequently describe the difficulties/frustrations they have obtaining/using/fitting garments.





**Q51 Please tell us about any treatments you have been prescribed for your Lipoedema. (Tick all that apply).**

Answered: 240 Skipped: 10

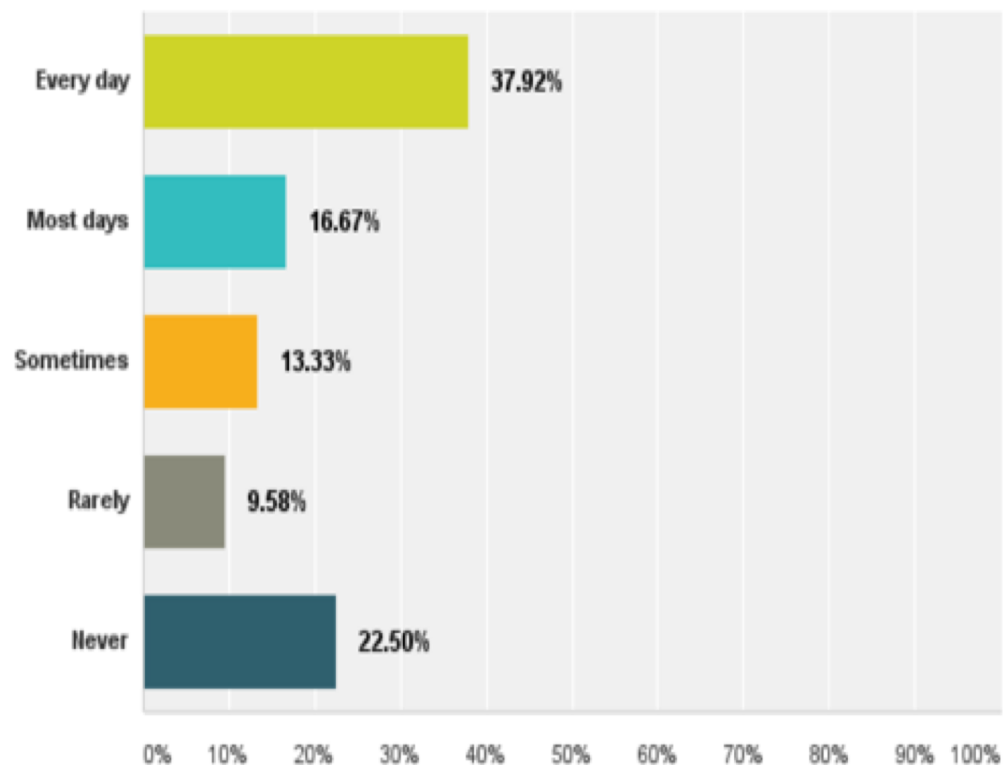


LipoedemaUK Big Survey 2012-2013:250 respondents



## Q52 If you have been prescribed compression hosiery, do you wear it:

Answered: 240 Skipped: 10



# 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 201

## Demographics:

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

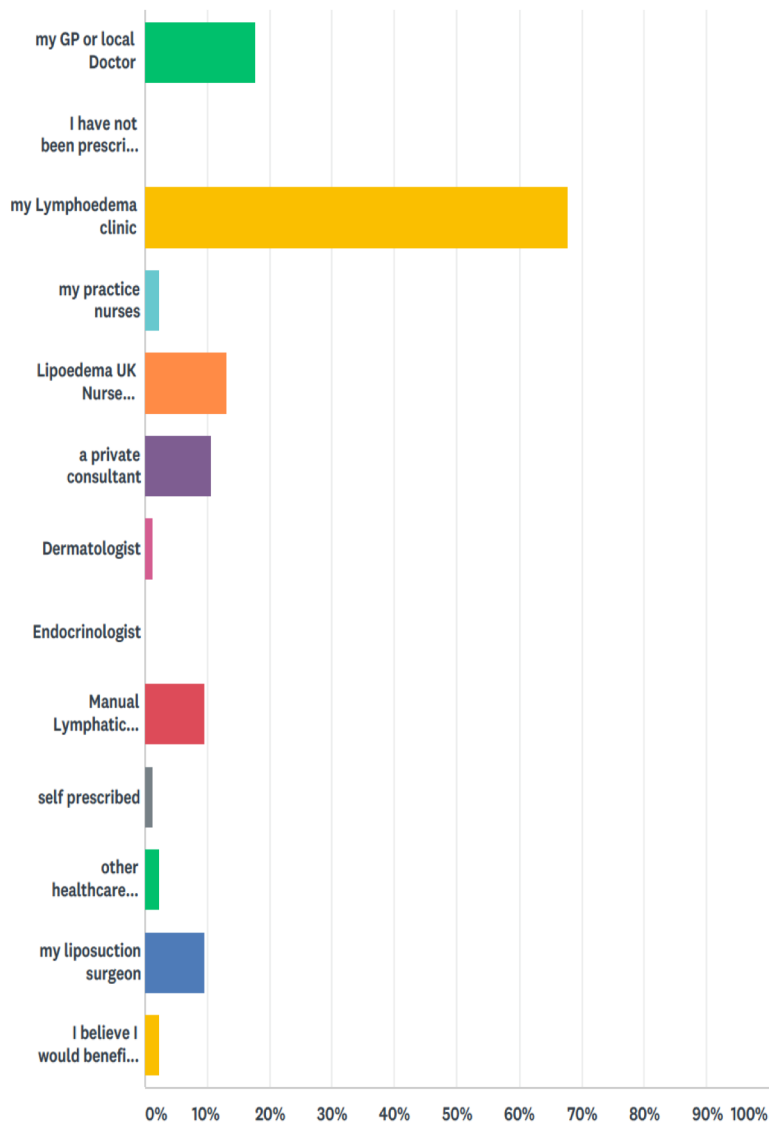
## Age at Diagnosis:

11-18yrs	1%
19 – 25 yrs	5%
26 - 40yrs	26%
41-50	27%
51-60	25%
61+	16%

**428 Respondents world wide; 250 within 48 hours**



# 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

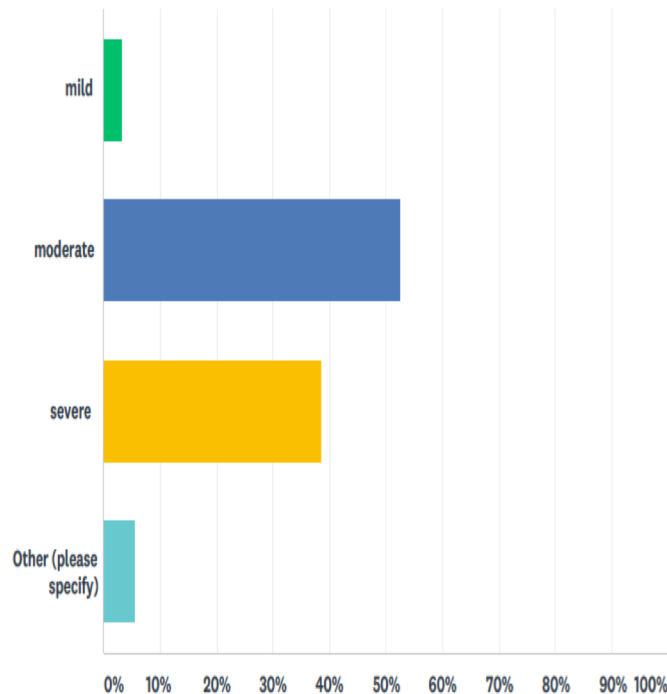
11% by MLD Therapists

5% were measured by a practice nurse

# Stage of Disease

Q6 Would you describe your Lipoedema as mild, moderate or severe?

Answered: 122 Skipped: 1



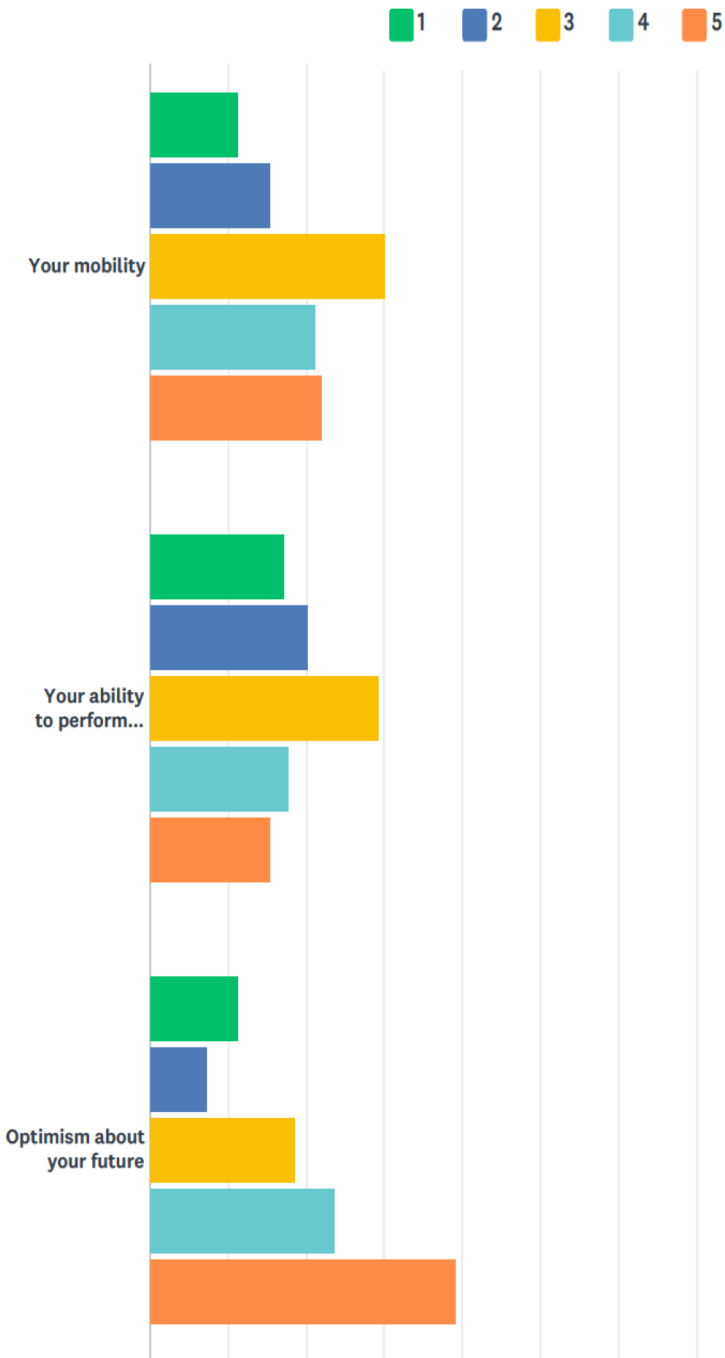
Majority of patients (93%) described their Lipoedema as Moderate to Severe

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

Confidence in social situations	8.94%	9.76%	19.51%	17.89%	43.90%	
	11	12	24	22	54	123
Your long term career prospects	24.14%	11.21%	18.97%	9.48%	36.21%	
	28	13	22	11	42	116

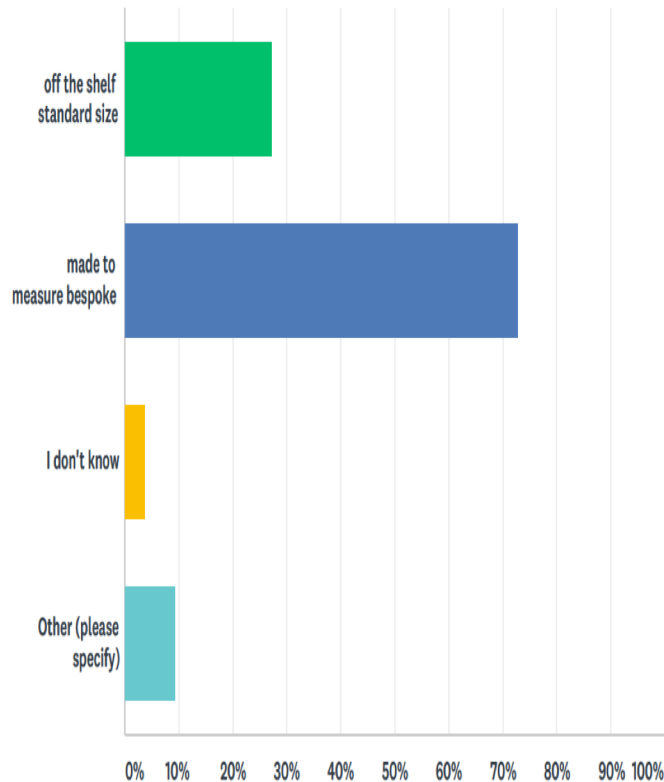
As predicted, the lipoedema had a significant impact on quality of life and activities of daily living



# The types and class of garments recommended

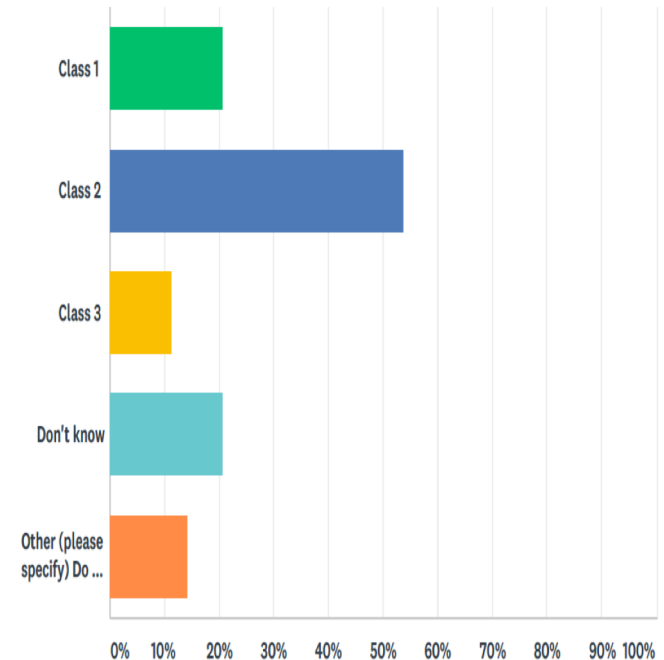
Q12 Are your current prescription compression garments an off the shelf size or made to measure for you.

Answered: 107 Skipped: 16



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

Answered: 106 Skipped: 17



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

# Problems patient experience with garments

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!

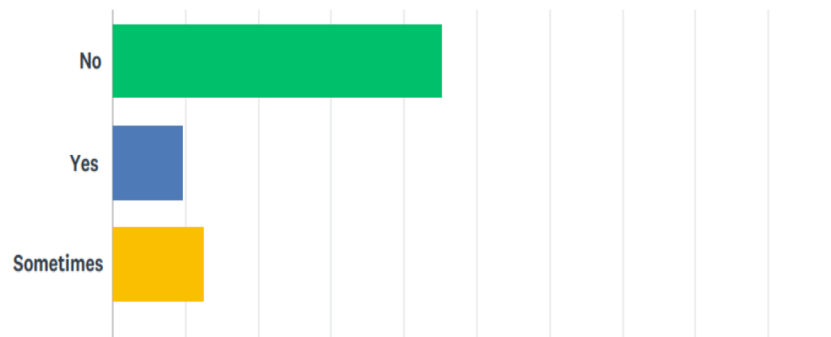
**The lymphedema clinic wants me in class 3 garments - I can barely cope with class 2 and they're uncomfortable as hell - I feel like a sausage stuffed into too little skin :/**

**Languishing at the bottom of the wardrobe!**

# How easy it was to get them dispensed?

Q16 Did you encounter any difficulty receiving the correct garments prescribed?

Answered: 104 Skipped: 19



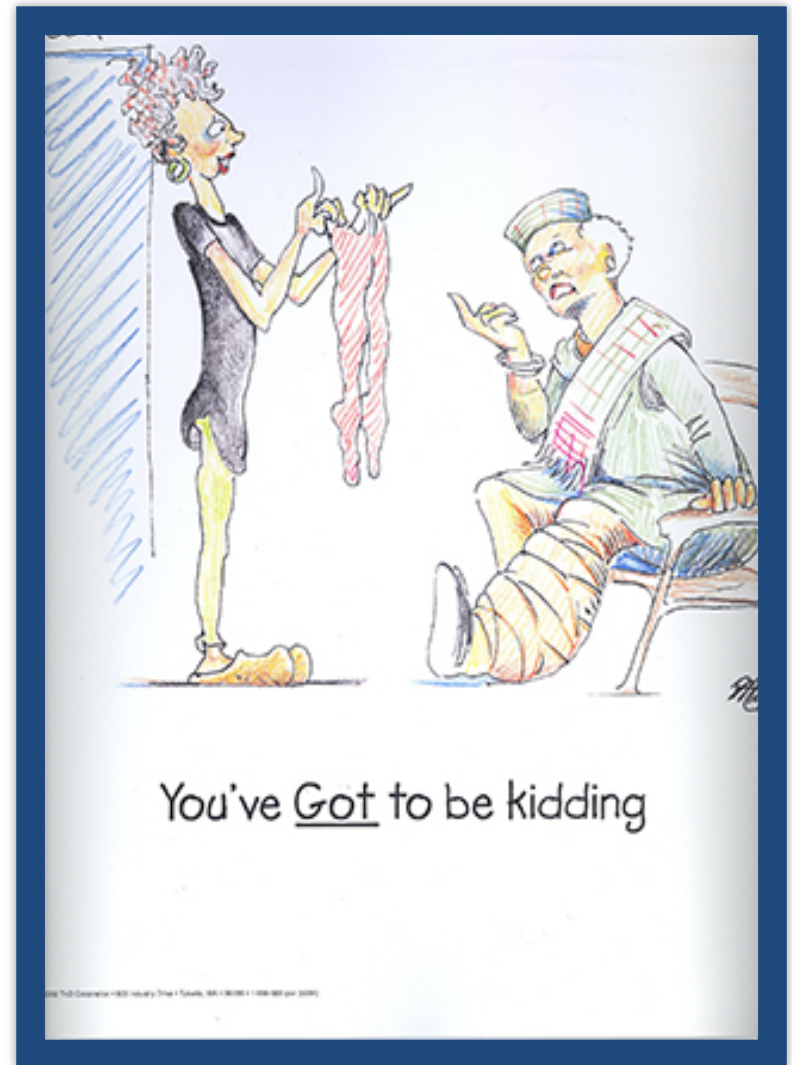
Although a number said they had no problems, over 44% of respondents commented on:

- 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.

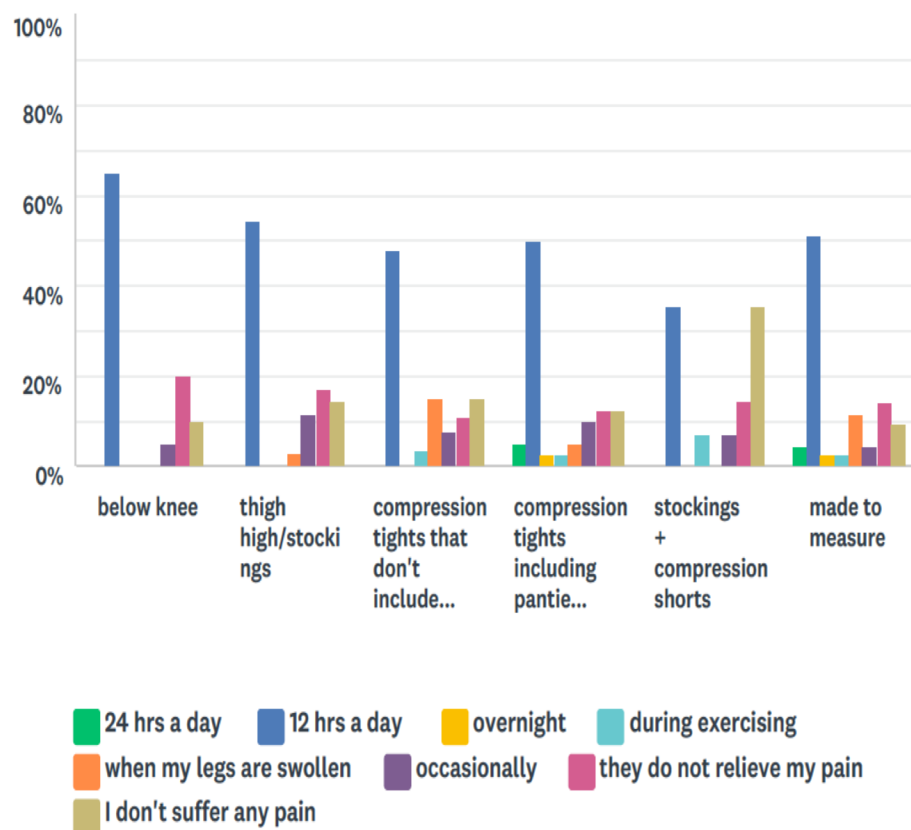
The remaining 12% used the manufacturers instructions, the internet, friends/family



# How the compression was used

Q19 If your compression garments relieve the PAIN your lipoedemous areas how often do you wear them?

Answered: 96 Skipped: 27

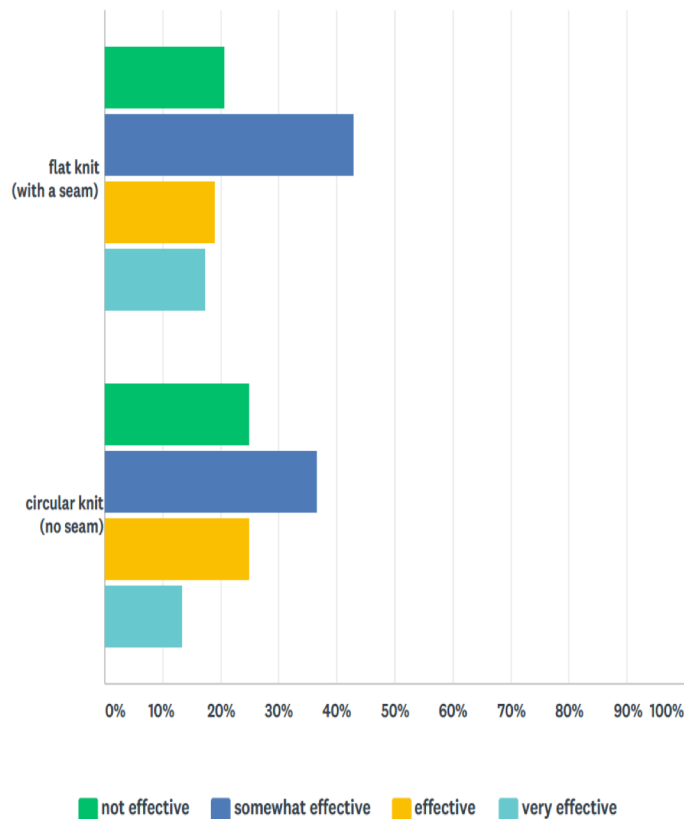


A great improvement over the first Big Survey where only 37% of patients wore garments everyday. Once patients are able to get the garments on, many find the garments actually improve the pain they experience

# How effective the compression was (Size reduction)

Q14 Have you experienced flat knit or circular knit garments? Please rate how effective you find them in reducing the SIZE of your lipoedemous areas.

Answered: 91 Skipped: 32



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:

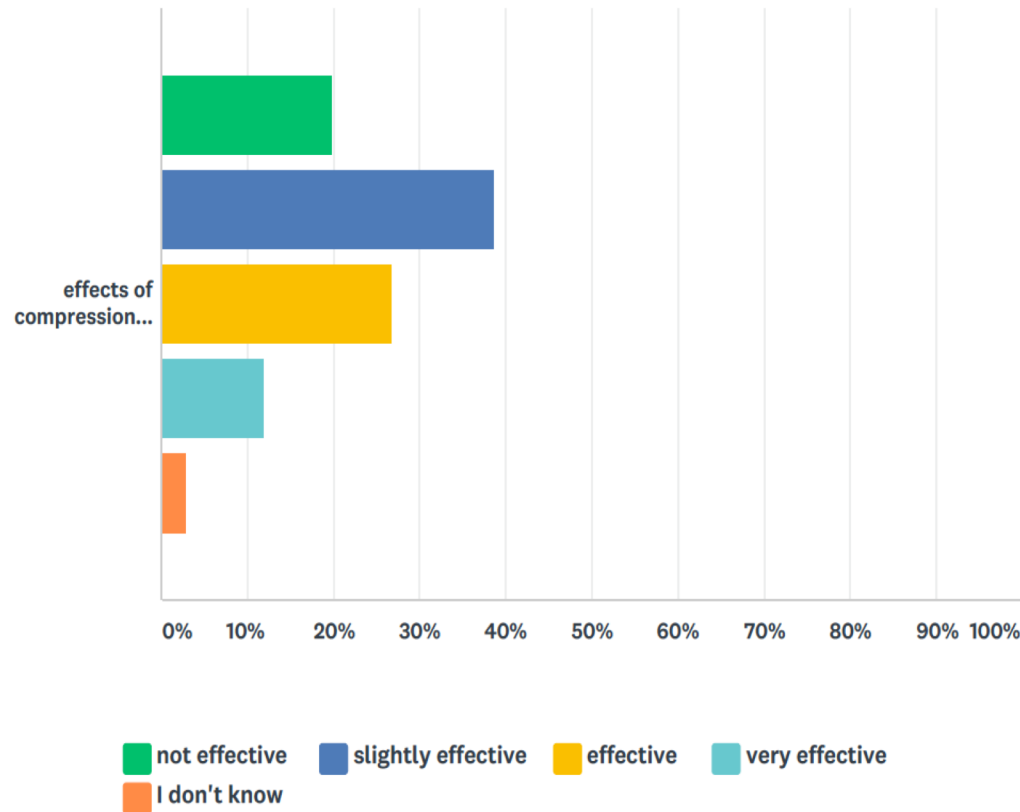
- To improve blood and lymphatic flow and prevent fluid retention
- Help **support** the loose connective tissue (less 'floppy/pendulous') and thereby enhances mobility
- Reduce** discomfort, pain and tenderness
- Protect** the limbs
- Improve** the cosmetic appearance of the limbs – helps to define/reshape/streamline

*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)

Answered: 101 Skipped: 22



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

# 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.

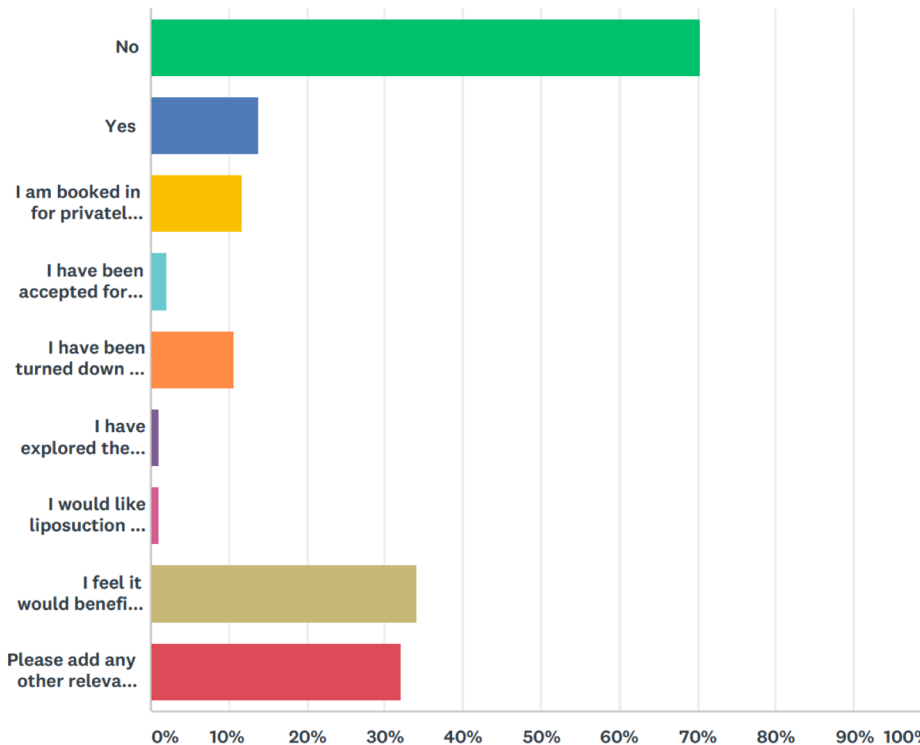
Without them my legs feel heavy, swollen, tender, painful, ‘loose’, ugly, vulnerable, and above all TIRED. I could not carry out my usual walking and day to day pursuits without wearing the tights"

78% of respondents felt that QoL had improved

# The types of garment used after Liposuction (if applicable) was also explored

Q28 Have you been treated with liposuction for your Lipoedema?  
select all that apply.

Answered: 94 Skipped: 29



13% of patients seen in clinics had surgery, 11% were awaiting surgery,  
10% had pursued funding – but were refused

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

# 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.