

# Lipoedema & The NHS

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At

Lipoedema UK's Conference

30th June 2018

# Session will cover

- \* Ethical dilemma
- \* How do we diagnose lipoedema?
- \* Treatments available on NHS/ not available
- \* Our experience of patients undergoing liposuction for lipoedema
- \* Implications for NHS
- \* New ways of working

# Introduction

This document has really helped to support the management of lipoedema in the NHS

And RCGP training



# Management in the NHS

- \* Many centres do not accept referrals for lipoedema - may be ca only
- \* Not seen as lymphatic failure
- \* Definitely an increase in recognition now receive referrals for lipoedema
- \* Diagnosis is not always correct

# How do we diagnose lipoedema

- \* Fundamentally subjective = difficult
- \* History taking - family history, PMH, medication
- \* Physical exam, measurement (perometer/MM), photography, videos, 5 's' score
- \* Weight - BMI, waist circumference

# Weight

- \* Big issue, growing issue!
- \* Many people carry weight on their lower half, not all pear shaped women have lipoedema
- \* We do not want to over diagnose or waste resources.
- \* Upper limb enlargement is very difficult to assess - loose, floppy tissues can be normal to upper arm (should be a bracelet at the wrist)
- \* Losing weight does impact on lipoedema and reduces risk of lipolymphoedema - I have concerns that liposuction does not always address a persons weight as other cosmetic procedures often do. This is due to minimally invasive procedure thus less healing concern BUT would be the most appropriate approach to secure some weight loss prior to surgery
- \* Lipoedema is not an excuse for obesity

# Pain

- \* We are careful how we approach asking patients about their pain as many have lived with the condition for many years prior to their diagnosis and assessment at a specialist service. They have led industrious and full lives until this point and a diagnosis should not change this.
- \* We would not say ooh isn't it painful?! We would try and focus on what does the pain limit you doing and then focus on that as a goal.
- \* We can diagnose, give advice on management but we do not have a magic wand!

# Expectation

- \* We have to be careful as lipoedema is lifelong and incurable.
- \* Expectations have to be managed and cause extreme frustration for some.
- \* This has implications for the NHS, lipoedema management can involve a huge amount of reassurance and support which can redirect time and resources from others this is difficult as many lymphoedema/lipoedema therapists do not have specialist psychological training to enable them to deal with more complex issues.

# Liposuction

- \* Again another ethical dilemma in the NHS as this is the only real treatment aimed at reduction and is not available on the NHS.
- \* It is difficult to see a patient for the first time, establish a trusting relationship, listen empathetically, often as the first person who has ever listened to them or understood the condition and then say “oh and the treatment you need is not available on the NHS and limited in the UK as a whole”
- \* NHS should be free at the point of delivery, patients become frustrated with maintenance, should we therefore see lipoedema patients at all?

# Liposuction cont . .

- \* We have over the last 2 years seen a number of patients self funding liposuction, not all have travelled to Germany.
- \* Huge sacrifices e.g. equity release from home, university fund.
- \* Patients will ask why can I not apply for exceptional/ individual funding and there is nothing to stop anyone applying BUT it is impossible to state any one patient with lipoedema is exceptional to another.
- \* They are all initially delighted with the results BUT over time there is a realisation that they still have lipoedema and will still require maintenance therapy, many remain seriously over weight.

# Unexpected Issues

- \* Patients have expected intensive (sometimes 4 weeks + and daily) MLD pre and post op as this is what has been recommended by their surgeon!
- \* We have also had patients ring and ask if we could get them some hosiery on prescription as the hosiery the surgeon was offering was too expensive!
- \* This is very difficult as we have no correspondence with the surgeon/clinic or hospital and no thought has been given to our clinic availability or resources.
- \* It is also difficult to justify as there is no gold standard evidence that pre and post MLD will enhance the results of liposuction. NHS requires hard fact to secure resources.
- \* Thanks to Lipoedema UK, we now have support for this dilemma. The surgery advice booklet advises that pre and post care must be factored in to any costs when planning liposuction and this may mean paying privately for MLD.

# Management of lipoedema in NHS

- \* Skincare - cellulitis risk reduction, red legs, hydration of the skin
- \* Exercise - NO exercise is forbidden or to be avoided. All exercise is beneficial and should be encouraged even resistance training.
- \* Compression - always provided non FP10 garments where needed e.g. Marena leggings, cycling shorts to be worn with mtm bk hose in those not able to manage leggings/cycling shorts. BUT we are all being scrutinised. Remember you should only pay 1 prescription charge per pair

# SPC

- \* Proximal to distal
- \* Patient purchase or offered on NHS in some lymphoedema clinics but again time and resources are scarce, one treatment takes 1+ hour with new machines and needs a private room space.
- \* Extends onto the body
- \* New modes to focus on specific areas
- \* What outcome measure do we use in Lymphoedema we measure for reduction? We rely on subjective patient feedback again difficult to justify



# New ways of working

- \* We are having to look at different options to continue our care and support of patients with lipoedema and to be creative
- \* We are victims of our own success, we accept self referrals for family members from our lipoedema patients often ending up with  $\frac{3}{4}$  generations attending the clinic!
- \* Our plan, see for initial assessment, investment of time, listen to patients concerns and establish trusting relationship and diagnosis along with care plan and goal setting. If purely lipoedema we will then discharge back to primary care for ongoing hosiery provision BUT with a referral to a new lipoedema support group, held locally away from RSUH every month.
- \* If lipolymphoedema will continue to have on going clinic monitoring

# SLIMBS - Lipoedema

- \* We have active patient run lymphoedema support group, we have learned a lot
- \* We need to access some funds/ resources to help with set up costs and identify some expert patients to run the group
- \* Every lipoedema patient will be given the opportunity to attend and gain support and interaction with others with this debilitating and distressing condition.
- \* There can be guest speakers for education and the clinic staff will attend as invited to provide updates and treatment related advice/support
- \* Some have argued lipoedema may be progressive and become lipolymphoedema BUT this should not happen in a managed group

**SLIMBS information sheet – supporting North Staffordshire Lymphoedema**

**SLIMBS** is a patient led group which supports patients with lipoedema and the work of the University Hospital of North Staffordshire Lymphoedema service. Its primary aim is to provide education, support and advice for lipoedema patients, their families and health care professionals. SLIMBS stands for:

**Staffordshire Lymphoedema information Management Buddying and support!**

**Chair:** Christine Jones

**Treasurer:** Debbie Jones

**Secretary:** Margaret Gaddes Tel: 07752 30464

**Website:** [www.slimbs.org](http://www.slimbs.org)

**Our meetings** are held at The Quaker Meeting House, Miller Street, Newcastle, ST4 6JF, on 18.30-12 a.m. usually 1st Tuesday each month. **All are welcome!**

Our website was set up in November 2013 to give basic advice and information about SLIMBS. [www.slimbs.org](http://www.slimbs.org)

We have monthly meetings, these have a strong social element, with time for a cup of tea or coffee, cake and a chat.

Alternate meetings have an educational focus. In December we have a bring and share meal, in August we have a meal out, and in March we hold our annual general meeting.

Every year we support the national lymphoedema awareness month.

The March 2018 initiative.

Members include those with primary/secondary lymphoedema (often cancer-related) or lipoedema, their families and the health care professionals who care for them. Since we began in 2010 we have steadily grown in membership and now have 60 enthusiastic and committed members. We act as a 'patient voice' and support the work of our excellent local lymphoedema service. Most of all we support and help each other and reach out to others in our community affected by lymphoedema.

SLIMBS information pamphlets are given out to new patients at the Lymphoedema Clinic.

We have produced and helped distribute 3 editions of our Newsletter to all local Lymphoedema patients.

We have even been on TV! 6 of our members were interviewed and filmed for an item on 'BBC Midlands Today' presented by Lisa and May, 14th May 2015. It was also televised at 18.30 on Friday 6.3.2015.

# Novel therapies

- \* Available in some UK lymphoedema clinics, poor evidence to support their use:
- \* Hivamat/deep oscillation therapy
- \* Physiotouch
- \* Low level laser therapy
- \* Kinesio tape

# Conclusion

- ❖ There have been a number of advances in compression and there continues to be significant investment from the hosiery companies to develop new and innovative products for patients required to wear life long compression for this debilitating condition.
- ❖ Technological and medical developments mean that hopefully compression will one day be unnecessary.

# BLS

- \* Become a Friend FREE of charge, receive regular updates, global emails and quarterly e-newsletter
- \* BLS annual Conference 3-4<sup>th</sup> October 2018



**BLS** BRITISH LYMPHOLOGY SOCIETY

## BLS Annual Conference

**1st-2nd October 2018**

Meet the Exhibitors Evening Buffet 30th September  
Workshops 3-5pm Tuesday 2nd October

**Confirmed Keynote Speakers:**

- Dr Hakar Brorson**  
(Consultant Plastic Surgeon)
- Dr Kristiana Gordon**  
(Consultant in Dermatology And Lymphatic Medicine)
- Dr Sinclair Gore**  
(Consultant Plastic Reconstructive And Aesthetic Surgery)
- Professor Vaughan Keeley**  
(Consultant Physician Specialising in Lymphoedema)



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Accommodation Available On Site

Yarnfield Park Training & Conference Centre, Stone, Staffordshire



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