



www.lymph-what-oedema.com
Quarterly Newsletter
May 2015

I have had an amazing year and on the 13th May 2015, Lymphwhatoedema's online support group celebrates its 1st birthday. Wow!! At the time of writing we have 398 members from all over the UK, in addition we have members in Europe and the USA. The website has had over 59,149 viewings.

To celebrate LWO's 1st birthday I have organised a Spring Event to be held 13th May, hosted by Mary Ann Evans Hospice. The Hospice and myself have organised speakers, demonstrations and Medi have sponsored a buffet lunch.

In 2015 LWO has joined Pinterest and Twitter. I have to say I still don't get Twitter and do struggle with it but it has given us another platform to get the word out that Lymphoedema exists; we exist.

This year across our social media we are being followed by National Cancer Support, Womb Cancer UK, Juzo, Medi and many more. Our Spring Event was advertised by both BLS and LSN and I appreciate their support.

We really are getting our message out there so I thought I would share the positivity message for our 1st birthday.

Knowledge is Power

Knowledge shared is— power multiplied

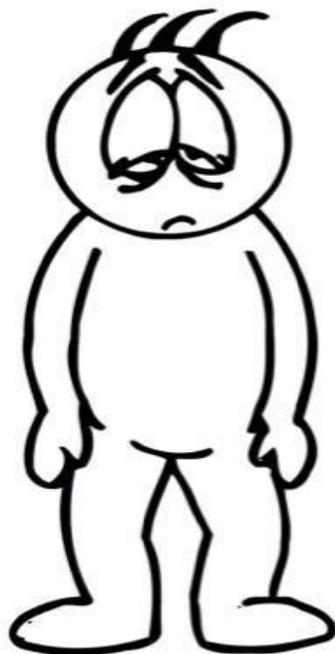
Together we are empowered



How does it feel?



FATIGUE AND LYMPHOEDEMA



Having lymphoedema makes your limbs feel heavy due to the swelling of lymph fluid build up

Lymphoedema can create fatigue for many who live with this condition

Foods that heal

Our members often ask how they can lose weight? Which foods are best for lymphoedema? Foods can cause inflammation, equally there are foods that are anti-inflammatory. Many of our members are looking for healthy options especially those who have been through chemotherapy or are taking anti-cancer drugs. Below is a guide. Please remember to check with your own health-care professional before undertaking any change in your diet.

Foods that cause Inflammation

- Alcohol
- Artificial Food Additives
- Common Cooking Oils
- Dairy Products (Milk)
- Red & Processed Meat
- Refined Grains
- Sugars
- Saturated Fats
- Trans Fats (hydrogenated)

Anti-inflammatory Foods

- Broccoli
- Blueberries
- Dark Leafy Vegetables
- Extra Virgin Olive Oil
- Ginger
- Green tea
- Kelp
- Papaya
- Salmon
- Sweet Potato

Did you know? Extra Virgin Olive oil is;

- Anti-bacterial
- Anti-inflammatory
- Anti-septic



Keep moving

If you have lymphoedema you have to move because the lymphatic system is moved by our muscles, not by your heart that moves the circulatory system.

If you are lying on the couch or with your feet up, shift position every 30 minutes. If you can exercise start with small goals every day.



My favourite quote is from the lady who writes lymphedemaandme.wordpress.com

“No matter how slowly you go, you are still lapping everybody on the couch”.

LWO encourages exercise. I realise when you are in terrible pain that this is very difficult to do and probably the last thing you want to hear. Your lymph fluid will not move on its own.

On our website there are a variety of exercises including breathing, arm and leg exercises. These exercises can be started slowly and built up, from sitting in a chair, lying down or standing. On the website there are videos to show you how.

Were possible do your exercises to your favourite music. Find a Healthy Steps class .

Aqua aerobics, swimming and walking are all good exercises.

Take a look at www.lymph-what-oedema.com/exercise

Breathing Exercises



Blowing bubbles is a good way to start your deep breathing exercises. Not only is it a brilliant way to open up your lymphatic system it is a wonderful way to control panic attacks.

Lymphoedema and deep breathing exercises!

Deep breathing exercises several times a day are vital to help move our lymph fluid along



Remember to put them into your daily routine

I know it is hard to remember to do, but deep breath when you are sitting, walking, resting

Just think of it as a means of keeping YOU well!

Skin-care

As we approaching warmer weather or going on holiday to a hotter climate looking after our skin is a top priority.

When you are hot and uncomfortable it is a big temptation to remove your sleeve. To do this in hot weather, puts you at high risk of increased swelling. Please consider your lymph nurse who then might have to fit you in for another appointment, this means someone else loses theirs.

Please keep wearing your compression sleeve/stockings

- Keep your skin clean
- Look for dry areas, cracks or rashes
- Moisturise daily after bath or shower
- Keep finger nails filed so that there are no sharp edges
- Avoid heavily fragranced detergents, lotions and soaps
- Protect from sunburn with SPF 30
- Protect your skin with clothes
- Remember you can get sunburn through clothes
- Avoid hot tubs, saunas and steam rooms
- Never use a sunbed

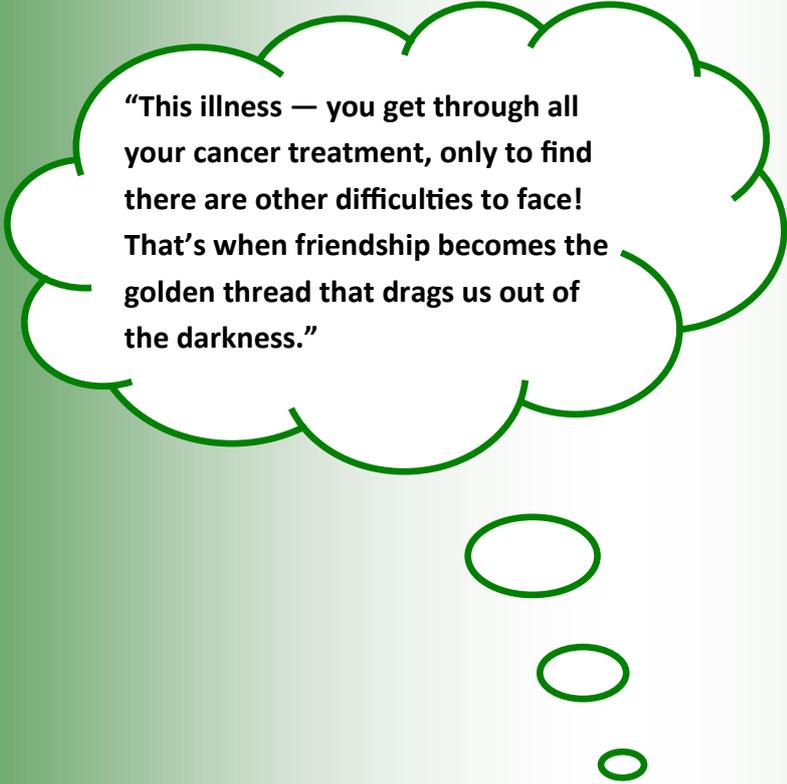


Lynne from the MAEH Lymphoedema Support Group has asked me to remind everyone that you can get bitten through your compression sleeves/stockings. Please keep checking your arm/leg have alcohol wipes, anti-histamines, anti-septic cream available. Don't forget those all important antibiotics.

Vitamin B1 has been suggested as an insect repellent. Taking B1 before going on holiday and while away might prevent you getting bitten.

Spray hats or scarfs with insect repellent or citronella which smells nicer.

Citronella candles keep bugs at bay.



“This illness — you get through all your cancer treatment, only to find there are other difficulties to face! That’s when friendship becomes the golden thread that drags us out of the darkness.”

Thank you to Estelle for the above quote.

I would like to take this opportunity to thank all the people who have supported me over the last 12 months. Special thanks to the Mary Ann Evans Hospice, Lymphoedema team for a all your encouragement and support. Most of all I would like to thank all the members of LWO who have helped make this an truly amazing 12 months. My personal success, and the success of Lymphwhatoedema couldn’t have been achieved without you support. You are all amazing people but most of all truly amazing survivors. Thank you from the bottom of my heart.

The British Lymphology Society have been running a petition that states that for every £1.00 spent on Lymphoedema Treatment a £100 is saved by the NHS. LWO has been supporting this campaign. Please help us get the message across to NHS England by signing this petition.

<https://you.38degrees.org.uk/petitions/save-the-nhs-100-for-every-1-spent-on-lymphoedema-treatments>



Online Support Group

For Primary and Secondary Lymphoedema Patients. The Facebook online support group is for anyone who lives with the lifelong condition lymphoedema or their family and friends.

The aim of the online support group is to be caring, informative & positive.

Lymphwhatoedema is patient driven and totally voluntary.

From time to time our members have a rant, that's ok, they are dealing with a lot.

As patients we support each other, we understand the anger, frustration and isolation that many lymphoedema patients feel.

You can join the online support group by going to;

www.facebook.com/groups/lymphwhatoedema

In this Newsletter I have used more visual aids, the posters shared via Pinterest

Further copies of this Newsletter can be downloaded from www.lymph-what-oedema.com/news

Lymph-what-oedema was founded by Gaynor Leech September 2013 and the online support group was set up in May 2014.

You can contact Gaynor through her website, blog or email:

lymphwhatoedema@gmail.com

All the material in this Newsletter is set out in good faith. Thoughts and interpretations are mine. Every effort has been made to acknowledge sources. Please remember I am not an expert, or professional health care worker. I am a patient who has lived with secondary lymphoedema since May 2011. Copyright © 2015