



**[www.lymph-what-oedema.com](http://www.lymph-what-oedema.com)**

## **Quarterly Newsletter**

**November 2015**

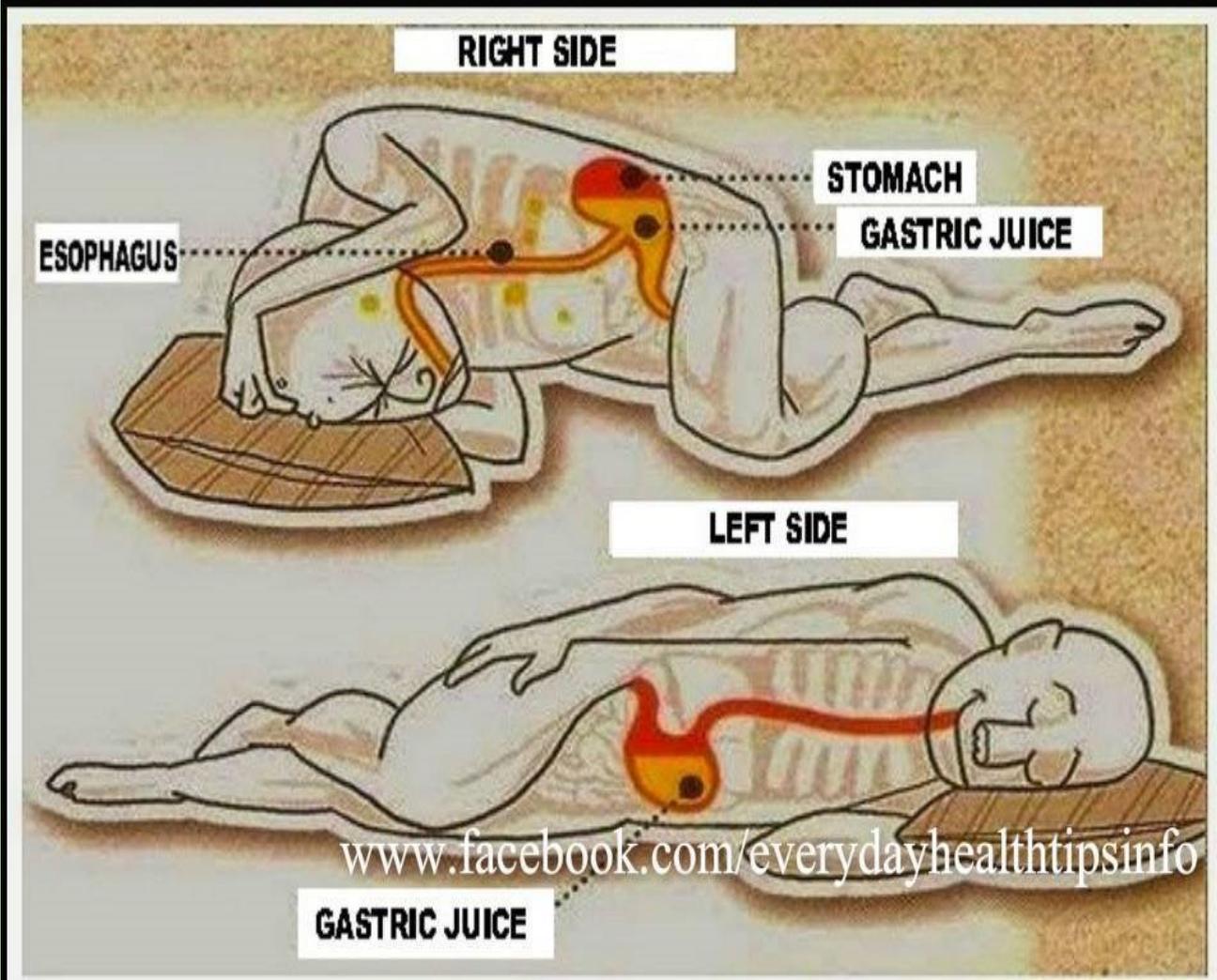
In September the website passed its 2 year anniversary and has had 83,571 viewings. The online support group has 592 members. Whilst I am absolutely thrilled with this success, I now have big decisions to make as to how this group moves forward. It has become abundantly clear that I need more volunteer help. I would like to thank Karen Taft and Sandie Evans for keeping the group map up to date also Chris Hunter and Karen Taft for all their hard work in vetting and adding new members to the online support group. Ladies you do take a weight off my shoulders your help is appreciated more than I can express. Thank you to Debra Stone who has agreed to proof read my work and to help with some admin. The MAEH support group remains solid and supportive. Finally big thank you to Declan and Georgia Leech. Declan for teaching me to use Excel, Georgia for teaching me Publisher and helping me to check all my research results. Their love and patience is amazing. You all contribute to our success.

Recently I have had meetings with Community and Voluntary Action (CAVA) and the Volunteer Centre for Nuneaton and Bedworth. Both these organisations have been very helpful, with advice and support. In the New Year there will be some changes but these should not affect our members and will enhance our service.

In the meantime I am looking for volunteer support in the Nuneaton, Bedworth area. I need 3 trustees and video volunteers as I am looking to put videos on You Tube.

Thank you to the Walsgrave Lymphoedema Support Group who have donated an office printer to LWO, this will make printing easier. I will be switching to the HP Ink replacement Service in December which will save me 70% on printing costs. I would also like to thank Mary Eaves for her unstinting support behind the scenes. Mary has stepped down as treasurer after 10 years of hard work with WLSG, she will carry on as a member. I would like to wish 'B' Barbara Brookes success as their new joint Chairperson with Pam Golder and Jean Grba as the new Treasurer. Wishing WLSG every success for the future and look forward to watching your membership grow.

# SLEEP ON THE LEFT SIDE IS GOOD FOR HEALTH.



[www.facebook.com/everydayhealthtipsinfo](http://www.facebook.com/everydayhealthtipsinfo)

Source/Reference: [www.justnaturallife.com](http://www.justnaturallife.com)  
[www.thecollectivesense.com](http://www.thecollectivesense.com) – Original Article Source

## MUST SHARE PLEASE.

Several of our members do not sleep well at night. From hot flushes, quilt on quilt off, restless leg syndrome, leg in, leg out or simply can't get comfortable. Painful legs can often be a sign of dehydration. Have a glass of water before going to bed or camomile or night time tea, very calming and relaxing. Deep breathing exercises help clear your head.

## Our day at George (Asda)



Ladies from Tamworth Wellbeing & Cancer Support Centre, Mary Ann Evans Hospice Lymphoedema Support Group and LWO members visiting George to talk about the problems we have with buying clothing including lingerie and shoes. Organised by Karen Taft. Uplifting and informative day and we all came away feeling that we had been listened to.

# My research

Over the last 18 months I have had several attempts to understand which type of lymphoedema our members have. This would then help me to provide information that would be relevant to our members. The initial poll was added to the website unfortunately only 60 members took part. On May 30th Karen Taft set up a poll asking where our members had their lymphoedema, for example arm/leg. In this poll 191 members responded, we still weren't getting a clear picture. On the 23rd July because of the questions we were getting from our members another poll was set up simply asking do you have Primary or Secondary Lymphoedema? You would think that this question would be easier to understand.

These are the questions that came up time and time again.

- I don't understand the question/jargon
- What's the difference?
- I have never been told, I am confused
- No idea, just been told "to get on with it"
- I had no idea, I could get help
- Too embarrassed or don't want to talk about it (3 members)
- Some members didn't want to add information on the support group

In the end, I messaged every member between 23rd July 2015 and 14th September 2015. The response was unbelievable, behind the scenes my private message box was very busy, my head spinning with all the information. I wondered what had I taken on. Many of our members were happy to give lots of information, others simply confirmed Primary or Secondary. Here are the results of LWO poll to the question do you have Primary or Secondary Lymphoedema?

<b>LWO Members 592</b>	
<b>Primary</b>	<b>149</b>
<b>Secondary</b>	<b>297</b>
<b>Lipoedema</b>	<b>15</b>
<b>Professionals</b>	<b>28</b>
<b>Not taken part</b>	<b>103</b>

## **PRIMARY LYMPHOEDEMA MEMBERS**

Our older primary members have been truly neglected by the NHS. Those diagnosed at birth were told that “they had to get on with it” and told there was “no treatment available”. These members were not told that compression garments or exercise would help instead they were told to lose weight or put on diuretics to get rid of the fluid. None of which helped. Only when those older members found our group and website did they realise that help might be available. Many of these primary members don't live in catchment areas where treatment is available. One of our members had lived with primary lymphoedema for 54 years before she realised that there was help available.

Three of our primary members were not diagnosed for 48, 42 and 28 years respectively. Often they were met with remarks by their Health-care professionals that they did not understand lymphoedema! Many of them, before they found their way to LWO, had to do their own research. In doing so these members gave themselves a voice.

## **SECONDARY LYMPHOEDEMA MEMBERS**

Whilst not all Secondary LE members have their lymphoedema due to being diagnosed with cancer, the majority have. Secondary lymphoedema members were the most angry and vocal. Although these members are grateful to be alive, they feel that being diagnosed with Lymphoedema is a double whammy. Often their heads are in a bad place due to them having had cancer. Some of them feel that being diagnosed with Lymphoedema is somehow their fault. How awful is this?

Here are some of the questions repeatedly asked by our members:

- Why wasn't I told when I was diagnosed with cancer, that this could happen?
- Lymphoedema wasn't mentioned in the information paperwork re my cancer
- Why did Lymphoedema only warrant half a page in the paperwork I was given?
- Why were no preventative measures put in place to lessen the impact
- Health-care professionals are dismissive, simply because they don't understand our condition.
- Why do we in the UK call Lymphoedema a 'condition'? Our American and Canadian members call it a 'disease'. “I am confused”.

Feelings of confusion and anger at the lack of information are common amongst our lymphoedema members. Finding courage to go for appointments with Health-care professionals often leaves our members stressed. They are so afraid of not being taken seriously. I appreciate that there are good health-care professionals who are working in very difficult circumstances to provide research and treatment for lymphoedema patients. Organisations like the Lymphoedema Support Network who do great work to support patients and raise the profile of lymphoedema. Whether a patient with Lymphoedema, an organisation supporting Lymphoedema patients, or LWO we all have a role to play in raising its profile.

On LWO we work tirelessly to listen, provide information and be supportive. We encourage members to print off any information they find or information we post as a group and take this information with them when they go for Health-care appointments. We ask them to make the most of their appointments and go prepared. As a group we are constantly telling all our members that they have to become their own advocates.

# Skin-care in Cold Weather

There is great emphasis on how to look after your Lymphoedema skin in hot weather. However, we must not forget that we need to care for our skin in cold weather.

Skin can become chapped and dry as the autumn and winter approaches. If you start to scratch because your skin has become dry then you may cause a break in the skin that would allow infection to get in.

Cold air and central heating can also have quite an affect on your skin. If you turn your central heating off at night or down low this will reduce your skin drying out whilst you snuggle under the duvet. This will also save you money on your heating bills!! Before going to bed drink a glass of water this will help your skin stay hydrated overnight. If you can't face water before you go to bed try a cup of Camomile or Night Time tea very calming and relaxing.

Body brushing will help get rid of dead skin cells and help your skin from drying out, leaving your skin silky soft. Furthermore body brushing helps to eliminate toxins and helps with cell regeneration. It gives a big boost to your lymphatic system by moving lymphatic flow. Body brushing stimulates the blood flow and circulation as well as sweat and sebaceous glands.

When you have your bath/shower make sure you dry your skin thoroughly. Especially between sensitive areas and the toes. Looking after your feet in cold weather is as important as in warm weather.

If you are more likely to wear socks in winter to keep your feet warm then make sure you change them every day. This will prevent bacteria building up and being transferred to your feet. Good shoes or boots are also important in the winter months to give your feet the support they deserve.

Moisturise your skin daily including your elbows, feet, heels, knees and legs to make sure you keep your skin in good condition. Preferably use a non scented low pH level moisturiser.

Keep hydrated this is good way of moisturising from within. If you can't face cold water try a glass of warm water with a slice of lemon or lime. Stay away from Caffeine like coffee and fizzy drinks. Try drinking herbal teas, there are so many different flavours to try.

Remember alcohol dehydrates the skin. Everything in moderation.

Another way to nourish your skin is to eat fruit and vegetables especially those with vitamins A, C, and E. Very few foods have vitamin D in and you need this for your skin. Oily fish such as herring, fresh tuna, mackerel, salmon and sardines are all good for you. Antioxidant foods such as broccoli, dark leafy vegetables, kiwi, peppers and tomatoes all contribute to your wellbeing.

# Drinking Water

I am often asked “how much water, should I drink?” Or “why should I drink water”?

Water is lost through;

- Your kidneys when you urinate
- Intestines through faeces
- Lungs when you breathe
- Skin through perspiration

One of the first signs of dehydration is feeling thirsty. These are signs to look for when you might become dehydrated;

- dark urine or not passing enough urine when you go to the loo
- headaches
- lack of energy
- feeling lightheaded

Those of us that have Lymphoedema should drink lots of water, you might be tempted to think the opposite. Drinking more water is important because lymph fluid has high protein content. To remove the protein from your tissues, it needs water. Drinking water means that "protein-traffic" moves better around the lymph system. When water flows it will clean itself therefore keeping the lymphatic system moving.

Benefits of drinking water are:

- De-stress—if you are stressed all your problems become worse. Drinking water provides more energy and eases tension.
- Lose weight—no calories, no carbs, no fat, no sugar. Helps your body work more efficiently. Helps digestion and muscle function.
- Keeps you looking young—acts as a natural moisturiser, prevents skin drying out, this is important because all of us who have lymphoedema have to look after our skin.
- Boosts mood and brain power—even when somebody who is mildly dehydrated can experience anger, confusion and depression.
- Regulates body temperature
- Cushions joints
- Helps flush out toxins and waste





## **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](http://www.facebook.com/groups/lymphwhatoedema)**

**Further copies of this Newsletter can be downloaded from [www.lymph-what-oedema.com/news](http://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](mailto: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**