



Lymph-what-oedema.com

Quarterly Newsletter

November 2014

Since our last Newsletter in August the website and Facebook online support group has continued to grow. The website is now showing 24,288 viewings and the members group has 242 members. We are patient driven and voluntary.

September 18th the website celebrated its 1st birthday

The members group continues to support both Primary and Secondary Lymphoedema. At the end of August I created a poll to see which lymphoedema our members had and the results are published in this Newsletter.

On the website I have added another page, titled Feelings. This page will eventually cover Anxiety, Body Image, Frustration and the Isolation that our members feel while living with lymphoedema.

In this issue of the Newsletter I have covered Anxiety, Reflexology, and one of our members story, a lovely lady who has lived with Primary lymphoedema all her life. I have also added more members comments, this was a popular feature in the last Newsletter. Other topics included are the battle our members have getting the Flu Jab and Antibiotics.

We also have a flyer which our members are slowly putting up in libraries, surgeries, clinics and other venues which will raise the awareness of lymphoedema.

Next year are we planning a get together for our members, details will be in our February Newsletter and will feature on the online support group as an event.

I would like to thank all our members for their continued support. In addition a big thank you to the Mary Ann Evans Hospice , Nuneaton for all their support and encouragement, especially from Kay, Nicky and Karen.



Flu Jab

At this time of year those that can are having their Flu Jabs. Life is difficult enough with LE but it appears that some of our members are having a battle to get theirs.

Having read the NHS guidelines I understand they are open to interpretation. However, LE patients have weakened immune systems and underlying health conditions. LE is lifelong and incurable. Surely prevention is cheaper than frequent Hospital or Surgery visits. I was once advised that I should not be sitting in a GP's surgery with lots of other patients who are coughing and spluttering all over the place.

Even if you put the medical reasons aside for not being eligible for a Flu Jab, standard procedures are also getting in the way. Chemists, Occupational Health & some Surgeries will only do arms. Here are some of the reasons used for not giving the injection;

“Can't have because I have LE in both arms”.

“LE in left arm, won't do right arm because I am right –handed”.

One of members who has had Flu Jab states “that's crazy, I have LE in both arms and just had mine in my bottom”.

Wherever possible stand your ground. However, I do understand that when you are weary this is not easy. We might only be a small group but we will keep plodding on one day someone will listen to us!!



Hugging is good medicine. It transfers energy and gives the person being hugged an emotional lift.

You need four hugs a day for survival, eight for maintenance, and twelve for growth.

Scientists say that hugging is a form of communication because it can say things you don't have the words for.

The nicest thing about a hug is that you usually can't give one without getting one.

Lymphwhatoedema

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.

Currently 230 members

Lymphoedema exists; we exist

Antibiotics

The advice given to LE patients when going on holiday is to take antibiotics. For antibiotics see your GP so that you are prepared whilst on holiday against developing cellulitis or other bacterial infections. The Lymphoedema Clinic at the Mary Ann Evans Hospice provide their patients with a letter available on request to take to their GP's asking for antibiotics.

Lymphwhatoedema members tell me that most GP's are sympathetic to giving antibiotics for Lymphoedema. However, GP's that don't understand the complications associated with lymphoedema often give the following reasons for not giving;

“its not ethical”

“its financial”

The reasoning as to why you have antibiotics is simple;

The financial argument being that a hospital stay is more costly than an emergency supply of antibiotics.

The medical argument is that nipped in the bud cellulitis is easier to treat and the patient is less likely to suffer damage to whatever Lymphatics are working.



Information available for GP's on the following web address;

www.thebls.com/docs/Cellulitis_Consensus_2013.pdf

Holiday first aid kit; www.lymph-what-oedema/holiday-care

Thank you to one of nursing members for putting the argument together for us. Always consult your own Health Care Professional.

Primary Lymphoedema

When I first started the website the emphasis was on Secondary lymphoedema, because I have Secondary lymphoedema. However, as Lymphwhatoedema started to grow more and more members with Primary lymphoedema joined us. I knew that Primary lymphoedema was genetic but for some reason it did not register that it ran in families. The best way for me to describe how this affects families is to let Elaine tell her story.

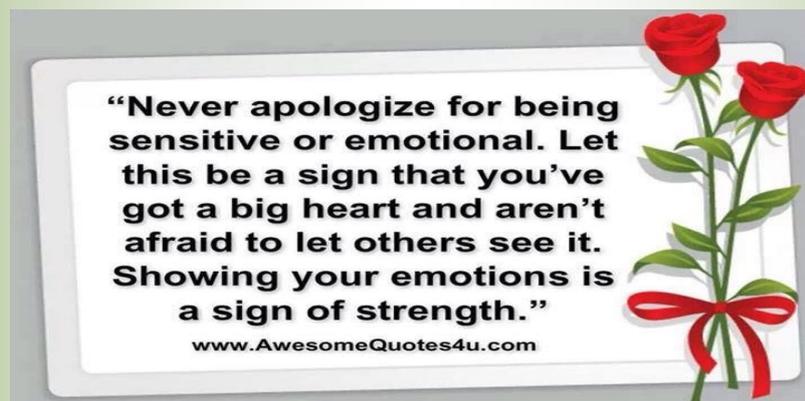
"I have primary lymphoedema in both legs. Because people in my family had lymphoedema as well I really didn't see it as a big problem. We were told there is no cure so we got on with our lives. There certainly where no lymphoedema clinics to go to. My father use to bandage his legs every morning before he went to work. Two of my brothers and I developed it in our teens. My sister was the only one who did not inherit lymphoedema. For my older brother and I, it was a nuisance but my younger brother suffered a lot of cellulitis.

I have now had lymphoedema for over 50 years and it wasn't until I recently joined one of the Facebook sites that I learned about secondary lymphoedema. My first visit to a lymphoedema clinic was in April 2014. I know nothing about MLD until I joined Lymphwhatoedema so this is all new to me and I have yet to master the technique. I am looking forward to the day when I look in the mirror to see a normal pair of legs again.

Forgot to say my son now has Lymphoedema and so have his 2 daughters. His sons do not show signs of having lymphoedema."

So the above was Elaine's post in her own words and I thank her for allowing me to add her story in this newsletter.

Primary lymphoedema - this term describes lymphoedema where there is an abnormality of development of the lymphatics. (Source Lymphoedema Support Network)



RLD (REFLEXOLOGY LYMPHATIC DRAINAGE)

There has been a lot of excitement on our online support group about the relatively new treatment of RLD. Research led by Cardiff Metropolitan University funded by Tenovus cancer charity and based on RLD, researched and developed by Sally Kay BSc(Hons), a professional complimentary therapist.

Her study found that following medical intervention 20% of breast cancer patients suffer lymphoedema.

Our online support group, has had several debates on RLD and we have been joined by Reflexologists who keep us up to-date. Reactions have been mixed with hope given to members who do not get any help or treatment and caution by those who feel more research is needed, specifically on Primary lymphoedema.

This is such a big subject to cover and I have written this as a centre piece so that I can show the comments our online support group members have posted. I do not have professional qualifications and I repeatedly tell people I read, speak and think as a patient. My advice is always before undertaking any new treatment to contact your own Health Care Professional.

I have enclosed links to Sally's Facebook page, the RLD website and Tenovus. The reflexology website also has a link to "find a therapist", take a look to see if there is one in your area. Please do your own research.

www.reflexologylymphdrainage.co.uk

<https://www.facebook.com/groups/38963331078913> (Approx. 1,170 members)

www.tenovus.org.uk

Another website I would refer you to is reflexscience.weebly.com this site explains in easy to read terms about research into reflexology and has a blog for the reader to leave comments.

Latest research results; <http://www.cardiffmet.ac.uk/alumni/Pages/Story-4.aspx>



RLD (REFLEXOLOGY LYMPHATIC DRAINAGE)

On learning about RLD there was great deal of excitement amongst our online members. Those members who have no support and no treatment this complimentary therapy has given new hope. To write a balanced article has been difficult. Sally Kay's research was on Breast Cancer Patients who developed arm lymphoedema and the results are impressive.

Primary lymphoedema patients who have this condition in their legs, are very keen to see if RLD can help them. A number of reflexologists have worked on Primary lymphoedema. I would like to see research on Primary lymphoedema patients because these are the patients that have lived with lymphoedema from birth or a very young age. They are often the patients that get very little help from the NHS in the form of treatment and support for their lymphoedema.

One of our members voiced concerns that practitioners may have very little knowledge of lymphoedema. The lymph system is a complex one and care has to be taken when moving lymph fluid around the body. Inexperienced practitioners could create serious problems. My understanding is that RLD trained reflexologists are taught the anatomy and physiology of the lymphatic system and how it works when damaged. I would encourage you all to research the reflexologist you use.

The treatment of lymphoedema is about management, self management and exercise. Therefore, RLD as part of a care package could be beneficial. Those of us who have lymphoedema know that SLD self management is a daily necessity to keep lymphoedema under control. To the best of my knowledge RLD does not provide techniques to incorporate this into your self management program.

Cost also has to be considered and I do have concerns what happens when treatment stops because a patient can no longer afford the service. Financially we live in a very uncertain world and some of our members are on very tight budgets.

This is all about giving choice to our members so that they can make their own decisions. I am sure this is a topic we will be returning to. In the meantime I have signed up for Sally Kay's Newsletter and will keep following the research, keeping you up-to-date with developments. My advice as always is to contact your own Health Care Professional before undertaking any new treatments.

Anxiety



Lymphoedema causes anxiety because you are constantly worrying what could go wrong and there are so many things you need to remember in the management of your lymphoedema. One of the biggest anxieties that all lymphoedema patients both Primary and Secondary feel is that their condition isn't taken seriously and many feel that they are not listened to. The list below shows the most common thoughts our online members have voiced.

- **living with the do's and don'ts**
- **lifestyle changes**
- **aware you are a bite or scratch away from infection**
- **someone else's cough/sneeze away from infection**
- **weakened immune system**
- **constantly tired**
- **no energy**
- **frustration with people who don't get lymphoedema**
- **weary trying to explain what lymphoedema is**
- **secondary lymphoedema is a reminder you have had cancer**
- **you are cancer free but left with a disability**
- **mobility problems for both Primary and Secondary lymphoedema**
- **learning what is do-able**
- **not recognised as a disability for both Primary and Secondary lymphoedema**
- **having to become your own advocate**

We do know that given the right help, support and treatment that lymphoedema is manageable.

POLL August – November 2014

Do you have Primary or Secondary Lymphoedema

Answers	Percent	Votes
Primary	38%	18
Secondary	62%	29

We have 230 members and 47 members voted. Thank you to those members for taking the time.

I am repeatedly asked by our members how they can get their GP's to understand their condition. The best way is to refer them to the Lymphoedema Support Network (LSN). Here is the web address followed by page titles where they can get further information about the BMJ learning module which also counts towards their CPD.

<http://www.lymphoedema.org>

<http://www.lymphoedema.org/Menu4/7BMJ%20Learning%20module.asp>

How to recognise lymphoedema

Practical assessment of oedema

What can I do for my patients

Cellulitis

There is no specialist service in my area

Guidelines

BMJ Learning Module

I am told by members that those GP's who have undertaken the BMJ Learning Module, have enjoyed the course. GP's can also telephone LSN on; 020 7351 4480

**Our members frustrations with lymphoedema and well
meaning people!**

**Constant reminder, I
had CANCER”.**

**“What’s wrong with your
arm?”**

“Lymphoedema—Google it”.

**“It took me 9 years post op
to be diagnosed”.**

**Our funding has been
cut”.**

**“Not enough emphasis or
money is spent on the NHS for
patients with lymphoedema”.**

The most powerful words you can say to someone with Lymphoedema is



“I Believe You”

“The lack of knowledge is awful. I just want someone to listen”.

“Time for reality check. Learning what is do-able with this condition”.

“Most people see a bit of swelling. For me it was the final straw post cancer. I live with it & its controlled but I hate it. Just another way I feel different”.

“Get use to being your own advocate”

Thank you to all the lovely ladies who provided these comments.



Abbreviations we use:

AB's antibiotics

DVT deep vein thrombosis

LE lymphoedema

MLD manual lymphatic drainage

MLLB multi layer lymphoedema bandaging

PALS Patient Advice & Liaison Service

RLD reflexology lymphatic drainage

SLD simple lymphatic drainage

SE's side effects

Always consult your own Health Care Professional

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

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

You can contact Gaynor through her website 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. I am a patient who has lived with secondary lymphoedema since May 2011. Copyright © 2014

Lymphoedema exists; we exist