



Lymph-what-oedema.com

Quarterly Newsletter

February 2015

Welcome to the first Newsletter of 2015. Last year (2014) was an amazing year for the website and our online support group. On a personal level I am amazed that this lifelong, incurable, manageable and treatable condition has taken me on a journey that I would never have envisaged nearly 4 years ago.

In addition to all the people I have met, I have also learnt new skills, like Microsoft Publisher so that I can publish the quarterly Newsletter. The new skills help with the running of the website and online support group allowing me to produce more information.

Our members on the online support group have continued to support each other and provide information which is positive and helpful. We often hear about the evils of the internet, but this website and the online support group would not have reached so many people. I am repeatedly told by our members that they do not feel so alone.

Please come and join us on www.facebook.com/groups/lymphwhatoedema

The challenge for 2015 will be to continue adding more information, keeping the website relevant and building on the success of last year.

Finally, excitement is mounting over the online support groups 1st anniversary event, to be held on Wednesday 13th May 2015 in Attleborough. There will be demonstrations, talks and a buffet lunch. There are two aims for this get together;

- 1. For Lymphoedema patients to meet each other**
- 2. Self management of Lymphoedema**

More details inside this Newsletter or online.



This is one of our online members Caryn Crompton, I can't repeat exactly what she wrote but I am sure you will get the drift. "Take that Tamoxifen, no more hot flushes for me"! Caryn has a lovely sense of humour and keeps us amused with cartoons and photographs like the one above.

While we all agree that Tamoxifen is keeping our cancer away, the side affects we all feel are far more than those listed. Now we are being told that instead of five years we will probably be on this drug for 10 years. A lot of unhappy ladies with this new development, including me.

Who understands Lymphoedema?

There has been quite a lot of frustration on the online support group during the month of January at cancelled appointments, also the lack of knowledge and understanding that our members receive from those who should be caring for them. As always it only needs one post. This post was from one of our new members, Rona;

“Well now I know where the name of the group comes from! The amount of people who haven't a clue what Lymphoedema is! And that's in the health profession!!”

This led to more posts on the same subject.

This is Pam's story. “As my father had Milroy's disease, I was diagnosed at birth, no such thing in those days, just had to put up with it. I had no help or support until I read an article in a magazine in Canada, about a pump this guy had invented, went to Oxford - Michael Sobell. Unbelievable someone could help me, 2 weeks of bandages plus pump for my legs to go down so that I could wear class 3 tights and the treatment reduced the pain. This happened over 30 years ago, thank goodness they now have units for people with oedema. Must say it's getting harder with all these budget cuts as they are closing down Lymphoedema clinics, better get off my soap box”.

Later in the week Pam posted. “Waited 7 months for my appointment, they just phoned up and cancelled, next appointment April, last seen July 2014. I screamed down the phone my support hosiery is my life line, 9 months without new tights (they might as well book me a hospital bed). I wear grade 3 compression and they only allow me 2 pairs per 6 months. Such madness. Rant over with. Before the budget cuts I use to get 6 pairs of compression tights as my oedema is serious. I will keep phoning the unit to speed up my appointment, but as the secretary said they are closing these units down.”

In reply Marion posted. “I cannot understand why the people who control budgets/prescriptions do not realize that if Lymphoedema sufferers had the correct support/treatment that it would actually save them money as without it we only need more treatment/support. If we do not receive treatment/support as and when the conditions requires it costs a lot more to treat. I am lucky, to now have a great unit supporting me but there were times when that was not the case, so the condition got worse”.

The above reactions are perfectly understandable because Lymphoedema patients are only ever a bite or scratch away from serious infection. The consequences of infection are having to take antibiotics, may include a hospital stay and further damage to an already compromised lymph system.



The battle for compression garments also causes problems. Lymphoedema patients are told to keep the compression garments on during the day and some patients have to wear them at night. They need at least two compression garments one to wash and one to wear at all times. These compression garments have a limited lifespan. Even with the most careful removal, wearing and washing they do deteriorate. Thank you to Rona, Pam and Marion for your contributions.

Body Image

Lymphoedema comes with lots of insecurities. We know that it is manageable and we know it can be treated however, body image can affect lymphoedema patients in the following way;

- low self esteem
- knowing you have to wear compression garments everyday of your life
- affects the type of clothes that you can wear
- affects how clothes look
- concealing what you perceive as being an imperfect body image
- even if others can't see your scars you know they are there
- finding clothes that fit you and your swollen limb
- finding shoes for swollen feet is a major task
- stockings/tights and socks big problem
- wearing toe caps
- the well-meaning person who asks lots of silly questions about your compression garments and still doesn't comprehend how you feel
- people who pre-judge you and assume your condition is all your own fault
- feelings of being different
- limbs that become very swollen
- limbs that are disfigured
- having to remove your wedding ring has a devastating affect

In my case dresses tops never seem to sit right which use to make me feel very self-conscious. Clothes didn't fit properly. Luckily for me a friend recommended a local seamstress. Now I have someone who works with me, makes the alterations I need and thoroughly gets my lymphoedema. I haven't solved all my problems, I have at least solved some of them.

One of our members said "I never look at a top, always the sleeve first". When you wear sleeve compression trying to find sleeves that will go over them is a big problem.

Feet can be a big problem as some members have to wear 'toe caps'. Members seem to prefer trainers and boots. Boots which are loose around the top, or with zips can help. Width fittings have improved greatly and you can now find shoes/boots in extra wide, E, EE, EEE, EEEE, and EEEEE. It is possible to find shoes described as 'Extra Stretchy' and strap extensions are also available. In most cases heels are nor advisable but some members will wear a low heel for a limited amount of time.

Lymphoedema legs can be a big problem but can be solved with fashionable baggy pants, long skirts and my favourite maxi dresses.

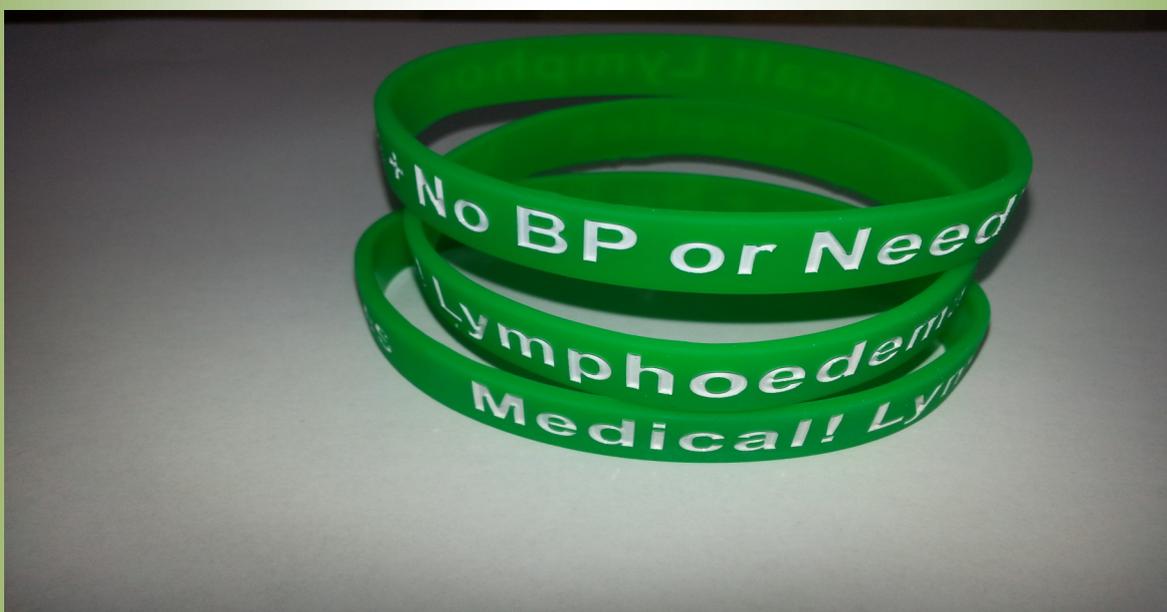
I know that we can't solve what's going on in our heads as easily. With patience and research there are ways in which we can disguise the problems that body image cause. Thank you to Alison, Helen and Karen for your posts.

Further information can be found at; www.lymph-what-oedema.com/feelings

One of the most devastating affects for most women with Lymphoedema is the removal of their wedding rings. Tight rings or bracelets that leave indentations are a serious risk and may restrict the flow of fluid. If your rings leave indentations it is better to remove them so that you do not have to go to the extreme and have your rings cut off. When you have been married for 40 years or more, the affects of not being able to wear your wedding ring is very upsetting. This is just another problem caused by the symptoms of Lymphoedema.



I have a few of these wristbands for sale through the website on the contact page. Very useful to wear if going on holiday or into hospital to alert healthcare professionals that no B.P. or Needles to be taken on your affected side.





“I would like to thank you lot for helping me learn about this condition in a nice way. Thank you”.



“This website is written from the heart”.

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

www.lymph-what-oedema.com

Spring Event

Wednesday 13th May 2015

10.00 a.m. - 4.00 p.m.

The Warren

Mary Ann Evans Hospice

Fliot Way

Nuneaton, CV10 7QJ

Demonstrations, Guest Speakers, including beverages and buffet lunch

Free Parking

Meet and chat to those who have Lymphoedema

Learn how to self-manage your Lymphoedema

Donations in aid of Mary Ann Evans Hospice, welcome



Registration Forms : www.lymph-what-oedema.com/spring-event or the Hospice

Healthy Steps - Qualified Instructor from Mary Ann Evans Hospice

Medi-skin care & hosiery

Trulife demonstration & fittings with Sally Redmond and team

Complimentary Therapist - Caroline Pearson



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

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