

Northern Lymphoedema Support Group Newsletter

Our next Meeting: Saturday 16th June 2018 between 2 p.m. and 4 p.m.

In Learning and Development Building, Lymphoedema Unit,

St Oswald's Hospice, Gosforth

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A Few Words From the Editor

Welcome to the summer newsletter, hoping you are all keeping well and have been managing to enjoy some long awaited sunshine after such a long winter!

In the last newsletter I made mention of our new home and garden, which by the way is the size of a postage stamp compared to the gardens we had previously, but much more manageable.

We have watched and waited to see what would materialise and I have to say the postage stamp has brought an abundance of floral variety... snowdrops, primula, daffodils, bluebells, alliums, a rose, montbretia, something pink we have

not managed to identify as yet, weeds and oh yes – a present from the local cat!

There is a yard to the rear which has 2 plum trees which have been trained into a vine, so if it's a good crop, its jam making for me again. There is also a raised bed with winter flowering jasmine, lilac, another rose, cytusus, another plant still awaiting identification and you guessed it, another present from the local cat!



When Richard left Wooler (which had been the family home for many years) he wanted to bring something from the old one to the new one and like many of the older houses there was always a washhouse outside, so the old sink was brought to Hexham and plans are afoot to make an alpine planter. Richard also suggested bringing the old toilet which could be filled with flowers, however I drew the line at that but having second thoughts now as it would have been quite useful for the local cat!!!

**NORTHERN LYMPHOEDEMA
SUPPORT GROUP
NOTES OF MEETING HELD ON
SATURDAY, 10 MARCH 2018 AT
2PM**

Apologies – Julie Waters, Lynn Milburn, Christine Luke, Marilyn Jones, Iris Anderson and June Patterson

Approximately 21 members were in attendance including Jill Lisle and Kath Clark from St Oswald's Hospice.

Carol thanked everyone for attending and welcomed the prospective new members. It was gratifying to have such a good attendance. Annual subscriptions were due which could be given to either Janice or Carol.

Julie had made good progress with the website. As it was Lymphoedema Awareness Week members were asked to show their support by wearing odd brightly coloured socks (photo below). "Socks to Lymphoedema". We sent photo together with the proceeds from the refreshments totalling £20 to the Lymphoedema Support Network (LSN) in London and received a lovely letter of acknowledgement.



As the traffic that day had delayed the arrival of many members we began with refreshments and the raffle.

We were delighted to welcome Christine Healy of Colour me Beautiful, Image Consultants, to demonstrate colours to suit one's natural colouring and advice on make-up. Christine began by giving information on her background and how she had become a consultant for Colour me Beautiful. Elizabeth and Carol bravely volunteered for colour matching and make up and it was amazing to see how the colour swatches highlighted their natural colouring. Christine stressed how the makeup was free of animal testing and British made. Christine demonstrated their magnetic compact which housed eye, cheek and lip colours all in one handy, refillable compact so that refills could be obtained to suit your own needs.

I was feeling very warm and red so asked about hiding high colouring so was targeted as the next guinea pig! Christine began with moisturiser, then added green make up so looked like Shrek until she added foundation and loose powder. I was transformed from "Beetroot Bons" to "Cool Dude" so just had to purchase some of that make-up!

Carol thanked Christine for such an illuminating demonstration.



Kath and Jill showed members a draft of a booklet/brochure that they intend to give to patients discharged from the Lymphoedema clinic when deemed to be able to manage their condition themselves. They asked what advice and information would be most useful for inclusion and noted suggestions re size of booklet and will report back at a future meeting.

Members were asked about a summer outing and either Bowes Museum, Ford and Etal or Woodhorn Museum were suggested. Bowes Museum appealed to many members and Carol agreed to make further enquiries.

Regarding speakers for future meetings, we hopefully have someone from LymphVision to talk about Lymphatic Imaging for the June meeting and a representative from Huntleigh Diagnostics in September. It was suggested that a demonstration of Kinesio Taping would be appreciated and this was noted for either next year or later in the year if the September speaker was unavailable.

Since the above meeting, Elizabeth Beardsley brought to our attention a Parliamentary Early Day Motion 1129 on behalf of Kendal Lymphology Centre sponsored by Tim Farron regarding the funding of the condition Lymphoedema on the NHS. It reads as follows:

“That this House notes that over 240,000 people in the UK are living with Lymphoedema; recognises Lymphoedema as a serious and debilitating illness which has a huge impact on patients’ lives, which if not properly treated can lead to traumatic complications such as limb amputations; congratulates the

specially trained staff at the Kendal Lymphology Centre for the excellent support they give to patients in the area who are diagnosed with Lymphoedema; further notes that the centre in Kendal is a nationally-renowned centre of excellence; thanks Morecambe Bay CCG for recommitting to funding the centre for another year; and calls on the Government to fund such clinics directly under the NHS and to open more clinics like the one at Kendal in additional locations to help more sufferers around the country. “

We are asked to support this motion by writing to our MPs and requesting their support. I have written to my MP Catherine McKinnell who is not only happy to support the motion, but has written to the Minister at the Department of Health on this issue.

We are lucky in the North East to have St Oswald’s Hospice and hope the NHS will continue their funding. However this motion could help other parts of the country who have no such clinics.

Kathleen Brown

Football Update



The Walking Football Team, Wentworth Wanderers, which I have recently joined, performed beyond expectations at their first Tournament held in Majorca. Competing in the over 55 year’s

category, we won 3 of our 6 group games before losing to a strong Leyton Orient team in the Quarter Finals.

As well as beating Feyenoord Old Stars, the team took great pride and joy from playing against ex-World Cup and Newcastle legend, Chris Waddle. It was his team, Hallam FC, from Sheffield, which deservedly won the Tournament. I am keen to explain that we only lost by only one goal to the eventual winners and look forward to reversing that result next year! We are planning to enter two teams into next year's Tournament; one in the 55-60 years category and one in the 60+ Cup. Who knows which ex-International World Cup player we may be competing against!

Richard Waters



Tips and Giggles

Bicarbonate of Soda

Sweeter tomatoes - Tomato plants like bicarbonate of soda too! Sprinkle a little around their roots regularly from the first planting. The bicarbonate of soda will reduce their acidity and make them even sweeter to eat.

Flushed with success – Every few weeks, sprinkle some bicarbonate of soda in your cistern. Leave overnight, then flush the next day for a sparkling clean loo.

And now for a giggle

Why don't sheep shrink when it rains?

If flying is so safe, why do they call the airport the terminal?

When dog food is new and improved tasting, who tests it?

Why is the time of day with the slowest traffic called rush hour?

Why is "abbreviated" such a long word?

Why is it that doctors call what they do practice?

A good juice bar puts their customers thirst!

"What am I supposed to do with this?" grumbled a motorist as a policeman handed him a speeding ticket.

"Keep it," the policeman said, "When you collect four of them you get a bicycle."



Early Day Motion 1129

As per the Early Day Motion 1129 previously mentioned in the minutes of the last meeting, they are keen for as many MP's as possible to sign up to this motion. You can always show your support by contacting your local MP explaining about the early day motion 1129. Further details can

be sought from the internet by going into Google, and entering early day motion 1129; it actually lists all the MP's that have already signed up to it.

I made contact with my local MP – Mr Guy Opperman from Hexham and although he does not sign EDM's he has recently updated his website with information regarding funding for Lymphoedema Services. One of his caseworkers pointed me in the direction of his website which provides a statement as follows:

Thank you for contacting me about lymphoedema and lipoedema services.

I welcome initiatives such as Lymphoedema Awareness Week. It is important to raise awareness of this condition, which primarily affects women, and presents many difficult symptoms. The swelling of limbs caused by lymphoedema and lipoedema can be distressing, and this condition must be properly addressed.

You may be aware that clinicians follow internationally recognised guidelines when it comes to the diagnosis, treatment and support of patients with lymphoedema, and the Royal College of General Practitioners offers an e-learning course to GPs, in order to improve doctors' understanding of it. I understand that between 75,000 and 220,000 people in England are affected by lymphoedema, and I hope that local health commissioners fund the most appropriate services for their populations.

There are a range of available interventions for lipoedema and lymphoedema, however a permanent cure has not yet been found. Low impact exercises like swimming or cycling are recommended, as well as massages and compression therapy. I understand that liposuction has seen positive results in recent years, however I am advised that several different operations may be required, and it is difficult to get NHS funding for liposuction, though this may vary across the country.

Roughly one in five people with lymphoedema of the arm contract it after breast cancer treatment. Much of the recent improvements in lymphoedema services have come following huge investment into cancer services, and the implementation of the new cancer strategy from 2015, which noted the importance of lymphoedema care. Furthermore, owing to over £1 billion total investment, the National Institute for Health Research is running three studies into lymphoedema, which will investigate the genetic component of this condition, and improve our understanding of its relation to breast cancer.

Thank you again for taking the time to contact me about this important issue.

I did email back to explain about our group and also made mention of learning modules available via the LSN.

(Please note images and jokes taken from internet. Early day motion taken from local MP website).

**NORTHERN LYMPHOEDEMA SUPPORT
GROUP**

Next Meeting: Sat. 16 June 2018

St. Oswald's Hospice

Learning and Development Building

2pm – 4pm

**All sufferers from lymphoedema plus relatives
and friends are welcome**

We will be pleased to present -

**Jane Wigg (RGN, MSc)
Of Lymphvision
Provider for NIRF Lymphatic Imaging**

**NB: The presentation will take place in the Learning and
Development Building as Jane will be speaking via Skype**

We hope to see you there. 😊

Important Member Notice

Dear Members,

**As part of the NLSG website compilation, photographs that have been taken at
past events and future events will be used on the website.**

**If you would prefer your photograph not to be used on our website can you
please let me know by 30th June 2018?**

**If I have not heard from you by that date, I will assume that you are happy for
photographs to be used on the NLSG website.**

**Thank you
Julie Waters**