

Northern Lymphoedema Support Group Newsletter

Our next Meeting: Saturday 15th September 2018

between 2 p.m. & 4 p.m.

In Day Care Unit, St Oswald's Hospice, Gosforth

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Hello and welcome to the autumn newsletter. Although the hot sunny days are beginning to fade, it has to be said we have had a wonderful summer. Temperatures have soared and it has felt like being abroad!

However, I have to say, I am looking forward to the cooler, fresher days of autumn when the leaves will be turning orange and red and it's time to grab that cardigan or jacket as the nights turn cooler (which for those of us with swollen arms, legs and other areas, a welcome break).

In the UK, our main topic of conversation tends to be in relation to weather...

"Oh it's so cold this morning" or "These temperatures are far too hot" or "This wind is too blowy" or "I'm so sick of this rain - it's so wet" and that was probably the weather report for one day!!

NORTHERN LYMPHOEDEMA SUPPORT GROUP

NOTES OF MEETING HELD ON SATURDAY, 16 JUNE 2018 AT 2PM

HELD IN THE LEARNING AND DEVELOPMENT BUILDING

Apologies – Marilyn Jones, Margaret Armstrong and Veronica Hostler.

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

Carol thanked everyone for attending and welcomed prospective new members. It was great to have such a good turnout. Annual subscriptions could be paid to either Janice or Carol.

Lists were available to sign for both the Summer Outing to Bowes Museum and Christmas Lunch at Nuffield Health on 8th December.

Carol thanked Jill and Kath for setting up the Skype presentation which will enable Jane Wigg RGN MSc of Lymphvision to kindly speak to us about NIRF Lymphatic Imaging.

Jane appeared magically on screen and began by describing her background. Jane had been treating lymphoedema for over 20 years and previously set up and ran a successful lymphoedema clinic. Currently running the Lymphoedema Training Academy and, to date, has helped over 600 therapists to

successfully complete their MLD training. Jane is the only authorised trainer of Fluoroscopy Guided Lymphatic Drainage (FG-MLD) in the UK and has worked closely with Professor Belgrado to bring the method to the UK.

Jane described the benefits of lymphofluoroscopy mapping which allows for the identification of individualised pathways using a near infrared (NR) camera and Indocyanine Green (ICG). The visualisation and identification of these drainage pathways will enhance lymphatic drainage. The benefits:

- Specialist Assessment
- Early identification
- Optimised FG-MLD
- Better outcomes
- Bespoke treatment
- Improved cost effectiveness of MLD sessions

Jane emphasised how important it is to keep moving for the lymphatic system. If veins are not working properly then the lymphatics will be affected.

Jane outlined what each appointment session entailed. The full assessment would take around 4 hours. Following the initial consultation, an injection of ICG will be put in either the foot or hand and an infra-red (NR) camera will be used. It will take approximately 2 hours to allow the dye to move through the lymphatic system, then the camera will be used again, a video will be captured and the pathways mapped. This will show where the fluid is draining and a new pathway can be found to where the drainage is good. She described any obstruction like a kink in a hosepipe. Following this procedure MLD can be more effective as with fluoroscopy the drainage blocks can be compensated.

As it was a lot of information to take in, we had a break for coffee and drew the raffle. Jane patiently dealt with many questions. One was the risk of infection and Jane reassured everyone on that point and described the only contraindications were if the patient suffered

from thyroid problems or was allergic to codeine. As to the cost, unfortunately this procedure can only be done privately at the moment and varied in cost from £750 to £1,050, depending on the chosen clinic.

Carol thanked Jane for a fascinating presentation.

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We are sorry that the summer outing to Bowes Museum had to be postponed. Carol tried to book the community bus but there were no dates available until September so hopefully we can rearrange then. Details will be given at the September meeting.

We are also considering not having a meeting at the Hospice prior to the Christmas Lunch. Arrangements could be made to collect anyone requiring a lift from Regent Centre and then all meet at the Nuffield at say, 12.30pm. Please let me know at the September meeting if this arrangement would be preferred.

Kathleen Brown

Anyone for Turmeric?

My friend Sue and I were talking recently about the different varieties of tea, in particular, herbal teas. Sue's cupboard contains an impressive selection of teas and although my preference would be builder's tea, Sue told me that although she loves herbal tea, she has to begin her day with a coffee and a sprinkle of cinnamon to get the engine going!

One morning a very sleepy Sue was making the usual coffee and accidentally picked up the wrong spice jar and ended up sprinkling turmeric in her coffee! On realising her mistake and giving herself a telling off she decided rather than wasting the coffee, to just add the usual spoonful of cinnamon and in her own words, it actually tasted fine.

Asking Sue why she used cinnamon in the first place, she replied, it was thought to lower sugar levels and turmeric apparently has anti-inflammatory properties, so anyone for a coffee, cinnamon and turmeric?



Talking of spices, Kathleen recently asked me if I had heard about ginger oil and how it may help the lymphatic system, which I hadn't, but I understand Kathleen was going to make enquiries and will hopefully be able to report back to us at the September meeting....



Website Update

Please note we are not far away from completing on this (I know... I have said that before as well)!

Currently the website is in draft format with just a few tweaks to make. Particular areas of the website have taken longer than anticipated, i.e. we have had to give consideration to a privacy policy and pithy statement. Thankfully we have had advice from St Oswald's Communication Department with regards to this which has been greatly appreciated.

These are all the elements of a website I hadn't really thought about, so a whole new learning curve for me!

Thank you all for being so patient ☺

September Speaker 2018

The speaker for our next meeting which is being held on Saturday 15th September 2018 is David Hutchinson of Huntleigh Diagnostics who specialise in Lymph Assist. David has recently joined the company so we will be sure to give him a warm welcome.

What do you know about Lymphoedema?

Since attending the NLSG meetings and also being an "ex" outpatient (discharged for good behaviour), although not an expert, my understanding of Lymphoedema has increased tenfold.

Attendance at Hospice appointments, meetings, talking to others who have the condition and information from the LSN has broadened my knowledge immensely.

From the early days when first referred and learning all about the bandages, massage, exercise, watching weight, skin care as well as rest, these were all the essential elements in how to "manage" the condition and become a good patient.

However being a good patient isn't always easy is it! We all have days when you can't face putting on the bandages, the weather is too hot and it's a struggle as the affected limb can swell. There are also the days when you don't feel able to exercise or willpower flags and you end up having an extra-large piece of cake when you know you should only have had a slither! Then again we are only human and we all have those off days so must remember, not to give ourselves a hard time.

The thing with Lymphoedema is, it can be so unpredictable at times! Some days I find the swelling is worse than other days and there is nothing I have done differently. This variability in the condition was actually mentioned at our last meeting by speaker Jane Wigg so it seems that our Lymphoedema can also have off days!



A Poem for autumn

In the other gardens
And all up the vale,
From the autumn bonfires
See the smoke trail!

Pleasant summer over
And all the summer flowers,
The red fire blazes,
The grey smoke towers.

Sing a song of seasons!
Something bright in all!
Flowers in the summer,
Fires in the fall!

Robert Louis Stevenson



Off to the Cinema

MOVIES



Up in Hexham, we have a small cinema called the Forum Cinema, very art deco in style and utilised to its full potential. In addition to the usual film releases they also

have live theatre from the National Theatre and the Royal Shakespeare Company as well as Wide Skies Films. There is a lovely café where they host afternoon teas, music and quizzes as well as local art exhibitions.

One of the best films I have seen this year is The Guernsey Literary and Potato Peel Society; a film set after World War II with the lead actress cast as a writer who ends up in Guernsey, but I had best not say anymore in case you have not seen it, however I will say it is a story of love and friendship, a worthwhile film indeed.

A film that was also shown at the Forum a few months ago was The Kite Runner, a novel by Khaled Hosseini. I remember reading the book years ago and when it was being advertised locally, Richard booked tickets for us to go. Although a fictional story, the author has drawn upon accounts of ethnic conflicts and the annual children's kite contests which were based on the author's own experience. It is a harrowing story but well written and although I always have reservations about reading a book then going to see the film (I always worry in case they don't manage to capture what was in the book), in this film's case I had no need to worry.

News

I noticed on the LSN website that Anita Wallace (LSN Chair) has been awarded the MBE for services with Lymphoedema Awareness and Patient Support.

Positive news, acknowledgement from the highest level. Well done Anita!

And....

The LSN has launched its YouTube channel! They are looking to upload videos with short explanations of Lymphoedema from Nurse Advisor Denise Hardy. These will be followed by other videos including skin care and patient stories as well as views from professionals.

It seems everyone is moving forward with technology, LSN on YouTube and NLSG will be on the web too (soon)!

If you have anything for the newsletter/website please let me know at the next meeting.

Please also note that the poem and pictures were taken from the internet.

Julie Waters