

Northern Lymphoedema Support Group Newsletter

Next Meeting will be the AGM which will be held on Saturday 14th March, 2.00 – 4.00 p.m. within the Learning and Development Room at St Oswald's Hospice, Gosforth



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A note from the Editor

Welcome to the first newsletter of 2020.
It is Sunday afternoon, the 9th February and as I write this newsletter from the comfort of my armchair, Storm Ciara is doing her best to cause havoc and damage outside. Hopefully by the time our first meeting arrives, weather conditions will have improved and we will be experiencing a warmer climate. Winter seems to last so long these days; it can feel like spring will never arrive; but it does eventually and its lovely to hear the birds singing whilst they busy themselves foraging for nesting materials, spring flowers appear in colourful abundance, buds on trees sprouting green foliage and

people emerging from their homes and out of hibernation!

Spring is a time of new beginnings and hope, it's one of my favourite times of year.

NLSG CHRISTMAS LUNCH 2019

It seems a long time ago now, but everyone enjoyed our Christmas Lunch on 14 December at Newcastle City Golf Club. It may have been more expensive than previous years, but it was a superb meal. There were 16 of us in the members' meeting room with comfortable seating arrangements. Following the meal, Violet Hart played some festive music and led us in singing a few carols and we also had a raffle. Thanks to all who donated money to the Hospice instead of exchanging Christmas cards. This raised £55 on the day and hopefully may be boosted by a further donation which will be handed over at our meeting on 14th March.

Thanks to Violet for the entertainment and Carol and Lynn who collected the money and to everyone for their kind support.

Kathleen Brown



Lymphoedema and me - Jenifer Harper

*I am fortunate in that – so far – I have only mild problems with my lower legs. Writing this piece has been quite a challenge since it has made me confront how little attention I pay to my condition and its requirements. I heartily recommend that **you**, reading this, go away and write about your situation. Ask Kathleen for her prompts - a great help in focussing the mind on stuff so easy to ignore.*

Weight had piled on through my 40s and fifties, with the odd swollen ankle in really hot weather, but the first serious problem was on a fly/cruise to the Caribbean in my late 50s. Ice helped, and the ship's doctor recommended I avoid the soup (too salty), and pop my lifebelt under the mattress to raise my feet.

Back home Tubigrip helped, or support tights. My GP prescribed stockings to help my varicose veins but I couldn't even pull them on. I used "helpful" tights, but mostly went bare-legged in summer and did a lot of dancing and swimming.

Aged 72 I moved to Newcastle and after another long flight was referred to the Freeman to see a Vascular Surgeon about a possible clot in my left leg. Negative results, but she had herself some experience of Lymphoedema and recommended the GP referred me to St Oswald's and also advised I be fitted with lightweight support hose because my hands were too feeble to cope with anything stronger.

None of my GPs ever claimed to know much about the condition. I found St Oswald's education sessions very informative and helpful and eventually settled on below-the-knee rather lightweight stockings. There has been some improvement and I am aware that my

condition is not severe. The group meetings of the support group have also been vital and I wish I had always been well enough to get to them. Tripudio should be part of my daily life but somehow gets lost along the way.

When I get up in the morning my first concern is to get to the loo before disaster strikes. Since both my knees are badly affected by osteo-arthritis I find it difficult to walk quickly after waking and am very wary of falling. I need two sticks to get me to the bathroom and it takes longer than I'd like.

I should, of course, put my stockings on then, as soon as possible, but often find I've been pootling around for about an hour – not good. So many good intentions wither as the day moves on and what passes for my life takes over; mostly anxieties about arthritis, loneliness, my approaching knee replacement operation(s?) and my son's health (he has a serious ongoing mental illness) and I struggle to sort out priorities, to take the best action in the here and now, for me, for him, for my lymphoedema.

These days I am very limited in going out – 2 sticks and bad weather do *not* work well, nor shopping, etc, so lymphoedema's impact is lost in the general immobility. There isn't any real problem with clothes, or shoes, though I do miss my bare-foot days and pretty sandals. Holidays are limited to simple travel, like getting a cruise from Newcastle and letting other people look after me – rare, but gorgeous! I can't stand really hot weather but do like getting rid of my cardigan and all those layers of winter clothing. I find trousers can cause knee problems and prefer longer skirts, just short enough to skim the steps on the Metro escalators safely (again, can't hitch up a skirt with two hands full of sticks!)

The nastiest part of my day (apart from putting them on in the morning) is

taking my stockings OFF. I can only do both on my bed and it hurts both my legs and my hands. A grouchy moment. I also struggle with the effort of applying the dreaded Hydromol without smearing it all over the bed or the floor and turning the air blue. Thank goodness I seem never to have thrown out any of my old tatty towels

So far, so good, though I await the knee operation(s) with some anxiety, both in terms of whether I can apply the stockings on my own or bend either knee enough to manage. Writing this has helped me think through my approach to my condition and how I am – or am not – managing it to my best advantage. Room for improvement, plainly.

Thank you for writing your experience of Lymphoedema Jenifer. You have touched on so many aspects of the condition - from having trouble donning and removing your support bandages as well as having additional health conditions to Lymphoedema, i.e. varicose veins, osteoarthritis as well as personal and family worries and concerns.

I think we can all relate to your story Jenifer, thank you for sharing this with us.



Lymphoedema news

How many of you are members of the LSN (Lymphoedema Support Network)? If you are, I am sure you will agree that the quarterly newsletters are very informative with up to date news regarding how Lymphoedema awareness and medical advances are progressing nationally. It also features member's stories, a bit like our newsletter this quarter!

I noticed an article about Jane Wigg, in the LSN winter edition; Jane spoke to our group a couple of years ago via Skype about Lymphfluoscopy or ICG fluorescent imaging. This is a technique where a small amount of tracer is injected under the skin and a

specialist camera is used to show where the lymphatics are working or failing. The aim of the process is to identify the specific areas within the affected limb or area of the body so that they can provide a bespoke MLD for that person, this makes sense, as all our bodies are different. Currently, this process is only available at a cost, but it goes to show how processes and techniques are advancing which is positive.

Jane also mentioned about getting into the habit of emptying your lymph nodes at various times throughout the day, particularly if you are not very active or have a sedentary job (that would be me, in front of a computer all day!) Jane advises to take a soft sponge ball or even a clean ball of socks, pop it in the nodal area that is appropriate for you, i.e. behind the knee, in the groin, under the armpit then move the limb to squeeze the ball about 4-5 times various times throughout the day. The application of gentle pressure against the targeted area will promote the shift of lymph fluid.

March meeting

Just to remind everyone, our meeting in March will also be our AGM therefore anyone wishing to contribute to the meeting is welcome to, just let one of the committee members know on arrival.

Jill Lisle from St Oswald's Hospice will be putting us through our paces with a quiz on Lymphoedema, so prepare to be quizzed! Additionally, if time allows, we may do some Tripedio.

Please note annual subscriptions will be due. If you are attending the meeting, please hand over your subs to Janice McConnell, if you are unable to attend please send a cheque for £5 payable to NLSG to Janice McConnell, the address is on the subs form which you will find at the back of the newsletter; the form also gives you the opportunity to make any demographic changes should you need to. Many thanks

Just a reminder of our meeting dates for 2020:

March 14th, June 13th, September 12th
December 12th

If you misplace these dates, look at our website, the dates of future meetings are there.

Hints and tips

One of the girls at work brings scrumptious soup in to work, its predominantly vegetables with pulses. Anyway, we got talking and I said how much I disliked preparing turnip, it's difficult to peel and there is lots of chopping involved at which point she told me she just cooks the whole turnip in the microwave and when it's cooked she takes the top off and scoops it all out!



Also instead of steeping and cooking the yellow split peas for hours and hours, just use pease pudding!

Now that you have time on your hands after making your

super healthy quick soup, its time to think about going outside and helping the birds with their nesting.



Do any of you ever visit open gardens?

Last June in Hexham, several gardens were open to the public all on the same afternoon and all within walking distance of each other. The gardens were all outstanding, there were plants for sale, refreshments, a string quartet in one garden as well as an abundance of ideas to take away with you, oh yes and the sun was shining for the best part of it. I have digressed but what I wanted to say was I saw a bird feeder full of pieces of old wool to help the birds out around nesting time, such a novel idea.

I don't have a garden anymore, but hopefully one of these days I too will be able to have my own wool feeder.



Book review

I am still waiting for someone to let me know about a good book they have enjoyed!

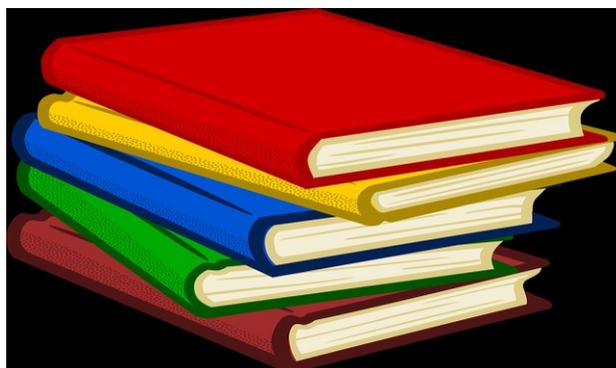
So, it looks like I am going to have to make another recommendation!

For Christmas my daughter bought me Noel Fitzpatrick's autobiography (the gentleman otherwise known as the Supervet).

It was a good read and what an interesting life, full of animal stories with trials and tribulations along the way especially whilst attending to farm animals!

Such a dedicated man on a mission who is constantly striving to provide the best animal care in the world.

A worthwhile read...



Please note pictures and some information taken from internet including LSN winter newsletter.