

# Thanet And North Kent

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## Lymphoedema Support Group

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### 15- December -2017

**Apologies:** Rita and Mike, Deirdre and John, Donna, Maria and Melanie, Tracy and Brian We missed Helen and Charyn and hope that you are both alright as it's been a while since we saw you in 2017. As always Muriel you are in our thoughts.

**Welcomes:** Ray and Anne from Medway and Marilyn and her husband Dennis all joined us

**Dear friends,** Thank you to all those members who attended the meeting on 25<sup>th</sup> November and those who were able to stay for the celebration buffet lunch and catch up. Despite a few unforeseen problems gaining access to the Function Room through the usual route, I think you will all agree it was a really good meeting

**Member news:** Deirdre hopes to be well enough to join us again in 2018 after difficulties resulting from a fall earlier in the year. All those sending apologies also sent their warm wishes for a Happy Christmas and a peaceful New Year to the group.

### **A few updates from our meeting:**

- **Meeting dates for 2018:** I have booked the 2018 dates which will follow the same pattern as 2017 to avoid Easter and Bank Holiday weekends in March and May. I will attach or send the poster / flyer with this letter
- **Advertising and contacts:** The 2018 Lymphoedema poster is now showing on all 3 large screens at the Whitstable Medical Practices. My daughter spotted it at Estuary View and one of the Lymphoedema Nurses saw it at Chestfield Medical Practice. The new posters and A6 flyers were available to the group and members will try to get them displayed across the area. A new one has been put up in the Podiatry Dept. of QVMH and since our

meeting I have updated the Lymphoedema Clinic waiting area poster along with flyers while the three consulting rooms have also received new posters.

- **Service problems:** There were reports that the new Administrative Hub appointment line is going straight to the answer machine. Denise Wilkes told us at the last meeting that telephone calls should not go unanswered in future as they transfer to an alternative phone, however Marilyn has had a different experience, having to leave a message but she had not received a call back a week later. The answer message was also questioned as it now says 'we will endeavor to get back to you in 48 hours' which leaves patients not knowing how long they should wait or if indeed they will be called back. Again problems with hosiery were aired by members including, difficulties with non GP prescription garments due to the lack of budget and limbs being measured incorrectly or wrong prescriptions received wasting NHS money. I have emailed DW regarding all these matters and comments
- Since the meeting I have been told that the Perometer limb measuring machine remains unusable due to technical issues and I was measured by hand at my recent appointment. There have also been issues with staff sickness and shortages in the past couple of months which explains the difficulties getting appointments in a timely manner. Do remember appointments are generally booked 6 weeks in advance so you need to contact the service in good time for Follow Ups. Hosiery Fits are usually more prompt
- Rolators were discussed as a good means of aiding walking for those who are compromised and do not get on with a walking stick. Anne felt it had given her the freedom to get out and do normal things again.
- **Speakers:** we will decide who we would like to invite at our January meeting and already have the possibility of Ray Rees talking about Oxygen Therapy to aid circulation
- **East Kent Cancer Action Group:** the next meeting will be February 2018 so there is nothing to report at present

We welcomed **Dee Stringer** a registered Lymphoedema Practitioner with her own company Swelling Matters. Dee also has a MIRMT Diploma in Holistic Massage and recently became the SE Regional representative of the British Society of Lymphology - BSL.

Dee deals with Lymphoedema and Lipoedema and offers therapies to reduce pain and swelling in affected limbs. She is an advocate of treating pre and post-surgery with a holistic approach to aid symptoms of secondary lymphoedema.

We were given a brief overview of the lymphatic system and how lymph fluid is moved around the body via the lymphatic vessels and its many nodes as part of the circulatory system. Lymph fluid is drained into the thoracic duct to be discharged from the body.

When the lymphatic system has been compromised either as primary lymphoedema or with node removal and/or damage in secondary lymphoedema, alternative pathways are needed to move the lymph fluid from the damaged tissue area to active nodes in another part of the body.

Lymphoedema can occur anywhere in the body and the build-up of lymph fluid causes changes to skin tissue including general thickening; a waxy and rigid feel – fibrosis; flaking-hyper keratosis; raised bumps and blisters –papillomatosis and Elephantitis – lymphatic Filariasis caused by a mosquito. Lymph fluid can also leak through the skin – Lymphorhea. We were shown pictures of these conditions and those living with lymphoedema at its worst.

Secondary Lymphoedema can occur following cancer treatments and lymph node removal, radiotherapy, venous disease, obesity and immobility, trauma or burns. Without pre and post operation management 40% of breast cancer patients and 80% of those having a mastectomy will develop lymphoedema of the arm/s. Some medications will also effect the lymphatics including Amiodipine prescribed for high blood pressure. Around 200,000 people in the UK are diagnosed with lymphoedema but many are living with the condition without a correct diagnosis.

Lipoedema is another chronic disorder often experienced alongside Lymphoedema, this is caused by fat deposits in the adipose tissue and occurs almost exclusively in women due to hormonal changes. It will always stop at the ankle and the limb will bruise easily on touching. Up to 2 million women in the UK have Lipoedema but only 11% of these receive a correct diagnosis.

Dee talked us through self-management techniques including Simple Lymphatic Drainage, SLD and deep breathing. Compression garments should be worn daily and as I think we are all aware your limb/s should be measured by a Lymphoedema Practitioner. Using Kinesiotape can aid pain relief; originally designed to help sports injuries it can be bought via the internet and in some pharmacies. Other specialist therapies include Manual Lymphatic Drainage, MLD often used in conjunction with multi-Layer bandaging; the use of the Hydroven Pump which mimics MLD; Low level Laser Light Therapy and Deep Oscillation therapy Hivamat 200 a form of electro static massage. Dee added that any form of massage with movements towards the heart, will aid circulation and can help lymph flow.

Dee was thanked for a very informative talk and the good advice that she offered.

As always our huge thanks to Avice for organising the raffle throughout the year and to you all for donating the wonderful array of prizes. Today's raffles raised **£16.00** Thank you too Ellen and Ken, for your kind donation to the group funds.

Another very big 'Thank you' to Brenda, Ray and Kay for doing the refreshments all year despite there being difficulties with getting hot water today! There were no treats from Ray as we had the lunchtime buffet to enjoy after our meeting.

A final thank you of course to you all for attending the Support Group meetings; whether for the first time or through the year it has been invaluable to meet with each other and offer friendship and support and for those who were able to stay and join the buffet lunch we all enjoyed some quality time together catching up.

**Meeting dates for 2018: Saturdays from 10.00am to 12.30pm in the QVMH Function Room:**

**27th January**

**24th March**

**19th May**

**21st July**

**22nd September**

**24th November (extended to 1.00pm)**

### **Wishing you all a Very Happy Christmas and a wonderful and peaceful 2018**

Take care everyone, keep smiling ☺ and I look forward to seeing you all on 28<sup>th</sup> January 2017 (weather permitting!) when we will have a chance to catch up with one another again. Avice will also collect the £12 subscriptions for those of you to wish to pay in advance for the whole year.

Best wishes

*Sarah x*

