

# Thanet And North Kent

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## Lymphoedema Support Group

**Treasurer:** Mrs. Avice Winfield, 25 Langdale Avenue Ramsgate Kent CT11 6RS Tel: 01843 587962

**Coordinator:** Mrs. Sarah Haydon, 5 Galley View Brook Lane Herne Bay Kent CT6 6EZ Tel; 01227 861121

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### 10- February 2018

**Apologies:** Deirdre & John and Alison who had kindly donated two lovely raffle prizes

We missed Ellen & Ken and Tracy & Brian. Muriel we hope that you are well.

**Welcomes:** We welcomed Amanda and met her husband Chris at the end, as well as Terry, Niki's husband

**Dear friends,** Thank you to all those members who attended the meeting on 27<sup>th</sup> January 2018. We had an amazing turnout with 19 people attending in total.

**Member news:** Deirdre is still not able to get out and sent her best wishes; we are thinking of you and hope that you will be well enough to join us in March.

Kay updated us on her amazing weight loss and news at her recent Follow Up appointment. Having lost 4 stone over the past 12 months (using Slimming Worlds eating plan) Kay has seen her legs reduce in size as well. At her last appointment Tracey Barton, Assistant Lymphoedema Practitioner, checked both limbs for evidence of Lymphoedema and told Kay that she could find no lymph fluid buildup effectively meaning that the Lymphoedema has gone! Kay still needs to wear her support hosiery but by maintaining a good weight, exercising and doing self-drainage daily she should be able to keep the buildup of any fluid completely under control.

While all these measures combined are proven to be the best way in which to reduce and maintain Lymphoedema not everyone will see the reduction in Lymphoedema to the extent that Kay has done and where episodes of cellulitis have damaged and hardened cell walls Lymph fluid may be far less easy to move. Kay is our 'miracle' and is a wonderful example of how determination has given fantastic results. Well done Kay!

### A few updates from our meeting:

- **Meeting costs:** Avice collected subs from those wishing to pay the £12 in advance for the whole year. The meeting costs remain at £2.00 per meeting to cover refreshments, printing/postage of newsletters (where applicable) and towards speakers' costs and other expenses alongside money raised by the regular raffle.
- **Function Room access:** I was contacted by Angela Lees, Lymphoedema Secretary QVMH, to confirm that we still required the Function Room after the Receptionist had enquired. I have confirmed that we will be here on each of the booked dates and also that I can access the room coming in via the main hospital entrance and the Porter for Heron Ward was informed that I will be on site accessing via the corridor
- **Advertising and contacts:** posters were available to those willing to try and get them up. I noticed that the LSN now have business style cards which might be a thought for our group to give out, maybe for 2019?
- **LSN Lymphline magazine:** I wrote an update for the Spring edition of the magazine with our Support Group's activities during 2017 and details of the 2018 meetings. I was slightly disappointed to hear back from the Chair, Anita Wallace that they would only have space to print the meeting dates, although she did congratulate us on being such an active group. We do get enquires passed on from the LSN and Amanda found us through them. Anyone can contact the LSN on **020 7351 0990** for advice while membership costs £15.00 annually and you receive 4 editions of their Lymphline magazine.
- **Administrative Hub update:** I had not heard back from Denise Wilkes following my email regarding the problems reported at November's meeting, however I was led to believe and have since had confirmation from DW that she had been off work; she is now back and apologized for the delay. I spoke with Sophie at the Hub in early January after leaving unanswered messages after Christmas. Sophie has helped to clarify why messages are not always actioned within 48 hours. When calling the Hub or Referral Point which covers six services, an Administrator checks appointment need with your patient care package and passes your request onto the appropriate clinic secretary, who will then call you back. Not all secretary's work five days a week so may not get back to you in 48hours however if you are concerned or have not heard back within a few days you should call the Hub again when the request will be escalated for a priority call back . I

also met Kirsty Channing, Referral Point Coordinator when I had my Follow Up appointment as she was sitting in at the clinic. She too was very helpful and is in charge of monitoring the efficiency of the Administrative Hub, in particular incidences when a patient has had to call the Hub twice regarding the same matter having not received a call back .The figures will be checked monthly and if the system has failed on too many occasions a solution will be found. Kirsty gave me her contact number so that I can pass on any member issues to her personally.

- **QVMH Herne Bay League of Friends ;** I saw the Spring 2017 newsletter in the Lymphoedema Clinic waiting area which had a large article about the funding given to the Lymphedema Service including information about the Tripudio exercise programme, as yet to be started by the service, and training of the Assistant Lymphoedema Practitioner. I noticed that they are looking for new members and donations of items to sell at their QVMH shop as well as for their annual fete in September. Membership is a lifetime, one off payment of £10, you then receive your own annual newsletter update. Contact: Mrs. Sue Dale, 31 Rowland Crescent Beltinge Herne Bay CT6 6RY (no Tel No given) or Treasurer: Mr. R Sidders 01227 372935.
- **Phone calls:** I have had another 3 telephone calls from patients and a medical practice who are trying to contact the Lymphoedema Service. Finding my details on the website they obviously prefer to contact a named person on a local number.
- **East Kent Cancer Action Group:** the next meeting will be 2<sup>nd</sup> February 2018, Sarah and Kay will attend. I realised that I had not in fact updated members from the October CAG meeting however there was little to report as news from the Living With and Beyond Cancer meeting was the same as the update given to us by Denise Wilkes in September. Our newsletter is shared with the CAG members as well as the MacMillan Support Services **NB:** Since our meeting it has been confirmed that the meeting will now be held on Friday 23<sup>rd</sup> March 2018.
- **DVDs:** These were both returned and have been passed on to others, the system is working well. Thanks to Avice for coordinating the loan of our two DVDs and if anyone would like to borrow one or the other please let Avice know.
- **Speakers:** Ray Rees has agreed to speak to us about Oxygen Therapy to aid circulation at our March meeting. Although the evidence that it is effective in the aid of Lymph flow is not that good, Ann reported feeling better in herself after some sessions at the Canterbury MS Centre. I will look into someone to talk about skin care and see if Palmers

(Cocoa Butter Body products) are able to come to the group. A representative from a shoe company possibly, although the shoe shop in Herne Bay let us down last year I could enquire again and dietary advice – I could ask an NHS dietician maybe? Maria mentioned a therapist who does Hydro Massage as well as selling her own brand of products without nasty additives! Maria has since passed on contact details for Caroline Lyons so I will see if she is available for May or July.

We all enjoyed chatting with one another, as we do not have speaker at our January meeting. Discussions included washing garments: many confirmed these can be machine washed at 30 degrees although fabric conditioner should not be used as it damages the elasticity of the material. Alternatively hand wash and then machine spin or hand wring then wrap in a dry towel before air drying. Garments should not be placed directly on a radiator but an ‘over radiator’ clothes ailer works well or a towel underneath on the warm radiator for a short period. Some garments can be tumble dried on cool but most did not find this helped with garment comfort. Size issues of made to measure hosiery MTM were also mentioned; the advice is that if your garment is uncomfortable even after a successful fitting appointment, that you should request a re-measure appointment. Garments may appear to fit initially but after wearing for a few hours problems can occur, I have been told it is better to wear a garment if you feel confident and it is not uncomfortable, for a few days prior to the fitting. Maria kindly helped Amanda with arm sleeve problems and showed how a separate glove is better than an all in one hand/arm garment.

**Raffle:** The raffle raised £19.00 and we had a great variety of prizes including the two Palmers Cocoa Butter goody bags donated by Alison left over from the Breast Cancer meeting last year. Thank you everyone for continuing to donate such lovely prizes.

Our thanks as always to Kay, Brenda and Ray for organising the tea and coffee. We managed to find an alternative water heater to use, a bit of a walk but needs must and good exercise! Ray’s baking talents were much appreciated but he now has competition ... Amanda is a chef and has promised to bake us some home cooked delights at a future meeting having been assured that she would not be stepping on Ray’s toes! Thank you Amanda.

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

24th March | 19th May | 21st July | 22nd September | 24th November (extended to 1.00pm)

Take care everyone, keep smiling ☺ and I look forward to seeing you all on 24<sup>th</sup> March when we will have a chance to catch up with one another again and will hear Ray speak about Oxygen Therapy for improved circulation.

Best wishes



Sarah x