

Thanet And North Kent

Lymphoedema Support Group

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9th February 2020

Dear friends, Thank you to all who attended the meeting on 25th January 2020 with 20 of us in total.

I am sorry to start the newsletter with some sad news; one of our original members Muriel Moore passed away at the age of 96 on 3rd February. Those of you who remember Muriel will know that she attended the group meetings regularly until about 2 years ago when she struggled to walk. She had still wanted to keep updated with the groups news and Avice visited her often. Avice and Kay have offered to attend her funeral on 20th February as I will unfortunately be working. Avice will also arrange to flowers or a donation from the group

A few updates from the meeting:

- **Speakers:** I contacted The Harmony Therapy Trust and had an immediate reply to say that they would be happy to source a therapist who could come to one of our meetings to talk about their work and demonstrate hand massage, however I have not heard back from them since so will chase this up. I have not had any further information from Anton Morgan Thorne the MacMillan Cancer Engagement Coordinator or feedback following the patient led group workshop in December and again will chase this. I will email Julia Oje, Registered Acupuncturist and Vodder Manual Lymphoedema therapist to ask if she will come to a meeting. Denis Wilkes will attend the meeting on 8th March 2020
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- **Contacts and telephone calls:** Health and Wellbeing Advisor wanting information for a client which was followed up and Craig contacted me and joined us today as a result

- **LSN- Lymphoedema Awareness wrist bands:** these are available to purchase. Please let her know if you would like one as we have a stock for members
- **Advertising:** I have placed a poster on the Community notice board in Herne Bay Sainsbury's and will take one to the Reculver Road and St Anne's surgery .We ideally also need some at the hospitals and Minor Injury Units locally
- **Finances:** our balance at the end of 2019 was £319.19 banked and £87.53 cash totalling £406.72. We had a large expenditure in November with the buffet, speakers and printing costs totalling £191.12p. Avicé will continue to collect subs of £2.00 at each meeting from those attending and the raffle increases our available budget for speakers expenses
- **East Kent Cancer Action Group CAG:** Sam Rose has now left the CA Partnership and Tracey Ryan is coordinating meetings at present. The initial 2020 meeting was held on 10th January but unfortunately I was unable to attend this. One of the actions from October's meeting was for the MacMillan newsletter to include something about the Lymphoedema Support Group .I am waiting to receive confirmation of what is required i.e. Meeting dates and details or a short article. Tracey is also chasing the GP Training regarding a talk on lymphoedema from a patient perspective

With no speaker at our January meeting we used the time to talk about the concerns that affect us, including the ongoing worry about lack of knowledge around Lymphoedema by GPs. The Lymphoedema Support Network LSN, does offer on line or CD training for all GPs and nursing teams this would form part of their Continued Professional Development CPD but this is not a compulsory module. Many GPs will see Lymphoedema as the Specialist Service responsibility into which they make referrals so do not feel a need to be further educated. However the Service does not make the initial diagnosis and cannot prescribe when antibiotic cover is required urgently for cellulitis or as a prophylactic measure. It is concerns such as these and the lack of understanding of the other side effects form Lymphoedema that cause patients increased stress and difficulties getting the right treatment in a timely manner

New techniques in Manual Lymphatic Drainage were discussed and questions were raised about the reasons why and how performing simple Self Lymphatic Drainage is important. An article in the latest LSN Lymphline magazine mentions the Movement and Drainage technique which involves regular quick actions to empty lymph nodes frequently. This is

achieved by gently pressing a soft ball or rolled up sock ball into the appropriate nodal area for your Lymphoedema i.e. the armpit, under the knee or groin area 4 or 5 times .Getting into a habit of this throughout the day can encourage the flow of lymph fluid to allow drainage through alternative pathways. This techniques is important if you are unable to remain active for long periods

There was a further discussion around lymphatic mapping, Lymphofluoroscopy . This gives imagery of the lymph nodes and vessels and from this it can be determined how best to drain the full nodes and help lymph flow from effected areas. Unfortunately Lymphofluoroscopy is not available generally on the NHS and is costly private procedure so most patients are still left guessing the best route in which to expel lymph fluid effectively. Discussing ideas with the Lymphoedema Practitioners at clinic appointments is sensible and asking to be shown the correct actions for your own body. One person at the meeting was able to show us their own lymph mapping images taken during hospital investigation into node blockages

An update on my own experience with Personal Independence Payment was given. Following an unsuccessful Mandatory Reconsideration to the initial decision by the DWP and a rather impolitely worded and totally incorrect response to the MR, I decided to appeal and correct the facts from assumption to the truth. My clinical records had been obtained at the start of my PIP journey but were not available to the Health Professional at my assessment and she knew nothing about Lymphoedema. Someone from the DWP with no clinical experience then decided they could read the records of limb volume and did so completely incorrectly ignoring actual limb measurements. I challenged these along with other inaccuracies and knew I could wait up to 12 months for the appeal to be heard by a tribunal .The DWP have to make a defence against the appeal and thank fully decided they could not do so. My PIP application was therefore reconsidered and I was awarded enhanced PIP on 21st December. If anyone is considering an application or has to go for an appeal do make sure you have all the evidence available and do not be put off by the DWP. It can be a very worrying and stressful time so do ask if you need help

The meeting was a good time to catch up with one another too and lots of conversations were had individually so I hope I have not missed anything important

Thanks to members for organising our refreshments and the raffle, which raised £24. Thank you all as always for continuing to support the raffle which helps raise funds for speakers

Meeting Dates: Saturdays from 10.00am to 12.30pm in the Function Room QVMH

Dates for 2020: Function Room at QVMH:

March 28th May 30th July 25th
September 26th November 28th

All are the fourth Saturday of the month excepting May to avoid the Bank Holiday weekend

Take care everyone, please keep smiling 😊 and I look forward to catching up with you all again on 28th March 2020 when Denise Wilkes will join us to answer questions and update us on the KCHT Lymphoedema Service

With very best wishes

Sarah x