

Thanet And North Kent

Lymphoedema Support Group

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6th August - 2019

Dear friends, Thank you to all who attended the meeting on 27th July, we had 19 in all. We do have some members who have not attended a meeting for some while so are no longer really active within the group. However it is not compulsory to attend a certain number of meetings in each year so I will usually send newsletters for the current year without attendance or apologies but cease when it is apparent that the person will no longer attend

A few updates from the meeting:

- **Speakers:** Denise Wilkes has apologised and will be unable to attend the meeting today, she is away but also the long drive would not be good at the moment .I will ask if she is free in September as unfortunately Jan Stuart, Lymphoedema Therapist can no longer join us for this meeting (she will come along next year now) NB: Denise is NOT available for September so I will find another speaker or we will have a speaker free meeting. At the November meeting we have a talk about Osteoporosis and meditation
- **Contacts and telephone calls:** Various – a gentleman telephoned wanting advice about travelling abroad with Lymphoedema including flights, insurance and general care .I always explain that I am not clinical but use my own experience and information from the LSN. I have had 3 calls from Lymphoedema patients from West Kent wanting information about the service and clinics in the Maidstone and Paddock Wood area. I have given the WK email details and also the SCS Referral point telephone Number
- I had a Follow-Up appointment with Heather Smith recently. As always she was very helpful and professional in her treatment and the clinical records made. Others in the group agreed

- I have had trouble getting made to measure hosiery from Sigvaris recently .It seems a code was missing or incorrect but the company did not contact the GP or pharmacy they just waited to be contacted which eventually the pharmacist did after I had asked on two occasions I eventually received the stockings after 6 weeks.
- I requested my clinical notes recently (for Personal Independence Payment PIP Evidence) should anyone need to do so you need to contact the KCH NHS Trust Legal Team via email: kcht.legal@nhs.net . The legal team will send a form which you must fill out and return along with certified personal documentation. They then have one calendar month in which to send the requested records which are free of charge. I asked for 2 years of Lymphoedema and Podiatry notes but actually received more than this , not all is relevant e.g. telephone calls , I highlighted the relevant evidence and then took my own copy of the notes
- **Personal Independence Payment benefit PIP:** A discussion followed on PIP. PIP can be applied for to help with some of the extra costs if you have a long term condition, ill-health or disability. It will be calculated on how a condition affects the person not the condition itself. You can apply if you are between 16 and the current State Pension age. You can apply for Attendance Allowance if you are over 65 years of age. PIP will replace Disability Living Allowance, DLA, if you already claim DLA you will get a letter telling you when this will happen and how you can apply for PIP from the Department of Work and Pensions, DWP. DWP currently states that if you were born after 4th April 1948 any DLA awards will cease and you will be sent a PIP letter but this may change as those of pensionable age are now given light reassessments in general. <https://www.gov.uk/pip> If you were born on or before 8 April 1948 you will continue to receive DLA if you already get it.

You can claim for either or both the Care and Mobility components of PIP. The form is quite long with you needing to give details of how your condition affects you on a daily basis for which you score points, however you should think about the worst it affects you not the best .We all forget that we get used to compensating for conditions and then see this as normal when in fact it would not be for someone without that condition. You will need to score 8 points for the Standard rate and 12 for the Enhanced rate of either component. You are given a calendar month from the date the form is sent to you which can take 10 days, so in reality about three weeks to complete and return it to DWP along with any evidence to support what you have written .This can be clinical records, GP or Consultant letters, prescriptions, any assessment you have had say for work etc. These do not have to be recent if the

condition is ongoing You can, send extra evidence as I did after you have sent your claim but make sure to explain that this is to follow, so no decision is made without the additional evidence. Make copies of everything that you send to DWP and get proof of postage in case what you send gets lost in the system. Keep records of any contact with DWP telephone calls etc. as you may need to refer to these if you have to go through an appeal. You will also have a Face to Face assessment with a Health Professional (physiotherapist, nurse) either in your home, which you can request, or at a designated centre (Canterbury for our area) You can have someone with you for support and to offer reminders when answering questions .Occasionally telephone assessments are given usually with no warning! Independent Assessment Services formerly ATOS carry out all assessments in the South East area.

Once DWP have the Face to Face report, your form and own evidence they will make a decision about entitlement, this takes 4 to 8 weeks at present. If you are not awarded PIP to the degree that you had expected you can go through a Mandatory Reconsideration supplying further evidence, explaining why you feel the decision is wrong in your case. If this is also unsuccessful you can then go for an Appeal which is independent and in around 70% of cases will be successful sometimes without you actually having to attend the appeal panel itself

The Gov.Uk website <https://www.gov.uk/pip> has a sample form and points explanation. Benefits and Work are an excellent resource where you can see the PIP application and criteria. For an annual fee (£15 – 20) you can access downloadable guides which are invaluable tools for understanding how you complete the forms, important language to use and what evidence to include <https://www.benefitsandwork.co.uk/>

- **Lymphoedema Awareness wrist bands:** we have purchased some of the new rubber lymphoedema alert wrist bands , all were bought by members and more will be purchased for others to buy next month
- **Updated LSN Leaflets:** What is Cellulitis and Managing Cellulitis have been purchased for group members.
- **Cellulitis:** A short discussion followed on antibiotics for cellulitis or as a precaution. Having recently had toenail surgery by the brilliant KCH NHS Trust Podiatry team I asked the GP for antibiotics in case of infection following surgery and these were prescribed however some GPs are not happy to do so .Make sure that your GP understands that Lymphoedema will put you at a high risk of bacterial infection and it

was mentioned that the GP can highlight this in an Alert tick box on your medical records so it is worth asking for this to be done

- **Lymphoedema DVDs:** Both of these (arm and leg) were loaned out to members and can be returned at the next meeting
- **Advertising:** Posters were taken for Herne Bay and WWX Sainsburys and Ramsgate library. The Lymphoedema Nurses are prompting the group to patients

Speaker: Clare Noel: Clare spoke to us about her own Lymphoedema journey and the self-management techniques that she has been using successfully

Clare has been under the care of Christine Wise, Lymphoedema Therapist since her Lymphoedema occurred following treatment for ovarian cancer in 2017. The Lymphoedema affects her groin and thigh. As she spend part of the year living in Greece where the heat causes additional problems she purchased a Deep Oscillation Therapy machine to use daily which was easily portable and worked well initially however the Lymphoedema then began moving into the upper leg and Christine Wise suggested a Hydroven Pump and sleeve which covers the buttock and leg .The pump mimics Manual Lymphatic Drainage and must be set at the correct pressure for each individual .Before use the surrounding nodes are cleared and then Clare uses the pump for a 45 minute cycle, having excellent results . The price can be prohibitive at around £1,800 plus £700 or so for the sleeve. Macmillan grants might be an option for Cancer patients, these are means tested and not guaranteed.

Clare had an appointment with Professor Mortimer recently to discuss a surgical option for treating lymphoedema however he felt there was now little presence of Lymphoedema and the dangers of surgery would outweigh any benefit

It must be remembered that everybody is different and what works well for one person may not be effective for another. Those who have had Lymphoedema for many years or have suffered recurring bouts of Cellulitis which hardens the cell walls may not get the same results as someone who is recently diagnosed when it may be easier to mover the Lymph fluid .It is important to use whatever technique or therapy that you find works well for you to maintain your own condition even if there is no reduction in limb volume. Walking works excellently for some but others cannot walk for any distance without extreme pain, weight loss is always advised but will not reduce limb volume in all cases

Clare also spoke about her experience attending a three day course on Tripudio Exercise, a movement therapy for Lymphoedema using gentle techniques either seated or standing. The Tripudio Flow technique is a series of movements to encourage lymph fluid to flow and move away from the affected limb. You would usually practise this on a daily basis

Although Clare can now register to teach Tripudio classes it is not something she feels able to commit to. She will be happy to go through the Flow with the group at a later date when we can give her time to do so.

The main issue Clare experienced with the course was it was suggested that Lymphoedema occurs as a result of the patient being at fault, having done something wrong to cause the condition. When Clare protested this fact the trainer did not take the comments well.

No one is at fault for having Lymphoedema whatever the cause, in the case of cancer treatments, loss of nodes and damage from Radio Therapy will put patients at a high risk of developing Lymphoedema whatever pre cautions are taken, those born with Primary Lymphoedema or developing Secondary due to trauma or for another reason cannot be blamed .It is very sad to hear that prospective Trainers are being taught to apportion blame in this way

We all thanked Clare for sharing her experiences with us and hopefully she can take us through the Tripudio Flow at January meeting as she will be away in September

The raffle raised £19.00. As always thank you to everyone who contributed to the lovely array of prizes

2019 Meeting dates : 28th September –TBC

23rd November – Osteoporosis and some mediation

Followed by celebration buffet lunch

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

Take care everyone, please keep smiling 😊 and I look forward to catching up with you all again on 28th September

With very best wishes

Sarah x