

Issue 3
Summer
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Lymph-notes

Keeping you in the loop about
St Oswald's Lymphoedema Service

Welcome to the third edition of Lymph-notes! If you have any suggestions for features or there's anything in particular you'd like us to cover in future issues then please email patientfeedback@stoswaldsuk.org. We look forward to hearing from you.

Bon Voyage...

You often tell us that as a Lymphoedema patient you worry about going away on holiday, but with a little thought and preparation before travelling, there is no reason why you should not have a wonderful, carefree and relaxing time. Careful planning is key so please follow the useful tips below and get in touch if you have any queries or concerns:



Vaccinations - if you require vaccines do not have them in an affected limb and if several are needed, try to space them out over a period of time.

Medication - before leaving for your holiday, check that you have enough medication and prescribed drugs and always carry your prescription sheet with you. As you are more at risk of infection in your affected area, and even more so if you have suffered from cellulitis in the past it may be best to take a course of antibiotics with you 'just in case' you require them. Please speak to your GP about this. Also, always carry your medication in your hand luggage as you never know when your suitcase may be lost!

Flying - request or pre-book a seat with extra leg room, always wear your compression garment a few hours before take-off, during the flight and for some hours afterwards, wear loose underwear and clothing, try to do simple exercises including breathing exercises and drink lots of water.

Car and bus travel - once again, it is vital to wear your compression garments, plan regular stops so you can take a walk and exercise your limbs.

Avoid sunburn - use a good quality sunblock (as high SPF as possible) and keep your affected limbs covered when on the beach.

Footwear - if you have leg lymphoedema, wear sandals to protect your feet from injury (soft 'jelly' shoes are perfect). Avoid walking barefoot whenever possible.

Swimming - wash your skin after you have been swimming in the sea or pool. This will remove any chemicals or salt. Always ensure your skin is dried carefully and reapply sunscreen.

Skincare - Be extra diligent and follow the skin regime recommended by your Nurse or Keyworker, applying moisturising cream/lotion at least once a day.

For more details and in-depth advice please pick up a copy of Holidays and Travel for people with Lymphoedema (LSN leaflet) from the Outpatient waiting area or it is also available to download online.

Speak it!



Speak it! is an app which can be used to convert written words into spoken words. It is available on iPad, iPhone, iPod and on Android devices too, such as Samsung and HTC.

As some of you will be aware, after having head or neck cancer you may develop problems with your speech so Speak it! can be a really useful tool.

The app was recently used in clinic and both the patient and nurse found it easy to use and very helpful. The app is very cheap to download and you don't need an internet connection to use it.

Continuing to educate

Within the first issue of Lymph-notes we told you about our pilot Patient Education programme. The sessions run for six weeks, are led by our Keyworkers and equip patients with the knowledge and skills to be able to self-manage their condition. The pilot will come to an end in July and due to its success we plan to continue to run the patient education programme from September. All new patients attending our Lymphoedema Clinic and Shiremoor Outreach Clinic will be invited to attend the programme.

One patient said:

“It’s been really good to know I’m not alone. I’ve increased my understanding of Lymphoedema and why I have got it.”

If you’re a new patient and you’re suitable for the programme, the Lymphoedema Team will be in contact with you soon.

Coming soon

We will soon be installing a flat screen TV in the Outpatient Waiting Area. This is to display information about St Oswald’s, the Lymphoedema Service, useful hints and tips and useful contacts.

We will also be introducing a book shelf in the waiting area where you’ll be able to buy second hand books. This will be refreshed each week to ensure new stock is always available.

Web wise...

In the first edition of Lymph-notes we printed details of useful websites, forums and other forms of social media relevant to Lymphoedema patients. Since then several patients have asked us to reprint these details so here’s a small selection that you may find useful:

Facebook - Groups include ‘Lymphoedema is part of who I am’ and the ‘Lymphoedema Support Network’. We also have our own St Oswald’s Hospice Facebook page so please ‘like’ us.

Twitter - The Lymphoedema Support Network are now on Twitter, follow them at @lymphsupport. Follow us: @stoswaldsuk.

Health Unlocked, Lymphoedema Support Network - www.lsn.healthunlocked.com - Connect with others living with Lymphoedema and the Lymphoedema Support Network team. Find answers to health questions from other patients, health issues and debates relevant to you and tools to help you make choices that are right for you. Ask other people with Lymphoedema questions, anything from where to buy wide wellies to issues around pain.

LymTeen - help and support for teenagers living with Lymphoedema. Find help and support, advice on fashion and skincare and there’s also the opportunity to ask a question.

If there’s any others that you’d like us to share with other patients please let us know.

Northern Lymphoedema Support Group (NLSG)

Please remember that the NLSG hold their meetings at St Oswald’s and their next meeting is on **15th June 2013**. If you’d like to come along or find out more please contact Monica Burns, Secretary on 0191 259 5793. The Guest Therapist for the meeting is Val Heslop, Val will be there to offer Reiki sessions to anyone who would like to partake.

Stay in touch...

If you’d like to receive Lymph-notes via email please drop us a line at patientfeedback@stoswaldsuk.org or complete one of our Lymph-notes forms in the Outpatient Suite and pop in the return box.

You can also download back issues of Lymph-notes from our website at www.stoswaldsuk.org/shop/adults/services/lymph-notes/

