



Lymph-notes

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

Welcome to the sixth edition of Lymph-notes! If you'd like us to cover something in particular in a future issue please email patientfeedback@stoswaldsuk.org

ILF Conference

Last month St Oswald's Lymphoedema and Communications teams presented at the International Lymphoedema Framework Conference in Glasgow about the value and outcomes of the patient focus groups we've held at the Hospice. The ILF Conference brings together experts from all over the world to discuss developments in the treatment of Lymphoedema and to share best practice. Lymphoedema patients were invited to the Conference for a dedicated 'Patients Day' to meet and learn from the experts. For more information visit www.ilfconference.org

The Children's Lymphoedema Specialist Interest Group (CLSIG) are also planning their second Lymphaletics event. This is a day of fun, games and education for children and teenagers with Lymphoedema, and their families, and will be held at Ponds Forge International Sports Centre in Sheffield on Saturday 13th September. To register please email gilliancraig@nhs.net or call 01224 556361.

Making an impression

NLNet, the Dutch network of people with lymphoedema and lipoedema, launched their new book 'Impressed By You' at the ILF Conference in June. The book contains 28 personal portraits and stories of how each patient has dealt with lipoedema and lymphoedema in their lives. The stories are very varied, and feature children, teenagers, women and men. Find out more and order a copy at www.lipoedema.co.uk/impressed-by-you/



Healthcare Professionals Conference

Through surveys and forums with patients, we've often heard that you are disappointed with the lack of understanding about Lymphoedema amongst healthcare professionals. As part of our role as an education provider and as one of the national leading experts in Lymphoedema care, we are hosting a conference for healthcare professionals in September to raise awareness of the condition, how to diagnose and treat it, and how and where to refer patients if they need further care. We hope to make this a regular event.

Living better with self-management

We're excited to be holding our first Patient Conference in September for Lymphoedema patients who have been discharged from our service. We've put together a programme of talks and workshops on a range of topics including weight management and exercises, foot care and goal setting to help patients to self-manage their condition. The conference takes place on Wednesday 17th September. If you are a discharged patient and you haven't received an invitation please email patientfeedback@stoswaldsuk.org



Happy holidays!

Many Lymphoedema patients say that they worry about going away on holiday with their condition, but there is no reason why you shouldn't be able to have a carefree and relaxing time if you do a little pre-holiday preparation. Careful planning is important, so use the helpful tips below when thinking of your summer plans. If you have any questions or concerns, please get in touch.



Travel - if you're travelling by aeroplane ensure you request or pre-book a seat with extra leg room and always wear your compression garment a few hours before take-off, during the flight and for a few hours afterwards. Wear loose fitting underwear and clothing whilst travelling, avoid alcohol and drink lots of water and try to do simple exercises and breathing techniques whilst flying.

Medication - before you leave for your holiday, make sure you have enough medication and prescribed drugs to last the duration of your trip and ensure you 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 could get lost!

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

Avoid sunburn - use a good quality sunblock (a high SPF) and keep your affected limbs covered when on the beach. Also try to prevent insect bites by using an insect repellent.

Clothing and footwear - clothing should be loose and light. Cotton is a good material as it is cool and absorbs sweat. Try to wear your compression garment as much as possible. If you have lymphoedema in your leg, wear sandals to protect your feet from injury and avoid walking barefoot where 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 re-apply 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.

Feedback Bank

Earlier this year we launched our Feedback Bank - a way for patients, families, staff, volunteers and visitors to tell us what they think of St Oswald's and our services. Whether you have feedback, comments, suggestions, compliments or complaints, we want to hear it. Feedback bank boxes and submission forms can be found around the Hospice, including Outpatients Reception. Alternatively, you can also email patientfeedback@stoswaldsuk.org. All feedback will be given consideration and if possible, your suggestions will be taken on board and changes will be made. We acknowledge all suggestions where contact details have been provided.



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 the forms in the Outpatient Suite waiting area and pop it in the return box. You can download back issues of Lymph-notes from our website or we can send them by email or post.