



Lymph-notes

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

Welcome to the eighth edition of Lymph-notes! It's a busy edition this month with lots of new updates for you. If you'd like us to cover something in particular in a future issue please email patientfeedback@stoswaldsuk.org. We look forward to hearing from you.

Let us know if you've changed your telephone number or moved address

At St Oswald's Hospice, we try our best to keep our records as up to date as possible to ensure that all our patients receive information that is appropriate to them. If you have recently changed your telephone number, or moved address, please let us know.

Holidays and travel

With the weather getting warmer, many of us are starting to think about summer holidays. We want you to have a stress free time if you are going away – and there's no reason why you shouldn't be able to have a relaxing time if you do a little pre-holiday preparation. Careful planning is important and the following tips have been prepared to help you. 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.



Travel insurance – travel insurance is essential if you are going abroad. You may need to contact some specialist insurers, so leave plenty of time to arrange this.

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 speak to your GP and take a course of antibiotics with you in case you require them. Also, always carry your medication in your hand luggage as you never know when your suitcase could get lost!

Vaccinations - if you require vaccines (ask your Practice Nurse if you are unsure), do not have them in an affected limb. If several vaccines are needed, try to spread them out over a period of time to avoid discomfort.

Avoid sunburn - use a good quality sun cream (at least SPF 30) 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 sun cream.

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

Changes to St Oswald's transport service

There have been some recent changes to our transport service which will affect you. Please see details of the changes and guidance below.

As demand for our Lymphoedema service has grown hugely over recent years, so too has the demand for our transport service. Unfortunately, as we have now reached our maximum capacity for patient transport, we have been forced to prioritise our transport service due to the cost to the charity and availability of volunteer drivers.

For our patients, this means that a free transport service, provided by the Hospice, will only remain available to **palliative care patients** and **patients who are undergoing multi-layer lymphoedema bandaging**.

Sadly this means that we can no longer offer you free patient transport provided by St Oswald's Hospice unless you meet the above criteria. Please note that the Patient Transport Service is still available, provided by the North East Ambulance Service. This is bookable through your GP so please speak to your GP practice for more information.

If you have your own transport, free parking is available at St Oswald's, either onsite or on the road adjacent to the Hospice, with pay at meter parking available on local streets. You may also be eligible for help with travel costs – for more information visit the [NHS Choices website](#).

Many thanks for your understanding and support in this matter. If any further queries, please don't hesitate to get in touch at patientexperience@stoswaldsuk.org.

New spoke clinics

Due to the increase in demand for our lymphoedema services over the last ten years, we've developed a 'hub and spoke' model of care. Our aim is to develop satellite sites around the region where patients with mild or uncomplicated lymphoedema can access care closer to home. Patients with complicated lymphoedema, however, are referred to our main hospice site in Gosforth. While we've operated an outreach service in North Tyneside for a number of years, last year we launched clinics in Blaydon (Shibdon Road) and Morpeth (The Mount), as many of our lymphoedema patients live in Gateshead and Northumberland. Going forward, we're planning to set up more 'spoke' clinics in strategic locations.

Don't be a 'no show' - please let us know!

On average, **30 patients** don't turn up for their appointments every month. If you cannot attend please let us know in advance, as these appointments would benefit others. This also applies to our Patient Education Programme. The sessions are currently fully booked but not everyone is turning up. As you can understand, this is unfair on other patients who are not able to access this service currently, even though there is availability. Many thanks for your support.

Patient forum... coming soon!

You will soon be able to join our new patient forum, an online resource for lymphoedema patients who are treated by staff at St Oswald's Hospice. Here you'll be able to chat to other people in similar circumstances, via a dedicated, private space on our website. More details are coming soon. In the meantime, if you would like to know more please contact Emma Wharfe at emmawharfe@stoswaldsuk.org.



New uniforms

An increasing number of patients are seen in hospital, at home, as well as at St Oswald's. Those of you who are treated in hospital are often familiar with hospital uniforms which distinguish different members of staff. To make sure you can recognise each member of staff by their uniform we have brought our uniforms in line with local hospital trusts. The following uniforms now apply to our staff members:

- Senior nurse - navy
- Nurse specialist - royal blue
- Keyworker - staff nurse uniform
- Auxiliary nurse - grey and white stripe

Northern Lymphoedema Support Group (NLSG)

The Northern Lymphoedema Support Network is a friendly group of people who all suffer from or are involved with lymphoedema. The group meets four times each year at St Oswald's, to exchange support and information, listen to speakers and ask questions to members of the Hospice's Lymphoedema Team.

The meetings are held in Day Hospice from **2.00pm - 4.00pm**. Future meeting dates are as follows:

- Saturday 19th September
- Saturday 12th December (**please note that this meeting will be held at 11am-12.30pm, followed by Christmas lunch at 1pm**)

If you'd like to come along or find out more please contact Monica Burns at nicburns@hotmail.com or Carol Knox on 0191 236 2600. Feel free to bring along a partner or friend and spread the word to other people with lymphoedema. The NLSG newsletter is also available to pick up from Outpatient Reception.

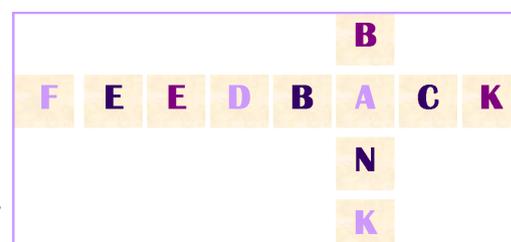
Prescription ordering

Compression garments are an essential part of the 'Long Term Control' phase of your lymphoedema treatment. A wide range of compression garments are now available on prescription, making it easier for you to obtain a long term supply.

As you have already been fitted with a compression garment in clinic which is the correct style, size and fit for you, **we may ask you to obtain any additional or replacement garments from your GP in future**. We will provide your GP with the information they need to ensure you continue to receive the correct garments.

Feedback bank

Last 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. If you've got any comments, suggestions, feedback, compliments or complaints, we'd like to hear from you. Feedback bank boxes and submission forms can be found around the Hospice, including Outpatient Reception. Alternatively, you can also email patientfeedback@stoswaldsuk.org. All feedback will be given consideration and where possible, your suggestions will be taken on board and action will be taken. 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 our Lymph-notes forms in the Outpatient Reception and pop in the return box. You can download back issues of Lymph-notes from our website at www.stoswaldsuk.org/lymph-notes/ or we can send them by email or post.