

St Oswald's Hospice Lymphoedema Service

Patient Information



we care

we campaign

we educate

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This leaflet is available in a range of formats. Please ask a member of staff if you require a different format. Thank you.

...welcome to St Oswald's Hospice Lymphoedema Service

We've put this booklet together to let you know what goes on at the Lymphoedema Service, who you might meet and other important information.

About St Oswald's Lymphoedema Service

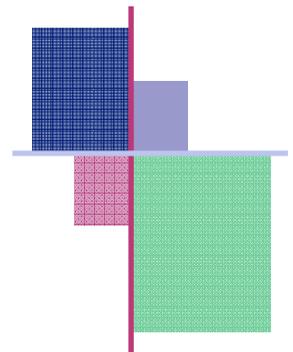
St Oswald's Lymphoedema Service is recognised as a centre of excellence and it is the largest specialist lymphoedema service provider in the North East.

The Lymphoedema Service at St Oswald's aims to offer a service to individuals with Lymphoedema, whatever the cause. We help patients to understand their condition and offer advice on how they can adapt everyday activities in order to successfully control their Lymphoedema.

We treat patients with both palliative and non-palliative care needs.

We have clinics at our main Hospice site in Gosforth, and also outreach clinics in Morpeth, Blaydon and Shiremoor. If you would like any further information about our Outreach Clinics please get in touch.

Please remember, we want you to feel as comfortable as possible during your visits so if you've any questions or comments after reading this information, please let us know.



Your first appointment

Prior to your first appointment, you might have a few questions about what to expect. Hopefully this booklet will answer them but if you have any questions please contact the service on 0191 246 9050.

What to wear

Please ensure you wear loose clothing to your appointment. You may be required to undress during your appointment depending on your treatment, so please wear suitable underwear. Also, depending on the area you require treatment you may also not be able to wear certain footwear when leaving the Lymphoedema Clinic.

Bringing someone with you

During your appointments at St Oswald's, we want to make sure you feel as comfortable as possible. Because of this, we'd like to remind you that you are welcome to bring a friend or family member with you to any of your lymphoedema appointments. Please also note that there may be particular occasions when we need to examine the area affected, and if you would like someone present during the examination please make your lymphoedema clinician aware.

During your appointment

Your appointment will take place in our Outpatient Suite. Please tell the Appointment Clerk on the reception desk when you arrive so that they can sign you in.

Your initial visit to the Lymphoedema clinic will take approximately 60 minutes, or 90 minutes, depending on whether you're seeing a Keyworker or Specialist (as outlined in your appointment letter). During this time we will obtain a full history from you to ensure that you receive the appropriate treatment. You will also receive information about your swelling and risk reduction/prevention advice.

Measurements will be taken of the affected limb(s), either manually or using a device called a perometer. A perometer is an infrared measuring device used to measure limb volumes. The perometer frame runs along a rail and moves up and down your arm or leg and measurements are recorded electronically. A perometer is quick and easy to use and allows us to accurately compare your measurements over time.

We will then be able to advise on the four elements that make up the treatment of Lymphoedema management; **skin care, massage, exercise and compression garments.**

Patient education programme

You may be invited to attend a five week education programme designed to equip you with the knowledge and skills to be able to self-manage your condition. Being able to manage your own condition can improve wellbeing, increase independence and improve quality of life. To find out more about the programme please ask a member of the team.

During your appointments

Our clinical team will make an assessment and plan a programme of treatment with you at your appointments. We're happy for relatives, carers or friends to be present if you wish.

All information shared with the clinical team will be treated in the strictest confidence (see 'Data Protection' on page 9). Other professionals, outside of the Hospice, who have previously been involved in your care or may be in the future, are considered to be part of the clinical team caring for you. When planning your care the clinical team will work with you, your family and carers and your community support (if you have any), to ensure you receive the support you need.

Sometimes we may need to share information with other healthcare professionals at St Oswald's, and also those external to the Hospice. In this instance, we will always ask you if we have your consent to do so and whether you would like to be sent a copy of this information.

Cancelling your appointment

If you are unable to attend an appointment please contact the Outpatients Department on 0191 246 9050 as soon as possible, giving at least 48 hours notice so that your appointment can be allocated to another patient. Due to the high level of demand for our services, if you fail to attend two appointments without advance warning you will be discharged from our care.

Contact us

The Lymphoedema Service direct telephone number is 0191 246 9050.

The Outpatient Suite is open Monday to Friday between 9.00am and 4.30pm.

If you have any concerns or queries please don't hesitate to get in touch on the above telephone number. Messages can be left on our voicemail if no one is available to take your call. We will always get back to you.

Our team

Kath Clark, Day Services Manager

Kath manages all Day Services, which includes Day Hospice, Focus on Living and Complementary Therapy as well as the Lymphoedema Service. Kath is also a Lymphoedema Nurse Specialist.

In addition to Kath, all of our practitioners are qualified healthcare professionals who have undergone specialist training. At your appointment you will be seen by a Keyworker or Specialist and we will ensure that you see the right person at the right time for your treatment.



The wider care team

As well as our Lymphoedema Service, our Day Services incorporates a Day Hospice, complementary therapies and Focus on Living.

We also have an Inpatient Ward and a Children and Young Adults Service.

Our multi-disciplinary team includes:

Nurses, auxiliary nurses, social workers, complementary therapists, chaplaincy, occupational therapists and physiotherapists.

If you'd like more information about any of the other services above, please pick up a leaflet in reception, let us know or visit our website; www.stoswaldsuk.org

Volunteers

We have over 1400 volunteers at St Oswald's who donate their time and skills to support staff in almost every aspect of our work.

Some volunteers work directly with patients, others provide crucial support behind the scenes or in our shops.

Without the support of our volunteers, we simply could not provide all our vital services to local people.

The role of our Lymphoedema Service Volunteers

Lymphoedema volunteers work directly with patients. They are trained to work alongside staff to ensure that a high standard of individual care is provided.

You will see lots of volunteers during your visits to St Oswald's. Their role is varied and can include meeting and accompanying patients to treatment rooms, assisting the team in gaining and recording your information, as well as other tasks such as removal of bandages and washing and moisturising limbs. They can also help in removal/ application of compression hosiery and recording limb volume, height and weight measurements.

When our volunteers are not required for direct patient care, they assist the team by carrying out tasks such as answering the phone, photocopying, collecting patient notes and checking stock.

If you do not wish a volunteer to be in clinic during your appointment please speak to a member of the team.

Important information

Health and safety

We are committed to ensuring the health and safety and welfare of everyone who use our facilities, so far as is reasonably possible. We also fully accept our responsibility for other persons who may be affected by our activities.

If you have any concerns or identify anything you feel maybe a risk to anyone, please let us know as soon as you can.

Should you have an accident or experience a 'near miss' whilst at St Oswald's, however small or insignificant you feel it might be, please speak to your nurse who will follow this up for you.

Infection control

St Oswald's recognises the importance of infection control and uses standard precautions in tackling the spread of infection.

We have a number of information leaflets available which detail the most common infections, how to deal with them and help prevent he viruses spreading. If you would like any of these leaflets, please speak to your nurse.

One of the main ways we can all help to stop the spread of infection is by regular and thorough hand washing. Washing our hands can prevent over 45% of infections from spreading. To ensure we wash our hands as thoroughly as possible, there is a step-by-step guide next to every sink in St Oswald's.

Please note that if you have experienced any symptoms of diarrhoea and vomiting within 48 hours of your appointment we ask that you stay at home and re-arrange.

We would ask that all visitors use alcohol gel when they enter and leave the Hospice. Many thanks.

Important information

Safe and sound

For all of our security, CCTV and controlled access protect the building 24 hours a day.

Data protection

St Oswald's safeguards your personal information in line with the Data Protection Act 1998. As well as adhering to our Information Governance Policy & Procedure, our staff and volunteers must also follow our Confidentiality Policy and Information Management & Security Policy. In doing so, we ensure that we can keep your personal information safe and secure.

We keep information about you in both paper and electronic format. This includes information from your health records and other personal information.

There may be occasions where we need to share your details with colleagues in other health care settings, like your GP or Community Nurse, as part of our collective commitment to your care. Whilst it's vital that those concerned with your care have access to the information that they need, it's also important that you and your carers can trust that personal information will be kept confidential and that your privacy is respected. If we need to share information, we will always ask for your consent to do so and whether you would like to be sent a copy of anything sent to other healthcare professionals.

If you'd like to obtain a copy of any of our data protection policies, have a query about how we protect your personal data, or would like a copy of the personal data that we hold on you, please speak to your nurse.

If you would rather we kept your personal information strictly private, again please let us know.

Accessing your information

You have a legal right to apply for access to health information or other personal data held about you. If you'd like to access your health records or personal data held by St Oswald's, you must do so in writing using our request form and send it to Helen Eadington, our Corporate Services Director, at the address on the back of this leaflet.

A formal process – outlined in our Information Governance Policy – is then followed. Under the Data Protection Act, requests for access to records should be met within 40 days. However, as per our policy, we aim to respond within 21 days where possible.

What other people say about us

Below are some quotes from patients. We thought you might like to hear from them what they think:

"I feel part of the family at St Oswald's. They question me. Reassure me. Give me encouragement to go to my consultant and put my mind at rest."

"St Oswald's and the clinic at the Shiremoor Centre have helped me to manage a lot of my symptoms myself. They've taught me about skincare, exercise, simple lymphatic drainage and compression garments. I'm extremely grateful to the Hospice for the treatment, support and advice that I receive. Having such an amazing support network is fantastic."

"If it wasn't for St Oswald's my whole lifestyle would be completely different, I wouldn't be able to work, drive or even do the little things for myself, like dry my hair or put on my makeup. To me, what St Oswald's provides is crucial, they offer so many different services to so many different people, and always with a smile!"

Comments and suggestions

We are committed to providing quality services and are constantly seeking ways to improve the care offered to you, your family, carer and friends. Any suggestions or comments as to how we could improve our services are very welcome.

Feedback boxes are located in Reception, Day Services and the Smoking Room. Please complete the appropriate slip with your comments and suggestions. All comments and suggestions are given consideration and if possible the suggested improvements will be made. We acknowledge all identifiable suggestions.

Your opinion matters

From time to time we carry out patient surveys and gather feedback. This is to make sure we are providing relevant and quality services for you and to comply with Care Quality Commission standards.

If you are asked for feedback, although it is not compulsory to take part, we would be very grateful if you could take the time to give us your honest feedback and comments.

Complaints

Sometimes when you try to complain to an organisation, it feels as though you're talking to a brick wall. But at St Oswald's, we always welcome your feedback. We hope that you will not have cause for complaint but if you're unhappy with something, then please make sure you let a member of staff know. We'll always do our best to solve any problems or issues that you might have.

However, if you are not satisfied with this response, a formal written complaint should be made to our Chief Executive. We have a formal complaints policy which will be followed in the case of all written complaints. A copy of the policy is available from a member of the nursing team.

Contacts

To make a formal complaint, please contact:

The Chief Executive
St Oswald's Hospice
Regent Avenue
Gosforth
Newcastle upon Tyne
NE3 1EE

Tel - 0191 285 0063

Email - enquiries@stoswaldsuk.org

Or alternatively:

Care Quality Commission
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

National Contact Centre Tel - 0300 061 6161

Email - enquiries@cqc.org.uk

Website - www.cqc.org.uk

Lymphoedema Service aims

What are we here for?

- To help people with lymphoedema to live a normal life
- To help people with lymphoedema to live an independent life
- To help people live with lymphoedema as part of who they are

What do we do?

- We put the lymphoedema patient at the centre of what we do
- We follow a holistic approach, ensuring we address not just a patient's physical symptoms, but their psychological and emotional needs too
- We understand, we listen, we support, we educate, we collaborate, and we care.

Vision 2025 strategic objectives

We have set out our strategic objectives and key actions for the organisation, for the next 10 years, which we are currently working towards. The actions have been branded our 'Vision 2025' as we aim to action them within 10 years.

Our actions:

- Develop expertise and capacity in life-limiting conditions
- Expand the children's hospice and facilitate independent living for young adults
- Develop more formal alliances with other local hospices in order to increase access to high quality care
- Lead on the development of a North East palliative care education centre
- Develop a dedicated Family Support Centre for carers and bereaved families
- Place our Lymphoedema Service on a sound commercial footing with a community-based network of provision

Extra information and support

Northern Lymphoedema Support Group (NLSG)

The NLSG hold their meetings at St Oswald's. If you'd like to come along or find out more please contact Julie on 01434 394855 or Carol on 0191 236 2600.

Lymph-notes

St Oswald's dedicated newsletter for patients lymphoedema. It's available to download from our website, pick up in the Outpatient Suite and via email. If you would like to be added to our mailing list to receive a copy please email patientfeedback@stoswaldsuk.org

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

You can follow the Lymphoedema Support Network at @lymphsupport or St Oswald's @stoswaldsuk.

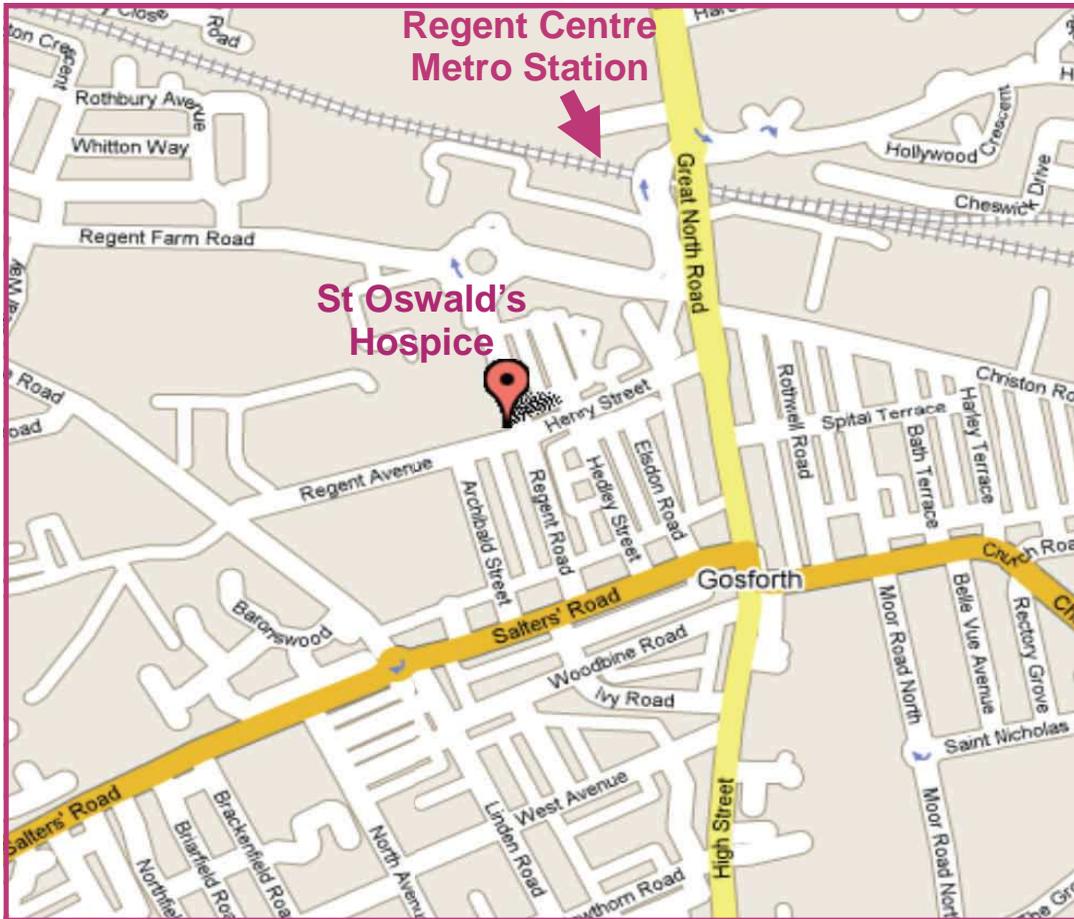
Thank you

Thank you for taking the time to read this information. If you have any questions please ask a member of the team.

There is a series of leaflets produced in-house and by the Lymphoedema Support Network available in the Outpatient Suite waiting area, for your perusal.

There is also a Patient Information Hub within the Adult Services section of our website. This includes downloadable copies of all St Oswald's produced leaflets. Visit www.stoswaldsuk.org/adults

How to find us



St Oswald's Hospice, Regent Avenue, Gosforth
Newcastle upon Tyne, NE3 1EE

Please use the Children's Service and Adults Day Services (West) entrance on arrival to the Hospice. The Outpatient Suite is past the Children's Service, at the end of the car park.

Limited parking is available in our free car park and we are easily accessible by the Metro and buses.

If you would like to know more about our work,
please visit our website:

www.stoswaldsuk.org

Find us on:



We are a registered charity and rely on voluntary
donations and legacies to enable us to care for
patients and families.

This leaflet can be made available in a range of formats on request.
Please ask a member of our team if you require a different format.
Thank you.

St Oswald's Hospice, Regent Avenue, Gosforth, Newcastle upon Tyne NE3 1EE

Lymphoedema Service Tel: 0191 246 9050

Fax: 0191 246 9052

Main Reception: 0191 285 0063

E-mail: enquiries@stoswaldsuk.org

Registered Charity No. 503386

