

Information and Advice on the Lymphoedema Service

You have been referred to the local Lymphoedema Service and have a booked appointment with a therapist. This information sheet will provide you with details as to what to expect and advice about your condition.

The Lymphoedema Service sees people who have swelling in any part of their body that has been present for longer than three months. You may also have been referred to the Lymphoedema Service if you have lipalgia syndrome (lipoedema) which is fatty and/or painful legs. During your appointment we will be able to assess whether you have any lymphoedema or if you are at risk of developing it. If you do not have lymphoedema, we can provide you with information to reduce the risk, but will not formally arrange to see you again. However, if you do need us you can just contact us for an appointment. If you have lymphoedema then together we will plan the best treatment for you.

Most patients who are referred to us will initially have a 30-minute virtual assessment over the phone or Video Call. This initial assessment allows us to understand what your problems are and we can then arrange to see you in person in the local service. A few patients may not need the initial virtual discussion and will just have a face to face appointment in the clinic instead. A clinic appointment usually last for around one hour. Before attending either appointment you will be sent a link electronically or on paper for LYMPROM[®]

What is LYMPROM[®]?

LYMPROM[®] is a Patient Reported Outcome Measure (PROM) for you to tell us the impact lymphoedema is having on your physical, mental and emotional health. Please complete LYMPROM[®], as it will really help us to understand your needs and plan your care.

How do I access LYMPROM[®]?

Most of the Lymphoedema Services in Wales are using digital access to LYMPROM[®]. What this means is you will receive an automated text via your mobile phone or an e-mail with a link to complete LYMPROM[®]. The notification will be sent from your local NHS service and is trustworthy. When you log in you will be asked for your surname, date of birth and postcode. You will never be asked for your bank details. You might find that you have to use a text code (sent to your mobile / landline) to verify your account the first time you login. You will receive these link

two weeks before an appointment. If you don't complete the link, you will also be sent a reminder message. If you cannot complete this yourself, maybe you could ask a relative or friend to help or we could send you a paper copy or ask you the questions over the phone.

What information is needed for my appointment?

It is helpful to get some information ready before your appointment:

- Have a **list of the medication** you take. This could be your repeat prescription list or you could write down what you take, when and how much.
- Think about, and even write down, some of your **past medical / health history**.
- If you already have any **compression garments**, let us know what type and wear or bring them with you.
- If you have any wounds or ulcers, please remember to bring the **bandages / dressings** with you, if you have them as we may not have your specific ones in stock.
- If you have completed **LYMPROM**® on paper, please bring that with you too.

So what happens at an assessment?

The therapist will ask you lots of questions about your health, wellbeing, your skin and body and of course the swelling. Things like what makes the swelling worse? Does anything make it better? When seen in-person, the therapist will also record more information and will measure your lymphoedema using a tape measure or different machines. We will always measure the affected lymphoedema and the unaffected side. We always take your weight and height too. The therapist will explain what lymphoedema is and tell you if you have any swelling in your body offering individual treatment plans and advice to help you. If you do not have any lymphoedema we will not formally arrange to see you again unless you contact us in the future. All Lymphoedema Services attempt to see patients on time so please don't be late.

What do I do if the appointment is not suitable?

If the appointment is not suitable, or you no longer wish to be seen, please let us know so we can give that appointment to someone else. Ring us leaving a message on the answer phone or email and we can rearrange the appointment for you if needed.

What will happen after my appointment?

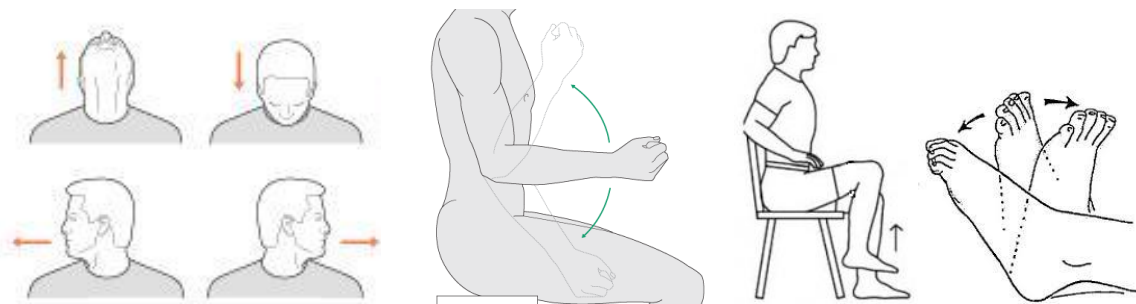
If you have Lymphoedema, the therapist will give you advice and together you can agree how best to manage your lymphoedema. Follow-up appointments might be in clinic or virtually (telephone or video). You should complete LYMPROM[®] ahead of each follow-up appointment so that your therapist can continue to plan and review your care based on what's most important to you. When you feel ready we may transfer your care to PIFU (Patient Initiated Follow Up). This means you can contact us when you need to be seen again if things change or you need new compression garments.

How can I let you know about my appointment experience?



After your appointment you may receive another link so you can provide feedback on your experience. Lymphoedema Services in Wales use an experience/ satisfaction survey called LYMPREM[®]. Your feedback is so important to us to help make sure that our standards of care meet your expectations as patients. You will also get a reminder to complete LYMPREM[®].

My appointment is not for a few weeks what can I do now?

1. It is helpful to keep your skin healthy by washing, drying and moisturising your skin every day. You can use any cream, as long as it does not irritate your skin and you are not allergic to it. Keeping your skin clean and well moisturised reduces the risk of a skin infection called cellulitis.
2. It is really good to keep active and moving. Even if you find it hard to walk or get around there are exercises to suit you. For example, stretching or moving whilst sitting:



3. If you have lymphoedema in your legs, then make sure that you do sleep in a bed so that the effects of gravity can be reduced. Even when sitting in the chair remember to put your legs on a stool if you can.
4. Lymphoedema Wales Clinical Network have also produced some films about Lymphoedema. The films are only a couple of minutes long and can be watched on any device (mobile phone, computer, tablet or laptop) that has internet connection. The easiest way to watch the films is to use a smart phone or camera on your tablet to picture the QR codes and a link will appear to watch the films. Or you can copy the links below onto an internet page: we have English and Welsh versions.

English: www.medic.video/n-lymph-edu 	Welsh: www.medic.video/cy-lymph-edu 
--	--

There are lots of different films to watch but a great one to start off is...

What is lymphoedema? and the ***Skincare*** one.

It may be useful to watch the films before your appointment, but please remember this is optional. You can always watch them after your appointment and share them with your family too.

The use of data to improve services

Under the General Data Protection Regulation (GDPR) and the Data Protection Act your health and care information will be held securely and confidentially in line with regulations. The Data Protection Officer within your local Health Board can provide more information on this.

Service evaluation and clinical audits are frequently undertaken within our Health Boards to ensure patients receive the highest quality of care and support continual improvement. This is only undertaken by those who have permission to access your Lymphoedema notes through the normal legal and ethical processes of data protection. Your information is kept securely following Health Board Information Governance guidance. If you would like further information about audit please contact: Lymphoedema.Network.Wales@wales.nhs.uk