

What to Expect from the Lymphoedema Service

A Guide for Patients and their Carers

Patient Information Leaflet

This leaflet is to help you understand what to expect from the Lymphoedema Service. You have been referred because it is thought you have lymphoedema or some other form of chronic swelling.

What is lymphoedema?

Lymphoedema is a collection of fluid causing swelling anywhere on the body but is mainly in the arms and legs. It is usually caused as a result of cancer or treatment for cancer, such as surgery or radiotherapy but people who do not have cancer can get lymphoedema. Some are born with the condition or develop it later in life due to the lymphatic system not developing properly. It can develop if recurrent cellulitis or vascular problems are present, following trauma from accidents or surgery or when a person's movement is limited in conditions such as multiple sclerosis, stroke or in the elderly. It is a condition that cannot usually be cured but can be treated.

What happens at the first appointment?

The first appointment will take about one hour and you will be seen by one of the clinical staff. The assessment will take place in a private room and all information is confidential and only shared with other health care professionals with your permission.

The clinical staff will take a medical history which includes past operations and illnesses, current treatments, medicines or tablets you are taking as well as a history of the swelling and any investigations you have had. An examination of the swollen area is necessary so it is better to dress in clothing and footwear that is easily removed.

The assessment may include using a tape measure to measure the limbs which gives an idea of the amount of swelling present. It is usually possible to give a diagnosis of lymphoedema or chronic oedema at the first appointment; although for some other investigations are necessary first.

A diagnosis of lymphoedema can sometimes be upsetting, therefore having a family member or close friend with you can help. However for some people a diagnosis of lymphoedema can be a relief especially if you have had the swelling for a long time without treatment and you may feel at last something is being done.

Treatment

Treatment is mainly a self-care programme involving skin care promoting hygiene to reduce the risk of infection; exercise to propel lymph fluid and improve mobility; massage to enhance drainage and compression, usually in the form of stockings and arm sleeves. Treatment may also include a course of bandaging and manual lymphatic drainage if required.

The advice given will depend very much on how much swelling there is, the condition of your skin and how you are feeling at the time. Your help will be needed to complete the care plan with time allowed for you and your family or carer to ask questions.

The lymphoedema team work closely with other health care professionals, such as your GP or district nurse, so will usually let them know what is happening to you when you attend the clinic.

Follow Up

An appointment will normally be made for you to be seen again at an appropriate time. Re-assessment enables everyone to know if the treatment plan is working and for any changes to be discussed.

Discharge

You will be discharged from the service when your swelling is controlled and you have the appropriate treatment plan in place. If discharged you can return to the service again at any time if you have further problems.

What we expect from you

Appointments

Appointments are arranged as much as possible to fit in with work or family commitments. It is important to keep your appointments and to turn up on time as this helps the smooth running of the clinics. If you know you have another commitment at the same time as your lymphoedema appointment it is important to ring and let us know as soon as possible or at least 24 hours before the appointment is due so we can give this time to someone else. Patients who regularly fail to turn up for appointments will be discharged from the service.

It is always necessary to let us know of any changes you have made to your care plan at your follow up as this may affect the way your lymphoedema is controlled. Your appointment can always be brought forward so please let us know if your swelling is getting out of control and you want to be seen sooner.

Transport

You may qualify for hospital transport if you have difficulty accessing clinics and are unable to use public transport. This can be arranged by contacting the Administrators.

Home Visits

Home visits are available if you do not go out at all.

Useful contacts

The Lymphoedema Office, Airedale Hospital
01535 292712

Lymphoedema Support Network

020 7351 4480

www.lymphoedema.org

Should you have any further questions or require further advice, please contact the lymphoedema service on 01535 292712

Write down any questions you may wish to ask:

If you require this leaflet in other languages or formats please telephone the Patient Advice and Liaison Service (PALS) on: 01535 294019 for advice.

Please raise any issue you may have about your care and treatment with a member of staff. Raising your concerns will not adversely affect the care you will receive.

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