

Welcome to the Lymphoedema Unit!

What is lymphoedema?

“What exactly is lymphoedema?” is a question that we are frequently asked by both caregivers and patients.

Lymphoedema involves an accumulation of lymphatic fluid and can be:

Primary lymphoedema as the result of a congenital defect in the lymphatic system

Secondary lymphoedema as the result of damaged lymph system, usually following treatments for cancer.

What does it mean to have lymphoedema?

Lymphoedema occurs most frequently in arms or legs and can result in reduced physical and psychosocial functioning in daily life. The swelling may give the patient difficulties with feelings of heaviness and strain, reduced mobility, negative sensitivity to physical contact of the affected area and, sometimes, pain.

The swelling can even increase the risk of erysipelas, sometimes referred to as “Holy Fire” or “St. Anthony’s Fire”. Erysipelas is an acute streptococcus bacterial infection.

For illustrating pictures, please look at the Swedish version.

Lymphoedema Unit

What We Do

We rehabilitate patients with lymph edema.

Our clinic treats patients of every age from across the entire country. Rehabilitation is given in periods of two to three weeks, in the form of daily ambulant care or weekly in-patient care. We also accept patients in need of occasional outpatient care.

Before treatment begins, our doctor examines the patient. Thereafter, in cooperation with the patient, an individual rehabilitation program is created. If the cause of the edema is unclear, the clinic's doctor contacts the referring doctor for a further examination to determine the underlying causes of the edema.

Children and Youth Weeks

One of our rehabilitation periods is focused on children and youth. During this time our activities become a forum for meetings with others. Families are invited to participate in information sessions and special activities. Treatments and group activities are intended to stimulate the patients to discover the right balance for them between exertion and rest. We try to vary our program and to surprise the participants in the selection of our training activities.

Rehabilitation Team

Doctor: The doctor has the medical responsibility regarding judgments of necessary rehabilitation, determination of a diagnosis and, when required, the issuance of a detailed report in cooperation with the doctor who referred the patient to Red Cross.

Lymph Therapist: The lymph therapist increases the flow of the lymph system with the help of manual lymph drainage and tests various compression materials, as well as instructing in self-care lymph system stimulation procedures.

Occupational Therapist: The occupational therapist does an individual assessment to determine how lymph edema impacts the individual's daily life, instructs and gives advice on how to carry out daily activities and shares information regarding adjustments for the person's environment and the availability of various tools and implements necessitated by the individual's lymph edema.

Physiotherapist: The physiotherapist determines the strength, mobility and functionality of the individual, as well as treating individuals and working with groups teaching the use of lymph stimulation methods created by exercise and breathing.

Head Nurse: The head nurse has responsibility for planning an individual's intensive rehabilitation as well as for giving advice and support in questions related to nursing care.

Assistant Nurse: The assistant nurse is responsible for the teaching of bandaging techniques, treatments involving the pulsator (also known as a pneumatic pump), as well as giving advice and support in issues of self-care.

Secretary: The secretary is responsible for booking doctor's visits and for the management of the patient's casebook.

Goals and Rehabilitation Methods

Goal

Our goal is to meet every individual with respect for them and for the current circumstances of their lives.

Rehabilitation

The purpose of rehabilitation is to reduce the lymphoedema and to create an opportunity for patients to participate in their own rehabilitation. We strive to share essential information, both practical and theoretic, so that the patient has the possibility to preserve their quality of life even with the challenges of lymph edema.

Our treatment makes use of complex decongestive physiotherapy (CDP), which includes manual lymph drainage followed by compression bandaging, as well as therapeutic physical training and skin care. Beyond this, patients participate in both individual and group education sessions and trainings.

The evaluation and assessment instruments that we use are presented under each respective area of rehabilitation.

In order to better our work and to maintain its quality, we request each participant, including both live-in and ambulant patients, to complete an anonymous evaluation form.

Manual Lymph Drainage

Manual lymph drainage is a special massage technique that stimulates the flow of lymphatic fluid and moves it from the swollen, non-functioning, part of the body to a functioning part of the bodies' lymph system. This, with the combination of a warm and relaxed environment, also creates a relaxation of the muscles and often causes a reduction of pain.

The effects of the lymph drainage, as well as results of the other forms of treatment, are controlled by the lymph therapist by measuring the affected areas through a special technique known as "Kuhnke".

The Lymph Therapists Massage Technique

Lymph drainage is a combination of various grips and movements with varied pressures that are used depending upon which type of lymph edema and tissue structure you have.

Light pressure and grips primarily affect the outer lymph system, while stronger pressure and grips affect the deeper lymph system.

Many experience a feeling of exhaustion following a treatment, especially in the first few days.

What you can do for yourself

By learning to do lymph massage for yourself, you will create a valuable tool to stimulate the flow of your own lymph system and to keep the edema soft and to thereby reduce, and perhaps even prevent, an aggressive progression of this chronic disability.

Create time to do your own massage and make it into a daily habit!

You may even receive help in teaching family members or friends who are willing to attempt using lymph drainage.

Pulsator

Compression treatment using the pulsator is a complementary additional treatment that is prescribed by the doctor.

The pulsator gives compression through the use of air pressure according to a program which can be adjusted for both pressure and time intervals.

Edema in the arm is treated by the use of a specially designed jacket, while edema in the leg is treated through the use of specially designed trousers or boots.

Testing of the appropriate designed pulsator clothing occurs during outpatient visits or during a rehabilitation period.

When a specialist in lymphoedema has prescribed use of the pulsator, it is even possible to receive treatments at home. (Note: This is possible only in the county of Stockholm, i.e. Stockholms län.)

Skin Care

Lymphoedema's swelling stretches the skin, which leads to the skin becoming thinner and less elastic.

Dry skin, eczema, athlete's foot, and even small sores, create gateways for bacteria to enter the body.

Their reduced immunity may cause a lymphoedema patient to be especially vulnerable to the skin disease "St. Anthony's Fire" – erysipelas – with sudden symptoms of chills, high fever, headache, vomiting, and the experience of overall illness. The skin becomes even more swollen, tender, red and increasingly hot.

What you can do for yourself

It is important to provide your skin with both lubrication and moisture.

You should lubricate your skin at least once every day in order to keep it as soft and flexible as possible.

If you believe that you have been smitten with erysipelas, contact your local or emergency clinic as soon as possible!

Compression

In order to increase pressure to the tissues, compression is required which counteracts the possibility that the enlarged lymphatic vessels leak lymph fluid, fat and protein out into the tissue. Even the veins' circulation is made easier by compression.

Compression Garments

Every stage of lymph edema requires a compression garment. In the case of a minimal edema that only gives a feeling of slight strain, or a swelling that occurs only after some sort of effort, it is possible that a low compression garment is adequate.

When the edema is more substantial and where tissues have become non-elastic or hard, garments measured after your own precise measurements and with a higher grade of compression, are required. Compression garments can be provided for every body part.

What you can do for yourself

Use compression garments with the correct fit every day.

To insure that compression garments maintain the correct fit and level of compression, it is important to care for them according to the directions delivered with the garments and to re-new them every six months.

Bandaging

Compression may even be achieved through bandaging.

Techniques of bandaging are taught and practiced during rehabilitation periods and are adjusted to each individual's personal requirements. Bandaging extends the effects of manual lymph drainage.

Prior to bandaging, the effected area is padded in order to increase the effectiveness of the bandaging. The bandages themselves are made of low- elastic, 100%, cotton.

What you can do for yourself

By learning the bandaging procedure for yourself, you may use it as a part of your own self-care. Attempt to create a routine which suites your life-style, so that bandaging becomes a regular part of your own self-care process.

Be sure to bandage each time you have received manual lymph drainage and during any physical exercise.

You may even request help in teaching family members or friends to assist you with the bandaging process.

Physiotherapy

Moderate methods of physical training, such as strength and condition training, water gymnastics and Nordic walking are offered during each rehabilitation period.

There is also a focus on the importance of rest through group sessions in the use of relaxation techniques and deep breathing.

Our goal is to increase the flow of lymph fluid and to maintain the strength and balance of the patient's body.

Water Gymnastics

Water pressure influences the flow of lymph fluid positively, while the comfortable 33-degree water temperature also contributes to an increase in mobility and can also assist in reducing pain. Only a handful of patients experience any discomfort related to the warmth of the water.

The day begins with group water gymnastics a few mornings each week.

Relaxation and Breathing Techniques

The ability to relax to and to recuperate is an important part of rehabilitation.

Deep breathing supports circulation in the veins, influences lymph circulation and brings peaceful relaxation.

Strength and Condition Training

The lymph system responds positively to light strength and conditioning exercise. This training takes place both in the presence of a physiotherapist and on the patient's own time.

Nordic Walking

Nordic Walking was originally referred to as "ski-walking" because it is done with poles similar to ski poles. Nordic Walking is a safe form of motion that increases condition and endurance. It also contributes to increased circulation and better mobility in and shoulders and neck.

Occupational Therapy

Lymphoedema can entail a reduced ability to function well in daily life. It can lead to problems in handling personal care and hygiene, as well as activities in the home, at work or during leisure time.

The purpose of occupational therapy is to increase your consciousness regarding how the patterns of your daily activities and your symptoms influence each other.

The goal is to achieve a balance between exertion and rest, where you experience the minimal impact of your symptoms.

We can measure this through the use of a self-estimate instrument, COPM, the Canadian Occupational Performance Measure.

Adaptation of Equipment

The putting-on and removal of compression garments can be made easier through the use of various tools and aids.

Plastic gloves give a better grip and make it easier to draw on and to adjust the compression garment. That compression garments sit comfortably is essential for a well-functioning compression.

The photograph demonstrates a more complex tool useful for arm compression garments.

Shoes and clothing may also need to be adjusted to your special needs and sometimes this may be achieved through use of your own ingenuity. Here is a photograph of a pair of rubber boots that have been adapted by a private individual so that the swelling in this persons' legs and feet does not have to be experienced as a limit.

The availability of tools that have a good ergonomic form has increased. We know that your symptoms can involve the adaptation or replacement of implements, equipment or the ways in which you work and that this requires time for training and practice so that they will function for you. We show and demonstrate the use of different types or products and support tools and aids. Following approval, some of these aids or tools can be given out during a rehabilitation period.

Adaptation of the Environment

Sometimes it is necessary to make adjustments at work or at home. We can give advice on solutions and act as an intermediary with companies that have appropriate products and services. The District Occupational Therapist works in cooperation with us to make visits to your home in order to determine the necessity of more thorough adjustments and measures that may be required there.

During a rehabilitation period, we provide opportunities for you to test less extreme adaptations or adjustments. These may include, for example, changing how one sits in order to open the angle of the pelvis which encourages better posture and which facilitates both breathing and the flow of the lymphatic system.

Group meetings provide the opportunity to share experiences with one another. They even create possibilities for you to give a brief description of your own specific needs.

Medicinal Care

Diagnose

If the diagnose is unclear, suggestions are given for medical examinations with which to determine the underlying cause. This is always done in cooperation with the referring doctor and/or the patient's family doctor. It is important to rule out causes such as high blood pressure, cardiac insufficiency, kidney failure or malignant lymphoedema. A lymphoscintigraphy is done in order to map the lymph systems functionality and distribution.

Medicine

There are no medicines currently registered in Sweden that directly affect the lymph system.

In other countries, herbal remedies, such as couramin, are used to improve the functionality of the lymph system, but this is not permitted in Sweden because of the side effects it has on the liver. Likewise, diuretics have no long-term effect on lymph edema.

Antibiotics are used to combat erysipelas (St. Anthony's Fire), which is a frequent complication of lymphoedema.

Alternative Methods of Treatment

Alternative methods of treatment that may be used parallel to CDP (complex decongestive physiotherapy), have not yet been approved by the Social Administration (Socialstyrelsen). If results cannot be achieved through the use of CDP, it may be possible for additional treatments to come into question, for example, a liposuction operation.

We measure the patient's life satisfaction through the use of a questionnaire according to Fugel-Meyer, LiSat.

Letters of Referral

Patient's living in the county of Stockholm (Stockholms län), need a letter of referral either from the doctor currently treating you or from your family doctor.

For patients from other counties who are seeking attention at our facility, a letter of referral is appropriate for a first visit with our doctor in the Lymphoedema Unit.

In order to participate in a rehabilitation period, a letter of referral is required from an expert care specialist.

Patients who have medical treatment insurance need both a letter of referral and an accepted payment offer.

Patients from EU countries are required to have a valid EU medical insurance card and, for a reserved visit, a valid authorization of payment (affidavit E112) from your home country.

For more information, please contact us.

Contact Us!

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Lymphoedema Unit

Senior Physician	Ulla Steen-Zupanc	08-791 1400
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Secretary	Ingrid Bozkaya	08-791 1412

Lymph Therapists/Physiotherapists

Pia Klernäs	08-791 1423
Anna Skördåker	08-791 1420

Lymph Therapists

Ingrid Berglund	08-791 1427
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Telephone Hours

Wednesday	15:15-16:00
<i>Open</i>	
Wednesday	13:00-14:00
<i>Open</i>	

Lymph Therapist/Occupational Therapist

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Occupational Therapist

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Assistant Nurses

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Division Orderly

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History of the Lymphoedema Unit

Swedish patients with lymph edema were a forgotten patient group for a long time, simply left to live with their “swollen limbs”. At the same time, there existed the necessary qualifications abroad to receive both diagnose and treatment, particularly in the USA, Germany and France.

In Sweden, serious consideration of the problems of lymphoedema was delayed until the 1970's. At that time, this occurred through the research and clinical activities led by the division for physical medicine at the Karolinska University Hospital with economic support received from the Red Cross Hospital in Stockholm. The significance of inspiration and of the driving forces behind this evolution, including the cooperation of patients, colleagues, politicians, attention from the media and the financial support of the Cancer Fund can not be over estimated when it comes to the development of treatment for lymphoedema here in Sweden.

In 1981, associate professor Iwona Swedborg, and the rest of the entire Lymphoedema Division, moved from Karolinska University Hospital to the Red Cross Hospital in Stockholm. During the following years, there occurred further development and a successive expansion in the activities of the Lymphoedema Unit. As the map indicates, through clinical work, engagement in research, plus the arrangement of assorted lectures, courses and seminars, the Red Cross Hospital quickly became a natural focus point throughout Sweden. With Iwona Swedborg as director, the Lymphoedema Unit also received international acknowledgement.

Already by the end of the 1980's, the lymphoedema team had created a program for the treatment of women who had been operated for breast cancer – the first of its kind in Sweden. They also participated in the creation of the national treatment program that is still in effect today. In 1996, Iwona Swedborg retired. Within the next few years there was a reduction of the Lymphoedema Division. The changing conditions of their contract with the County Council of Stockholm (i.e. "Landstinget"), was one contributing factor. At the same time, many patient associations came into being. Some of these worked for an increase of support in the treatment of lymphoedema.

In October 2001, Ulla Steen-Zupanc, a specialist within rehabilitation medicine, was hired to perform a further development of the Lymphoedema Unit. Of significance for the continuation of development for the Lymphoedema Unit, was that the County Council of Stockholm reached a decision regarding the treatment of the rehabilitation of patients after being treated for cancer, and this included the treatment of lymph edema.

Even now, Iwona Swedborg continues her engagement with the Lymphoedema Unit as a medical consultant.