

# LYMPHEDEMA

## ITS CAUSE AND HOW TO MANAGE IT



**THERAPIES. HAND IN HAND.**

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Dear Patient,

Your doctor has told you that you have lymphedema. Perhaps this is the first time in your life that you have ever heard of such a condition. Or perhaps you have already heard something about it from your friends and family. Whichever is the case, you would probably like to know a lot more – what the causes are, what you can do and, above all, the extent to which it will affect your life.

To deal with the most important point first: lymphedema is a long-term condition and you will have to change your lifestyle in certain ways to cope with it. But once you make those changes, you will be able to live an almost normal life without too many restrictions.

The purpose of this information booklet, which is based on the latest medical and scientific knowledge, is to tell you more about living with lymphedema. If your own doctor or therapist suggests a slightly different approach, however, you should follow their recommendations. Only your own clinicians are familiar with your particular situation and are in a position to offer you specific advice.

We wish you all the best!

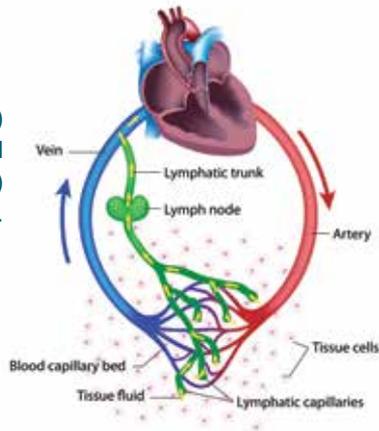
# 1. Lymphedema... which organ is actually affected?

Whenever we hear “lymph...”, most of us immediately think of lymph nodes. We know that we have them in the neck and groin, for example, and that they can become swollen when inflamed. This is certainly true, but not the whole story. The lymph nodes, which are present throughout our body (there are several hundred of them), are part of an interconnected lymphatic system.

## 1.1 The lymphatic system: structure and function

The lymphatic system is a transport system accompanying, and closely associated with, the blood circulation system in our body.

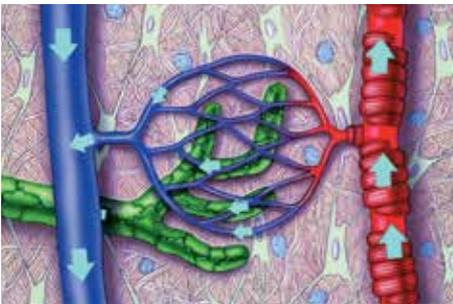
The lymphatic system (shown in green) runs closely alongside the blood circulation system with its arteries (red) and veins (blue).



- From the heart, the arteries, which are large vessels, carry oxygenated and nutritionally rich blood to the organs and tissues of the body. These vessels then branch out into a large number of very narrow vessels with porous walls (capillaries) giving away the oxygen and vitally important nutritionally rich substances. At the same time, these capillaries are absorbing debris from the surrounding tissues in addition to carrying oxygen-poor blood back to the heart. These narrow vessels, then branch again to form large vessels, called veins, which return the blood to the heart. The capillaries are permeable to allow an exchange of substances in

and out of the organs and tissues. The arteries supply the organs with blood, which is rich in oxygen and nutrients. In turn, the veins transport metabolic waste products and carbon dioxide away from the organs and tissues. Approximately 10% of the waste is left in the tissues. The transported waste materials are then excreted via the kidney and liver through the veins. The blood vessel system is therefore a closed circuit and its pump is the heart.

- The lymphatic system has a similar structure: it also has vessels and capillaries and as mentioned previously, lymph nodes at repeated intervals along the vessels. The lymphatic system, however, is only a one way circulatory system. It begins with its capillaries directly in the organs and tissues where they can absorb excess fluid and proteins. This protein-containing fluid is known as lymph fluid or lymph and – in contrast to blood– is colorless or light amber. The lymph is transported by the lymph capillaries to the large conducting vessels of the lymphatic system. These vessels finally empty into the veins at the heart, connecting the lymphatic system with the blood vessel system. The flow of lymph fluid is caused by the rhythmic pulsation of the lymph vessel walls (alternately contracting and relaxing) and the contracting and relaxing of skeletal muscles. The movement of the lymph system toward the heart depends on the motions of the muscle and joint pumps as the lymph vessels have one-way valves.

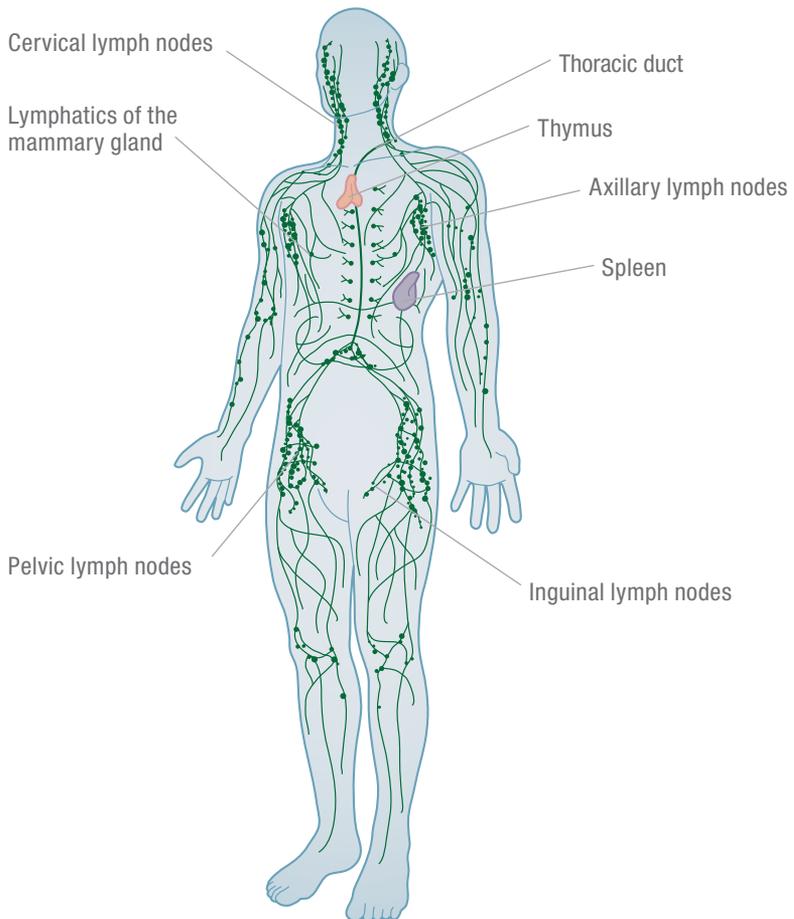


The large conducting vessels (arteries in red, veins in blue, lymph vessels in green) branch out into tiny tubes (capillaries). These are responsible for the exchange of nutrients and metabolic waste products, among other things. Lymph fluid is also produced in this region.

Therefore, both the veins and lymph vessels have the job of removing waste substances. The veins cannot do this alone as some substances can only be removed by lymph, particularly larger molecules such as proteins. The lymph capillaries have large pores to “pull” in these

substances dissolved in water. The excess absorbed water is filtered out of the lymphatic system in the lymph nodes, which then have an important regulating function. The lymphatic system has other functions, such as a role in the body's immune defense system, which will not be discussed here. Even so, it is clear that damage to the lymphatic system will mean that proteins and tissue fluid simply remain where they are in the tissues – between the cells. The resulting swelling of tissues caused by accumulation of lymph fluid is known as lymphedema.

## The Lymphatic System



## 2. Impairment of the lymphatic system and its consequences

Impairment of the lymphatic system has many different causes. Two main causes can be identified:

- **Primary Lymphedema:** The lymphatic system may be abnormal from birth. It may also develop during that person's life, when the lymph system is no longer able to cope with the demands placed on it. It is called "primary" because the cause of the impairment is found in the structure of the lymphatic system itself.
- **Secondary Lymphedema:** The lymphatic system is fully adequate and functions perfectly; however due to some external influence (such as an injury, surgery or radiation), it becomes damaged. This can adversely affect its function and can ultimately lead to secondary lymphedema.

### 2.1. Primary lymphedema

Primary lymphedema can have a variety of causes. For example, the lymph capillaries may be absent (aplasia of the initial lymph vessels); in such cases only modest amounts of lymph fluid can be produced.

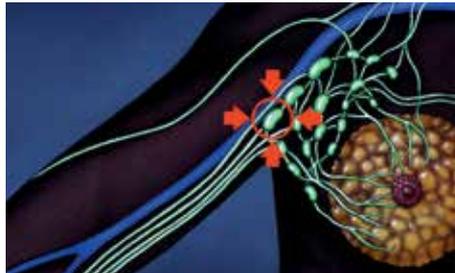
Sometimes there are simply too few lymph vessels in the body, or they are too narrow (hypoplasia). The lymph transport capacity is then insufficient to remove the accumulating lymph fluid.



Primary lymphedema is usually caused by lymph vessel malformations present from birth.

The most obvious sign of decreased lymphatic function is a swelling – lymphedema. However this does not necessarily appear immediately and may only develop gradually due to a continuous overload on those lymph vessels that are still functioning. If primary lymphedema first appears between the age of one and 35 years, doctors refer to it as Lymphedema praecox (= premature lymphedema), and if it develops after the age of 35 it is known as Lymphedema tardum (late onset lymphedema). In some cases the swelling is already apparent at birth (congenital lymphedema). Primary lymphedema may occur with an increased frequency in certain families or may develop sporadically, as a random event.

**A frequent cause of secondary lymphedema is the surgical removal of lymph nodes, e.g. from the armpits of breast cancer patients.**



## 2.2. Secondary lymphedema

Anything that injures a healthy lymphatic system can potentially result in permanent damage leading to secondary lymphedema. These harmful factors may include surgical removal or damage to lymph nodes (common cancer detection procedure) and may include radiation. Bacterial, viral, or fungal infections may further advance the lymphedema. In some tropical countries, viruses or worms can impact the lymph system, leading to lymphedema.

In the Western world, however, the most common cause is the treatment for malignant tumors. Cancer cells can migrate through the lymph vessels to the nearest lymph nodes where they form metastases. The lymph nodes in the affected area are removed to examine them for cancer cells, which will indicate future treatment, such as additional surgery, chemotherapy and/or radiation. This procedure often damages the lymphatic structures in this area, and prevents adequate lymph drainage of the vessels leading up to the area.

Radiation therapy can damage the lymph vessels, but the successful treatment of the cancer must be given precedence when deciding on the therapeutic approach.

Removing the lymph nodes means that lymph drainage is interrupted. When the lymph nodes in the armpit are removed because of breast cancer, lymph drainage from the arm is impaired. If lymph nodes in the groin are removed, drainage from the affected leg and from the genitals is impaired.

In some cases, the body finds ways of compensating for this damage to a certain extent. For example, it can stimulate existing lymph vessels to increase their performance or create connecting branches (anastomoses) to other lymph vessels or veins. However, a degree of impairment will always remain due to the fact that lymph nodes cannot be regenerated.

Depending on how well this compensatory mechanism works and the degree of stress to which the particular person's lymph system is subjected, it may be that no lymphedema occurs at all. On the other hand, lymphedema may develop either very soon after the operation, or after a delay of several years.

### 2.3. The different stages of lymphedema

We have already seen that lymphedema does not always develop overnight as the body has certain compensatory mechanisms at its disposal. Once it has started to develop, however, complicated mechanisms come into play which cause the lymphedema to progress over a period of time. The accumulation of protein-rich fluid in the tissues causes cells to be activated that produce new connective tissue substance. Doctors refer to this process as fibrosis.



**Secondary arm lymphedema resulting from the removal of lymph nodes and/or radiation therapy for breast cancer.**

The processes occurring in the skin and subcutaneous tissue, in untreated lymphedema, also show certain similarities with chronic inflammation. Although not recognizable as an inflammation from outside the body, the altered conditions weaken the skin's immune defense system. As the severity of the lymphedema increases – the skin becomes more susceptible to bacterial infections such as erysipelas (cellulitis) and to fungal infections. These infections in turn affect the lymphatic system and worsen the lymphedema, setting off a vicious cycle.

The clinical stages of lymphedema are defined according to these individual developmental steps:

- Stage 0: This is the situation in which the lymphatic system is already functioning inadequately, and it is still coping – by means of compensatory mechanisms – with the lymph that is produced. No edema is present.
- Stage I: The lymphatic system is overburdened with excess lymph fluid; and a protein-rich soft swelling develops in the affected area. It can be indented by applying pressure. When the affected arm or leg is raised, the swelling reduces on its own.



**Stage I of lymphedema: the tissue is still soft; this seen during examinations when it can still be indented by applying pressure.**



**Stage II of lymphedema: excessive connective tissue has already formed and begins to harden**

- Stage II: The swelling is already characterized by the presence of excess connective tissue; fibrosis and sclerosis have developed. Indentations can only be produced by applying strong, deliberate pressure; raising the limb no longer reduces the swelling.



**Stage III of lymphedema: The skin is hardened and exhibits growths. Sometimes large bulges are present.**

- Stage III: The swelling is extreme. Skin changes are evident and is hard to the touch and may show wart-like growths. Sometimes large bulges are present (called lobules). Lobules are fluid filled and may also develop fibrosis. The risk of inflammation and infection (erysipelas/ cellulitis) is high, and the skin is vulnerable to the development of deep, poorly healing wounds.

### 3. Management of lymphedema

Because of the mechanisms described above, there is little point in simply ignoring the condition and allowing it to take its course. It will then almost inevitably become steadily worse.

The sooner you begin a suitable program of therapy, the better are your prospects of preventing disease progression and of improving your condition, and returning to a less severe stage. Stage 1 patients can sometimes manage their lymphedema with light or little compression if precautions are followed and they monitor the extremity closely.

### 3.1. Complex decongestive therapy (CDT)

Complex decongestive physiotherapy (CDT) consists of two phases. In Phase 1, the aim is to achieve the best possible result in terms of reducing the swelling. The purpose of Phase 2 is to maintain and further improve the situation with respect to any existing fibrosis and sclerosis. CDT is divided into two phases:

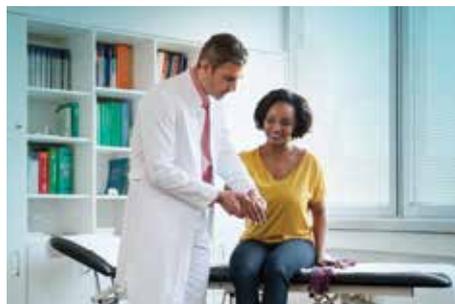
- **Phase 1 edema reduction**
- **Phase 2 maintenance**

Complex decongestive physiotherapy is a combined form of therapy, both phases consisting of four elements. All the elements have particular contributions and can only be fully effective if applied together. The four elements of CDT are:

- **Skin care**
- **Manual lymph drainage (MLD)**
- **Compression therapy**
- **Exercise therapy**

CDT Phase 1 usually takes between 2-4 weeks or less if therapy is commenced at Stage I of the illness. It can take much longer (several months) if the disease has already reached Stage III.

For a specialized physician, a clinical examination is often enough to diagnose lymphedema of the arms or legs. This should be done early on to prevent the disease progressing.

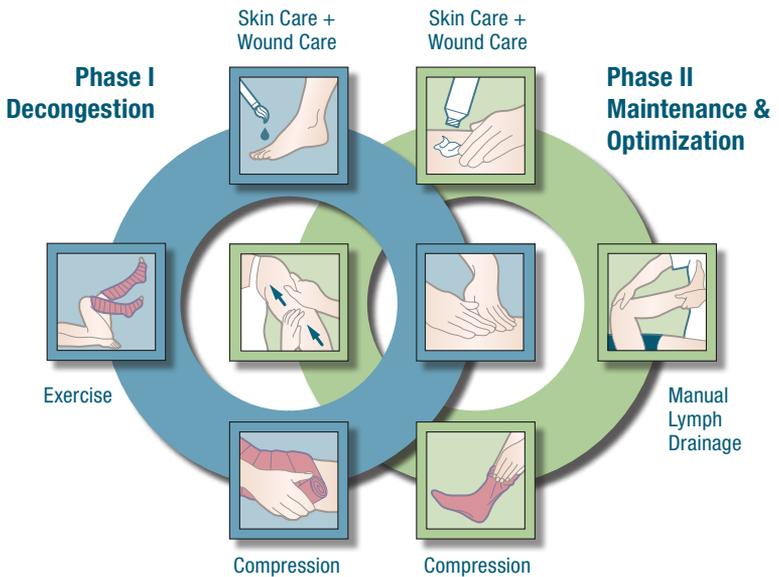


Phase 2 of CDT is usually continued indefinitely – one exception, as mentioned above, is when the condition can be returned to Stage 0.

### 3.2. The four elements of CDT

#### Skin care:

Regular protective skin care in lymphedema is essential as the skin is vulnerable to inflammations and infections. As already explained (see 2.3), infections can further aggravate the disorder. To help prevent bacteria



Complex decongestive physiotherapy consists of two phases. Phase I (blue) is devoted mainly to edema removal, phase II (green) to maintaining and further improving the therapeutic outcome.

The following measures are applied in both phases:

- Skin care
- Manual lymph drainage
- Compression therapy
- Exercise therapy

Even in severe forms of lymphedema complex decongestive therapy can provide considerable benefits (left: before, right: after).



Photo courtesy of the Norton School

from penetrating through the skin, therefore, it is important to keep the skin as intact as possible.

Skin care should be carried out twice daily, in the morning and evening. You can choose a product suitable for your personal needs in consultation with your doctor.

### **Manual lymph drainage (MLD):**

Manual lymph drainage (MLD) is performed by therapists specializing in this therapy. It should not be confused with conventional massage. The purpose of MLD is to stimulate the pulsation of the lymph vessel walls, which accelerates drainage of the lymph in the lymph vessels that are still functioning.

You may be surprised to find that your therapist starts the MLD much higher than where you see the swelling. This is because the visible lymphedema always has its cause somewhere else. You can compare it to a traffic jam where the actual cause, such as the road being blocked by an accident, is sometimes located some distance away. The problem can be

Regular protective skin care is indispensable since skin affected by lymphedema tends to develop infections and inflammations.





Manual lymph drainage can move lymph fluid from the swollen region into parts of the lymphatic system that are still functioning, from where the lymph can then be transported away.

solved by clearing the accident site or by creating a bypass, but not by attempting to push one's way forward from behind. MLD is usually performed three to five times per week, but the frequency is more dependent on the patient's stage and medical condition.

### **Compression therapy:**

Manual lymph drainage increases the flow of lymph in the still functioning lymph vessels, allowing more of the accumulated fluid to be carried away by the lymph capillaries. This process can be greatly enhanced by suitable compression therapy. This therapy has a positive influence on the pressure conditions in the tissue. Since we have not considered this aspect so far, here is a brief explanation:

The exchange of fluids between the capillaries of the blood circulation and lymphatic system and the organs, such as the skin, is dependent on differences in pressure. The direction of flow is always from the area of higher pressure to the area of lower pressure. When everything is intact, nature has provided a combination of varying vessel diameters, different protein and glucose concentrations in the fluids and special pumping mechanisms to ensure that the flow goes in the right direction. In other words, from the arteries into the tissue, and from the tissue back into the veins and lymph vessels. In lymphedema, the lymph vessels are no longer working properly and, these pressure conditions are disturbed. As a result, too much fluid accumulates in the tissue. The idea behind compression therapy, therefore, is to assist the tissue by applying pressure from outside, which allows the fluid to flow back into the lymph vessels and veins.

Depending on the severity of lymphedema, different degrees of pressure are needed for this purpose. In Phase 1 of CDT (edema reduction) compression bandages, together with padding materials, are used for compression therapy. The advantage of a compression bandage is that it can be continuously adjusted as the swelling decreases. In this phase of therapy, short-stretch materials provide optimal results.

The short-stretch bandages provide a natural resistance to the pressure exerted on the tissue during movement of the muscles. This promotes the return flow of lymph and brings about a reduction in the swelling.

In Phase 2 of CDT (maintaining and improving the result), medical compression garments are generally used.

Medical compression garments help maintain the result achieved in reducing the edema. They can be more stretchable than the bandages which makes them more pleasing to wear and allows easier application. Due to the greatly differing degrees of lymphedema, garments often have to be custom-made.

Compression garments are also available in various compression classes (compression pressures) and different styles (stockings, open or closed toe, gauntlets, arm sleeves etc.) and can thus be selected to suit individual requirements perfectly.

**In Phase 1 of the therapy a compression bandage made from low-stretch bandages is applied.**



As you and your therapist start talking about which garments might work best for you, it's good to know the basics about the different types of compression.

**Flat Knit:** Flat-knitted garments are those that are knitted on specially made machines that have a double row of needles facing each other at a 90 degree angle. The advantage of flat knitting is that exceedingly complex shapes can be knitted. These garments come out of the machine in a flat format and must be sewn together at a later stage. Once sewn together, the garments will look just like your arm or leg! Flat-knitted garments are extremely well suited for larger or unusually shaped limbs, and for those patients with stage 2 (or greater) lymphedema.

Compression garments of the Elvarex® brand have been an indispensable feature of lymphological care.

- The flat-knitted stocking is made to suit your individual sizes, ensuring the best possible fit. This is extremely important for a product that has to be worn every day, but not while sleeping.
- The unique-knit fabric prevents the stocking getting caught in skinfolds.
- Some experts believe that the special knitted fabric not only provides compression (acts as “compression aid”), but also exerts a micromassage effect when worn during exercise or movement.

**Elvarex® compression garments have proved successful in the management of lymphedema and are available in a style to suit any individual need.**



**Circular Knit:** Circular-knit garments are those that are knitted on a round cylinder. These garments are seamless and more tubular shaped vs custom garments. Circular knitted garments have a bit more stretch, and are best suited for patients with mild to moderate lymphedema with normally shaped limbs.

**Wrap / VELCRO® products:** Over the last few years, wrap products have become more and more utilized in the world of lymphedema for both phases of therapy. They should be short-stretch in nature to assist with the muscle pumping like traditional bandages. They attach with VELCRO® which makes them adjustable and easy to put on and take off. During your maintenance phase, they are highly suitable for use at night instead of bandaging. Also, there may be times when your arm or leg swells for some reason. These products are great to help get your limb back to normal size to fit back in your compression stocking or sleeve.

**Chipped foam products:** There are many different chipped foam based products on the market today. Most times you may see them being used as bandage alternatives or “night garments,” but they are also suitable for daytime use. They are very comfortable and easy to put on and take off. Because of the channels of foam designed into these garments, they can help soften up those hard fibrotic areas.

Please follow your doctor’s advice regarding the garment quality, style and compression class that are most suitable for you. As soon as you are accustomed to putting on, taking off and wearing it, you will come to value the relief provided by your compression garment.

In use, you should wear your compression garment every day for as long as you are up and about. Take the garment off at bedtime; arm sleeves may be an exception to this rule depending on what your doctor advises.

• **Exercise therapy:**

Exercise therapy is the fourth component of CDT. Compression bandages or compression garments are worn during this therapy.



Regular physical exercises promote lymph drainage.

Exercise therapy allows the compression to exert its affect to the fullest and helps drain fluid from the tissue.

You should perform your exercises as often as possible, for example two to three times a day (both in Phase 1 and in Phase 2 of CDT). Which particular exercises are most suitable for you depends on which part of your body is affected by lymphedema. Your therapist will design a program of exercises especially for you. Perform your exercises as diligently as possible and only continue as long as you feel no pain. Include the side of your body not affected by lymphedema in your training.

## 4. How can you help make the therapy successful?

- Follow your doctor's and lymphedema therapist's instructions and advice regarding your therapeutic program.
- Should you notice anything unusual (redness and excessively warm skin, inflammations or wounds, pain, an increase in the swelling, or perhaps that your compression garment doesn't fit properly) please consult your doctor immediately.
- Success with CDT depends on your full cooperation: regular skin care, wearing the compression garments, keeping your appointments with the lymphedema therapist and performing the recommended exercises are all up to you!



Consistent application of the CDT therapy, which includes wearing the compression garment will allow you to lead an almost normal life without restrictions.

## Some more useful tips to remember:

- **Your diet...** should be balanced. If you are overweight, you should try to lose weight under your doctor's guidance, as obesity places an additional burden on the lymphatic system.
- **Your responsibility:** Having your blood pressure measured, a blood sample taken, injections, acupuncture and so on, should not be carried out on the affected arm or leg. Please remember to inform whomever it is that you have a lymphatic condition.
- **In your leisure time...** you should protect yourself against over-exposure to the sun (which also includes tanning beds), because the warmth causes widening of the vessels, and secondly because sunburn puts even more stress on your already affected skin. It is also advisable to be cautious around insects – their bites or stings can cause inflammations that may worsen the lymphedema.
- **In the home and garden...** try and take precautions against injury (e.g. wear protective gloves) and avoid overstraining (e.g. carrying heavy objects).
- **Your sporting activities...** are important and beneficial – although you should restrict them to a reasonable level. Types of sport involving extreme stress can have an adverse effect on the lymphedema. If in doubt, just ask your therapist or physician.
- **Your clothing...** can still be fashionable but avoid restrictive items such as narrow bra straps and tight elastic bands.

# BSN medical Lymphedema Management Product Line:

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Synthetic Padding Bandage



**JOBST® Bella™ Lite**  
Ready-to-Wear Armsleeve  
and Gauntlet



**Tricofix®**  
Tubular Gauze Stockinette



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**Isoband®**  
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**CompriFoam®**  
Open cell foam bandage



**JOBST® FarrowWrap®**  
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BSN medical Inc., an Essity company  
5825 Carnegie Blvd. Charlotte, NC 28209-4633  
Tel. (+1) 704 554 9933 Fax (+1) 704 358 4558  
To order toll-free: BSN medical (+1) 800 552 1157

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