

Reducing the risk and identifying Lymphoedema following lymph node removal

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The surgery you are about to have or have just had will remove lymph nodes at the top of your leg/groin/pelvis. Your surgeon will explain why this is important for you but one side effect of this is that the lymphatic system may not work as well as it used to and a build-up of fluid may occur in the leg, foot or groin/pubis area. This can happen immediately after surgery or many years later. This is commonly known as lymphoedema.

What are the signs of lymphoedema?

Diagnosing lymphoedema early will help to manage symptoms and control swelling more easily. The symptoms of early lymphoedema include:

- swelling of the limb affected
- change in sensation (the limb or area may feel heavy, tight, full or stiff)
- skin changes
- aching

Symptoms vary depending on whether lymphoedema is mild, moderate or severe. In early lymphoedema, the swelling may not be very noticeable, but pressure might leave a mark or indentation on the skin. In later stages, the skin often hardens and there may be more complex skin problems. Severe lymphoedema may interfere with your ability to do everyday things. Any new swelling, pain, discomfort or redness in the affected groin or leg may indicate lymphoedema.

People who have had a sentinel lymph node biopsy (SLNB) are still at risk of getting lymphoedema, although the risk is lower. The sentinel node (or nodes, as there may be more than one) is the first node that lymph fluid from a part of the body drains to.

It's not clear why some people develop lymphoedema after certain cancer treatments and others don't. It's thought that some things, such as overuse of a limb (causing inflammation) or a skin infection may trigger swelling in someone who's at risk of developing lymphoedema. The body responds to inflammation and infection by producing extra fluid to help deal with it. If the lymphatic system in that area isn't working as efficiently as it should be, the extra fluid could overload it and lead to lymphoedema.

There is also a small risk of fluid collection from where the lymph glands were removed; this may form a lymphocyst. Lymphocysts normally resolve on their own; the fluid is either reabsorbed back into the body or can leak out through a weak point in the skin, for example through the groin wound incision. If this does happen please do not be alarmed. Occasionally these cysts can become infected and require an admission to hospital for intravenous antibiotics.

How can I prevent this from happening?

It's not possible to completely prevent lymphoedema, but the following steps may help reduce your chances of developing the condition. If you already have lymphoedema, this advice may stop it getting worse.

The part of your body affected by lymphoedema is more vulnerable to infection of the build-up of fluid within the tissues. Any cuts in your skin can allow bacteria to enter your body and may quickly develop into an infection. Skin infections can also damage your lymphatic system and cause lymphoedema to develop.

You can reduce your chances of developing skin infections by:

- not having injections or blood pressure readings in the affected area whenever possible
- treating cuts and scratches immediately with an antiseptic cream
- using insect repellents to prevent insect bites
- moisturising the skin daily to keep it supple
- avoiding very hot baths and showers – the heat from saunas, steam rooms and sun beds may also increase the swelling
- using sun cream with a high sun protection factor (30+ SPF) to prevent sunburn
- using anti-fungal powder to prevent fungal infections in your skin or feet
- cutting your nails with nail clippers
- seeing a podiatrist for foot and nail care – but make sure you tell them you have lymphoedema
- if your lower limbs are affected, wearing shoes that fit correctly and provide support on the top of your feet is essential
- using an electric razor if you need to shave to reduce the risk of cutting yourself
- not wearing tight-fitting clothing or jewellery

What about exercise?

Regular, gentle exercise is very important, especially after surgery, but you should be careful not to do anything too strenuous. Increasing your exercise levels suddenly or lifting heavy weights can put too much demand on your lymphatic system and lead to swelling. If you do overdo things you may notice your 'at risk' limb aches or becomes pink, hot or swollen. Standing still for long periods or repetitive movements may also cause swelling. Physical activity will help you feel better generally and help to keep your weight down. It also encourages deeper breathing, which stimulates lymph flow. Breathing exercises on their own or as part of yoga or pilates can also be beneficial.

What about travelling?

When going on holiday you should make sure you have a supply of insect repellent and antiseptic cream. A two week supply of antibiotics may be obtained from your GP to take if you notice any signs of infection. These may be red, hot areas on your leg or groin or a 'flu-like' feeling.

Here are some tips on what you can do to reduce your risk of developing lymphoedema when travelling:

- avoid sitting in one position throughout the journey
- move around frequently and do gentle stretching exercises when travelling by air or train
- during longer car journeys, make regular stops and get out and walk around
- wear comfortable clothes and shoes, and avoid anything tight-fitting or restricting
- wear flight socks that fit well
- use luggage on wheels that can be pulled instead of picking up or carrying heavy luggage

Who can I contact for advice if I think I may have lymphoedema?

Your clinical nurse specialist will be able to give you basic advice and can refer you to a physiotherapist who specialises in lymphoedema. Quite often a referral will be made to a local hospice as they offer specialised lymphoedema assessment and support. If you do have any queries or think you are developing lymphoedema then please contact the department sooner, do not wait for your next hospital appointment as lymphoedema can be treated much more successfully if caught early.

Coping with your emotions if you have lymphoedema

Coping with lymphoedema can be difficult because it changes the way your body looks and can have an impact on your lifestyle. You may find it emotionally challenging to accept these changes. Many people experience different feelings such as:

- self-consciousness
- guilt
- anger
- low mood.

It's natural to have these emotions. Talking to your nurse specialist, your friends and family or a counsellor can help. It's important to explain how you feel to those around you. They'll be able to provide you with the support you need. Talking to others who have lymphoedema can also be a great source of help. You can do this through support groups or online forums such as the Macmillan online community or the Lymphoedema Society.

Data Protection

Any personal information is kept confidential. There may be occasions where your information needs to be shared with other care professionals to ensure you receive the best care possible.

In order to assist us to improve the services available your information may be used for clinical audit, research, teaching and anonymised for National NHS Reviews. Further information is available in the leaflet Disclosure of Confidential Information IL137, via Gateshead Health NHS Foundation Trust website or the PALS Service.

This leaflet can be made available in other languages and formats upon request