

## Breast Cancer Related Lymphoedema – information for patients

This information is primarily to help with the concerns you may have when being admitted to hospital, for instance for an operation. The anaesthetists and other doctors who will be looking after you may not have had particular experience in dealing with patients with lymphoedema or in understanding what they need to do to reduce as much as possible the chance of making lymphoedema worse before, during and after your operation. We have produced a version of this [information sheet for doctors](#) and *you may wish to* take a copy with you.

It is still unclear why some people develop lymphoedema after breast surgery and others don't. Similarly, it is not entirely clear what might make it worse. This means that effective advice on how to prevent it getting worse will be the exception rather than the rule. The advice offered in many of the publications and web-sites is practical and common sense, but all too often has little scientific evidence behind it. It is far easier to repeat advice than to check if it actually makes a difference.

We are concerned that whilst the number of places where advice can be sought is growing (a good thing) there is too much variation in their advice. This leads to confusion and anxiety instead of the confidence they are supposed to build.

The following are real life examples that patients have reported:

“I was given a booklet on arm care and prevention of lymphoedema from my hospital. Taking blood pressure and having injections in the at-risk arm are listed among the possible triggers of lymphoedema and therefore to be avoided.”

“My breast care nurse said that the arm on the affected side has to be protected for life.”

“I have had some doctors trying to convince me that it isn't a problem to take blood from my at-risk arm but have been told by others not to allow anyone to do anything to that arm for any reason, except in an emergency.”

“Don't be ridiculous – it's been four years since your op – there will be no risk of lymphoedema now.”

We have looked in detail at the evidence behind many of the recommendations and this review is available as an appendix if you wish to read it. There are several areas where we support the widely published suggestions, but still others where there is either no evidence or that there is conflicting advice on the same topic.

The greatest risk is of infection developing in the arm, and the skin is the most effective defence against this occurring. Extreme care of the skin is essential. There are some procedures that may increase the risk.

The key procedures on the arm with lymphoedema that cause concern are:

- Being given drugs intravenously
- Having an Intravenous drip inserted
- Having a tourniquet applied
- Having your blood pressure measured
- Having blood taken

Intravenous therapy – inserting a 'drip' into a vein and giving fluids or drugs – does increase the potential risk of introducing infection, but has not been clearly shown to increase the risk. The presence of lymphoedema means that there are problems with fluid draining from that limb, for whatever reason, and increasing the amount of fluid or drugs that the limb has to remove can't seem sensible. If there are alternative sites available these should be used.

It is very important to be aware that there are occasions where the ability to give fluids rapidly – where there is life-threatening blood loss for instance – overrides any such concerns.

Drugs may need to be given through a vein. Chemotherapy is a common example, and as these drugs may harm the veins there is a risk of 'using up' the ones in the other arm or feet. Commonsense suggests that if the administration of life-saving drugs is necessary, they should be given by any route possible, but if there is a need for repeated treatment a

more long-term IV access is used. This is usually a plastic catheter (tube) inserted through the skin into a deeper vein, usually in the neck, that can be kept in place for weeks.

Surgery for compression of nerves at the wrist (carpal tunnel syndrome) is common in lymphoedema and a tourniquet is routinely used in this form of hand surgery in the upper limbs to enable the delicate surgery to be performed. There is no evidence that using a tourniquet for up to 10 minutes has any long term effect although there may be a temporary increase in lymphoedema.

Having blood taken (venepuncture) from a vein by a skilled practitioner is very unlikely to introduce infection into the limb. However, where there are alternative sites it is commonsense to use them instead, even if this means 'unusual' sites such as the feet.

Measuring blood pressure involves a simple cuff on the arm which is inflated above the pressure in the arteries, and then rapidly deflated to record the blood pressure. There is no evidence that this makes any difference at all to the risk of developing lymphoedema. However, the changes in the volume of the arm may affect the accuracy of the recording and for this reason using another limb if possible is sensible.

**In summary:**

We all need to work together to ensure that we take as many sensible precautions to prevent lymphoedema getting worse, even though we do not know why it does in some people and not others.

There are no absolute rules on avoiding procedures, but it is obvious that avoiding such risks where possible is the best practice, whilst recognising that there will be occasions where this is not safe. Even then the risk is very small.

## FREQUENTLY ASKED QUESTIONS - RELATED TO HOSPITAL ADMISSION:

1. What can make me get lymphoedema?
2. If I have lymphoedema what will make it worse?
3. Will they take my blood pressure on my affected arm?
4. Will they take blood from my affected or at-risk arm?
5. What if they want to put a drip in my affected arm?
6. What about injecting drugs into that arm?

### **1. What can make me get lymphoedema?**

We do not know why up to a third of patients get lymphoedema after surgery affecting their axillary lymph nodes, nor why it can take a year or more to develop. There are many suggestions of ways to avoid triggering lymphoedema. However there is a lack of evidence to back some of these suggestions

### **2. If I have lymphoedema what will make it worse?**

Once lymphoedema develops there are several possible methods of trying to avoid worsening of the condition. The risks of any medical procedure on the affected arm making it worse are small, but where possible, avoiding using the affected or at-risk arm is sensible. Some procedures such as using a tourniquet during surgery on that arm may make it worse for a while, but not permanently.

### **3. Will they take my blood pressure on my affected arm?**

There is no evidence that having your blood pressure measured on that arm will have any effect. It will not cause the onset of lymphoedema and it will not make established lymphoedema worse. It may be less accurate if lymphoedema is present and may be more uncomfortable. It is for these reasons that using an alternative limb is sensible.

### **4. Will they take blood from my affected or at-risk arm?**

This is one procedure that may increase the risk of triggering lymphoedema or of making it worse where present. This is because of the very small risk of infection. Skilled operators are less likely to cause problems but if there is a choice of sites commonsense suggests avoiding an 'at risk' arm.

### **5. What if they want to put a drip in my affected arm?**

The insertion of a cannula (plastic tube) through the skin into a vein remains a potential source of infection until it is removed. Very careful management of this is necessary to reduce the risk of cannula-based infection.

**However**, where it is necessary to give fluids or blood because of major injury or blood loss, rapid access and transfusion is life saving. This takes precedence over any other consideration, including the small risk of triggering or exacerbating lymphoedema.

### **6. What about injecting drugs into an affected or at-risk arm?**

The absorption of drugs from the 'at risk' arm is less predictable than if given through other veins in alternative limbs. If there is a need to give drugs regularly, such as for chemotherapy, a more permanent IV catheter may be inserted into a deeper vein which will make it more convenient and safer for you.

We would advise against injecting into the 'at risk' arm or arm with lymphoedema but with the same comment as above – if there is a life-saving need for an injection and that is the most accessible route this must take precedence over all other considerations.

## LYMPHOEDEMA WEB RESOURCES

Living with Lymphoedema after breast cancer

<http://www.breastcancercare.org.uk/server/show/nav.490>

Reducing the risk of Lymphoedema

<http://www.breastcancercare.org.uk/server/show/nav.489>

Management of cellulitis in lymphoedema. (February 2007)

Coping with lymphoedema following a mastectomy or a lumpectomy (March 2006)

What is cellulitis? (January 2006)

[www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn)

Prevention of upper limb lymphoedema. (February 2007)

[www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn)

Lymphoedema. Advice on self-management and treatment. (2007)

[www.beaconsfield-publishers.co.uk](http://www.beaconsfield-publishers.co.uk)

Reducing the risk of lymphoedema. (November 2006)

[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

Lymphoedema awareness: reducing your risk. (2006)

Living with lymphoedema after breast cancer. (July 2006)

[www.breastcancerhaven.org.uk](http://www.breastcancerhaven.org.uk)

Understanding lymphoedema. (2006)

[www.be.macmillan.org.uk/orders](http://www.be.macmillan.org.uk/orders)

Lymphoedema. A guide for cancer patients. (2007)

[www.royalmarsden.nhs.uk](http://www.royalmarsden.nhs.uk)

Risk of cellulitis

[www.thebls.com/concensus.php](http://www.thebls.com/concensus.php)