



Lymphoedema Department

Head and Neck Lymphoedema Risk Reduction Advice, following treatment, and/or surgery for Head/Neck Cancer

This advice leaflet will provide information to help you reduce the risk of developing lymphoedema. Although most lymphoedema develops in the first few years following treatment/surgery for head/neck cancer, there is a small lifelong risk, so the guidelines should always be followed.

What is Lymphoedema?

Lymphoedema is a persistent swelling of any part of your body, but it commonly occurs in the arms, breast, hands and legs. Swelling can also affect the chin, cheeks, eyelids and neck. One, some or most of the lymph nodes in your head and/or neck can be removed during surgery to check whether any cancer cells are present. The lymph nodes and vessels that have been damaged or removed cannot be replaced, so the lymphatic drainage routes are reduced or altered, which can cause the fluid to build up in the surrounding tissues. When you are having cancer treatment you may have some swelling to your head and/or neck; it usually starts slowly and is easier to treat when it is mild.

The swelling is a collection of fluid within the tissues under the skin which cannot be drained by a needle. This fluid, known as lymph, is colourless and odourless, but it is rich in protein. The high protein content of this fluid causes dryness of the skin which can result in flaking, thickening, and blistering.

Why are you at risk of developing lymphoedema?

This may be because you have recently had surgery or treatment where lymph nodes have been removed or treated with radiotherapy, or had an infection. The lymph nodes and vessels that have been damaged or removed cannot be replaced, so the lymphatic drainage routes are reduced or altered and this in turn disrupts normal lymphatic flow.

When does lymphoedema occur?

Lymphoedema usually develops within the first three years post-surgery or radiotherapy, but it can occur many years later. Therefore, there is a lifetime risk of developing lymphoedema following cancer treatment where the lymph nodes have been removed or damaged.

Is lymphoedema curable?

Lymphoedema is a long-term condition, which means that once it has developed, it can be controlled but is unlikely to ever go away. The symptoms of lymphoedema usually respond well to treatment and this means that in most cases it can be controlled.

How can I reduce my risk of lymphoedema?

It is still not known what exactly causes lymphoedema, but the following may help to reduce the risk of developing it:

• Weight Management

Gaining weight and being overweight is a big risk factor in developing lymphoedema. Being overweight can increase your risk of developing lymphoedema. It is important to maintain a healthy weight by eating healthily and carrying out regular exercise. If you are unsure what a healthy weight for you should be ask your health care professional for advice.

Movement and Exercise

Gentle movement, exercise and activities will help the muscles pump lymph fluid more effectively through your body. It helps to improve and maintain flexibility and keeps your bones strong. Being more active helps you achieve and maintain a healthy weight and it may improve your emotional wellbeing.

The following exercises are taken from the British Lymphology Society #everybodycan information leaflet and a full copy can be seen at www.thebls.com – (you will need to type 'every body can' in to the search box on the website).

Activity to help with swelling of the face, head, or neck:

- Start with some deep breaths, simple neck stretches and shoulder shrugs and circles to stimulate lymph flow generally (ie stretch your arms out as far as you can, so that you are stretching your rib cage and expanding your chest and lungs).
- 2. Making some exaggerated A, E, I, O, U movements with your mouth so that your face and neck muscles stretch can be particularly helpful. Simply opening and closing your mouth widely is also a good stretch for facial muscles.
- 3. Rapid blinking can help if there is swelling around the eyes.
- 4. Keeping your head still, rolling your eyes to look up as much as you can, holding for a couple of seconds, then looking downwards, then to each side is also useful for swelling around the eyes.
- 5. Chewing gum, sticking out your tongue or any movement that moves skin and muscles of the face is good. Singing loudly is great for the movement and because you need to take bigger breaths.

Pacing yourself is important. Set yourself personal and achievable goals as sometimes keeping a record of how much activity you do can be beneficial in achieving your goals.

Try to do a little every day and build up to around 20-30 minutes of head and neck specific exercises (ie 10-15 minutes in the morning and the same in the evening), daily. Remember to pace yourself and listen to your body.

For general fitness and wellbeing there are exercise schemes specifically for patients who have had cancer at various leisure centres throughout Dorset.

There are specific exercise videos available on YouTube; a good starting point is one by Cancer Research UK (search in the search engine for video) https://www.youtube.com/watch?v=RWjTkBM5Prw

Avoid wearing tight clothing, scarves, and jewellery around the neck.

Prevent or reduce infection - look after your skin

Performing daily skin care can help to prevent infection and subsequently lymphoedema:

- Wash your skin daily with warm water and soap.
- Following surgery you may have altered skin contours, as tissue and muscle position can be altered. Ensure you dry your skin thoroughly between any skin folds. Apply moisturising cream (not perfumed) to your skin – it does not matter which brand, as long as your skin likes it, to prevent it from dryness.
- o Treat any cuts or scratches by cleaning and then applying an antiseptic cream
- o Prevent sunburn by using a high factor sun cream
- Use an electric razor to remove unwanted hair
- o Avoid, where possible, needle-stick procedures such as tattoos.

Cellulitis signs and symptoms

Skin infections such as cellulitis could cause lymphoedema, so it is vital that you check for signs of infection. Although it is not common in the head and neck, it is still possible and requires immediate review. Symptoms can appear suddenly and make you feel unwell. Signs of infection can include:-

- Swelling of your skin in the affected area
- o Skin feels hot to touch
- o Redness or rash
- o Pain
- o Generally feeling unwell.

If you think you have an infection, seek medical help from your GP or the out of hours service. It is important to act quickly to prevent the infection from getting worse. You will need antibiotics and you must take them for no less than two weeks.

Looking after your Scar

A scar forms as a result of surgery. Scars are part of the healing process, and we would hope that all are flat, supple and with minimal redness after 12-18 months. During the healing process adhesions can form under the skin and cause tightness, pain, increased sensitivity and reduce the flow of lymph fluid.

Scars can be helped by the following advice:-

- Try to look at your scar. The surgery may have changed your body, and you may need time to adjust to your new body image and how you feel about yourself.
- When your scar has healed, it is important you start to touch and move the scar and
 the surrounding tissues. Massage the scar in a circular motion with a non-perfumed
 cream to moisturise the area to keep your skin supple. Focus on the harder, lumpy
 areas as this will soften and reduce the lump. Touching and massaging the scar will
 help to reduce adhesions that can form post operatively. It will also reduce tightness
 and sensitivity and increase movement within the scar and surrounding soft tissues.

Other possible post-operative symptoms:

- Nerve disturbance
- Dry mouth
- Impaired speech
- Hearing loss
- Fatigue.

How likely a treatment is to cause these issues depends on multiple factors including size/position of the cancer, general health beforehand and type/level of treatment. For some these changes can be mild and improve as the body heals; for others these changes may be more permanent. Please discuss these with your lymphoedema or Head and Neck specialist for further assessment and advice.

Remember the following three things:-

- 1. Maintain a healthy body weight
- 2. Move your body
- 3. Reduce risk of infection.

Contact Numbers:

We hope that you have found this information useful. If you have any questions or are worried about anything, please speak to the following Dorset County Hospital Staff:

Lymphoedema Department: 01305 255370

Emma Diaz, Lymphoedema Nurse Specialist Dawn Johnston, Lymphoedema Staff Nurse Lucy Harris, Lymphoedema Staff Nurse

Useful Videos:

<u>www.lymphoedema.org/information/self-management-videos</u> (click on the video relating to head/face/neck SLD)

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If you have feedback regarding the accuracy of the information contained in this leaflet, or if you would like a list of references used to develop this leaflet, please email pals@dchft.nhs.uk



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