



Information for patients with skin cancer who require lymphadenectomy

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Introduction

At the outpatient clinic it is difficult to take in all of the information that you have been given and we therefore hope this booklet helps to clarify and reinforce what you have been told.

You will have been told at your clinic appointment that you have skin cancer in one of your lymph nodes. This may be a recurrence of a previously treated skin cancer or it may be a new cancer you were previously unaware of. This is called an 'unknown primary' and you may need further investigations to establish if there is a primary site of disease that also needs treating.

The first part of the booklet looks at the lymphatic system. This may help you to understand a more about how it works and how the cancer spreads. The next section provides you with information about the operation and about the care you are likely to receive in the future. The last section looks at your feelings and how to cope with the news.

If you have any concerns or queries after reading this booklet, please speak to one of the Macmillan Clinical Nurse Specialist (CNS) team on **0121 371 6777**.

The lymphatic system

The lymphatic system is a complex network of tubes (lymphatic vessels), lymph nodes (or glands) and other organs such as the spleen. The lymphatic system helps to transport substances around the body and is part of the body's natural defence against infection.

The lymphatic vessels are filled with a fluid called lymph. The lymph carries nutrients and waste products around the body.

The lymph circulates through the lymphatic vessels and spreads through the lymph nodes, which act as a filter. There are lymph nodes throughout the body. However they are mainly found in groups particularly in the neck, groin, and under the arms.

Skin cancer can spread from the skin and travel in the lymphatic vessels. When cancer passes into the lymph node it can make it swell and you may then be able to feel the lymph nodes. Sometimes the presence of cancer cells is picked up during an investigation before any swelling is noticed.

What does this mean?

Skin cancer in a lymph node from an unknown primary or spread of skin cancer to lymph nodes can be serious. In most cases it does mean that the cancer has spread from where it started, and that further spread may well occur. However, it does not mean that further spread is inevitable.

The operation

The purpose of the operation is to remove all the lymph nodes in the affected area. Even nodes which are not enlarged are removed as they may have cancerous cells within them.

Depending on which group of lymph nodes are affected you will require surgery to one of 3 different areas; the neck, the axilla (armpit) or the groin. The length of stay and complications you may experience will vary depending on the area operated on.

The operation will be carried out by a Consultant Plastic Surgeon or one of their team. You will need to stay in hospital and will require a general anaesthetic. The length of your stay may vary from three to ten days depending on the exact type of operation and how quickly you recover. Occasionally it may be longer if there are complications.

Before the operation

You will receive a letter to confirm the date of your operation and date of your admission to hospital. You may be asked to telephone your consultant's secretary to confirm that you are able to attend.

You will be asked to attend the Pre Admission Clinic before your operation. Here you may have a blood test taken, a chest X-ray, an ECG (tracing of your heart) and be asked questions about your general health.

You may be asked to come in to hospital on the day of your operation or be admitted the day before. Occasionally, due to emergency admissions, your operation may need to be postponed. Should this occur, we will organise a new date for you as a priority.

Sometimes it's necessary to undergo other tests prior to your operation or in the months following. Please be aware that there may be a wait of a few weeks before the tests are carried out. Below is a brief description of some of the tests which you may need. You may not need to have all of them and there may be other tests not listed here which are required but you will be informed of which tests are needed and given appropriate information as necessary.

CT scan

This is a scan which gives a detailed picture of your body's internal organs and lymph nodes. It is not an uncomfortable test but can take up to an hour to carry out. You should expect to be in the department for at least two hours. Patients are usually

given a drink or injection to highlight some of the organs. This scan is done as an outpatient and there may be a few weeks wait for an appointment. This can help the surgeon in planning your operation and can also show us whether there are any indications that your cancer has spread elsewhere in your body. Sometimes the scan shows us areas of uncertainty that need further investigations to clarify. This is not unusual and need not be a cause for concern.

Ultrasound scan

This test uses sound waves that bounce off internal organs to create a picture. This test is painless; gel will be rubbed on to your skin to make the scan picture clearer. It is the same test that is used to see the baby with pregnant mothers.

PET CT scan

This test may be used for patients who have an unknown primary and may help us to establish where the original cancer is/was. It combines the use of a mildly radioactive substance to enhance areas of high metabolic activity with a CT scan. If an area of high metabolic activity is seen this may be where the original cancer is but can also highlight areas of inflammation or infection. Additional investigations may be needed if the PET CT shows any areas of concern.

Potential complications of the surgery

Prior to the operation you should be aware of the following potential complications:

- **Infection:** Infection in the wound can cause pain, redness, and swelling and delay wound healing. Any infection will be treated with antibiotics and dressings. Occasionally further surgery will be required.
- **Seroma and Lymphoedema:** Because the lymph vessels are cut during the operation, after surgery the lymph fluid tends to accumulate within the wound and within the limb. The

fluid within the wound is removed by plastic tubes, these are removed when the drainage reduces. There is further information on both of these below.

- **Seroma:** Many patients will experience a build up of fluid underneath or around the wound after the drains have been removed. This occurs particularly after having surgery to the groin and axilla but it may also affect those having surgery to the neck. This is called a seroma and it may sometimes need to be drained using a needle and syringe. This can be done at an outpatients visit if required. It may need to be drained more than once if the fluid builds up again. However if the seroma is not painful it can be safely left and the fluid will be reabsorbed over time.
- **Lymphoedema:** The fluid can sometimes accumulate in the limb and cause limb swelling. Often this resolves as your wound heals but can remain as a permanent problem. This is called lymphoedema. If you have had surgery to the axilla you may experience arm or chest swelling on the same side and if you have had surgery to the groin you may experience swelling in the leg or abdomen on the same side. Patients sometimes also get swelling after surgery to their neck nodes. Whether this occurs, and it's extent, is variable. Please see the section on lymphoedema for more information.
- **Wound breakdown/delayed healing:** Some patients may find that their wound takes longer to heal than they expected, or that the wound may reopen and fluid may leak. The nurses in the plastic surgery clinic will help to manage this with appropriate dressings and can liaise with your district nurses or practice nurses. Please be reassured that they are experienced in the care of patients undergoing this type of surgery and in the management of any complications that can occur during healing.

The plastic surgery clinic can be contacted on **0121 371 5472** if you have questions or worries about your wound. If you need advice out of hours please contact your GP surgery or local A+E.

If you are seen nearer home because of concerns about your wound please also inform the CNS team on **0121 371 6777** so that we can keep your Consultant informed. You may be asked to attend the clinic for review.

- **Reduced movement:** If you have had surgery to the neck you may experience neck and shoulder stiffness and surgery to the axilla may result in reduced arm movement or a stiff shoulder. This may occur as a result of the scarring but will usually improve with time, exercise and sometimes physiotherapy.
- **Haematoma:** This is caused by bleeding within or behind the wound after the operation. It can cause wound swelling and delayed healing. The blood is usually removed by the drainage tube placed in the wound or by the body's natural absorption process, but occasionally further surgery is required to remove it.
- **Altered sensation:** The area around your scar may feel different or feel numb. This may improve with time, but may be permanent. It does not affect the movement of the area.

After the operation

After returning from theatre you may be wearing compression stockings to help prevent blood clots. You will need to wear these until you are fully mobile again. You may also be given an injection each day to prevent blood clots forming.

On the day of the operation you are likely to feel sleepy but you should be able to sit out in the chair the following day.

You will experience some discomfort but will be offered regular pain killers to help alleviate any pain.

Some patients may need to have a tube called a catheter to help you pass urine which will be removed a few days after your operation.

You will have one or two wound drains. These are thin tubes with a bottle attached into which lymph fluid drains. The drains will stay in place until the amount of fluid has decreased so that they can be safely removed. Some patients go home with drains

still in place. In this case a member of the ward staff will explain how to care for the drain and who to contact with any concerns once you are home.

Once your drains have been removed wearing a supportive, close-fitting garment, such as a cycling top or cycling shorts may help with any swelling. You may wish to consider purchasing this before your admission into hospital. Some patients find a sports bra or support tights work well for them.

You will be given any specific instructions about your wound on discharge. This may include when to have stitches removed, when to see your GP practice nurse or when to attend a dressing clinic appointment at the hospital.

A physiotherapist may see you on the ward to show advise you on some exercises, and you may be referred to a local outpatient physiotherapy service if needed.

Information about the ward

Most patients are admitted to the admissions unit on the morning of surgery and will be transferred to a ward following the operation.

Many patients will be cared for on Ward 408 following surgery. This ward is situated off the main corridor on the fourth floor. The telephone number for the ward reception is **0121 371 4080**. Ward 408 is a 36 bedded ward divided in to 16 side rooms and 5 single sex 4 bedded bays. Each bed has a television and pay phone facility.

Visiting times:

Our visiting times are 11:00 – 20:00 daily, including weekends.

A maximum of 3 visitors per patient are allowed at one time. Children under the age of 16 are welcome to visit patients in our hospitals when accompanied by a responsible adult. Please remember that babies and children under the age of 5 are particularly vulnerable to the infections that can be present in hospitals.

What to bring

Beside your bed will be a small locker for you to store your personal belongings. Please bring with you:

- A towel, night clothes, slippers and toiletries
- A small amount of money is useful. A pay-television is available above your bed or you may wish to buy newspapers, sweets etc from the mobile shop. Please do not bring large amounts of cash or valuables
- Any walking aids you normally use
- Any medicines or tablets you normally take
- Books and magazines may help to pass the time

Mobile phones are allowed on the wards but we can not accept responsibility if it is lost or damaged. You should be mindful of other patients who may not be feeling well when you chose to use it.

Discharge

During the first week after you've been discharged it is important that you have someone to help you with cooking and shopping and to ensure that you are safe at home. If you live alone you should arrange for a relative or friend to stay with you or visit daily. If you are concerned about this, please inform a member of nursing staff on admission.

You will not be able to drive for at least the first few weeks after your operation. It is important that you check with your doctor before returning to driving as your insurance may not cover you in the event of an accident.

You will need to return to the Plastic Surgery Outpatient Clinic for a check up at regular intervals. This may be several times each week at first.

If at any point you are concerned about your wound, please contact the plastic surgery clinic on **0121 371 5472** for advice and possible review. You have had specialist surgery and it may be

important for you to be reviewed here.

The results of your operation will be explained to you at your consultant appointment. This may be up to six weeks after your surgery.

Additional treatment

Many people ask whether there is any additional treatment that may be helpful to prevent the cancer from coming back. Depending on your individual situation the following may be considered:

- You may be referred to an Oncologist, a cancer specialist, to consider additional treatments that may be helpful to reduce the risk of your cancer returning in the future. This is not chemotherapy but newer types of drugs that are now available for some patients with surgically treated melanoma. You may hear these treatments referred to as targeted treatments or immunotherapy. The oncologist will discuss which of these treatments is appropriate to you and then provide you with information about the benefits and possible risks/side effects of further treatment before you decide if you wish to go ahead with it. Please ask your Doctor or Nurse Specialist if you want to know more about this.

If you have been referred to us from another hospital outside of Birmingham, you will be referred for this treatment to be given locally to you rather than at the Queen Elizabeth Hospital Birmingham.

- Secondly, for some types of cancer radiotherapy can sometimes be useful if there is concern that some of the cancer cells may still be present in the treated area. Radiotherapy is the use of high energy rays that can destroy cancer cells. The treatment is used to reduce the risk of your cancer returning in this area but is not without side effects. Your consultant may ask an Oncologist to see you to discuss this additional treatment. Please be aware that if your wound is not healed or you have a large seroma in the weeks following surgery it may not be possible to have radiotherapy.

- Thirdly, trials may be available of new treatments that may help to delay and possibly even prevent further recurrences. If you are eligible for any trials, we will discuss this with you, but please do ask if this is important to you and has not been mentioned. It is very important to remember that these are treatments of uncertain value - they may, or may not be helpful.
- Your Consultant may wish to do further investigations to try and pick up any early signs of the return of your cancer. They will discuss this with you during your ongoing follow up care.

Lymphoedema

Following this type of surgery you are at risk of developing a condition called lymphoedema. This is a chronic swelling of the soft tissues. It develops following the operation because the tubes (lymphatic vessels) that drain lymph fluid are disrupted. Lymphoedema may develop soon after surgery or a few weeks or months after treatment. If this occurs you will be referred to a local specialist lymphoedema team for assessment and management.

The following advice has been provided by the Macmillan lymphoedema nurse:

Skin care

- Wash the limb thoroughly daily. Pay particular attention between the fingers and toes
- Apply a moisturising cream to the limb
- Avoid having blood taken or injections in the affected limb
- Never have blood pressure readings taken on the affected limb
- If you injure the affected area apply an antiseptic cream and observe for redness, heat, or swelling as this may indicate infection. If this happens get antibiotics straight away from your GP
- If you have had the glands in your armpit removed wear gardening gloves when working in the garden

- Do not wet shave the affected limb. Use an electric razor or cream

Exercise and movement

You should:

- Use the limb normally
- Avoid heavy lifting, pushing or pulling of heavy objects
- Continue indefinitely with any exercises advised in hospital, so as to maintain good joint mobility. Swimming and cycling are good exercises but do not over do it
- Exercises should be performed slowly, gently and rhythmically. Pain is not gain

If you develop any new swelling of the limb once all your treatment is completed and your wound is healed please let the clinical nurse specialist know.

Your feelings

Everyone reacts differently when told they have cancer or that their cancer has come back. There is no right or wrong way to feel. Some of the feelings you may experience include shock, fear, anger, guilt, and isolation.

- **Shock:** This is a common immediate reaction. At first you might feel quite numb and unable to accept what's happened. You may not be able to take in information and may not be able to ask questions. It can take a while for everything to sink in. The numbness can sometimes act as a kind of anaesthetic and may enable you to get through all the important practical arrangements. You may also feel detached and strangely calm.
- **Fear and uncertainty:** To be told that the cancer has come back can be very frightening. You may find that you become scared about what will happen to you in the future or worried about those close to you and how they may cope.

- **Denial:** Sometimes you do not want to know what is going on, and do not wish to talk about it. You may try to carry on as if everything is normal. This is a useful mechanism as it allows you time to come to terms with things although it may be difficult for those around you to cope.
- **Blame and guilt:** Some people try to look for a cause or reason for the cancer to have returned. It is normal to want an explanation. It is easy to think that you or someone else is to blame.
- **Isolation:** Sometimes you may wish to be left alone or the fact that you have cancer can make you feel isolated. This can be particularly the case with skin cancer as people are often less familiar with this type of cancer recurring elsewhere in the body.
- **Anger:** You may feel angry that the cancer has returned. This can make you irritable and short tempered and so you may take your feelings out on someone else.

Learning to cope

There are many things which you can do to help.

The team will give you information regarding your cancer and its treatment but if there is anything that you want to ask, please do so.

Bring a friend or relative with you to the clinic to listen to what is said, and write down questions you have and bring them with you when you come to the outpatient clinic.

Let family, friends and health professionals know how you feel. Don't bottle up feelings. Allow yourself time to come to terms with the diagnosis. Set yourself achievable goals.

Who can help?

There are many people who can help.

1. Macmillan clinical nurse specialist – skin cancer

This is a nurse who has undergone specialist training and works within the hospital as part of the specialist skin cancer team. The nurse can help you to cope with the progression of your melanoma as well as providing information about melanoma and its treatment. Please do call if we can provide any help or support on **0121 371 6777**.

2. Your consultant

Your consultant and their team are also there to help you and your family.

3. Your GP and district nurse

4. Local and national support groups

These groups allow you to meet or talk to others who have experienced cancer. Many offer one to one support, complimentary therapies, trained counsellors, and group meetings. You can contact them anonymously.

5. Spiritual help

Many local religious groups offer help and support.

6. Counsellors

Counselling offers the chance to explore your feelings and experiences in a supportive and confidential environment.

Support groups and further information

There are many local and national support groups, some of which are listed below:

Local information centres and support groups:

University Hospitals Birmingham NHS Foundation Trust:

The Patrick Room

Cancer Centre

Heritage Building

Queen Elizabeth Hospital Birmingham, B15 2TH

Tel: **0121 371 3539 / 3537**

Health Information Centre
Birmingham Heartlands Hospital
Bordesley Green
Birmingham, B9 5SS
Tel: **0121 424 228**

Patient Information Centre
Good Hope Hospital
Rectory Road, Sutton Coldfield
Birmingham, B75 7RR
Tel: **0121 424 9946**

Sandwell and West Birmingham Hospitals NHS Trust

The Courtyard Centre
Sandwell General Hospital (Main Reception)
Lyndon, West Bromwich
Birmingham, B71 4HJ
Tel: **0121 507 3792**

Walsall PACT (Patient Advisory Cancer Team)
Tel: **0800 783 9050**

National support groups

Macmillan Cancer Relief **0808 808 0000**

National information web sites:

Macmillan Cancer Relief – www.macmillan.org.uk

Cancer Research UK – www.cancerresearchuk.org

Dermatology
Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston, Birmingham, B15 2GW
Telephone: 0121 371 5111
