

Cambridge Breast Unit

Patient resource pack

Personal information file

This file will provide you with information about your condition and your treatment.

Further inserts will be offered to you according to your wishes and needs.

If you feel there is any other information you would like, please do not hesitate to ask one of the team looking after you. The telephone numbers are on page six.

Personal details

Name

Address

.....

.....

Post Code

Tel: home:.....work:.....

Mobile:

E-mail:

Questions I would like to ask at my next appointment

1.

2.

3.

4.

5.

6.

Your diagnosis

Being told you have breast cancer requiring treatment will probably mean you are going to experience many different emotions, for example shock, fear, anger, a sense of helplessness and a loss of control. You may feel disbelief because you don't feel ill.

You may be frightened about the future and what it holds for you. These are all normal reactions, which may affect you, your family and friends at this time.

We understand this is a very difficult time for you. We aim to keep you and your family informed about your treatment. This will be discussed with you on an individual basis, at every stage.

It can be very difficult to take everything in when you are first told about your cancer diagnosis. This booklet is designed to supplement the information given to you personally by the team.

If you have any concerns or questions about your diagnosis or treatment please contact us. We will try to resolve any issues you may have.

You have been diagnosed with:

Grade: _____

You have been recommended to have:

Breast care specialist nurses and nurse practitioners

This section provides you with more information about the Nurse Consultant, Breast Specialist Nurses and the Nurse Practitioners role.

Breast Care Nurse Consultant, Specialist Nurses and Nurse Practitioners are fully trained, senior nurses who have expert knowledge and experience of breast cancer and its treatments, as well as non-cancerous breast problems and breast screening. Nurse consultant and practitioners hold various clinics for new patients, such as follow up and early discharge clinics. We work closely with other health professionals such as doctors, nurses and liaise with GPs and Community Nurses to ensure the continuity of care in hospital and at home.

We are the link between you and the breast care team both in the hospital and at home.

The Breast Care Nurse Consultant/Nurses/Practitioners can help by:

- Spending time with you and you partner to offer emotional support and advice
- Helping you to choose and understand the treatments being offered
- Being a point of contact if you are worried about any aspect of your care or diagnosis for as long as you need it
- Seeing you before and after your surgery on the ward
- Checking if you have any problems with your wound after surgery
- Aspirating the fluid (serums) that accumulates after your surgery
- Providing information on breast prosthesis and lymphoedema
- Aspirating seromas
- Assessing your wound if you have any problems post surgery

We want to hear from you if you have any questions to ask – no matter how silly you think the question is!

Monday – Friday 0900 – 1700. We have an answer phone if there is no one in the office. Please leave us your details and we will get back to you as soon as we can. If you have any problems with your wound at the weekends, please contact ward L4 on 01223 348500.

- **01223 586756**
- **01223 586573**
- **01223 596291**
- **01223 586960**
- **01223 596093**

What is cancer?

The body is made up of groups of specialised cells, for example skin, liver, bone, breast cells etc. Worn out cells are replaced by new ones. The growth and repair of these cells occurs in an organised and controlled manner. The right numbers of new cells are produced to replace the old ones.

This process can go wrong. One cell may develop its own pattern of growth and division, producing more and more abnormal cells. These abnormal cells may eventually develop into an abnormal mass of tissue or into a lump (also called a tumour). Tumours may be benign or malignant. The pathologist can tell by examining cells whether they are benign or malignant. Benign tumours are harmless. Unless they are causing problems, for example pain, they are generally left alone.

Malignant tumours consist of cancer cells. Some cancer cells have the ability to break away from the original (or primary) tumour and spread to other parts of the body. When these cells reach a new site they can continue to grow and divide to form a new tumour. This new tumour is referred to as a **secondary deposit or metastatic disease**. Treatment can be offered for both primary and secondary disease. The majority of patients have 'early' breast cancer, which is present only within the breast.

It is important to remember that breast cancer is not one disease. There are many different types, which are all treated in different ways. You may find that other patients are undergoing a different treatment plan to yours.

What is breast cancer?

Breast cancer is the most common form of cancer among women in developing countries, accounting for more than 18% of all female cancers. One in nine women in the UK will develop breast cancer at some time in their life. Breast cancer is rare in women under 30, but occurs more frequently in later life. Men can also develop breast cancer but this is uncommon. The good news is that more women than ever are surviving the disease as a result of early detection and improved treatments.

Breasts and their function

Breasts are largely composed of fatty tissue, which supports the milk producing glands. Each breast is divided into several lobules where milk is produced when a woman is breast-feeding. From each lobule tiny tubes join up to form the milk ducts. These carry the milk to the nipple.

Under the skin a 'tail' of breast tissue extends into the armpit (axilla).

The breast tissue is sensitive to certain hormones, which are chemical messengers circulating in the bloodstream, which can help control the growth, and development of cells. Two hormones secreted from the ovaries, **oestrogen** and **progesterone** largely determine the hormonal control of the breast.

Lymph glands

The armpit contains a collection of **lymph glands** (also called lymph nodes). The lymphatic system is a network of lymph glands connected throughout the body by minute structures called lymph vessels. The lymph glands act as filters, by trapping bacteria, worn out cells and debris. The lymph fluid flows from the breast to the lymph glands in the armpit. The lymph glands may be the first site for a secondary cancer deposit to develop.

Involvement of the lymph glands does not necessarily mean that the cancer has spread elsewhere (for example, to the bones, lungs or liver).

Causes of breast cancer

The causes of breast cancer are not yet fully understood but studies have identified women who have a higher risk of developing breast cancer. Some of the risk factors are as follows:

- Breast cancer in several close relatives, especially first-degree relatives, for example mother, sister, aunt) and early age at diagnosis
- Early onset of periods
- Late menopause
- No children or children later in life (over 35yrs of age)
- Some types of oral contraceptives (risk is increased after more than 10 years of use)
- Hormone replacement therapy
- Obesity after the menopause

Even if you have one of these risks factors, it does not necessarily mean that you are at increased risk.

There is a further information sheet if you have a family history of breast cancer and are concerned about this.

Breast cancer treatment

There are several ways of treating breast cancer. Each case is different, and so your treatment will be tailored to your individual needs

The treatment of breast cancer is usually consists of a combination of:

- **Surgery**

There are several different types of surgery. Your surgeon will discuss with you the most suitable options for your cancer

- **Radiotherapy**

X-rays used to treat the breast area

- **Chemotherapy**

Drugs given by tablet or injection that kill or slow the growth of the cancer cells

- **Hormone therapy**

Anti-cancer tablets to treat hormone sensitive cancer

- **Targeted therapies**, for example Herceptin

Surgery and radiotherapy treat a particular part of the body. Chemotherapy and hormone therapy involve agents, which travel in the bloodstream and treat the whole body.

We know from previous studies that the extent of the surgery does not influence the survival from your breast cancer ie. having more aggressive surgery (mastectomy) does not necessarily mean you will live for a longer period of time.

The main objectives of breast cancer surgery are to:

- Provide adequate excision (remove as much as is helpfully necessary for your treatment) of the tumour and lymph node areas.
- To find out more about the tumour and if the disease has spread to lymph nodes in the armpit.
- To cure early non-invasive cancers such as 'ductal carcinoma in situ' (DCIS) If this applies to your diagnosis, please refer to page 23.

National organisations for information and advice for patients with breast cancer

CANCER BACKUP

Telephone: 0808 800 1234

www.cancerbackup.org.uk

BACKUP is registered charity providing information about all aspects of cancer as well as emotional support for cancer patients and their families. BACKUP's cancer information service is staffed by a team of specialist-trained nurses and supported by a panel of medical specialists. BACKUP also provides books related to cancer that will be supplied free of charge.

BREAST CANCER CARE

Telephone: 0808 800 6000

www.breastcancercare.org.uk

Breast cancer care is a national organisation offering free help, information and support to women with breast cancer or other related problems. Its services include:

- Help lines
- Information
- Support for partners
- The lavender trust – support for young women with breast cancer
- Prosthesis fitting service
- Volunteer service

Breast Cancer Care also provides books related to breast cancer that will be supplied free of charge to patients.

They have just launched a new live chat room for men every Wednesday between 2000-2100 hours.

For details visit: www.breastcancercare.org.uk/chat

Breakthrough Breast Cancer

Telephone: 020 7025 2400

www.breakthrough.org.uk

Breakthrough is a charity committed to fighting breast cancer through research and education and has established the UK's first dedicated breast cancer research centre.

Macmillan Cancer Relief

Telephone: 0808 8082020

www.macmillan.org.uk

Local support groups

The Mary Wallace Cancer Support Centre

The main concourse at Addenbrooke's Hospital

Telephone: 01223 596379

www.marywallacecentre.org.uk

The centre offers a drop in service that provides support, information, help and advice. It is a place to have a cup of tea (a compassionate ear) to talk things through with someone.

The Mary Wallace Cancer Support Centre

7 Red Cross Lane

Cambridge

Telephone: 01223 596379

This centre provides a relaxation group for patients and their carers. Go and unwind and relax your mind for a brief period, to bring about a sense of inner calm and wellbeing. They also offer alternative therapies and practical advice on healthy eating.

The Young Ones Support Group

7 Red Cross Lane

Cambridge

Telephone: 01223 596379 or **Email:** infor@marywallacecentre.org.uk

Are you in your 20's 30's or 40's? Do you have breast cancer? If so you are warmly invited to the **Young Ones Support Group**, run by specialist breast care nurses. Guest speakers are invited on alternate months. We meet on the second Wednesday of each month at 1930 hours.

Cambridge Cancer Support

1a Stockwell Street (off Mill Road)

Cambridge

Telephone: 01223 566151

www.cambridgecancerhelp.org

This group offers support to anyone who has had cancer, and also their carers and friends. Complementary therapies are available. The centre is open from 1000 – 1300 hours on Tuesday and Wednesdays.

Newmarket Breast Care Support Group

ABC Centre

Newmarket Hospital

Suffolk

Telephone: 01284 713281 Andrea Prior

Meetings are held on the second and fourth Thursday of each month, 1930 – 2100 hours at the ABC centre at Newmarket Hospital. As well as a chance to meet and chat with others, advice is provided on how to help yourself. Visiting speakers and an aromatherapist attend regularly.

Bosum Pals Patient Support Group, Bedford branch

Telephone: Andrea King 01234 214455

Telephone: June Griffin 01224 822315

This is a patient-led support group. If you have either had a breast operation or are awaiting surgery you may feel that you would like to discuss your fears and feelings with someone who understands. Why not come along to one of their meetings, which are held on the second Wednesday of every month at 1930 hours in the Primrose Oncology Centre, Bedford Hospital. This is a social meeting with an opportunity to speak to other patients and the breast care nurses. A variety of social events are organised throughout the year.

The internet or world wide web

There are a considerable number of web sites dedicated to breast cancer. These need to be scrutinised closely as anyone can put information they chose on the Internet. If you access a good web site please let us know.

Before your operation

Between the time of your diagnosis and admission to hospital for surgery the breast care nurses are available to provide support, advice and information. Everyone has different needs at this time.

You can make an appointment to come back and see the breast care nurses if you would like to discuss your diagnosis and planned treatment. If you would like to see your surgeon again, this can be arranged for you.

A letter will be sent out informing you of your admission date.

Prior to your surgery you will be asked to attend for 'pre-clerking'. This involves:

- An examination to check your general state of health
- Listening to your heart and lungs
- The doctor will want to know about any current medication you are taking
- A number of routine tests are carried out such as:
 - Chest x-ray
 - Electrocardiogram (ECG), which is a recoding of your heart
 - Bloods tests

This pre-clerking is carried out a few days before your surgery. If you are to be admitted on:

- Monday for surgery on Tuesday, it will be the Thursday before
- Wednesday for surgery on Thursday, it will be the Tuesday before

You will be given your consent forms to read through and will have the opportunity to discuss your operation with the surgeon **before your surgery**.

You will then be asked to sign your consent forms.

You may be examined again and the side and site of your operation be marked.

The breast specialist nurses will visit you before and after your surgery on the ward. This will give you the opportunity to discuss any concerns you may have relating either to your surgery or subsequent care and treatment.

Both your GP and District Nurse will be informed of your planned operation and the date for surgery.

The District Nurse may contact you prior to your admission to discuss any care aspects you might require following your discharge from hospital.

Your hospital stay will be up to five days, though may be longer when breast reconstruction has been carried out.

After your operation

Immediately after your operation you will be transferred to the recovery area in theatre. You will be looked after there until you have woken up from your anaesthetic. You will then return to the ward. You are likely to be away from the ward for two to three hours.

Following your return to the ward, you may remain drowsy and sleepy for a few more hours. For this reason we recommend that only close family members visit on this day.

Once you have recovered from your anaesthetic you will be able to start eating and drinking and also to get up from your bed. Most women are surprised at how quickly they can resume caring for themselves and be fully mobile.

A number of breast cancer operations will be performed in the **day surgery unit**.

Is the surgery painful?

The amount of pain experienced following surgery is different for each woman. On the whole, most women experience less pain than they expected. Some have little or no pain at all, which can usually be controlled with mild painkillers (such as paracetamol). Regular painkillers will be offered to ensure you remain pain free.

At home again

In the early days following your operation a vast amount of 'internal energy' will be required by your body to repair itself. This may leave you with only small amounts of energy for the rest of the day. You will find that your body will naturally pace itself. After a particular activity you may find that your energy levels are dipping and you will have to rest.

As the days and weeks pass, your energy store increases so that after about three to six weeks you will have returned to your normal daily pattern. During this time you may find that there are good days when you have lots of energy and days when you feel more tired. **This is normal.**

Housework

In the first few weeks you may find it helpful just to do light housework such as dusting and preparing light meals. Someone else may best undertake more energy demanding work such as vacuum cleaning and shopping. As your energy levels increase you will be able to incorporate more of your daily tasks into your daily routine.

Physical exercise

If you participate in some regular sporting activity it is usually advisable to refrain from this in the first few days and to take a rest. When your energy levels increase your body will tell you it is ready to go back to your sport.

Sexual intercourse

There are no restrictions from a medical point of view. You may need to experiment with different sexual positions to prevent wound discomfort.

Coping with breast cancer and its treatment can be physically and psychologically demanding, both of which can lead to your feeling very tired. You may not feel any desire to have sexual intercourse, which is quite a normal reaction.

Your husband/partner may have concerns about the timing of resuming sexual intercourse. It is helpful in these circumstances if you can talk to one another about your feelings in a frank and open manner.

Driving

The main requirement for driving is that you feel safe behind the wheel. This involves being able to perform an emergency stop or to swerve very quickly. In the early days arm/shoulder discomfort may prevent you performing these procedures. When you feel ready we would recommend that you go for a short drive to see how well you can manage.

You should also check with your insurance company as some impose restrictions on driving for a minimum period of time after surgery.

Insurance

Obtaining insurance -just because you have a cancer diagnosis does not mean that you will be unable to get any insurance at a future date.

If you need any information on matters such as life insurance, travel insurance or mortgages you can visit the web site for the Association of Medical Insurance Intermediaries, which will have a list of insurers in your area:

www.amii.org.uk

Breast cancer – sexuality and body image

Large numbers of women are now surviving breast cancer, and sexual health following treatment is an important issue for many women.

As with all other aspects of cancer care information needs regarding sexuality differ for each individual.

Sexuality implies more than just an ability to engage in sexual intercourse. It concerns the way we view ourselves. Our body image is the way we look and how we feel about ourselves. All cancer treatments have the potential to affect our sexual health.

Cancer and its treatment can impact on body image in several ways. You may have a different view of your body following diagnosis and treatment from the one you had before. Your breast cancer will have left you with visual reminders of your experience:

- Surgery can change the external appearance of the body.
- Radiotherapy can change the texture of the tissue in the breast area.
- Chemotherapy and hormone therapy can induce menopausal symptoms such as vaginal dryness, hot flushes, weight gain and hair loss.

These changes can be temporary or permanent.

In order to engage in a rewarding sexual experience one of the first requirements is to feel desirable, which in turn can lead to sexual arousal. Feeling desirable or attractive may be difficult for you at particular times during your treatment. Sexual desire can be dampened by:

- Tiredness
- Anxiety or depression
- Concern about how your partner views your body

Your husband or partner may also have some concerns. One of the most common concerns is the timing of sexual contact. Some women will appreciate early contact whilst others will prefer to wait.

Talking to each other can help avoid misunderstandings.

Adjusting to any of these potential changes may be easier for some women than others. The breast care nurses are available to discuss any concerns you or your partner may have and to provide support and advice.

Further information

Cancer BACKUP and Breast Cancer Care produces some excellent booklets on sexuality and body image.

Visit www.breastcancercare.org.uk or telephone 0808 800 6001

Visit www.cancerbackup.org.uk or telephone 0808 800 1234

Complementary therapies

Having a diagnosis of cancer is nearly always accompanied by confusion; a feeling of anxiety and a sense that life will never be the same again.

Holistic or complementary therapies can offer treatment options that in some cases may complement conventional approaches. Complementary therapies can help promote a state of relaxation and a feeling of calm. Through alleviating stress, the body has more energy to concentrate on healing, both physically and emotionally.

If you are considering complementary forms of medicine, please do not hesitate to discuss this with your breast care specialist nurse.

For further information contact:

The Mary Wallace Cancer Support Centre

7 Red Cross Lane

Cambridge

Telephone: 01223 596379

Or visit: www.cancerbackup.org.uk

Breast reconstruction

If you are to have a mastectomy for breast cancer treatment or in some cases ductal carcinoma in situ (DCIS) we will discuss the various options with you. If you are suitable for breast reconstruction you will be referred to a plastic surgeon.

Some women choose to have no reconstruction at the time of primary treatment. For many the treatment of breast cancer is sufficient and they prefer to defer decisions on breast reconstruction. Other women may find that they are overwhelmed by the amount of information that needs to be considered before reconstruction.

Some women may opt for a delayed reconstruction. For other women immediate reconstruction helps them come to terms with the need for their surgery and is an integral part of their cancer treatment.

Breast reconstruction is not a replacement breast, but provides a mound in order that the emotional impact of the loss of a breast is reduced. There will then be no need for an external prosthesis.

Immediate breast reconstruction

Immediate breast reconstruction is offered at the same time as your mastectomy. There are several advantages of immediate reconstruction:

- The avoidance of a period of time without a breast mound.
- The preservation of the natural skin of the breast in a skin sparing mastectomy may give the breast a more natural appearance.
- A planned delayed reconstruction may be perceived as yet another operation.

Breast reconstruction does not prevent the detection of recurrent cancers.

It is important to remember though that even immediate breast reconstruction may mean more than one operation to create a breast and nipple. And there may be minor adjustments that need doing.

If **radiotherapy** to the chest wall is recommended after mastectomy you may be advised not to have immediate reconstruction. The radiation may effect the reconstruction. If an implant is used, there is a higher risk of capsule formation (hardening of the prosthesis) and the reconstructed breast becomes hard. If another part of the body is used in the breast reconstruction, this transferred tissue is also vulnerable to the effects of radiotherapy.

Delayed reconstruction

Women who choose delayed reconstruction may have experienced the physical and emotional effects of a flat chest following their mastectomy and difficulties dealing with a prosthesis. After about a year to allow the body as a whole to recover, you may consider a delayed reconstruction. Some advantages are:

- Your other treatments are now completed.
- You will have had more time to come to terms with your breast cancer, diagnosis and treatment.

Similar choices of reconstructive options are offered to women considering immediate reconstruction. Each option will be discussed with you to suit your individual need.

You will be referred to the plastic surgeons to discuss the best reconstruction option and given the contact number for the breast care reconstruction specialist nurse.

Further tests if required

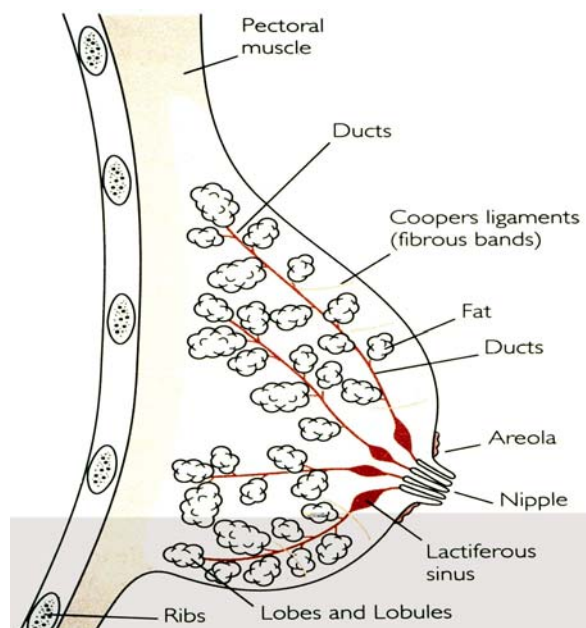
Breast cancer may affect other bodily functions if it spreads away from the breast; either via the blood stream or the lymphatic system. The usual sites that can be involved are:

- the liver
- the lungs
- the bones

The following tests are sometimes done to detect or monitor these abnormalities

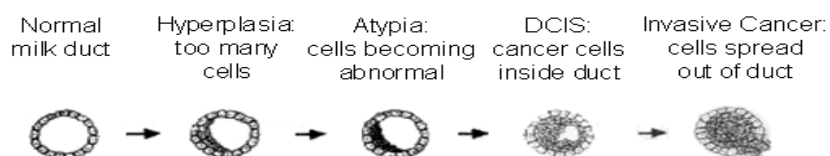
- **Blood tests** - to assess general well being and liver function.
- **Chest x-ray** – to rule out any lung or bone problems.
- **Liver scan** – either an ultrasonic scan or CT of the liver to look for abnormalities.
- **Bone scan** – to look for bone spread. This involves using a low dose radioactive tracer, which can highlight any abnormalities particularly in the spine and ribs.
- **Magnetic resonance imaging (MRI)**. This is a scan that uses a magnetic field and radio waves rather than x-rays, which with the help of a computer, can build up a detailed picture of the body. It is used as an additional test to mammography to help diagnose breast disease.

Ductal Carcinoma in Situ



What is DCIS?

Ductal carcinoma in situ (DCIS) is a change to the cells that line the ducts of the breast. If left untreated it may develop into a breast cancer. When DCIS develops, the cells that line the ducts grow out of control but **do not move outside the duct**.



How will I know if I have DCIS?

Most women with DCIS have no signs or symptoms, although a few will develop a lump or nipple discharge. DCIS is mostly seen on mammograms as small specks of calcium.

Why should DCIS be treated?

The cells within the breast ducts that have developed into DCIS, if left untreated, may go on to become an invasive cancer that can spread to other areas.

How is DCIS treated?

Depending on the type of DCIS you have and its appearance under the microscope, your surgeon may give you a choice of operations.

- **Wide local excision** – Surgery to remove DCIS. Under a general anaesthetic your surgeon will remove the DCIS with a small area of healthy tissue around it. This treatment is most effective for women with a small area of DCIS.
 - **Advantages:**
 - Most of the breast remains intact.
 - **Disadvantages:**
 - Some DCIS may be missed because it was not always visible on mammograms.
 - DCIS can come back or invasive cancer can develop from any DCIS left behind.
- **Wide local excision plus radiotherapy** – Surgery to remove the area of DCIS, followed by radiotherapy. Under a general anaesthetic your surgeon removes the abnormal tissue and a small area of healthy tissue around it. Six weeks after your surgery radiotherapy is then given to the breast. This is an x-ray treatment, which kills cancer cells and reduces the risk of further DCIS or invasive cancer developing in the breast.

Within the Eastern region, radiotherapy is usually carried out at Addenbrookes Hospital Cambridge or the North Middlesex Hospital (for Epping/Harlow patients).

- **Disadvantages:**
 - Radiotherapy is given daily over a period of three weeks and this means frequent visits to Cambridge (Monday to Friday).
 - Side effects from radiotherapy.
 - There is still a small risk of DCIS or invasive cancer coming back.

DCIS does not usually involve removing the lymph glands under the arm (axilla). In certain cases your surgeon may discuss removing just a few lymph glands (SLN).

- **Mastectomy** – Surgery to remove the whole breast. Under a general anaesthetic the whole breast, including the nipple is removed. There is usually one long scar on the chest wall. For large areas of DCIS this may be the only treatment, though you may want to consider breast reconstruction.
 - **Advantages:**
 - Radiotherapy is not usually required. The chance of DCIS or invasive cancer returning is very small.
 - **Disadvantages:**
 - The whole breast is removed.

Please see pages 28, 29 and 42 for more information.

Who can I talk to?

Your breast care nurses are very happy to discuss any worries or fears.

Breast Cancer Care has a good support network in this area and your Breast Care Nurse will be happy to put you in touch with them.

You can seek a second opinion if you are unsure of what option you want to follow.

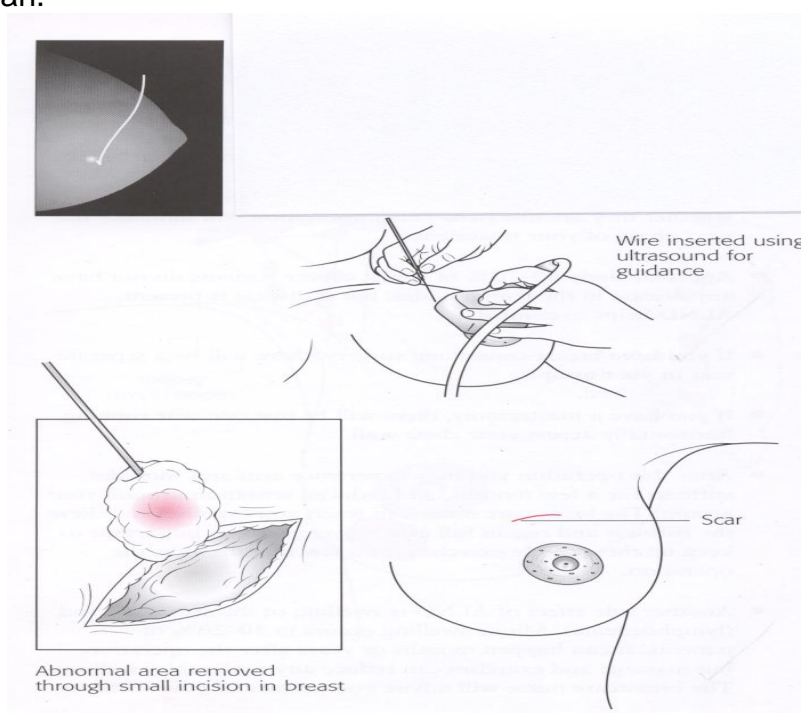
Breast surgery using a wire guide

Why do I need a wire insertion before surgery?

Mammograms are able to pick up very small areas in the breast that need further investigation and often these areas cannot be felt. It has been recommended that you have a small area of your breast removed under general anaesthetic because the area cannot be felt. It will therefore be necessary to pass a small wire into your breast to guide the surgeon during the operation.

How is it done?

On the day of your operation, you will be taken to the breast unit. A local anaesthetic is injected into the breast to numb it before a radiologist inserts a fine guide wire with the aid of an ultrasound scan.



The wire is left in place while you are taken to the operating theatre and given a general anaesthetic. The surgeon then removes the abnormal area using the wire as a guide. To ensure the correct area is removed, the breast tissue is x-rayed while you are still asleep. The breast tissue that is removed is then sent to the pathologist for further analysis.

You will have a small scar 3 – 5 cm long and you will have dissolvable stitches and steri-strips over your wound. You should be able to go home within 24 hours of your surgery.

When will I know the results?

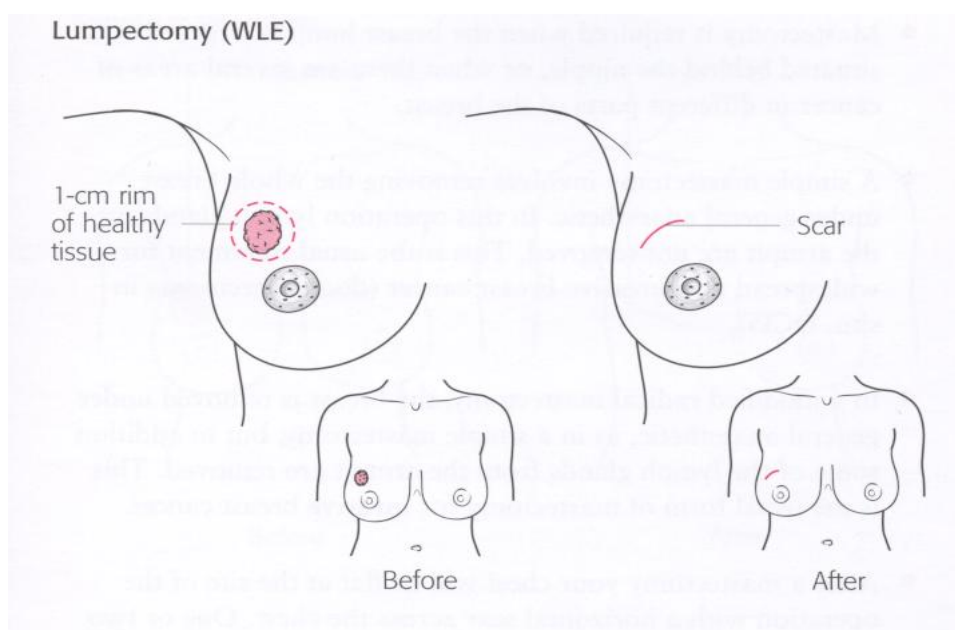
Before leaving the ward, you will be given a date to return to the Breast Unit for the results of your surgery, in two weeks.

Any further treatment that is recommended will be discussed with you then.

Wide Local Excision (Lumpectomy)

You have been recommended to have a wide local excision of your breast cancer (sometimes called a lumpectomy). It involves removing the breast lump with about 1cm of healthy breast tissue. The appearance of the breast afterward is usually good, as excessive amounts of breast tissue are not removed.

In about 5 – 10% of cases a second operation is required because cancer cells are seen under the microscope extending up to the edge of the breast tissue that was removed.



Following your wide local excision you will be offered radiotherapy to the remaining part of your breast.

This treatment reduces the chance of the tumour recurring in the breast and is standard practice now in the UK. The radiotherapy will be carried out in an Oncology centre and will be coordinated by a Consultant Oncologist.

Radiotherapy is normally given five to six weeks after surgery and is administered for a short time each day, Monday – Friday, over a three and a half week period.

When will I know the results?

Before leaving the ward, you will be given a date to return to the breast unit for the results of your surgery, in two weeks time. Any further treatment will be discussed with you then.

Adjuvant systemic therapy (more treatment)

Despite adequate regional treatment of breast cancer (surgery with or without radiotherapy) the cancer in some cases can come back afterwards. This is due to cancer

cells that spread from the original tumour and cannot be detected by any of our current testing mechanisms. We can predict the risk of cancer coming back based on features from your original tumour such as:

- Size
- Whether any of the lymph nodes taken were involved
- Grade of the tumour

We use these results to decide whether you should have any further treatment.

There are several different types of adjuvant therapy, which have been shown to improve your survival. These include:

- Chemotherapy
- Suppression (drug therapy)or removal of the ovaries (surgery)
- Hormone therapy (for example, tamoxifen, aromatase inhibitor)
- Herceptin

An individual adjuvant treatment plan will be recommended based on your pathology results and whether or not you continue to have periods (pre or post menopausal).

Further information on these treatments will be given to you when your treatment plan is discussed.

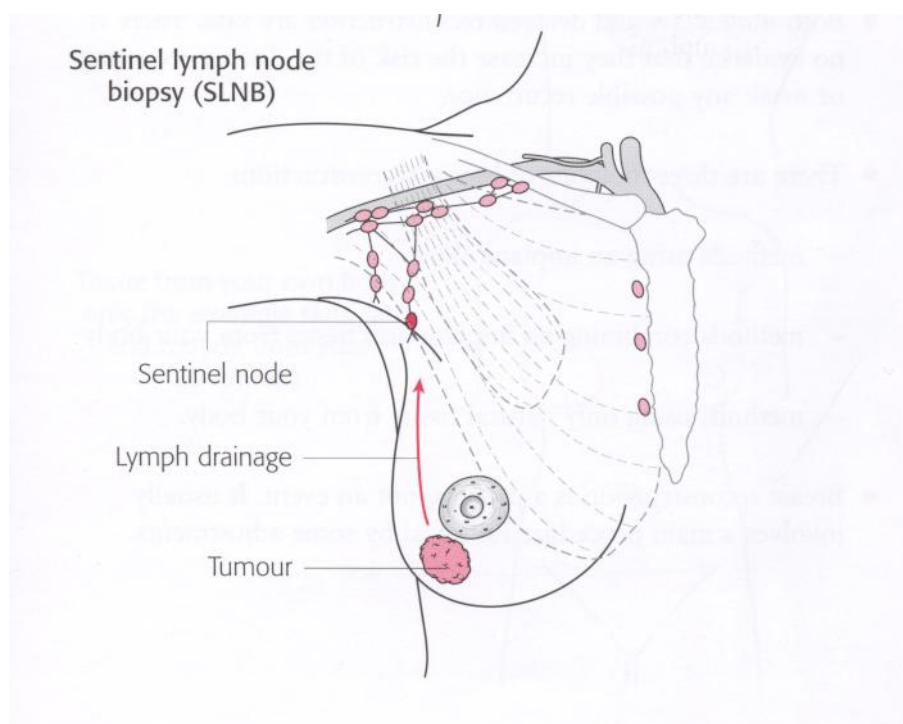
Axillary surgery

The lymph nodes under the arm (axilla) drain a large area of lymphatic fluid from the breast. Sometimes breast cancer can spread to the lymph glands under the arm. As part of your breast cancer treatment, we have recommended the removal of some lymph glands to determine whether they have been affected by cancer or not.

Sentinel Lymph Node Biopsy (SLN)

SLN is a new technique that usually removes only a small number of glands. The 'sentinel lymph node' is the first to receive lymph fluid from the breast and is therefore most likely to contain cancer cells if they have spread.

As only a third of patients have affected lymph glands this avoids having all of the glands removed in the majority of patients.



How is the SLN Identified?

Between 4 – 24 hours before your operation a small amount of radioisotope tracer is injected into your breast. From there it is carried into the armpit by the lymph vessels. While you are asleep blue dye is injected around the areola (pigmented area around the nipple), and this also travels to the SLN by a similar route as the radioactive tracer.

During the operation we will use a probe to identify any SLN's that have been highlighted by the radioactive tracer and the blue dye. The SLN's will be removed for pathological examination.

If we cannot identify the SLN because neither dye nor tracer has reached the lymph glands in the armpit (this occurs in approximately 4-5% of patients), we will proceed to remove the majority of the remaining lymph glands.

In rare circumstances, when it is obvious that the SLN is involved with cancer, we will remove the remaining lymph glands in your armpit during the same operation.

Based on the experience of other international centres, there is a small possibility that by adopting the technique of removing only one or two glands an occasional gland containing tumour cells may be left behind. This occurs in less than 5% - 10% of all patients.

Are there any side effects from the radioactive tracer or blue dye?

We do not expect any specific risks from the radioactive tracer, as the dose is less than the natural dose that you would receive from the environment over three months. The blue dye injection may cause blue discoloration of the urine for a few days following the operation. A blue discoloration of the skin can last for up to three months, or more after the operation. Mild allergic reactions to the blue dye can occur in less than 1.8% of patients. More severe allergic reactions are rare and occur in only 0.2% of patients (ie in two patients for every 1000 patients treated).

When will I get the results?

Approximately two weeks after your surgery. Following a detailed examination by the pathologists we will know if the SLN is involved with cancer cells or not. You will be given an appointment to come back to the breast unit before you go home.

If this further analysis does show cancer cells in one or more SLN's, a second operation will be necessary to remove further lymph glands from the armpit.

This second operation will usually take place approximately two weeks after your pathology results are available.

Wound care

It is recommended that you wear a bra as soon as possible following your surgery. This will act as a support to your breast.

- Your dressing will be removed after two to seven days.
- You will have dissolvable stitches that take about four to five months to dissolve and steri strips (small pieces of tape) over the wound. They help wound healing and improve the final appearance of the scar. You can remove these after seven days in the bath or shower.
- Your scar may feel lumpy and firm during this time.
- You may lightly shower or bath once the dressing is removed but do not get the wound soaked for a few days.

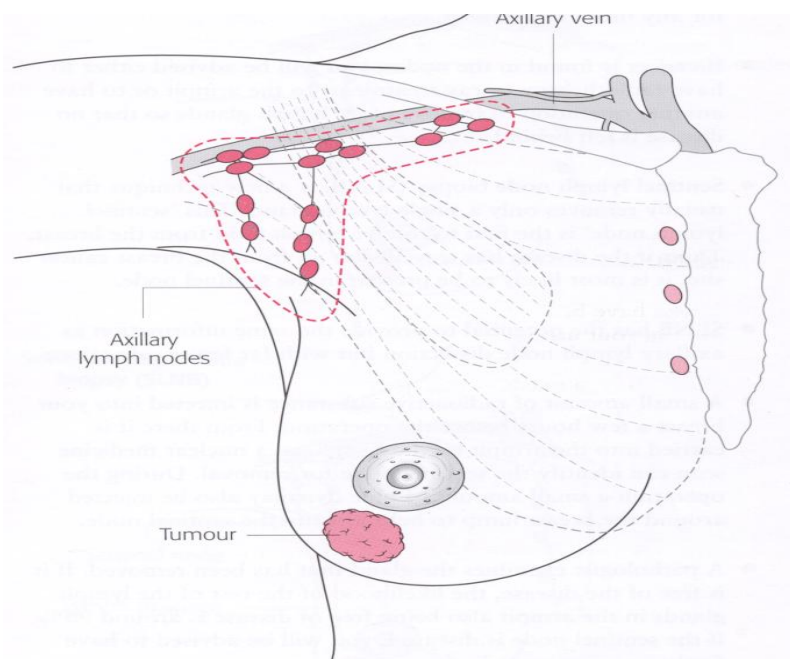
- Following your surgery you may feel that there is some fluid (serum) in the wound. Serum is a clear straw coloured fluid produced by all wounds. A **seroma** is a collection of this fluid deep to the wound and the body normally absorbs it. This is nothing to worry about and will usually disperse.
- However if the wound becomes red, inflamed or painful this may be a sign of infection. This may settle down but if you are concerned contact your district nurse or GP. Alternatively you may contact in the first instance the breast specialist nurses on:

01223 596093

01223 586960

Axillary surgery

The lymph nodes under the arm (axilla) drain a large area of the lymphatic fluid from the breast. Sometimes cancer cells from the tumour can spread to the lymph nodes. You have been advised to have an axillary clearance, which removes the majority of these nodes. This will reduce the chance of a local recurrence of the cancer under the arm. We will also be able to see if the nodes are involved with cancer; this in turn helps us plan any adjuvant therapy (further treatment).



Are there any side effects from an axillary clearance?

Following an axillary clearance a number of patients will experience:

- Swelling of the arm (lymphoedema)
- A sensation of numbness and tingling on the inner aspect of the upper arm as a result of the division of a nerve, which supplies the skin of that part of the arm.
- Shoulder stiffness. You will be given some exercises to overcome this problem

Wound care

- Immediately after your operation you may have wound drains in place and a dressing over the wound. These drains collect tissue fluid into a small container, which is emptied daily. If you think how much fluid there is in a small blister you can imagine how much fluid collects after a breast operation. If this is not removed you may become very uncomfortable.
- The drain will be removed after two to five days when the volume is less than 50 mls.

- You may remain in hospital until the drain is removed or you can go home with the drain. This will be discussed with you. The District Nurse will visit you daily to assess the drainage and empty the drain; she will then remove it for you at the right time.
- Your dressing will be removed after two to three days. You will have dissolvable stitches in place, which will take four to five months to dissolve, and steri strips (small pieces of tape) over the wound. They help wound healing and improve the scar. You can remove these after seven days in the bath or by shower.
- Your scar may feel lumpy during this time.
- You may shower once the wound dressing has been removed, even with the drains in place, but do not soak the wound for the first few days.

- Following your surgery you may feel that there is some fluid (serum) in the wound. Serum is a clear straw coloured fluid produced by all wounds. A **seroma** is a collection of this fluid deep to the wound and the body normally absorbs it. This is nothing to worry about and will usually resolve.
- However, you may notice a large soft swelling (a bit like a golf ball) under your arm, and if it becomes painful, and causes you difficulty in putting your arm down by your side, you may have to have the fluid removed. This is normally a painless procedure and happens in about 40-50% of women.
- If the wound becomes red, inflamed or painful this may be a sign of infection. This may settle down but if you are concerned contact your district nurse or GP. Alternatively you may contact in the first instance the breast specialist's nurses on:

01223 596093

01223 586960

When will I know the results?

Before you go home you will be given an appointment for two weeks time. You will be informed how many of your lymph nodes have cancer in them and what further treatment you will need (adjuvant therapy) will be discussed with you.

Adjuvant therapy (more treatment)

Despite adequate local treatment of breast cancer (surgery with or without radiotherapy) the cancer in some cases can come back afterwards. This is due to cancer cells, which spread from the original tumour that cannot be detected by any of our current testing mechanisms. We can predict the risk of cancer coming back based on features from your original tumour such as:

- Size
- Whether any of the lymph nodes taken were involved
- Grade of the tumour

We use these results to decide whether you should have any further treatment.

There are several different types of adjuvant therapy, which have been shown to improve your survival. These include:

- Chemotherapy
- Suppression or removal of the ovaries
- Hormone therapy (for example, tamoxifen, aromatase inhibitor)
- Herceptin

An Individual adjuvant treatment plan will be recommended to you based on your pathology results and your menopausal status (pre or post menopausal).

Further information on these treatments will be given to you when your treatment plan is discussed.

Swelling of the arm (lymphoedema)

It is quite normal to experience some swelling around the area of the operation and occasionally in the arm after surgery to treat breast cancer. This usually improves within a few weeks as the wound heals.

However a small minority of people experience more persistent arm swelling which becomes lymphoedema. It might occur at any time following surgery. Usually it would be a few months later but sometimes it is several years. It isn't possible to estimate one person's risk against another, therefore guidance regarding the risks and suggestions for prevention are available to everyone who has axillary lymph node surgery.

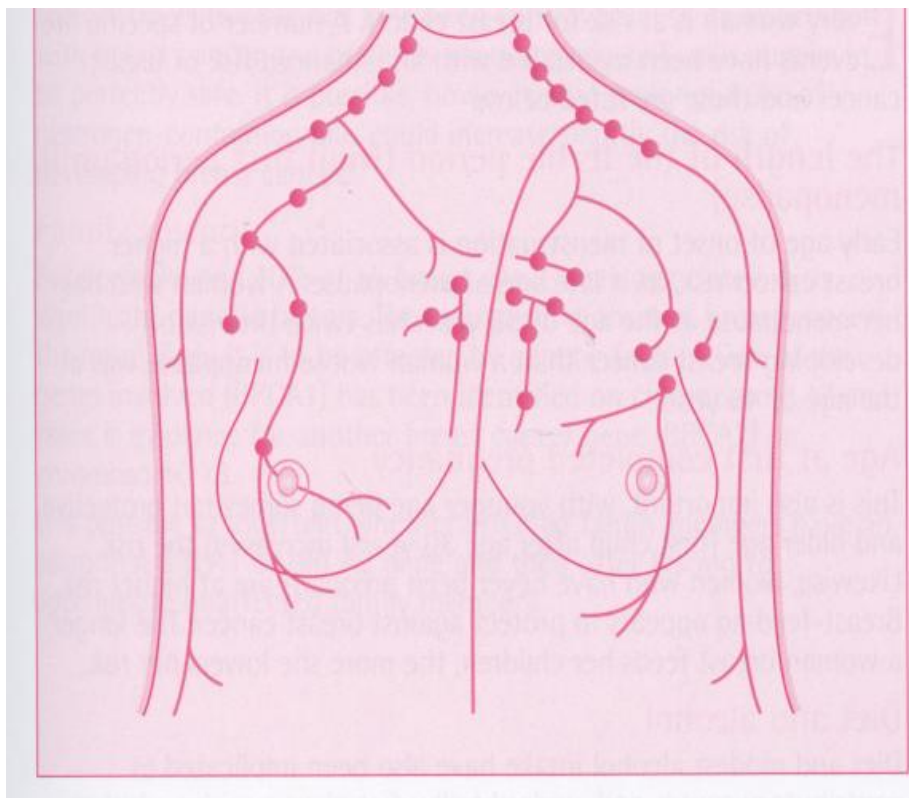
What is lymphoedema and why does it happen?

Lymphoedema is associated with cancer treatment, when lymph nodes are treated either with axillary clearance surgery, or with radiotherapy. Either of these treatments can cause damage to the vessels connected to lymph nodes, probably through the formation of scar tissue. Therefore, in some people, there can be an impairment of the lymphatic system in that area of the body.

When the function of the lymphatic system is impaired or damaged (despite successful cancer treatment), it means the system works less effectively, and as a result an increase of fluid accumulates in the tissues. If the lymph vessels cannot keep up with the extra demands on their drainage capacity, then swelling can develop which is called lymphoedema, as the fluid cannot drain away.

What is lymph?

Lymph is a colourless fluid that forms in tissues of the body. It normally drains back into the blood circulation through a network of vessels and nodes called the lymphatic system. Oedema means swelling.



Lymph nodes in the upper body

What do I do?

Discuss the problem with your GP, or your breast care nurse, who will refer you to the breast clinic for assessment of the swelling. You are likely to be referred to the lymphoedema clinic for advice on treatment. It is possible that you will be referred for investigations, as very occasionally swelling can be an indication of recurrence of breast cancer.

Caring for your arm after surgery

There are some simple precautions you can take to reduce the risk of developing lymphoedema and the following section highlights the ways in which you can help by taking extra care.

As one of the functions of the lymphatic system and lymph nodes is to help fight infection, much of the advice is to look after your skin and avoid damage. If the majority of the axillary (under the arm) lymph nodes have been removed you may be more prone to developing an infection on this arm or hand.

In reducing risk of damage you will reduce the risk of infection, which could potentially lead to the disturbance of the lymphatic system and lymphoedema.

Also, putting additional strain on the arm can overload the remaining lymph drainage pathways, so the following is advised:

- Use the other arm to carry heavy cases or shopping bags.
- Avoid using this arm continually for repetitive movement without taking a break.
- Use your arm as normally as possible as movement helps the lymphatic system.
- After surgery introduce other activities and sports gradually, building up gently.
- Wear gloves for protection when doing household task, taking hot dishes out of the oven and gardening.
- Rubber gloves should be worn when using harsh detergents or steel wool etc.
- Whenever possible avoid having injections, blood samples or blood pressure measurements taken on this arm.
- Electric shavers or hair remover cream should be used for underarm hair removal
- Treat even small grazes, cuts or insect bites with antiseptic and keep them clean until healed. See your GP at the first signs of infection – if the skin becomes inflamed or feels warm or tender. Your GP will prescribe a course of antibiotics.
- Take extra care with fingernails and cuticles, as damage to surrounding skin can lead to potential infection. Use hand/cuticle cream regularly.
- Use insect repellent to prevent bites while you are on holiday or in the garden.

Please remember that the aim of this information is for lifelong guidance rather than postoperative treatment advice.

Breast Radiotherapy

Radiotherapy treats breast cancer using machines called **linear accelerators** that produce high-energy X-rays.

Treatment planning

- Before starting your course of radiotherapy it is necessary to plan the treatment.
- The planning session lasts approximately 30-45 minutes and takes place in the simulator or on the radiotherapy CT scanner. You will be required to lie still with both arms raised above your head during radiotherapy.
- You will need to remove the top half of your clothing to allow the treatment area to be marked. Vest tops are ideal garments to wear or gowns/covers are available.
- During the planning session the machine will move and the room lights dim.
- Each patient will have an individualised plan to treat the breast/chest wall area. For some patients the lymph nodes in the armpit and/or the area above the collarbone will also be treated.
- During planning, reference points on the skin will be defined using several small tattoos (usually two to four tattoos). The tattoos are made with dark ink and feel like a pin prick when each tattoo is done. They are about the size of a pinhead and are permanent, but may fade with time.

Radiotherapy treatment

It takes time to produce the individualised plan so there will be a gap between the treatment planning appointment and the start of treatment.

Radiographers on a linear accelerator carry out treatment, and they will explain the procedure before the first treatment. You will be in the treatment room for 10-15 minutes but the treatment is much less. Treatment is delivered from several directions and the machine moves around you during treatment and comes close, but will not touch you.

When the radiographers are satisfied with your position they will leave the treatment room, but they can see you on close circuit television throughout the treatment. You should not feel anything during treatment but the machine does make a noise. You must keep still during treatment but continue to breathe and swallow normally.

Boost

Some people will require boost treatment to the area where the cancer was removed. This treatment may be planned during the first planning session or a separate clinic visit. The

treatment area will be marked on your skin and a map of the treatment area taken. It is not necessary to keep these pen marks on.

Radiotherapy review

During your course of treatment you will have clinic appointments with a doctor or a specialist radiographer to see how you are getting on and sort out any problems. In addition, the radiographers will be happy to discuss any concerns on a daily basis.

Side effects

Radiotherapy affects everybody differently. Many people will experience little or no side effects.

During radiotherapy

Any side effects that occur during treatment should be temporary.

- Radiotherapy can sometimes cause some soreness, reddening to the skin within the treatment area. Therefore it is important to look after your skin and avoid any irritants.
- Levels of tiredness vary greatly between individuals. Generally tiredness increases as the treatment progresses and may continue for several weeks/months after the end of the treatment.
- Hair loss only occurs in the treated area and does not affect the hair on the rest of the body.

Please see '**Advice for radiotherapy patients-breast**' information sheet for advice on how to look after yourself during and after your treatment.

After radiotherapy

Side effects experienced during treatment usually reach a peak approximately one to two weeks after completion of treatment and usually take several weeks to settle down. The radiographers will advise you about post-radiotherapy skin care. Once the skin starts to return to normal, you can begin to reintroduce products. If irritation occurs leave it a few more days and then try again.

Long-term effects

Long-term effects are **uncommon** but can occur in a **small percentage** of people.

- Radiotherapy can cause the breast tissue to become more fibrous and less elastic. This can lead to shrinkage and firmness of the breast. People who have had breast reconstruction with implants may experience contraction of the capsule around the implant. Occasionally it is necessary to remove the implant.
- There may be a change in the appearance of the skin. The skin within the treated area may appear slightly darker. In some cases the blood vessels may become dilated, giving the appearance of broken vessels in the skin. This effect is known as telangiectasia. Though this can be unsightly, it does not cause any problems.
- Breast pain, tenderness and sometimes swelling may be experienced several months after treatment.

Rare side effects

Modern radiotherapy techniques mean the following side effects are extremely rare and do not occur in the majority of cases.

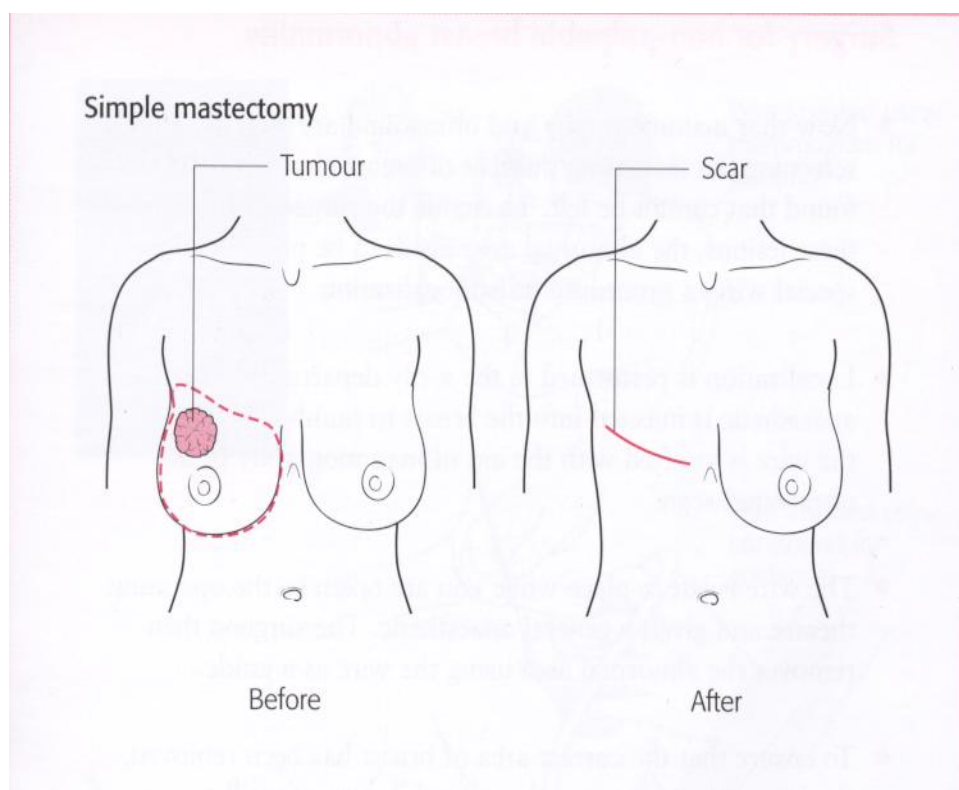
- A small part of lung may be included in the treated area. In a very few cases this may result in a degree of breathlessness.
- Radiation can in some cases affect the heart if the left breast is treated. The risk of heart damage is slightly higher in patients with known heart problems before radiotherapy and if certain types of chemotherapy have been received.
- Some patients may experience weakening of the bones, which may result in fractures of the ribs, and collarbone.
- Rarely damage to the nerves in the arm can occur which may cause tingling, numbness, pain, weakness and sometimes loss of movement.
- Swelling in the arm, known as lymphoedema, may develop in some women.

Mastectomy (Removal of the breast)

You have been recommended to have a mastectomy. Mastectomy is required when:

- The breast lump is large, the breast is small or it is situated behind the nipple
- When there are several areas of cancer in different areas of the breast
- Widespread non-invasive DCIS (ductal carcinoma in situ).

Mastectomy involves removing the whole breast under a general anaesthetic. After the mastectomy your chest will be flat at the site of the operation with a horizontal scar across the chest.



(The shape of your scar may vary slightly from the above diagram)

Wound care

- Immediately after your operation you may have wound drains in place and a dressing over the wound. These drains collect tissue fluid into a small container, which is emptied daily. If you think how much fluid there is in a small blister you can imagine how much fluid collects after a breast operation and if this is not removed you may become very uncomfortable. The drain will be removed after two to five days when the volume is less than 50 mls.

- You may remain in hospital until the drain is removed or you can go home with the drain. This will be discussed with you. The District Nurse will visit you daily to assess the drainage and empty the drain; she will remove it for you at the right time.
- The dressing will be removed after two to seven days, you will have dissolvable stitches in place which take about four to five months to dissolve and steri strips (small pieces of tape) over the wound, they help wound healing and improve the scar. You can remove these after seven days in the bath or by shower.
- Your scar may feel lumpy during this time.
- You may shower once the wound dressing has been removed, even with the drains in place, but do not soak the wound for the first few days.
- Following your surgery your wound will be bruised and there may also be a build up of fluid which can make it swollen and puffy for a while. This should gradually disappear over a few weeks.
- Occasionally, quite a lot of fluid can build up in the areas around the wound; and you may hear a gurgling noise. This is known as a **seroma** and can be drained off by the Specialist nurses.
- However if the wound becomes red, inflamed or painful this may be a sign of infection. This may settle down but if you are concerned contact your district nurse or GP. Alternatively in the first instance the breast specialist nurses on:

01223 596093

01223 586960

When will I know the results?

Before you go home you will be given an appointment for two weeks time. You will be informed of the results from the histopathological examination of the breast tissue. Any further treatment (adjuvant treatment) you may need will be discussed with you then.

Adjuvant therapy (more treatment)

Despite adequate local treatment of breast cancer (surgery with or without radiotherapy) the cancer can come back. This is due to cancer cells which spread from the original tumour and cannot be detected by any of our current testing mechanisms. We can predict the risk of cancer coming back based on features from your original tumour such as:

- Size
- Whether any of the lymph nodes taken were involved
- Grade of the tumour

We use these results to decide whether you should have any further treatment.

There are several different types of adjuvant therapy which have been shown to improve your survival. These include

- Chemotherapy
- Suppression or removal of the ovaries
- Hormone therapy
- Herceptin

An individual adjuvant treatment plan will be recommended to you based on your pathology results and your menopausal status (pre or post menopausal).

Further information on these treatments will be given to you when your treatment plan is discussed

Breast prosthesis

Immediately after a mastectomy you may be concerned about your appearance. Before you leave hospital, the breast care nurse or ward nurse will fit you with a lightweight fabric breast form or comfee.

As it will take several weeks for your wound to heal, you can wear your comfee to give you shape and some protection. It can be worn inside your bra, or pinned to your vest, cami-top or petticoat.

When will my permanent prosthesis be fitted?

A more permanent prosthesis (breast form) is usually offered to you about six to eight weeks after your surgery when the wound has healed and your skin has become less sensitive.

If you are due to have radiotherapy, it is better to wait until three to four weeks after this has been completed.

The permanent breast form is made to closely simulate the shape size and softness of your natural breast. It is weighted to give the correct balance.

When you come for your fitting please bring your bras with you and a couple of your favourite tops, so that you can see and feel how your breast form will look when you are fully dressed.

Your prosthesis will be fitted free of charge and renewed every two to three years depending on the manufacturers guarantee time.

Before your appointment for prosthesis fitting

It is important to have a well fitting bra to ensure that your prosthesis is held securely within the cup. There are many choices of suitable bras on the market. Ideally you should have an under-band of approximately one inch and a half-inch space centrally between the cups. There are specialist firms, which make mastectomy bras (pocket lined bras) and some patients like to use these. Wired bras can be worn if they are properly fitted.

Most large department stores, as well as specialist underwear shops, will have trained fitters who are used to advising women who have had breast surgery, and will help you find the most suitable choice for you. If you feel that your current bras may not be suitable, please seek advice.

Local retailers:

- Robert Sayle
- Marks and Spencer

- Douglas (Great Shelford)
- Harways (Newmarket)
- Eloise Lingerie (near Bury St Edmunds)

(They offer a fitting service and have a mail ordering facility. This is by appointment only 01284 828787).

Specialist activities:

Your breast specialist nurse will be able to give you advice about items such as swimwear.

Hormone therapy

Hormone therapy is an effective form of treatment for breast cancer. The female hormone, oestrogen, can encourage the growth of breast tumours. Hormone therapy can cause the cancer cells to grow slowly or stop growing, by either blocking the production of oestrogen or preventing its action on cells.

Oestrogen is a natural female hormone. It is produced mainly by the ovaries until the menopause, after which the ovaries cease to function. Following the menopause the adrenal glands and fatty layers under the skin produce small amounts of oestrogen.

Tamoxifen

Tamoxifen is a drug commonly used as part of the treatment for breast cancer. It belongs to a group of drugs known as endocrine or hormonal agents and is also described as an anti-oestrogen drug.

How does Tamoxifen work?

The hormone oestrogen stimulates some breast cancers. These cancers are known as oestrogen receptor positive tumours. Tamoxifen works partly by blocking the effects of oestrogen on cancer cells, so stopping them from growing – this is why it is called anti-oestrogen.

What are the benefits of taking Tamoxifen?

Taking tamoxifen significantly reduces the risk of oestrogen receptive cancers coming back and improves overall survival in all age groups. For women who have been through the menopause there is some evidence to suggest that tamoxifen slows down the process of bone loss, reducing the risk of osteoporosis (thinning of the bones). Long-term changes in the pattern of various diseases have been recognised in large groups of patients taking tamoxifen for several years. There are fewer deaths from heart disease and strokes.

What are the side effects?

The majority of women tolerate tamoxifen very well and may not experience any side effects at all. It may help to know that even if the side effects are mild other women have experienced them.

Common side effects:

- Hot flushes. These may gradually lesson over the first few months but some women continue to have them for as long as they take the hormone therapy. If

you are having troublesome hot flushes do not hesitate to discuss this with a member of the breast care team.

- Another common side effect is slight indigestion or mild nausea.
- Weight gain can be a problem for some women.

Less common side effects:

- Other possible side effects include changes in mood, vaginal dryness or discharge, itching, hair thinning dry brittle nails and alterations in normal sleep patterns. Women who are having regular periods may find that their periods become less regular, light or stop completely.

Rare side effects:

- There is a very slight risk of experiencing other side effects, which can be more serious. These include changes in your vision or thrombosis (blood clots).
- If you experience any symptoms that are not usual for you these should be reported to your doctor as soon as possible.
- Tamoxifen can also affect other parts of the body; such as the lining of the womb (endometrium), which may become thickened.
- It can rarely cause formation of polyps, ovarian cysts and cancer of the womb. The chances of this happening are extremely small. However any unexpected bleeding or pain should be reported to your doctor as soon as possible.
- Long-term side effects are monitored and you will be screened for them.

When should I take the tablets?

- A single daily dose is usually prescribed (20mg).
- For most women, meal times are generally consistent and although tamoxifen does not need to be taken with food, some women find this helpful in combating any initial nausea at the beginning of treatment.
- The time of day does not matter, it is only important to get into a routine.
- Tamoxifen takes some weeks to build up in the body, so although it is important to take the tablets regularly, an **occasional** missed dose does not really matter.

Remember to take them on holiday with you.

Will Tamoxifen affect my fertility?

Tamoxifen is not a contraceptive and you must use other precautions to avoid pregnancy, even if your periods stop while on treatment.

The specialist nurses in breast care will be happy to discuss the options, which are available to you.

If you are considering pregnancy following a diagnosis of breast cancer you should discuss this with your breast cancer specialist.

It must be stressed that the benefits of tamoxifen greatly outweigh the risks associated with its use.

References

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Please ask if you require this information in other languages, large print or audio format: 01223 216032 or patient.information@addenbrookes.nhs.uk

Potete chiedere di ottenere queste informazioni in altre lingue, in stampato grande o in audiocassetta.

Italian

若你需要本信息的繁體中文、大字體或音訊格式的版本，請要求索取。

Cantonese

तमने आ माहिती वीछ भाषाओमां, मोटा अक्षरोमां अथवा सांभजी शकाय ओवा माध्यम (ओडीओ डोमेन्ट)मां जेठती छोय तो कृपा करीने पूछो.

Gujarati

تکایه پرسیار بکه نه گهر نه وزانیاریهت دهوی به زمانیکی تر . به بیٹی گه وره یانیش به شیوهی دهنگ

Kurdish

آگر آپ کو یہ معلومات دوسری زبانوں میں، بڑے الفاظ کی اشاعت میں یا آڈیو ٹیپ پر درکار ہوں تو براہ مہربانی اس کیلئے درخواست کریں۔

Urdu



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For advice on quitting, contact your GP or the NHS smoking helpline free, 0800 169 0 169

Document history

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