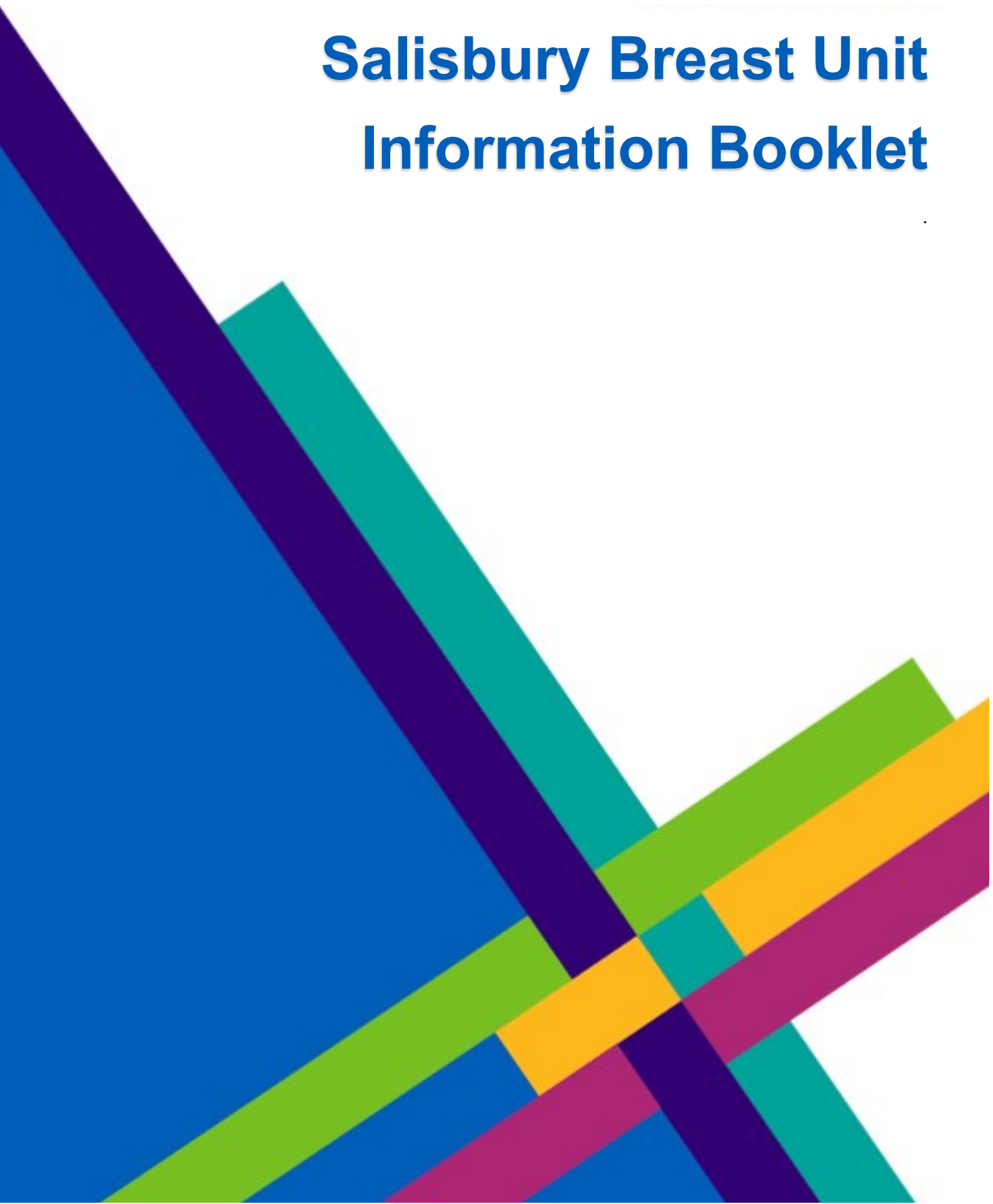




Salisbury
NHS Foundation Trust

Salisbury Breast Unit Information Booklet



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This booklet has been produced to provide you with information throughout your care.

We hope that this booklet will be helpful to you. Further written information will be given as appropriate at each stage of your care pathway

If you need your information in another language or medium (audio, large print, etc) please contact Customer Care on 0800 374 208 or send an email to: customercare@salisbury.nhs.uk

You are entitled to a copy of any letter we write about you. Please ask if you want one when you come to the hospital.

Please complete The Friends & Family Test to tell us about your experience at: www.salisbury.nhs.uk/patients-visitors/friends-and-family-test/ or download our App from the Apple App store or Google Play Store.

The evidence used in the preparation of this leaflet is available on request. Please email: patient.information@salisbury.nhs.uk if you would like a reference list.

If you think of something that is not included in this booklet, and you think that it would help others if it were included, please contact the Breast Team on 01722 033 620 (ext. 5910) or email: patient.information@salisbury.nhs.uk

Important milestones

Initial clinic visit

Diagnosis of breast cancer

keyworker: _____

Pre-operative check with Breast Specialist Nurses

Date: _____

Time: _____

Place: Pre-operative Assessment Unit

Operation

Date: _____

Time: _____

Place: Surgical Admissions Lounge / Day Surgery Unit

Post-operative visit

Date: _____

Time: _____

Place: The Breast Unit

Consultant: Miss A Aertssen ☐

Miss V Brown ☐

Miss R Fiddes ☐

Oncology appointment in Nunton Unit

Date: _____

Time: _____

Consultant: Dr J Bradbury ☐

Radiotherapy appointment

Date: _____

Time: _____

Place: _____

Consultant: _____

Date: _____

Time: _____

Place: _____

Consultant: _____

Other appointments

Date: _____

Time: _____

Place: _____

Consultant: _____

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Place: _____

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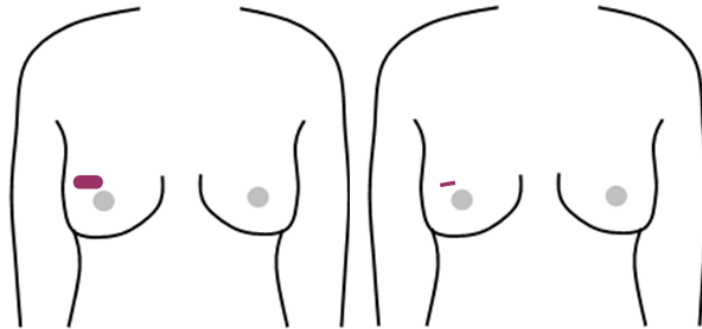
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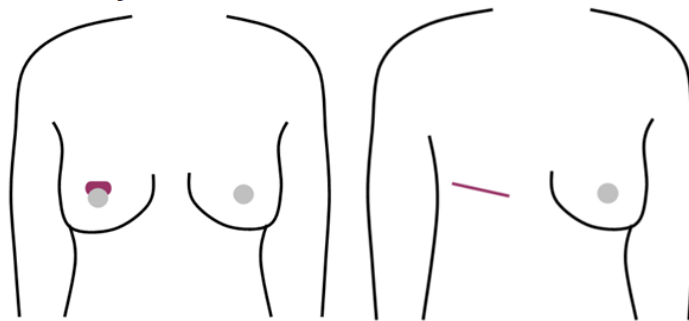
Your treatment plan - to be completed by your Surgeon/Clinical Nurse Specialist

Surgical treatment options to the breast:

Breast-conserving surgery (wide local excision or lumpectomy:



Mastectomy:



Surgical treatment options to the axilla (armpit)

- Axillary Clearance - remove lymph nodes draining the breast
- Sentinel Node Biopsy - selected lymph nodes are removed and analysed.

Post-operative results

- Tumour size:
- Tumour grade:
- Lymph nodes:
- Oestrogen receptor:
- Her 2 receptor:

Post-operative treatments

Chemotherapy -	recommended ☐	discuss this ☐	not required ☐
Radiotherapy -	recommended ☐	discuss this ☐	not required ☐
Drug therapy -	recommended ☐	discuss this ☐	not required ☐

At any stage of your care you are entitled to ask for copies of letters sent to your GP. Ask any member of your breast team who can organise this.

Treatment of breast cancer and related information

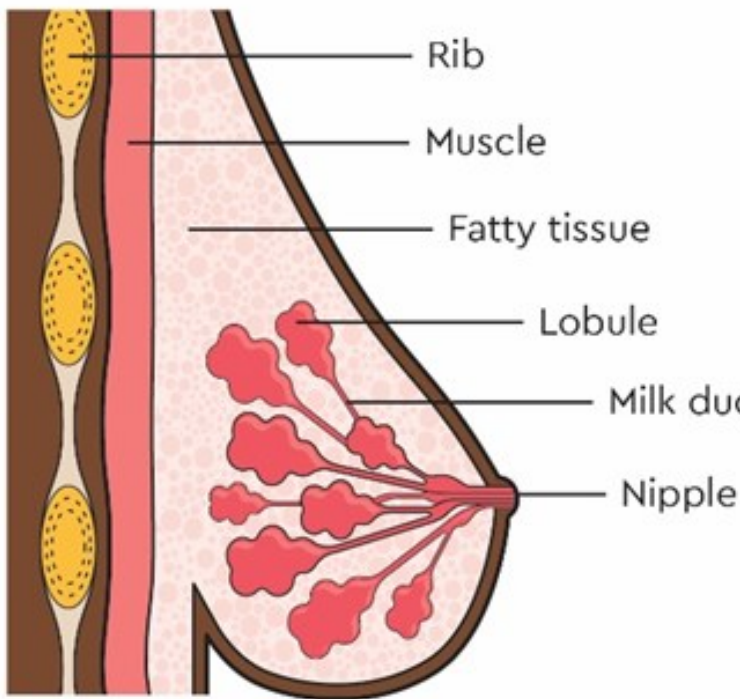
The structure of the breast

The breast is connected to muscles on the wall of your chest. It is made up of fatty tissue. In women, within the fatty tissue are lobules or milk-forming glands. Milk drains from these glands into breast ducts during breast-feeding. Milk then leaves the ducts through your nipple if you breast-feed a baby.

What is breast cancer?

Cancer begins in cells, the building blocks that make up tissues. Tissues make up the breasts and other parts of the body.

Normal cells grow and divide to form new cells as the body needs them. When normal cells grow old or get damaged, they die, and new cells take their place.



This image was produced by Macmillan Cancer Support and is reused with permission.

Sometimes, this process goes wrong. New cells form when the body doesn't need them, and old or damaged cells don't die as they should. The build up of extra cells often forms a mass of tissue called a lump, growth, or tumour.

Breast cancer cells can spread by breaking away from the original tumour. They enter blood vessels or lymph vessels, which branch into all the tissues of the body. The cancer cells may be found in lymph nodes near the breast. The cancer cells may attach to other tissues and grow to form new tumours (known as secondary tumours) that may damage those tissues.

Breast cancer can usually be diagnosed before an operation by a combination of examination, X-ray (mammogram), ultrasound and needle biopsy. Only rarely, is the disease not diagnosed before an operation and then a diagnostic biopsy is performed.

The lymphatic system

As well as a circulatory system that transports blood from the heart to the rest of the body, your body has a second circulatory system known as the lymphatic system.

The lymphatic system is made up of a network of vessels (channels) and glands called lymph nodes, which are distributed throughout the body. Lymph nodes are small, oval glands that remove

unwanted bacteria and particles from the body. They are part of the immune system (the body's natural defence system).

The lymphatic system has two important functions:

- It helps to fight infection. The lymphatic system contains a fluid called lymph, which is full of infection-fighting cells known as lymphocytes.
- It drains excess fluid from tissue. As the blood circulates through your tissue, it leaves behind waste products such as fluids and proteins. This material and fluid is removed from the tissues by the lymphatic system, which filters out any bacteria or viruses and drains the remaining lymph back into your blood.

Different types of cancer

There are two different types of breast cancer; invasive and non-invasive, they are classed depending on their ability to spread.

Non-invasive breast cancers

This type of cancer does not spread to elsewhere in the body. The most common type of non-invasive breast cancer is ductal carcinoma in situ (DCIS). Cancer cells are found inside the milk ducts but have not yet spread through the walls of the ducts into the breast tissue. Nearly everyone diagnosed with DCIS at an early stage is able to have the cancer completely removed. In some cases, DCIS may take many years to develop into an invasive form of breast cancer. Since there is often no lump, non-invasive breast cancer is usually found by breast screening.

Invasive breast cancers

Invasive breast cancer is usually spotted because it produces a lump in the breast. The most common type of invasive breast cancer is called invasive ductal carcinoma (IDC) and causes around 80% of all breast cancers. Cancer cells are found in both the ducts and the breast tissue. These cells can metastasize (spread) to other parts of the body.

Invasive lobular carcinoma (ILC) accounts for between 10-15% of all breast cancers. With ILC, cancer cells initially grow in the lobes of the breast and can spread to both other areas of the breast as well as other parts of the body.

Risk factors for breast cancer

The causes of breast cancer are not yet completely understood but there are certain factors known to increase the risk and include:

- Age. Approximately 80% of women diagnosed with breast cancer are aged over 50.
- Family history. Women whose mother, sister or daughter developed breast cancer have

increased risk of developing the disease. If any of these relatives developed breast cancer before menopause, this adds to the risk.

- Previous breast cancer. If a woman has had cancer in one breast already, there is an increased risk of developing a cancer in the other breast.
- If periods started early (before age 12) or if menopause happened after age 50.
- Women who do not have children or who have their first child after the age of 30.
- Radiation. Exposure to radiation such as radiotherapy at a young age, such as for the treatment of Hodgkin's disease.
- Taking hormones. Women who take the pill or are on HRT have a slightly increased risk of breast cancer.
- Obesity. There is some evidence to suggest that being overweight can contribute to the risk.
- Diet. Diets that are high in fat and alcohol are linked to an increased risk of breast cancer.
- Not breast feeding. There is evidence that women who breast feed are at less risk of developing breast cancer

There is **no** evidence that damage to a breast, such as a knock or bruise, causes cancer.

Why should breast cancer be treated?

With conventional treatment the long-term outlook for women with breast cancer is good. Left untreated, or treated solely by alternative means (such as diet, herbal remedies or homeopathy) the tumour will slowly progress. This results in problems of ulceration and bleeding from the breast. In the longer term there will be an increased likelihood that the tumour will spread to other parts of the body.

How is breast cancer treated?

The treatment of breast cancer involves a multidisciplinary team (MDT) approach. An MDT is a group of doctors and other health professionals with expertise in a specific cancer, who together discuss and manage an individual patient's care. They plan the treatment that is best for you. Members of this team are specialists in the surgery, pathology, drug treatment (chemotherapy) and X-ray treatment (radiotherapy) of breast cancer.

The Breast Specialist Nurse, breast clinic co-ordinator and surgeon are usually involved in your care immediately after diagnosis and they co-ordinate treatment. They are available throughout treatment to help you with any problems or questions that you may have.

The initial treatment is nearly always **surgery**. There are two main types of operation:

Breast-conserving surgery (often referred to as wide excision or Lumpectomy) – this is the

removal of the tumour with a small margin of normal tissue.

Mastectomy – complete removal of the breast and nipple.

Axillary surgery - either the operation will involve removing lymph nodes draining the breast from under the arm (axillary clearance) or sentinel lymph node biopsy. This is done to remove any tumour that may be present under the arm, to give information on the long-term outlook and also to guide further treatment, in particular chemotherapy.

Types of surgery

Breast-conserving surgery (wide excision / lumpectomy)

This operation involves removing an area of breast tissue, made up of the tumour surrounded by a narrow margin of normal tissue.

This operation is usually performed as a day case.

The skin wound is normally covered by a waterproof dressing which can be left on for up to 7 days. The Breast Specialist Nurses will discuss this with you at the pre-op assessment appointment.

Mastectomy

This is the complete removal of the breast. Normally the lymph nodes under the arm are removed through the same wound during this operation. This operation requires an overnight stay with a wound drain in place (see page 27).

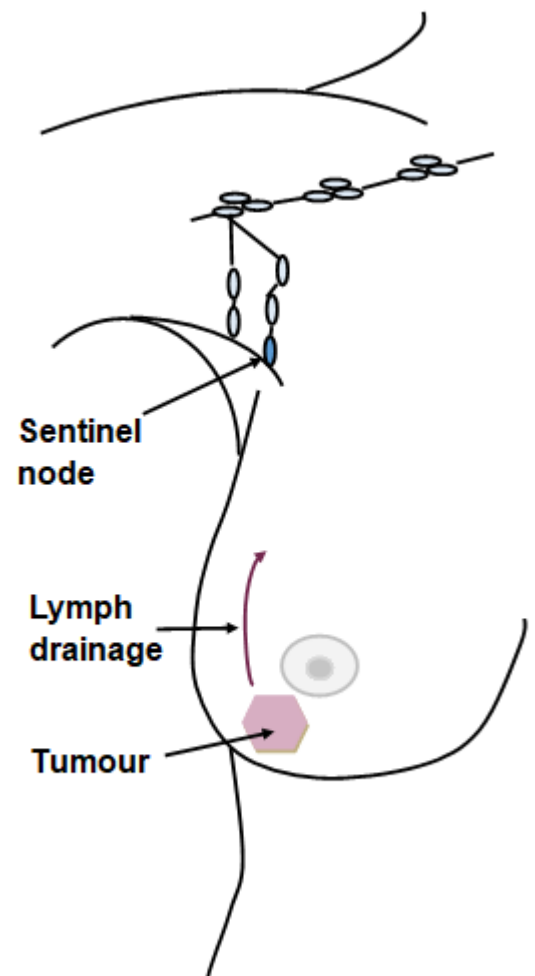
The breast is removed and the skin closed as a horizontal line across the chest wall. The wound is covered by a light waterproof dressing; this may be removed by the nursing staff to inspect the wound, but otherwise does not need any attention.

After the operation you will be fitted with a temporary lightweight breast form (Cumfie) by the Breast Specialist Nurse or ward nurse.

An appointment for the Breast Fitting Clinic, about 5 weeks after your operation for a prosthesis (breast form), will be given to you at the results clinic approximately a week after your surgery.

Sentinel Lymph Node Biopsy

This is a way of detecting any spread of cancer to the lymph nodes and is a form of sampling. It



involves injecting a small amount of radioactive material and a blue dye that identifies the first - or 'sentinel' node(s) to receive lymph fluid from the tumour.

If this sentinel node is clear it usually means that the other nodes are clear too. This means that removing the lymph nodes under the arm may be avoided. This can reduce the risk of lymphoedema.

Further surgery to remove other nodes may be carried out during the same anaesthetic if the sentinel node is affected by cancer. About 20 - 25% of people who have sentinel node biopsy go on to have further surgery to try to make sure that all the affected lymph nodes have been removed.

Sentinel node biopsy is the standard care for patients with cancers where ultrasound shows there is no evidence of lymph nodes being affected and when the surgeon cannot feel any enlarged lymph nodes in the armpit. If enlarged lymph nodes can be found with an ultrasound, or if the surgeon can feel them, then sentinel node biopsy is not a suitable procedure. Your appropriate surgery will be explained to you by your consultant.

Breast Lymph Node Assay

At this breast unit, we are able to test whether the sentinel node(s) contain cancer cells while we do your breast surgery. This one-stop test, called a breast lymph node assay, takes about 45 minutes and is performed while you are asleep under anaesthetic.

If the breast lymph node assay shows that cancer cells have spread to the sentinel lymph node(s), the surgeon will carry out an axillary clearance to remove the remaining lymph nodes that drain the breast in your armpit. This avoids the need for a second operation. This also means that you will know whether or not the breast cancer has spread to the lymph nodes, and whether a full axillary clearance was necessary, as soon as you wake up from your operation instead of waiting for the results from the pathology laboratory.

What happens next?

After you wake up from your operation, your surgeon or Breast Specialist Nurse will be able to tell you the results of the breast lymph node assay, whether any cancer cells had spread to your lymph nodes and if an axillary clearance was carried out.

The length of time you will have to stay in hospital after surgery will vary depending on the extent of your surgery, your recovery and your personal circumstances at home, but you will usually be allowed home the same or following day. When you are discharged from hospital you will be given information about taking care of your wound, the follow-up care you will receive and any side effects you may experience. If there is any thing that you do not understand, ask one of the Breast Specialist Nurses. You may find it useful to make a note of things you want to ask on the notes page in this diary.

What are the advantages and disadvantages of breast lymph node assay?

Advantages

Sentinel node biopsy is a procedure now carried out in most patients having breast surgery. Before sentinel node biopsy was introduced, all or most of the lymph nodes were removed from the armpit regardless of whether or not cancer cells had spread to this area. However, cancer cells spread to the lymph nodes in only around 40%, or 2 out of 5, of early breast cancer patients. Sentinel node biopsy therefore reduces the number of patients having unnecessary surgery as it determines whether or not cancer cells have spread in your armpit before axillary clearance is carried out. It is better to avoid axillary clearance in patients with negative lymph nodes as it reduces the risk of the side effects.

Breast lymph node assay test has the advantage that, if cancer cells are detected, additional nodes can be removed during the same operation, avoiding the need for a second operation. Patients may be able to spend less time in hospital, have any additional treatment (such as radiotherapy or chemotherapy) more quickly and may also be able to return to normal activities sooner. There is also no waiting time for the results of the sentinel node biopsy. At the results clinic, the following week, you will be told how many lymph nodes were affected with cancer.

Disadvantages

The normal risk of surgery and anaesthetic may be slightly increased as the surgery time will be longer due to the time it takes to carry out the breast lymph node assay. Every effort is taken to keep this time to an absolute minimum (about 30 - 45 minutes) by carrying out the breast surgery while waiting for the results of the breast lymph node assay. If the breast lymph node assay shows that cancer is present, the surgeon will proceed to an axillary clearance, under the same anaesthetic.

Allergies

As part of the sentinel node biopsy you will be given two injections - a radioactive solution before your operation, and a blue dye during your operation. This combination of radioactive solution and dye has been used in many thousands of patients in Europe and the USA with no side effects. However, about 1 in 100 patients have an allergic reaction to the dye. In most patients this is mild, but in 1 in 2000 patients this is a severe reaction. When a severe reaction occurs your surgeon will concentrate on treating the reaction and may decide not to complete the surgery if this is in your best interests. If the surgeon decides to continue with the operation you will be monitored very closely.

Please let your surgeon or one of the Breast Specialist Nurse know if you suffer from any allergies, including food allergies. Severe allergic reactions may indicate it would be better not to use the blue

dye. Axillary clearance would then be the procedure of choice.

Axillary clearance

This is an operation to remove a number of the lymph nodes from under the arm that drain the breast.

The wound is about two inches long and lies behind the breast muscle and is not usually visible.

Everyone has a different number of lymph nodes but on average there are around 20 lymph nodes in the armpit.

The number of lymph nodes removed will depend on the type of surgery your doctor recommends.

Which breast operation?

Your surgeon will give you advice but the final choice of operation rests with you. However, in general terms, mastectomy is often recommended if:

- The lump is large in relation to the size of the breast.
- The lump is in the central part of the breast – the nipple may well be involved in the tumour.

If a mastectomy is advised, we will discuss breast reconstruction with you. Breast reconstruction can be done at the same time as the mastectomy or delayed until the cancer treatment has been completed. We usually advise against immediate reconstruction if we have a good reason to think that radiotherapy may be needed after a mastectomy.

After surgery

Some people experience pins and needles, burning, numbness or darting sensations in the breast area and down the arm on the operated side. These symptoms are quite common and may go on for a few weeks or even months. The scar might feel tight and tender. **If you have had breast-conserving surgery you may find it more comfortable to wear a supportive bra, even in bed at night, though if you are comfortable without a bra that is fine too.**

Your arm and shoulder on the operated side are likely to feel stiff and sore for some weeks or months. Your Breast Specialist Nurse or surgeon will give you advice about exercises to help you regain the movement that you had before the operation. Exercise is an important part of the healing process, which you should continue after you go home as advised. If doing the exercises is uncomfortable you may find taking painkillers before doing them can help. If you have had radiotherapy it is important to continue these exercises, probably for at least two years.

Breast reconstruction

Immediate reconstruction:

Advantages:

- You will notice less change in your body image after the operation.
- You will need fewer separate operations.

Disadvantages:

- The result may be less good if, in the long run, you need radiotherapy after the mastectomy and reconstruction operation.
- Reconstruction can be major surgery and recovery can take time. This can cause a delay to the start of cancer treatment such as chemotherapy. In this case a delayed reconstruction would be advised.

Delayed reconstruction:

- You may get the cancer part of the treatment over more quickly.
- You may be unsure about whether to have a reconstruction or not, or which type to have and prefer to wait.
- You may need radiotherapy after the operation and therefore feel it wiser to delay reconstruction until the situation is clearer.

There are several main types of reconstruction:

- A simple implant can be placed under the skin and/or muscle sometimes with supporting tissue. This is a safe and simple option with few complications, but may not give a natural feeling result as some of the tissue flap reconstructions.
- Using a flap of skin and muscle from the back (latissimus dorsi flap). This operation uses skin and muscle from the back and also an implant to reproduce the breast mound. This operation is slightly more complicated than the simple implant procedure but may give a better cosmetic result.
- Using a flap of skin and fat, from below the waist line (known as a DIEP flap - deep inferior epigastric perforator). This operation often gives the best cosmetic results, but involves lengthy surgery and recovery and has a higher risk of complications.
- There are numerous other ways to reconstructing a breast depending on your body type and personal preferences including buttock and thigh flaps.

There are very detailed information sheets available about breast reconstruction, please ask if you

would like one.

If you would like to discuss breast reconstruction at any stage, please talk to a member of the team. We will then ask a plastic surgeon to see you in the Oncoplastic clinic here at Salisbury District Hospital, and she or he can discuss all the options.

Treatments in addition to surgery

Clinical trials

Specialists working in breast cancer are constantly trying to improve the treatments available. The only way to do this is to carry out trials of new treatments or new ways of giving established treatments. In Salisbury we have several trials on offer but not all patients are suitable to enter them. Your Oncologist will discuss this with you when you are seen for an initial consultation if there are suitable trials currently available.

Drug Therapy

Once the breast care team has made an assessment from the operation results when treatment is recommended. Drug therapy is often used either in combination with, or occasionally instead of surgery. Drug therapy takes two forms:

- Chemotherapy - Which is given to you via a drip in your arm. Many patients will have both chemotherapy and hormone therapy.
- Hormonal therapy - Which is usually given as tablets

Chemotherapy

Chemotherapy is given by the Oncology team who are specially trained to administer these drugs. Treatment is given on an out-patient basis on the Pembroke Unit and at this time you will be under the care of the oncology consultant. Usually the decision to offer chemotherapy treatment is made once the results of surgery are known. In certain circumstances however chemotherapy is given before surgery to shrink the tumour.

Many patients worry about chemotherapy but before your treatment starts you will see the doctor and other members of the oncology team. They will go through everything with you and give you information about the drugs recommended for you and the likely side effects. Most treatments are given as an outpatient once every three weeks and usually for six treatments. Although different drugs have their own specific side effects, general side effects of chemotherapy are listed below.

Some patients manage to continue working through their chemotherapy treatment, however, this is an individual's choice as everyone reacts differently to the treatment and so it is worth seeing how you manage with the side effects with each treatment.

Side effects of chemotherapy

Infections – chemotherapy lowers the white blood cells, which are important in fighting infection. Having a lower white cell count makes patients on chemotherapy more prone to infection. When you start your treatment you will be told how to contact the oncology unit for advice. This service is available 24 hours a day on the ward.

Nausea and vomiting – these may occur with any chemotherapy. All patients are given anti-sickness drugs before the chemotherapy is given, and to take home afterwards. It is unusual to be sick but if you are then the anti-sickness medication can be changed to control the problem for the next course of treatment. Make sure you tell us if you are sick.

Sore mouth – often patients feel that their taste temporarily alters with treatment. Occasionally patients do get mouth ulcers; medication can be given to treat and prevent this. This can be reviewed with the team or consultant before each treatment.

Hair loss – unfortunately the drugs we use to treat breast cancer usually cause hair loss. We do offer cold cap treatment that can be effective at preventing this, but it doesn't work for everyone. We do also offer a wig service - there is normally a small cost involved. Hair loss is temporary and it will grow back once the treatment has ended.

Infertility - chemotherapy may affect the functioning of the ovaries either temporarily or permanently. This will have implications for younger women wishing to have children in the future. If this is an issue for you please let the doctor know as we can arrange for you to see a fertility expert at the hospital.

Fatigue - Fatigue means tiredness and lack of energy. You feel as if you can't do things at your normal pace. We all feel this at times. With this type of fatigue, your body is letting you know that you are overdoing it. The tiredness is usually short term and you feel better after you stop and rest.

Fatigue for people with cancer can be very different. The cancer or its treatment may make you feel very tired. The tiredness may not go away even when you rest. It can go on for weeks, months or even years after you finish treatment. Most people get back to their normal energy levels from between 6 months to a year after the end of cancer treatment.

Fatigue is very common in people with cancer. It can be the most troubling symptom. It affects between 7 and 9 out of every 10 people (70 to 90%).

In addition to chemotherapy treatment, there are also antibody agents used in some types of breast cancer. Herceptin (trastuzumab) is one of these and may be suitable for some patients.

Radiotherapy

This involves using a machine known as a linear accelerator, which gives a high dose of X-rays given by specially trained staff. Radiotherapy equipment in this region is available in Southampton,

Poole and Bath. If radiotherapy is considered appropriate you will usually be referred to the unit most convenient for you.

How it works

Radiotherapy is effective at killing cancer cells. It affects normal cells as well, but they are able to repair themselves more readily. Radiotherapy can destroy or shrink cancerous growths and is very effective in preventing cancer cells reappearing after surgery.

Patients who receive radiotherapy

Radiotherapy is usually given following breast-conserving surgery (lumpectomy). It is given to the remaining breast tissue on that side. Occasionally it may be recommended to the chest wall after a mastectomy and if some of the lymph nodes under the arm are affected.

If breast cancer spreads elsewhere in the body at a much later stage, radiotherapy can be used to improve symptoms such as pain affecting the bones.

How is radiotherapy given?

Radiotherapy is the use of X-ray treatments. During treatment you lie on a couch in a specific position normally with your arms supported over your head. The beams are then precisely directed to the area to be treated. You do not feel anything with the treatment. The exact details of treatment vary depending on the advice given by your X-ray oncologist. Usually the treatment is given over five days a week for three to five weeks. Each treatment session lasts only a few minutes.

Common side effects

- General – people often feel tired with radiotherapy.
- Local – radiotherapy can cause a local skin reaction very much like sunburn, with redness of the skin and also itching.

You will be given advice from the radiotherapy centre on how to care for your skin.

What to expect after we have discussed your referral for radiotherapy

You will be given or sent an appointment to see the oncologist to discuss and arrange your treatment. You will not receive any planning or treatment at this appointment. After this you will receive a separate appointment for planning.

First, the treatment has to be planned to ensure that it is given accurately and in a position that is easy to reproduce. This involves a scan such as CT to appropriately target the breast tissue. You are likely to be given three small, permanent marks which will be used as reference marks when having your treatment. The planning session takes approximately 30 minutes.

Following the planning session, arrangements will be made for you to attend the radiotherapy centre

for your course of treatment. This is normally two to three weeks later and involves daily (Monday to Friday) sessions.

Hormone Therapy

The pathologist will test the tumour to see if it expresses receptors (markers on the cell) sensitive to the female hormone oestrogen. If this is the case the tumour is oestrogen receptor positive.

Hormone therapy is of benefit in patients whose tumours are sensitive to the female hormone oestrogen. If your tumour is receptor positive (i.e. sensitive) then we recommend that you take a hormone tablet for five to ten years. This can have some side effects including hot flushes, nausea and weight gain and occasionally causes thickening of the lining of the womb (over a long period of time, i.e. years.)

This may be Tamoxifen (for pre and post menopausal women) or other hormonal tablets called aromatase inhibitors (e.g. Anastrozole or Letrozole) prescribed for post-menopausal women. If this is the treatment advised we will explain this to you. Similarly if you would like to discuss this therapy with us please feel free to do so.

Recovering from your surgery

Is it normal to still get aches and pains in my breast/chest several months after my surgery?

Many women continue to get aches and pains in their breast or underarm area for many months after their surgery. These can be made worse by radiotherapy and can continue for a year or more. If, however, you develop a new pain worsening over two to three weeks then contact us to arrange a review.

Why do I have a strange sensation on the inside of my arm?

This is usually due to surgery interfering with the nerves in the under arm area, resulting in a changed sensation (often numbness) affecting the underside of the upper arm. This altered sensation can be either temporary or permanent.

My scar feels hard and lumpy. Is this normal?

Post-operatively this may be due to the healing process and formation of scar tissue. Gently massaging the scar with a moisturising cream can help soften the hardened area and even out the scar line (whatever moisturising cream you usually use is suitable). Any new lump in or around the scar should be checked by your surgeon.

What is this 'tight pulling' sensation stretching down my arm?

This is a common post-operative problem known as 'cording'. It is thought to be caused when the lymph vessels harden and tighten due to the surgical procedure (particularly axillary surgery). This

side effect can either settle by itself or be encouraged to 'ease' by massaging and stretching the affected area.

Can I wear deodorant?

Yes, there are no proven studies to suggest otherwise.

I've developed swelling of my arm. Is this normal?

Some women who have had surgery to remove lymph nodes from their armpit, (axillary node clearance) develop swelling of the arm in the weeks or months after their surgery. This is known as lymphoedema and is due to disruption of the normal channels that the lymph fluid flows through away from the arm. If this happens to you, please contact the Breast Specialist Nurse who can refer you to a lymphoedema clinic for further advice on this. You may, for example, benefit from wearing a compression sleeve or from special massage.

If, however, you develop swelling of an arm many months or even years after your original surgery, you should contact the breast care unit to arrange a review by your consultant.

See the section on lymphoedema on page 29 for more information.

Recovering from your chemotherapy

How long will I remain tired for?

Almost all women feel very tired by the end of their chemotherapy. This can then get worse if they are then receiving radiotherapy. Your tiredness should start to improve 1 to 2 months after your last cycle of chemotherapy and then steadily improve. However it can take at least 6 months before your energy levels will return to normal and some women will still feel tired 12 to 18 months after the end of their treatment.

When will my hair grow back and when can I dye it?

Most women find that their hair starts to grow back 3 to 4 weeks after their last chemotherapy session. The hair grows slowly to begin with and can be quite thin and 'fluffy', but over time the hair thickens up and after 6 months most women will have a good head of hair again. As your new hair will be rather delicate, we recommend that you wait for 6 months before using chemical, permanent or semi-permanent dyes on your hair. However, it is safe for you to use herbal or non-permanent dyes whilst you are waiting.

Why have I put on weight?

It is quite common for women who have had chemotherapy for breast cancer to gain some weight during their treatment. The chemotherapy drugs themselves do not cause weight gain but the steroid tablets that we use as anti-sickness tablets can increase appetite. Many women also find

that their diet changes whilst they are on chemotherapy and that they do less exercise than usual because of the tiredness that it can cause.

When will I recover feeling in my finger/toes?

If you have developed pins and needles or numbness of your fingers or toes during your chemotherapy treatment, this should gradually improve in the weeks and months after the end of your treatment. However, you may find that it initially gets worse after your treatment before it starts to get better. A small number of patients may find that sensation in their fingers or toes remain altered permanently.

Can chemotherapy treatment affect my fertility?

Chemotherapy for breast cancer can bring on the menopause earlier than it would have naturally occurred. This is more common if you are close to menopausal age when you start your treatment. Some women therefore find that their periods stop whilst they are having chemotherapy and never come back.

If you do have premature menopause as a result of chemotherapy, this will affect your ability to have children (fertility). Your oncologist will discuss this with you before you start chemotherapy.

Recovering from radiotherapy

How long will radiotherapy side effects last for?

Radiotherapy causes acute side effects which occur during treatment, and tend to peak at the end or up to two weeks after finishing treatment. Most skin reactions resolve and completely heal by 4 to 6 weeks after radiotherapy.

Up to half of patients treated may experience rib tenderness or shooting pains in the breast. These generally settle within a few months of radiotherapy although can persist intermittently longer term.

Many patients feel tired both during and after radiotherapy. This is generally worse if you also received chemotherapy. Tiredness tends to improve about 6 weeks after completing radiotherapy but it can often take several months to recover.

When can I go out in the sun?

Sensible precautions should be taken in the sun and sunburn should be avoided. The treated area may be more sensitive and should be covered. High factor sun cream should be used, at least factor 20.

Once the skin reaction has settled it is possible to return to activities such as swimming. This is normally possible within a month of treatment finishing.

Will I get any long-term side effects from my radiotherapy?

Long term effects are rare but can occur in a small percentage of people. There may be a change in the appearance of the skin, with the skin within the treatment area being darker and firmer to the touch, and the breast may be smaller in size.

After a mastectomy the chest wall can feel tight and there may be permanent skin changes if there was a severe skin reaction.

People who have had breast reconstruction with implants may experience contraction of the capsule around the implant.

Occasionally it is necessary to remove or exchange the implant. There is a slightly increased risk of rib fracture in the treated area and a small risk of heart damage after left-sided treatment.

Occasionally radiotherapy can cause inflammation of a small area of lung tissue. There is a very small risk of a second cancer developing in the treated area as a result of radiotherapy.

The Psychological Support Team for people with cancer and their families

What is The Psychological Therapies Support Team?

This team is made up of a clinical psychologist, a counsellor, a social worker and an assistant psychologist. All of these people are professionally trained and qualified to help you deal with your emotions. None of them prescribe medication. Instead, they are trained to encourage you to talk about your difficulties, listen to you and get a full understanding of your problems. They can then help you to develop ways of coping with your emotions.

How can they help me with my cancer?

A member of the team will spend time listening to how a diagnosis of cancer or having a relative with cancer has left you feeling. It is very common for you to feel fear, worry or sadness. The people in this team recognise that cancer affects the whole person and those around them, not just the “ill” part of someone’s body.

You may also have to deal with other stresses, such as financial pressure or worries about your family. These problems can become extremely difficult and it is common for people to feel overwhelmed. The team can help you see clearly how your diagnosis may affect you at this time.

What happens to the information I tell the Team?

What you tell the team is confidential. This means that they will not talk or write about anything you say without your permission.

How do I get in touch?

Ask any member of your medical team to complete a referral form for you. The Psychological Support Team will make you an appointment. You will either be asked to attend the Clinical Psychology Department at Salisbury District Hospital, or you will be seen on the ward if you are an in-patient.

Thoughts and questions

It is sometimes useful to note down any questions or concerns that you may have before you come for your pre-operative assessment appointment and any other visits:

[illegible]

Risks of a breast operation

The risk	What happens	What can be done about it?
General risks of an operation		
Infection	A wound may become infected causing pain, redness and possibly discharge. The rate of risk is less than 1 in 10.	Infections are usually minor and are treated successfully with dressings and/or antibiotics. Further hospital treatment is rarely needed.
Excessive bleeding	Damage to a blood vessel occurs in about 1 in 300 operations.	This problem may need a blood transfusion and you may need a second operation to stop the bleeding.
Altered sensation	There may be a change in sensation after any of these operations, which affects people in different ways.	These symptoms become less noticeable to you over time, but may never settle completely.
Mastectomy		
Altered sensation	There may be a change in sensation of the skin of the chest wall.	These symptoms usually become less noticeable over time, but may never settle completely.
The appearance of the scar	There is often a bulge in the scar in the area under the arm.	If this causes problems, the scar can be revised, often under local anaesthetic by general or plastic surgeons.
Breast conserving surgery (wide excision)		
Altered sensation	There may be a change in sensation of the skin, particularly after operations around the nipple.	These symptoms usually become less noticeable over time, but may never settle completely.
Cosmetic appearance of the breast	Although we take great care, there may be a noticeable dimple in the breast where the lump has been removed.	Very rarely the appearance of the breast can cause distress. If this is the case, then we will ask a plastic surgeon to advise.
Need for second operation	Once the tissue has been analysed under a microscope, it may show that not all the tumour has been removed.	A second operation will be needed to remove a wider margin of breast tissue, or even to perform a mastectomy.

The risk	What happens	What can be done about it?
Axillary clearance		
Altered sensation	There may be a change in sensation to the skin on the inside of the arm.	These symptoms become less noticeable over time, but may never settle completely.
Seroma	A seroma is a collection of fluid that may form under the wound	The fluid is removed using a small needle. (See also 'Seroma' page 28)
Lymphoedema	This is swelling of the arm after lymph node removal under the arm. the risk is less than 1 in 10, but increases if you need radiotherapy under the arm as well as surgery. It is important to remember that this is a life-long risk.	You will be given detailed advice from the Breast Specialist Nurses on how to reduce the risk of lymphoedema. If swelling does occur, they will help you to keep it under control. (See also 'lymphoedema' page 28)
Reconstruction		
Cosmetic appearance of the breast	It is not possible to construct a replica of your breast, and very occasionally women are not satisfied with the result of reconstruction.	The plastic surgeons will take care to show you the range of results before your operation. Some revision surgery may be possible to improve the result.
Loss of tissue	When a complex flap is used, some of the tissue may die, which will delay healing.	The dead tissue will be removed. Sometimes a skin graft is used to aid healing
Muscle weakness	When muscle is moved as part of the reconstruction you may notice some weakness. This is most noticeable when an abdominal muscle has been used.	Occasionally women develop a hernia in the abdominal muscles, which would need a further operation.

What will happen after the operation?

If you stay in overnight, you will be visited the following morning by the Breast Specialist Nurse who will discuss with you any concerns that you may have. They will also:

- discuss with you any exercises that you should do to help your recover
- give emotional support • discuss the risk of lymphoedema of the arm
- tell you about the possibility of a seroma (see page 28)
- tell you about a breast prosthesis, if this is required.

Most operations involving a wound drain are done as an in-patient. This means that you spend at least one night in hospital. Depending on your home circumstances and the extent of the operation you will usually be able to go home the day after the operation.

The wounds are closed using an absorbable stitch; this means that the stitch does not need to be removed after the operation and covered with a waterproof dressing.

Care of your wound

You should look out for

- extensive bruising of the breast, enough to cause discomfort
- signs of infection in the wound such as severe pain, fever, redness or discharge from the wound
- day case patients will be asked to make an appointment with their practice nurse for a wound check approximately 5 days after surgery or remove yourself after 5 days (this will be discussed with you prior to surgery).

If you are concerned about the wound after discharge from hospital please contact your practice nurse at your GP surgery or one of the Breast Specialist Nurses.

Early discharge with a drain

After mastectomy and occasionally breast conserving surgery a wound drain is inserted to remove blood and tissue fluid and allow good healing. The wound drain here is designed to be easily managed by the patient at home (see next page). You will leave hospital with the wound drain in place and will receive support at home from the community nurses. The nurses on the ward will arrange this when you are discharged from hospital.

Removal of drain

The drain is removed when the amount draining is less than 30 mls in 24 hours or after approximately 8 days, whichever is sooner. The drain will either be removed by the community nurse or at your first follow-up visit to the hospital.

Most patients are ready to go home within 24 to 48 hours after operation. This means that the drain should be left in place. Most patients will feel capable of looking after the drain once we have given them some simple information, similar to that in this leaflet - plus they will have support from the community nurses.

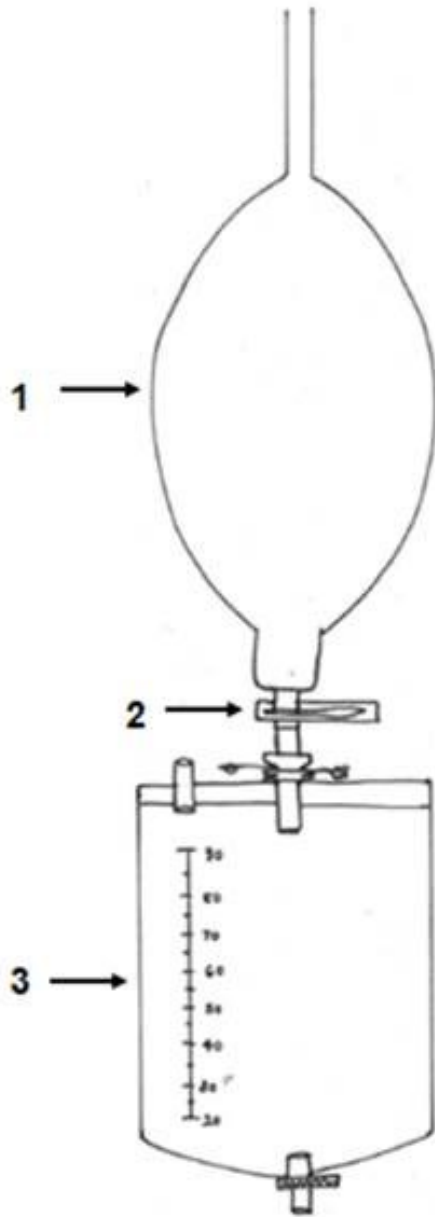


Diagram of the drain ready for emptying

Emptying the bulb (2) into the main bag.

- Open clamp 2
- Squeeze the bulb 1, to empty the fluid into the main bag 3

Re-activating drainage

- With bulb 1 squeezed, close the lower clamp 2

Changing the main bag

When the fluid level is between 300 - 400ml:

- Make sure clamp 2 is closed
- Unscrew the main bag 3 and seal it with the cap
- Attach a new bag.

Disposal of bags

Snip the corner off the full bag and empty it down the lavatory. Dispose of the used bag in the rubbish bin.

Drain logbook

Use this chart to note down the amount in your drain each day. When the amount drained is less than 30 ml in 24 hours it can be removed by the community nurse.

Day after operation	Amount drained per 24 hours / mls
1	
2	
3	
4	
5	
6	
7	

Contact the breast care team if:

- The area of the wound around the drainage tubing feels swollen or warm
- The wound under your arm or on your chest feels swollen or warm
- The drainage tubing has been pulled out so that the holes in the tubing are showing (this may be noticed by you because the bulb keeps filling with air, but little fluid is draining)
- The amount of fluid draining each day is increasing rather than decreasing
- The fluid suddenly seems to stop draining altogether.

What complications can happen after breast surgery?

Seroma

A seroma is a collection of fluid that may form under the wound in the early weeks after a breast operation, particularly if the lymph glands under the arm have been removed. This collection will be noticed by you as an increasing swelling under the wound and may be uncomfortable. Unlike an infection of the wound a seroma is not associated with redness of the skin and does not need antibiotic treatment.

If you suspect that there may be a seroma or if you are worried about the wound in another way please feel free to contact The Breast Care Department during working hours on 01722 336 262 ext. 5910 or contact your ward of discharge out of hours.

If you do have a seroma one of the Breast Specialist Nurses can remove the fluid with a syringe. This is a simple and painless procedure. The fluid may recollect over a few days and need further treatment, but it always settles down in a few weeks.

Lymphoedema

This is swelling of the arm due to damage to the lymphatic drainage of the arm. Lymph is a colourless fluid that drains from the tissues and flows in the lymphatic system. Damage to the lymphatic system can occur after surgery or radiotherapy under the arm and can lead to swelling of the arm. You will be given advice to reduce the risk of lymphoedema; some of the most important things to remember are:

- Wear gloves when gardening and washing up.
- Treat cuts, burns and grazes to the arm with antiseptic and get antibiotics from your doctor if you notice signs of infection (hotness, redness, tenderness).
- Use a strong sun block to avoid sunburn.
- Avoid blood sampling, vaccinations and blood pressure measurement from the operated side.

- Use insect repellent on your operated arm.

Lymphoedema can be controlled by a combination of arm exercises, massage and supporting garments.

Weekly lymphoedema clinics are held in the breast care department and run by the Breast Specialist Nurses.

Cellulitis

Cellulitis is an acute spreading inflammation of the skin and fat with pain, swelling and redness of the arm. It can occur at any time after a breast operation and can increase your risk of developing lymphoedema.

The risk of developing cellulitis can be reduced if you take the precautions that have been given to reduce lymphoedema, such as using protective gloves for gardening. If you feel that despite taking these you have or may have cellulitis it is important that you seek urgent medical advice.

Long Term Follow-Up

You will be seen by one of the surgeons at about one week after your operation. We will discuss the results of the operation and develop a plan for your future care with you. The Breast Specialist Nurses will also make arrangements to see you in their clinic and will be in regular contact with you. Please do not hesitate to contact them directly or via the breast service co-ordinator if you have any problems.

Breast Care Follow-up

- Annual mammograms around the month of the original surgery usually for 5 years here at Salisbury District Hospital.
- Clinic review with Oncology/Surgeon or Breast Specialist Nurses to discuss individual follow-up plan.

In the past, it has been traditional for patients who have completed their treatment for early breast cancer to be seen at regular intervals by their Oncologist or Surgeon for follow-up. Many patients find these hospital visits a great source of anxiety and not particularly helpful unless they have a particular concern. Salisbury breast unit now uses a system which allows you to arrange follow-up appointments as and when you need them, for up to 5 years after the end of your treatment. This is self-supported management (PIFU) and puts you in control of your follow-up.

Free prescriptions for people affected by cancer

Since 1 April 2009, people under the age of 60 diagnosed with cancer in England have been eligible for free prescriptions. Anyone having treatment for cancer, the effects of cancer or the effects of cancer treatment can now apply for exemption certificates from their GP or oncology clinic.

You can apply for an exemption certificate by collecting an FP92A form from your GP surgery or oncology clinic. Exemption certificates mean all your prescriptions will be free.

VAT exemption

If you have had a mastectomy and buy specialist products such as a mastectomy bra or swim wear, you don't have to pay VAT under something called group 14 of the zero rate schedule for the VAT tax act 1983. Many mastectomy bra stockists are aware of this clause and will ask you to sign a VAT exemption form when you buy from them. You will be able to find out more about this concession through your Breast Specialist Nurses.

Contacts

For queries particularly about surgical out-patient visits, operation details, outstanding results:

Breast Service Co-ordinator: **01722 336 262** **Ext 4768**

For queries about social or medical problems:

Breast Care Department: **01722 336 262** **Ext 5910**

Contact: Breast Specialist Nurses

Ward contact details:

Britford Ward: **01722 429 379** **Direct dial**
01722 336 262 **Ext 2233/4379**

Burns Ward: **01722 336 262** **Ext 3507**

Downton Ward: **01722 336 262** **Ext 2182**

For queries about your chemotherapy here at Salisbury or radiotherapy at Southampton:

Oncology secretary: **01722 336 262** **Ext 2785**

Oncology outpatient reception: **01722 336 262** **Ext 4382**

For queries about your radiotherapy: (if not at Southampton)

Poole **01202 448 789**

Bath **01225 825 663**

A very useful source of information, emotional support and advice on symptom control at any stage in your condition is provided by:

Palliative Care Team: **01722 425113** **Direct dial**

Patient Transport Link Service

Salisbury and 12-mile radius ctswsalisbury@outlook.com

Salisbury City only - community transport Voluntary Care Scheme **01722 410 123**

Support

Wessex Cancer Trust: **01722 421 781**

Salisbury Support & Social Group: **01722 328 290**

North Dorset Cancer Support Group: **01747 856 700**

Other sources of information

Macmillan: **0808 808 0000**

Concerns or questions about living with cancer - free helpline (9am-8pm, Mon-Fri).

Breast Cancer Now: Free helpline, Information and support **0808 800 6000**

The Lymphoedema Support Network (LSN): **020 7351 4480**

Information and support plus they sell helpful items such as wrist tags for use in hospital.

Penny Brohn Cancer Care, Bristol **0845 123 23 10**

A charity offering specialist support including complementary therapies, advice & counselling for people living with cancer & their supporters www.pennybrohncancercare.org

Breast Cancer Haven, Wessex Free support for anyone affected **01329 559 290**

Websites for further information

There is a vast amount of information about cancer on the internet. This information can be very valuable to those facing cancer in making decisions about their illness and treatment. It is, however, important to consider the credentials and reputation of the organisation providing the information since any group or individual can post information to the Internet.

Please ask your doctor or nurse to recommend you specific websites or to explain anything that you find on a web page that worries or concerns you.

General Cancer Information

Cancer Research: www.cancerresearchuk.org

British Lymphology Society (BLS): www.thebls.com

The Lymphoedema Support Network (LSN): www.lymphoedema.org/lsn

National Lymphedema Network: www.lymphnet.org

Breast Cancer Now: www.breastcancernow.org

Macmillan: www.macmillan.org.uk

NHS: www.nhs.uk

Understanding NICE guidance: www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance

Information for younger women:

Lavender Trust

Through Breast Cancer Now web address above. If you are a younger woman with breast cancer and you have any concerns, do get in touch telephoning the free National helpline on: 0800 800 6000

Free, confidential welfare entitlements and money advice

Macmillan Benefits Advisors are available to give specialist benefits/money advice for people affected by cancer and their families. It is your choice if and when you want to see the advisor.

Salisbury Citizens Advice

Tel: 01722 441393

Monday to Friday to make an appointment with the benefit advisors, or email macmillan@cabsalisbury.org.uk

Hampshire Macmillan Citizens Advice Service

Tel: 0344 847 7727 (9.30am - 4.40pm Monday to Friday, 5pm - 7pm Monday and Wednesday)

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www.salisbury.nhs.uk/wards-departments/departments/cancer-services/