



Recovering from breast surgery

Information for patiënts

You or a family member will undergo a breast operation. The purpose of our booklet is to tell you about recovery after the operation. More specific the medical details, the care you will need and the possible psycho-emotional impact.

During your stay in hospital, you can ask questions to the doctors, nurses and your track companionship at all times. They will be pleased to help.

If you have questions before or after admission, feel free to contact one of the people listed below.

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WHAT IS BREAST CANCER?

prof. dr. Marie-Rose Christiaens

Breast cancer is the most common form of cancer in women in Europe and Northern America. In Belgium I in 10 women develops breast cancer at some stage in their life. Yearly approximately 9500 new cases are diagnosed in Belgium. We do not know the cause, although there are some individual risk factors, the most significant being family precedents. But even so, only 5 to 10% of cases are caused by hereditary factors; the vast majority just happens.

Breast cancer in men is rare, and concerns just 1% of all breast cancers. Treatment is broadly the same as in women.

A tumor (or cancer growth) is the result of an excessive formation of new cells due to a derailed cell division. The rate at which this occurs depends on, inter alia, the type and stage of the cancer. Therefore, it is of great importance that tumors are removed or treated as soon as possible. A biopsy or punction will confirm the diagnoses. Before any surgery however, various tests are carried out to check whether the cancer has spread. The tests usually consist of a blood test, X-ray of lungs and skeleton, a liver ultrasound and bone scan.

The treatment of cancer involves various medical disciplines: the 'surgical' (surgery and gynecology), medical oncology (chemotherapy, anti-hormonal and immunotherapy), radiotherapy.

BREAST ANATOMY

The breast essentially consists of

- mammary glands (lobuli) X
- × mammary ducts (ducti) linking the glands to the
- × surrounding fatty and connective tissue
- × blood vessels
- X lymph vessels



lobes

Lymph vessels are like blood vessels but carry lymph. Lymph is a clear fluid that contains immune cells and tissue debris derived from infected or damaged sites in the body. Most of the lymphatic vessels of the breast lead to the lymph nodes that are located in the armpit. Lymph nodes are small grape-like structures that are important in fighting infections and removal of waste.



Some malignant cells have the ability to penetrate into lymphatic or blood vessels. They begin to grow and cause the lymph nodes to swell. Once breast cancer cells start growing in the lymph nodes, it is more likely that they have already spread to other organs. In order to determine the best method of treatment, it is important to know whether the breast cancer cells have reached the lymph nodes in the axilla.



TREATMENT

INTRODUCTION

A tumor or swelling in the breast does not always imply a malignant tumor or cancer. A tumor can be benign – such as a fibro adenoma or a cyst or simply an inflammation accompanied by swelling, and not everyone with a 'swelling' will need the same operation.

The choice of operation is primarily determined by the benign or malignant nature of the breast disease. In malignant disease, we take into account the stage of the disease, size of the tumor in relation to the breast, the location of the tumor in the breast, and many other factors. In our center, we use a multidisciplinary approach to care involving different medical disciplines and a non-medical staff (nurses, counselors, therapists) for guidance and support. The doctors consult weekly in a multidisciplinary oncology council (MOC). This means that your treatment plan has been decided on by several doctors from various disciplines.

SURGICAL TREATMENTS

In most benign cases, only the swelling is removed. This is called a lumpectomy.

In malignant cases only a small part of the lesion is removed (= biopsy) initially for microscopic examination and additional testing (e.g. determination of receptors for hormonal sensitivity). Subsequently, breast-conserving surgery or an amputation (= mastectomy) will then be proposed in the majority of cases. In almost all cases, a single or multiple axillary node(s) will also be removed. This is called a sentinel lymph node removal or axillary dissection or removal.

Breast conserving surgery

It is now possible to save the breast in a large number of cases due to the development of radiotherapy. This requires however a combination of surgery and radiation.

The tumor is removed with some 'healthy' breast tissue and the overlying skin. The final microscopic examination will determine

whether the tumor has been removed completely. Surgery is always followed by radiotherapy of the whole breast and an extra dose (a boost) at the place where the tumor was taken.

Breast conserving treatment is possible ONLY if the following conditions are met:

- X There is only one malignant tumor in the breast. Mammography doesn't show extensive areas of suspicious calcifications (micro calcifications) apart from the tumor itself.
- X The tumor is no bigger than 3 to 4 cm.
- The size of the breast compared to the size of the tumor must be sufficient to guarantee the complete removal of the tumor while maintaining an acceptable cosmetic result.
- X The patient must agree to 5 a 6 weeks radiation therapy after surgery. In case of refusal breast conserving treatment cannot be performed.
- X The general health of the patient must allow radiotherapy. Women who already have received breast radiation before cannot have it again. Pregnant women are usually not eligible for radiotherapy given the risks for the baby.

After surgery, careful monitoring is required to watch for a possible resurgence of breast cancer. These controls consist of regular clinical examination, occasional blood sampling and an annual mammogram and ultrasound. The location of controls is discussed with you and can also be at your GP's or other specialist.

If any of the above conditions cannot be met, it is best to consider breast removal.

Occasionally, the microscopic examination in the laboratory may reveal that the tumor was not completely removed through breast conserving surgery. In this situation, you will be asked to consider, in a second operation, to proceed to an amputation.

Localization of non-palpable tumors

Non-palpable tumors that need to be surgically removed must be localized in such a way that the surgeon is able to remove them accurately.

There are several ways to do so. The usual way is by means of a hook wire threaded through a fine needle. Under ultrasound or mammographic guidance, the needle is positioned correctly and then the wire is carefully fed through the needle and hooked around the tissue. This procedure is performed under local anesthesia. Thereafter, another mammography is then used to show the position of the needle in relation to the lesion. So that the surgeon can see the exact location



of the tumor and use the wire to remove it. The risk of complications with this procedure is rare. During the operation, radiography and/or ultrasound are taken again to make sure that the tumor is completely removed.

Removal and biopsy of the sentinel lymph node (sentinel node)

In some specific cases, only the sentinel lymph node(s) are removed, as opposed to the complete axillary dissection or removal. If this (these) lymph node(s) contain no malignant cells, it can be assumed that the other lymph nodes are not affected.



When is this procedure executed?

- X There are no suspicious, palpable glands in the armpit, no suspicious nodes after puncture under ultrasound – and a small (relatively) proved malignant tumor.
- X There is an 'in situ' cancer for which amputation is required or 'invasion' is suspected.
- X There was no previous radiotherapy of the breast.
- There was no preceding chemotherapy. In the event that chemotherapy is needed before surgery, the sentinel lymph node can also be detected, removed and examined prior to chemotherapy.
- Some previous interventions in the breast may cause contraindications and should be viewed individually.

How does the sentinel procedure work?

A few hours prior to the procedure (in some cases the day before), a solution containing a radioactive tracer is injected. The tracer travels the path that the cancer cells would most likely take from the breast



area to the 'sentinel' node. After a few hours a (gamma) camera is used to identify the sentinel lymph node. If this is not the case, more tracer fluid may be injected. The surgeon often injects an additional blue dye into the area behind the nipple. With the help of the gamma probe and the dye, the sentinel node – the one that first takes up the dye – can be removed by making a small incision in the armpit.

After removal of the tumor, the sentinel node is removed and the node is given a 'quick' examination by a pathologist. If tumor cells in the node are found at that time, the regular complete axillary removal is performed immediately. This possibility is always discussed with you beforehand. If no maligne cells are found at that time, further extended microscopic examination of the lymph node is carried out. And you are contacted by telephone a few days later. If this examination reveals presence of cancerous cells as yet, the regular axillary lymph node clearance is scheduled in a second surgery.

"What else do i need to know?"

- X The used radioactive tracer is not harmful to yourself or your surroundings.
- In rare cases no sentinel lymph node is found and a complete axillary removal is performed.
- The blue dye may give you a 'gray' appearance the first 24 hrs. You may have gray lips, green blue urine, and the areola may have a blue discoloration a few weeks to months.

Breast Removal (Mastectomy)

During mastectomy, the entire breast gland and the overlying skin and nipple are removed. Because the mammary gland extends into the armpit, this results in a flat chest wall with a preferably horizontally running scar (depending on the location of the tumor) from the middle of the chest to the armpit.

An external breast prosthesis can be worn, and there may be the possibility of reconstruction in a first or second time. After the operation, a drain (tube) is fitted to initially remove blood, and later on wound fluid.



Axillary Removal

Even if the lymph nodes in the armpit feel normal, microscopic examination may reveal cancer cells. On the other hand, swollen glands may be non-cancerous and just a sign of reaction (e.g. biopsy). If the lymph nodes are really affected, they usually must be removed. The information from the microscopic examination of the nodes is important for the determination of further treatment, since damage to the lymph nodes is an indication of micro-lesions that cannot be detected otherwise.

"Are all the lymph nodes removed? How many?"

For the biopsy, only one lymph node is removed for microscopic examination and special tests. If it is then necessary to proceed to complete axillary removal, the number of nodes depends from patient to patient. On average there are fifteen nodes that can be found in different levels (I-II-II).

"What are the consequences of complete axillary removal?"

Immediate effects

After your operation, a drain (plastic tube) is fitted to remove blood and wound fluid. As long as the tube is in place, the shoulder should be kept 'relatively' quiet. After a few days exercises by a physiotherapist start to avoid stiffening of the shoulder. It is important that you perform these exercises at home. The drain remains 3 up to 6 weeks. At home, it is advisable to slowly increase arm motion. However, in case of overload a tense and tired feeling in your arm may occur with or without swelling of upper arm and elbow. This often is seen in combination with an overloaded shoulder.

After removal of the drain, it is possible that a few evacuating punctures are needed.

Due to the interruption of the cutaneous nerves a 'dormant' or 'tingling' sensation may be felt in the skin of the armpit, the inside of the upper arm and the flank. This disorder usually disappears over time, but a number of patients experience permanent numbness. You may rub this area daily with a lotion.

Delayed effects

Any surgery to the axillary nodes maintains a lifelong risk for lymph edema. In case of sentinel node removal, the risk is low. The normal drainage of the lymph has changed: moisture and proteins are insufficiently drained and attract moisture that accumulates in the tissues. Real lymph edema is only diagnosed as the circumference of the arm at several places is increased by 2 cm or more. In this case, combination of lymphatic drainage, bandaging, exercises with an experienced physiotherapist and wearing a support stocking is recommended. If pain or other worrying symptoms occur, you should see your doctor. In our center, preventive lymphatic drainage is discouraged since its effect is not proven, and since the other aspects of arm problems need to be tackled first.

Lymphatic vessels and lymph nodes also play a role in clearing infections. After axillary surgery, part of that function is lost and

any wound, insect bite or minor superficial infection can lead to inflammation of the lymphatic vessels, called lymphangitis. This condition gives a red discoloration of the skin, high fever, general malaise and local accumulation of lymph, causing lymph edema.

If you experience one of these symptoms, it is important that you consult a doctor as soon as possible to start antibiotic treatment. Sometimes a short hospitalization for antibiotics through a intravenous drip is necessary. Even though the procedure was carried out correctly, there is no guarantee that lymph edema won't occur later on. Lymph edema may occur soon after surgery or only after years. It is possible to treat lymph edema, but it cannot be cured. Therefore prevention and if necessary, continuous treatment with great discipline is very important!

Prevention of real lymph edema

Lasting alertness

- I. Rest with arm in high position may help if there is an overload or pain, but not with lymph edema.
- Avoid repeated heavy lifting and frequent performing of the same movement (e.g. large quantities of ironing, cleaning windows). You will find your personal maximum permissible load. Not moving is also bad, so dosing your efforts is the message.
- Pressure on the affected arm is discouraged: tight clothes or tight bracelets, wearing rings in the case of lymph edema on fingers, blood tests, drips and blood pressure measurements.
- 4. Try to avoid bathing in water above 38° C, hot saunas and extreme cold.
- 5. Use a daily moisturizer to prevent cracking and flaking. Check your skin daily on scratches, blisters, redness and softening of skin folds.
- 6. If you often travel by plane, ask your doctor if a special stocking is needed.
- 7. Wear a comfortable fitting bra with wide shoulder straps that prevent constriction of the superficial lymph vessels of the shoulder and a wide elastic lower edge. By a light weight prosthesis.

- 8. Maintain a healthy, balanced diet and avoid obesity, as this is a risk for lymph edema to occur.
- 9. If you injure yourself or get an insect bite, disinfect your skin immediately with an alcohol solution and cover the wound with a sterile dressing. Check the wound daily for signs of infection. As long as the skin is damaged, rinse with water and disinfect daily, then recover with a plaster. In case of redness, heat, pain, swelling or fever consult your doctor. He or she will decide whether you should start antibiotics.

TIPS:

- Fring in your purse a bag with individually wrapped disinfectant wipes and plasters (this way you always have a supply).
- X To avoid cuts in less sensitive axillary skin areas, use an electric shaver. Hair removal cream is also allowed.
- X Avoid injuries by pets (cats) and insects. Disinfect them well.
- Wear gloves and a long sleeved T-shirt when gardening. Be careful when taking care of roses and plants such as yuccas, cactus ...
- X Handel raw meet with gloves.
- X Apply good hand hygiene and proper nail care.

- X Use a thimble when sewing.
- X Avoid sunburn and be careful while cooking, ironing ...
- Y Protect your skin sufficiently when using caustics and detergents.
- X Watch out for minor injuries when wearing jewelry, wear them 'loose'.

Signals of beginning lymph edema

- Heavy, tense, tired feeling in the arm
- Shooting pain or tingling
- Redness, stiffness, tenderness
- Sudden tightening of clothes

When these symptoms don't disappear after a period of rest with your arm in high position, please contact your doctor to rule out other causes. You may then be referred to the lymph edema center. Contact via secretariat of the physiotherapy, tel. 016 34 85 50.

In order to book a consultation in this center, you always need specific forms and a letter of reference from your GP or specialist. In case of swelling, loss of function or impaired movement don't hesitate to contact your doctor.

ADJUVANT TREATMENT

The usefulness of the 'after' treatment

Numerous large studies have already demonstrated the beneficial effect on survival or cure of further treatment following breast operations.

There are two kinds of further treatment: 'local' and 'systemic' therapy.

Local treatment consists of radiotherapy. Its purpose is to eliminate any remaining cancer cells in the breast or scar tissue of the mastectomy. Thus minimizing the risk of local relapse and improving survival.

Systemic further treatment can consist of chemotherapy, antihormonal, 'targeted' therapy (e.g Herceptin[®] or a combination). With additional general treatment the risk of distant metastases may significantly be reduced.

How the risk is determined

A sum is made of multiple risk factors which in part will be known from the microscopic examination of the tumor and the axillary nodes. Tumor size, the type of tumor (hormone-sensitive, HER2positive ...), the degree of differentiation (= the degree to which the tumor resembles normal breast tissue), the number of affected lymph nodes in the armpit are all taken into account. Your general health and age also play a role. It is therefore clear that before surgery something can be said about potential radiotherapy, but little about general treatment. This can in fact only be determined if all results of the tests on the removed tissue are available and this takes at least 2 weeks after surgery.

All the benefits of the proposed post-treatments should be weighed against the side effects for you as an individual. This sometimes requires a subtle decision in multidisciplinary oncological counsil with doctors of different disciplines. The proposal will be discussed with you during the postoperative consultation, approximately 3 weeks after your surgery. After receiving detailed information about possible advantages and disadvantages, you make a shared decision with your doctor.

All further concrete information will be given at the start of treatment and can be found in the brochures on chemotherapy (Cyztra,) radiotherapy, or anti-hormonal therapy that you receive from the hospital.

Twice a month a tour of the radiotherapy department is organized to familiarize patients with the specific setting and the procedures.

Ask your nurse or track guide for the upcoming dates, or check the hospital website.

FOLLOW-UP

Once your treatment has been completed, you will be advised to have regular check-ups. Your doctor will suggest an individual plan. During each consultation, the doctor inquires about complaints or problems and conducts a clinical exam. A blood sample may be taken and a mammography, whether or not in combination with ultrasound, is planned annually. For patients participating in trials extra intermediate check-ups may be necessary.

TRACK COMPANIONSHIP

From the moment of your diagnosis within the breast center, a personal track guide to 'navigate' you through the process will be assigned to you.

Your track companion will offer you and your family psychosocial support and nursing education throughout treatment. Through information and education you will understand your disease and treatment in a way that you will be better prepared to anticipate certain side effects and you will become more involved in the decisions that are taken.



This person will help you and your partner in dealing with the diagnosis, practical issues (household, transportation ...) and psycho-emotional issues or tensions. Your track guide can also easily refer you to a physiotherapist, psychologist or sexologist if needed.

Track guidance is free of charge and each contact is combined with scheduled (medical) appointments at the hospital. Additionally, there is a telephone service on working days between 9 and 17 hours to address all your questions and concerns.

FREQUENTLY ASKED QUESTIONS

How can I prepare myself for the operation?

To prevent infection through tiny injuries you are asked not to shave under your arm. This will be taken care of by the nurses just before surgery. It is best to take a bath or shower before you set off. Makeup and nail polish must be removed, as well as rings on both hands. You should bring with you any medicines which you take at home. And you are also expected to bring your own toiletries.

• Will I be able to sleep?

If you want, and after checking with your doctor or nurse, you can take a sleeping tablet. Before the operation you will be given a tablet to relax. Following your preoperative consult, the anaesthetist will also decide whether you should discontinue taking any of your usual medications.

• Can I have anything to eat before the operation?

From midnight before the day of the operation you mustn't eat or drink anything. Nor must you smoke. During the operation you will be given the necessary fluid and medication through a drip (a tube connected to a blood vessel).

• How long shall I have to wait before I can eat and/or drink?

Depending on your status you will receive some water to drink a few hours after surgery, and it will be decided how long you will need a drip. Normally you will only get something to eat the next morning to avoid nausea and vomiting. If your operation takes place in the morning, you don't feel sick and the nurse has extensively checked for bleeding, you may have a light meal the night of the operation.

• Shall I feel pain?

During the operation you will of course feel nothing. Afterwards you may experience pain. You will therefore remain in the recovery room after the operation, and your condition will be monitored constantly. For instance, if you have any pain you will receive a pain killer. If you feel any pain or discomfort, make sure to tell the nurse promptly, before it gets any worse. Overall, we get little severe pain complaints after a breast-conserving operation or mastectomy.

• Can I get out of bed after surgery?

It's best to stay in bed the day of your operation. For safety's sake, the first time you get up, is under the supervision of the nurse. The next day you may walk around the room or in the hallway if you feel up to it. Movement and assuming a normal posture is important for your recovery.

Besides this, the doctor will also prescribe a preventive treatment against blood clot formation. This means that you get a subcutaneous injection – usually in the abdomen – the evening before surgery until the day of discharge from hospital (or possibly longer if medically indicated).

How shall I be when I wake up?

With a compressive dressing

This bandage promotes good drainage of blood and fluid and will remain snugly in place for the first 2 days. After that, the bandage will be replaced by a specially modified postoperative bra, that was measured the night you came in the hospital. If you have had a breast-conserving operation and a sentinel procedure (without additional axillary removal), the nurse will already remove the bandage the day after surgery. At that time you may wear a regular wireless bra.

With one or more drains

You will have one or more drain(s) if:

- X you have undergone a mastectomy;
- X you have had an axillary removal;
- X the cavity of the breast-conserving surgery is large.

The drain(s) ensure that the wound fluid and old blood is evacuated. During the first few days after surgery this fluid is red; afterwards it becomes lighter (pink to red transparent yellow). The amount of fluid is measured daily. Careful registration of the amount in 24 hours is very important. Once the amount has dropped to 20-30 ml/day, removal of the drain may be decided during the wound care consultation. Therefore always bring the fluid registration document to the consultation.

• How will my breast area feel?

After an operation in the axillary region, after mastectomy or breast conserving surgery you will experience numbness of the skin running from the breast area to the underside of your arm. Over time, the feeling may come back, but some patients talk about altered sensation for a very long time. When stitches and Steris trips (small stickers) are removed, you may rub the wound area with a body lotion daily.

• Shall I dare to look?

The first time your dressing is changed, you may find it difficult to look and have very mixed feelings. Be patient and give yourself some time. The confrontation with a changed body requires many steps and does not work from one day to the next. It's best not to wait until you get home. Your nurse will certainly support you. If you prefer to look just by yourself, do not hesitate and tell the nurse afterwards so that your dressing can be attended to. Your partner may be very helpful too, so please definitely look and talk about your wound together.

• Can I move my arm after the operation?

Standard advice is that the arm is rested in a relaxed position the first 24 hours as much as possible. This means that your forearm and hand can safely move within a given plane, while keeping your shoulder quiet. A raised, cramped shoulder however brings trouble. The type of operation will determine what you can and cannot do. The general rule is that you can only move beyond your pain threshold from the fifth day onward (= often the day of discharge).

Breast-sparing surgery and sentinel procedure:

The day after surgery you may move your arm within your pain threshold. Heavy objects should not be lifted during the first 3 weeks. It is important that your arm has its normal mobility before the start of the radiotherapy, this means that you can extend your arm above your head.

Breast amputation and sentinel procedure:

The day after surgery you should start moving your arm slowly and keep your shoulder still. However, you should still be careful with some lateral or upward movement. Two days after the operation, you should start moving more to prevent a 'stiff' shoulder.

Axillary removal:

The first 24 hours you must strictly observe limitation of movement of the shoulder, but the arm must remain relaxed. Then you may gradually move a bit more. The physiotherapist will help you to exercise while in hospital and hand you some exercises on paper (also see topic physiotherapy after axillary removal). At discharge you will receive an attest for physiotherapy to continue at home.

• How long must I stay in hospital?

Breast conserving therapy and sentinel:

2 nights, 3 days. The day after surgery you are discharged from hospital.

Breast amputation with or without axillary removal / breast conserving surgery with axillary removal:

6 nights, 7 days. Five days after your operation you go home. Most likely, you will still have (a) drain(s). Once a week you come to the hospital for wound control and possible removal of the drain(s).

• Shall I need home care?

Your nurse will discuss with you what type of home care you may still need, how long it lasts and how best to organize this care. Home care can either be provided through your health insurance scheme or by a private independent home visiting nurse.

You will always receive a prescription, printed information and materials and we'll contact a home visiting nurse from the hospital.

Wound progress and the quantity of fluid removed via the drains will be recorded on a special form. This report will serve as a reference for contacts between your doctor, the home nurse and the surgeon. You bring this form with you when you come to the wound care consultation.

• How soon can I have a bath or shower?

Five days after surgery you can have a shower. However, if drains are present, the insertion points should not get wet to prevent infection. This means that you can only shower your lower body with a hand shower. The sutured wound on your breast should not be lathered with soap but just use water and pat dry afterwards. Two days after the removal of the drains (and if all wounds are closed) you can have a regular shower.

For bathing you should not have drains and should not 'soak' the sutures ('low' bath).

In all cases you need to observe good hygiene with mild soap (armpit!) and a clean towel. Be careful when getting in and out of the bath, mind your arm. It is often easier to move from a lying to a kneeling position, and only then proceed to stand.

• Shall I be more prone to infections after surgery?

If the lymph nodes in the armpit have been removed or when radiotherapy was administered to the armpit, you are more susceptible to infection on the operated side, NOT on the other side (See the section on prevention of arm problems).

• When can I return to work?

The recovery time is different for each woman, from several weeks to several months, depending on the treatment and the type of work you perform. Some women feel ready to make considerable effort after a short time, others need more time. Try to find a happy medium: you will best judge for yourself what you are capable of. When you resume your activities it's important that your posture feels comfortable, not only for your back, but also for your arm and shoulder. Support your arm if possible, and take proper rest periods.

• I feel sluggish and tired after the treatment, what can I do?

In this case, you can participate in a rehabilitation program 'KanActief' at UZ Leuven. This program runs over about 10 weeks and usually starts at the end of treatment. It includes basic and tailored fitness training, combined with information sessions on life style after diagnosis.

• Will I be able to drive ?

If you have one or more drains you, you should not drive.

If the wound is sufficiently healed (3 weeks after surgery or after removal of the drains), you can drive your car. But don't forget that the condition of your arm and shoulder is not yet optimal. Wearing a seat belt remains mandatory even after breast surgery.

• Will I be able to do any sport?

Some sports are more stressful to your arm (tennis, squash, canoeing, cross-country, skiing, bowling ...) than others, but the most important parameter remains how your arm feels about it and how you go about it on the sport. It is wise to start carefully and then gradually increase the duration and intensity. See section 'Physiotherapy after armpit clearance'.

The most suitable sports are: swimming, jogging, cycling, walking ... Swimming and aqua gym aerobics are ideal sports for preventing of lymph oedema. Information on a tailored swimsuit

and swim prosthesis can be obtained from your track guide. After a mastectomy it is best to wear a swimsuit that fully covers the breast and underarm area.



• Can I sunbathe?

Moderate sunbathing is allowed, unless your doctor has forbidden it. Make sure you don't get sun burnt and avoid excessive warming, especially on the operated side and in the irradiated area. Use a sunscreen with a high protection factor and avoid prolonged exposure to direct sunlight and keep out of the sun between II am and 3 pm.

It is not sufficient to simply cover your arm. Exposure to the sun means that your whole body warms up and and that your blood vessels are dilated. This slows down the circulation of blood and lymph which is conducive to edema. Prevention is better than cure!

Is my illness hereditary?

Breast cancer can occur in families. If there is a risk of a hereditary form your doctor will tell you this and refer to the Centre for Human Genetics of UZ Leuven. If you have any questions regarding heredity, you should contact your doctor or make an appointment with a doctor or counselor through the secretariat of the CME (tel. 016 34 59 03 or 016 34 59 03).

EXTERNAL BREAST PROSTHESES

When you undergo a mastectomy your body image changes. Although the pain you feel about the loss of your breast cannot be lessened, the use of a breast prosthesis can really help you to regain your self-confidence. And wearing a prosthesis is important for your posture, especially for your back. It's all the more important if you have large breasts.

Buying a prosthesis can be an emotional experience. It sometimes happens that all the emotions surrounding your illness and your operation come to a head at that precise moment. Hence its purchase is not an easy task and you should not go alone. Your track guide will give you all the needed information. Upon admission to the hospital, your nurse will already fit a postoperative bra with a symmetrical filling. This means that you go home with a sense of security to the outside world. For patients with a large or very small bra size, we recommend to always see a 'bandagist' for a comfortable bra before you come into the hospital. Prostheses usually have a full refund rate, lingerie should be paid for yourself.

PHYSIOTHERAPY AFTER ARMPIT CLEARANCE

Two days after the operation you will receive treatment from a physiotherapist to restore mobility of your shoulder as quickly as possible.

WHY SO SOON?

After an operation in the armpit, some complications may occur that reduce the mobility of your shoulder. A physiotherapist must attend to these as promptly as possible.

POSSIBLE COMPLICATIONS

✓ Under the upper arm and along the outside of the chest a burning or tingling sensation may occur. This is because nerves which give feeling in the skin were cut during the operation. This is a normal phenomenon and usually lasts 2 to 6 weeks. Some patients are left with sensitive or insensitive patches on the skin of their arm.

This hypersensitivity is not conducive to the mobility of the shoulder, with the result that forced postures are adopted ('Napoleon-like': arm away from the side of the body and hand on the stomach in order to reduce the burden as much as possible).

- Many of the lymphatic vessels are cut during surgery. They're so small that they cannot be repaired. But your body adapts and the loss is compensated by the development of a series of small pre-existing alternative routes. After the removal of the axillary lymph nodes a fold in the skin often remains, running through the armpit and down the inside of the arm. In this fold there are lymph vessels which are damaged and no longer carry fluid. Subsequently they dry up and shrink and result in taut like cords (lymph strands) under your arm. They may be painful and this pain may extend to the wrist. In these cases it is usually difficult to stretch the elbow.
- A third possible complication is a spasm of the main chest muscle. This can cause a sharp, shooting pain along the front of the shoulder and chest. The muscle cramps because you do not move your arm enough or not normally. The sooner you stretch your arm and reach out for things in the usual way, the less risk you run experiencing this pain.

Movement will solve most of these problems.

As a first exercise to learn to relax, it is sometimes necessary to learn a good breathing technique. Mastering your breathing by letting it out slowly and gradually, and breath in deeply helps you to relax and concentrate better. You then start to make movements in all directions with your shoulder and do exercises with your elbow held straight in order to stretch the skin properly. The second day after the operation the physiotherapist comes along and starts with some simple exercises. They become gradually more difficult towards the time that you will leave the hospital. Once at home, you are advised to continue exercises under the guidance of a physiotherapist. Heat therapy, electrotherapy and various massages are NOT recommended. Only movements of the shoulder joint through active and passive mobilization, transverse stretch, stretching, and any scar treatment are important at this time. The appropriate prescription will be delivered before you go home by one of the doctors in hospital.

After axillary node removal you are entitled to 60 physiotherapy sessions (under the category known as 'FA' pathology), with 60% reimbursement from your Belgian medical insurance scheme. Your physiotherapist must complete a notification form for the doctor acting for the insurance scheme. You will receive the necessary papers from the hospital. If you need more than 60 treatments, the rate of reimbursement will be lower.

If a distinct swelling (lymph edema) in your arm occurs, you should see a doctor. When other causes have been excluded, and your doctor prescribes manual lymphatic drainage, you are entitled to a refund according to another system. This requires a detailed motivation for treatment for the medical officer of your insurance. There is no limit then to the number of treatments.

When the scar has healed sufficiently, it is advisable to move the skin around the scar (scar massage) to prevent adhesions in the tissues underneath which could restrict your movements. You can ask your physiotherapist, your partner or you can try it yourself.
SOME EXERCISES YOU CAN DO YOURSELF

Squeeze Exercise

- Sit down and keep both arms straight for your body. Make sure the wrists are higher than the elbow and elbow above the shoulder.
- X Squeeze 10 times with both hands. Make circles clockwise 5 times and 5 times counterclockwise.





Butterfly Movement

- X Sit down and place both hands on the neck. Keep the elbows together.
- Try to open as far as possible and close the elbows until they touch each other, repeat 10 times.

Wall Crawling

X Stand facing the wall with your feet about 15 cm from the wall. Rest your forehead against the wall in order to keep balance. Put the palm of your hands just above your head against the wall. Start 'walking' with your fingers up the wall, going a bit higher each time. 'Walk' up until the elbow of your 'good' arm is completely stretched. 'Walk' with your hand on the side operated on as high as you can. Repeat 5 times.





Turning circles with both arms

- X Sit down and keep both arms alongside the body. Place both hands on the shoulders.
- Make circles as large as possible with both arms together, 5 times in one direction and then 5 times in the opposite direction.

While seated

- X Sit on a chair, elbows 90° pleated at shoulder height, palms facing forward.
- Move both arms simultaneously downwards (like elbows at shoulder height), as far as possible and then back up again (up and down in one time).



HOW CAN I COME TO TERMS WITH MY OPERATION?

There is no easy answer to this question. You will find a number of tips and tricks based on questions that other women have asked before you.

"WHY ME? WHY NOW?"

We all try to come up with a personal response. This is a perfectly normal part of the process of coming to terms with the illness emotionally. Some people try to find an explanation in their own temperament or character, earlier life-style or traumatic experiences in their past life. It is important to realise that scientific research has still not established what exactly causes breast cancer, how it happens and what major factors play a role in it.

It can happen that the illness brings a whole series of elements to light, sometimes it can indeed be related to specific events. Whatever worries you in this respect, what really matters is to express it. The fact that breast cancer has a frequent occurrence does not make your problem any less serious. Remember that you are not the only victim and that a large number of women have already had to face it.

"HOW CAN I AS A WOMAN LEARN TO LIVE WITH A BREAST THAT HAS BEEN DISFIGURED OR AMPUTATED?"

The most important purpose of a breast cancer operation is to make sure you have absolutely the best chances of surviving. This means that you will have to find how you carry on living with this change to your body. But it does not mean that it will necessary be easy or straightforward. The point is to come to terms with a loss: you are losing your familiar image of your body. There is a risk that you will feel to some extent sexually diminished.

An important thing to remember in dealing with this situation successfully is that you have to accept that you will be saddened by your loss. It is quite legitimate to regret what you no longer have. Only then can you gradually accept the loss and face up to it. You have to realise and accept that you will regularly feel sad so that you can start thinking about other things and focus on other aspects of your life.

Another important thing that will help you to come to terms with your loss is gradually restoring the highest possible level of self-esteem. After all, a breast operation, and especially a mastectomy, changes your body and can undermine your self-awareness and your confidence.

Living after a mastectomy also means that you will grow into a new self and learn to appreciate and respect your body all over again. To do that, you must find the courage to see and touch the scar, not just you on your own but your partner too. In the hospital, the first steps to do this will be taken before you leave. You will be encouraged to look at the scar with your partner before discharge.

Your self-confidence in relation to the outside world can improve if you can tolerate a prosthesis, and make a decision on the fact that you do or do not want a breast reconstruction.

The third important prerequisite for a healthy grief is that you stay in touch with family, friends and significant support figures, both during and after hospitalization. You will find ways and means of taking up your normal life again, with all the demands and responsibilities that it entails, however tired you may be and however anxious you may feel about the future.

To adjust to your new situation in life as smoothly as possible it is important to consider what impact the operation will have

- > on your home life (is there someone you can rely on in the next few weeks to take over some of your tasks or will you need a home help?)
- X and at work (can you still carry on doing your job? Do you have alternative possibilities?)

"WHY IS IT SO IMPORTANT TO TALK ABOUT MY FEELINGS AND ACCEPT THE PROSPECT OF DEPRESSION?"

If you cannot allow yourself to let others see what you are feeling, you are going to be very lonely.

Many people assume that you cannot burden others with the concerns and anxieties that this illness will cause. But no one can get through this period without help and support.

Other people will also find it difficult to work out what attitude they need to take to help you. They also have to face anxieties that they do not always feel they can share with you.

Accepting these feelings and expressing them can be much better than bottling them up inside you. It may well be that you may have to tell your family how they can best help you. If what you need is a chat or if you prefer to be left alone from time to time, the best thing is always to say so. Otherwise there will be no proper communication and misunderstandings may arise.

"Facing breast cancer means facing uncertainty, anxiety for the future, questions about the prospects for full recovery and cure. WILL I EVER GET OVER THE ANXIETY? HOW CAN I LEARN TO LIVE WITH IT?"

The purpose of the treatment that you are undergoing now and in the coming weeks or months, is to beat the illness. But it often takes years before you really dare to believe in it. Worrying that the disease will spread imperceptibly is very common, though it usually dissipates gradually over time.

Even so, this worry can recur - when you go for a check-up, when you notice symptoms that may or may not be related to the illness, when you remember the illness itself or the treatment.

Some patients cannot get the anxiety out of their minds and some let themselves almost swallow in it. They find it difficult to take decisions and to enjoy what they still have.

What matters is that you find a way of coming to terms with your anxiety.

One way of doing so is to consider not what you have lost but what you are sure of having. One thing you can be sure of after the operation is that you will no longer have malignant cells in you. Of course you will need thorough medical follow-up afterwards to confirm this.

The really useful thing you can do is write down the questions you want to ask and the anxieties you are feeling before you go to the doctor. You will be performing a great service both to yourself and your doctor. Sometimes it can be helpful if someone goes with you, someone you can trust to discuss things with and listen to you. But if for one reason you feel unsure of yourself, do not hassle the doctor for an earlier appointment. It is better to see to it yourself that you do not allow your anxieties to take over, but stay realistic.

Your confidence in the future must develop gradually, along with the strength to start making long-term plans.

"SHOULD I TELL MY CHILDREN THAT I HAVE BREAST CANCER, THAT I AM TO HAVE A MASTECTOMY?"

Children, however young they are, immediately sense tensions in the family. All children react in their own way. Small children will send cries for help by sleeping badly or going off their food. Older children will begin wondering what they are being told and what is being withheld from them. Telling them too much, can be a shock, but not telling them anything can also be harmful. Children can get all kinds of fantasies that are far worse than the reality. This does not mean you must share all details with them. You know your child better than anyone else.

It is a good thing to make the first move yourself. It is really important to explain things step by step and answer questions calmly and simply. For children, a shared concern is less of a concern and a shared sadness means less sadness.

It is also important to let your children express their feelings. You can help them by putting their feelings into words for them, for instance by saying to them, "I can see you're unhappy because Mummy is not at home". Playing games also gives children an opportunity to express their feelings.

And something else that can be really helpful is if there is someone they trust (teacher, family member etc.) whom you can go and see together for advice.

Children find it easier to understand and accept bodily changes. They usually have less problems than you will with accepting disfigurement.

More information on talking to childeren: www.cancer.org www.cancer.net

"HOW CAN I GET MY PARTNER ACTIVELY INVOLVED IN THE PROCESS? WILL OUR (SEXUAL) RELATIONSHIP SURVIVE?"

At such difficult times, the feelings of partners are sometimes rather overlooked. They are left with their own fear that they may lose the person that they love. They may also find that they scarcely have the time to cope with their own emotions.

They'll certainly find themselves confronted with all sorts of unaccustomed tasks (finding someone to help with domestics may be one way out of this difficulty, and is also a good idea when you come home from hospital). It often seems difficult to talk to each other about concerns and fears, and each of you may be frightened of offloading onto the other an additional burden. Just being able to cry together can be a relief. It is important to be able to share fear and despair, rather than always trying to remain strong for the other person's sake.

Some men tend to try and deal with illness by rationalizing it, but this doesn't mean that they care any less.

Some women don't dare show their partner their scar, because they're afraid that they might see shock in their partner's eyes. You need to remember that any expression of shock that you may perceive is not directed against you as a person, but rather at what has been done to you.

It may take quite some time before women can really accept that their partner wants to make love to them, perhaps because of the importance of breasts in lovemaking for both men and women. It is therefore unrealistic to pretend a breast doesn't matter. But your personality doesn't dependent on having two whole breasts. It's not just the scar that may get in the way of lovemaking, but also fear, worries about the future, and perhaps pain.

At such times, cuddles, caresses and intimate moments can provide an opportunity to express your (sexual) feelings.

Some of you may not (yet) be involved in a relationship, and may wonder "what will happen if I meet a man and want to take things further?" The change in your body can, of course, be a bit of a mental hurdle to clear when you're building a new relationship. There's often a big fear of rejection. The one and only way to overcome this hurdle is to be able to communicate openly. In other words, you should try to express your fears and anxieties to your friend; listen to him to find out whether and in what ways it bothers him.

Above all try to believe that your new relationship has no less chance of succeeding because you have lost a breast.

It may be that having read this text you find there are things that affect you personally or things that you feel you can't resolve on your own and you would like to discuss. For this reason, there's always a possibility to talk to your track guide, or to the psychologist or sexologist of the breast centre.

BREAST RECONSTRUCTION

Breast reconstruction is the restoration of the structure on the breast where the breast has been removed during a mastectomy. Patients who decide not to carry out a reconstruction can choose to wear an external prosthesis.

WHAT IS BREAST RECONSTRUCTION?

During a surgical procedure a new breast structure can be formed. Reconstruction can be done at the time of the mastectomy or at a later time, in a new surgical procedure. In order to construct a breast structure, synthetic implants can be used, or the surgeon can use body tissues of the patient. The term reconstruction includes the reconstruction of the nipple and areola.

Not all patients who have or will undergo mastectomy, opt for a reconstruction. Many opt to wear an external breast prosthesis.

There are several techniques to create a new breast, nipple and areola. Sometimes changes to the other breast are made to improve the symmetry between both breasts. It is important to have realistic expectations about the results to be achieved. Preliminary discussions with the plastic surgeon may help to create a correct image. The new breast can look natural and feel normal for someone else. For the operated woman the "new breast" and the abdomen feels different and often this breast has little skin sensation and may feel numb.

RECONSTRUCTION USING SYNTHETIC IMPLANTS

Synthetic implants are teardrop-shaped inner bags filled with silicone or a saline solution. To prevent the formation of scar tissue around the implant, the implant often is placed under a muscle rather than just underneath the skin.

Implants can be inserted just after performing the mastectomy (same procedure), but usually it is opted to do so about a year after treatment. If necessary, small implants can be used so that the skin and muscles of the chest wall don't have to be excessively stretched.

For larger implants to be inserted, it is often necessary to first stretch the skin and tissues. This is then done by placing a so-called temporary expander. The temporary expander is a refillable (with physiological water) prosthesis having a silicone wall. The expander is provided with a flap that is implanted in the area where the reconstructed breast will be formed. During the implantation, a small amount of physiological water is injected into the prosthesis. The patient should then see the surgeon at regular intervals to continue to fill the expander. After three to six months, the overlying skin and muscles will be sufficiently stretched to remove the temporary expander and insert the final implant (silicone or saline water filling them). The nipple and areola will be reconstructed in later interventions. This above procedure may have the following potential disadvantages:

- capsule formation around the implant (= a bag of scar tissue around the implant that may possibly harden and calcify)
- infection of the implant (the implant must then be removed)
- perforation of the implant through the skin (this is certainly possible if the skin is stretched with an expander)
- leakage of the implant

These complications can occur at any time after the reconstruction and the risk is higher after radiation therapy to the breast (30 to 40%).

Most patients experience quite a bit of pain during the first 24-72 hours after the operation due to the lifting of the chest muscle in order to fit the prosthesis underneath. The breast will be swollen and sensitive.

RECONSTRUCTION WITH OWN (AUTOLOGOUS) TISSUE

Breast reconstruction can also be done using your own skin and fat from other parts of the body. We then talk about a tissue 'flap'.

Benefits:

- most natural results with symmetry and a natural feeling and warm temperature
- no foreign objects in the body
- delayed complications are almost nonexistent
- Instural evolution: when experiencing weight gain or loss the newly formed breast will follow the rest of the body and will also show a natural aging process

Disadvantages:

- Siven the complex connection between blood vessels, damage to the blood supply can occur during the operation. This may lead to immediate tissue death. If this happens, the new breast must be removed. Emotionally this is stressfull. On the other hand, it is so that this complication almost exclusively occurs in the immediate period after the procedure. The probability of failure is almost nonexistent after discharge from hospital.
- After the operation you will experience pain both at the location where the tissue was removed and also in the area of the new breast.

There are several types of reconstructive 'flaps':

× LD flap

× DIEP flap

× SIEA flap

🗴 GAP flap

🗶 TMG flap

LD Flap

The "LD flap" uses the muscle 'Latissimus Dorsi '(= a muscle located in the upper half of the back) in order to reconstruct a new breast. This muscle is rotated forward, usually to cover an implant and protect it against its potential known disadvantages. Sometimes only skin and muscle volume are sufficient to obtain symmetry, making an implant unnecessary. But usually, the muscle alone is insufficient to create a symmetrical result. Along with the muscle, skin and fat can also be moved to fill the shortage of skin in the chest area.

Since an incision is made under the shoulder blade, there will be a scar at your back after the operation. This scar can be quite dominant and disturbing, especially when an attempt to transpose as much tissue as possible together with the latissimus dorsi muscle was made in order to avoid a prosthesis.

 \rightarrow The procedure takes two to three hours.

Free perforator flap: DIEP, SIEA, S-GAP

Fat, skin, supplying and draining vessels from another body part are entirely disconnected. Than they are moved with a supplying and draining blood vessel to the chest. The other part of the body may be the abdomen (DIEP/SIAE) or the buttocks (S-GAP).

Veins and arteries are cut and restored at the level of the chest. Since the removal of a vessel from a muscle or from adipose tissue is a complex procedure, the operation is best performed by a plastic surgeon who specializes in microsurgery. Today, applying new techniques, muscle tissue is left in place and recovery is smooth, with the exception of the TMG flap.

This operation takes about six hours for the reconstruction of one breast.

RECONSTRUCTION OF NIPPLE AND AREOLA

Three to six months after the initial reconstruction, the reconstruction of a nipple and areola may be performed. This period is necessary for the breast to evolve to a final shape and position and to determine the correct position of the new nipple. Today the reconstruction of nipple and areola don't require additional tissue removal from other parts of the body.

The nipple is usually reconstructed with two or three small flaps, derived from the skin of the new breast. This results in a number of tiny scars in the vicinity of the new nipple. These scars will be camouflaged by the tattooing of the areola. Optionally, the nipple can be reconstructed by transplanting a part of the other nipple. Of course this is only possible if the remaining nipple is large enough.

The areola is simulated by a tattoo approximately one to three months after the reconstruction of the nipple. This procedure is not definitive and must often be repeated as the pigment may fade.

THE DECISION MAKING PROCESS

If you opt for a breast reconstruction, there are two important considerations:

- Will it be an immediate or delayed reconstruction?
- Will it be a reconstruction with synthetic implants or autologous tissue?

Immediate or delayed reconstruction

- X This choice is always made in consultation with your physician and according to the findings upon diagnosis.
- **X** Benefits of immediate reconstruction:
 - You are not faced with the loss of a breast, however the new breast will not be a copy of your own breast and also

needs acceptance. Initially there will be no nipple and you will experience numbness of the skin.

• One procedure instead of two means less cost, and only one recovery period

X Benefits of late reconstruction:

- More reflection time on the reconstruction type
- Possible shortcomings of the reconstruction may get better accepted
- No adverse effects on the newly formed tissues from potential after treatment (chemo, radiation)

Reconstruction with synthetic implants or autologous tissue

X Synthetic implants

- Can incur cracks or other damage, they can harden
- Shorter operation time, shorter recovery time
- Pain after surgery is limited to the area of the reconstructed breast
- Almost certain that they need to be replaced at some point

X Autologus tissue

- The new breast is soft and looks natural
- No insertion of foreign objects
- Long operation time: postoperative discomforts are not to be underestimated, but disappear completely, especially in muscle-sparing surgery (perforator flaps).
- Longer recovery period
- Complications are almost exclusively confined to the hospitalization period.

MYNEXUZ

Breast cancer patients treated at UZ Leuven can use mynexuz, the secure web application for patients. Accessing mynexuz, you receive customized information about your treatment. You additionally get an overview of your appointments and invoices.

Visit the web address www.mynexuz.be (or www.uzleuven.be/mynexuz).

SELF-HELP GROUPS

(Verify by phone if they speak English.)

Bewuster Verder Leven Kortrijk

Kwadepoelstraat 50 8550 Zwevegem Contact: Francine Dewilde, tel. 056 75 63 81

Onthaalcentrum Boratie vzw

Stadsomvaart 79A 3500 Hasselt Tel. 0479 85 64 34 (Monday 10 - 12 and Tuesday 14 - 17)

Onthaalcentrum Naboram vzw

Minderbroedersrui 19 2000 Antwerpen Contact: Frieda Paternoster, tel. 03 234 35 66 (Monday and Thursday from 13.30 - 16.30)

Samen Verder Kempen vzw

Acacialaan 2 2300 Turnhout Contact: Chris Peeters, tel. 014 72 52 66

The Wave vzw: zelfhulpgroep voor vrouwen: borstamputatie en borstreconstructie

(support group for women with mastectomy and breast reconstruction) Karel Oomsstraat 1/55 2018 Antwerpen Contact: Ingrid Deherve, tel. 0475 49 15 93 (Every day in the morning) Website (focused on reconstruction): www.ping.be/the-wave

OTHER USEFUL ADDRESSES

Vlaamse Liga tegen Kanker (VLK) -Flemish League against Cancer

Koningsstraat 217/Rue Royale 217 1210 Brussel Tel. 02 227 69 77 – 02 227 69 71 E-mail vl.liga@tegenkanker.be Website www.tegenkanker.net

Stichting tegen Kanker (Cancer Foundation)

Leuvensesteenweg 479 1030 Brussel Tel. 02 736 99 99 Fax 02 734 92 50 E-mail info@kanker.be Website www.kanker.be

Vlaamse Kankertelefoon, (Flemish Cancer Telephone) tel. 070 22 21 11

Vereniging voor Kankerbestrijding

Zaterdagplein 13, bus 13 1000 Brussel Tel. 02 219 48 20

Website: www.borstkanker.net

MBC-FUND

The MBC-Fund (multidisciplinary breast cancer fund) aims to promote and support research and realization of special projects in the diagnosis, treatment, support and follow-up of patients with breast cancer.

- Donations may be made to account 734-0194177-89 mentioning "gift MBC - kredietnr. EKS-FOMBCI-P3610".
- \rightarrow For donations from 40 euros you a tax certificate will be send.

THE HARDLING FUND

The Hardling Fund was founded with the aim to create opportunities for more supportive staff of breast cancer patients. This includes creating appropriate counseling rooms, providing professional guidance, lectures, organization of informational activities ... Fund resources are managed under the responsibility of Prof. Marie-Rose Christiaens, Department oncological surgery.

More information is available on http://www.kuleuven.be/mecenaat/Fondsen/geneeskunde/ Hardelingenfonds.html

Recovering from breast surgery

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Published by University Hospitals Leuven Herestraat 49 3000 Leuven tel. 016 34 49 00 www.uzleuven.be As a patient, you can consult your appointments, invoices and personal details online via **mynexuz**. For more information, go to <u>www.uzleuven.be/en/ mynexuz</u>.

