

# PREVENTIVE MASTECTOMY

*How to prepare  
and what to expect*

Practical Guide



September  
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This guide was developed by the Belgian non-profit organisation BRCA+ network. It is the result of the collaboration of many women who have already undergone a preventive mastectomy and who have shared their valuable advice.

We would particularly like to thank the two members of our Scientific Committee, Ingrid de Biourge, physiotherapist specialised in breast cancer management, and Charlotte Spaas, clinical psychologist in genetics, for their valuable contributions to this guide.

We would also like to thank:



**RIZIV-INAMI**

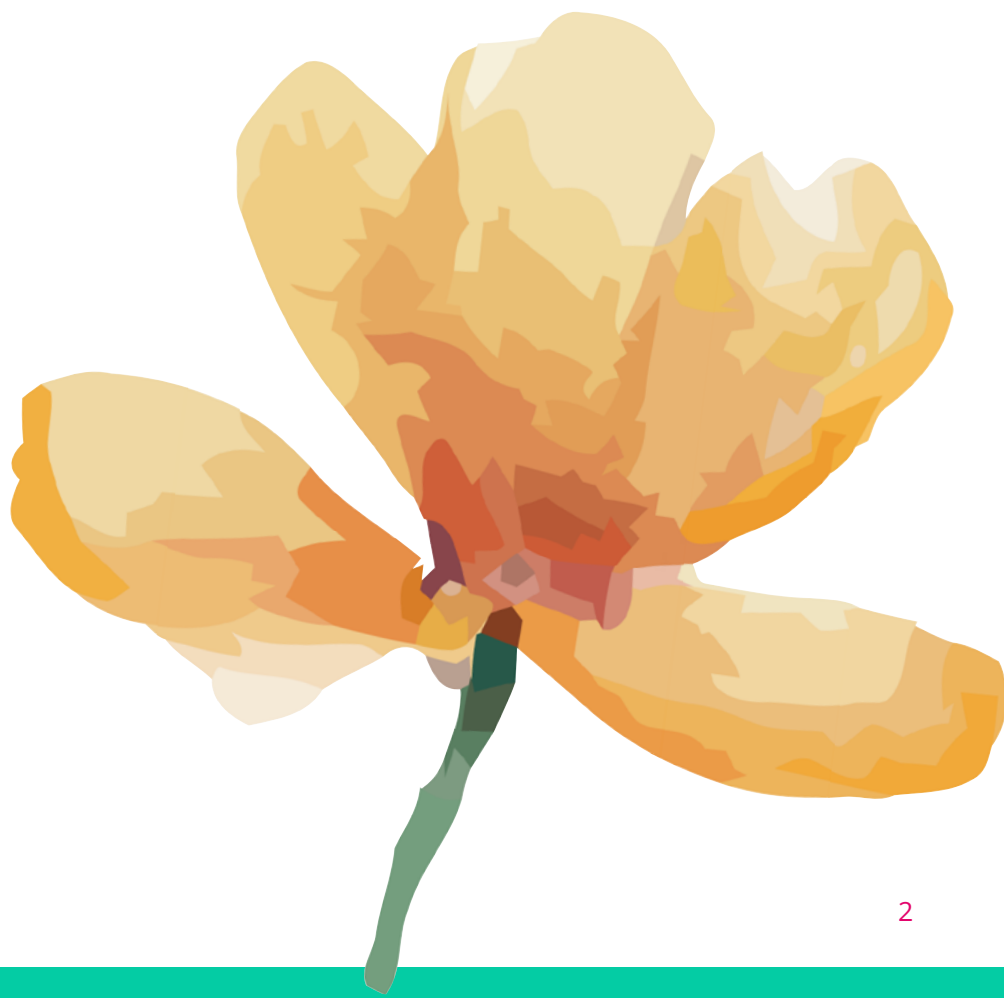
for the administrative information provided.

Graphic design: Milton Pereira. A heartfelt thanks for his work, his dedication and his generosity.

This guide is constantly evolving and new editions will be published as other women and professionals share their advice.



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# Introduction

This guide was designed to help women who have decided to have a preventive mastectomy. It is based on the personal experience of many women who have a genetic predisposition to breast and ovarian cancer and who have already undergone risk-reducing mastectomy. Women planning to have this operation were also consulted to gather their feedback on what they expect from the guide and how best to meet their needs. The two members of our Scientific Committee, Ingrid de Biourge and Charlotte Spaas, as well as the INAMI-RIZIV also contributed by providing valuable information.

This guide contains useful advice and information on the practical and psychological aspects of the period before, during and after mastectomy. It does not intend to provide medical-scientific advice. To do this, please contact the team of doctors and nurses who are following you.

This guide is a living document. The experiences of other women will gradually enrich it, and additional editions will be published. If you have had a risk-reducing mastectomy and find that some advice is not included in this guide, write to us at [info@brcanetwork.be](mailto:info@brcanetwork.be).

**Your sharing can help many other women!**



# About BRCA+ network

BRCA+ network is the Belgian association which represents and supports carriers of a genetic mutation which increases the risk of developing breast and/or ovarian cancer. We are a patient association created with the aim of spreading information about BRCA+ genetic mutations, raising awareness, supporting each other, and creating spaces for the exchange of experiences and stories.

## Our mission:

- We raise awareness about hereditary cancers linked to a BRCA+ genetic mutation<sup>1</sup> and defend the rights of carriers of these mutations
- We support BRCA+ carriers on a practical and psychosocial level
- We create spaces for the exchange of experiences for all the carriers of these mutations living in Belgium.

Visit our website for more information:  
[brcanetwork.be](https://brcanetwork.be).

1.

### BRCA= BReast CAncer gene

With the + sign we indicate all other genes that have characteristics similar to BRCA and that lead to an increased risk of breast and/or ovarian cancer (PALB2, BARD1, BRIP1, RAD51C, RAD51D, ATM, CHEK2, TP53, MLH1, MSH2, MSH6).

## How can we support you?

Preventive mastectomy is such a life-changing experience that no one should have to go through it alone.

If you are having surgery in Belgium and are looking for support, we can help you in the following ways:

- **Join our Facebook group 'BRCA+ network FR/NL/EN'**, open to all those who have a hereditary predisposition to breast and ovarian cancer and who live in Belgium. The group is a forum for sharing and exchanging experiences, stories and knowledge.
- **Talk to one of our BRCA+ buddies.** BRCA+ buddies are women who have already undergone preventive mastectomy (with implants, DIEP, etc.) and who are willing to share their experience with you, listen to you and give you practical advice. Fill in the form on the 'BRCA+ buddies' page of our website to talk to a buddy: <https://brcanetwork.be/brca-buddies/>.



# What is a preventive mastectomy?

A preventive or risk reduction (double) mastectomy is a surgical procedure which consists of removing both healthy breasts. It is offered to women who are at very high risk of developing breast cancer due to a genetic mutation or in the event of a strong family history of breast cancer (but without a genetic predisposition).

For high-risk women who have not developed the disease, a bilateral preventive prophylactic mastectomy can reduce the risk of breast cancer by 90% or more. Please note that traditional breast monitoring will remain necessary. Indeed, although preventive prophylactic mastectomy reduces the risk by 90% or more, there may still be residual breast cells remaining in the preserved tissue.

For high-risk women who have already been diagnosed with breast cancer, this operation can help reduce the risk of developing a second breast cancer.

Preventive mastectomy is a permanent and irreversible procedure. If you are planning to have children, you should, therefore, take into account that the operation prevents breastfeeding. In addition to genetic risk, factors such as age, other medical conditions, lifestyle, and mental health will be taken into consideration to determine whether or not a preventative mastectomy should be performed.

Women who undergo a preventive mastectomy have the option of reconstructing the shape of the removed breasts or opting for a cosmetic flat closure (without reconstruction). Women who choose to have their breasts reconstructed have several options. Breasts can be reconstructed using implants (saline or silicone). They can also be reconstructed using autologous tissue (that is, fat tissue from other parts of the body). Breast reconstruction surgery can be performed (or started) at the time of the mastectomy (immediate reconstruction) or later (delayed reconstruction). Delayed reconstruction can take place months or even years after the mastectomy. **For more information on reconstruction techniques, we suggest you consult the following links:**

- [MeReconstruire \(FR\)](#)
- [Les chirurgies de réduction de risque, Geneticancer \(FR\)](#)
- [Podcast "Naître princesse, devenir guerrière", série spéciale sur la reconstruction mammaire \(FR\)](#)
- [Preventieve borstoperatie and Borstreconstructie \(NL\)](#)
- [Types of reconstruction \(EN\)](#)

**Mastectomy remains a personal choice. High-risk women who decide not to undergo this operation can still opt for frequent radiological screening. Visit our website on the "Risk Management" page for detailed information on the current Belgian guidelines for screening high-risk women.**

# *(At least) 6 months before your surgery*



## ADMINISTRATIVE ASPECTS

1. **Breast reconstruction** is (almost always) fully reimbursed in Belgium, whether it follows a mastectomy due to breast cancer or a high risk of cancer, provided that you do not take a private room in the hospital (unless your insurance medical permits; see point 2 below). You only pay your personal costs, that is to say, the co-payment and any supplements. Discuss your case with your doctor to determine the amount you will be entitled to.

**Breast reconstruction using a prosthesis or breast expander** is fully reimbursed as part of a preventive mastectomy since it is considered a mutilating treatment.

Since 2016, INAMI and several Belgian hospitals have signed an agreement regarding the pricing of supplements for **autologous breast reconstruction** (with your own tissues). This is now fully reimbursed by ordinary health insurance if you opt for a shared or double room. Make sure the hospital where you are treated is part of the agreement, and don't hesitate to ask the hospital and your health insurance company for more information. Here is the link to the INAMI convention and the complete list of participating hospitals: [Reimbursement of autologous breast reconstruction / Terugbetaling van borstreconstructie met eigen weefsel.](#)

2. We recommend that you ask the hospital where you are going to have the operation for clear financial information in the form of a pre-surgery quote of the various expenses (possibly including the INAMI codes). It is also very important to contact your mutual insurance company before surgery, present your dossier to them and ask them for clear information on what will or will not be covered financially. The more information you ask for at this stage, the fewer surprises you will have later on.
3. If you have **hospital insurance**, check in advance what it covers and what it doesn't cover. Sometimes, the co-payment is only refunded if you are in a double room and not in a private room. If you do not have hospitalisation insurance, check in advance what your compulsory health insurance can cover.

Hospital insurance is (non-mandatory) insurance that covers costs not reimbursed by basic health insurance in the event of hospitalisation. Sometimes, the insurance cost may be fully or partially covered by your employer. Find this out.

This site gives you an overview of the hospitalisation insurance available in Belgium (2022 prices): <https://www.mon-assurance-hospitalisation.be/> (note: the price of insurance varies depending on age and personal situation).

In addition, some hospital insurance plans foresee a waiting period of 6 months (called *stage*) from the date of signing the insurance. This waiting period is the latency period between the moment the contract is signed and the moment the insurance becomes active. During these few months, you have already started paying for your insurance, but your hospitalisation costs may not be fully covered. When planning your surgery, if you have hospitalisation insurance, make sure the surgery date does not fall within the 6-month waiting period. If you still need to have surgery on this date, ask your health insurance provider for information.

4. If your operation includes lipofilling (aspiration of fat from another part of the body and reinjection into the breasts), be sure to ask your surgeon whether or not it will be reimbursed, as it is not always a given that it will be reimbursed.

## PLANNING THE MASTECTOMY

5. Once you decide to have a preventive mastectomy, you will look for a hospital and surgical team you can count on. Please note that if you opt for a mastectomy with reconstruction, in most cases, the operation will be carried out by **two surgeons**: the breast specialist, who will do the mastectomy, and the plastic surgeon, who will do the reconstruction. You should have at least one consultation with each of them. In some cases, only one surgeon may be offered to you. Please note that having an appointment with plastic surgery (and sometimes also the breast specialist) takes several months as a “potential new patient”. It sometimes takes a considerable amount of time to be able to obtain these different opinions.

6. If you opt for reconstruction, be aware that several factors can influence the **type of reconstructive surgery**. These include the size and shape of your breast, your age and health, your history of illnesses and surgeries, your history of smoking and obesity, and the availability of autologous tissues. We recommend asking for at least **2 or 3 different opinions**. On the one hand, each doctor has their own preferences and way of explaining, and on the other hand, the “human match” is also important. It is helpful to prepare a list of questions in advance and write down the answers during the consultation.

### Questions you may want to ask your surgeon during your consultation include:

- skin sensitivity
  - the shape and size of the breast desired, if a change is possible/required
  - experience in relation to prosthetics or reconstruction with own tissues
  - the scars
  - postoperative care.
7. When planning the operation with the surgical team, take into account that you will be on **sick leave** for at least a month from the day of the operation, or longer if you move around a lot or lift heavy objects during your work. The duration of the work stoppage will also depend on the type of reconstruction you will have and the progress of the post-surgery period.



## TRAINING

### 8. To make the post-surgery weeks easier:

- take care of your body and its tone before surgery. The sooner, the better, since we know that a moving body is a stronger body. Everything is good to do to boost your body and its muscles. This will make you more independent and more confident in the future.
- Find out, via your future physiotherapist or the surgical team, what movements will be required to get out of bed and move around independently and safely with maximum comfort. Each surgical technique will have its specific indications and guidance for the future. A post-surgery physiotherapy consultation will provide specific strengthening exercises linked to your surgery and give you useful advice immediately post-operatively, which should be enough to optimise all of this. Don't hesitate to schedule one.

## GET SUPPORT

9. Ask your medical staff to direct you to **support groups** where you may find people willing to share their experiences. BRCA+ network can help you and connect you with women who have had the same type of surgery as you and are willing to share their experiences. In most hospitals, there is a specialised psychologist with whom you can have one or more consultations and whom you can contact again afterwards if needed. If not offered, don't hesitate to ask for consultation with a specialised psychologist yourself!



# A few weeks before your surgery



## PREPARE YOURSELF MENTALLY AND PSYCHOLOGICALLY

- 10. Stop googling!** The Internet can be both useful and harmful. When it comes to surgical experiences, it's often the negative experiences that are shared online. Every experience is unique, and reading about possible complications harms your mental (and physical) health. Trust the medical staff and instead look for tips, advice and suggestions on how to prepare on a practical level.
- 11.** It is completely normal to have many questions in your mind before surgery. These questions may concern anaesthesia, post-surgery procedures, do's and don'ts, and much more. Write down **these questions as they come to mind** and ask them to the medical staff following you during the last consultations or directly upon your arrival at the hospital, depending on the type of question. Never be afraid to ask questions that are "too stupid" or to ask a question again if you are not sure you have understood the answer! Also, take your time to ask the questions, do not feel pressured if the appointment is taking "too long".
- 12.** In the days before surgery, **try to do what you enjoy and what makes you feel good.** As much as possible, avoid all sources of stress (mental and physical) and focus on activities that make you feel relaxed and happy. If you feel that it is necessary to do mourning work linked to this surgery, small symbolic things can be done. They will help some of you: pre-surgery photos, a symbolic gift, an artistic materialisation of this decision, etc.
- 13.** If you have a certain beauty routine, make appointments (i.e. beautician, hairdresser, etc.) immediately before the operation, as you will not be able to do this in the weeks following the procedure. However, remember that you will be asked not to put varnish or other products on your nails and to remove your piercings on the day of the operation.

## PREPARE FOR THE SURGICAL AFTERMATH

### 14. Buy or borrow everything you need for your post-surgery recovery.

#### Personal hygiene

- ❑ Dry shampoo and conditioner
- ❑ Wash cloths
- ❑ Intimate wipes

After surgery, you will not be able to take a full shower while the drains and stitches are in place. A shower accessory and a shower chair can help you wash your lower body.

Intimate wipes, dry shampoo and dry conditioner will save your life! You can get these products from a supermarket or pharmacy. If you can find antibacterial wipes, even better.

#### Clothes

- ❑ Post-surgery bra (wireless and front closure)
- ❑ At least two comfortable button-up pyjamas
- ❑ Loose button-front shirts and cardigans
- ❑ Flowy pants that are not too long (avoid zippers and tight pants)

Regarding the bra, ask the surgeon what they want, if the hospital provides it or if you should bring it on the day of your hospitalisation. We recommend having at least two bras, as you will need to wear them for several weeks. So it's best to have at least one spare. Choosing a bra is very personal, and what is comfortable for some is not comfortable for others. Plus, very expensive bras aren't necessarily more comfortable!

As for the size, unfortunately, it is difficult to choose in advance the one that suits you best, especially if you have opted for reconstruction with breast augmentation or reduction. Read the size guide carefully and ask your surgeon for advice. We advise you to buy only one bra before the operation, test it after the operation, and possibly buy another (if it is comfortable) or change brands (if it is not comfortable). After the operation, you can go to a bandage specialist to try different models. Brands available online and from bandages include ZBRA, BRABIC, Amoena Leyla, and Anita, but many others are available. When it is possible to switch from post-surgery bras to simpler bras, traditional lingerie stores (Etam, for example) offer several lines of very comfortable and not-too-expensive, wire-free bras.

As long as you have drains in place and can't raise your arms, loose, open-front pyjamas, tops, and shirts will be your best friends. Leggings aren't particularly comfortable because they are difficult to put on and take off and can be too tight when you're on the couch or in bed. Flowy pants are recommended.

## Sleep

- ❑ **Wedge-shaped cushion (or similar, for example, doomoo evolving baby loungers or nursing cushion)**
- ❑ **Half-moon cushion**
- ❑ **Mastectomy pillows**

For the first month after surgery (and probably much longer), you will need to sleep on your back. Additionally, it will be difficult to lie flat and you will probably prefer to sleep with your back at 45/60 degrees. A wedge-shaped cushion (or similar) is very practical for sleeping in a semi-sitting position by placing it vertically! Some also recommend a half-moon cushion (which is placed under the knees) to make sleeping easier.

Some women who have opted for DIEP reconstruction may find it more comfortable to sleep in a recliner rather than in their bed. If you have the possibility of having one at home, even on loan for a few weeks, it will certainly do you good, to sleep or simply to rest and relax your back thanks to different positions! Getting up from a regular chair or couch requires some work from the abs. The lift chair helps elevate you enough so you can lean forward and let your legs do the work.

Some women report relief from mastectomy cushions (heart-shaped or other cushions) because they support the arms. In some hospitals in Belgium, non-profit associations offer these pillows, which are provided free of charge (ask the medical staff). If this isn't the case for you, any small underarm pillow will also do the trick.

## Essential accessories

- ❑ **Drainage bags or pockets/belt\***
- ❑ **A back scratcher**

Depending on their length, there are different ways to manage drains. The most commonly used are drainage bags and drainage pockets/belts. Drainage bags are simple canvas bags (tote bag style) that go up to at least the thigh or knee, while the drainage belt can be purchased online or created at home with an elastic band and straps. fabric pockets. Some hospitals offer one or the other.

As the mobility of your arms will be somewhat limited in the weeks following surgery, a back scratcher can be very useful!

*\* Note: As you will read below, drains will be placed under the breasts to drain the blood and lymphatic secretions that form immediately after the operation.*



15. We hope that **physiotherapy sessions** will be prescribed for you following your operation. Do not hesitate to talk to your surgeon about it. Certain techniques and exercises will have to wait for a certain post-surgery period, but the physiotherapist will adapt their work according to your surgery, and , above all, your needs.

Physiotherapists specialising in breast cancer will offer you a guarantee of quality care. Postural work, shoulder mobility, lymphatic drainage, scar monitoring, sensory and body integration work and comfort treatments are different possibilities for your therapist to define.

During the post-surgery period, it may be difficult for you to actively search for a physiotherapist specialising in breast cancer in your city or region. Start your research before surgery.

16. **Organise logistics in advance.** During the post-surgery period, you will need a lot of help and support. If you live alone or are the only adult in the home, arrange shifts with friends or family to get constant help around the house for at least two weeks. Particularly if you've had DIEP reconstruction and won't be able to use your arms, abdominal and pectoral muscles much, having someone to help you with even the smallest tasks will make a world of difference. Depending on your personal situation (for example, if you are having chemo) or depending on the insurance you have, your mutual insurance company could reimburse you a certain amount in service vouchers or can send help to your home, such as for cleaning, to look after your children, etc.

Ask for more information at least 6 months in advance.

As it is recommended not to carry heavy loads, if you have children, be aware that you will not be able to carry them in your arms for several weeks after the operation (the exact number will be communicated to you by the surgeon and the physiotherapist).

As you will read later, if you have pets, arrange with friends, family, or specific services to leave your pet for a few weeks immediately after surgery. Indeed, the risk of zoonotic infections is high in the post-surgery period.

Here is a list of approved animal boarding facilities in Belgium:

- [List of approved animal boarding facilities as of February 1, 2024](#)
- [Pensions erkend door Dierenwelzijn Vlaanderen dd. 8/4/2024](#)
- [List of approved animal establishments \(Brussels\) / Lijst van de erkende inrichtingen voor dieren \( Brussel \) .](#)

Also, organise your discharge from the hospital in advance and find someone who can pick you up. Special services in your city can also provide help at home and in arranging transportation. These may be private services or services offered by your mutual insurance company.



17. If you are asked to change dressings and drain bottles yourself and you do not feel comfortable, you can contact a home nurse (through the hospital or your health insurance). If you are looking for a home nurse through mutual insurance, you must contact them well in advance. However, in some cases, disinfection and dressing changes will be carried out in the hospital throughout the post-surgery period and you will not have to do it yourself. Check with your doctors.

18. Just before you go to the hospital, **prepare your home for your return.** Place everything you might need within easy reach. For example, in the kitchen, place the things you use most (salt, oil, wipes, plates, glasses, etc.) so that you don't have to lift them or reach out. When it comes to food, if you don't have constant help at home, it can be helpful to do some big shopping and prepare and freeze some meals in advance. Buy foods that are not in heavy or difficult-to-open containers (for example, vacuum-sealed jars).

## PACKING YOUR BAG FOR THE HOSPITAL

19. You will stay in the hospital for at least 3/4 days. **Pack your hospital bag in advance.**

The list of essential items in your suitcase includes the following:

- ❑ Identity document and, if applicable, insurance documents and papers required for admission to the hospital
- ❑ Phone, phone charger and extension cord - hospital outlets are often located on the wall behind the bed, and an extension cord is necessary to always have your phone within reach

- ❑ Headphones
- ❑ 1 or 2 pyjamas and a change of clothes for when you leave the hospital (we suggest an open front shirt)
- ❑ Ompression stockings, if the hospital does not provide them
- ❑ Toiletries (soap, toothpaste, toothbrush, comb, etc.)
- ❑ Your personal effects, if you have them (glasses, hearing aids, dentures, prosthetic devices, etc.)
- ❑ Anything you like to entertain yourself (books, crosswords, TV series, podcasts, magazines, etc.)
- ❑ Snacks (in easy-to-open bags or containers)
- ❑ Non-slip socks and slippers
- ❑ Travel pillow and, if you have one, your nursing pillow
- ❑ Hair dryer
- ❑ A small fan (if summer)
- ❑ Sleep mask (especially if shared room)
- ❑ Throat lozenges, very useful after the operation
- ❑ A lip balm, you will probably have a dry mouth and lips
- ❑ We do not recommend taking valuable items with you. Although some hospitals have safes or the ability to lock your bedside drawer, your room will always remain open, and the hospital takes no responsibility for theft.

## PRE-SURGERY INSTRUCTIONS

20. During the final consultation with your surgeon, you will receive specific instructions on how to prepare for the operation. These instructions include medicines and food supplements that you usually take. Please tell your surgeon and anesthesiologist the **full list of medications and dietary supplements you usually take**. Follow your doctor's instructions about changing the dose or stopping these medications and supplements before surgery.
21. A few weeks before the operation, a **staphylococcus test** may be carried out to find out if you carry the bacteria. If the test is positive, do not panic. The medical staff will give you instructions on how to decontaminate yourself at home before the operation. In many cases, decontamination involves showering with a special soap and using antibacterial nasal ointment and mouthwash. Whether you test positive or negative, **wash your hands frequently** with soap and use an alcohol-based hand sanitizer.
22. Do not use any **beauty products** on your skin, nails or hair from the day before the operation.
23. Stop **eating and drinking** before midnight the day before the procedure.



# Hospital stay



## ADMINISTRATIVE ASPECTS

24. In some cases, on the day of hospital admission, you may be asked for a **deposit** (which will then be refunded). This depends on the existing agreements between your hospital and the different insurance companies. Find out in advance from the surgery department secretariat.

## DAY OF SURGERY

### 25. Some basic rules:

- Do not wear makeup, lotion, nail polish or deodorant.
- If you normally wear contact lenses, wear your glasses instead.
- If you're on your period, use a pad instead of a tampon (you may not be able to change pads for several hours).

26. Before the procedure, your skin should be as clean as possible. To reduce the risk of infection, the day before and the morning of the procedure, you will be asked to **shower your body (and perhaps your hair too) with a special antiseptic soap**. The medical staff will provide you with the soap and give you specific instructions for showering, or you will be asked to purchase the soap yourself at the pharmacy. PS. Not all hospitals provide hairdryers. If you prefer to avoid having wet hair, we recommend bringing one with you.

27. Feeling anxious right before entering the operating room is very common and completely normal! The good news is that you can take **tranquillisers**. If you are not offered one, ask the medical staff if you can get one.

28. The surgeon will make **marks on the breasts** to indicate where the incisions will be made.

29. From the day of the operation, until you leave the hospital, you will spend a lot of time with your head on the pillow and will not be able to **take care of your hair** in an autonomous manner. If you have long or medium-length hair, do two side braids before entering the operating room. Ask the nurse if bobby pins are accepted in the operating room.

30. If you have never had surgery, it is completely normal to be concerned about the effectiveness of **general anaesthesia**. Once again, good news... you'll sleep like a baby and you won't notice a thing at all! You will wake up slowly in a monitored post-anesthesia room and, when you are fully awake and stable, you will be taken to your room or, if necessary, you will spend the night in intensive care for further monitoring.

Depending on the type of intervention and the approach of the surgical team, there are multiple therapeutic means for pain management. Do not hesitate to ask your surgeon about what they plan to best relieve you (infusion, oral painkiller, anti-inflammatory, paravertebral block, etc.).

## POST-SURGERY DAYS

31. It is likely that the **first night after the operation** you will not sleep much due to the comings and goings of nurses who will regularly check your temperature, blood pressure, etc. In some cases, the surgeon may decide to place a **heat lamp** or, if you have had flap reconstruction, an **inflatable hot air blanket** over the breasts to improve vascularity. This lamp will be activated at regular intervals by the nurses.

32. Nausea may be present after surgery but will be relieved by the care of the nurses. In the early post-surgery period, you will keep the surgical drains which are put in place during the surgery (the number varies depending on the type of operation). It's completely normal that you don't know how to deal with all this material around you. Ask for help with whatever is needed. This is normal and well known by caregivers and it is only a matter of a few days. Take care of yourself and let yourself be pampered!

Furthermore, in the 48 hours following the operation, your throat may be irritated and resuming good breathing may cause you to cough, especially if you have undergone flap reconstruction. It is essential to regain good air volume after this type of surgery despite the tension felt in the stomach. If you have to cough, hold your stomach with a large cushion or with both arms to cough effectively without making a big movement of your stomach!

Do not hesitate to ask the nurses/physiotherapists for help and support.

Finally, for each, a few breathing exercises in cardiac coherence (with the free respiration lax application, for example), can help you relax, oxygenate your tissues and regain good thoracic mobility.

33. If you have had DIEP reconstruction, you will need to wear a large **belt that compresses your abdomen** after the operation and during the entire recovery period (normally a minimum of 6 weeks). Normally, this belt is provided by the hospital. Your surgeon will give you instructions and tell you when to remove it. If you had the opportunity to work on your stomach before surgery, waking it up would be easier. After surgery, the physiotherapist will be able to start the "abdominal awakening" with you and prepare for your safe physical recovery (abdominal control).

34. Some women experience constipation after surgery. This is usually due to the number of medications taken. In addition to eating plenty of fibre and drinking plenty of water, stool softeners and laxatives can help. Ask your medical staff for advice.

35. This advice may seem superfluous and obvious, but don't hesitate to **ask** the nurses and anyone who assists you for help! You have just undergone major surgery and it is normal that you are not independent and feel overwhelmed. The help you need may include **physical and psychological support**. In many hospitals, a team of onco-psychologists can support you. Don't hesitate to ask the medical staff if you can speak to one of them.

36. Ideally, you should **return to walking** quickly after surgery. It is for your comfort but also to help your body regain control and avoid complications linked to bed rest.

In reconstructions using implants or latissimus dorsi, the first lifting will generally be done by nurses, without much difficulty. You will just have to find your feet and reassure yourself in your movements.

If you had a free flap reconstruction, we recommend that you seek help from a physiotherapist. He will be able to guide you in your movements to protect the surgery but also to allow you to move with more comfort. The apprehension can be significant, the body sometimes needs a little more time to stabilise the tension (head spinning the first few times) but things will progress quickly, you are impressive! Your back will probably bother you the first few days. Changing your position, sitting a little or even walking a few steps will do you a lot of good! If you have the opportunity to enjoy a little shoulder or back massage, don't hesitate!

## LEAVING THE HOSPITAL

37. Plan your return home in advance. If someone is picking you up in a car, **put small pillows in the car** so you can place them under your arms and under your seat belt. Driving home can be scary, especially if your home is far from the hospital. Warn the person with you that they will need to drive slowly, especially around bends, roundabouts, and bumps.
38. It is very likely that you will leave the hospital with **surgical drains** still in place. The nurses will explain to you how to take care of the drains and, if necessary and, depending on the type of drains, how to change the containers where the liquid is deposited. When you are shown how to replace them, take a video with your cell phone. It will be very useful when you are at home and have to do it yourself.
39. Normally, a **physiotherapist** will visit you before you leave the hospital. If not, ask medical staff to speak to a physical therapist for clear instructions on what you can and cannot do once you return home.





40. Before leaving the hospital, ask your doctors to clearly tell you when you should worry (and when you shouldn't!). Also, ask them what medications to take for pain and constipation, and don't forget to ask them for all the certificates you need (for work, for sport, etc.), the medical prescription for physiotherapy sessions, including the intervention operating code (very important to benefit from reimbursement from the mutual insurance company), and the prescription for possible home care.

Normally, for preventive surgery, you are only entitled to **18 physiotherapy sessions** (like the general population, with three different pathologies per year). If there has been lymph node surgery or in the event of a transfer to intensive care (to be certified via the surgical code or the document certifying the transfer to intensive care), you will be able to benefit from a greater number of sessions reimbursed at the best rate (for a pathology on the Fa list).

See INAMI-RIZIV website: <https://shorturl.at/HE5QY>). Before leaving the hospital, do not forget to ask your surgeon for the necessary documents to obtain reimbursement for your physiotherapy sessions.

41. During the post-surgery period, you will normally need to visit the hospital at least once a week to change dressings until the drains and stitches are removed. In some hospitals, **post-surgery follow-up appointments** are not automatically made. Before leaving the hospital, check with the medical staff (and possibly the secretariat) whether your appointments have already been made or whether you need to arrange them yourself.
42. Before you leave, ask your nursing staff for **clear instructions** regarding: dressings, incisions, drain care, pain medications, showering after surgery, and any other questions that come to mind.



# Recovery at home



## T-REX WEEKS

43. During the first weeks following surgery, your body will need time and progress to regain full mobility. This improvement must be done daily by following the instructions given by your medical team. If necessary, you can seek support so that the consolidation of your surgery can be done flexibly. In the first few days after surgery, you will experience what is known as the T-rex era, meaning your arm mobility will be limited, and you will find yourself using your forearms more. That's why, before leaving for the hospital, you should establish a **base camp**, that is, a place where you keep all the items you will need (for example, painkillers, water, books, lip balm, hand cream, etc. etc.). Some women have used a bed table tray (like this one) for this purpose.

## TRUST THE HEALING PROCESS

44. It is normal to have swollen, sore and bruised breasts. It is also normal for scars to itch, this is part of the natural healing process. Lack of sensation in the breasts or part of them is also part of the healing process - it will take some time before it returns (fully or partially). Nipples are a separate issue. How it feels after a nipple-sparing mastectomy varies greatly from woman to woman, but in general, it will never be the same. Immediately after the operation, it is completely normal for the nipples not to be sensitive. Some women report regaining some sensitivity after months (or years), others not.

You should contact your medical team immediately if you have:

- Fever above 38°C
- Increased swelling or redness appearing on the reconstructed breast
- Shortness of breath
- Pain that increases or is not relieved by medication
- Red marks draining from the incision
- Pus or strong odour coming from the incision
- Any other symptoms communicated by medical personnel.

45. Every time you think of a question to ask your doctor or nurse at your next appointment, write it down somewhere. It will be very helpful to have a **written list of questions**.

46. As soon as you feel comfortable and no longer feel severe pain, try taking short walks, with someone's help and taking precautions if you still have the drains in place. "Returning to the world" can be scary, but starting to be active again is part of healing and will benefit your overall well-being (as well as reducing the risk of blood clots and pneumonia).

47. And above all, **be patient** with yourself and those who care for you. Let's be honest, sometimes we are our own worst enemies, especially if we partially lose our autonomy. Remember that everything will pass and that you will make immense progress every day, bringing you closer to healing and regaining your autonomy. And don't forget your caregiver(s)! Caring for someone who is having a mastectomy comes with many responsibilities and is not always easy. Be lenient with your caregiver(s), and do not hesitate to be open about what you need and how you feel.

## MAINTENANCE AND HYGIENE OF SURGICAL DRAINS

48. As previously stated, it is highly likely that you will return home with the **surgical drains** still in place. **Carefully follow the drain care instructions** that were given to you by medical staff. Important aspects to keep in mind are:

- define a measurement time and keep it for the duration of the intervention on the pipes
- place the drains on a horizontal surface when measuring and record the measurement in a notebook
- it is normal for your drains to discharge small solid pieces.

49. **Wash your hands** often and, if you cannot do so, disinfect them with them, especially when replacing drain containers. Keep your surroundings clean and change bath towels, pillowcases and sheets regularly throughout the period you will be having the drains.

50. Pets are not always man's best friend, especially in the presence of comorbidities. If you have pets in the house, it is very important to prevent them from coming into contact with your wounds/drains, as the **risk of zoonotic infections** is high during the post-surgery period. See point 14 for a full list of approved pet boarding facilities in Belgium, should you ever decide to leave your pet elsewhere for a few weeks.

51. Don't underestimate or ignore **emotional healing**. A mastectomy triggers many emotions and conflicting feelings, due not only to the physical discomfort, but also to a new perception of your body and the way you see yourself. Consider seeing a psychologist if you're feeling particularly overwhelmed and this feeling doesn't go away over time.

Touch/massage can also help you take care of your body and connect to it. Taking the time to be touched, massaged and to connect to your feelings will help you in the process of integrating this new bodily feeling. You can ask a masseuse for these treatments or discuss these questions with your physiotherapist.

## LONG-TERM HEALING

52. Your **long-term recovery and healing** will depend on many factors, including your age, general health, and the type of reconstruction. For example, recovery from a mastectomy can take four to six weeks, and even longer if you have breast reconstruction surgery at the same time. It may take several months for your body to adjust to the change, which is completely normal.

53. The process of **familiarising yourself with scars** takes different forms and timing for each woman and cannot be predicted in advance. You may feel overwhelmed but also quite indifferent. Some helpful coping mechanisms include showing your scars to your partner, family, and/or friends, having photos taken of you (artistic or otherwise), or simply taking the time to accept them without pushing too hard.
54. Let's talk about **sexuality!** With a few small precautions, you can begin sexual activity whenever you feel ready. If you are in a relationship, it may be useful, as a first step, to show your partner your scars to familiarise themselves with this new reality (together). Name what can be done and what is felt or not. Support for discovery and touch can help ease things. In any case, during the first three months following the operation (or more, depending on the type of reconstruction you underwent), avoid putting pressure on the breasts and making sudden movements because they are still in the process of healing.
55. If you choose not to have breast reconstruction during your preventive mastectomy, there are many varieties of **external breast prostheses** that can help you feel more comfortable. Ask your surgeon for advice, and be aware that external breast prostheses that have been purchased from an approved bandage specialist are reimbursed. On this page of the INAMI website, you can consult all the reimbursement criteria for external breast prostheses. You can consult the list of distributors and manufacturers of approved bandage products here: <https://webapps.a.riziv-inami.fgov.be/ctm/Home/>.
56. **Avoid extreme temperatures** (hot baths, saunas, frostbite, sunburns). If you expose yourself to the sun, always remember to put SPF 50 **sunscreen** on your breasts and décolleté (as well as on the rest of your body) and not to expose your scars to the sun. A light-coloured swimsuit is recommended to avoid heat build-up on your breasts. In any case, as the sensitivity of your breasts will be reduced, always make sure that they are not too hot and reddened. Always seek advice from your doctor.







# Final thoughts

Undergoing a mastectomy is no easy feat, both physically and psychologically. There will be times of discouragement, pain, conflicting feelings and slow adaptation to your body. It's normal to feel sad, worried, relieved, ambivalent, nervous, irritable, or angry at some point, and you should not deal with these feelings alone. Don't hesitate to seek emotional support from friends, family, or women in our community, or to reach out to a professional.

However, you will be amazed at the progress you make every day, physically and emotionally. And there will be that moment when you look in the mirror and say "I DID IT" and you will be proud of yourself like never before! Mastectomy is a long journey, and you will need to arm yourself with patience, self-love and inner strength, but we are sure that you will get through it, and you will be even stronger and more beautiful than before.

- If you're looking for practical support or want to chat with someone who's been there before, or
- If you have had a mastectomy and you think there is advice missing in this guide, or
- If you are about to have this operation and want advice that is not in this guide,

**... please contact us: [info@brcanetwork.be](mailto:info@brcanetwork.be) !**



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do it!*



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