

INFORMATION FOR WOMEN CONSIDERING
PREVENTIVE
MASTECTOMY

BECAUSE OF A STRONG FAMILY HISTORY
OF BREAST CANCER



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INTRODUCTION

This booklet is intended for women with a strong family history of breast cancer who may be considering the option of surgical removal of their breasts as a way of reducing their risk of developing breast cancer. This type of surgery is known as preventive or prophylactic mastectomy.

If this is you, this booklet presumes that you have already attended a family cancer service (or other genetic counselling service), breast surgeon or oncologist to discuss in detail your breast cancer risk and the options that may help you reduce your risk.

If you haven't already done so, you will need to have your risk assessed to see if the information provided in this booklet applies to you. There are some contact details for services that may be useful to you in the back of the booklet (see pages 29 to 33).

Preventive mastectomy (see page 8) is not particularly common. There are many issues to be considered and the reasons for making any decision will be different, depending on each woman's situation. You may want to discuss your situation with any or all of the following:

- Your family doctor
- Family cancer service or other genetic counselling service
- Breast surgeon
- Psychiatrist and/or clinical psychologist
- Support person, such as a friend or family member.

We hope this booklet will help answer some of the questions you may have about preventive mastectomy. This booklet also aims to help you develop a list of questions to ask the different health professionals you talk to when considering the surgery. It is not intended to replace seeing them. Remember, talking to a doctor about preventive mastectomy does not mean you have to go ahead with the surgery.

The booklet aims to:

- Provide information about preventive mastectomy.
- Explain what the surgery might involve and how it might affect you.
- Discuss your options following surgery, such as reconstruction.
- Explore some of the feelings you might be experiencing.
- List some of the services available to help you.
- Help in your decision making.

There are many things for you to consider if you are thinking of having preventive mastectomy. You may find it helpful to keep a notebook handy to jot down questions you would like to ask professionals as well as their answers.

The important thing to remember about preventive mastectomy is that there are advantages and disadvantages to the surgery. It is your choice whether or not you have the surgery.

The decision is yours to make when you feel ready to make it.

Options for women with a strong family history of breast cancer

There are a number of options for women at increased risk of developing breast cancer and these should be taken into account when considering whether or not to have preventive mastectomy:

- Doctors suggest limiting alcohol consumption, avoiding hormones such as those found in hormone replacement therapy (HRT) and the oral contraceptive pill, and eating a diet low in fat and high in vegetables.
- Regular breast examinations, mammography (with or without breast ultrasound) and breast Magnetic Resonance Imaging (MRI) may be beneficial for women at high risk of breast cancer, as they can help to detect breast cancer at an early stage — though they don't prevent it.

It's important to be aware that most breast cancers found at an early stage have a good outcome. The usual surgical treatment when breast cancer is detected early is removal of the lump (lumpectomy) so that the breast is conserved.

- If you are post-menopausal, it may be possible for you to take part in an international trial called IBIS II using the drug anastrozole. This study is being done to find out if anastrozole can help prevent breast cancer in women who are at increased risk of breast cancer. You should discuss with your doctor the benefits and disadvantages of taking part in this study. Alternatively, you can call the toll free number 1 800 640 709 for more information.
- You may wish to consider having a preventive mastectomy. Women who learn that they have inherited a faulty gene that increases their risk of developing breast cancer might be particularly interested in this option.

Why do some women with a strong family history of breast cancer consider preventive mastectomy?

In addition to a strong family history of breast cancer, there may be other factors influencing a woman's decision about preventive mastectomy. These may include:

- Having an inherited change identified in one of the breast cancer protection genes (BRCA1 or BRCA2) that makes the gene faulty. Being born with these faulty genes means the woman has an increased risk of developing breast cancer.
- Having already had breast cancer in one breast and being concerned about the risk of cancer occurring in the other breast.
- Having multiple breast biopsies, which may increase anxiety about breast cancer risk. Sometimes this tissue is benign but it may suggest an increased risk of breast cancer. It is important to discuss with your surgeon what the biopsy findings mean for you.
- A woman's anxiety about breast cancer. Anxiety about developing breast cancer can have a major impact on day-to-day living, particularly for women who have an increased risk of developing cancer because of their family history. It is important for you to talk about your breast cancer anxiety with an appropriate professional (such as a clinical psychologist or psychiatrist) before making a final decision about whether or not to undergo preventive mastectomy.

Making a decision about preventive mastectomy can be a difficult process. That's why some clinicians and surgeons routinely require women who are considering the surgery to consult a clinical psychologist or psychiatrist to support them during the decision-making process. The choice to have preventive mastectomy is a very personal one; the right decision for one woman may not be right for another.

WHAT DOES PREVENTIVE MASTECTOMY SURGERY INVOLVE?

Preventive mastectomy involves the removal of breast tissue before a breast cancer has occurred in an effort to prevent breast cancer. In a very small percentage of women who undergo this surgery, breast cancer is found at the time of surgery or when the tissue is sent to pathology.

When deciding whether preventive mastectomy is right for you, it is important to know what's involved. Talking to a breast surgeon and reconstructive surgeon about your particular situation is the best way of finding out what the surgery may involve and what it means for you. Talking to these surgeons does not mean you have to go ahead with the surgery.

Before finding out more about preventive mastectomy, you may find it helpful to review the anatomy of the breast (see diagram, right).

Usually organs in the body such as the kidneys and heart are contained in a 'capsule' that separates the organ tissue from the rest of the body. This is not the case with the breast. Breast tissue blends into surrounding body tissue, which makes it difficult to distinguish between where the breast ends and the surrounding tissue begins. This is particularly true in the lower part of the breast and in the part of the breast that extends into the armpit (called the axillary tail).

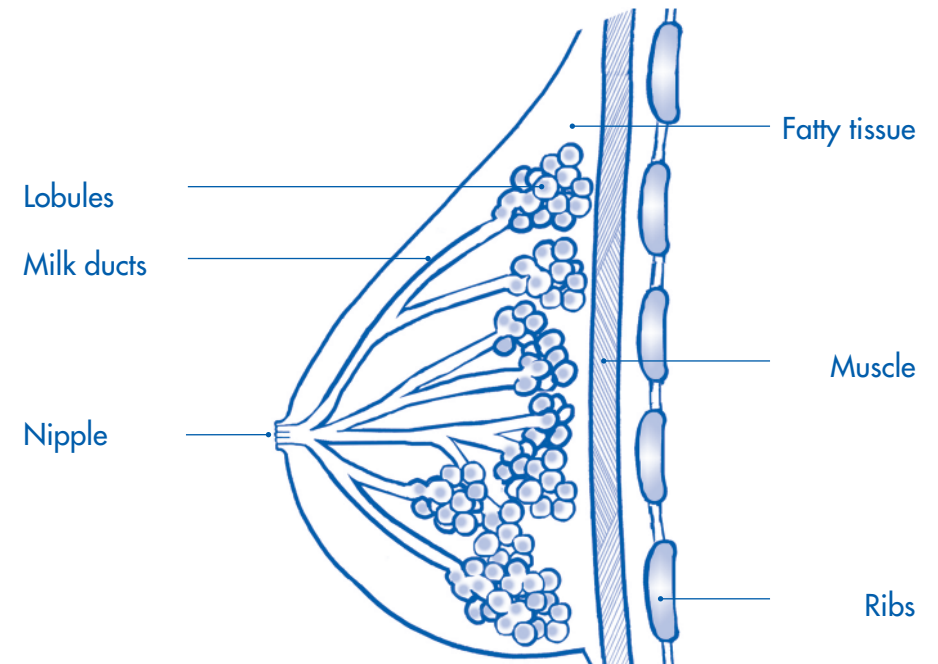


Illustration: Greg Smith/Cancer Council NSW

It is possible to remove nearly all the breast tissue in most post-menopausal women, because they tend to have a moderate amount of fat between their skin and breast tissue. It is more difficult however, to remove all the breast tissue in younger women where there may not be as much fat between the skin and the breast tissue.

Surgeons use different approaches when performing preventive mastectomy. The amount of breast tissue that is left behind will vary according to the approach.

The following pages provide information about the approaches currently used. It is important, however, that you discuss these in detail with your surgeon and ask whether there are any new developments or new techniques available.

As you speak to different professionals about your surgical options, the terms they may use can vary. It is important to clarify what the terms mean before deciding on the type of procedure you select.

Total mastectomy

A total mastectomy involves removing as much of the breast tissue as possible. The nipple, the coloured skin around it (called the areola) and most of the skin covering the breast is also removed.

Skin sparing mastectomy

This approach involves removing as much of the breast tissue as possible, as well as the nipple and areola. The skin that was covering the breast is preserved, making it easier to maintain the contour of the breast when reconstruction is done.

Subcutaneous mastectomy (skin/nipple sparing mastectomy)

In this procedure, as much of the breast tissue as possible is removed while leaving in place all the skin, the nipple (which contains breast ducts) and the areola. While subcutaneous mastectomy gives the best cosmetic result, some breast tissue remains.

It is important to note that the surgery that gives you the best cosmetic outcome may not be the most effective at reducing your risk of developing breast cancer. It is important to discuss this point with the professionals you talk to when making your decision.

Questions you may want to ask your surgeon:

- Is a particular type of surgery better for me?
- Where will the cuts be made to remove the breast tissue?
- What will the scars look like?
- If I choose breast reconstruction, when would you advise me to have this done?
- Who do you recommend to do the reconstruction?
- What are the costs involved?
- How long would I have to wait before I can have the surgery done?
- Is there anyone who has had a mastectomy that I could talk to?
- If I'm not having reconstruction done, are there ways of helping me to look my natural shape after the surgery?

Can breast cancer risk be reduced or eliminated?

In theory, if all the breast tissue is removed, a woman's risk of developing breast cancer should be eliminated. In practice, in a total mastectomy all the breast tissue that can be seen by the surgeon is removed. Unfortunately, it is very difficult to remove every single breast cell, so there is still a small risk of developing breast cancer after a mastectomy as there may be some remaining breast tissue.

In a subcutaneous mastectomy, since the nipple and some breast tissue are left behind, the risk of developing breast cancer has not been reduced as much as it could have been by total mastectomy.

What does the published research about preventive mastectomy show?

Several studies have looked at how effective having a preventive mastectomy is at preventing the development of breast cancer. Here are summaries of three studies published in medical journals between 1999 and 2004:

1) An American study published in January 1999 reported on 639 women with a family history of breast cancer who had a preventive mastectomy of both breasts from 1960 to 1991. The study showed having a preventive mastectomy reduced these women's risk of developing breast cancer by more than 90% (Hartmann 1999).

2) Following on from the previous study, a group of women identified as having either a faulty BRCA1 or BRCA2 gene were studied to determine how much their risk of developing breast cancer was reduced by having a preventive mastectomy. Their risk reduction estimates ranged from 85% to 100% (Hartmann 2001).

3) A study conducted in 11 medical centres in North America, the UK and the Netherlands looked at women identified as having either a faulty BRCA1 or BRCA2 gene who'd undergone mastectomy of both breasts (or bilateral mastectomy). This study also reported a significant reduction in breast cancer risk (Rebbeck 2004).

While large studies of the effects of total mastectomy and skin sparing mastectomy are not yet available, experts believe that after these types of surgery the risk of developing breast cancer is much less than 10% and more likely to be about 1% to 2%. That is, out of every 100 women who have had a preventive mastectomy, about 1 to 2 of them will be at risk of developing breast cancer.

So after having preventive mastectomy, a woman's risk of developing breast cancer is less than that of a woman in the general population. About 8 out of 100 women in the general population (8%) will develop breast cancer at some time in their lives.

If I decide to undergo preventive mastectomy, what is the best age to have it done?

This is an individual decision but the following should be taken into account:

- Whether you've already had children or are planning a family and would like to breastfeed.
- The impact that developing breast cancer would have on your family responsibilities and lifestyle.
- Your current age. For women identified as having a faulty breast cancer protection gene (BRCA1 or BRCA2), the estimated risk based on their age is as follows:
 - At 15 years of age, the risk of developing breast cancer over the next 10 years is very small.
 - By age 40 the risk of developing breast cancer over the next 10 years is 10% to 20%. This means that at least 80% of women this age won't get breast cancer in the next 10 years.
 - At 70 years of age, most women who are going to develop breast cancer will have already done so.

A specialist at the family cancer service or a breast surgeon can give you an estimate of your personal risk of developing breast cancer in the next 5 to 10 years, as well as your risk over your lifetime. Some women find this helpful in deciding if or when to proceed with surgery.

An important point...

While it is possible to estimate the risk of developing breast cancer based on the woman's family history, it is not possible to predict which of these women at 'high risk' will actually develop breast cancer. This is also true in women who carry a particular faulty gene that increases their risk of developing breast cancer.

This means that some women who choose to have preventive mastectomy may never have gone on to develop breast cancer.

Satisfaction with preventive mastectomy

Some studies have been conducted asking women how satisfied they are with their decision to have a preventive mastectomy. Metcalfe (2004) and Frost (2005) reported that the majority of women (70% to 97%) were satisfied with their decision to have the surgery. However, some women did report body image or sexual dissatisfaction after their surgery.

It is important to discuss all of the above considerations with your doctor.

BREAST RECONSTRUCTION

Breast reconstruction is a procedure where the breast is rebuilt either using implants, tissue from another part of the body or a combination of both techniques.

It is performed by a breast or plastic surgeon with expertise in breast reconstruction. There have been many recent improvements in this procedure.

However, reconstruction after mastectomy to reduce cancer risk is not the same as having surgery to enlarge the breasts for cosmetic reasons. After a preventive mastectomy and reconstruction the breast will look 'lifelike' under clothing but will actually look and feel different than it did originally.

There are different types of reconstruction procedures available. You will be given options and your preference may depend on the amount of time you can devote to the surgery, in terms of hospital and recovery time when you will not be able to lift things, do housework, drive etc. Although your preference is important, the type of surgery and method used will depend on many additional factors, some of which include your weight and body shape and whether or not you are a smoker.

It is your choice as to whether or not to have breast reconstruction, which is usually done at the same time as the preventive mastectomy. If you aren't sure at the time of your mastectomy, it can be done later.

If you decide not to have a breast reconstruction but would like to maintain a breast shape when you're wearing clothing, you can decide to use an external prosthesis.

The following breast reconstruction options may be offered to you:

- Implants filled with saline or silicone gel.
- Tissue taken from your belly.
- Tissue taken from your back in combination with an implant.

"I was dealing with so many things leading up to my mastectomy. I didn't feel like I could make a decision about reconstruction as well at that time so I waited and had my reconstruction a few years later."

"I wanted to have reconstruction using my own tissue but had to go with implants because I was thin and didn't have the excess skin around my stomach that was needed."

"I don't wear a prosthesis and I'm not interested in a reconstruction. The only concession I make to appearance is wearing loose fitting clothing."

"I have decided against reconstruction. For me, having the mastectomy did not affect the way I felt about myself as a woman."

"Having a reconstruction was the right decision for me. I feel terrific. I can do everything I want without worrying about a prosthesis."

"I had a reconstruction but I had a few problems. Although I'm happy with it now, I'm not sure that I'd make the same decision again."

Advantages and disadvantages

Some **advantages** of having a breast reconstruction may include:

- Avoiding an external prosthesis (this may particularly appeal to active women and those who live in warm climates).
- Allowing you to wear all clothing and swimwear without having to think about your choice.
- Allaying some of the daily reminders of the mastectomy surgery.
- Lessening the possible impact on self-esteem and sexuality.

Some **disadvantages** of having breast reconstruction may include:

- Not being happy with the look and feel of your reconstructed breasts.
- Having additional surgery.
- A longer recovery may be needed depending on the type of surgery.
- The need for more operations if there are complications.
- Additional scarring if tissue is taken from another part of your body.
- Longer operation time.
- Other potential side-effects such as discomfort or pain; infection; firmness of the breast; need for future implant replacement; and/or some loss of strength in the arm or stomach.
- Financial costs.

Whatever choice you make, it's important to be realistic about the possible outcomes. This is one of the factors reported as important in studies looking at satisfaction after breast reconstruction. In a 2006 study on satisfaction, 80% of women reported that they would choose to undergo the same type of breast reconstruction again, and 43% reported complications (Bresser 2006).

Cost

The cost of breast reconstruction will depend on many things including:

- Whether public or private services are used.
- The type of reconstruction.
- The fees charged by the surgeon and other health professionals involved in the surgery.

Speak with your surgeon and your health insurance company (if you have private cover) regarding the costs involved.

Other factors that may affect the timing of your surgery

These include:

- Long waiting lists.
- Possibility of having surgery delayed to make room for someone in need of urgent surgery to treat their cancer.

For women also considering preventive oophorectomy (surgery to remove ovaries to reduce ovarian cancer risk), an additional consideration may be needed if their preference is to use their own tissue for reconstruction. The reason for this is that a mesh is used to rebuild the area where the tissue is taken from the abdomen for breast reconstruction. This mesh would need to be cut to perform the oophorectomy, creating a slightly weaker mesh after the surgery.

Some questions that you might like to ask the breast or plastic surgeon about reconstruction:

- What are the different types of reconstruction available and how are they done?
- Which approach would you recommend for me and why?
- Can I have nipple reconstruction? How are they created?
- What sort of implants can be used?
- Can I pick the reconstruction size?
- Can I see any pictures of breasts before and after reconstruction?
- What will the scars look like?
- Will I have any feeling or sensation in my reconstructed breasts?
- Is breast reconstruction covered by Medicare?
- What are the costs?
- Do I still need to have breast screening?
- Will breast reconstruction interfere with breast screening?
- Can mammography damage a breast implant?
- If I do get breast cancer, would scar tissue or a breast reconstruction make it difficult to detect?
- How long would I have to wait before I can have the procedure done?

Additional information can be found at the following websites

Please note that the following websites are from the US and Canada respectively and some of the information may not be relevant to you (particularly information regarding costs).

www.facingourrisk.org

www.vch.ca/breastreconstruction

HOSPITAL STAY & RECOVERY

Preventive mastectomy (and breast reconstruction, if you choose to have one) is major surgery and involves a general anaesthetic. If you decide to have this surgery, a drip is put in your arm while you are in the operating theatre. After surgery, you will first be given pain relief through the drip or by injection, but after a while, tablets will be given to relieve the pain.

The amount of time you stay in hospital depends on the type of surgery and your recovery time — it is usually between two and four days, though it can be longer.

The wounds are covered by dressings and one or two temporary tubes may be inserted to remove any fluid that builds up and collects in the wound. These drainage tubes are kept in place with tape.

Suitable nightwear after the surgery is a front-opening nightdress or pyjamas. Those with loose sleeves and no cuffs are best so the drip and drainage tubes can be passed through.

The tubes coming out of the wounds are removed when the drainage has slowed and excess fluid will not accumulate. Some women are discharged from hospital with these tubes still in place. If this is the case, you will be shown how to look after them before you go home.

The wound should be healed completely within six weeks of the surgery. Occasionally there may be a collection of fluid or blood at the operation site. This usually clears up but sometimes it may need to be drained by a doctor.

Following mastectomy, most women experience some numbness or pins and needles across their chest for several months, but this is rarely permanent. This is because nerve endings have been cut during surgery and it can take some time for them to grow back.

I've heard of women getting swelling in the arm after mastectomy. Will this happen to me?

When a woman has a mastectomy because cancer is already present, lymph nodes are taken out. This is because the cancer may have spread to the lymph nodes. The lymph nodes are part of the body's defence system, which fights anything that tries to invade it (such as germs or cancer). Swelling in the arm and hand after mastectomy (called lymphoedema) may happen as a result of these lymph nodes being removed.

Since preventive mastectomy involves removing healthy tissue, there is no need to take out lymph nodes, so swelling of the arm and hand is very unlikely.

Possible complications

All surgery has a risk of complications. The main possible complications are infection, bleeding and/or a blood clot forming in the leg (known as deep vein thrombosis or DVT), which may then lead to a blood clot on the lung (called a pulmonary embolus). These are rare and clinicians will make every effort to prevent them.

As with all surgery that requires a general anaesthetic, there is a very small risk of other more serious complications such as a chest infection or even death. These risks are low in breast surgery, although they are slightly increased in women who have heart or lung conditions or diabetes.

Possible complications should be discussed with your surgeon and anaesthetist.

Returning to your usual level of activity

Check with your surgeon about how long you should allow before returning to your usual level of activity. This will depend on the type of surgery and the family, social, work and sporting commitments that you have.

The importance of continued breast checks after preventive mastectomy

There is still a small chance of developing breast cancer after mastectomy. Talk with your doctors about what breast checks you will need in the future.

MAKING THE DECISION

Women have very different attitudes about their breasts and discussion about preventive mastectomy can evoke a wide range of emotions.

There are many women who have an increased risk of developing breast cancer who feel that preventive mastectomy is a very extreme procedure and know they wouldn't have it done. Some women know immediately that preventive mastectomy is best for them and others spend a great deal of time considering it before making a decision.

If you are considering preventive mastectomy, it is important to take as much time as you need and to have access to information so that you know you've made the right decision for you.

The information in this section has been gathered from published material and the personal stories of women in Australia and overseas who've considered having or have had preventive mastectomies.

A woman's decision about preventive mastectomy will be influenced by many things. These can include her experience of cancer in her family and the effect that having a family history of breast cancer has on her now.

"My mother and two aunts died of breast cancer. I often imagined that I felt a lump in my breast, and then I'd become depressed and lie awake at night imagining all sorts of things. Having three young children, I naturally worried about them. What would happen if I wasn't around for them?"

Some women said they had feelings of panic and anxiety when trying to decide whether to have the surgery. They found it hard to concentrate, felt irritable and were snappy with family members.

"It took me months to make a decision. Some days I would wake up and say 'I'm definitely having it done'. Other days I would think I was crazy. I'd try to imagine what it would be like without breasts, although there was the option of reconstruction."

"For me, the process involved in making a decision about preventive mastectomy seemed to have three stages. The first was very emotional as I identified with all my family members that I had seen struggling with breast cancer and then contemplated the impact of similar struggles on my own life. The second stage was more analytical; I focused on gathering whatever information I could. The third stage combined elements of the two as I drew on the experiences of others who had already faced such decisions."

After considering the procedure, some women decide it is not for them.

"I was seriously considering preventive mastectomy. Since taking this step did not offer complete confidence that I would not develop breast cancer, I decided to forego it and instead look further into other options."

Some women who aren't in a relationship may feel worried about having preventive mastectomy, because they are uncertain what impact it might have on becoming intimate with another person.

Naturally, the decision-making process will differ from person to person. It's up to you to decide if and when preventive surgery is right for you. Take time to discuss your concerns with those close to you and your health care team, to help you decide what you want to do.

The reactions of family and friends

Some women choose to discuss their options and decisions with family and friends. Others prefer to be more private and discuss their options only with selected individuals. There is no right or wrong way to deal with the decision-making process.

For women in a relationship, discussing with their partner how they both feel about the decision and trying to anticipate some of the difficulties that might arise helps make it easier to adjust after surgery.

"When I told my husband that I was considering having preventive mastectomy he was horror-struck. He just did not understand how I could have both of my breasts removed when they were perfectly healthy. Gradually my husband came around to my way of thinking. The more information I gathered, the more he understood what I was facing."

Everyone reacts differently to stressful situations. Some people close to you may not be as supportive as you would like. Others may find they don't know what to say or are afraid of saying the wrong thing.

You may feel a bit like you're the only one who understands what it's like to go through this experience. It's important to remember that support is available. Services that you can contact are listed on pages 28 to 33.

The reactions of health professionals

Most health professionals in this area are sensitive to the complex issues involved when considering preventive surgery. Given that preventive surgery is uncommon in Australia, however, some health professionals you come across may seem uncomfortable about your choice. They may not appreciate the difficulties you experienced when faced with the decision about whether or not to have preventive surgery. If you find you are not able to relate to a particular health professional, don't be afraid to seek out a second opinion.

After the mastectomy

There is often a sense of relief when the surgery is over, but coping with the physical and emotional consequences of surgery is another challenge. Some women find it hard to adjust to the appearance of their body after mastectomy. Others adjust quickly and relatively easily.

While preventive breast surgery may reduce worry about the risk of developing breast cancer, it is a big change to a woman's body and may affect the way she sees herself.

However well prepared she is, no woman can really know how she will feel about the loss of her breasts until she experiences it.

You may wonder about whether you would still feel physically attractive after surgery and how you and your partner might react to seeing your changed body.

Usually changes in our body occur gradually, which gives us time to adjust to how we see ourselves. With surgery, an abrupt change occurs, so it may take time to get used to a new self-image.

It is natural to experience stages of sadness or grief while you adapt to these sudden changes.

Sexuality

Sexuality is as natural as the need for food and rest. However, it is usually one of the first needs to be affected when someone is in pain, anxious, depressed or grieving.

Preventive surgery can evoke a wide range of emotions, from relief to sadness about the loss of your breasts, so this time may be confusing for you and those close to you. To feel such complex emotions is natural, and their impact on your sexuality may be lessened by identifying and discussing them prior to surgery.

Some women get a great deal of stimulation from their breasts and preventive mastectomy will diminish this. Unfortunately, even reconstruction cannot completely make up for the loss of sensation.

One way of dealing with this could be to explore other ways of being intimate with your partner before surgery to make things easier afterwards.

After surgery, you may not feel like being intimate for some time while you are recovering. Try to be patient and kind with yourself. It is important for you to allow time to adjust to the loss of your breasts and to heal on a physical and emotional level.

Other women experience these feelings too. Take your time and resume intimacy when you feel ready.

If you'd like to talk to someone about measures that could help with the physical and emotional changes you might experience after preventive mastectomy, ask your doctor at the family cancer service or your breast surgeon who they'd recommend.

WHERE YOU CAN YOU GET

INFORMATION & SUPPORT

You may find it important to have people you can talk to about your feelings. Your family and close friends may be able to provide the support and understanding that you need during difficult times, but sometimes it can be beneficial to have an independent person to talk to.

There are plenty of health professionals who can give you support. These include your general practitioner, staff at a family cancer service, your surgeon, nurses and a clinical psychologist or psychiatrist with experience helping women in your situation. These professionals can help you explore the effect the surgery may have on you. They can also teach you some techniques to reduce anxiety, such as slow breathing and relaxation.

The Breast Cancer Support Service can provide trained volunteers who can offer support and practical advice, such as information about breast prosthesis and clothing for women who haven't had a breast reconstruction. More information about the Breast Cancer Support Service is listed on page 32.

The following pages suggest a number of agencies that you could contact for information and support.

Contact details

Family cancer clinics and genetics services

The list below has contact details of specialist family cancer services and genetic counselling services throughout Australia.

Australian Capital Territory & New South Wales	
Camperdown	Royal Prince Alfred Hospital Department of Molecular and Clinical Genetics Missenden Rd, Camperdown, NSW 2050 Ph: (02) 9515 5360 Fax: (02) 9550 5389
Canberra	The Canberra Hospital The Clinical Genetics Department Ph: (02) 6244 2133 Fax: (02) 6244 4625
Darlinghurst	St Vincent's Hospital Family Cancer Clinic Victoria Rd, Darlinghurst, NSW 2011 Ph: (02) 8382 3395 Fax: (02) 8382 3386
Kogarah	St George Hospital Hereditary Cancer Clinic Cancer Care Centre Gray St, Kogarah, NSW 2217 Ph: (02) 9113 3815 Fax: (02) 9113 3958
Liverpool	Liverpool Hospital Department of Clinical Genetics Locked Mail Bag 7103 Liverpool, NSW 1871 Ph: (02) 9828 4680 Fax: (02) 9828 4650
Newcastle and rural outreach services	Hunter Family Cancer Service PO Box 84, Waratah, NSW 2298 Ph: (02) 4985 3132 Fax: (02) 4985 3133
Penrith	Nepean Hospital Clinical Genetics Department PO Box 63, Penrith, NSW 2750 Tel: (02) 4734 3362 Fax: (02) 4734 2567

Randwick	Prince of Wales Hospital Hereditary Cancer Clinic High St, Randwick, NSW 2031 Ph: (02) 9382 2551 Fax: (02) 9382 2588
St Leonards	Royal North Shore Hospital Family Cancer Service St Leonards, NSW 2065 Ph: (02) 9926 6502 Fax: (02) 9926 6433
Westmead	Westmead Hospital Familial Cancer Service Department of Medicine Westmead, NSW 2145 Ph: (02) 9845 6947 Fax: (02) 9687 2331
Wollongong	Wollongong Hospital Wollongong Hereditary Cancer Clinic Illawarra Cancer Care Centre Ph: (02) 4222 5576 Fax: (02) 4222 5793
Queensland	
Herston	Genetic Health Queensland Royal Children's Hospital and District Health Service Herston Road, Herston, QLD 4029 Ph: (07) 3636 1686 Fax: (07) 3636 1987
Brisbane	Brisbane North Breast Cancer Family Clinic PO. Box 227, Virginia Business Centre, Virginia, QLD 4041 Ph: (07) 3350 7425 Fax: (07) 3350 5102
South Australia	
North Adelaide	Women's and Children's Hospital Familial Cancer Unit C/- South Australian Clinical Genetics Service 72 King William Rd, North Adelaide, SA 5006 Ph: (08) 8161 6995 Fax: (08) 8161 7984

Tasmania	
Hobart	Royal Hobart Hospital Tasmanian Clinical Genetics Service GPO Box 10611, Hobart, TAS 7001 Ph: (03) 6222 8296 Fax: (03) 6222 7961
Victoria	
Parkville	Royal Melbourne Hospital Family Cancer Centre Grattan St, Parkville, VIC 3050 Ph: (03) 9342 7151 Fax: (03) 9342 4267
Parkville	Royal Children's Hospital Family Cancer Centre C/- Genetic Health Services Victoria Flemington Road, Parkville, VIC 3052 Ph: (03) 8341 6201 Fax: (03) 8341 6390
Melbourne	Peter MacCallum Cancer Institute The Jack Brockhoff Foundation Familial Cancer Centre Locked Bag 1, A'Beckett St Melbourne, VIC 8006 Ph: (03) 9656 1199 Fax: (03) 9656 1539
Clayton	Familial Cancer Centre Monash Medical Centre 246 Clayton Rd, Clayton, VIC 3168 Ph: (03) 9594 2026 Fax: (03) 9594 6022
Western Australia	
Subiaco	Familial Cancer Program King Edward Memorial Hospital, Level 3, Agnes Walsh House, 374 Bagot Road, Subiaco, WA 6008 Ph: (08) 9340 1603 Fax: (08) 9340 1725

National Breast and Ovarian Cancer Centre

The National Breast and Ovarian Cancer Centre has a website — its address is www.nbcc.org.au.

You can search using the words “**prophylactic mastectomy**” to see if any new information has been added.

Cancer Council Helpline

This is a free and confidential telephone information service provided by each State and Territory Cancer Council. The national phone number is 13 11 20. You can also request services in languages other than English.

Breast Cancer Support Service

Each State and Territory Cancer Council also provides a Breast Cancer Support Service. This free and confidential service can be contacted by ringing the Cancer Council Helpline number on 13 11 20 or toll free on 1800 422 760. The TTY number for deaf or hearing-impaired people is 02 9334 1865.

The Breast Cancer Support Service may be able to match you with a woman of similar age and cultural background who has had a mastectomy because of existing breast cancer, and possibly reconstructive surgery. Your support person is a trained volunteer who can offer practical and emotional support.

Please note that because of the small number of women who have had preventive mastectomies, it is unlikely at this stage that the Breast Cancer Support Service will be able to put you in touch with someone who has had this specific type of mastectomy.

Breast-care nurses

Some hospitals have breast-care nurses who can explain what to expect before and after surgery. If you're interested in talking to a breast-care nurse, your breast surgeon or staff at a family cancer service can arrange this for you.

More information (free of charge)

- “*Looking ahead: after breast cancer surgery*” a book available from the Breast Cancer Support Service or by calling the Cancer Council Helpline on 13 11 20.
- A booklet on breast reconstruction called “*Breast Reconstruction — making an informed decision*” available from The Cancer Council WA website www.cancerwa.asn.au or by calling 13 11 20.
- “*Breast Reconstruction: your decision*” — a video available from the Wesley Breast Centre in Queensland, phone (07) 3232 7246. Also available on loan from Cancer Councils, call 13 11 20.

An internet search using the words “preventive mastectomy” or “prophylactic mastectomy” brings up quite a lot of information. However, some of the articles can be a bit difficult to understand and you may find them confusing. Further information on breast cancer and treatment can be found at the following websites:

Cancer Council Australia www.cancer.org.au

Cancer Council Victoria www.cancervic.org.au

Cancer Council NSW www.cancer council.com.au

Cancer Council South Australia
www.cancersa.org.au/asp/home.aspx

Cancer Council Tasmania www.cancertas.org.au

Cancer Council Western Australia www.cancerwa.asn.au

Gynaecological Cancer Society of Queensland
www.gcsau.org

National Breast Cancer Centre www.nbcc.org.au

References

- Bresser, P.J., C. Seynaeve, et al. (2006) "Satisfaction with prophylactic mastectomy and breast reconstruction in genetically predisposed women." *Plastic and Reconstructive Surgery*. **117**(6): 1675-82.
- Calderon-Margalit, R and O. Paltiel (2004). "Prevention of breast cancer in women who carry BRCA1 or BRCA2 mutations: a critical review of the literature." *International Journal of Cancer*. **112**(3): 357-64.
- Frost, M. H., J. M. Slezak, et al. (2005). "Satisfaction After Contralateral Prophylactic Mastectomy: The Significance of Mastectomy Type, Reconstructive Complications, and Body Appearance." *Journal of Clinical Oncology*. **23**(31): 7849-56.
- Hartmann, L. C., D. J. Schaid, et al. (1999). "Efficacy of Bilateral Prophylactic Mastectomy in Women with a Family History of Breast Cancer." *New England Journal of Medicine*. **340**(2): 77-84.
- Hartmann, L.C., T.A. Sellers, et al (2001). "Efficacy of Bilateral Prophylactic Mastectomy in BRCA1 and BRCA2 Gene Mutation Carriers". *Journal of the National Cancer Institute*. **93**(1): 1633-37.
- Marteau, T. and M. Richards (1996). "The Troubled Helix"., Cambridge University Press.
- Metcalfe, K. A., J. L. Semple, et al. (2004). "Satisfaction with breast reconstruction in women with bilateral prophylactic mastectomy: a descriptive study." *Plastic and Reconstructive Surgery*. **114**(2): 360-6.
- Rebbeck, T. R., T. Friebel, et al. (2004). "Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: the PROSE Study Group." *Journal of Clinical Oncology*. **22**(6): 1055-62.

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Further copies of this booklet are available from

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PO Box 317

St Leonards NSW 1590

Phone: (02) 9926 7324

Fax: (02) 9906 7529

Cancer Council Helpline

Phone: 13 11 20

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Important: The information in this booklet is current at the date of production. Please check with your doctor or genetic counselling service for any new information.

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