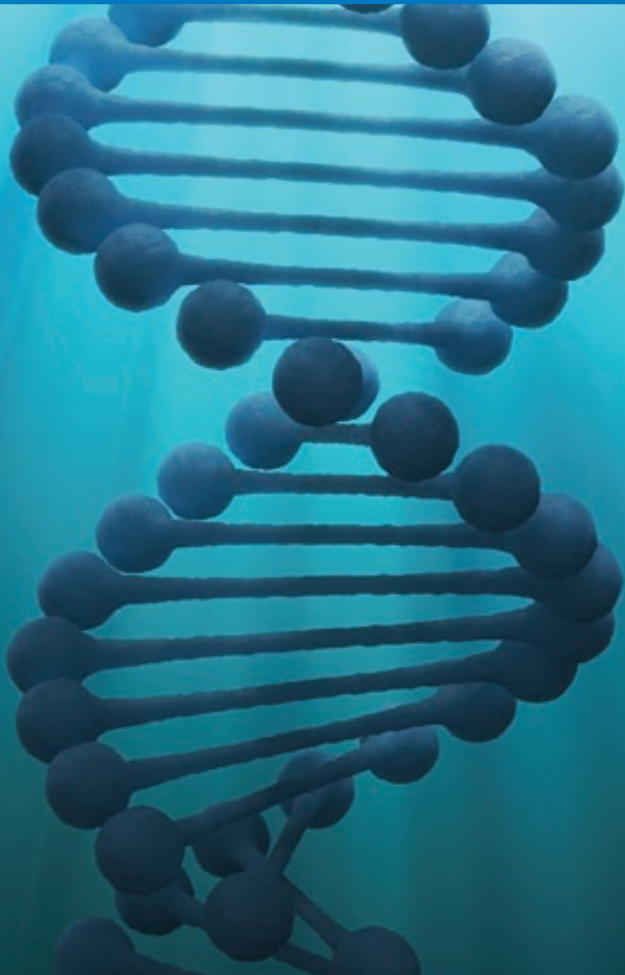




University Hospital
Southampton
NHS Foundation Trust

Risk-reducing mastectomy

Information for patients



We have written this booklet for women who are considering having a risk-reducing mastectomy. You may be thinking about this if you have a strong family history of breast cancer or if you are carrying a genetic variant that increases your risk of developing breast cancer. It explains what a risk-reducing mastectomy is and what the operation involves.

The decision as to whether to have this operation is a difficult and personal one to make. We hope this booklet will help to answer some of the questions you may have and help you to decide whether this operation is right for you. If you have any further questions or concerns, please speak to a member of our team, your surgeon or your breast care nurse.

What is a risk-reducing mastectomy?

A risk-reducing mastectomy is an operation where both of your breasts are surgically removed when there is no evidence of cancer, to help reduce the risk of a breast cancer developing.

Your surgeon will talk to you about the different types of mastectomy and explain the risks and benefits of each type, to help you make an informed decision.

Family history

Breast cancer is a common disease, affecting approximately one in seven women during their lifetime.

For the majority of women who are diagnosed with breast cancer, there is not a single high-risk inherited factor to the cancer. If this is the case in your family, although your own risk of developing breast cancer would be slightly increased, a risk-reducing mastectomy would not be recommended.

However, for a small number of women who are diagnosed with breast cancer (approximately 5%), it seems that an inherited factor is largely responsible. This inherited factor is a gene variant that can be passed from one generation to the next.



Women with breast cancer

Women with inherited breast cancer

Genes are our cells' instruction manuals. We each have around 20,000 pairs of genes which are present in almost every cell of our bodies. Our genes tell our cells how to function normally.

Some families have a greater chance than normal of developing breast cancer due to a genetic cause - a variant in one or more genes known to increase the risk of breast cancer. Variants in these genes can occur in both women and men, so a gene variant can be inherited from either your mother or your father. If this is the case in your family, a risk-reducing mastectomy may be recommended.

Risk

Risk can be difficult to understand and explain, but basically, it is the chance that something may or may not happen. We all have different ideas of our own risk based on our feelings, beliefs, and experiences. Our genetics team can assess what risk there may be of a gene variant in your family by looking at your family history. We can also look at what your own risk of developing breast cancer will be.

It is difficult to estimate your exact risk and your risk may change as new information comes to light. However, we do not usually recommend surgery or other interventions until we have the necessary information to be confident in our risk assessment.

Risk assessment and risk management

As per National Institute for Health and Care Excellence (NICE) guidelines, we will only recommend this type of risk-reducing surgery (bilateral mastectomy) for people who have a high risk of developing breast cancer.

If after our risk assessment, we feel this surgery is suitable for you, you will have an appointment with a breast surgeon and breast care nurse to discuss the different types of operations available to you.

You will also be referred to a counsellor or psychologist for a one-off appointment before your operation to discuss your feelings about making this important decision. Our genetics team, your breast surgeon and other healthcare professionals will also work closely together to provide support and information to help you reach a decision.

It is important that you take time to think through all your options, ask questions and discuss any concerns you have. If you would like to talk to a woman who has had this type of surgery, please ask a member of our genetics team or contact the breast service to be put in touch with women in your local area.

It is also helpful to think about who will support you (such as family members and friends) while you make this decision, and then during and after the operation (if you choose to take this option).

We have included a list of helpful contacts who can also help and support you while you make this decision at the end of this booklet.

Risk-reducing breast surgery

If you have a risk-reducing mastectomy, there will still be a risk that you may develop breast cancer. Having both breasts removed will reduce your risk significantly, but it is impossible to remove the breast tissue entirely and therefore a small risk will remain. The level of risk will depend on how much breast tissue remains. Experts estimate that after the operation, the chance of developing breast cancer is less than 5% (1 in 20).

The reason for doing a risk-reducing mastectomy is to remove as much of the breast tissue as possible. Usually, the skin covering the breast is left intact, so that the breast can be reconstructed to a shape and size that is acceptable to you.

Your surgeon may want to remove one breast at a time, meaning you will have two separate operations (allowing time for recovery between each one), or they may decide to remove both breasts at the same time. You can discuss this with your surgeon to come to a decision that you are both happy with.

Emotional issues

You will naturally have experienced many different emotions in coming to your decision and you may experience a range of different emotions after your operation. Your breast care nurse is an experienced nurse available to support you during this time.

Sexuality

Having breast surgery may affect how you feel about yourself. Your self-confidence and image of yourself as a woman may change. To some women, breasts are seen as a focus of sexuality and are part of a woman's identity.

It is helpful to be aware that you may have strong emotions once your breasts are removed, and these emotions may have an effect on your intimate relationships. It may take time to come to terms with the loss of your breasts and how your body looks after the operation.

If you have a partner, it can be helpful to talk to them about how they feel about your breasts being removed and what effect it may have on them.

Considerations

As mentioned earlier, it is important to think carefully about all the pros and cons of this operation. Below are several questions to consider before making a decision. Some of these questions may trigger emotions you were perhaps not aware of and you may not have the answers to. We have included a list of helpful contacts at the end of this booklet if you would like to talk to someone.

- Have you thought about what your breasts will look like after the operation?
- Have you discussed having this operation with your partner or family?
- Who will be there to support you if you do have the operation?
- What are your feelings about other options instead of surgery?
- How is your experience of cancer within your family affecting your decision?
- Are there other people in your life who are affecting your decision?
- What do your breasts mean to you?

Most people will experience a sense of loss before, during or after their mastectomy. However, it is also common for people to feel good about having taken a positive decision to control their health and look after their body. When people have an operation for whatever reason, it is common for moods to go up and down, sometimes feeling positive and optimistic, sometimes upset, tearful or even despondent (low spirits from loss of hope or courage).

This range of moods is normal and is not a problem unless the mood becomes fixed. Most people get through these feelings with the support of family and friends, but if your mood does become fixed, for example, feeling depressed, it may help to seek professional advice, from your own GP or from a member of the healthcare team caring for you.

Personal record

Name: Date of birth:

Hospital number: G number:

Genetics service

Risk assessment by genetics service

Date:

Name: Signature:

High-risk gene carrier?

Yes No If not, carrier risk assessed as:

Initial discussion with genetics service about surgery

Date:

Name: Signature:

Discussion:

Follow-up genetics appointment

Date:

Name: Signature:

Discussion:

Follow-up appointment after your operation (genetics)

Date:

Name: Signature:

Discussion:

Psychological assessment

Appointment with counsellor or psychologist

Date:

Name: Signature:

Discussion:

Breast or plastics service

First appointment with breast or plastic surgeon

Date:

Name: Signature:

Surgical options discussed:

- No reconstruction
- Scars
- Complications
- Types of reconstruction and typical results
- Recovery time
- Written information

Discussion:

Breast care nurse appointment

Date:

Name: Signature:

Discussion:

Follow-up discussion with breast or plastic surgeon

Date:

Name: Signature:

Discussion:

Multidisciplinary review

Date:

Discussion:

Breast MRI scan (it is recommended that you have a breast MRI scan once a year if you are between 30 and 50 years old)

Date of last breast MRI scan: (if applicable)

Mammogram (it is recommended that you have a mammogram once a year if you are between 40 and 70 years old)

Date of last mammogram: (if applicable)

Operation

Date:

Further information

If you would like more advice or information about any aspect of having a risk-reducing mastectomy, please contact us at:

- **Wessex Clinical Genetics Service**

Princess Anne Hospital
Coxford Road
Southampton
SO16 5YA

Telephone: **023 8120 6170**

Website: **www.uhs.nhs.uk/genetics**

Useful contacts

- **Breast Cancer Now**

Helpline: **0808 800 6000**

Other enquiries: **0333 207 0300**

Website: **www.breastcancer.org**

- **Cancer Research UK**

Telephone: **0808 800 4040**

Website: **www.cancerresearchuk.org/about-cancer**

- **Macmillan Cancer Support**

Telephone: **0808 808 0000**

Website: **www.macmillan.org.uk**

Web page: **www.macmillan.org.uk/cancer-information-and-support/worried-about-cancer/causes-and-risk-factors/risk-reducing-breast-surgery**

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If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

www.uhs.nhs.uk/genetics

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