

Risk-reducing mastectomy

Information for patients



This booklet has been written for women who may be considering having a risk-reducing mastectomy because of a strong family history of breast cancer. It aims to answer some of the questions people have who are considering this surgery.

The booklet also has a section at the end for women who are choosing to explore this surgical option further. This is a record for both you and the healthcare professionals you meet. Please bring this booklet with you when meeting different healthcare professionals so that the section can be signed and dated.

What is risk-reducing mastectomy?

This is an operation where both your breasts are removed when there is no evidence of cancer, to help reduce the risk of a breast cancer developing. If you are considering having a risk-reducing mastectomy because of your family history of breast cancer, this booklet is designed to help explain what is involved before you decide whether this surgery is for you.

This decision is a difficult one to make but there will be healthcare professionals who you can discuss issues with and who will be able to support you whilst you are thinking about the different options.

You may consider this operation if you have seen members of your family affected by breast cancer, or if you are carrying a genetic fault that increases your risk of developing breast cancer.

Family history

Breast cancer is a common disease, affecting approximately one in ten women during their lifetime. Many of us will therefore know someone who has had breast cancer.

For the majority of women who are diagnosed with breast cancer, there is not a strong inherited component to the cancer. In this situation although your own risk of developing breast cancer would be slightly increased, surgery would not be recommended.

For a small number of women (approximately 5% of women who have breast cancer) it seems that an inherited factor is largely responsible.



This inherited factor is a faulty gene that can be passed from one generation to the next by either the mother or father. If there has been a gene mutation identified in your family you will have a one in two (50%) chance of inheriting it. If you have inherited the gene mutation it doesn't mean that you will definitely develop breast cancer, but it means that your risk is increased.

If you have not inherited the gene mutation your risk of developing breast cancer will be similar to that of the general population, despite your family history.

In families where there are a number of relatives with breast cancer, usually diagnosed at an early age, there may be a gene mutation being inherited. It is important that you discuss your own family history with a doctor who specialises in genetic diseases. This is to see whether there is a chance that your family may have an inherited factor for breast cancer and to discuss your own risk of developing it. You will be able to discuss whether your family could be considered for genetic testing. However, it is important to know that not all families can be tested for a gene mutation.

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 experience. Your local genetics department will be able to work out what risk there may be of an inherited factor in the family by looking at your family history. They will also be able to look at what your own risk of developing breast cancer will be.

Everyone's understanding of their own risk will be different. Your own idea of what your risk of developing breast cancer is may be different from your true risk. If you are unclear about your own risk this can be discussed with you by a member of the genetics department.

Risk assessment and risk management

It would be helpful to be seen by the genetics department who will be able to work out your risk of developing breast cancer. This is done by gaining information on your family history. We will look at members of the family who have been affected with cancer and at what age, and who in the family has not developed cancer. We will also talk about other options available such as screening and entry in to appropriate research studies.

You will be seen by the breast surgeon and breast care nurse to discuss what different types of operation are available.

We also would strongly advise that you have an appointment made with a counsellor or psychologist, which will provide an opportunity for you to discuss your feelings about making this important decision. The genetics doctor, breast surgeon, and other healthcare professionals will also be able to provide support and information for you to help you reach a decision, working closely together as a team.

It is important that you take time to think through all your options and have the opportunity to ask questions and discuss any concerns you have. If you would like to talk to a woman who has undergone this type of surgery please do ask the genetics or breast service and they can put you in contact with women locally.

It is also helpful to think of who will support you (such as someone in your family or friends) while you make this decision and also during and after the surgery if you choose to take this option. A list of helpful contacts is included at the end of this booklet.

Risk reducing 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.

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

The surgeon may want to remove one breast at a time, meaning you will undergo two operations allowing time for recovery between each one, or it may be decided to remove both breasts at the same time.

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 can affect how you feel about yourself. Your self-confidence and image of yourself as a sexual woman may change. In our society 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 will take time to come to terms with the loss of your breasts and how your body looks after the surgery.

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. Also, please remember that there will be professionals available to help you through difficult periods.

As mentioned earlier, it is important to think carefully about all the pros and cons of this operation. Below are a number of questions to consider. Some of these questions may trigger emotions you were perhaps not aware of and you may not have the answers to. There are contact numbers at the end of the booklet if you need to talk to someone.

Considerations

- Have you thought about what your breasts will look like after surgery?
- 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.

This range of moods is quite normal in a crisis 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 stuck, for example in a depressed mood, it may help to seek professional advice, from your own GP or from the doctors or nurses at the hospital where you had your operation.

Many people may not know what to say to you during or after this operation. They may feel inhibited or embarrassed. Having a mastectomy to remove healthy breasts is not common and therefore it is unlikely others will have a full understanding of the decision you have made.

Some people may even avoid you rather than say the wrong thing and this may leave you feeling offended or lonely. If you can, give a clear message about whether you want to talk about the operation and your feelings around this. You may want time on your own, or you may only want to talk about your decision and the operation with certain friends.

Many people would rather carry on as normally as possible. If you have a partner they may be able to help with this, by letting others know how you feel about talking. Some friends may also feel better if they feel there is something they can do in a practical way, like helping with childcare or shopping for example. Do bear in mind that some friendships will become closer as a result of the experience you are going through.

Personal record

Name: Date of birth:

Hospital number: G number:

Genetics

Risk assessment by genetic service: Date:

Name: Signature:

BRCA1/2 carrier?

Yes No If not, carrier risk assessed as:

Initial discussion with genetics service re surgery:

Name: Signature:

Discussion:

Follow up genetic appointment Date:

Name: Signature:

Discussion:

Follow-up appointment post-surgery (genetics)

Date:

Name: Signature:

Discussion:

Date:

Name: Signature:

Discussion:

Psychological assessment

Appointment with counsellor/psychologist

Date:

Name: Signature:

Discussion:

Date:

Name: Signature:

Discussion:

Breast/plastics service

First meeting with breast/plastic surgeon

Date:

Name: Signature:

Surgical options discussed:

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

Discussion:

Breast care nurse appointment

Date:

Name: Signature:

Discussion:

Follow up discussion with breast/plastic surgeon

Date:

Name: Signature:

Discussion:

Follow up discussion with breast/plastic surgeon

Date:

Name: Signature:

Discussion:

Multidisciplinary review

Date:

Discussion:

Breast MRI within 3 months prior to surgery

Date:

Mammogram within 3 months prior to surgery

Date:

Surgery Date:

Copy surgical report and any histology to genetics

Further information

If you need more advice or information about any aspect of 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 Care**

5-13 Great Suffolk Street
London SE1 0NS

Helpline: **0808 800 6000**

Other enquiries: **020 7384 2984**

Website: **www.breastcancercare.org.uk**

- **CancerHelp UK**

Cancer Research UK
Angel Building
407 St John Street
London EC1V 4AD

Tel: **0808 800 4040**

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

- **Macmillan Cancer Relief**

89 Albert Embankment
London SE1 7UQ

Tel: **0808 808 2020**

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

This booklet was written by:

Wessex Clinical Genetics Service
Princess Anne Hospital
Coxford Road
Southampton
SO16 5YA

**If you need a translation of this document,
an interpreter or a version in large print,
Braille or on audiotape, please telephone
023 8120 4688 for help.**

www.uhs.nhs.uk/genetics

© 2016 University Hospital Southampton NHS Foundation Trust. All rights reserved.
Not to be reproduced in whole or in part without the permission of the copyright holder.

Version 4. Published May 2016. Due for review May 2019. GEN010.01