

Understanding NICE guidance

Information for people who use NHS services

Women with breast cancer in the family

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care of women with breast cancer in the family (familial breast cancer) in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for women with breast cancer in the family but it may also be useful for their families or carers or for anyone with an interest in breast cancer.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe breast cancer or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 16.



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The advice in the NICE guideline covers:

- the care of adult women who may be at increased risk of developing breast cancer because of a family history of breast or other cancers.

It does not specifically look at:

- women who have already been diagnosed with breast cancer
- men, but the recommendations may be relevant to some men because, although rarer than in women, men may get breast cancer and this may run in families.

This guideline is an update of recommendations about women with breast cancer in the family that NICE made to the NHS in 2004. The advice on magnetic resonance imaging (MRI) for breast cancer screening has changed, but all the other advice is the same.

Your care

Your care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain familial breast cancer and the tests and treatments for it simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular tests and treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in asking for what you want) if needed.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk) and searching for information on 'consent'.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

Familial breast cancer

Breast cancer is the most common cancer in women in the UK, making up almost 1 in 3 of all cancers in women. About 10% (10 in 100) of women in the UK will develop breast cancer by the time they are 80 years old. This is known as the lifetime risk of breast cancer in the general population.

Sometimes breast cancer runs in families. This is called 'familial breast cancer' or 'hereditary breast cancer'. Even if you have one or more relatives who have, or have had, breast cancer, it does not necessarily mean that breast cancer runs in your family. Because breast cancer is common, more than one woman in the family may develop it by chance.

However, familial breast cancer may be a possibility if there have been more cases in one family than would normally be expected. It may also be a possibility if there are other cancers in your family that are related to breast cancer, such as ovarian cancer or certain other cancers that develop at a young age. If this is the case, you may have a higher risk of developing breast cancer than women in the general population.

When breast cancer does run in the family, it may be caused by a fault in one of the genes that is known to be linked with breast cancer. Three genes have been found that are linked to breast cancer – these genes are called *BRCA1*, *BRCA2* and *TP53*. If one of these genes is faulty, it can result in an increased risk of developing breast cancer (see page 12 for information on genetic testing). However, the number of women with a faulty gene is very small and having a faulty gene does not automatically mean that a woman will develop breast cancer.

It's important to remember that most women – even women with an increased risk of breast cancer compared with the general population – do not get breast cancer.

Risk factors

Breast cancer is not due to a single cause and there are many factors that may affect your chances of getting it. The same risk factors seem to affect all women, whatever their family history, but the impact of the risk factors (to either increase or reduce risk) may be greater for women at risk of familial breast cancer because their chances of getting breast cancer are higher.

Age is the biggest known factor that influences the chance of developing breast cancer in women. Around 80% (4 out of 5) of all detected breast cancers occur in women over the age of 50.

Other risk factors include taking hormone replacement therapy (HRT) or the combined contraceptive pill, drinking alcohol, and being overweight after the menopause.

If you are concerned about your risk of breast cancer

If you are concerned about your risk of breast cancer, first talk to your GP. They should ask you about whether you have blood relatives who have had breast cancer (this is called 'taking a family history').

What your GP will want to know

Your GP will want to know if a faulty breast cancer gene has already been identified in a family member. If this is the case, you may be referred directly to a team of healthcare professionals with expertise in genetics and breast cancer, called specialist genetics services.

If a faulty gene has not been identified in your family, your GP should investigate your family history to work out whether you may be at an increased risk of breast cancer. Your GP will want to know about blood relatives on both your mother's and father's sides of the family because the faulty genes can be passed down either side of the family.

For each member of your family who has had a diagnosis of cancer, your GP will also want to know as much of the following as possible.

- The age at which any cancer (not just breast cancer) was diagnosed.
- Where in their body the cancer started (for example, the ovaries, lung or breast).
- Whether the same family member has had more than one cancer, including whether breast cancer occurred in both breasts (known as bilateral breast cancer).

It is important to remember that breast cancer can be passed down either your mother's or your father's side of the family.

Your GP will also ask about your ethnic background, as certain ethnic groups are more likely to carry faulty breast cancer genes. For example, the faulty genes are around 5–10 times more common in people with certain Jewish ancestry.

Your GP should also ask about your family history of breast cancer if you have breast symptoms (such as a lump), or if you are considering taking the oral contraceptive pill and you are over the age of 35, or if you are considering taking HRT.

If you don't already know the answers to these questions, your GP may ask you to do some 'homework'. It can be helpful to discuss your family history with other members of your family.

What your GP should do

Using this information, and possibly with the aid of questionnaires or computer programs, your GP should determine whether you may have an increased risk of developing breast cancer.

Being breast aware

Whether you are at increased risk or not, your GP should advise you to be 'breast aware'.

This means:

- knowing what is normal for you
- looking at and feeling your breasts
- knowing what changes to look for
- reporting any changes without delay
- attending routine breast screening if aged 50 or over.

If your GP thinks you **may** have an increased risk of developing breast cancer, you should be offered a referral to a breast care team (a team of healthcare professionals with expertise in breast cancer, usually at a cancer centre at a hospital).

What the breast care team should do

The breast care team should estimate your risk of developing breast cancer using your family history information, and possibly with the aid of questionnaires or computer programs. If your risk is about the same as the risk in the general population, you will not need further care by the breast care team and can be referred back to your GP. Your GP will provide you with the same care given to all women of your age.

You are unlikely to be at increased risk and will not need a referral if you have only one relative who was over 40 when they were diagnosed with breast cancer.

Breast cancer risk

Women who have an increased chance of developing breast cancer compared with the general population are classified into two groups:

- women at raised risk
- women at high risk.

It's important to remember that most women do not get breast cancer. Even if your breast care team tells you that you have a raised or high risk of developing breast cancer, it does not mean that you will develop breast cancer.

Raised risk

Your risk of developing breast cancer is 'raised' if you have an estimated 3–8% risk (3 to 8 in a 100 chance) of developing breast cancer between the ages of 40 and 50 years and a lifetime risk greater than 17% but less than 30% (17 to less than 30 in a 100 chance). Remember that the lifetime risk for the general population is 10% (10 women in 100 develop breast cancer).

High risk

Your risk of developing breast cancer is 'high' if you have an estimated 8% (8 in 100) or greater risk of developing breast cancer between the ages of 40 and 50 years and a lifetime risk of 30% (30 in 100) or greater. You are also considered to be at high risk of developing breast cancer if there is a 20% or greater chance of finding a faulty high-risk gene in the family.

Less than 1% of women (1 woman in 100) are at high risk of developing breast cancer.

Care of women who are at raised or high risk

The type of care you receive will depend on your estimated level of risk.

If it is estimated that you are at raised risk of developing breast cancer, you will generally receive care from the breast care team. You should be offered support and information appropriate to your individual needs.

If it is estimated that you are at high risk of developing breast cancer, you should be offered a referral to a specialist genetics service that can make a more detailed estimate of risk and discuss your options.

Questions you might like to ask your breast care team

- Please tell me more about breast cancer.
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?

Screening options for women who are at raised or high risk

Women who are estimated to be at raised or high risk of developing breast cancer may be offered screening with mammograms and sometimes with MRI scans. Screening for breast cancer using mammograms and MRI is called 'surveillance'.

Mammograms and MRI scans take images of the inside of the breasts. Mammograms use low-dose X-rays to make the images and MRI scans use magnetic waves. The breast care team looks at these images to search for lumps or other signs of cancer.

Depending on your age and estimated risk, your breast care team will offer mammograms, MRI or a combination of both.

Yearly mammograms should be offered to women between the ages of 40 and 49 who have a raised or high risk of breast cancer. Women aged 30 to 39 should only be offered a mammogram if it is part of an approved research study, or nationally approved service that is 'audited' (this means that the service is monitored to see how well it is working). This is because it is not yet clear whether mammographic surveillance is helpful in the early detection of breast cancer in women at increased risk in this age group.

Yearly MRI screening **may** be offered to women between the ages of 20 and 49 if they have a high risk of breast cancer, including women who have one of the faulty high-risk genes.

From the age of 50, women are offered mammographic surveillance every 3 years as part of the NHS Breast Screening Programme (further information is available on the NHS website: www.cancerscreening.nhs.uk/breastscreen). Most women over 50 at raised or high risk of developing breast cancer do not generally need to have mammograms more often than women in the general population. This is because cancers are easier to detect in this age group and are therefore identified earlier. The cancers are also likely to be slower to grow. More frequent mammograms should only be offered if the woman is taking part in a research study.

Whatever a woman's age and circumstances, a healthcare professional should discuss her individual situation to help her make a decision about whether or not to have a mammogram or an MRI scan. Written information should be provided that explains the benefits and risks of mammograms and MRI scans.

Sometimes the results of mammograms or MRI scans are not clear and additional tests or scans may be needed. These may turn out to be negative but can be uncomfortable and cause worry.

There is also a risk that mammography or MRI might give a 'false positive' result. A false positive result would indicate that the woman has breast cancer when in fact she does not. Further tests and scans would show that there is no cancer present.

Other imaging options

Women should not be offered ultrasound scans as part of their regular surveillance programme. However, this method may be used occasionally in individual situations to answer a particular question when a woman is at high risk of developing breast cancer.

Questions you might like to ask about breast cancer screening

- Am I entitled to mammography or MRI scans?
- Please give me more details on the risks and benefits of mammograms and MRI scans.
- What do these scans involve?
- I am aged 30 to 39. Is there a research study that I can take part in?

Additional options for women estimated to be at high risk

Only a very small proportion of women (less than 1%) are estimated to be at high risk of developing breast cancer.

Genetic counselling

A genetic counsellor is someone with special expertise in the links between genes and disease. All women who are estimated to be at high risk should be offered a referral to a genetic counsellor. This can be very important in helping a woman understand how her family history and lifestyle affect her risk of developing breast cancer. Information about genetic counselling and what it involves should be provided before it starts.

The genetic counsellor (sometimes a geneticist – a doctor who is an expert in the links between genes and disease) should estimate the woman's risk of developing breast cancer based on her family history and individual risk factors. This should be presented in a way that is understandable, and a written summary should be provided. Before this is given, the likely accuracy of the estimate should be explained. The effects of this knowledge on individual women and their family members should also be discussed.

Genetic testing

The aim of a genetic test is to find out if there is a faulty gene (*BRCA1*, *BRCA2* or *TP53*) in the family. A genetic test should be offered if there is at least a 20% (1 in 5) chance of this. Before a woman decides if she wants to have a genetic test, a genetic counsellor or geneticist should discuss what it involves, what a positive, inconclusive or negative test means and how long it will take to get the results. The effects of knowing the results for the woman and her family members should also be discussed. A full discussion usually takes two appointments.

To give the best chance of finding a faulty gene, the test must first be carried out on a relative who has had breast cancer or ovarian cancer (the same faulty genes are linked to both types of cancer) and who is willing to give a blood sample. If there is no such relative available, then a genetic test cannot be done.

If a faulty gene is found in the family member who has had breast or ovarian cancer, the test can then be offered to other members of the family who have not had the disease. This is because the doctors know exactly what gene fault they are looking for in the family members who have not had breast or ovarian cancer.

If the test shows the same gene fault in an unaffected relative, this means they are at high risk of developing breast cancer. If the gene fault has been found in the relative who has had breast or ovarian cancer but isn't found in an unaffected family member, she and her children will be at no more risk than anyone else in the population.

If a faulty gene cannot be found in the relative with breast or ovarian cancer the test is said to be 'inconclusive'. If this is the case, the doctors will not do a test on unaffected relatives and will use the woman's family history alone to work out her risk.

Remember though, even a woman at high risk will not necessarily develop breast cancer.

Questions about finding out your breast cancer risk

- Please give me more details about the tests I should have.
- What do these tests involve?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?

Surgery to reduce the risk of developing breast cancer

For a small number of women who are at high risk of developing breast cancer, there is the possibility of reducing their risk by having surgery. This involves removing as much tissue as possible from both breasts (called a bilateral mastectomy) so that it is very unlikely for cancer to develop there. This operation greatly reduces, but does not completely remove, the risk of breast cancer. The breast tissue that is removed will be examined for signs of breast cancer.

The options for breast reconstruction (which means rebuilding the breast using tissue from another part of the body or using synthetic 'implants') should be discussed before the operation.

Some women who carry a faulty gene are at a higher risk of ovarian cancer as well as breast cancer. These women may also have their ovaries removed (called an oophorectomy). Oophorectomy before the natural menopause will also greatly reduce the risk of breast cancer as well as nearly all risk of ovarian cancer. In this type of surgery, the woman's ovaries and fallopian tubes should be removed. The removal of the ovaries will result in an early menopause and the woman will not be able to have children. The consequences of this should be discussed when considering the operation.

Before deciding to go ahead with risk-reducing surgery, the advantages and disadvantages of each type of surgery should be fully explained. The possible impact of surgery should also be discussed including, for example, how a woman may feel about her body and how other people see her, and the effect that surgery may have on the relationship between her and her partner.

If she wishes, she can be put in touch with support groups with women who have undergone similar surgery.

Making informed decisions

If you are concerned about your family history of breast cancer, you should be given the following standard written information:

- risk levels in the general population and in people with a family history, including a definition of family history
- the message that, if your family history alters, your risk may alter
- breast awareness information
- lifestyle advice regarding breast cancer risk, including:
 - HRT and oral contraceptives
 - lifestyle, including diet and alcohol
 - breastfeeding, family size and timing of having a family
- contact details of those providing support and information, including local and national support groups
- information about bringing a relative or friend to appointments
- details about clinical trials or studies that may be appropriate for you to take part in.

If required, you may also receive:

- advice about how to obtain a full family history
- information about how your risk will be assessed
- details of your likely risk of developing breast cancer
- details of mammographic and MRI surveillance options (see page 10), if appropriate, including the risks and benefits
- details of counselling and genetic testing, including what the tests mean
- information about the risks and benefits of surgery to reduce the risk of developing breast cancer (when it is being considered), including both the physical and psychological impact.

More information

The organisations below can provide more information and support for people with breast cancer. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Breakthrough Breast Cancer, 08080 100 200
www.breakthrough.org.uk/genetics
- Cancerbackup, 0808 800 1234
www.cancerbackup.org.uk
- Breast Cancer Care, 0808 800 6000
www.breastcancercare.org.uk
- The National Hereditary Breast Cancer Helpline, 01629 813000
www.breastcancer genetics.co.uk

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

About NICE

NICE produces advice (guidance) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG041

You can order printed copies of this booklet from the NHS Response Line (phone 0870 1555 455 and quote reference N1131).