Family history,
genes and breast cancer

breast cancer care

This booklet explains how your family history can sometimes affect your risk of developing breast cancer. It looks at how risk is assessed, the options for managing your risk and other things you may need to consider. It also includes information on genetic testing.

This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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Introduction

If you or one of your close relatives has been diagnosed with breast cancer, you may have concerns about what this means for you and other members of your family. This booklet is for people who'd like to know more about breast cancer in families.

The first part of this booklet looks at the main risk factors for developing breast cancer, how having breast cancer in your family can sometimes increase your risk and what to do if you're concerned. This includes information on how risk is assessed and genetic testing.

The second part of the booklet is aimed at people who have an increased risk of developing breast cancer, including gene carriers (people who have inherited an altered gene). There is also information for people who have had breast cancer and remain at high risk of developing a new breast cancer. It looks at the options for managing your risk such as breast screening and risk-reducing treatment.

There is also information about things you may want to consider in the future, including concerns you may have about having children.

Although this booklet mainly talks about women, much of the information is also relevant to men.

Breast cancer risk

This section of the booklet looks at what factors might affect someone's risk of developing breast cancer, whether your family history can increase your risk and how risk is assessed.

How breast cancer starts

Breast cancer starts when cells in the breast begin to divide and grow in an abnormal way.

All cells contain genes that tell them how to grow and function. Sometimes a change can occur in a gene that means the cells begin to function in an abnormal way. This is known as an altered gene (you might also hear this called a gene change, fault or mutation). Altered genes can be either **inherited** or **acquired**.

- **Inherited** altered genes are passed down from one of our parents (see 'Inherited altered genes' on page 8).
- **Acquired** altered genes develop due to a combination of things such as getting older and environmental and lifestyle factors.

Although breast cancer is very common, only a small percentage of cases are due to inheriting an altered gene.

For more information on genes and cancer see the Cancer Research UK website cancerresearchuk.org/about-cancer/what-is-cancer

Breast cancer risk factors

Most breast cancers are caused by a combination of many different things.

While the exact causes are still unknown, research has shown that some things can increase or decrease the likelihood of getting breast cancer.

These are called 'risk factors'. However, everyone is different so no one can say for certain who may or may not get breast cancer. Someone with many risk factors may not develop breast cancer while another may have very few and be diagnosed with it.

There are three main risk factors for developing breast cancer, which are things we can't do anything to change. These are:

- being a woman
- getting older
- having a significant family history.

Being a woman is the biggest risk factor for developing breast cancer. In the UK, around 62,000 people are diagnosed with breast cancer each year, and of these around 390 are men.

Age is the next most important risk factor. The older you are, the higher your risk. Most breast cancers (around 80%) occur in women over the age of 50. Most men who get breast cancer are over 60.

A small number of people have an increased risk of developing breast cancer because they have a significant family history (see page 9). This may be because an altered gene that increases the risk of breast cancer runs in the family (see below).

There are other factors that can slightly increase the risk of developing breast cancer, such as being overweight, and some factors that slightly decrease the risk, such as having children at a younger age.

You can find out more about environmental and lifestyle risk factors for breast cancer on our website (breastcancercare.org.uk), or on the Cancer Research UK website cancerresearchuk.org

Inherited altered genes

People who have inherited an altered gene (usually known as gene carriers) will be at a high risk of developing breast cancer and possibly other cancers. Around 5% of women with breast cancer are gene carriers.

The most common inherited altered genes that increase the risk of breast cancer developing are called BRCA1 (BReast CAncer1) and BRCA2 (BReast CAncer2). Inheriting an alteration in another gene called TP53 (tumour protein p53) also increases the risk, although this is much rarer.

Some genetic conditions that are caused by other rare inherited altered genes also increase the risk of breast cancer, although not by as much as the BRCA1/2 or TP53 altered genes. These are:

- Peutz-Jeghers syndrome (altered STK11 gene)
- Cowden syndrome (altered PTEN gene)
- hereditary diffuse gastric (stomach) cancer (altered E-cadherin (CDH1) gene).

If one of these conditions runs in your family, you will also be managed as being at high risk for developing breast cancer (see 'Managing your breast cancer risk' on page 19).

Being a gene carrier will increase your risk of developing breast cancer significantly, but it doesn't necessarily mean you'll get breast cancer. Other things such as age, lifestyle and environmental factors also contribute to the likelihood of cancer developing.

There are a number of other genes that have been shown to increase the risk of developing breast cancer, but more research is needed to know how much the risk is increased and how to manage this risk.

Finding out about your family history and your risk

If you're concerned that your family history might mean you or other members of your family have an increased risk of developing breast cancer, the first step is to talk to a healthcare professional. Who you should talk to first will depend on your situation.

- If you have not had breast cancer yourself, you can talk to your GP (local doctor), who will ask about your family history and may refer you to a specialist family history clinic or a regional genetics centre (depending on where you live).
- If you have been diagnosed with breast cancer yourself, you can speak to a member of your specialist breast care team who will be able to refer you to a specialist family history clinic or a regional genetics centre if appropriate.

You should be referred for further assessment of your risk if:

- you or one close relative has had breast cancer before the age of 40
- you or one close relative has had breast cancer in both breasts (bilateral breast cancer)
- you have had breast cancer known as triple negative (in particular if you were diagnosed under the age of 50)
- two or more close relatives have had breast cancer (or you and one close relative if you have had breast cancer)
- you have close relatives who have had breast cancer and others who have had ovarian cancer
- a male relative has had breast cancer
- you are of Ashkenazi Jewish ancestry.

You might also be referred if:

- you or a relative has had sarcoma (cancer in the connective tissues, for example in the muscle or bone) before the age of 45
- you or a relative has had glioma (a type of brain tumour) or childhood adrenal cortical cancer (cancer in the outer layer of the adrenal gland)
- your family has had a number of cancers at a young age
- your family has had a number of cancers linked to one of the other rare inherited altered genes (see page 9).

Your risk assessment appointment

Try to find out as much about your family history as you can from other relatives before your appointment. You may be asked to complete a questionnaire about your family history before being offered an appointment or you may be asked for this information at your appointment. The person looking at your family history will understand if you can't find all the relevant information.

At the appointment you'll be asked about any type of cancer in all your blood relatives on both sides of your family. This includes your mother and father, sons and daughters, brothers and sisters, aunts and uncles, nieces and nephews, cousins, grandparents, great uncles and great aunts.

You'll be asked:

- for your known family history on both sides, including family members who have not had cancer, and the age at which any of them died
- how the people diagnosed with cancer are related to you (for example mother, father, sister, brother, cousin)
- how the people diagnosed with cancer are related to each other
- what type of cancer each person had
- how old each person was when diagnosed
- whether the same person has had more than one cancer (including cancer in both breasts)
- about your ethnic background
- about your own breast cancer diagnosis (if you have been diagnosed).

If you don't have information about your family history or your blood relatives, your risk assessment can only be based on whatever information you have.

At the end of your appointment, if your specialist team has enough information you will be told what your level of risk is based on your family history.

Different levels of risk

Healthcare professionals can't say for sure whether someone will develop breast cancer and a person's level of risk may change over their lifetime, for example if a close relative develops breast or ovarian cancer in the future.

Whatever your breast cancer risk is, you'll be offered information and support that's relevant to you as an individual.

General population risk (average or near population risk)

If a person is at general population risk, this means their risk of developing breast cancer as a result of their family history is the same as (or very similar to) that of the general population.

If only one person in your family has been diagnosed with breast cancer over the age of 40, you're likely to be at general population risk. Most breast cancers are not inherited and so do not increase the lifetime risk for other family members.

As breast cancer is the most common cancer in the UK, if you're at general population risk it's important to be breast aware and tell your GP if you notice any unusual changes.

Between the ages of 50 and 70, women are invited for a routine mammogram (breast x-ray) every three years as part of a national breast screening programme. Breast screening can pick up breast cancer before there are any signs or symptoms. The sooner breast cancer is diagnosed, the more effective treatment is likely to be.

You can find out more about being breast aware and breast screening in our booklet **Know your breasts: a guide to breast awareness and screening**.

It's important to go back to your GP if your family history changes – for example if another relative develops breast or ovarian cancer.

Moderate risk (familial or raised risk)

People in this category are at higher risk than the general population, but it's still more likely that they won't get breast cancer as a result of their family history.

A person at moderate risk may have had several relatives diagnosed with breast cancer but no obvious pattern of the disease. Although breast cancer might have affected people in several generations of their family, they tend to be affected at older ages.

A person may also be considered to be at moderate risk if one close relative developed breast cancer under the age of 40.

If you're at moderate risk, you're likely to be offered regular screening. Your specialist may also discuss with you the possibility of risk-reducing drug treatment. See the 'Managing your breast cancer risk' section on page 19 for more information.

It's important to go back to your GP if your family history changes – for example if another relative develops breast or ovarian cancer.

High risk (hereditary or increased risk)

People in this category are more likely than those at moderate risk to develop breast cancer but this doesn't mean they definitely will.

A person at high risk will usually have had several close relatives on either the mother or the father's side diagnosed with breast

cancer, ovarian cancer or both over several generations (for example grandmother, mother and daughter). They will often have been diagnosed at a young age.

If you're at high risk, you will be given more information on the options available to you, including breast screening and risk-reducing treatments. You may be offered genetic counselling and the possibility of genetic testing will be discussed (see page 14).

See the 'Managing your breast cancer risk' section on page 19 for more information on breast screening, risk-reducing treatments and support for people at high risk.

If you have had breast cancer

If you've been diagnosed with breast cancer, your specialist will discuss the risk of the cancer coming back (recurrence). For more information see our **After breast cancer treatment: what now?** booklet.

Having had breast cancer slightly increases your risk of developing a new primary breast cancer and your family history may increase this risk further. A new primary breast cancer is when a new breast cancer develops, not the original cancer coming back.

If your family history puts you at moderate or high risk, you will continue to have increased screening after your follow-up period ends to check for signs of a new primary breast cancer. See 'Breast screening for people at increased risk' on page 19.

If you are at high risk, your specialist may discuss the possibility of additional surgery to reduce the risk of developing a new primary breast cancer. If you are found to be a gene carrier, your specialist may also discuss surgery to reduce the risk of ovarian cancer. See 'Risk-reducing surgery' on page 24.

How you might feel

Finding out that you're at moderate or high risk can cause many different emotions. You may feel more anxious about your breast health, or afraid of what the future holds for you and your family.

See our 'Support for you' section on page 33 for details on how Breast Cancer Care can support you during this time.

Genetic counselling

If you're considered to be at high risk of developing breast cancer, have a complex family history or if further investigation into your family history would be helpful in understanding your risk, you will be offered a genetic counselling appointment at a regional genetics centre.

You'll meet with a genetic counsellor (a healthcare professional with specialist knowledge about genetics and inherited illnesses) or a clinical geneticist (a doctor with specialist training in genetics).

They can help you understand more about your family history, your risk of developing breast cancer (and possibly other cancers) and the options that may be available to you, such as genetic testing, breast screening and treatments to reduce the risk of cancer developing. Sometimes this may be done over several visits.

For some people, genetic counselling can be a very emotional time. You may feel anxious talking about your risk and what this means for you and those around you. Your genetic counsellor will have a lot of experience talking through the issues involved and will be able to offer you support if you need it.

Genetic testing

Your genetics team will tell you if genetic testing is an option for you. Genetic testing will try to find out if there is a known altered gene that runs in your family. If genetic testing is an option for you, it is your decision whether you want to have the test or not.

In the NHS, genetic testing is usually only available through a genetics centre and after you've had genetic counselling. However, at some hospitals pre-test counselling and genetic testing may be provided by the breast and gynaecology specialist teams (for example by the

surgeon or oncologist), and if post-test counselling is needed this would be done by the genetics team.

There are two stages to genetic testing.

Stage one – a full screen (diagnostic test)

The first stage of testing is to try to find out if one of the known altered genes runs in your family.

Altered genes can be difficult to find and there is a better chance of finding an altered gene in someone who has already been diagnosed with breast or ovarian cancer.

If you have been diagnosed with breast or ovarian cancer then the test can be done on you. If you haven't had breast or ovarian cancer and no one in your family who has is available for testing, you may be able to have the test yourself. Your genetic counsellor will be able to tell you if this option is available.

How the test is done

The test involves taking a blood sample and sending it to a laboratory where the DNA (deoxyribonucleic acid) is tested for the known altered genes. The results from this test are usually available within two to three months.

A positive result

If an altered gene is found, your genetics team will then know which one runs in your family and can search for it more easily in other family members (see 'Stage two – a predictive genetic test' on the next page).

A negative/inconclusive result

As it can be hard to find an altered gene, sometimes a genetic test produces a negative/inconclusive result. This means a known altered gene hasn't been found, but your family history may still be due to an altered gene that hasn't been identified yet. You will continue to be managed as high risk.

A variant of unknown/uncertain significance

Sometimes the result can show an alteration in one of the known breast cancer genes (BRCA1 or BRCA2), but it is not known if this particular alteration can cause cancer (called a variant of unknown/uncertain significance (VUS)). Your genetics team will advise you and family members how to interpret the results of this first test.

Stage two – a predictive genetic test (targeted genetic test)

If an altered gene is found in one family member during the full screen/diagnostic test, other blood relatives will then be able to have a genetic test to see whether they also carry the altered gene. This is called a predictive genetic test. The result of a predictive genetic test usually takes about four weeks.

A negative genetic test result

If the predictive genetic test shows that you don't have the altered gene (a negative result), your risk of developing breast cancer is the same as women in the general population. For more information on general population risk, see page 11).

Having a negative result also means any children you have, or may have in the future, won't inherit an altered gene.

A positive genetic test result

If you've had a positive result, this means you are a gene carrier (have inherited an altered gene) and your chance of developing breast cancer (and possibly other cancers) is far greater than the general population (see opposite).

You will be offered regular screening, drug treatment or risk-reducing surgery but you don't have to take up any of these options.

You are likely to have many questions such as how to tell your family and whether to have screening or risk-reducing treatment. You will be offered post-test counselling and your genetics counsellor will be able to support you and talk through your feelings and concerns.

The second part of this booklet includes information and support for people who have been confirmed as a gene carrier. You can also talk to someone who has been in the same situation through our Someone Like Me service or on the 'Genes and breast cancer' section of our discussion Forum (see 'Support for you' on page 33).

Cancer risks for gene carriers

Being a gene carrier doesn't necessarily mean you'll go on to develop breast or ovarian cancer. However, you do have a higher risk than people in the general population. The risks are different for men.

Cancer risks for women who carry a BRCA1/2 gene

	BRCA1	BRCA2
Breast cancer	60–90% lifetime risk (up to 80 yrs)	45–85% lifetime risk (up to 80 yrs)
Breast cancer in the contralateral (opposite) breast for gene carriers with breast cancer	Up to 50% lifetime risk	Up to 50% lifetime risk
Ovarian cancer	40–60% lifetime risk	10–30% lifetime risk

Cancer risks for men who carry a BRCA1/2 gene

	BRCA1	BRCA2
Male breast cancer	0.1–1% lifetime risk (near population risk)	5–10% lifetime risk
Prostate cancer	Lifetime risk is similar or very slightly higher than the general population	Up to 25% lifetime risk
Pancreatic cancer	No evidence of increased risk	Up to 3% lifetime risk (depending on the family history)

TP53 gene carrier risks

If you have an altered TP53 gene, the lifetime risk of developing cancer is up to 70% for men and up to 90% for women.

For more detailed information on age-related cancer risks for gene carriers see the Institute of Cancer Research's Cancer Genetic Clinical Protocol 2 and 3 (icr.ac.uk/protocols).

Will my children inherit the gene?

If you have children, each of them has a 50% chance of being a gene carrier. If you are planning to have children, there is a 50% chance they will be a gene carrier. The risk is the same for boys and girls.

People need to be over 18 before any assessment of their risk of breast cancer can take place. See 'Talking to your family about your risk' on page 27 and 'Worries about having children' on page 31 for more information.

Managing your breast cancer risk

This section of the booklet is for people who are at an increased risk of developing breast cancer, including people who have been confirmed as a gene carrier (people who have inherited an altered gene). It is also for people who have been diagnosed with breast cancer and remain at an increased risk because of their family history.

It explains the different options for managing your risk that might be available to you and includes information on talking to your family.

Breast screening for people at increased risk

If you have been assessed as being at moderate or high risk of breast cancer, you will be offered regular scans and/or mammograms to check for breast cancer. This is known as screening. The aim of screening is to pick up breast cancer before there are any obvious signs or symptoms. The sooner breast cancer is diagnosed, the more effective treatment is likely to be.

The type of screening you'll be offered will depend on:

- your age
- whether you've had breast cancer
- your level of risk.

If you're at high risk, the type of screening will also depend on your individual likelihood of being a gene carrier. If you are told that you have more than a 30% chance of being a gene carrier, your screening will start earlier and go on for longer.

Screening may include a mammogram (a breast x-ray) or an MRI (magnetic resonance imaging) scan, which uses magnetic fields and radio waves to produce a series of images of the inside of the breast.

Younger women won't usually be offered mammograms as they are more likely to have dense breast tissue, making the mammogram images less clear.

Your breast screening recommendations will be based on national guidelines.

- England and Wales follow the National Institute for Health and Care Excellence (NICE) – Familial breast cancer guideline (CG164).
- Scotland follows the Health Improvement Scotland – Familial breast cancer report.
- Northern Ireland follows the Health and Social Care (HSC) – Higher risk surveillance programme.

See 'Further information' on page 38 for details of all national guidelines.

Men are not offered screening, even if they are gene carriers. This is because even though a man's risk for developing breast cancer increases, the increased risk is still less than women in the general population.

NICE screening recommendations for women at moderate or high risk of breast cancer who haven't had breast cancer

	Risk group					
Age (years)	Moderate	High	High with more than 30% chance of a faulty BRCA gene	High with a faulty BRCA1 or BRCA2 gene	High with more than 30% chance of a faulty TP53 gene	High with a faulty TP53 gene
20–29	None	None	None	None	Yearly MRI	Yearly MRI
30–39	None	You may have a yearly mammogram	Yearly MRI and possibly yearly mammogram	Yearly MRI and possibly yearly mammogram	Yearly MRI	Yearly MRI
40–49	Yearly mammogram	Yearly mammogram	Yearly mammogram and yearly MRI	Yearly mammogram and yearly MRI	Yearly MRI	Yearly MRI
50–59	You may have a yearly mammogram	Yearly mammogram	Yearly mammogram MRI if mammogram shows dense breasts*	Yearly mammogram MRI if mammogram shows dense breasts*	Mammogram as part of the population screening programme MRI if mammogram shows dense breasts*	You may have yearly MRI
60–69	Mammogram as part of the population screening programme	Mammogram as part of the population screening programme	Mammogram as part of the population screening programme MRI if mammogram shows dense breasts*	Yearly mammogram MRI if mammogram shows dense breasts*	Mammogram as part of the population screening programme MRI if mammogram shows dense breasts*	You may have yearly MRI
70+	Mammogram as part of the population screening programme	Mammogram as part of the population screening programme	Mammogram as part of the population screening programme	Mammogram as part of the population screening programme	Mammogram as part of the population screening programme	None

*If the breast tissue is dense the mammogram image may be less clear so an MRI scan will also be used.

National (population) breast screening programmes

Once your increased screening stops, you'll usually be transferred onto a national (sometimes called population) breast screening programme.

- If you are under 70 you will be invited for a routine mammogram every three years (in England some breast screening centres are taking part in a trial where the age range has been extended to 73 years of age).
- After the age of 70 (or possibly 73) you can still have a mammogram every three years, but you will have to contact your local breast screening unit directly to get an appointment.

NICE screening recommendations for women who have had breast cancer

If you've had breast cancer you will have increased screening for five years as part of your follow-up care.

Once your follow-up period ends, if you are at moderate risk you will have the same screening recommendations as women at moderate risk who have not had breast cancer (as above).

If you remain at high risk of developing another breast cancer or are a BRCA gene carrier, you should be offered:

- yearly MRI scans if you're aged 30–49
- yearly mammograms if you're 50–69.

If you're over 70 (or 73) and your follow-up period has ended, you can still ask for a mammogram every three years as part of a national breast screening programme.

If you have an altered TP53 gene, you will not be offered mammograms but you may be offered yearly MRI scans between the ages of 20–69.

Information about screening

Your specialist team should give you information about the possible benefits and risks of screening. You can also read more about these in our booklet **Know your breasts: a guide to breast awareness and screening**.

Treatment to reduce the risk of breast cancer

If you're at moderate or high risk, your healthcare professional should talk to you about the possibility of treatment to reduce your risk.

You should be told about all the possible risks and benefits of these treatments, and by how much they may reduce your risk of developing breast cancer.

Men are not offered risk-reducing treatment, even if they are at increased risk or are gene carriers. This is because even though their risk is increased it is still less than women in the general population.

Drug treatment

Research has shown that taking drugs called tamoxifen, anastrozole or raloxifene for five years can help reduce the risk of developing breast cancer in women at moderate or high risk. However, the evidence for gene carriers is limited. Current evidence suggests while drug treatment may be useful in BRCA2 gene carriers, the benefit for BRCA1 gene carriers is less certain.

Tamoxifen and anastrozole are usually used as a treatment for some breast cancers, and raloxifene is used to treat or prevent osteoporosis (bone thinning) after the menopause.

Your genetics team will talk to you about the possible benefits and side effects before you make a decision. See our **Tamoxifen** and **Anastrozole** booklets for more information about their side effects. There is more information on raloxifene and its side effects on our website.

Who might be offered drug treatment?

If you are at high risk and are pre-menopausal (haven't yet been through the menopause), your genetics team may recommend tamoxifen for five years. This may also be considered if you are pre-menopausal and at moderate risk.

If you are at high risk and are post-menopausal, your genetics team may recommend tamoxifen, anastrozole or raloxifene for five years. This may also be considered if you are post-menopausal and at moderate risk.

Oral contraceptive pill and cancer risk

Evidence has shown that taking the oral contraceptive pill (OCP) can protect women from developing ovarian cancer, and the longer you take it the greater the benefit. However, it can also slightly increase the risk of developing breast cancer, but when you stop taking it this increased risk starts to decrease and goes back to that of the general population after 10 years.

Taking the OCP may slightly increase and decrease your risk of some other cancers too. There aren't any guidelines that recommend taking the OCP to reduce the risk of ovarian cancer and your genetics team can discuss this with you.

Risk-reducing surgery

Risk-reducing surgery is an option for gene carriers and for some women at high risk, whether they have or haven't had breast cancer. It will not be offered to women at moderate risk.

Surgery to remove both breasts

If you are at high risk of developing breast cancer, or are a BRCA1/2 or TP53 gene carrier, your healthcare professional should discuss the possibility of surgery to reduce your breast cancer risk.

Risk-reducing surgery involves removing the breast tissue from both breasts. This type of surgery is called a bilateral mastectomy.

A bilateral mastectomy can significantly reduce the risk of developing breast cancer by 90–95%, but it cannot completely remove the risk.

Risk-reducing mastectomy (to both breasts or to the remaining breast) is also an option for women who have had breast cancer and are at high risk of another breast cancer developing.

You'll usually be offered breast reconstruction at the same time as a mastectomy. For more information see our **Breast reconstruction** booklet.

Your healthcare professional should discuss with you all the possible risks and benefits of having risk-reducing surgery. You may also find it helpful to read Macmillan Cancer Support's Understanding risk-reducing breast surgery booklet (see 'Further reading' on page 39).

You can also talk to someone who has been in the same situation through our Someone Like Me service or on the 'Genes and breast cancer' section of our online Forum (see the 'Support for you' section on page 33).

Surgery to remove both ovaries and fallopian tubes

Women who carry an altered BRCA1 or BRCA2 gene are also at higher risk of developing ovarian cancer (see page 17). Ovarian cancer risk starts to increase significantly from the age of 40 for BRCA1 gene carriers and from the age of 50 for BRCA2 gene carriers.

For pre-menopausal women who are BRCA gene carriers, having surgery to remove the ovaries and fallopian tubes has been shown to reduce the risk of ovarian cancer by up to 90–95%. This type of surgery is known as a bilateral salpingo-oophorectomy (BSO). For pre-menopausal women who carry the altered BRCA2 gene, it may also reduce the risk of breast cancer.

Your specialist team will be able to advise you on when you may want to have risk-reducing surgery to the ovaries and fallopian tubes. Factors to consider will include your age, if you want to have children or add to an existing family and whether you are a BRCA1 or BRCA2 gene carrier.

If you have any other benign (not cancer) womb conditions, your specialist may also discuss removing the womb at the same time as your ovaries and fallopian tubes (a total hysterectomy).

Deciding whether, or when, to have a risk-reducing BSO is a very personal decision. You may also wish to find more information from OvDex (The Oophorectomy Decision Explorer), a computer program developed by Cardiff University to help you make decisions about having a risk-reducing BSO (ovdex.co.uk).

Managing menopausal symptoms following a bilateral salpingo-oophorectomy

If you are pre-menopausal, having a BSO will cause an early menopause. For some women, menopausal symptoms can be severe and have a negative effect on everyday life. Symptoms include:

- hot flushes and night sweats
- vaginal dryness
- loss of libido (sex drive).

If you're under 50 and haven't had breast cancer, your specialist will discuss the option of taking hormone replacement therapy (HRT) up until the age of a natural menopause (usually around 50) to help with any menopausal symptoms as a result of your surgery. There is good evidence that taking HRT will not affect the reduction in breast cancer risk gained from having the surgery.

If you have had breast cancer, taking HRT after a BSO is not usually recommended. However, if your breast cancer was oestrogen receptor negative and your symptoms are affecting your everyday activities, your specialist can discuss with you the risks and benefits of taking HRT. Our **Menopausal symptoms and breast cancer** booklet discusses ways to help manage menopausal symptoms.

Going through an early menopause can affect your bones, which can increase your risk of developing osteoporosis in the future. Osteoporosis is a condition where your bones lose their strength and become fragile and more likely to break (fracture). If your specialist team is concerned about your risk of developing osteoporosis, they may suggest a DEXA scan at the time of surgery to check your bone health. Follow-up DEXA scans may also be recommended in the future.

You can find more information about bone health and osteoporosis on the National Osteoporosis Society website nos.org.uk If you've had breast cancer and would like to know more about bone health see our **Osteoporosis and breast cancer treatment** booklet.

Other considerations

Clinical trials

There are clinical trials being carried out to find out more about genes and breast cancer. It's possible that you'll be offered the chance to take part in one of these trials.

There is more information about clinical trials on our website, the Cancer Research UK website or the UK Clinical Trials Gateway. BRCA PROTECT, a research clinic set up by University College London, is currently looking for volunteers to help with their research into reducing risk in BRCA gene carriers. See 'Useful organisations' on page 34 for more information.

Insurance

Currently, if you've had a predictive genetic test for breast cancer you don't have to disclose the result when you apply for insurance such as life or health insurance (under a certain amount). However, insurance companies do ask about your family's medical history and if you have a significant family history of breast cancer you may be charged a higher premium. If you've had a diagnosis of breast cancer, you will have to disclose this and it may be more difficult to get travel insurance. Find out more about breast cancer and travel insurance on our website.

If you would like more information, Genetic Alliance UK has produced an information guide on insurance and genetic conditions, available on their website geneticalliance.org.uk

Talking to your family about your risk

If your family history puts you at an increased risk, this will mean that other members of your family will also be at an increased risk. It's important to talk to your family so that they are aware of this. They then have the chance to make choices about having their own risk assessed and managing their risk.

Talking to your family after a positive genetic result

If you've had a positive genetic result, it is especially important to talk to your family about your result because first degree relatives (such as brothers and sisters and children) will have a 50% chance of also being a gene carrier.

Your genetic counsellor can help you work out the best way to do this. They may have prepared letters that you can adapt and send to your relatives. You may feel it would be better to tell your relatives face to face, or you may prefer to phone or email them.

Their reactions may vary. It may come as a complete shock to them. Some relatives may choose to ignore the result and may even find it difficult to talk to you afterwards. Others will be glad that you have warned them about the possibility that they may be a gene carrier and will then want to have a genetic test themselves.

No one is to blame for the genes they inherit or pass on, but telling your family that they may be a gene carrier will give them the option to discuss the possibility of genetic testing and manage their own risk.

Talking to your children after a positive genetic result

Many parents worry about telling their children that an altered gene runs in the family and it can be difficult to know the right time.

Even though you may find it difficult, talking to your children as soon as you feel ready can be helpful for you both. Children can be quick to pick up on secrets and are often less frightened if they know what is happening. If they feel left out they may think they have done something to upset you or they may make up their own story about what is happening. Being open and honest will make them feel valued and help them to trust you.

However, you may want to consider your child's maturity, any other stressful things going on in their life and whether you've adjusted to the news yourself yet. When to tell your child is a very personal decision and you know them better than anyone.

Tips for talking to children

- Children and teenagers usually respond better to informal conversations, often while you are doing things together.
- Give them small amounts of information at a time, to help them understand at a pace that is right for them. Let them know you will keep coming back to the conversation and that they can too.
- Depending on their age, children will have a different understanding of genes and cancer. Ask them to say in their own words what they think is happening so you can see if they are confused about anything.
- Children may find it hard to express their concerns or worry about upsetting you. Reassure them that they can ask you anything and, if they do ask a question, make sure you have understood why they are asking it.
- If you don't have an answer to a question, explain that you don't know or that you will try to find out.
- Include positive messages about what can be done now you know you are a gene carrier. Let them know that children and young people are not at risk and they have just as much chance of not inheriting the gene.
- Keep talking with your children regularly about what's going on so they feel involved and informed and are able to ask any questions. You may need to repeat explanations, especially to younger children.

The Royal Marsden NHS Foundation Trust has published information on what children are likely to understand about genes at different ages. Nottingham University Hospitals NHS Trust has also produced information on talking to children about genetic conditions. See 'Further reading' on page 39 for details.

In the future

This section looks at other things you may want to think about in the future if your family history puts you at an increased risk of breast cancer.

Changes to your family history

If you are currently considered to be at moderate risk it's important to go back to your GP if your family history changes – for example if another relative develops breast or ovarian cancer. If necessary you may then be referred to a breast or genetics clinic for further assessment.

Being breast aware

Whatever your level of risk, it's important to remain breast aware. Get to know how your breasts look and feel so you know what is normal for you and can be more confident noticing any unusual changes. If you notice a change, see your GP or breast specialist. The sooner breast cancer is diagnosed, the more effective treatment may be.

You can find out more about being breast aware in our booklet **Know your breasts: a guide to breast awareness and screening**.

For more information on staying breast and body aware after breast cancer treatment, see our booklet **After breast cancer treatment: what now?**

Worries about having children

Fertility and treatment

Some treatments for reducing the risk of breast cancer and for treating it can affect fertility.

Some risk-reducing treatments may affect your fertility, for example surgery to remove the ovaries and fallopian tubes will affect fertility permanently.

You will also be advised not to get pregnant while taking tamoxifen, and you should stop taking it for at least eight weeks before trying to conceive.

Your specialist will discuss any effects on fertility with you when considering risk-reducing treatment options.

If you have been diagnosed with breast cancer, treatment such as chemotherapy can affect your fertility. Also, if you are taking tamoxifen, because of the length of time it's taken for, you may go through a natural menopause while taking it. You can find out more in our booklet **Fertility and breast cancer treatment**.

Passing on an altered gene to children

If you or your partner is a gene carrier, you may be concerned about passing on the altered gene to future children. Your genetic counsellor will be able to talk through the options that might be available to you and your partner to avoid passing on the gene (see below) but many people choose to have children without any intervention.

Pre-natal diagnosis (PND)

There are two procedures that can look for a known altered gene while you are pregnant – chorionic villus sampling (CVS) or amniocentesis. Both of these procedures are done by a doctor specialising in foetal medicine (the care of babies while they are still in the womb). However, these two procedures are not routinely available and won't be suitable for every gene carrier.

Pre-implantation genetic diagnosis (PGD)

If you're thinking about becoming pregnant, you may want to talk to your genetic counsellor about pre-implantation genetic diagnosis (PGD). PGD involves going through an in-vitro fertilisation (IVF) cycle, where an egg is removed from the woman's ovaries and fertilised with sperm in a

laboratory. The fertilised egg, called an embryo, can be checked for the known altered gene. Only embryos that do not carry the breast cancer gene will be transferred to the womb.

PGD isn't available to everyone on the NHS. As with IVF, couples must meet set criteria including age, weight, whether you have other children from the same relationship and whether you or your partner smoke.

PGD is currently only offered in a few hospitals in the UK. You may need to travel some distance for the treatment.

Egg or sperm donation

You may also want to consider egg or sperm donation (depending on which parent has the altered gene) to avoid passing on an altered gene.

Planning to start or continue your family is a very personal decision. You may want to find out more information from Genetic Alliance UK, Guy's and St Thomas' Centre for PGD and the Human Fertilisation and Embryology Authority (see page 35).

Support for you

Concerns about you or other family members inheriting breast cancer are very common for women who have a family history of breast cancer.

Finding out that you and your family are at increased risk of developing breast cancer can cause many different emotions. You may feel more anxious about your breast health or afraid of what the future holds for you.

Breast cancer not only affects you but also your relationships with other members of your family. If you have children you may find that you have concerns about their health, or you may have new anxieties about having children in the future.

All cancer genetics clinics have genetic counsellors who you can talk to about how you're feeling. There are also a number of organisations that may be able to support you during this time (see 'Useful organisations' on page 34).

Breast Cancer Care's services, including our Helpline and Ask Our Nurses email service, offer information and support to anyone concerned about breast cancer in families.

Our Someone Like Me service can put you in touch with a trained volunteer who has had experience of the issues you're facing, whether you're undergoing genetic testing or have been told you are a gene carrier. Talking privately over the phone, where and when it suits you, means you can ask any questions you like and talk openly without worrying about the feelings of the person listening. Some of our volunteers can also chat via email. Call **0345 077 1893** or email **someonelikeme@breastcancercare.org.uk**

You can also find support day or night from people who have experienced what you're going through on the 'Genes and breast cancer' section of our Forum.

Useful organisations

BRCA Link NI
Website: brcani.co.uk/index.html

A voluntary organisation based in Northern Ireland helping people to access information and support about being a BRCA gene carrier.

BRCA PROTECT Research Clinic
Website: brcaprotect.org

A research clinic at University College London Hospital that is looking at more effective and less invasive ways of reducing breast and ovarian cancer risk for women who are gene carriers. It needs women volunteers to come forward and take part in the research.

For more information or to volunteer, call 020 3447 2125 or email brcaprotect@ucl.ac.uk

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BRCA Umbrella
Website: brcaumbrella.ning.com

A social network (including a blog, forum and local support group network) for people at high risk of breast cancer, BRCA gene carriers, and their family and friends.

Cancer Research UK
Website: cancerresearchuk.org

A UK cancer research and awareness charity. Their website includes information on genes, risk factors and clinical trials.

FORCE (Facing Our Risk of Cancer Empowered)
Website: facingourrisk.org

A non-profit organisation dedicated to improving the lives of individuals and families who have an altered gene or are at high risk of breast and ovarian cancer. Based in the USA but have a UK support network based in Essex.

Genetic Alliance UK
Website: geneticalliance.org.uk

Formerly the Genetic Interest Group (GIG). A national charity working to improve the lives of patients and families affected by all types of genetic conditions.

Guy's and St Thomas' Centre for PGD
Website: pgd.org.uk

Expert information on fertility and pre-implantation genetic diagnosis (PGD).

Human Fertilisation and Embryology Authority
Website: hfea.gov.uk

An independent regulator, providing information about IVF and fertility treatments in the UK.

National Hereditary Breast Cancer Helpline
Helpine: 01629 813 000
Website: breastcancergenetics.co.uk
Email: canhelp@btopenworld.com

Provides help and information for people concerned about their family history of breast cancer, and has a database of women prepared to share their own experiences with others.

Nick of Time (Keeping Abreast)
Website: keepingabreast.org.uk

Nick of Time supports women considering their options and choices after finding out they are at high risk of breast cancer or are a gene carrier. Based across Norfolk and Cambridgeshire.

Ovacome
Support line: 0845 371 0554
Website: ovacome.org.uk
Email: support@ovacome.org.uk

A charity that provides support and information for women affected by ovarian cancer, their families and friends.

Ovarian Cancer Action
Website: ovarian.org.uk
Email: info@ovarian.org.uk
Helpline: 0300 456 4700

A charity that funds research and provides information and support to women with ovarian cancer.

OvDex (The Oophorectomy Decision Explorer)
Website: ovdex.co.uk/cancer_risk.html

An online tool to help you find out more about your options for reducing your ovarian cancer risk.

Macmillan Cancer Support
89 Albert Embankment, London SE1 7UQ
General enquiries: 020 7840 7840
Helpline: 0808 808 0000
Website: macmillan.org.uk
Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. It also has information for people who are worried about cancer risk in their family.

The UK Clinical Trials Gateway
Website: ukctg.nihr.ac.uk/clinical-trials

Provides information to help people make informed choices about taking part in clinical trials, including guidance on how trials work and details of current trials.

Further information

National breast screening guidelines for people at increased risk

England and Wales

National Institute for Health and Care Excellence (NICE) – Familial breast cancer guideline (CG164)
nice.org.uk/guidance/CG164

Scotland

Health Improvement Scotland – Familial breast cancer report
healthcareimprovementscotland.org

Northern Ireland

Health and Social Care (HSC) – Higher risk surveillance programme
cancerscreening.hscni.net/2081.html

Further reading

Understanding risk-reducing breast surgery
Macmillan Cancer Support
be.macmillan.org.uk

A beginner's guide to BRCA1 and BRCA2
The Royal Marsden NHS Foundation Trust (2016)
royalmarsden.nhs.uk

Cancer Genetic Clinical Protocols
Institute of Cancer Research (2015)
icr.ac.uk/protocols

Talking to children about genetic conditions
Nottingham University Hospitals NHS Trust (2015)
nuh.nhs.uk/patients-and-visitors/leaflets-and-resources

Fruit Fly Collective Cancer Cloud Toolkits
fruitflycollective.com/cancer-cloud-kits

These toolkits are designed to help talk to children of different age levels about cancer. Although aimed at children whose parents have been diagnosed, they might also be useful in talking about cancer in general.

Notes

4 ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone who knows what it's like or want to read more about breast cancer, here's how you can.

Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).

Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at **forum.breastcancercare.org.uk**

Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at **breastcancercare.org.uk**

See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you.
Visit **breastcancercare.org.uk/in-your-area**

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate by post

Please accept my donation of **£10/£20/my own choice of £** ☐

I enclose a cheque/PO/CAF voucher made payable to **Breast Cancer Care**

Donate online

You can give using a debit or credit card at **www.breastcancercare.org.uk/donate**

My details

Name _____

Address _____

_____

_____ Postcode _____

Email address _____

We might occasionally want to send you more information about our services and activities

☐ Please tick if you're happy to receive email from us
☐ Please tick if you don't want to receive post from us

We won't pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, Chester House, 1–3 Brixton Road, London SW9 6DE

About this booklet

Family history, genes and breast cancer was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.

For a full list of the sources we used to research it:

Phone 0345 092 0808
Email publications@breastcancercare.org.uk

You can order or download more copies from www.breastcancercare.org.uk/publications

For a large print, Braille, DAISY format or audio CD version:

Phone 0345 092 0808
Email publications@breastcancercare.org.uk

When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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