FAMILY HISTORY OF BREAST CANCER: MANAGING YOUR RISK

BREAST CANCER NOW The research & support charity

We're here

About this booklet

It's normal to feel anxious if you are at an increased risk of developing breast cancer.

You may have inherited an altered gene that increases your risk of developing breast cancer, such as BRCA1, BRCA2 or PALB2. Or you may have a higher risk because of your family history or because you've had breast cancer before.

This booklet explains the different options available to help you manage your risk.

It also covers topics such as how to talk with your family about being at increased risk and coping with worries about passing on an altered gene.

You cannot reduce your family history risk of breast cancer. If you'd like information about breast cancer risk and lifestyle factors like alcohol, smoking and physical activity, see our leaflet **Reducing your risk of breast cancer**.

Cancer risk and altered genes

Some people have a higher risk of developing breast cancer, and possibly other cancers, because they have inherited an altered gene.

Genetic testing is used to find out whether you have an inherited altered gene.

An altered gene may also be referred to as a gene change, fault, variant or mutation.

BRCA1, BRCA2, PALB2 and other altered genes

The most common inherited altered genes that increase breast cancer risk are called BRCA1 and BRCA2. BRCA stands for BReast CAncer.

BRCA1 and BRCA2 genes usually protect us from developing breast and ovarian cancer. However, inheriting an alteration in one of these genes increases the risk of developing cancer.

PALB2 is a gene that normally controls cell growth to help stop cancer developing (known as a tumour suppressor). Inheriting an alteration in this gene may increase your risk of developing breast cancer and some other types of cancer.

Other less common altered genes may also increase the risk of developing breast cancer and some other types of cancer.

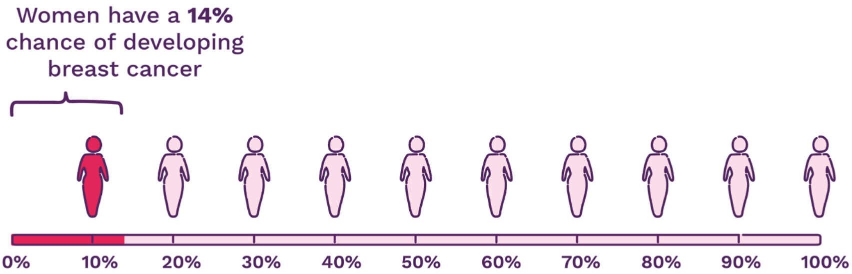
How altered genes affect cancer risk

A person with an altered gene is sometimes referred to as a gene carrier.

Being a gene carrier does not mean you will develop breast cancer, ovarian cancer or other related cancers.

However, you will have a higher risk than the general population.

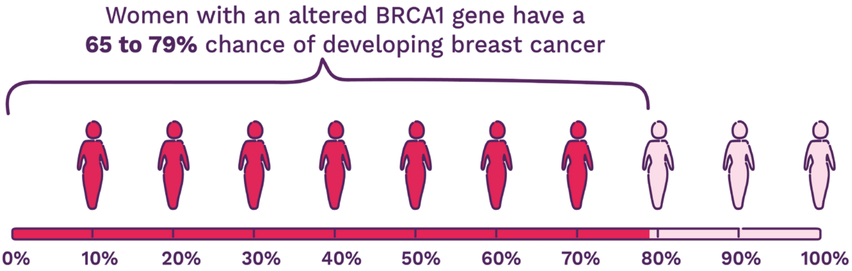
General population



During their lifetime:

- 1 in 7 women will develop breast cancer (this is a 14% risk)
- 2 in 100 women will develop ovarian cancer (this is a 2% risk)

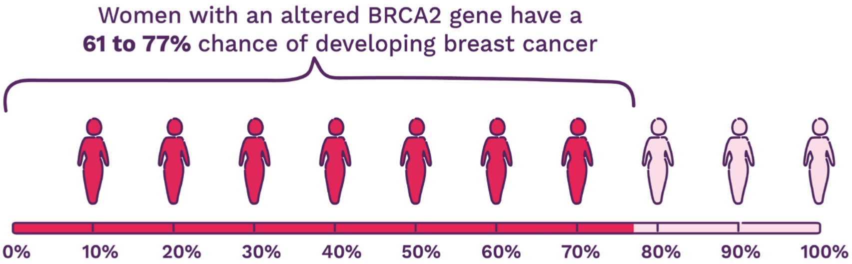
BRCA1



During their lifetime:

- Between 65 and 79 in 100 women with an altered BRCA1 gene will develop breast cancer (this is a 65 to 79% risk)
- Between 40 and 60 in 100 women with an altered BRCA1 gene will develop ovarian cancer (this is a 40 to 60% risk)
- 1 in 250 men with an altered BRCA1 gene will develop breast cancer (this is a 0.4% risk)
- Up to 20 in 100 men with an altered BRCA1 gene will develop prostate cancer (this is an up to 20% risk)

BRCA2



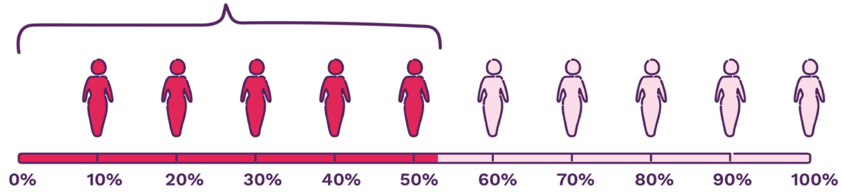
Women with an altered BRCA2 gene have a **61 to 77%** chance of developing breast cancer

During their lifetime:

- Between 61 and 77 in 100 women with an altered BRCA2 gene will develop breast cancer (this is a 61 to 77% risk)
- Between 10 and 30 in 100 women with an altered BRCA2 gene will develop ovarian cancer (this is a 10 to 30% risk)
- 4 in 100 men with an altered BRCA2 gene will develop breast cancer (this is a 4% risk)
- Up to 25 in 100 men with an altered BRCA2 gene will develop prostate cancer (this is an up to 25% risk)

Less common altered genes

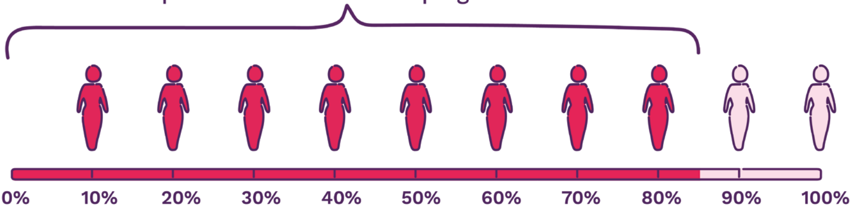
PALB2


Women with an altered PALB2 gene have a **17 to 53%** chance of developing breast cancer

In their lifetime:

- Between 17 and 53 in 100 women with an altered PALB2 gene will develop breast cancer (this is a 17 to 53% risk). This risk is also affected by how many people in your family have been diagnosed with breast cancer
- Less than 1 in 100 men with an altered PALB2 gene will develop breast cancer (this is a less than 1% risk)

TP53


Women with an altered TP53 gene have an up to **85%** risk of developing breast cancer

In their lifetime:

- Up to 85 in 100 women with an altered TP53 gene will develop breast cancer (this is an up to 85% risk)
- Up to 90 in 100 men and women with an altered TP53 gene will develop any type of cancer (this is an up to 90% risk)

Having an altered TP53 gene is also known as having Li-Fraumeni syndrome.

Moderate risk genes

Moderate risk is higher than the general population. However, it’s still more likely the person will not get breast cancer.

RAD51C or RAD51D

In their lifetime:

- Between 16 and 20 in 100 women with an altered RAD51C or RAD51D gene will develop breast cancer (this is a 16 to 20% risk)
- Between 7 and 10 in 100 women with an altered RAD51C or RAD51D gene will develop ovarian cancer (this is a 7 to 10% risk)

CHEK2

In their lifetime:

- Between 23 and 27 in 100 women with an altered CHEK2 gene will develop breast cancer (this is a 23 to 27% risk)

ATM

In their lifetime:

- Between 21 and 24 in 100 women with an altered ATM gene will develop breast cancer (this is a 21 to 24% risk)
- Between 5 and 10 in 100 men and women with an altered ATM gene will develop pancreatic cancer (this is a 5 to 10% risk)
- Between 2 and 3 in 100 women with an altered ATM gene will develop ovarian cancer (this is a 2 to 3% risk)

Other genes

Some genetic conditions caused by rare altered genes are also associated with an increased risk of breast cancer.

These include:

- Peutz-Jeghers syndrome (altered STK11 gene)
- Cowden syndrome/PTEN hamartoma tumour syndrome (altered PTEN gene)
- Hereditary diffuse gastric (stomach) cancer syndrome (altered E-cadherin (CDH1) gene)
- Neurofibromatosis type 1 (altered NF1 gene)

If one of these conditions runs in your family, your genetics team will talk to you about your risk of breast and other cancers.

Managing your risk

There are options available to help you manage your risk of breast cancer.

These include:

- Regular breast screening
- Risk-reducing medication
- Risk-reducing surgery

The following sections look at these options in more detail.

Genetic counselling

Before or after genetic testing, you'll be offered an appointment 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).

You may be offered an appointment where you'll meet different members of the multidisciplinary team (MDT) who specialise in breast and ovarian cancer that runs in families (hereditary). This may include a:

- Breast surgeon
- Plastic surgeon
- Women's reproductive health specialist (gynaecologist)
- Cancer specialist (oncologist)
- Nurse specialist
- Research nurse
- Clinical psychologist

They can help you understand more about your risk of developing breast cancer and other cancers and the options that may be available to help you manage your risk.

This may be done as one visit or over several visits.

It's completely natural to feel emotional or anxious talking about your risk and what it means for you and your relatives. Your genetics team will be experienced in talking through the issues involved and will be able to offer you support.

Breast screening for people at increased risk

If you’ve been assessed as being at moderate or high risk of developing breast cancer, depending on your age you’ll be offered regular breast screening to check for breast cancer. This is known as enhanced screening or surveillance.

The aim of screening is to detect breast cancer early, before there are any obvious signs or symptoms. The sooner breast cancer is diagnosed, the more successful treatment is likely to be.

Your family history clinic or genetics team will arrange your breast screening. Depending on your risk level, this will either be within the breast clinic or through referral to a local NHS breast screening programme.

What does breast screening involve?

Breast screening may include:

- A mammogram (breast x-ray)
- An MRI (magnetic resonance imaging) scan - uses magnetism and radio waves to produce a series of images of the inside of the body

The type of screening you’re offered will depend on:

- Your age
- Whether you’ve had breast cancer
- Your level of risk

As well as carrying out a family history risk assessment, some clinics may also do a more detailed cancer risk assessment. This looks at factors like your reproductive history and lifestyle to decide what screening you should have.

Younger women are not usually offered mammograms. This is because they’re more likely to have dense breast tissue, which can make mammogram images less clear.

If you're at high risk, the type of breast screening will also depend on your individual likelihood of having an inherited altered gene.

Breast screening recommendations

Your breast screening recommendations are based on national guidance:

- England and Wales follow the National Institute for Health and Care Excellence (NICE) – Familial breast cancer clinical 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

Information about breast screening

Your genetics team or family history nurse should give you information about the possible advantages and disadvantages of breast screening.

Whether you go for breast screening is your choice. It’s important you have the information you need to make your decision.

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

Why are men with an altered gene not offered breast screening or risk-reducing treatment?

Men are not offered breast screening or risk-reducing treatment, even if they have an inherited altered gene. This is because their overall risk of breast cancer is lower than women in the general population.

It’s still important to check your chest area regularly and know what looks and feels normal for you. You can find more information about the signs and symptoms of breast cancer in men on our website **breastcancernow.org**

NICE screening recommendations for women who have not 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	Consider 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	Consider 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	Consider a 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	Consider a 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

Table © National Institute for Health and Care Excellence

A small number of women at very high risk will be offered breast screening before the age of 30. Your genetics team will assess your individual risk and refer you to the NHS breast screening programme for regular MRI scans, if you're eligible.

National (population) breast screening programmes

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

If you're 70 or under, you'll be invited for a routine mammogram every 3 years. After the age of 70 you can still have a mammogram every 3 years, but you'll have to contact your local breast screening unit to get an appointment.

Is there screening for ovarian cancer?

There's currently no NHS screening programme for ovarian cancer. This is because there isn't an effective way of detecting ovarian cancer at an early stage. However, NICE guidance on familial ovarian cancer does state that screening can be "considered" for some people who have a known increased risk.

Ongoing research is looking at ways of screening for ovarian cancer. Your genetics team will talk to you about any trials that may be suitable for you.

See page 44 for a list of ovarian cancer organisations.

NICE screening recommendations for women who have had breast cancer

If you have had breast cancer, you'll have increased breast screening as part of your follow-up care. You will have this for 5 years or longer, depending on your age. The table on page 15 shows what you can expect after this 5-year period ends, depending on your risk level and age.

	Risk group			
Age (years)	**Moderate**	**High**	**High with an altered BRCA1 or BRCA2 gene**	**High with an altered TP53 gene**
20-29	None	None	None	Consider a yearly MRI
30-39	None	Yearly mammogram and yearly MR	Yearly mammogram and yearly MRI	Consider a yearly MRI
40-49	Yearly mammogram	Yearly mammogram and yearly MRI	Yearly mammogram and yearly MRI	Consider a yearly MRI
50-59	Consider a yearly mammogram	Yearly mammogram	Yearly mammogram	Consider a yearly MRI
60-69	Mammogram as part of the population screening programme	Yearly mammogram	Yearly mammogram	Consider a 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	None

Medication to reduce the risk of breast cancer

If you're at moderate or high risk, your genetics team should talk to you about the possibility of medication to reduce your risk of developing breast cancer.

Taking medication to reduce the risk of breast cancer is known as chemoprevention. This is not the same as chemotherapy, which is used to treat cancer.

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

Tamoxifen, anastrozole and raloxifene are available on the NHS for some women with an increased risk of developing breast cancer.

Research shows taking tamoxifen, anastrozole or raloxifene for 5 years can help reduce the risk of developing breast cancer in women at moderate or high risk due to their family history.

However, the evidence remains uncertain for people with an inherited altered gene. Current evidence suggests while risk-reducing medication may benefit people with an altered BRCA2 gene, the benefit for people with an altered BRCA1 gene is less clear.

At the moment, it's unclear whether risk-reducing medication benefits people with other altered genes. If you have questions about this, speak to your treatment team.

Who might be offered risk-reducing medication?

Your team may recommend you take tamoxifen for 5 years if:

- You're at high risk
- You're over 35 years old
- You have not been through the menopause (are pre-menopausal)

Tamoxifen may also be considered if you are pre-menopausal and at moderate risk.

If you're at high risk and post-menopausal (no longer having periods), your team may recommend anastrozole, tamoxifen or raloxifene for 5 years. This may also be considered if you are post-menopausal and at moderate risk.

If you have an altered gene, you may be offered risk-reducing medication, depending on the type of gene.

If you decide to take risk-reducing medication, you'll still be offered regular breast screening (see page 12).

You will not be offered medication if you have already had risk-reducing surgery (see page 20).

Deciding whether to have risk-reducing medication

Your genetics or breast team will talk to you about the possible benefits and side effects of medication.

They'll also tell you by how much the medication may reduce your chances of developing breast cancer. This will depend on your individual situation.

NICE has decision aids for both pre- and post-menopausal women who may be considering medication to reduce their risk of developing breast cancer (see page 42).

Side effects

Like all drugs, tamoxifen, anastrozole and raloxifene can cause side effects.

Tamoxifen and anastrozole commonly cause menopausal symptoms. These include:

- Hot flushes
- Night sweats
- Vaginal dryness
- Reduced sex drive
- Mood changes

These symptoms are often more intense than when the menopause happens naturally.

Raloxifene can cause side effects such as hot flushes and sweats, and flu-like symptoms.

Tamoxifen and raloxifene increase the risk of blood clots, such as a DVT (deep vein thrombosis). If you have a history of blood clots, you may not be able to take these drugs.

You should not take tamoxifen, anastrozole or raloxifene if you’re pregnant or planning to start a family as the drugs may be harmful to a developing baby.

Our booklets **Tamoxifen** and **Anastrozole (Arimidex)** have more information about these drugs and their possible side effects.

If you have had or are having treatment for breast cancer

If you've had breast cancer, because of your family history you'll have a slightly higher risk of developing a new primary breast cancer. This is different from the original breast cancer coming back (recurrence).

If your family history puts you at moderate or high risk, you may continue to have increased screening after your follow-up period ends (see page 15).

If you had genetic testing during your breast cancer treatment and were found to have an altered gene, your treatment team may discuss additional surgery to reduce your risk of developing a new breast cancer.

This may be offered at the same time as the surgery to treat your breast cancer. Having an altered BRCA gene may also affect the breast cancer treatments you're offered.

If you have genetic testing after finishing treatment for breast cancer, your genetics or treatment team may talk to you about your individual risk of recurrence when discussing options for managing your genetic risk.

Your treatment team will talk through your options and support you with your decision. Your genetics team may also arrange for you to see a women's reproductive health specialist (gynaecologist) or cancer specialist (oncologist) to discuss surgery to reduce the risk of ovarian cancer (see page 29).

Risk-reducing surgery

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 to 95%, but it cannot completely remove the risk. This is because it's not possible to remove all the breast tissue during a mastectomy.

Who might be offered risk-reducing surgery?

Your genetics or breast team should discuss the possibility of risk-reducing surgery if:

- You're at high risk of developing breast cancer
- You have an altered BRCA1, BRCA2, PALB2 or TP53 gene

Risk-reducing surgery may also be an option if you've had breast cancer and are at high risk of developing another breast cancer.

If you have an altered CHEK2 or ATM gene, surgery may be discussed with you depending on your family history.

What does risk-reducing surgery involve?

The 2 main types of risk-reducing surgery are:

- Bilateral mastectomy – removal of both breasts including the nipples
- Nipple-sparing mastectomy – removal of both breasts but leaving the nipples

Breast reconstruction

Breast reconstruction is surgery to create a new breast shape after a mastectomy.

The 3 main options are reconstruction using:

- Your own tissue taken from another part of your body – most commonly the lower part of your tummy (abdomen)
- A breast implant
- A combination of tissue and an implant

You may be offered more than 1 option. Your surgeon may explain why they think a particular breast reconstruction option is best for you.

Breast reconstruction is usually offered at the time of your risk-reducing surgery (immediate reconstruction). However, you can have reconstruction months or years after your risk-reducing surgery (delayed reconstruction).

You may be advised not to have a breast reconstruction or to consider a delayed reconstruction. This is usually because of other medical conditions or lifestyle factors that may increase the risk of complications during or after surgery.

Some women choose not to have reconstruction and prefer to wear an external breast form (prosthesis). Others choose not to have a reconstruction or use a prosthesis.

Comparing types of surgery

	Bilateral mastectomy without reconstruction	Bilateral mastectomy with reconstruction using an implant	Bilateral mastectomy with reconstruction using your own tissue	Bilateral mastectomy with reconstruction using a combination of your own tissue and an implant
Approximate length of surgery	2 to 3 hours	3 to 6 hours	4 to 8 hours	3 to 6 hours
Average hospital stay	Day surgery or possibly overnight stay	1 to 3 days	3 to 7 days	2 to 5 days
Approximate recovery time	4 to 6 weeks	6 to 8 weeks	6 to 12 weeks	6 to 12 weeks
Scars	Chest area only	Scar on breast only Possible circular scar around darker area of skin near the nipple (areola), on either side of the nipple or an inverted T-shaped scar under the breast	Scar on the breast and scar at the donor site (the area from which tissue was taken)	Scar on the breast and scar at the donor site (the area from which tissue was taken)
Things to consider	You may consider wearing an external breast prosthesis You may consider delayed breast reconstruction at a later date	May not be suitable for large drooping breasts May be suitable if no excess tissue is available for other types of reconstruction May need further surgery in future to change implants May not be suitable if you smoke	2 sites of recovery Need to have suitable amount of tissue from donor area to recreate breast size May not be suitable if you are diabetic, overweight or smoke May not be suitable if you are very slim	2 sites of recovery May need further surgery in future to change implants May not be suitable if you are diabetic, overweight or smoke

Nipple preservation

Your breast team may discuss the option of keeping your nipples. This is known as nipple preservation or a nipple-sparing mastectomy.

This operation involves removing all the breast tissue while leaving the nipples (nipple preservation).

Your breast team will discuss the risks and benefits of nipple preservation, including loss of sensation and function of the nipple, and let you know if it’s an option for you.

If nipple preservation is not an option, or you decide you don’t want to keep your nipples, your breast team will let you know what options are available after your risk-reducing surgery and breast reconstruction. These may include nipple reconstruction and nipple and areola tattooing (the areola is the darker area of skin around the nipple).

Some women use stick-on nipples (a nipple prosthesis). These can be custom made, sometimes by the hospital, or bought ready-made.

Some women choose not to have a nipple on their reconstructed breast.

You can find out more about nipple reconstruction and tattooing in our **Breast reconstruction** booklet.

Deciding whether to have risk-reducing surgery

Choosing whether to have risk-reducing surgery is a very personal decision. There’s no right or wrong choice and it’s important to do what feels right for you.

There are lots of factors to consider, including the type of surgery and the timing of your surgery.

It can help to talk to someone else who has made a similar decision. We can put you in touch with someone who has had risk-reducing surgery or the type of breast reconstruction you’re considering through our Someone Like Me service (see page 39).

For information about breast reconstruction, see our **Breast reconstruction** booklet. For information on breast prostheses, you can read our booklet **Breast prostheses, bras and clothes after surgery**.

You may also find it helpful to read Macmillan Cancer Support’s booklet “Understanding risk-reducing breast surgery” (see page 41).

Questions to ask your breast surgeon

It's important to make sure you have all the information you need before deciding about surgery. You may find it helpful to write down any questions and to take notes during your appointments. Taking someone with you can also help you remember what's discussed and give you extra support.

You may want to ask your surgeon:

- Which reconstruction options would be suitable for me and why?
- What are the benefits, limitations and risks of this type of surgery?
- Would I be able to keep my nipples?
- When would I be able to have my surgery done?
- How long would I have to stay in hospital?
- What is the recovery time for this operation?
- When would I be able to move about, walk, drive and exercise?
- How much pain is there likely to be?
- Would I need to wear a special bra after the operation?
- Can you show me where the scars would be on my body and how big they would be?
- Can you show me any photographs or images of your previous breast reconstructions?

Discussing your operation with your breast surgeon before deciding is important. They'll want to make sure you fully understand the process and, if you're having reconstruction, have realistic expectations of how your reconstructed breasts will look and feel.

Timing of your surgery

When to have risk-reducing surgery is your decision.

There are many things to consider, such as:

- Your age
- The age at which any family members were diagnosed with cancer
- How anxious you feel about your cancer risk
- Whether you’re considering having children and if breastfeeding is important to you
- If you have children already, their ages and possible childcare requirements while you recover
- Important life events such as your education or career
- Any existing health conditions you have

It’s important to take as much time as you need to make the right decision for you.

Changes to your body after risk-reducing surgery

Adjusting to how your breasts and body look after surgery can be difficult. Getting used to physical changes such as scars and loss of sensation can take time.

A breast reconstruction will not feel, look or move exactly the same as your natural breast.

There will be loss of sensation in the reconstructed breast and anywhere you have additional scars. Loss of sensation can be difficult to come to terms with and can take time to adjust to.

Talking to your breast team and asking for photographs of their previous work can help prepare you for what to expect after your operation.

Talking to someone who has had a similar experience can also be helpful. Our Someone Like Me service can arrange for a volunteer to talk to you by email or phone (see page 39).

Surgery to remove the ovaries and fallopian tubes

If you have an altered BRCA1 or BRCA2 gene, you're also at higher risk of developing ovarian cancer.

Ovarian cancer risk starts to increase significantly:

- From the age of 40 if you have an altered BRCA1 gene
- From the age of 45 if you have an altered BRCA2 gene

For pre-menopausal women who have altered BRCA1 or BRCA2 genes, having surgery to remove the ovaries and fallopian tubes has been shown to reduce the risk of ovarian cancer by up to 90 to 95%.

This type of surgery is known as a risk-reducing bilateral salpingo-oophorectomy (RRBSO).

For pre-menopausal women who have an altered BRCA2 gene, some studies suggest having an RRBSO may also reduce the risk of breast cancer.

Your genetics team can explain more about the risks and benefits of the surgery.

Deciding whether to have surgery

You'll see a gynaecologist who can advise you on when you may want to consider risk-reducing surgery to the ovaries and fallopian tubes.

Deciding whether or when to have an RRBSO is a very personal decision.

Things to consider include:

- Your age
- If you want to have children or add to your existing family
- Whether you have an altered BRCA1 or BRCA2 gene

The womb is not usually removed as part of an RRBSO. However, if you have any other benign (not cancer) womb conditions, your specialist team may also discuss removing the womb at the same time as your ovaries and fallopian tubes. This is known as a total hysterectomy.

PROTECTOR trial

There is ongoing research looking at performing RRBSO surgery over 2 operations. The fallopian tubes are removed first, and the ovaries are removed during a later operation. The benefit of this approach is that it delays the onset of menopausal symptoms.

This surgery is currently only offered in the UK as part of a clinical trial called the PROTECTOR trial. Your specialist team will let you know if this is offered at your hospital and if you're eligible for this trial.

Managing menopausal symptoms after surgery

If you're pre-menopausal, having an RRBSO will cause an early menopause. You'll stop having periods and you'll no longer be able to get pregnant.

Menopausal symptoms can sometimes be severe and have a significant impact on quality of life.

Symptoms include:

- Hot flushes and night sweats
- Vaginal dryness
- Changes to sex drive
- Weight gain
- Mood changes

If you're under 50 and have not had breast cancer, your specialist team will discuss the option of taking hormone replacement therapy (HRT) to help with menopausal symptoms.

If you have had breast cancer, taking HRT after an RRBSO is not usually recommended. However, if your symptoms are affecting your everyday life and you have tried non-hormonal ways to manage them, your specialist team may discuss the risks and benefits of taking HRT for your individual situation.

Our **Menopausal symptoms and breast cancer** booklet includes ways to help manage menopausal symptoms.

Bone health

An early menopause 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.

If your specialist team is concerned about your risk of osteoporosis, they may suggest a bone density scan (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 on bone health and osteoporosis on the Royal Osteoporosis Society website theros.org.uk

The pill and cancer risk

If you have a family history of breast cancer, you can usually still take the oral contraceptive pill.

However, if you're over 35 your GP will discuss this with you. This is because there is a very slight increased risk of breast cancer associated with taking the contraceptive pill. This risk increases with age.

If you have an altered BRCA1 gene, this will also be discussed with you. This is because the contraceptive pill can slightly increase your risk of breast cancer while reducing ovarian cancer risk.

The pill should not be taken just to reduce the risk of ovarian cancer. Your genetics team can discuss this with you.

HRT and cancer risk

If you're taking, or thinking about taking, HRT, it's important to discuss this with your GP, genetics team or a menopause specialist. They will consider your individual family history and risk level, as well as other factors like your age, to help decide if HRT would be suitable for you.

If your family history means you have a moderate or high risk of developing breast cancer, or you have an inherited altered gene such as BRCA1, BRCA2 or PALB2, you may be advised not to take HRT as it could increase your risk further.

Alternatives to HRT are available to help manage menopausal symptoms. Your genetics team or GP can provide information and advice about these.

You can find information about alternatives to HRT on the NHS website nhs.uk

You can also find out more about managing menopausal symptoms on our website **breastcancernow.org**

Talking to your family

If you have an altered gene or your family history puts you at an increased risk of breast cancer, other members of your family may also be at an increased risk.

Talking to your family means they can make choices about assessing and managing their own risk.

Talking to your family after a positive genetic result

If you have an altered gene, it's important to talk to your family about your result if you feel comfortable doing so.

First-degree relatives (such as brothers, sisters and children) will have a 50% chance of having an altered gene.

You may feel nervous to tell family members that they may be at increased risk of developing cancer. But your genetics team can support you. They should provide you with prepared letters you can give to your relatives. The letters will suggest they see their GP to discuss the possibility of a referral to a genetics centre.

You may feel it would be better to tell your relatives face to face, or you may prefer to phone or email them. This may feel particularly daunting if you have a difficult relationship with any of your family members, but your genetics team can offer advice and support.

How family members may react

People react to difficult information in different ways.

Some relatives may seem shocked, while others might ignore the result or find it difficult to talk about.

Others will be glad you told them about the possibility they may have an inherited altered gene and will want to have a genetic test themselves.

Remember no one is to blame for the genes they inherit or pass on. Telling family members they may have an altered gene will give them the option to discuss genetic testing and manage their own risk.

Talking to children

You may feel worried about talking to your children, grandchildren or other children in your family about your genetic testing results. You may also feel that by not telling your children, you are protecting them.

You know your children better than anyone and every family communicates differently. There are no set rules, and what you say will depend on factors like their age and personality.

Younger children may only need a small amount of information, whereas teenagers may want to know more and have lots of questions.

Being open and honest and talking to your children as soon as you feel ready can be helpful for everyone.

Children won’t be offered genetic testing for breast cancer risk until they are 18. Once your child is 18, they can decide whether they’d like to be tested.

Tips for talking to children

- Children and teenagers usually respond better to informal conversations, often while you're doing things together
- Give them small amounts of information at a time to help them understand at a pace that's right for them
- Ask them to say in their own words what they think is happening so you can see if they're confused about anything
- Reassure them they can ask you anything, and be ready to answer their questions
- Include positive messages about what can be done now you know you have an altered gene, that you have choices to reduce your risk and that having an altered gene does not mean you'll definitely develop cancer
- Let them know 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 happening so they feel involved, informed and able to ask any questions. You may need to repeat explanations, especially to younger children.

Worries about passing on an altered gene in the future

If you or your partner has an inherited altered gene, any children you have will have a 50% chance of inheriting the altered gene.

Your genetics team can talk through options you may want to consider when planning a family.

While some people look at ways to avoid passing on the gene – such as not having a biological family or considering adoption – many people choose to have children without any intervention.

It's completely natural to feel emotional when making a decision. It's important to take your time and do what feels best for you and your family.

Your genetics team can give you information and support. They can also refer you to specialist fertility services to talk through your options, if you're eligible.

Looking for an altered gene when you're pregnant

You may choose to get pregnant naturally and have pre-natal testing.

This involves taking a sample of tissue from the placenta or the fluid that surrounds the baby in the womb to see if your baby has inherited the altered gene.

You can then decide whether to continue with the pregnancy. If you do continue your pregnancy, having an altered gene does not mean your child will definitely develop cancer in the future.

This procedure may not be routinely offered. Your genetics team can talk to you about your options.

Support for you

If you're worried about passing on an altered gene or are finding these decisions difficult, we're here.

You can call our free helpline on **0808 800 6000** to speak to our specialist nurses, or talk to us online at **breastcancernow.org**

You can find more information about the support we offer on page 39.

Avoiding passing on an altered gene

Pre-implantation genetic diagnosis

You may want to talk to your genetics team about pre-implantation genetic diagnosis (PGD).

PGD involves going through an in-vitro fertilisation (IVF) cycle, where an egg is removed from the ovaries and fertilised with sperm in a laboratory.

The fertilised egg (embryo) can be checked for the known altered gene.

Only embryos that do not carry the altered breast cancer gene will be transferred to the womb.

PGD is not available to everyone on the NHS and is currently only offered in a few hospitals in the UK.

Genetic Alliance UK and Guy's and St Thomas' PGD centre (see page 42) have more information about pre-implantation genetic diagnosis.

Egg or sperm donation

Depending on which parent has the altered gene, you may want to consider using donated eggs or sperm to avoid passing on the altered gene.

The Human Fertilisation and Embryology Authority (see page 42) has information about egg and sperm donation.

Other considerations

Clinical trials

Clinical trials are being carried out to find out more about genes and breast cancer. You may be offered the chance to take part in one of these trials.

You can search for clinical trials on the Cancer Research UK website or Be Part of Research website (see page 40).

Insurance and genetic testing

If you've been tested to see if you have the same altered gene as a family member (predictive genetic test), you do not 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. If you have a significant family history of breast cancer, you may be charged a higher premium.

If you've been diagnosed with breast cancer, you'll have to disclose this. It may also be more difficult to get travel insurance.

Genetic Alliance UK and the Association of British Insurers (see pages 41 and 42) have information on insurance and genetic conditions on their websites.

Changes to the breast or chest area

Whatever your level of risk, and even after risk-reducing breast surgery, it’s important to look and feel for changes to your breast or chest area so you know what’s normal for you.

Contact your GP or breast team as soon as possible if you notice any changes that are unusual for you. If you’ve previously had breast cancer, you can contact your treatment team.

The sooner breast cancer is diagnosed, the more successful treatment is likely to be. You can find out more about changes to look and feel for in our booklet **Know your breasts: a guide to breast awareness and screening**.

For more information on the signs and symptoms to be aware of after breast cancer treatment, see our booklet **After breast cancer treatment: what now?**

Further support

If you have any concerns about breast cancer risk and your family history, you can speak to our specialist nurses through our free helpline on **0808 800 6000** or at **breastcancernow.org**

Our Someone Like Me service can also put you in touch with someone who has been through a similar experience to you. They’ll be on hand to answer your questions and offer support.

You can also speak to other people with a family history of breast cancer on our online forum **forum.breastcancernow.org**

Find out more about the support services we offer at **breastcancernow.org/support**

Useful organisations

Breast reconstruction

Flat Friends

flatfriends.org.uk

A UK charity dedicated to supporting people who have chosen not to have breast reconstruction, as well as those waiting for delayed reconstruction or still deciding.

Keeping abreast

keepingabreast.org.uk

Provides information, support, practical help and advice for those considering breast reconstruction, as well as real-life patient stories.

Restore: Breast Cancer Reconstruction Support

restore-bcr.co.uk

Information and support around breast reconstruction.

Clinical trials

Be Part of Research

bepartofresearch.nihr.ac.uk

Find out about health research that's taking place across the UK.

Cancer Research UK

cancerresearchuk.org/about-cancer/find-a-clinical-trial

You can search for clinical trials.

Family history, cancer risk and altered genes

BRCA Chat

brcachat.com

Charity that aims to help anyone navigating a BRCA (or other) gene alteration.

BRCA Link Northern Ireland

brcani.co.uk

Based in Northern Ireland, helping BRCA gene carriers access information and support.

FORCE (Facing Our Risk of Cancer Empowered)

facingourrisk.org

For individuals and families with an altered gene or at high risk of breast and ovarian cancer. Based in the USA but has a UK support network

Genetic Alliance UK

geneticalliance.org.uk

Works to improve the lives of patients and families affected by all types of genetic conditions.

Macmillan Cancer Support

macmillan.org.uk

Provides information about family history, genetics and cancer risk. Also publishes a booklet called “Understanding risk-reducing breast surgery”.

National Institute for Health and Care Excellence

nice.org.uk/guidance/cg164/resources

Decision aids for women considering drug treatment to reduce their risk of developing breast cancer.

Royal Marsden NHS Foundation Trust

royalmarsden.nhs.uk

Publishes a booklet called "A beginner's guide to BRCA1 and BRCA2", which is also available online.

Fertility issues

Guy's and St Thomas' Centre for PGD

guysandstthomas.nhs.uk/our-services/pgd

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

Human Fertilisation and Embryology Authority

hfea.gov.uk

Provides information about IVF and fertility treatments in the UK.

Insurance

Association of British Insurers (ABI)

abi.org.uk

Information on genetic testing and insurance.

Menopause and menopausal symptoms

Daisy Network

daisynetwork.org

Support group for women who experience premature menopause.

Menopause Matters

menopausematters.co.uk

Information about the menopause, menopausal symptoms and treatment options.

Women's Health Concern

womens-health-concern.org

The patient arm of the British Menopause Society (BMS).

Osteoporosis

Royal Osteoporosis Society

theros.org.uk

Dedicated to improving the prevention, diagnosis and treatment of osteoporosis

Ovarian cancer

Eve appeal

eveappeal.org.uk

Funds research and raises awareness of gynaecological cancers, including ovarian cancer, and has information on inherited risk.

Ovacome

ovacome.org.uk

Support and information for women affected by ovarian cancer, their families and friends.

Ovarian Cancer Action

ovarian.org.uk

Provides information and support to women with ovarian cancer.

NOTES

BREAST CANCER NOW The research & support charity

We're Breast Cancer Now, the research and support charity. However you're experiencing breast cancer, we're here.

Life-changing support

Whoever you are, and whatever your experience of breast cancer, our free services are here. Whether you're worried about breast cancer, dealing with a diagnosis, working out life with or beyond treatment – or someone you love is.

World-class research

We support over 290 of the brightest minds in breast cancer research. They're discovering how to prevent breast cancer, live well with the disease, and save lives. Every day, they get closer to the next breakthrough.

Change-making campaigns

We fight for the best possible treatment, services and care for everyone affected by breast cancer, alongside thousands of dedicated campaigners.

Could you help?

We don't get any government or NHS funding for our support services or health information. So, we rely on donations and gifts in wills to make our vital work happen. If you'd like to support us, go to **breastcancernow.org/give**

ABOUT THIS BOOKLET

Family history of breast cancer: managing your risk was written by Breast Cancer Now'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:
Email **health-info@breastcancernow.org**

You can order or download more copies from
breastcancernow.org/publications

We welcome your feedback on this publication:
health-info@breastcancernow.org

For a large print, Braille or audio CD version:
Email **health-info@breastcancernow.org**

Medical disclaimer
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BCN244 Edition 2, next planned review September 2027

BREAST CANCER NOW The research & support charity

We’re here

Information you can trust, support you can count on

Whatever breast cancer brings, we’re here for you.

Whether you’re looking for information about breast cancer or want to speak to someone who understands, you can rely on us.

Call **0808 800 6000** to talk things through with our helpline nurses.

Visit **breastcancernow.org** for reliable breast cancer information.

Breast Cancer Now

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The White Chapel Building
10 Whitechapel High Street
London E1 8QS

Trusted Information Creator
Patient Information Forum