Welcome to Breast Cancer Choices.

This website will help you think about whether you want to have a genetic test to find out if you have an altered BRCA gene (sounds like 'bracka').

- Use the 'next' arrows to work through the website.
- Hover over highlighted words (with a dotted line below) for a definition.
- You may find it helpful to look at this with friends or family.

This website is for you if:

- You have had a diagnosis of **breast cancer** under the age of 50
- And you have been offered **genetic testing**

What are my options?

- You can decide to have genetic testing
- You can decide not to have genetic testing
- You can wait to decide at a later date

BRCA test at a glance

What is a BRCA test?

- A BRCA test tells you whether you have an altered BRCA gene and is done by taking a sample of blood.
- There are three possible results:
  - An altered BRCA gene has been found
  - An altered BRCA gene has not been found
  - An alteration has been found but we are not sure what this means
- An altered BRCA gene increases your chances of developing cancer.
- Test results may take 4 - 12 weeks to come back.

What are my chances of having an altered BRCA gene?

- Having an altered BRCA gene is very uncommon.
- Only 3% (3 in 100) breast cancers are caused by altered BRCA genes.
- Age at diagnosis, family history of breast or ovarian cancer and type of breast cancer can increase your chances of having an altered gene.
- Altered BRCA genes are passed down from your mother or father.

What does it mean if an altered BRCA gene is found in me?

- Having an altered BRCA gene increases the chance of new cancers, such as breast and ovarian.
- If you have an altered BRCA gene, your close family (sons, daughters, brothers and sisters) have a 50% (1 in 2) chance of having the altered gene.

What can be done if I have an altered BRCA gene?

- If you have an altered BRCA gene, you can reduce your chances of future cancer by having risk-reducing surgery. You can also choose to have regular breast screening, make changes to your lifestyle or do nothing.

What does it mean if an altered BRCA gene is not found in me?

- There is less chance that your breast cancer happened because of an altered gene.
- Not all breast cancer genes have been found. If you have a strong family history of breast and/or ovarian cancer, you and your family may still have a higher chance of these cancers.
- There are other genes linked to breast cancer which may be tested as part of the BRCA test and your clinician will discuss this with you.

	My options		
	Have a genetic test	**Not have a genetic test**	**Wait to decide at a later date**
What does this option involve?	• A blood test. • 6-8 weeks wait for test results. • Find out whether you have an altered BRCA gene.	• No blood test. • No wait for test results	• Wait to decide whether or not to have test. • Ask GP for a referral to the genetics clinic at any time.
What are the possible benefits of this option?	• More accurate idea of your chance of future cancers. • Could help make decisions about options to reduce your chance of future cancers, such as surgery. • Find out if your family has a chance of having the altered gene. • If you tell your family you have an altered gene, they can decide about having a test. • Some women prefer to have all tests done during their treatment.	• May be less stressful not knowing results. • If you have a high chance of future cancers, may still be able to take steps to reduce your chance of getting another cancer. • Do not have to tell family members about test. • If you change your mind later on you can still get tested.	• Can think about whether or not to have test when ready. • Can discuss test with family when ready
What are the possible disadvantages of this option?	• May feel worried before or after results. • If you have an altered gene, you may worry about telling family members that they might have an altered gene. • May not find the answers you were looking for. • Not all breast cancer genes have been found, so a negative result cannot exclude a genetic risk. • Results can sometimes be uncertain.	• May feel more worried not knowing results. • Will not find out whether you have an altered gene and your family members may not be able to have a genetic test.	• Having a test at a later date may make you feel worried. Some women prefer to have all tests done during their treatment.

Support

You may feel that you need support to make your decision, whilst you are waiting for the result or after you have had your results. You may also want more information or to talk to someone. There are a number of charities and organisations which can help with this. If you have medical questions, you may also want to write these down and ask your healthcare professionals.

National Hereditary Breast & Ovarian Cancer Helpline

This is a charity set up to support people concerned about their family history of breast and ovarian cancer. They have a helpline which can provide information. They also have a database of women happy to share their own experiences with others.

 01629 813000 (available 24 hours a day)

Web: Click here

Younger Breast Cancer Network UK

This is a group for young women in the UK/Ireland who have been diagnosed with breast cancer at a younger age. There is a private chat group on Facebook which you can join by messaging the administrators. To find this, you can search for 'younger breast cancer network' on Facebook.

Web: Click here

BRCA Umbrella

This is a charity set up for people with altered BRCA genes by people with altered BRCA genes. They have an online forum and run events.

Web: Click here

Breast Cancer Care Helpline

Breast Cancer Care have a helpline which can be called free. You can call this if you have a query, want to talk things through or want to find more support.

 0808 800 6000

Opening hours:

- Monday - Friday - 9am - 5pm
- Late opening Wednesday - 9am - 7pm
- Saturday - 9am - 1pm

Breast Cancer Now Information

Breast Cancer Now have information on breast cancer and genetics.

Web: Click here

Macmillan Information and Support Line

Web: Click here

They also have a support line which can be called between 9am-8pm and is free to call from most mobile networks:

0808 808 00 00

Shine Cancer Support

Shine is a support group for people in their 20s, 30s and 40s with cancer. They have online and local support networks.

Web: Click here

Cancer Research UK

Cancer Research UK have an online chat or nurses you can call:

Web: Click here

0808 800 4040 Mon - Fri 9am - 5pm

Research Trials

There are a number of research trials looking into breast cancer genetics. You can find out more about different research trials in the links below. Using search terms such as 'BRCA', 'breast cancer genetic' and 'breast cancer family history' helps to narrow the search.

If you would like to take part in a research trial, you would need to discuss this with your healthcare team. Trials often have strict eligibility criteria and are sometimes only open in certain areas of the country.

Cancer Research website

You can search for 'breast cancer' research trials that are currently recruiting participants.

Web: http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial

UK Clinical Trials Gateway

Web: http://www.ukctg.nihr.ac.uk

Further reading

This list includes some of the most recent research articles about altered genes related to breast cancer.
If you would like to read any of them, just click on the website link.

1. This article is about how the Breast Cancer Choices website was developed:
Grimmett, C., Brooks, C., Recio-Saucedo, A., Armstrong, A., Cutress, R., Evans, D. G., Copson, E., Turner, L., Meiser, B., Wakefield, C. E., Eccles, D., & Foster, C. (2019). Development of breast cancer choices: a decision support tool for young women with breast cancer deciding whether to have genetic testing for BRCA1/2 mutations. Supportive Care in Cancer, 27(1), 297-309. https://doi.org/10.1007/s00520-018-4307-x

2. This is a very new article about the risk of cancer with a BRCA1 or BRCA2 alteration:
Li et al (2022) Cancer Risks Associated with BRCA1 and BRCA2 Pathogenic Variants. Journal of Clinical Oncology.

3. This article is about the risks of prostate cancer for men with the BRCA 1 or BRCA2 alteration: Nyberg T, et al … Antoniou AC. (2020) Prostate Cancer Risks for Male BRCA1 and BRCA2 Mutation Carriers: A Prospective Cohort Study Eur Urol. PMID 31495749

4. This article is about risk reducing surgery:
BCFR, BCFR, Mavaddat, N., et al (2020). Risk-reducing salpingo-oophorectomy, natural menopause, and breast cancer risk: an international prospective cohort of BRCA1 and BRCA2 mutation carriers. Breast Cancer Research, 22(1), [8]. https://doi.org/10.1186/s13058-020-1247-4

5. This article is about the risks of cancer with a differen nt gene alteration in another breast cancer risk gene called PALB2:
Yang X, et al … Antoniou AC, Tischkowitz M. (2020) Cancer Risks Associated wWith Germline PALB2 Pathogenic Variants: An International Study of 524 Families J Clin Oncol. PMID 31841383
And this is a leaflet about PALB2: https://www.ukcgg.org/media/12008/information-for-palb2-carriers-and-their-families-v1-nov2021-1.pdf

6. This article looks at the future health of young women with breast cancer who have the BRCA variant:
https://doi.org/10.1016/S1470-2045(17)30891-4

Meet The Team

This decision aid has been made with the help of young women with breast cancer, healthcare professionals (including surgeons, geneticists, oncologists and nurses), researchers and experts in genetics and developing patient resources.

Special thanks to all the young women who have taken part in the research.

Our research team:

- Prof Claire Foster (main investigator)
- Ass. Prof Chloe Grimmett (researcher)
- Prof Ramsey Cutress (consultant surgeon)
- Dr Ellen Copson (consultant oncologist)
- Prof Diana Eccles (main investigator)
- Dr Kate Morton (researcher)
- Dr Bettina Meiser (researcher)
- Dr Charlotte Brooks (researcher)
- Dr Munaza Ahmed (consultant in clinical genetics)
- Dr Alex Recio-Saucedo (researcher)
- Prof Irma Verdonck (researcher)
- Dr Gillian Crawford (consultant genetic counsellor)
- Dr Saskia Sanderson (researcher)
- Lesley Turner (patient representative)
- Jackie Harris (clinical nurse specialist, breast cancer care)
- Prof Gareth Evans (consultant in medical genetics)
- Dr Anne Armstrong (consultant oncologist)
- Prof Claire Wakefield (researcher)
- Dr Rebecca Foster (research fellow)

Thinking through your decision

Pros and cons of having a genetic test

The exercise below is to help you think about what is important to you when making a decision about genetic testing. Move the bars below along to which option feels most relevant for you. Press 'next' at the end and you will get a summary of your answers. There is a 'print' button if you would like to print a copy of your summary.

Reasons to *have* a test	Reasons to *not have* a test
It is important for me to know whether or not I have an altered BRCA gene	**It is not important for me to know whether or not I have an altered BRCA gene**
I would prefer to know about my future chance of new cancers	**I would prefer not to know about my future chance of new cancers**
I would want to make decisions about options which could reduce my risk if I had an altered gene	**I would not want to make decisions about options available if I had an altered gene**
If a genetic alteration is found, I could tell my family members about the test results	**I would not want to tell my family members about the test results**

If something else is on your mind we have left some space for you to add your thoughts. You can leave this blank if you wish.

How do you feel about having a genetic test for breast cancer?

Think about the information you have read and your answers to the questions above. How are you feeling about having this genetic test?

Move the bar along.

I want the test	I am unsure about whether I want to have the test	I do not want the test

What next?

- You may now be **sure** about whether or not to have a BRCA test. You can discuss this with the genetics service or the healthcare professional who discussed genetic testing with you.
- You may be **unsure** about whether you want the BRCA test and want further information or advice.
- You can print the compare your options table and your decision exercise. This may help to discuss your thoughts with family/friends or a health care professional.
- You could write down any questions you still have about genetic testing. These can be shared with family/friends or your health care professionals.

Click here for support

You may feel that you need support to make your decision, whilst you are waiting for the result or after you have had your results.

How do breast cancer genes work?

Main points

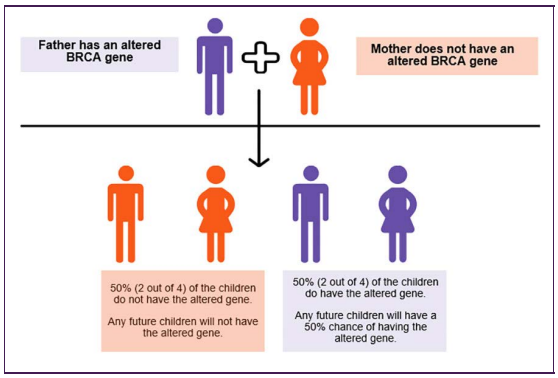
- When working normally, BRCA genes protect us from breast and ovarian cancer. When they are altered, they increase our chances of getting cancer.
- Altered BRCA genes are passed down from our parents.
- If you have an altered BRCA gene, your close family (sons, daughters, brothers and sisters) have a 50% (1 in 2 chance) of having the altered gene.

What are breast cancer genes?

- Everyone has BRCA1 and BRCA2 genes. When they are working normally, they help to protect us from cancer. They are called **cancer protection genes**. They protect us from cancer by helping to repair damage or destroying damaged **cells** in our body.
- Genes are passed down from our parents.
- If someone has an altered BRCA gene, they have a higher chance of getting cancer. This does not mean that they will definitely get cancer.
- Even if you have a strong family history of breast cancer, this does not mean you will definitely have an altered BRCA gene.
- When someone has a strong family history of breast cancer but an altered BRCA gene is not found, the cancers may still be linked to genetics. Experts think there are genes which are linked to families that have not yet been found. Genetic tests will not always give you a clear answer about what is causing the increased chances of breast cancer within your family.

How are altered BRCA genes passed down through families?

- Altered BRCA genes can be passed down from your Mother or Father.
- If a mother or father has an altered BRCA gene, any children (boys and girls) have a 50% (1 in 2) chance of having the altered gene.
- The diagram below shows how altered BRCA genes are passed down in families. Click to enlarge



- If you have an altered BRCA gene, your sisters and brothers and children will also have a 50% (1 in 2) chance of having the gene. If you have two children, one or both or none of them may have the altered gene.
- If an altered BRCA gene was passed down from your Mother, her brothers and sisters would have a 50% (1 in 2) chance of having the gene. If an altered BRCA gene was passed down from your Father, his brothers and sisters would have a 50% (1 in 2) chance of having the gene.
- If you have an altered BRCA gene, where possible, your Mother and Father should have genetic testing to see which side of the family the altered gene was passed down from. This will help to find out the chance of cousins, aunts and uncles having the altered gene.
- Altered BRCA genes do not skip generations but not all individuals who have altered BRCA genes develop cancer. For instance, men have a low risk of getting breast cancer. This is because they have small amounts of breast tissue and low levels of female sex hormones. This can make it look like the altered BRCA gene has skipped a generation.
- It is possible that you could be the first person in your family to have the altered BRCA gene, but this is extremely rare.

What are my chances of having an altered BRCA gene?

Main points

- About 3% (3 in 100) breast cancers are caused by altered BRCA genes.
- Having a strong family history of breast cancer does not mean you will definitely have an altered BRCA gene. Even when an altered BRCA gene is not found, families with a strong family history of breast cancer may still have a **higher chance** of breast cancer.
- Having had cancer yourself and a strong family history of breast cancer (particularly at a young age) makes it more likely that you will have an altered BRCA gene.

How likely is it that I have an altered BRCA gene?

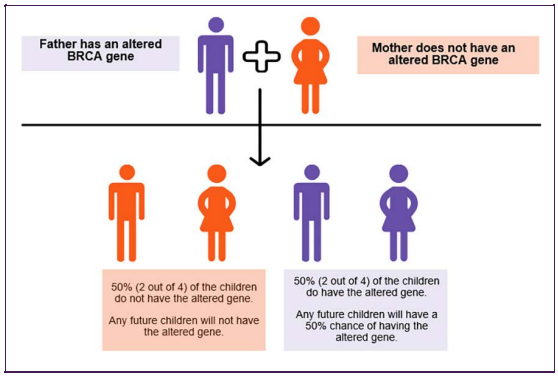
- Around 3% of breast cancers are caused by altered BRCA genes. This means that about 3 out of 100 people with breast cancer will have an altered BRCA gene. Even if you have a **strong family history** of breast cancer, this does not mean you definitely have an altered gene. A strong family history can also happen just by chance or because of genetics which are not linked to known altered genes. Breast cancer can also happen **just by chance**.

What increases my chances of having an altered BRCA gene?

- Breast cancer diagnosed under the age of 50
- Having breast cancer in both breasts
- Relatives who have had breast cancer at a young age (under 50)
- Men in the family who have had breast cancer
- Family or personal history of **ovarian cancer**
- Diagnosis of **triple negative breast cancer**
- The chances of having an altered gene are higher in some ethnic groups, for example **Ashkenazi Jew** and Polish

You may wish to talk to your healthcare professional about your personal chance of having an altered gene.

Click here for how genes are passed down.



Click to enlarge

Who can have BRCA testing?

- People with a higher than usual chance of having an altered gene can currently be tested on the NHS.
- A genetics clinic can give you an idea about your personal chance of having an altered BRCA gene by looking at your age, your family history and your type of breast cancer.

What does the test involve?

Main points

- A BRCA genetics test involves having a blood test.
- You will usually wait about 6-8 weeks for the results.
- There are three different possible results. You may have an altered gene, not have an altered gene or have an uncertain result.
- There are other genes linked to breast cancer which are not tested as part of the BRCA test.

What happens at the genetics clinic?

Some women are offered a genetic test by their **oncologist** and do not attend a genetics clinic. If you have been referred to the genetics clinic, you will be invited for an appointment. During this appointment, you will see a **genetics specialist** or genetics counsellor who will:

- Discuss your family history with you. It is helpful to bring along as much information as possible about your family history. This includes details about any cancers your male and female relatives have had. Some women without a strong family history of cancer may still be offered a genetic test. This would depend on their cancer diagnosis and age at diagnosis.
- Work out whether you could have a genetic test and whether this could be helpful for you.
- Discuss your chances of having an altered gene.
- Help you decide whether or not to have genetic testing. You do not have to decide right away.

How is the test done?

- The test involves taking a sample of your blood. This sample is tested to find out whether you have an altered BRCA gene.
- This sample will be tested in a genetics laboratory.

How long would I have to wait for my test result?

- It can take about 6-8 weeks for genetic test results to come back. This is because searching for an altered gene is like trying to find a single spelling mistake in a large book. The time that it takes may depend on your personal situation.
- You can ask your genetics clinic how long it may take for your results to come back.

How will I get my results?

You may get your results by letter, phone or face-to-face. Your genetics clinic may give you a choice about this. If an altered gene is found, you would be offered another genetics clinic appointment to discuss this further.

What are the different possible results?

There are three possible test results:

1. Negative result (an altered gene was not found)

- This means an altered BRCA1 or BRCA2 gene was not found.
- Your family history may strongly suggest a genetic link. There may be options to look for other altered genes.

2. Positive result (an altered gene was found)

- This means you have an altered BRCA gene and:
  - You may have a higher chance of getting a second breast cancer or ovarian cancer.
  - There are ways to reduce your chance of future cancers. You can find out more about your options in the 'What results mean for me' section.
  - Other **blood relatives** can have a genetic test to find out if they have the same altered gene.

3. Variant of uncertain significance

- This means a change was found in the BRCA1 or BRCA2 gene but it is not known if this change is linked to cancer.
- Research is looking into these unknown alterations. If new information about these changes is found more tests may be done.

What about other genes?

- BRCA1 and BRCA2 were the first breast cancer genes to be found and are the most commonly tested.
- There are some other altered genes which have also been found to increase a woman's chance of breast cancer. Examples of these include:
  - TP53, PALB2 and PTEN

  These altered genes are much less common than BRCA1 and BRCA2. They are not included in routine BRCA testing unless the genetics clinic thinks they should be looked at based on your family history.
- Other genetic alterations have been found that can slightly increase a woman's chance of breast cancer. These changes are common but are not thought to be useful for assessing risk or deciding about cancer treatment.
- BRCA testing is different from the **Oncotype DX test**.
- If you are concerned about other altered genes, you should discuss this with your **genetics specialist**.

Can I have genetic testing with a private company?

You can have genetic testing privately. Women may choose to do this if they are not able to have a genetic test within the NHS. This may be because they do not have a strong family history. If you are thinking of having a test privately, you will need to think about the following:

- If you do not have a strong family history of cancer, there is a low chance that you will have an altered gene. There may be a higher chance of you having a negative or **variant of uncertain significance** result.
- The tests can be expensive.
- If you decide to look into private testing you may want to ask:
  - The price of the test
  - Which genes they test for
  - If counselling is available to help you decide if you need or want to have a test
  - How you will receive the results

What would the results mean for me?

Main points

- Having an altered BRCA gene means that there is a higher chance of future breast and ovarian cancer.
- If you have an altered BRCA gene you can choose to do nothing, or consider risk-reducing surgery, regular screening and make healthy lifestyle choices.
- Some people may find it stressful to have genetic testing.

Will taking the test have any impact on my breast cancer treatment?

- Genetic tests sometimes help to make decisions about surgery, chemotherapy, targeted treatments and research trials. Some women have chemotherapy before surgery and may have a genetic test while they are waiting for their surgery.
- There are research studies that are looking at treatments which are targeted at treating or preventing cancers linked to altered BRCA genes. For instance, **PARP inhibitors** are a type of medication which is being tested to treat BRCA-related cancers. You may be offered the chance of taking part in research studies shortly after diagnosis. If you are interested in research studies in the area, see the page on research trials at the bottom.

What would having an altered gene mean for my future chances of cancer?

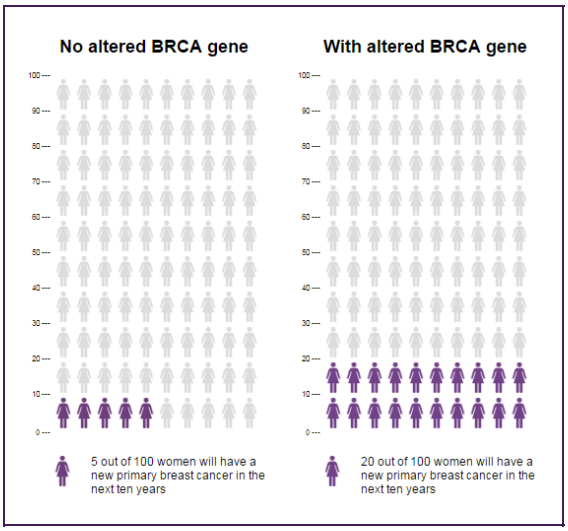
Having an altered BRCA gene means that you have an increased chance of developing future cancers. This includes new breast cancers and ovarian cancer. The next section includes more detailed information about this.

Click here if you would like to read more about this, including figures.

Breast cancer

- An altered BRCA gene means the chance of developing a **new primary breast cancer** is higher.

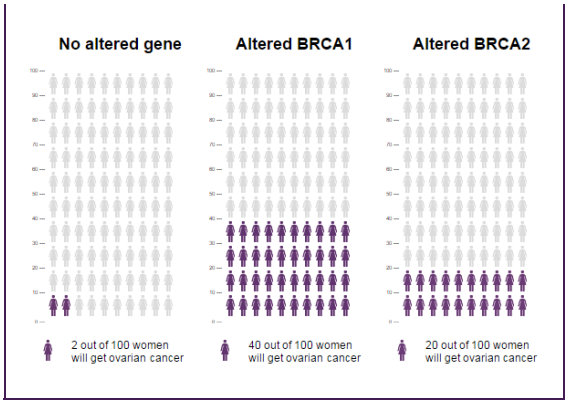
If I've had breast cancer, what are my chances of having a new primary breast cancer in the next ten years? Click to enlarge



- During the 10 years after diagnosis, women who have altered BRCA genes have about a 20% chance of having a new primary breast cancer on the opposite side. During the 10 years after diagnosis about 5% of breast cancer survivors who do not have an altered BRCA gene have a new primary breast cancer on the opposite side.
- Scientists do not have the information to estimate lifetime risk.

Ovarian cancer

The chance of having ovarian cancer over lifetime: Click to enlarge



- Around 2 in 100 women in the general population will get ovarian cancer at some point in their life.
- Around 40 out of 100 women with BRCA1 will get ovarian cancer at some point in their life.
- Around 20 out of 100 women with BRCA2 will get ovarian cancer at some point in their life.

Other cancers

Having an altered BRCA gene can also increase your chances of other cancers, such as pancreatic and skin (melanoma). These cancers are still very uncommon.

What are my options if I have a positive result for an altered gene?

If you have an altered gene, you will be given options of what to do next. There are several things you can do to help reduce your chances of future cancers. You do not need to make a decision straight away. You would discuss your options with your clinical team and may consider:

Taking no action

- You can choose to take no action. You will still be offered regular **mammogram**s.

Having increased screening

- When women have had a breast cancer diagnosis, they are offered regular **mammogram**s. However, if you have an altered BRCA gene, you may be offered increased screening, for instance **MRI** scans.

Making healthy lifestyle choices

- Eating a healthy diet, exercising, not smoking, drinking little or no alcohol and being a healthy weight can help to reduce the chances of getting cancer.

Having a **risk-reducing mastectomy** (surgical removal of both breasts)

- A **risk-reducing mastectomy** can help to reduce your chance of a **new primary breast cancer** by 90-95%. This surgery does not reduce the chance of your current cancer returning somewhere else or in breast tissue.
- You may consider having a reconstruction after a risk-reducing mastectomy. Risk-reducing surgery can be done with or without **breast reconstruction**.
- You do not need to decide about this surgery straight away.

Macmillan provides further information about risk-reducing breast surgery: click here.

Having a risk-reducing **salpingo-oophorectomy** (surgical removal of ovaries and fallopian tubes)

- A **salpingo-oophorectomy** involves removing the ovaries and fallopian tubes. This surgery reduces the chances of both breast and ovarian cancers. Some tissue in this area (the peritoneum) cannot be taken out. There is still a small chance cancer which behaves like ovarian cancer can happen in this tissue.
- The risk of developing ovarian cancer could be reduced by 80-90%. Out of 100 women with an altered BRCA1 gene, around 40 will develop ovarian cancer at some point in their life. If those women had an oophorectomy, around 5 would develop ovarian cancer at some point in their life.
- Having this surgery will mean that you are no longer able to have your own children. It will also cause you to have an early **menopause**. Some women have fertility treatments before chemotherapy and choose to wait to have the surgery after having had children. The chances of getting ovarian cancer is low at younger ages.
- You do not need to decide about this surgery straight away.

Take medication

- Some women take **hormone therapies** for their breast cancer. This can also reduce the chance of getting a new breast cancer.

What are my options if I choose not to have a genetic test?

- If you choose not to have a genetic test, you may still be able to have **risk-reducing surgery** and increased screening. This will depend on your personal situation and if you have a high chance of getting more cancers. NHS guidance click here suggests that women who have had breast cancer should have screening for 5 years.
- Women who remain at a high risk of future cancer or have a high chance of having an altered gene may be able to have screening after this. You would need to talk to your healthcare professionals about this.
- You would need to talk to your healthcare professionals about your options.

How might having a genetic test make me feel?

- Some women may find waiting for BRCA test results makes them feel worried or stressed. Finding out the results and the implications of these results may also be stressful for some people.
- Other people may not be too worried or may find knowing the results is less stressful than not knowing.
- You don't have to decide about genetic testing right away.
- There is a link to available support at the bottom of the page. You may find it helpful to talk to people who have gone through this or to a healthcare professional.

Will taking the test have an impact on my life insurance?

- Insurance companies may increase your insurance premium because of your personal or family history of cancer. Since you have had a cancer diagnosis, this may increase your premium. You need to disclose your diagnosis and treatment for breast cancer when starting or renewing insurance policies. It is very unlikely that genetic testing results would affect your personal insurance situation more than your cancer diagnosis.
- If your test result shows that you do not have an altered gene, the insurance company may be able to take this into account.

What would the results mean for my family or future family?

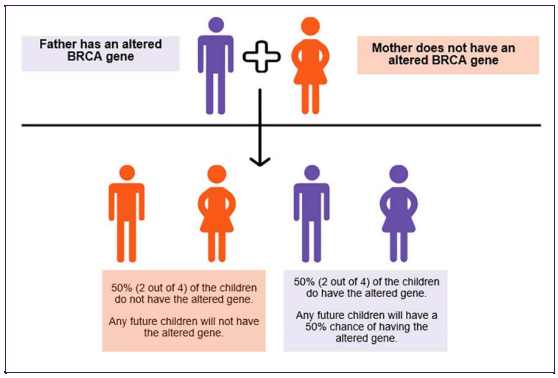
Main points

- If you have an altered BRCA gene your family members can choose to get tested. Only adults can be tested.
- If your family members are found to have the altered BRCA gene they can choose to do nothing, have increased screening, take medication which helps to reduce the chances of cancer, have risk-reducing surgery and making healthy lifestyle choices.
- If you have an altered BRCA gene, you will be advised to talk to your family members about this. The genetics clinic can support you with this.

If I have an altered BRCA gene, how likely is it that my family has it?

- If you have an altered BRCA gene, your close blood relatives would have a 50% chance (1 in 2) chance of having it. This includes any children, brothers and sisters and parents. If you have two children, this does not mean one child will definitely have the genetic alteration – it is possible that neither child has it or both of them could have it.

Click here for how genes are passed down.



If I have an altered BRCA gene, what does this mean for my family's future chances of cancer?

If you have an altered BRCA gene it is possible that other family members also have the gene. Children, brothers and sisters and parents all have a 50% (1 in 2 chance) of having the altered gene. How genes are passed down diagram: Click here

If family members do have the altered BRCA gene this increases their chances of getting certain cancers.

Click here if you would like more information on your family's future chances of cancer if they have the altered BRCA gene.

The women in my family

Type of cancer	A woman with an altered BRCA 1 gene	A woman with an altered BRCA 2 gene
Breast cancer	60-90% chance of getting breast cancer during their life	45-85% chance of getting breast cancer during their life
Ovarian cancer	40-60% chance of getting ovarian cancer during their life	10-30% chance of getting ovarian cancer during their life

The men in my family

Type of cancer	A man with an altered BRCA 1 gene	A man with an altered BRCA 2 gene
Breast cancer	0.1-1% chance of getting breast cancer during their life	5-10% chance of getting breast cancer during their life
Prostate cancer	Chance of getting prostate cancer is similar or slightly higher than the risk for the general population	20-25% chance of getting prostate cancer during their life

What options are available for the women in my family if I have an altered BRCA gene?

- Your family members can choose to get tested from the age of 18. Some people choose to wait until they are nearer 30 - the age when screening starts for **gene carriers**. If they are found to have the altered gene, they can choose to:
  - Have breast cancer screening (a yearly **MRI** and possibly yearly **mammogram**s) from the age of 30.
  - Take **chemoprevention** drugs.
  - Have risk-reducing surgery – this may include a **double mastectomy** or ovary and fallopian tubes removal (**salpingo-oophorectomy**). Surgery does not have to be done straight after test results. Timing is personal and should be discussed with healthcare professionals.
  - Make healthy lifestyle choices such as eating a healthy diet, exercising and not smoking.
- Your family members may choose not to get tested. They may still be able to have the options above. They would need to discuss this with a healthcare professional.

What options are available for the men in my family if I have an altered BRCA gene?

- Close male relatives (over the age of 18) can ask their GP for a referral to their local genetics service. They will be offered genetic testing.
- There is a small chance of men getting breast cancer. Normally men are advised to practice breast awareness (routinely checking breast tissue). They can also reduce their chances of cancer by making healthy lifestyle choices, such as eating a healthy diet, exercising and not smoking.
- Men with an altered BRCA gene have a higher chance of getting **prostate cancer**.
- They may be able to enter a research trial which is looking at prostate cancer screening. You can find where to search for research trials using the link at the bottom of the page.

Can children have a genetic test?

- Children (under the age of 18) are not offered genetic testing for altered BRCA genes. This is because children have a very low chance of getting breast or ovarian cancer.

If I do not have an altered BRCA gene, what options are available for my family?

- If you do not have an altered BRCA gene your family members will not need to have a BRCA test. This may be different if they have cancer on the other side of their family.

If they are worried about their chance of getting cancer, they would need to discuss this with their doctor.

How can I discuss genetic testing with my family?

- You may wish to discuss genetic testing with your family before having a test. Some women choose not to discuss the genetic test until after their results.
- If you have a positive result (a result showing you have an altered gene) the genetics clinic can give you a letter to give to your family members.

What options are available for planning a family if I have an altered BRCA gene?

If you are planning a family and have an altered BRCA gene, you have several options:

- You may choose to try to have your children without any treatments. Each of your children will have a 50% (1 in 2) chance of having the altered BRCA gene.
- You may look into adoption.
- You may choose to use **donor eggs**.
- You may consider **prenatal testing**.
- You may be able to have pre-implantation genetic diagnosis – this is a technique used with **IVF (in vitro fertilisation)** to select **embryos** which do not have the altered gene. To find out more about this click here.

Other people's stories

Main points

These stories are provided by women who have made a decision about genetic testing. They agreed to share their experience with you. The stories may be helpful as you make this decision yourself. It is important to remember that people's individual views and experiences will be different.

Katie decided to wait until after her treatment is finished to decide about genetic testing

“I think that perhaps if had tried to make a decision about whether I wanted to know if I had an altered gene or not at the same time as my diagnosis, it would have been a little bit too much. It was a bombshell to find out that I had cancer in the first place. I had a manic couple of months after first being diagnosed - there's just so much going on. But since then, I've had time to think about things like genetic testing. I have thought about if a genetic test result did come back positive, what would I do about it? When the time comes and I do have the test done, I'll know what I want to do. I've had time to think about it.”

Katie, age 28 when diagnosed.

Laura decided to have genetic testing and had a negative result (an altered gene was not found)

“I decided to have the BRCA test mainly because of my older sister, I've got a daughter who's six and I have a younger sister who's eight years younger than me. It was more to protect them by finding out if I carry the altered gene. Also, I wanted to have the test to help make a decision about whether or not to have another mastectomy or any more surgery. In my personal situation, it was just another test that I was having done, amongst all the other things that I'd been having during my treatment.”

Laura, age 37 when diagnosed

Sarah decided to have genetic testing and had a positive result (an altered gene was found)

“When I was diagnosed with breast cancer, genetic testing was offered to me quite early on because of my age, my mum had breast cancer and I had **triple negative breast cancer**. It was never really in question whether or not I was going to have the test. If the test had been offered to me ten years ago, I think I would have taken it then because I would rather know either way. For me, the unknown is more difficult so I think it was just something I needed to know.”

Sarah, age 34 when diagnosed

Amy decided to have genetic testing and had an uncertain result (a variant of uncertain significance was found)

“After I found out that there's things you can do to prevent cancer and that I would know for my own three children, I thought I'm going to go ahead with it. It means that if my children have the same gene that I've got they could have screening from a younger age. So I really did it for the children. It took about eight weeks for the results to come initially. My BRCA1 results were negative, but they found an unknown [a **variant of uncertain significance**] in my BRCA2 results. I did feel relieved that I haven't got an altered BRCA1 gene. But I was told that they're not sure about BRCA2 and on top of that they also found something else they've never seen before, so I'm quite unique. After my first results, I was asked to enter a research study so they can look into my results further. So I did another blood test and it will now take 12 months before I find out about that one. If I've got an altered BRCA2 gene then we can look at extra screening and preventive surgery.”

Amy, age 37 when diagnosed

Vicky decided not to have genetic testing

“I originally thought well maybe it would be worth knowing whether I have the altered gene and that's why I went through the first part of the genetic testing. But once I went into it further, I realised there were not a lot of options. I was already down for yearly mammograms once the treatment was finished anyway because of my age and family history of ovarian cancer. I didn't want to go down the route of having an oophorectomy and double mastectomy because I hadn't had a family at that point. My partner and I really wanted to have a family in the future. There was no guarantee that I would have the altered gene. I could sit there with the weight on my shoulders knowing about whether or not I have the gene, but I could also be hit by a bus tomorrow. Even if I had taken the test and they found the altered gene, I was not going to have any of the preventative surgery because I still wanted to have a family.”

Vicky, age 31 when first diagnosed and offered genetic testing

Jenny is unsure about whether or not to have a genetic test

“I'm not totally sure about what to do. I know that knowledge is power but I've had my children when I was ready to have them. If I was to discover that there was a genetic link, and my daughter also had that link, it almost kind of writes her future. In a way, it might make her make decisions in her future not necessarily because she wants things to happen at a certain time but she might be concerned that she might get breast cancer.”

Jenny, age 45 when diagnosed