Target Ovarian Cancer

Genetic testing and hereditary ovarian cancer

A guide for anyone with ovarian cancer and their families

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Target Ovarian Cancer
30 Angel Gate, London EC1V 2PT

Support line: 020 7923 5475

info@targetovariancancer.org.uk

targetovariancancer.org.uk

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Introduction

If you have a diagnosis of ovarian cancer, it's a common reaction to wonder what caused it or worry that other family members may be at risk. This guide talks through what genetic variants are, which gene variants are hereditary (can be passed through families) and what a family history of ovarian cancer means. It explains whether your family members are at risk of developing cancer as well. It also explains whether you and your family could have a genetic test, and what it might mean for you and your family if you do have hereditary ovarian cancer (cancer that can run in the family).

This guide has been written with the help of health professionals and experts in ovarian cancer and genetics. We've also included thoughts from those who have a gene variant or hereditary ovarian cancer themselves or are at risk and have been through many of the experiences you're facing. We hope it provides you with enough information to make an informed decision about having a genetic test, and supports you and your family in dealing with what the results of the test might mean for you if you choose to go ahead.

We understand how isolating it can feel to have a diagnosis of ovarian cancer. That's why we offer a full programme of support and information across the UK including opportunities to connect with others going through similar experiences. If you would like to know more, or if you have any questions or concerns about any of the information you read in this guide, please get in touch with us.

With warmest wishes,
From all of us at Target Ovarian Cancer

What is a cell?
Cells are the building blocks that our bodies are made of. We have lots of different types of cells that do different things.

What is DNA?
DNA stands for deoxyribonucleic acid. It's a chemical in our cells that tells the cells how to work and behave.

What is a gene?
Genes are made up of short sections of DNA. Our genes carry information about us like the colour of our eyes.

Why do genes have names?
Genes have names so that we can tell them apart. This helps us to talk about any problems or changes in specific genes.

What is a mutation or variant?
A **mutation** or a **variant** are terms used to describe a change in the DNA code of the gene that affects how the gene works. Many different words are used to describe these types of gene changes. 'Mutation', 'disease-causing alteration', 'gene variant' or 'pathogenic variant' are all terms you may come across. We will use the term **gene variant** or **genetic variant** to describe a change in a gene which is known to cause cancer.

There are different types of ovarian cancer. To be able to fully understand what your treatment options are it's helpful to have specific information from your medical team about your diagnosis. This includes the type of ovarian cancer and the stage and grade. You can use the space below to record this information if you wish. You can find out more about the different types of ovarian cancer, stages and grades at **targetovariancancer.org.uk/types**

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Is my ovarian cancer hereditary?

Cancer is a common illness so it's not unusual to have more than one family member with the same type of cancer and/or different types of cancer within one family. However, some families may have a greater chance than normal of developing ovarian cancer.

Up to 20 per cent of cases of ovarian cancer (one in five) occur because of changes (a variant) to one or more genes known to increase the risk of ovarian cancer. The changed version of this gene will have been passed on from your mother or father. Some types of ovarian cancer (such as high grade serous epithelial ovarian cancer) are more likely to be caused by a variant in a gene than others (such as mucinous or germ cell ovarian cancer).

How do variants in genes cause cancer?

Genes are instructions made from our DNA which tell the cells in our bodies how to work. Every cell in our body contains genes that decide and control our body's functions, growth and appearance. Each person has two copies of most genes, one inherited from their mother and one from their father.

In general, our genes enable our cells (the building blocks that make up our body) to function normally. However, sometimes the genes that we have inherited have small changes, known as genetic variants. If one of our genes has a variant, this can sometimes result in an increased risk of developing certain illnesses compared to people who don't have it.

Someone with a gene variant usually has a 50 per cent (one in two) chance of passing it on to their children.

What is a genetic variant?

When a change occurs in an inherited gene it's called a genetic variant. You might hear it called a mutation, faulty gene, altered gene, disease-causing alteration or a pathogenic variant elsewhere. But in this guide we call it a **gene variant** or **genetic variant**.

What is meant by hereditary or familial ovarian cancer?

Hereditary means the passing on of specific characteristics from one generation to another – in this case, passing on a variant in a gene. The term **familial** means something that occurs or tends to occur in families.

Familial cancer or **hereditary cancer** is a cancer which has developed as a result of carrying a variant in a gene. Throughout this guide, we refer to it as **hereditary ovarian cancer**.

How do I know if I have hereditary ovarian cancer?

At the time of publication (November 2022), anyone diagnosed with high grade serous epithelial ovarian cancer (the most common form of epithelial ovarian cancer) in England and Scotland is offered access to genetic testing. The genetic test may include looking for variants in the **BRCA1, BRCA2, BRIP1, MLH1, MSH2, MSH6, PALB2, RAD51C** and **RAD51D** genes, even if there's no history of ovarian cancer in your family. If you have a family history of ovarian cancer and you're diagnosed with epithelial ovarian cancer you may be offered testing for the same genetic variants.

At the time of publication (November 2022), anyone diagnosed with high grade serous epithelial ovarian cancer in Wales is offered access to genetic testing for variants in their BRCA1 and BRCA2 genes, even if they have no family history of ovarian cancer. If you have a family history of breast and/or ovarian cancer you may also be offered access to a wider test looking at further genes. There are plans to offer access to genetic testing for the same gene variants as those in England and Scotland in early 2023 so ask your treatment team what's currently available.

In Northern Ireland, anyone diagnosed with high grade serous epithelial ovarian cancer is offered access to genetic testing for variants in their BRCA1 and BRCA2 genes, even if they have no family history of ovarian cancer. If you have a family history of breast and/or ovarian cancer you may also be offered access to a wider test looking at further genes.

You may not be eligible for genetic testing due to the specific type of cancer you have (for example mucinous, germ cell or sex cord stromal tumours) but it's important that you discuss genetic testing with your treatment team or a genetic counsellor (a professional who is trained to talk to you about the risks and benefits of genetic testing) to find out if testing is appropriate.

Variants in genes such as BRCA1 and BRCA2 can occur in anyone in any family so a genetic variant can be inherited from either your mother or your father. They're more common in some communities than others. For example, members of the Ashkenazi Jewish population are approximately five times more likely to have a BRCA1 or BRCA2 gene variation, and so are more at risk of developing hereditary ovarian and/or breast cancer than people from the general population.

"I had no previous family history of cancer, on either side of my family, other than an uncle who died of bowel cancer. I didn't even know about possible familial risk until I attended a Target Ovarian Cancer event, after a question was asked to the expert panel."

Shani

"I think it is very important to find out your BRCA status as not only can it affect you... but also – more importantly – you can protect your family too. Keeping my daughter 'safe' has helped to keep me driven throughout my treatments. I was diagnosed simultaneously with both breast and ovarian cancer in July 2014 and then found out I had inherited a BRCA mutation from my father. I am also Ashkenazi Jewish which I know now meant I was at a much higher risk. I didn't know before my diagnosis that you could inherit ovarian or breast cancer from a man. It's hard enough being told you have cancer but knowing that it was a BRCA mutation that had caused both my cancers made me angry in that it could have and should have been prevented. Knowledge is power."

Alison

What should I consider if I have hereditary ovarian cancer?

There are a number of things to think about if you find out you have hereditary ovarian cancer. Firstly, there's the impact on you – it may affect treatment of the ovarian cancer. Over the last few years new drugs have been developed that target ovarian cancers specifically in those with a BRCA1 or BRCA2 gene variant and you may be eligible for treatment with these drugs. You should speak to your oncologist about this. Some hereditary ovarian cancer genes also increase your risk of developing other cancers, including breast cancer. So you would need to consider ways to manage this increased risk. Your medical team will support you with this.

Secondly, there could be an impact on family members who may also have inherited the gene variant which could put them at increased risk of ovarian and breast cancer. This guide talks through these considerations and gives more information on each.

Tumour profile testing

All tumours have genetic variants that occur as the tumour develops. These are called **somatic** variants and aren't present in the normal healthy cells of a person who has cancer. Somatic variants can't be inherited.

When a tumour is removed during surgery, or a small sample of tissue is taken from the tumour during a biopsy, the tissue will be sent to a pathologist (a professional who studies the changes in the body's cells caused by disease). They will study the tissue under a microscope and may arrange more tests on the tissue to **profile** it. This tumour profiling test gives information about the somatic variants. It can help the medical team identify which treatments the tumour is most likely to respond to, and in some cases whether you're eligible for treatments or certain clinical trials (medical research studies that investigate potential new drugs, new ways of giving treatments or different types of treatments and compare them to the current treatments).

The inherited genetic variants we talk about in this guide which may increase the risk of developing cancer are known as **germline** gene variants. This is because they occur in the body's germ cells – cells that develop into eggs and sperm. Germline variants can be passed on from parent to child when a sperm and egg come together. Both germline and somatic testing should be done if you have ovarian cancer.

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Gene variants and ovarian cancer

Hereditary ovarian cancer is most commonly caused by a variant in either the BRCA1 or BRCA2 gene. Some variants in other genes such as RAD51C, RAD51D, BRIP1, PALB2 and mismatch repair (Lynch Syndrome) are also known to increase the risk of ovarian cancer, but researchers have not yet found all the genes linked to an increased risk.

What are the BRCA1 and BRCA2 genes?

The BRCA1 and BRCA2 genes (BReast CAncer genes) were discovered in the mid-1990s in families that had a lot of cases of breast cancer. BRCA1 and BRCA2 genes normally help protect you against cancer because they help repair breaks in DNA that can lead to cancer. But variants can occur in these genes which can increase the risk of developing breast cancer. They also increase the risk of developing ovarian cancer in a woman's lifetime from two per cent (two in 100 chance) to:

- Up to 60 per cent (60 in 100 chance) for BRCA1 gene variants.
- Up to 30 per cent (30 in 100 chance) for BRCA2 gene variants.

Variants in the BRCA1 or BRCA2 genes account for the majority of hereditary ovarian cancers. About 15 per cent of women (15 in every 100) who develop ovarian cancer have a variant in either their BRCA1 or BRCA2 gene.

Gene variants can increase your risk of cancer, whatever your sex. It's important to understand that not everyone who inherits a variant in their BRCA1 or BRCA2 gene will develop cancer but it does greatly increase the risk.

Which other genetic variants put me at risk?

Variants in the BRCA1 and BRCA2 genes account for most hereditary ovarian cancer cases. However, variants in other genes can also increase the risk of ovarian cancer:

- Lynch Syndrome (which used to be known as Hereditary Non-Polyposis Colorectal Cancer or HNPCC) increases the risk of bowel cancer. It's linked to variants in one of the genes **MLH1, MSH2, MSH6** and **PMS2**. A woman with a variant in the MLH1, MSH2, or MSH6 gene has an estimated 10 to 17 per cent (up to 17 in 100) chance of developing ovarian cancer at some point during her lifetime. There's no significant increased risk for PMS2. The chance of developing other cancers including in the lining of the womb (endometrium), small bowel, urinary tract, stomach, gall bladder and pancreas can also be increased by a variant in one of the Lynch Syndrome genes.
- Variants in the **RAD51C, RAD51D** and **BRIP1** genes can increase the risk of developing ovarian cancer. But these variants are very rare. If you have a RAD51C gene variant there's a 5–20 per cent risk (up to 20 in 100 chance) that you will develop ovarian cancer in your lifetime. If you have a RAD1D gene variant there's a 5–25 per cent risk (up to 25 in 100 chance). If you have a BRIP1 gene variant the risk of developing ovarian cancer is 5–10 per cent (up to 10 in 100 chance).
- Variants in the **PALB2** gene mainly increase the risk of developing breast cancer. PALB2 genetic variants give you a small increased risk of ovarian cancer of 2–10 per cent (up to 10 in 100 chance) across your lifetime, almost all of which happen after the age of 50.

Variants in the **STK11** gene may also increase the risk of developing ovarian sex cord-stromal tumours – a different type of ovarian cancer. Variants in this gene cause Peutz-Jeghers syndrome, which is an extremely rare condition estimated to affect one in 100,000 people. While evidence is limited, it's suggested that people with Peutz-Jeghers syndrome have an 18 per cent risk (18 in 100 chance) of developing gynaecological cancers by age 70.

Variants in different genes carry different increases in risk. A clinical geneticist (a doctor who specialises in genetics) or a genetic counsellor will be able to give you a more accurate and personalised risk assessment.

This guide focuses on information about BRCA1 and BRCA2 gene variants as they account for most hereditary ovarian cancers.
For the most up-to-date information about genetic testing, please contact Target Ovarian Cancer's support line on 020 7923 5475 or support@targetovariancancer.org.uk

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Getting tested for a BRCA1 or BRCA2 gene variant

What should I do if I think I have hereditary ovarian cancer?

Your oncologist or another member of your medical team may have already talked to you about genetic testing. Many hospitals offer genetic testing in the same place that you're having or had your treatment (the oncology clinic). This is called **mainstreaming**. Others may refer people to a genetics centre (a specialist clinic that looks at everything to do with medical genetics including genetic testing) for a more in-depth conversation about genetic testing.

If you've been diagnosed with ovarian cancer and not offered genetic testing, arrange to talk with your oncologist and discuss whether you may be eligible. There might be reasons why genetic testing isn't appropriate for you and your team can discuss this with you.

If you haven't been offered a test and you're still wondering whether genetic testing might be right for you, you may still be able to ask for a referral to a genetics centre via your GP or oncologist. You can find your nearest centre by searching **genetic clinics** at **bsgm.org.uk**

You may then be offered the chance to speak with a genetic counsellor to help you decide whether or not a genetic test is appropriate for you, and what the impact would be for you and your family members if you do go ahead.

What should I consider before having a genetic test?

There are some important things to think about before going ahead with genetic testing. In particular, you should think about the impact of the testing on yourself and on those who are close to you. It's important that you have a chance to discuss all your concerns and uncertainties about genetic testing before you decide whether or not to have the test.

Your medical team should give you written information about genetic testing and you should have the chance to ask them any questions that you might have. It's important to tell your team if you still have unanswered questions or if there's anything you're not sure about after your discussion with them. If you haven't spoken to one already, it might be helpful for you to be referred to a genetic counsellor before deciding whether to have genetic testing.

Considerations for you

Some people find it helpful to have an explanation for why they developed cancer. There could be other implications for you if you have a hereditary cancer risk as you will have an increased risk of developing other cancers. In the case of the BRCA1 and BRCA2 genes you will have a higher risk of developing breast cancer (in comparison to the general population). Your options for managing this risk will depend on your current cancer diagnosis and treatment. There's more information about this in Chapter 7 of this guide.

The results of genetic testing may also impact your ovarian cancer treatment. There's more information about this in Chapter 7 of this guide.

Considerations for your family

A second consideration is the impact on your family. Other members of your family may also have the gene variant if you do. This can include your mother or father, siblings, aunts, uncles and cousins, depending on which side of the family the variant is passed down. If you have a BRCA1 or BRCA2 variant your children have a 50 per cent (one in two) chance of having inherited it and therefore being at increased risk. They also have a 50 per cent (one in two) chance of having inherited a normal copy of the gene from you if you have the gene variant. In that case, they would not have an increased risk of cancer.

Who's at risk with a BRCA1 or BRCA2 gene variant?

Anyone with a variant on the BRCA1 or BRCA2 gene is at a higher risk of developing cancer:

- Women, trans men, non-binary people with ovaries, and some people with differences in sex development with a BRCA1 or BRCA2 gene variant have a high risk of developing breast and ovarian cancer. If you have had surgery that's removed your breasts or ovaries your risk is lower, but a small risk still remains.
- Men, trans women, non-binary people with a prostate, and some people with differences in sex development:
  - have a smaller increased risk of developing male breast cancer but no increased risk of prostate cancer with a BRCA1 variant.
  - have an increased risk of developing prostate cancer and male breast cancer with a BRCA2 gene variant.
- There may also be a small increased risk of pancreatic cancer for anyone of any sex who carries the BRCA2 variant.

"I felt that I was on a hamster wheel of cancer after being diagnosed. It's hard to keep your head in gear while being practical the whole time."

Berni

There's information in Chapter 6 of this guide about discussing your genetic test result with your wider family.

Due to the potential implications, it can be very helpful to discuss genetic testing with your relatives at an early stage. If you have contact with your local genetics centre prior to deciding about genetic testing, they will talk about these issues with you in more detail.

When should I have genetic testing?

If you're eligible for a genetic test, it's important to ask yourself, "When is the right time for me to have genetic testing?" Having genetic testing soon after a cancer diagnosis can be distressing.

But having genetic testing early also means that people with a gene variant can receive treatment such as PARP inhibitors at an earlier stage. These are a group of drugs which work by stopping cancer cells repairing themselves. There's more information about PARP inhibitors in Chapter 7 of this guide. If you feel that now isn't the right time to have genetic testing, you may choose to think about it again at a later stage. You may be able to have DNA stored (from a blood sample) so that it's available for genetic testing in the future.

Who's at risk if they have a PALB2 gene variant?

Women, trans men, non-binary people with ovaries and some people with differences in sex with a PALB2 gene variant have a high risk of developing breast cancer, and a small risk of developing ovarian cancer. They also have a small increased risk of developing pancreatic cancer.

Men, trans women, non-binary people and some people with differences in sex development with a PALB2 variant have a small increased risk of pancreatic cancer and of male breast cancer. There is no evidence for an increased risk of prostate cancer, but studies have been small so far.

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What is a genetic test and what are the possible results?

The stages of a genetic test

1. Deciding if the test is right for you

In many places genetic testing is done by the same team and in the same place as your ovarian cancer treatment. This means that someone in your medical team will speak to you about genetic testing during one of your oncology appointments. You may be asked to complete a form about your family history. You may find it helpful to talk to your family members to gather as much information as possible. Don't worry if you can't answer any/all of these questions. Many people don't know about their family history and it's important to remember that not knowing doesn't affect your eligibility for a test.

During the appointment you will be given information about what a genetic test involves, when you can expect the results and what the results might mean for you and your family. You will also be able to ask questions. It's important that you take your time to think about whether you want to have the test. Some centres will want you to wait until your next appointment to decide. If you're struggling with the decision you should be given the option to talk to someone, such as a genetic counsellor, about your feelings.

If your treatment centre doesn't offer genetic testing then your oncologist can refer you to the local genetics centre for the test. You will be asked to make an appointment to visit the genetics centre where a clinical geneticist (a doctor who specialised in genetics) or a genetic counsellor will discuss with you what's involved in a test and what this might mean for you and your family.

"At the first meeting, they talked about the likelihood of it being genetic, and completing the family history forms. Because an aunt on my dad's side had died of ovarian cancer, and another of breast cancer, the counsellor said this indicated a strong familial link."

Berni

2. Having the genetic test (blood test)

After this, if you choose to go ahead with the test, you will have some blood taken to be tested. In lots of oncology clinics this will happen during your next routine blood test (for example a blood test before having chemotherapy). In other oncology clinics you may have the choice to go back to the clinic at a different time because your appointment is too soon or not soon enough.

Your blood sample will be sent to a genetics laboratory to be tested. In some places, you will be given a choice of how you'd like to receive the results of the test – whether by phone or in writing, or sometimes face to face.

3. Receiving the results

The time it takes for your blood test to be analysed and the results to be available varies slightly between the genetics centres. You will be told how long it will take for yours. It's usually between four and eight weeks.

When you're told about your test result, you will be given some more information about what the result means and what the next steps are. You will also be able to speak with your treatment team in the oncology clinic (or the genetics team at the genetics centre) who will talk you through your result and the next steps in as much detail as you need.

What are the possible results of a genetic test?

There are three possible results for testing for BRCA1 and BRCA2 gene variants:

1. **Variant present – sometimes called a positive test result.**
   Testing identifies a variant that causes a significant change to the gene and is therefore very likely to be the cause of your cancer.
2. **Variant not present – sometimes called a negative test result.**
   Testing has not identified any gene variants.
3. **Variant of unknown significance (VUS) – sometimes called an inconclusive test result.**
   Testing may identify a variant in the gene where there may be some uncertainty whether or not this would cause an increased cancer risk. While a VUS is not currently known to cause an increased cancer risk, a small number may get changed to a variant that causes a significant change to the gene and is cancer causing in future.

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What is the impact of the different results for me and my family?

What is the impact of ‘variant not present’?

Some people can feel relief and reassurance if they’re not found to have a genetic cause for their cancer.

If you have this result, and don’t have a family history of ovarian and/or breast cancer (two or more close relatives with either ovarian or breast cancer), it’s most likely that your ovarian cancer was a one-off in your family (or **sporadic**). It means your risk, and the risk of your children, developing breast cancer and other cancers associated with the BRCA1 and BRCA2 genes is probably similar to the general population.

If you have this result but have a strong family history of ovarian and/or breast cancer, the result can be less helpful. But researchers still don't know all the variants in different genes that may increase the risk of ovarian cancer, so it's possible that you have a variant in a different gene not found by this test. This means there's still a level of uncertainty even after genetic testing.

The results of genetic testing may also have implications for the treatment you're offered for ovarian cancer. There's more information about this in Chapter 7 of this guide.

Can my family members still receive a genetic test if my result is 'variant not present'?

Predictive genetic testing is a test adult members of your family can choose to have to find out if they have inherited a genetic variant and have an increased risk of developing cancer. If your result is 'variant not present', genetic testing wouldn't be available for the rest of your family as this result makes it less likely that there's a significantly increased risk of developing cancer in your family. If you have a family history of ovarian and/or breast cancer, close relatives may still have an increased risk of developing cancer. There may be options for them to manage this risk, which your genetics specialist can advise you about.

"My test came back negative which was good but also left a lot of questions unanswered for me and my relatives. I still have a strong family history which leaves us wondering why and what the unknown possible risks are."

Sue

What is the impact of 'variant of unknown significance' (VUS)?

If you've been told the result showed a genetic variant of unknown significance (or VUS), this means that the test has found a gene variant in the BRCA1 or BRCA2 gene but it's not known if it causes an increased risk of ovarian cancer or not. The majority of VUS results are likely to be harmless differences in a person's genes, but if it hasn't been seen many times before, then it's included in the test report as being of unknown significance. The proportion of those who are given a VUS result is decreasing as researchers learn more and more about the different variants that increase the risk of ovarian cancer. It may also mean that your VUS is reclassified over time. As more is discovered about genes, there's likely to be further information about the VUS in the future and you may like to contact your local clinical genetics service to discuss this in a few years' time.

Can my family members still receive a genetic test if my result is 'variant of unknown significance' (VUS)?

If you have a VUS, your unaffected family members won't be offered predictive genetic testing. But if you have family members who have had breast or ovarian cancer as well, they may be offered testing to help work out the significance of the VUS.

If a VUS is found, your family may feel more uncertain than before. You may find the uncertainty very difficult to understand or deal with emotionally, as it's less clear whether you and other family members have an increased risk. So it's important that you ask your doctor or genetic counsellor for support and advice about the options available to you.

What is the impact of 'variant present'?

If you've been told there's a variant present, you'll be told whether the variant is in your BRCA1 or BRCA2 gene. The result will have an impact on your risk of developing other cancers, the risk of your family members developing cancer, and it may also have an impact on your treatment for ovarian cancer. You will receive more counselling to explain the impact of this result.

"The genetic counsellors were brilliant and very sensitive in the way they approached it. They offered further support and counselling."

Berni

"I was very stunned. After I'd completed the family history form I'd been told I was at a very low risk of having the gene mutation so didn't have any counselling about what the impact of a positive test would be."

Shani

How might I feel?

"It adds another dimension to the journey, just when you think you're through it and can get off the wheel; finding out about BRCA throws you off kilter. It's the hardest part to deal with because you know cancer is not going away."

Berni

Naturally people can have very different feelings and reactions when they find out they have a gene variant that explains their cancer diagnosis. At first you might feel shock, anger or anxiety. You might expect to have a gene variant and feel glad to have an explanation for the cancers in your family.

"I felt like I'd been diagnosed all over again, which sounds dramatic, but I was really shocked. I got over this shock by reassuring myself that at least my children would know about their risk."

Shani

"If I'm honest, knowing I have a faulty gene has given me a sense of relief because it helped explain why I was unlucky to get cancer twice. But then I realised the implications for my family."

Adele

With time, most people adjust to this new information. Many are pleased that although it doesn't change their own diagnosis, there's important information available for other family members.

"My sister pointed out that now she can be monitored and will not have to go through the same as me."

Berni

It's important for you and your loved ones to remember that you can't control the genes you inherit from your parents or the ones you pass on to your children.

"I felt a bit guilty that I could have passed this on to my children, but you can't choose what genes you pass on."

Shani

You'll have the option of a follow up appointment with your local clinical genetics service to further discuss how you're feeling and the impact the result can have on you and your family. They'll be able to provide you with further information and tell you where you can access further support.

What is the impact on my treatment and my risk of other cancers?

If you have ovarian cancer and a variant in the BRCA1 or BRCA2 gene, the risk of developing breast cancer is also increased. For a woman in the general population the lifetime risk of developing breast cancer is about 15 per cent (15 in 100 chance). If you have a BRCA1 or BRCA2 variant, the risk is around 65 to 80 per cent (up to 80 in 100 chance). Remember, an increased risk doesn't mean you will definitely develop breast cancer. There are a number of risk management options which we talk more about in Chapter 7 of this guide.

"When I was diagnosed 15 years ago as having a BRCA1 gene mutation following my ovarian cancer diagnosis, I wasn't offered information about preventative surgery as less was known about it then. I did unfortunately go on to be diagnosed with breast cancer 10 years later, and now get regular follow ups. The clinicians are always approachable and I have their phone numbers if I'm ever worried about anything. I had a recent scare and called them, and was seen by the clinician the same day."

Diane

Your risk of breast cancer with a PALB2 gene variant

A PALB2 variant also increases the risk of breast cancer. For women, trans men, non-binary people and some people with differences in sex development with a PALB2 variant the risk is around 45 to 65 per cent (up to 65 in 100 chance).

There's ongoing research into new treatment options for those with ovarian cancer who carry known variants in the BRCA1 or BRCA2 gene. You can find out more about this research at **targetovariancancer.org.uk/clinicaltrials**. Studies indicate that the prognosis (prediction of how your ovarian cancer might change in the future) for BRCA1 or BRCA2 carriers may be better than for those with no gene variants because carriers can have an increased response to specific therapies. We talk more about the impact of having a BRCA1 or BRCA2 gene variant on your treatment in Chapter 7 of this guide.

What is the impact on my family members?

What is predictive testing?

If your test shows that you have a BRCA1 or BRCA2 gene variant ('variant present'), it's possible that your relatives will also have a BRCA1 or BRCA2 variant. So adult members of your family can choose to have a genetic test to find out if they have inherited the same gene variation.

This is called **predictive testing** because a positive result ('variant present') for them means they have an increased risk of developing cancer. It doesn't mean they have cancer or are definitely going to develop it.

The variant in your BRCA1 or BRCA2 gene is likely to have been inherited from your mother or father. If they're unaware of their BRCA1 or BRCA2 status, they can access advice about testing, as can their siblings, nieces and nephews (your aunts, uncles and cousins).

It's important to note that anyone who inherits a BRCA1 or BRCA2 variant, whether or not they develop cancer themselves, may pass the variant on to their children.

Remember, not everyone with a BRCA1 or BRCA2 variant will develop cancer.

What does this mean for my siblings?

Your full siblings (with the same mother and father) will have a 50 per cent (one in two) chance of also carrying the BRCA1 or BRCA2 gene variant and will be able to access predictive testing. The chance for half-siblings may be less than 50 per cent depending on family history, but they can still ask for predictive testing.

What does this mean for my children?

Your children will also have a 50 per cent (one in two) chance of inheriting the BRCA1 or BRCA2 gene variant. Testing is only available to adults over the age of 18 because the risk management options are either not available or not yet necessary for those under 18 and it's important that they make their own informed choice about whether or not to be tested.

"My mum had never had cancer, and wasn't aware of BRCA until I got ovarian cancer and was tested. She subsequently also tested positive and at the age of 75 was diagnosed with breast cancer – caught and treated very early because she was put on a screening programme because of her BRCA status."

Sharon

How do I tell them and how might they feel?

If your relatives are aware that you're having genetic testing, a conversation about the results may happen naturally. Depending on how you're feeling (physically and emotionally) it can feel like a difficult discussion to have. It can be particularly challenging if there are young family members you want to share the information with. You may struggle with the thought of potentially passing on a gene variant to your children. All these feelings are completely normal so please remember you're not alone. You may find that talking to your partner, if you have one, or a friend can be beneficial. Your local clinical genetics service is also available to provide support.

You may find that your relatives are wondering whether they have an increased cancer risk and are very accepting of the news about a gene variant. It means they're able to have a predictive genetic test that can allow them to take action if they're at increased risk.

Many people choose to have predictive genetic testing because they would rather be aware of any increased risk of cancer and take up the chance to have regular tests or even surgery (a risk-reducing operation) to manage this risk. However, knowing about a possible increased cancer risk may cause anxiety for relatives. Some people are concerned about the possible impact on their work or insurance. There's more information about this in Chapter 8 of this guide. Some people are worried about the impact a possible increased cancer risk might have on future relationships and having children of their own. There's no right or wrong way to feel and there's help and support available, including from your local clinical genetics service.

"I was really worried for my children, but relieved to know they can be tested and be alert for the signs. I was open with my family the whole way through about what it might mean for them."

Shani

"When I was first diagnosed as a BRCA gene carrier, I wanted my daughter tested straight away, but was counselled against it as she was only 13. They said she should be at least 18 and should be fully aware of the implications of the possible results."

Adele

You may find you have relatives who are resistant to genetic testing and who prefer not to receive the information. You may have relatives that you're not in contact with. These situations are challenging and can be distressing. Your local clinical genetics service will be able to discuss this with you. If you think it will be helpful, they can provide an 'open letter' that you can send to relatives that explains about the gene variant and the genetic testing available to them.

"I was given a letter by my genetics service to share with my brothers and children explaining the gene and about being tested."

Shani

Ultimately, whether and when your relatives decide to have predictive genetic testing is up to them. Everyone is different and some people adjust to the news quicker than others. You'll have given them an option that may not otherwise have been available to them.

"All my family are aware, and some have already been tested. My three daughters have had very different reactions. One is finding it difficult to cope with cancer deaths in the family and then my subsequent diagnosis, but says she will get round to getting tested. One does not want to be tested, and did not even want to know the result of my test, but I felt it was important she had all the information. One has been tested and also carries the BRCA1 mutation, and says her team have been fantastic. She's been offered counselling and will be talking to them about preventative measures soon."

Berni

There's a section in Chapter 8 of this guide on implications for a family member who's also found to have a BRCA1 or BRCA2 variant.

7

I have ovarian cancer and a BRCA1 or BRCA2 gene variant – what now?

How can I manage my increased risk of breast cancer?

A genetic counsellor will discuss with you the different ways of reducing your risk of developing breast cancer. There are three options to consider – **screening, risk reducing surgery** and **drug treatment**. The choice will take into account your current health and predictions of whether your ovarian cancer might grow or change. You may also be referred to a family history breast cancer clinic where specialists in this area will take over your care.

Screening

The NHS runs a breast screening programme for women throughout the UK. Women between the ages of 50 and 70 are typically invited for breast screening every three years, but those at high risk can access screening tests before the age of 50 and any woman can request screening to continue after the age of 70. If you have a BRCA1 or BRCA2 gene variant you will be considered for yearly MRI scans and mammograms (breast screening) from the ages of 30–40 onwards. Ask your genetic counsellor for further information. Screening aims to detect tumours that are too small to be felt by you or your doctor. Breast screening won't stop breast cancer developing, but it will help detect cancers at an early stage, when they're easier to treat.

"My counsellor explained about the increased risk of breast cancer and that I should be screened every year."
Shani

Risk-reducing surgery – bilateral mastectomy (removal of both breasts)

If you have a BRCA1 or BRCA2 gene variant, having surgery (an operation) to remove both breasts may be an option to greatly reduce the risk of developing breast cancer. Speak to your medical team about options for this surgery. They may recommend that you don't have it until after you have recovered from your ovarian cancer treatment. Risk-reducing breast surgery can't guarantee that you won't develop breast cancer, but the risk afterwards is small enough that breast screening isn't needed. It's likely that you'll be offered the option of having reconstructive surgery to rebuild both breasts using implants and/or tissue from another part of your body. This may be carried out at the same time as the natural breast tissue is removed or it may be done at another time as a separate surgery.

Surgery will have a very big impact on you both physically and emotionally, especially following an ovarian cancer diagnosis. It's important that you take your time and discuss all the advantages and disadvantages with a counsellor and your medical team before making a decision.

The NHS breast screening programme offers screening to trans women and to trans men who haven't had top surgery (chest reconstruction). However, you'll only be automatically invited for screening if you're registered as a female with your GP. Talk to your GP about screening if you have any concerns.

"As I'm still dealing with the aftermath of cancer treatment, the counsellors and clinical team have agreed to discuss preventative surgery in a few more months as I feel I need to take a breath. I think I will have it but haven't decided about reconstructive surgery – I have an appointment with the plastic surgeon to help me decide."
Berni

Managing your increased risk of breast cancer with a PALB2 gene variant

As a PALB2 gene variant can also increase the risk of breast cancer, if you have the gene variant you should be offered advice on managing this risk. You will also be considered for yearly MRI scans and mammograms from the ages of 30–40 onwards. Surgery to remove both breasts may also be an option.

Drug treatment and lifestyle choices

In some cases, **chemoprevention** may be considered to reduce the risk of breast cancer. Chemoprevention doesn't mean having chemotherapy. Chemoprevention is the use of drugs to try to reduce the risk of breast cancer developing. It can also be used to delay the cancer coming back (recurring). This includes treatment with drugs such as tamoxifen, anastrozole and raloxifene. Tamoxifen and anastrozole are usually used as treatments for breast cancer, and raloxifene is used to treat or prevent osteoporosis (bone thinning) after the menopause. In this situation they are given to reduce the chance of you developing breast cancer. Your genetics doctor (geneticist), genetic counsellor or breast cancer specialist can discuss this with you and give you written information on the absolute risks and benefits of chemoprevention, including the side effects of the drugs and how much they might reduce the risk before you make a decision.

If you have ovarian cancer and have a BRCA1 or BRCA2 gene variant you should be offered advice about other factors which may affect your risk of breast cancer. These include:

- The use of the oral contraceptive pill, which can increase the risk of breast cancer. (If you stop taking the pill, this increased risk of breast cancer gradually reduces again.)
- The use of hormone replacement therapy (HRT) which, depending on your clinical circumstances, may increase your risk of developing breast cancer. Your clinician should discuss with you whether the increased risk outweighs the benefit, and the alternatives.
- Reducing how much alcohol you drink, stopping smoking, and maintaining a healthy weight through healthy eating and exercise to reduce your risk.

What does this mean for my treatment for ovarian cancer?

There are a number of drugs in use and in development that are targeted at cancers in those with a variant in their BRCA1 or BRCA2 gene. Ask your clinician if your genetic test result impacts your access to different treatments or clinical trials.

Targeted therapy (PARP inhibitor drugs)

PARP inhibitors are a group of drugs which work by stopping cancer cells from repairing damage in its DNA, with the aim that the cancer cells will die. They're taken via the mouth as a tablet.

Targeted therapy with PARP inhibitors is a type of **maintenance treatment**. A maintenance treatment aims to increase the amount of time that the cancer remains inactive (when the cancer stops growing) after your initial treatment (usually surgery and chemotherapy). This means that you might be able to have a longer gap before needing more chemotherapy.

There are three PARP inhibitors currently in use in the UK for ovarian cancer: **niraparib** (Zejula®), **olaparib** (Lynparza®), and **rucaparib** (Rubraca®).

You can receive a PARP inhibitor if you have advanced ovarian cancer (stage 3 or 4) and have recently had and responded to platinum-based chemotherapy (usually carboplatin/cisplatin and paclitaxel). Which drug you're offered will depend on which nation in the UK you live in, whether you have a BRCA variant, if your tumour tests positive for homologous recombination deficiency (HRD, see Chapter 9) and which medication your team think will suit you best.

"It's been four and a half years since my stage 3 ovarian cancer diagnosis. I've had one recurrence but thanks to the PARP inhibitor olaparib I currently have no sign of active cancer and I'm feeling fantastic!"
Wendy

At the time of publication (November 2022), in England, Wales and Northern Ireland you can access:

- Olaparib after your first-line (first course of) treatment onwards if you have a BRCA variant.
- Olaparib with bevacizumab (Avastin®) from your first-line treatment if your tumour tests positive for HRD (see Chapter 9).
- Niraparib as a maintenance treatment after your first-line or second-line treatment only if you have a BRCA variant.
- Niraparib after your first-line treatment onwards if you don't have a BRCA variant.
- Rucaparib after your second-line treatment onwards, whether you have a BRCA variant or not.

At the time of publication (November 2022), in Scotland you can access:

- Olaparib after your first-line treatment onwards if you have a BRCA variant.
- Olaparib with bevacizumab from your first-line treatment if your tumour tests positive for HRD.
- Niraparib after your first-line treatment onwards, whether you have a BRCA variant or not.
- Rucaparib after your second-line treatment onwards if you don't have a BRCA variant.

For the most up to date information about which PARP inhibitors you can access visit **targetovariancancer.org.uk/drugs**

Taking part in clinical trials about treatment

Some clinical trials have restrictions on the number or the types of cancer treatments that you've had before. For more information about research on PARP inhibitors and other studies specifically designed for those with a BRCA1 or BRCA2 variant or hereditary ovarian cancer talk to your medical team, visit **targetovariancancer.org.uk/clinicaltrials** or call our specialist nurse-led support line on **020 7923 5475**

"I was diagnosed with ovarian cancer in 2009, and subsequently tested positive for a BRCA1 mutation. Following surgery and chemotherapy, I had about 10 months of remission before cancer returned. I then joined a clinical trial for a PARP inhibitor rather than have more chemotherapy. I was happy to be generally living a normal life with no nasty side effects; my cancer shrunk to 'non-measurable disease', and my CA125 tumour marker went from 204 to 10. I am very grateful for the trial that gave me a fantastic year without chemo. Although the drug stopped working for me after 10 months, it is still working for others, and I am hopeful that my involvement helps others."
Sharon

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What does this mean for a family member with a BRCA1 or BRCA2 gene variant?

Risk reducing options

If a family member has predictive testing and has been found to carry a gene variant, they will have had genetic counselling to discuss what this means for them and risk management options. In all cases, they will be supported in making decisions by a team of professionals.

In the previous section we outlined the options for breast cancer. However, family members may also want to consider risk reducing options for ovarian cancer.

Removal of both ovaries and fallopian tubes – bilateral salpingo-oophorectomy

Having surgery to remove the ovaries and fallopian tubes greatly reduces the risk of developing ovarian cancer. It may also, to a much lesser extent, reduce the risk of breast cancer, although the evidence for this is unclear. There's still a small remaining chance of developing primary peritoneal cancer which is treated in the same way as ovarian cancer. The peritoneum (a large, thin sheet of tissue that lines the organs in the tummy) can't be removed during preventative surgery so this small risk remains. Removing the ovaries and the fallopian tubes is classed as major surgery.

If you haven't gone through the menopause before surgery, removal of both ovaries will cause the immediate start of the menopause. This is known as **surgical menopause**. If you've already gone through the menopause before surgery, you won't experience surgical menopause.

Your medical team will discuss the advantages, disadvantages and risks of taking hormone replacement therapy (HRT) to manage the side effects of early menopause. HRT is usually recommended to reduce your side effects from early menopause unless you've had breast cancer. Whether you're a BRCA1 or BRCA2 carrier or not, taking HRT until the recommended age of 51 doesn't increase your risk of breast cancer.

In the future, it may be possible to have this surgery in two stages – firstly, removal of the fallopian tubes where ovarian cancer is thought to start, and secondly, removal of the ovaries. This can delay the start of the menopause while still protecting against the development of ovarian cancer. At the time of publication (November 2022) this is only available in a research trial.

"My sister was diagnosed with breast cancer about a month before getting her BRCA result. She took immediate action, with a bilateral mastectomy and reconstruction. A few months after completing treatment, she had her ovaries removed, minimising her risk of ovarian cancer. Six years later she remains cancer free."

Adele

"My niece plans to have surgery on completion of her family."

Adele

Surveillance

There's currently no screening process for ovarian cancer. Risk-reducing surgery is the best way to manage the risk of developing ovarian cancer if you have a variant in your BRCA1 or BRCA2 gene. But many people choose not to have this operation straight away. Some choose to wait because they want to have children, others may want to avoid early menopause and/or the symptoms related to menopause. Some people may not be well enough to have surgery and so want to wait until they're feeling well and the operation is less of a risk.

Contraceptive pill

Anyone who has ever used the oral contraceptive pill is much less likely to develop ovarian cancer than those who have never used it. Using the contraceptive pill can reduce the risk of developing ovarian cancer by as much as 50 per cent (one in two). It's not clear whether taking the contraceptive pill increases the risk of developing breast cancer in those with a BRCA variant. Some studies suggest an increased risk while others have not found this link.

If you're thinking of taking the oral contraceptive pill you should first discuss your options with your GP/breast team and/or genetic counsellor.

Other implications

Family planning

A genetic counsellor will be able to provide more information to your family members about having children and the impact on the children they've had already.

The family planning options for people with a BRCA1 or BRCA2 variant are:

- To have children without any intervention – each child would have a 50 per cent (one in two) chance of inheriting the variant.
- To not to have children at all.
- Adoption, where a child or siblings who can't be brought up within their birth family become permanent legal members of a new family.
- Egg or sperm donation, when eggs or sperm are collected from someone and given to someone else's fertility treatment.
- Pre-implantation genetic testing for monogenic disorders (PGT-M), which used to be called pre-implantation genetic diagnosis (PGD) – some couples may choose this option to avoid passing the BRCA variant to their children. PGT-M involves removing your eggs to fertilise with sperm in a test tube and create embryos (IVF). When the embryos start growing but are still tiny (at a few days old), a cell is removed

and is tested for the hereditary condition. Once the genetic status is determined, you can have an embryo that doesn't have the condition put back to try to start a pregnancy.

- Prenatal testing – some couples may choose to get pregnant naturally and have a test during the pregnancy to see if the baby has inherited the BRCA1 or BRCA2 gene variant. The couple could then decide whether to continue with the pregnancy. This isn't a common request from couples at risk of passing on a risk of cancer that develops in adults.

Your family members may want to discuss their options with their geneticist who can explain the implications and the funding options available, but it's important to note that there's no right or wrong answer.

"I was originally told about the possibility of using PGD to have children early on when talking to a genetic counsellor about having the BRCA mutation. The genetic counsellor also told me about the other options including having children naturally in the hope that they would be born without the gene mutation or conceiving naturally then having the embryo tested at 12 weeks. It was through her that I was referred onto a hospital that carries out PGD where I was further informed about PGD in detail. All parents want to protect their children from harm and although I am aware that PGD can't get rid of all the health risks to my unborn child, it does mean that my child won't have the genetic make-up that puts it at such a high risk of breast and ovarian cancer. I also don't want them to have to make the decisions I've had to make on whether to have risk reducing surgery or not, or for them to have to decide on how to have children or for them to worry about it. For me and my family using PGD means that the gene fault stops with me; future generations of my family will never have to worry about a gene that puts them at such high risk of cancer."

Carly

Insurance

An open-ended agreement is in place which guarantees that anyone who has had a predictive genetic test (for breast and ovarian cancer) can take out life and critical illness insurance cover without disclosing the results of the test. This agreement, known as the **Code on Genetic Testing and Insurance**, has been in place since October 2018.

Check the Association of British Insurers (ABI) for the latest guidance at **abi.org.uk** or call **0207 600 3333**

Genetic Alliance has more information about how to get insurance with a genetic condition. Search **insurance and genetic conditions** at **geneticalliance.org.uk**

9

Getting tested for homologous recombination deficiency (HRD)

If you've recently been diagnosed with advanced high grade ovarian, fallopian tube or primary peritoneal cancer (stage 3 or 4), alongside testing for gene variants you should be offered testing for homologous recombination deficiency (HRD). This is now available in England, Wales, Scotland and Northern Ireland. Speak to your oncologist to see if this is an option for you.

What is HRD?

Our DNA (a molecule in our cells that contains our genetic code and tells the cells how to work and behave) is constantly being damaged and repairing itself. This repair process is called **homologous recombination**. When our body is unable to repair breaks in DNA this is called **homologous recombination deficiency**. It means that, in those with a diagnosis of ovarian cancer and whose tumour tests positive for HRD, cancer cells have a harder time repairing themselves.

Until recently it was thought that HRD was caused mostly by BRCA1 or BRCA2 gene variants. It's now understood that HRD can include a number of genes across the homologous recombination repair pathway. It's been found that around half of women with advanced high grade serous ovarian cancer have HRD.

What does the HRD test involve?

A sample of your tumour is needed to test for HRD. This can be taken during surgery or through a biopsy. A biopsy involves taking a small sample of body (tumour) tissue so that it can be examined under a microscope.

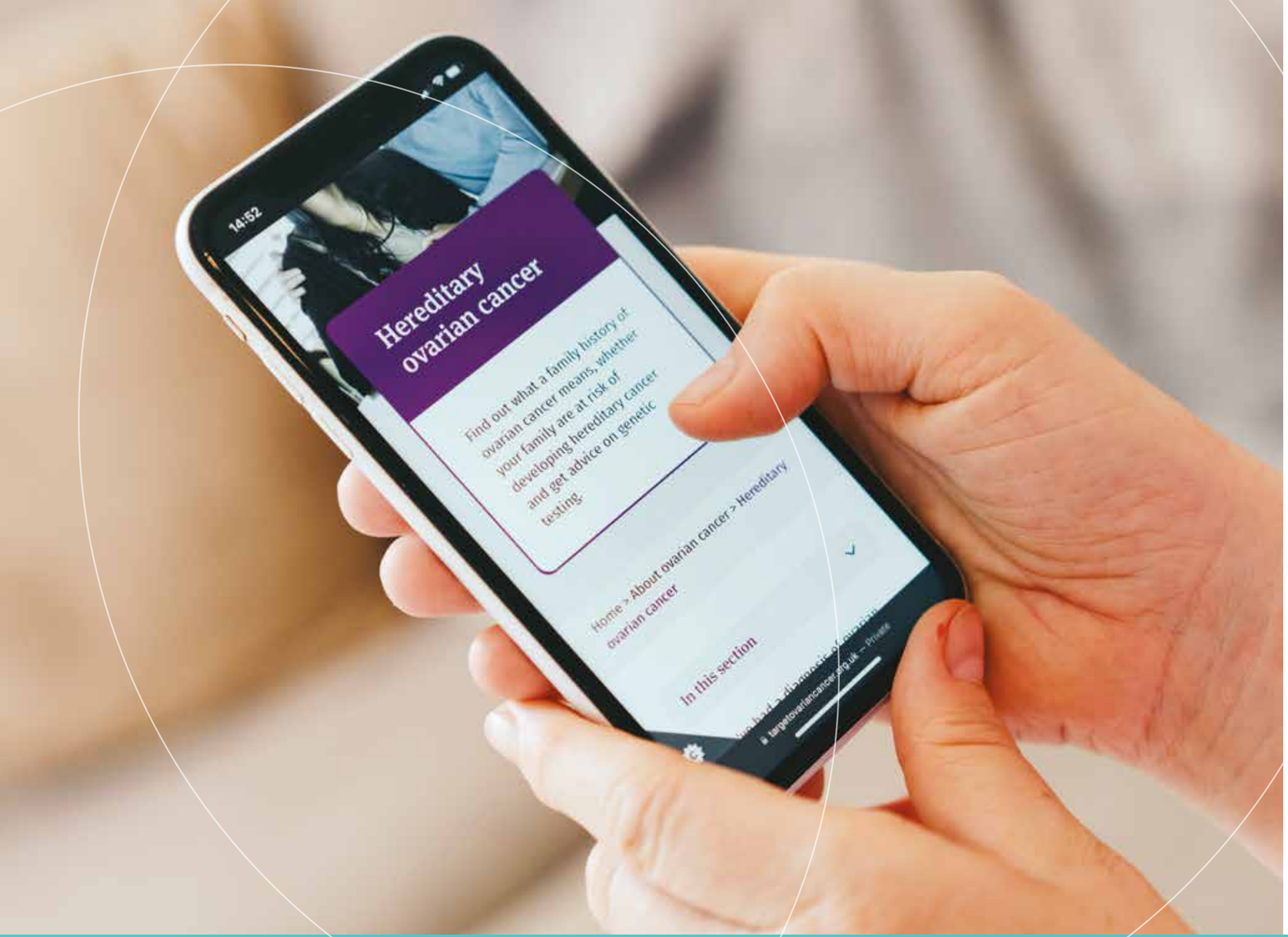
This type of testing is called **somatic testing**. This means it only picks up variants that are present in the tumour. It doesn't pick up if variants are present in the germline cells (changes in cells that are inherited from parents and are present in all cells of the body) too. Some people may have a variant present only in the tumour, while others may have it present both in the tumour and germline cells. So a test for a germline BRCA variant should be done separately.

What does it mean if my tumour tests positive for HRD?

If your tumour tests positive for HRD certain treatments are more likely to be effective. This includes PARP inhibitors. These are a type of targeted therapy that block the action of the PARP enzyme in cancer cells, which means they can't repair certain types of DNA damage. Being HRD positive means cancer cells have a harder time repairing themselves. PARP inhibitors further block this repair mechanism causing more cancer cells to die.

"I'm HRD positive, which my oncologist told me he suspected would be the case. Part of my tumour was sent to Salt Lake City for testing, I've never been to the States but part of me now has! My results came back about six weeks later and my oncologist told me not to be alarmed. He reassured me that ladies who test positive for HRD often react better to treatment with PARP inhibitors."

Alexandra



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Further sources of support

Target Ovarian Cancer

This guide is for anyone who has been diagnosed with ovarian cancer and who would like to know more about genetic testing and hereditary ovarian cancer.

If you would like more information on dealing with practical and emotional needs after a diagnosis of ovarian cancer, we have a lot of information on our website and a range of information guides offering guidance and support.

- **What happens next?** – a guide for anyone with a recent diagnosis of ovarian cancer
- **Back here again** – a guide for anyone with recurrent ovarian cancer
- **My care, my future** – a guide for anyone living with incurable ovarian cancer
- **A younger woman's guide to ovarian cancer** – information on treatment, relationships, fertility and facing an early menopause
- We also have a range of mini guides about specific issues including finances, diet and nutrition, complementary therapies, sex and intimacy, and living with a stoma.

You can download or order all of our guides from our website at **targetovariancancer.org.uk/guides**

Support line

If you're worried about anything you've read in this guide or would like more information, get in touch with our support line. You can call us about anything to do with ovarian cancer. Our specialist nurses are here to listen. Call **020 7923 5475** (Monday to Friday from 9am–5.30pm) or visit **targetovariancancer.org.uk/supportline**

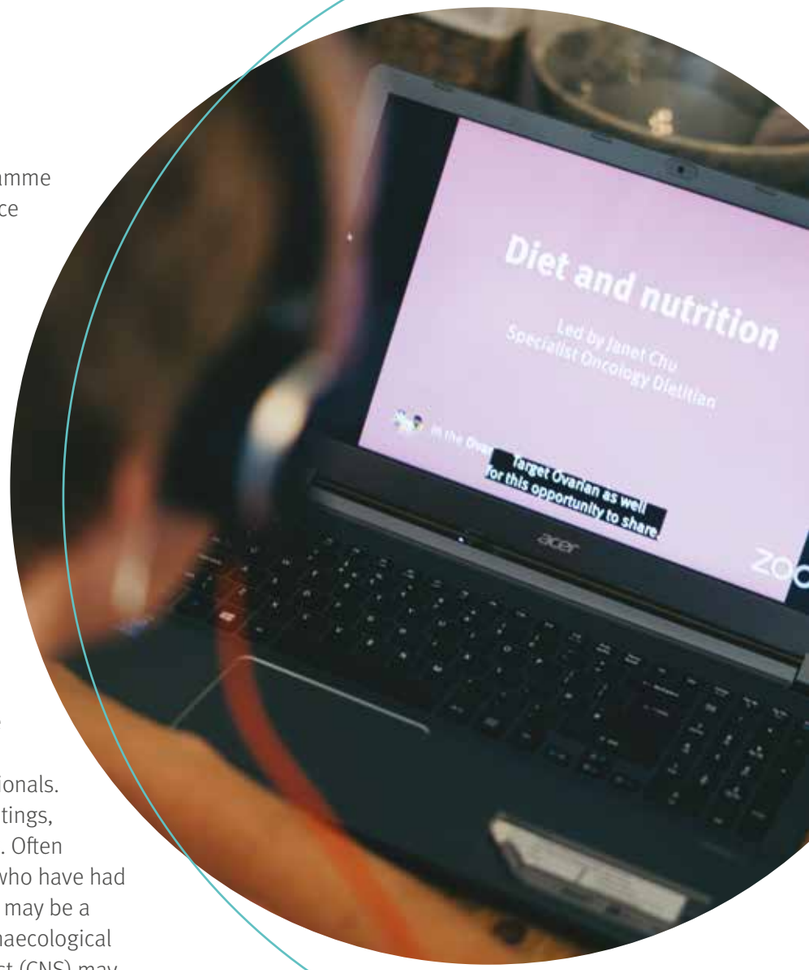
Facebook groups

Join our Ovarian Cancer Community on Facebook, a private group for anyone affected by ovarian cancer (including loved ones) to connect, share experiences and support one another. Keep in touch with Target Ovarian Cancer and experience our digital events together with your family and friends. Hear from clinicians and our specialist nurses to learn more about ovarian cancer. Join at **facebook.com/groups/ovariancancercommunity**

You can also join our private Facebook group, In Touch, which is a safe space just for those with a diagnosis, to talk to others and share experiences. Join at **facebook.com/groups/intouchtargetovariancancer**

Support events

Target Ovarian Cancer runs a programme of regular free digital and face-to-face events across the UK to support anyone living with and beyond ovarian cancer. These events offer an opportunity to meet others and provide support and information on everything from latest treatments to coping emotionally and living well with ovarian cancer. You can find out more at **targetovariancancer.org.uk/supportevents**



Support groups

Simply being around others who understand what cancer involves can help. Some groups like to share fears and worries or arrange talks about cancer from different professionals. Some groups arrange lunches or outings, which can help to boost your spirits. Often groups are general, with members who have had different types of cancers, but there may be a group specifically for those with gynaecological cancers. Your clinical nurse specialist (CNS) may run a support group locally or you can visit **targetovariancancer.org.uk/supportgroups** to find a group near you.

Other sources of support and information

Genetic Alliance UK
geneticalliance.org.uk | **0300 124 0441**

Macmillan Cancer Support
macmillan.org.uk | **0808 808 0000**

Cancer Research UK
cancerresearchuk.org | **0808 800 4040**

Breast Cancer Now
breastcancernow.org | **0808 800 6000**

BRCA specific support

BRCA Kent: a support group and online support forum for those with a BRCA1 or BRCA2 variant based in Kent
brcakent.org.uk

BRCA Umbrella Support and Social Network: an online support forum for those with a BRCA1 or BRCA2 variant
brcaumbrella.ning.com

There are several BRCA peer support groups on Facebook with members based in the UK and overseas
facebook.com

PALB2 specific support

PALB2 Interest Group: an international group of scientists sharing information for PALB2 carriers and their families
palb2.org

Websites for further information

Association of British Insurers (ABI)
abi.org.uk | **0207 600 3333**

National Institute for Health and Care Excellence (NICE guidelines for familial breast cancer)
nice.org.uk/guidance/CG164

Notes

Useful contacts You can use this space to record useful contacts such as your clinical nurse specialist etc.

Questions I want to ask

My next steps

About Target Ovarian Cancer

Target Ovarian Cancer is the UK's leading ovarian cancer charity. We work to:

- improve early diagnosis
- fund life-saving research
- provide much-needed support to anyone with ovarian cancer

We're the only charity fighting ovarian cancer on all three of these fronts, across all four nations of the UK. Ovarian cancer can be devastating. But there is hope – Target Ovarian Cancer. We work with people affected by ovarian cancer and health professionals to ensure we target the areas that matter most for those living with ovarian cancer.

All our information and publications are subject to an information production system that ensures quality and impartiality. All our publications are peer reviewed by experts in their field, health professionals and those affected by ovarian cancer.

We hope that you have found this publication useful, if you have any comments or suggestions please do let us know.

To access our list of references for this publication please contact us directly.

We make every effort to ensure that the information we provide is accurate. If you are concerned about your health, you should consult your doctor. Target Ovarian Cancer cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information on websites to which we link.

Our commitment to diversity, equity and inclusion

Target Ovarian Cancer is committed to embedding diversity, equity and inclusion into every area of the charity. We have embarked on a programme of work to make sure we're reaching and representing everyone who needs us, actively looking at how we can make sure our support reaches everyone affected by ovarian cancer, and that it reflects the communities we serve. Through this work we are taking time to learn more and think carefully about the needs of, and challenges faced by, people we currently support, and those that we could support.

You can find out more about our immediate plans on our website at **targetovariancancer.org.uk/equity** and if you'd like any more information please email us at **info@targetovariancancer.org.uk**

Our nurse-led support line is here for anyone affected by ovarian cancer – if you have a diagnosis, or if you're a family member or a friend supporting someone living with ovarian cancer.

We're open from 9am–5.30pm, Monday to Friday.

Call us on **020 7923 5475**

More information and support for anyone affected by ovarian cancer can be found at **targetovariancancer.org.uk**

Target Ovarian Cancer
30 Angel Gate, London EC1V 2PT

Support line: 020 7923 5475

info@targetovariancancer.org.uk

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