WHAT JEWISH WOMEN SHOULD KNOW ABOUT BREAST & OVARIAN CANCER

How your heritage can influence your optimal health care.

Dr Lesley Andrews

This booklet has been written by

Dr Lesley Andrews

in conjunction with the staff
of the Hereditary Cancer Clinic
and the Institute of Oncology
of the Prince of Wales Hospital
Randwick, N.S.W

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If you would like any further information about your risk of breast or ovarian cancer, or your screening, cancer prevention or genetic testing options, please contact the Hereditary Cancer Clinic on 9382 2551

Contents

Glossary

Ashkenazim — Jews whose origins can be traced back to Eastern Europe, many coming from Germany.

BRCA genes — BRCA1 and BRCA2 - genes which we all carry which have a role in protecting women against breast and ovarian cancer. 2% of Ashkenazi Jews carry a faulty BRCA1 or BRCA2 gene.

CA-125 — A protein produced by healthy ovaries in small amounts. Levels may rise significantly when a cancer occurs, and can be used to detect ovarian cancer.

Gene — A segment of our DNA which provides a code for a protein. Each protein has a specific function in the cell.

Hysterectomy — Surgical removal of the uterus (womb).

Laparoscopy — A surgical technique where instruments are introduced through several small incisions in the abdomen and a camera is used to see inside the abdominal cavity. This technique can be used to perform abdominal operations without a large incision.

Mastectomy — Surgical removal of a breast.

MRI — Magnetic Resonance Imaging - a new technique used to obtain images of soft tissues such as the breast which does not use conventional radiation.

Oophorectomy — Surgical removal of the ovaries.

Prophylactic — Preventive; not done to treat cancer, but to prevent it.

Salpingo-oophorectomy — Surgical removal of the fallopian tubes and ovaries.

TVU — Trans-Vaginal Ultrasound - an ultrasound of a woman's reproductive organs using a small device inserted into the vagina to get a clearer image of the ovaries, tubes and uterus.

Foreword

WOMEN today are better informed about their health care than ever before, and take an active role in maintaining health and preventing illness. There is widespread information about cancer prevention and early detection for common cancers, such as breast cancer, through the public media and specialised government funded programs. Most of what we read applies to people at average risk of developing cancer.

However, a small number of women are at much higher risk of some cancers than average. These women may be unsure what screening and preventive options are suitable for them. Many of these women are not even aware of their increased risk.

A woman's risk of developing breast or ovarian cancer is strongly influenced by her family history of cancer. This is partly because a small proportion of these cancers (5-10%) are due to the inheritance of certain genetic factors. Although these genetic factors are found in people throughout the world, they are amongst a number of genetic traits which are more common in people of Ashkenazi Jewish ancestry than members of the general population. While this does not mean that all Jewish women are at increased risk of breast or ovarian cancer, it does mean that the risks for some Jewish women are much higher than average.

This booklet is to help Jewish women learn about their risk of breast and ovarian cancer and what they can do about it. For most women, it will be all they need to know. But for some women it will raise questions and concerns. If at any time you are worried about the best health care for yourself or a member of your family, please contact the Hereditary Cancer Clinic at the Prince of Wales Hospital on 9382 2551 or one of the other familial cancer clinics listed at the back of this booklet.

Why do Jewish women need different information?

You have probably heard the statistics before - that 1 in 12 Australian women will develop breast cancer at some time in their lives, and that most of those women will be aged over 60. At least three quarters of them will not die of breast cancer.

You may also have heard that ovarian cancer is much less common, affecting approximately 1 in 100 Australian women, most of whom are also aged over 60.

So why do we all know someone whose life was tragically cut short by breast or ovarian cancer at a young age? Why does there seem to be more families devastated this way amongst our Jewish community than amongst our non-Jewish friends?

In many cases, the answer lies in our genetic makeup.

Ashkenazi Jews of today descend from a relatively small population group. Originally persecuted and expelled from Germany and other areas of Western Europe, the Ashkenazim expanded in the communities of Eastern Europe, particularly Poland and Lithuania, and later dispersed throughout the world. Ashkenazi Jews, that is those descended from Germany and Eastern Europe, make up the majority of the world's Jews today, and about 90% of Jews living in cities such as Sydney and Melbourne.

Conversion to Judaism was until recent times quite uncommon, and so the gene pool remained much as it has been for centuries. Ashkenazim are like a large family, with shared genetic similarities. Like any large family, some of those genetic traits are recognisable physical features such as facial appearance or body shape. Other shared genetic traits may need sophisticated genetic testing to identify and have no effect on the health or wellbeing of the individual. However, in some cases those traits may be faulty genes which are associated with a particular illness. For example, you may know that the inherited condition Tay-Sachs disease is extremely rare outside the Jewish community. Research over the last decade has found that faulty genes which predispose to the development of breast and ovarian cancer are also more common amongst Ashkenazim than other people.

Key Point

Ashkenazi Jews do not have more faulty genes than any other population. They do however tend to have the same faulty genes as other Ashkenazim, resulting in some faulty genes being more common and others being far less common, when compared with a population of mixed ethnicity.

What do genes have to do with cancer?

Have you ever wondered how our skin cells start growing after we cut ourselves and then miraculously stop once it has healed? The answer lies in our genes. We tend to think of genes as making us different from each other - our eye colour, our blood group, how tall we grow. However our genes also are responsible for all the functions of our body which we all share. Genes are recipes for proteins which control our cells. Importantly, some of these proteins are the triggers for our cells to divide and grow, as well as the brakes which regulate that growth.

If a cell develops mistakes in these growth controlling genes, a cancer may develop. Although such mistakes occur often, particularly as we get older, cancer is usually prevented by other genes which detect and repair such mistakes. Only when all the safe guards break down does a cancer actually occur.

Sometimes a person inherits a faulty repair gene which means that they are at greater risk of cancer. Most repair genes are important for protecting us against certain types of cancer, so an inherited faulty repair gene only increases the risk of getting particular types of cancer. We know of two repair genes which are important in protecting us against both breast and ovarian cancer. These genes are called BRCA1 and BRCA2. There are other such genes which protect us against breast and ovarian cancers which researchers around the world are trying to identify.

We all carry 2 copies of BRCA1 and of BRCA2 - one inherited from our mother and one from our father. Most of us have two perfect copies of these genes, but

approximately 2% of Ashkenazi Jews carry a faulty copy of one of these two genes, inherited either from their mother or their father. Females who carry a faulty BRCA1 or BRCA2 gene have a much greater risk of developing breast or ovarian cancer than average. They are also more likely to develop cancer at a younger age than is normally seen. Males who carry a faulty BRCA1 or 2 gene are at only slightly increased risk of some types of cancer, depending on the particular gene fault. Both males and females can pass the faulty gene on to their children.

Key Point

All cancer is caused by mistakes in growth regulating genes developing in a group of cells over time. These mistakes have not been corrected by the cell's own repair genes. Some people inherit a faulty repair gene, which increases their risk of getting certain types of cancer.

How are breast and ovarian cancer related to our Jewish ancestry?

Most breast and ovarian cancers occur for reasons we don't really understand. However about 5% of all breast cancer and about 10% of all ovarian cancer in Australia occurs in women who carry an inherited fault in a gene which normally protects against the development of these cancers. Throughout countries such as Australia, the USA and the UK whose population is from mixed ethnic backgrounds, these gene faults are found in about 1 in 500 people (0.2%). However, these gene faults are found in 1in 50 Ashkenazim (2%). Therefore, in addition to the background risk of developing breast cancer which all women have (around 8%), Ashkenazi Jewish women have an additional 2% risk of carrying a gene fault which increases their risk further. The same gene fault also increases a woman's risk of developing ovarian cancer.

It is not known why certain faulty genes are more common amongst Ashkenazi Jews than other populations. Research has shown that these gene faults have been present amongst Jews since before the destruction of the second Temple, and have been found in many Jewish communities. While there is the theory that these gene faults may persist because of a beneficial effect which was greater for Jews than non-Jews because of their particular living conditions, there is little evidence to prove this. It is more likely a chance effect that these gene faults were more common amongst the Eastern European Jewish community from which all Ashkenazim descend.

Some people feel that Jews are unique in having a genetic condition related to their ancestry. This is not the case, with many populations who have a shared ancestry also having shared genetic faults. This is particularly common where outsiders don't commonly marry into the group. This may be due to religious practice or to physical isolation. No matter what our ethnic background, geneticists have shown we all carry at least 6 or 7 faulty genes which may cause disease. People of a shared background tend to carry the same faulty genes as each other, but no more faulty genes overall than any one else.

Key Point

Ashkenazi Jews have descended from a small group in Eastern Europe. By chance about 2% carried these faults in either the BRCA1 or BRCA2 genes. Because of minimal conversion, these faults are found just as commonly in Ashkenazim today. Jews do not have more faulty genes overall than any other population group, but share common gene faults.

What are the effects of carrying a faulty BRCA1 or BRCA2 gene?

Two genes have so far been discovered which are important in protecting women against breast and ovarian cancer. They are called BRCA1 and BRCA2. We all carry two copies of each of these genes. Because the BRCA1 and BRCA2 genes are repair genes, carrying a faulty BRCA gene does not cause cancer on its own. As we age, cells may make mistakes in their growth controlling genes, and in most cases these will be repaired by genes such as the BRCA genes, particularly when we are young. If a woman carries a faulty BRCA gene, she is at higher risk of developing a breast or ovarian cancer than women who have normal BRCA genes. She is also at greater risk of developing a breast or ovarian cancer at younger ages than women with normal BRCA genes.

Although much research has been done, we cannot be precise about the exact risk of cancer associated with these gene faults, as it varies from family to family. However, for a woman with a faulty copy of either BRCA1 or BRCA2, the average risk of developing breast cancer at some time in her life is about 60-70%. The risk of developing ovarian cancer is between 20 and 60%, depending on the precise gene fault and her family history.

When we have a child, we pass on one copy of every gene. Our child gets a second copy of every gene from our partner. Because a woman with a faulty BRCA gene also carries a normal copy of the same gene, there is a 50:50 chance she will pass on the faulty copy and an equal chance she will pass on the normal copy. The same applies for every child she has, no matter whether

she has 1 or 15! These genes are not linked to genes we normally recognise, such as appearance, so a child who looks like their mother is not more likely to carry any faulty gene which their mother carries.

These gene faults are carried equally by both men and women. Male carriers may have some increase in their cancer risk, but it is minimal compared to females with the same gene fault. They can pass the gene faults on to their daughters and sons in the same way as a female. That is why a woman's family history of breast or ovarian cancer in her father's mother or sisters may be significant.

Key Point

Only 5-10% of all breast and ovarian cancer is due to an inherited gene fault. These gene faults can be inherited from either the mother or the father. A woman who carries a faulty BRCA gene is at increased risk of both breast and ovarian cancer. Each of her children has a 50:50 chance of inheriting the same gene fault that she carries.

How do I know if one of these gene faults is in my family?

Typically families with a faulty copy of the BRCA1 or BRCA2 gene have several cases of breast cancer occurring before the age of 50 or have one or more cases of ovarian cancer. Unfortunately, because many Jewish families do not know their history due to the impact of the Holocaust or family dispersal from migration, the presence of a genetic predisposition is not always evident.

If there have been no cases of breast or ovarian cancer in either your mother's or your father's side of the family, it is unlikely that you carry one of these gene faults. If you have one or more cases of breast or ovarian cancer in your family, then your family **may** carry a faulty copy of the BRCA1 or BRCA2 gene. Rarely, males may get breast cancer and this may indicate a genetic predisposition. However it is important to remember that most cancers are not associated with such a faulty gene, but occur for other reasons.

The only way to know for certain is by testing a blood sample for the two gene faults of BRCA1 and the single gene fault of BRCA2 which are known to be more common amongst people of Ashkenazi Jewish ancestry.

This testing is done through the Hereditary Cancer Clinic at Prince of Wales Hospital and similar clinics around Australia (see page 32 for contact details). Jewish women with any personal or family history of breast or ovarian cancer are offered testing. In most cases there will be no charge for the testing, but there may be a fee for the genetic consultation at some centres. The results are usually available in 4-6 weeks.

Can my own doctor arrange testing?

Although this may be more convenient, this is not the best way. Doctors around the world agree that because of the complexity of genetic testing and the implications for health care, this type of testing is best provided through specialised clinics. Many decisions need to be made about genetic testing and subsequent health care, and there are both advantages and disadvantages to each choice. These choices are best made with the expertise and support of a specialised clinic.

Key Point

Genetic testing for breast/ovarian cancer predisposition is available for Jewish women with a personal or family history of breast or ovarian cancer at minimal cost through specialised familial cancer clinics.

What are the advantages of this type of genetic testing?

If a woman is found to carry one of these gene faults she has more precise information about her future risks of cancer. If she has already had a breast cancer it will alert her to the fact that she has a greater chance of developing a new breast cancer in her remaining breast tissue (either in the other breast or in the same breast if she did not have a mastectomy). This may influence her decisions about screening, prevention or about the management of her breast cancer if she has just been found to have a cancer and is considering her options for treatment.

Women who have not had cancer previously will be alerted to the fact that their risk of developing breast cancer is much higher than average, and that they are at risk at a younger age than other women. This means they can commence appropriate screening earlier and can also consider preventive options. The same applies regarding their risk of ovarian cancer.

In many cases there may be a history of breast cancer and women in the family may already be aware they are at increased risk of breast cancer and be having appropriate screening. Genetic testing may provide additional information by alerting them to their increased risk of ovarian cancer and enable them to have additional screening or take preventive measures. Without genetic testing these women may not have been aware of their increased risk of ovarian cancer.

In some cases it will already be known that a particular gene fault is present in a woman's family and she will be offered testing to see if she has inherited the gene fault or not. In this case, if her test shows she does not carry the gene fault, then she can be relieved of anxiety about being at high risk and avoid unnecessary screening.

Key Point

Genetic testing can alert a woman to her increased risk of breast cancer and her increased risk of ovarian cancer and enable her to make appropriate health care decisions. In some cases it will relieve her of the anxiety that she carries a gene fault previously found in other family members.

What does a parent's positive test result mean for their children?

We all have two copies of every gene, including the BRCA1 and the BRCA2 genes. We inherited one of each from our mother and one of each from our father. If someone carries a faulty copy of a BRCA gene inherited from one parent, they will almost always have a normal copy inherited from the other parent. (Research indicates that most embryos inheriting two faulty copies of either BRCA gene will miscarry). We pass one copy of every gene on to each of our children. Therefore, if a parent carries a faulty BRCA gene, each child has a 50:50 chance that they will inherit the faulty copy and an equal chance they will inherit the normal copy.

Rarely in some Jewish families, each parent will carry a different BRCA gene fault and some of their children may inherit both a faulty BRCA1 gene and a faulty BRCA2 gene. This appears to result in similar cancer risks as if only one faulty gene is inherited.

Carrying one of these faulty genes has no effect on the health of children or young adults. In families known to carry a faulty BRCA gene, parents are encouraged to inform their adolescent children of the increased risk of cancer and offer them the opportunity to speak to a familial cancer service when the time is right for them. Some will choose to get more information in late adolescence and others may choose to wait. Discussions at a familial cancer clinic will include the offer of genetic testing, but this is done when each individual feels it is the right thing for them. Young women will be advised of

their risks of carrying the faulty gene and of developing cancer and will be offered strategies for early detection and prevention of cancer.

Key Point

If a parent carries a faulty BRCA1 or BRCA2 gene, there is a 50:50 chance that their child has inherited the same gene fault. Testing is best deferred until the child can make their own decision as an adult.

What health care measures are available for women with an identified BRCA gene fault?

BREAST CANCER

Women who are found to carry a faulty copy of BRCA1 or BRCA2 are advised to have their breasts examined by a doctor every six months and to undergo a mammogram and breast ultrasound annually from the age of 35, or younger if a relative has had breast cancer before the age of 40.

Breast screening does not prevent cancer, but is used to detect cancer at an earlier stage. It is known that cancers are less likely to recur if they are small and have not spread to the lymph nodes.

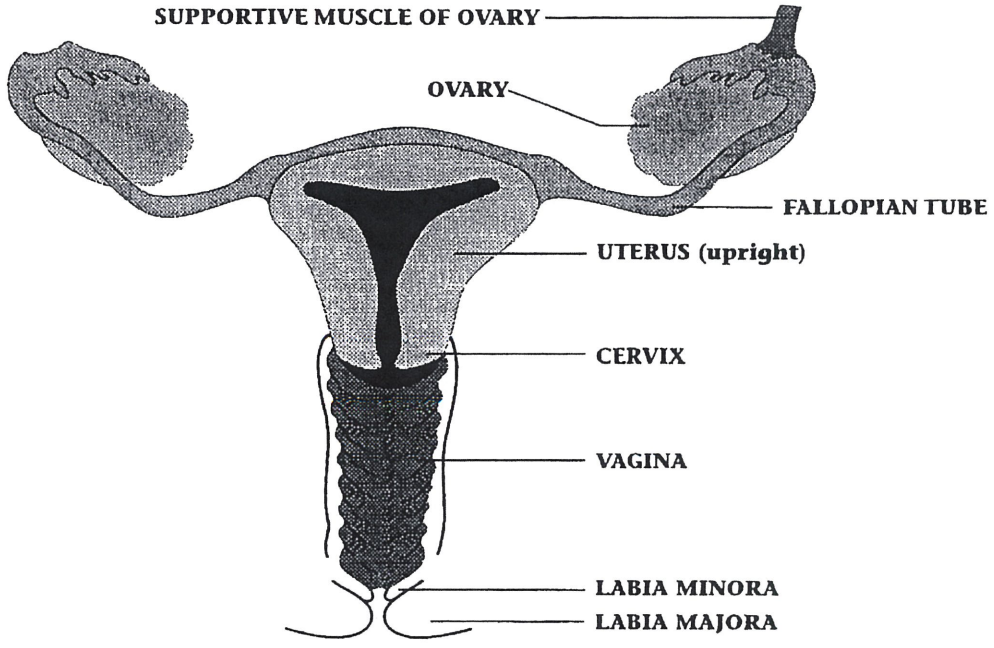
A new type of breast screening using Magnetic Resonance Imaging (MRI) may be available through some centres in the next few years. It is believed that MRI breast screening may detect cancers earlier than mammograms, with fewer cancers spreading to the lymph nodes.

There are limited options for preventing breast cancer. Tamoxifen(TM), a drug used widely in the treatment of breast cancer, may prevent some types of breast cancer in women with an inherited predisposition. This is still being evaluated and Tamoxifen(TM) is not yet approved for use as a preventive drug in women without a past history of breast cancer in Australia under the Pharmaceutical Benefits Scheme. Women can discuss its use individually with their doctors.

The only proven method of preventing cancer is to surgically remove a woman's breast tissue (prophylactic mastectomy). This can be followed by breast reconstruction. Tiny amounts of breast tissue may remain, and there is a small chance that a cancer will occur in these remaining cells. This occurs in 1-2% of women undergoing prophylactic mastectomy.

OVARIAN CANCER

It is difficult to detect ovarian cancer at a curable stage, as this type of cancer spreads early in its development. Pap smears are not useful in detecting ovarian cancer. This is because the ovaries are quite some distance from the cells sampled from the cervix during a Pap smear (see diagram below). Women at increased risk are offered annual screening for ovarian cancer using a trans-vaginal ultrasound (where a small device is inserted into the vagina). This is offered from the age of 35, as ovarian cancer is extremely rare before this age. Unfortunately, even when detected this way, most cases of ovarian cancer have spread beyond the ovaries, making treatment more difficult.



women are also offered a blood test to measure the levels of a protein calle CA125 which rises in most cases of ovarian cancer. However, CA125 levels a very variable, and may rise for reasons other than cancer, causin unnecessary anxiety. Recent research suggests that if this test is going to b done, repeating it every 3 months might be better, although this has not ye been proven to be beneficial.

As with breast cancer, screening does not prevent ovarian cancer, but is aimec at detecting it at a curable stage. There are limited options for reducing c woman's risk or preventing ovarian cancer. However it is known that using the contraceptive pill for at least five years may reduce a woman's risk of ovarian cancer. Because we are unsure about the effects of long term use of the Pill on the risk of breast cancer in high risk women, we do not routinely recommend use of the pill as a method of preventing ovarian cancer.

The only method of preventing ovarian cancer is surgical removal of the ovaries and fallopian tubes (prophylactic salpingo-oophorectomy). This is recommended around the age of 40, once childbearing is completed. This surgery can be done using 'key-hole' (laparoscopic) surgery in most cases. The fallopian tubes should always be removed at the same time. Consideration may be given to removing the uterus at the same time (hysterectomy), but this depends on each individual woman's needs.

In premenopausal women, this surgery will result in the abrupt onset of menopausal symptoms. If a woman has not had a past history of cancer, she may be prescribed hormones to alleviate these symptoms. Following ovarian removal, these hormones have been shown not to increase her breast cancer risk, as they are at lower levels than what her body would have produced had

she kept her ovaries. These hormones will be gradually discontinued sometime before the age of 50. For women who cannot be prescribed hormones, other medications are used to alleviate menopausal symptoms. Women who have their ovaries removed before the menopause have a lower risk of breast cancer than those who keep their ovaries, even if hormone replacement is taken.

Key Points

Women at increased risk are recommended to have regular breast examination and mammography to detect cancer at an early stage.
Some women may consider surgical removal of the breasts to prevent breast cancer, followed by breast reconstruction.

Ovarian screening is commonly not effective in diagnosing ovarian cancer at a curable stage, and women at high risk are recommended to consider surgical removal of the ovaries at around the age of 40. In most cases, hormones can be used to treat menopausal symptoms.

What are the disadvantages of this type of genetic testing?

Genetic testing is different to other types of medical tests in a number ways. Firstly, a positive test result gives information about our genetic make-up, but not about our current state of health. It indicates that a woman is at high risk of developing cancer, but it does not tell definitively if she will get cancer, or what type, or at what age.

For some women, knowledge of their genetic predisposition can give a woman the confidence to make difficult health care decisions and a sense of empowerment and control over her future. However, for other women, such knowledge may result in increased anxiety about the future and lead to decisions which may be difficult to make. The impact of the test result needs to be carefully considered before having the test.

Secondly, genetic testing gives information not only about ourselves, but about our family. A positive gene test may indicate that other women in the family who have had cancer almost certainly carried the same gene fault. This is information which they may or may not want. Once a woman knows that she carries such a gene fault she must consider who should know that information. Passing on such news is often difficult, especially to family who are not close or who live overseas.

Many women with a faulty BRCA gene find that the most distressing thing is the knowledge that their children, particularly their daughters, may have inherited the same faulty gene. Few women blame their parents for passing

the fault on to them, but many feel guilty about passing it on to their children. This is one situation where emotions often outweigh logic! It is important to remember that we have no control over the genes we give our children, but we can control what information we give them.

Healthy women who are found to carry a BRCA gene fault may have difficulty in obtaining some types of insurance policies, such as life and disability insurance. Existing insurance is not affected.

The complexity of these issues is why genetic testing is only offered through specialised clinics. Each woman who attends a clinic will be counselled about the implications of any testing result and provided with expertise and support to enable her to make the choices about her health care which are right for her.

Key Point

Genetic testing can result in increased cancer anxiety, feelings of guilt, difficulty in communicating information to extended family members and discrimination with regard to some types of insurance. Staff at the Hereditary Cancer Clinics assist women and their families in dealing with these issues.

What happens at a Hereditary Cancer Clinic Appointment?

Before an appointment at the Hereditary Cancer Clinic at Prince of Wales Hospital or other genetics services, a genetic counsellor will speak with you by phone at a convenient time, to draw up a family tree with details of all cases of cancer which have occurred in your family. This is important in the evaluation of your overall cancer risk. It is useful if you can obtain as much information as possible from other relatives beforehand, particularly regarding who had cancer and at what age. So that the information is as accurate as possible, we try to confirm details of cancer diagnosis with the written permission of the affected person (or their close relative if they are deceased).

At the clinic appointment you will usually be seen by both the genetic counsellor and a doctor trained in Hereditary Cancer. They will go over the family tree and provide you with the following information:

* What is the likelihood that there is a genetic predisposition to an increased risk of cancer present in your family
* How likely is it that you carry this genetic predisposition
* What is your risk of developing particular types of cancer
* What screening and preventive options are available
* Whether genetic testing is appropriate for your family

As well as providing you with information about cancer, genes and your cancer risk, an important part of the consultation is finding out how you feel

about the information and the choices you may face. Some people who come to the clinic can be reassured and given appropriate screening information and will not need another appointment. For others, it may be the beginning of a process involving many decisions about testing and cancer screening and prevention. The role of the clinic is to provide you with the support you need to make the decisions that are right for you.

Key Point

Before an appointment at the Hereditary Cancer Clinic, a genetic counsellor will draw up a family tree. It is useful if you can obtain as much information as possible about all cases of cancer which have occurred on both sides of your family.

What does genetic testing involve?

If you decide to have genetic testing, you will have a blood sample taken - nothing very complicated in that! The process before and after the blood is taken is a bit more complex though.

After you have discussed the option of genetic testing fully with the Hereditary Cancer Clinic Staff you will be asked to sign a consent form. This is to ensure that you fully understand what testing is being done. You will be asked to nominate who you would like to be informed of the test results, such as your doctors or other family members in the event of your death. As genetic testing results have implications for other family members, you will be asked for permission to use this information for the health care of other family members.

Once the blood is taken it undergoes a series of steps necessary to extract the DNA, which is then tested to see if the BRCA1 and 2 genes carry any of the faults known to be common amongst people of Ashkenazi Jewish ancestry. This testing takes 4-6 weeks. Fortunately, most women who have a BRCA genetic test will not be found to carry one of these gene faults. While this provides some reassurance, a woman's cancer risk needs to be evaluated based on her family history. In most cases a woman will be reassured that the breast cancer in her family is unlikely to have had a genetic basis. In some families however, there may be evidence of another cancer predisposing gene fault and further genetic testing will be offered.

The test result is always given in person, not over the phone. It is a good idea to bring along your partner, a friend or other family member. Getting a test

result can be stressful and it's always good to have a second pair of ears as well as someone to share the news - whether it's good or bad!

Key Points

Genetic testing requires a blood sample, after signing a consent form. The results take 4-6 weeks and are given at a clinic appointment, not over the phone.

What happens next if a gene fault is found?

When the result is given that a woman does carry a gene fault, women respond differently. Some like to have some time alone with their partner or friend to take in the result, others have many questions to be answered. It is easy to feel overwhelmed by the news, so it is important to take one step at a time.

The first step is just letting the news sink in. A woman may feel angry, she may feel anxious about getting cancer or if she has had cancer in the past, she may be relieved to finally have an explanation for why it happened to her. After a few weeks we suggest a follow up appointment to go over the issues which are important.

Women who carry a gene fault are faced with decisions about their health care. Advice will be given about screening and preventive strategies. Women who are considering preventive mastectomies will be referred to both a breast surgeon and a reconstructive surgeon to discuss their options. Some couples will also choose to see a counsellor to explore how such surgery will affect their relationship. Women who are in the age group where they are at risk of ovarian cancer will be referred to a gynaecologist to discuss preventive removal of the ovaries. It is important that women at high risk have regular screening while they are taking their time to make these decisions.

Women who have children, particularly teenage daughters, may seek advice on what and how to tell their daughters about the implications for them. Any

young woman who is at risk of carrying a gene fault is encouraged to come to the clinic to get information and discuss issues of concern for her, even if she is not considering genetic testing at the time.

After a woman has let her immediate family know about her test result, the staff at the clinic will encourage her to inform more distant family members who may not know they are at increased risk of cancer. The clinic can help by writing letters which the woman can send to her family. While it may initially be a difficult subject to broach, most people end up being extremely grateful to have been given the opportunity to know more about their cancer risks.

After a positive test result, the clinic staff periodically review women to address their concerns and advise them of new information or invite them to participate in new research studies. The clinic welcomes ongoing contact to ensure that each woman receives optimal health care.

Key Point

A positive test result takes time to sink in. The Hereditary Cancer Clinic provides referrals to relevant specialists to help women decide what health care is best for them and helps women disseminate the information to their extended families.