Patient information

Breast Cancer Clinic

Women attending the high risk familial breast cancer clinic

What is familial breast cancer?

Familial breast cancer is caused by genetic changes, called mutations, that are passed down within the family. This type of breast cancer makes up about five to ten percent of all breast cancers.Mutations in the BRCA1 and BRCA2 genes are the most common causes of familial breast cancers. However, there are at least 30 different genes that may also be involved.
Women that have these mutations may have an increased risk of breast cancer in their lifetime. They may also be at risk of other types of cancer such as ovarian cancer, pancreatic cancer and skin cancer.

How do I know if I am at risk of familial breast cancer?

In most cases, female breast cancer is caused by changes to genes that occur during a woman's lifetime. These changes are not passed down within the family. Some things may increase the risk of developing breast cancer including:

- Age and obesity
- Too much alcohol, using hormone replacement therapy for more than five years
- Early age at puberty and late age at menopause; not having children

The risk of familial breast cancer goes up as the number of members of the family with breast cancer increases. For example, if a woman has two or more first-degree family members such as mothers, fathers, brothers and sisters, or second-degree family members such as aunts, uncles, nieces, nephews and grandparents, that have breast cancer.
Additionally, the risk of familial breast cancer increases if the family members affected by breast cancer were diagnosed with breast cancer when they were under 40 years of age or had breast cancer is in both breasts.

How is the risk of familial breast cancer measured?

There are 2 main ways of measuring the risk of familial breast cancer.

1. Recording the details of breast cancers within the family including:

- The number of first or second-degree relatives who have had breast cancer
- If the cancer was in both breasts and if there is male breast cancer or ovarian cancer within a family.
- Using the Familial Risk Assessment – Breast and Ovarian Cancer (FRA-BOC) online tool to group the risk of familial breast cancer.

Based on the family history, the FRA-BOC tool puts a woman into 1 of 3 risk groups. Group 3 includes women at the highest risk. These women may have a 50 percent or greater risk of developing breast cancer in their lifetime. Women in this FRA-BOC high-risk group 3 make up about 1 percent of our community.

2. Testing for mutations

At least 30 different genes are known to cause familial breast cancer. However, most familial breast cancers are caused by mutations in the BRCA1 and BRCA2genes.

To find these mutations, a blood test is often done at public laboratories at the Princess Alexandra Hospital and Genetic Health Queensland.

Testing is also done at many private facilities with Medicare rebate available under certain conditions.

Managing the increased risk of familial breast cancer

Women who have a higher risk of familial breast cancer may use some of the options below to manage or reduce their risk of breast cancer:

1. Women at a higher risk of familial breast cancer may develop breast cancer at a younger age. It is recommended that these women start a screening program at age 30, that involves tests including a mammogram, ultrasound and breast MRI. This screening program is much more detailed than the ones usually carried out in community for women over the age of 50. Screening will not stop breast cancer from developing. However, the aim is to find any breast cancer at the earliest possible stage to have better results.

2. A screening program can also be combined with risk lowering medication using oestrogen lowering or oestrogen blocking drugs such as Tamoxifen and Arimidex. These drugs have been shown to greatly lower the chances of breast cancer in women.

3. Preventative (prophylactic) mastectomy, which is surgery to remove the breasts, is another option to reduce the risk of breast cancer. It is usually performed at the same time as plastic surgery to reconstruct the breast. This option of major surgery does not suit all women, especially for women still in the process of having their families and wanting to breast feed. However, it may be the best option for women with a proven gene fault after gene testing.

Choosing to have breast removal surgery needs a detailed talk with a specialist surgeon to make sure that women thinking about having this surgery understand the benefits and risks.

The role of the Familial Breast Cancer Clinic, Princess Alexandra Hospital

The Familial Breast Cancer Clinic is for women who have a strong family history of breast cancer. The Clinic offers counselling and advice about how to best manage each woman's risk of developing breast cancer.

The Familial Breast Cancer Clinic offers:

- Documentation of the family tree
- A personal risk assessment
- Review by a Clinical Geneticist and advice on formal genetic testing
- A tailored screening program
- Review by a specialist surgeon and nurse to discuss the options of risk lowering medication or preventative-breast surgery. If a woman is offered and decides to go ahead with breast surgery the surgeon will also book the surgery at this clinic.
- Referral to Gynaecological Services if the woman is also, at high risk of ovarian cancer
- Recommendations for lifestyle changes

Who is eligible to attend the Familial Breast Cancer Clinic at Princess Alexandra Hospital?

Women aged 30 to 65 years will be able to attend the Familial Breast Cancer Clinic at Princess Alexandra Hospital, if they have a referral from their local doctor or specialist and who have one of the following criteria:

1. Familial Risk Assessment – Breast and Ovarian Cancer(FRA-BOC) Risk Category 3 which includes women at high risk of developing breast cancer, who have the following features:

- Two first-degree or second-degree relatives on one side of the family with breast or ovarian cancer, plus one or more of the following features on the same side of the family:
    - An additional relative(s) with breast or ovarian cancer
    - Breast cancer before the age of 40 years
    - Breast cancer in both breasts
    - Breast and ovarian cancer in the same woman
    - Jewish ancestry
    - Breast cancer in a male relative
- One first or second-degree relative with breast cancer at age 45 or younger, plus another first or second degree relative on the same side of the family with sarcoma at age 45 or younger
- Members of the family which has the high-risk breast cancer gene mutation
- Women who may have a high risk of ovarian cancer.

2. Women who have had genetic testing that has shown they have a mutation in a gene that is known to increase the risk of breast cancer.

Contact us:

Familial Breast Cancer Clinic
Princess Alexandra Hospital
Research Wing, Level 4

- Upon arrival in the foyer of the main hospital, walk straight past Starbucks and down the corridor
- You will come to an open air seating area on your right
- Head towards this area but keep left and walk down the pathway towards the R-Wing
- Take lifts up to Level 4

Mobile: 0455 890 420

Partnering with Consumers - 2.9 Where information for patients carers, families and consumers about health and health services is developed internally, the organisation involves consumers in its development and review. *Standard 2, 2nd edition*

Date created: November 2019
Review date: November 2022
Brochure no. PIB0547/v1

Queensland Government