Younger women with breast cancer
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Introduction

This booklet looks at the different issues, feelings and experiences you may have as a younger woman diagnosed with primary breast cancer. This is breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm (axilla).

Breast cancer is not common in younger women, so being diagnosed at a younger age can be very isolating. However, every year in the UK, around 5,000 women under the age of 45 are diagnosed with breast cancer. The thought of having cancer may never have crossed your mind, or it might be something you thought only happened to older people.

We hope that this booklet will address many of your concerns. If you have further questions, need more information or would like to know how other women in your situation have been affected, see ‘Helping you face breast cancer’ on page 56.

You may find it useful to read our booklet Breast cancer and you: diagnosis, treatment and the future which looks at emotional issues that people with breast cancer may face at any age. We also have a leaflet called Support for younger women with breast cancer, which outlines Breast Cancer Care’s services for younger women.

'I had the perception of breast cancer being an older woman’s illness and I had never heard of someone my age (31) getting breast cancer. When I was diagnosed I remember thinking there may have been a mix up with the results and it was all a huge mistake.'

Indira
Your diagnosis

Most people vividly remember how they felt when they were told they had breast cancer. Whatever your initial feelings, you may go on to experience many different emotions over time. This section looks at how you might feel when you’re diagnosed, how you might go about telling other people, and some other concerns you may have at this time.

Your feelings

Being told you have breast cancer can come as a huge shock. It can be particularly unexpected because of your age. You may find it difficult to take in your diagnosis or question if it’s really true.

You might not know much about breast cancer and feel unprepared to make decisions about your treatment. Having breast cancer at a young age often involves making choices about your future sooner than you would have otherwise. At times you can feel like you’ve lost control over what’s happening in your life and feel isolated, anxious, angry and frightened. These are all common feelings. However, everybody responds differently and you can have some, all or none of these feelings at different stages of your diagnosis and treatment.

‘I was shocked and devastated to hear that I would have to have a mastectomy and chemotherapy. It was really helpful to have my husband with me, though, as he was a huge source of support.’

Ruth
Telling other people

Telling someone you have cancer is difficult whatever your age. As a younger woman you can find it particularly hard to talk to people about your breast cancer. This could be because you have no experience of serious illness, or you’re still coming to terms with the shock of your diagnosis. Talking openly about your cancer and your thoughts and feelings can be difficult, especially at first, but it can make it easier for the people around you to offer help and support.

You might be the first person among your family, friends or work colleagues to be diagnosed with cancer and those close to you might struggle to accept what has happened to you. People can react in various ways. For example, a parent or partner might constantly offer help, advice and support, even if you’d like some space or time alone. Some people will distance themselves from you. For more information on how your diagnosis can affect your relationships with other people, see the section on 'Relationships' on page 42.

'It was really hard, there’s no easy way to tell anybody you have cancer. People were upset but supportive too. I think I gradually told those that needed to know over a few days.'

Sarah

'I told my 16-year-old daughter first and she just cried and I held her. My 19-year-old son was very positive: “You’re young and fit, Mum, you can get over this.”'

Joanne
If you have children, deciding how and what to tell them can be very difficult. It’s probably best to be open and honest as it can be less frightening for them to know what’s going on, even if they don’t fully understand. Children often imagine the worst, or that they have done something wrong, so you may need to reassure them this isn’t the case. There’s no one right way of telling them and so much depends on their age and your family situation. Our booklet *Talking with your children about breast cancer* may help you decide how and what to tell them. Our picture book *Mummy's Lump* might be useful when explaining your breast cancer to young children. You may also like to give a copy of our comic book *Medikidz Explain Breast Cancer* to older children.

'I decided to send a group email to friends as I did not have the emotional energy to contact them individually.'

Ruth

'My mum lives about 120 miles away and I found it very difficult telling her over the phone.'

Vicky
Breast cancer in families

Breast cancer is the most common cancer in women under 40. Most breast cancers are not inherited and do not increase the lifetime risk for other family members.

A small number of women have an increased risk of developing breast cancer because they have a significant family history. A family history records past and present cancers of your blood relatives (people related by birth, not marriage) on both sides of your family over several generations. This includes your mother and father, sons and daughters, brothers and sisters, aunts and uncles, nieces and nephews, cousins, grandparents, great uncles and great aunts. The increased risk may be because they have inherited an altered gene. About 5% of all people diagnosed with breast cancer have one of these genes. The most common breast cancer genes are BRCA1 and BRCA2.

Having breast cancer at a young age can mean being at increased risk of having an altered gene. Depending on certain features of your cancer diagnosis, you may be offered a referral for an assessment to find out if you’re eligible for genetic testing. However, most young women with breast cancer don’t have an altered gene.

Women diagnosed with triple negative breast cancer under the age of 40 may be referred to a specialist genetics clinic. This is because triple negative breast cancer can be more common in women with an altered BRCA1 gene. Breast cancer is triple negative when it isn’t stimulated to grow by the hormones oestrogen or progesterone or the protein HER2 (you may see this written as ER- PR- HER2-).

"I was diagnosed with a BRCA1 mutation which has impacted significantly on the whole family. We are all grappling with the implications of what this means and our different ways of coping have caused tension and stress."

Tamsin
If you’re concerned about your family history, speak to a member of your breast care team, who may be able to refer you directly to a genetic counsellor (a healthcare professional with specialist knowledge about genetics and inherited illnesses) or clinical geneticist (a doctor with specialist training in genetics).

For more information, you can read our Breast cancer in families booklet. The National Institute for Health and Care Excellence (NICE) is an independent organisation responsible for providing evidence-based national guidance on effective ways to prevent, diagnose and treat ill health. NICE guidance only applies to England. NICE has produced an online guide called Familial breast cancer (breast cancer in the family), available at www.nice.org.uk/guidance/cg164/informationforpublic

**Diagnosis during pregnancy**

Some women are diagnosed with breast cancer during pregnancy or shortly after giving birth. This can lead to many different and complex emotions which can be overwhelming. There’s no evidence that breast cancer during pregnancy is more aggressive than breast cancer occurring at other times. However, for some women there may be a delay in diagnosis because of the difficulty of detecting a cancer in the breast at this time. There’s also no evidence that having breast cancer during pregnancy affects a baby’s development in the womb.

The treatment offered to you if you’re pregnant will depend on the type and extent of your breast cancer and at what stage of your pregnancy it’s diagnosed. Your treatment team will include breast cancer specialists (oncologists) and they will liaise with an obstetrician (a doctor responsible for your pregnancy). Many women choose to carry on with their pregnancy while having breast cancer treatment, although some women choose not to. For more information, see our booklet Breast cancer during pregnancy.

The Royal College of Obstetricians and Gynaecologists (RCOG) has an online publication called Pregnancy and breast cancer. You can find it on the RCOG website www.rcog.org.uk/en/patients
Breast cancer treatments: a summary

Younger women can be offered a number of treatments for breast cancer. Here’s a summary of some of the treatments used. Your specialist team will consider many different factors when deciding the best treatment for you.

- **Surgery** is often the first treatment for most women with breast cancer. It aims to remove the cancer with a margin (border) of normal breast tissue to reduce the risk of the cancer coming back in the breast and try to stop any spread elsewhere in the body.
- **Chemotherapy** uses anti-cancer drugs to destroy cancer cells. Chemotherapy can be given before surgery or after surgery and before radiotherapy.
- **Radiotherapy** uses high energy x-rays to destroy any cancer cells left behind in the breast area after surgery.
- **Hormone therapy** drugs block the effects of the female hormone oestrogen on cancer cells. They’re only used if your breast cancer is hormone receptor positive. The most common drugs used in pre-menopausal women are tamoxifen and goserelin (Zoladex). Clinical trials are looking at whether drugs called aromatase inhibitors may be effective in treating pre-menopausal women with early breast cancer alongside ovarian suppression (see below).
- **Targeted therapy** is a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow. The most widely used is trastuzumab (Herceptin). Only people whose cancer has high levels of HER2 (HER2 positive), a protein that makes cancer cells grow, will benefit from having trastuzumab.
- **Ovarian suppression** involves removing the ovaries or stopping them from working.

For more information about treatments for breast cancer, see our booklets *Treating breast cancer, Chemotherapy for breast cancer, Radiotherapy for primary breast cancer* and our booklets on individual hormone therapies and targeted therapies.
Fertility

Some of the breast cancer treatments you’ll be offered can affect your fertility. The following information describes how different treatments can affect fertility and what options may be available to you.

Talking about fertility

Women often don’t talk to their specialist team about fertility. This could be because they don’t know their treatment can affect fertility, they feel overwhelmed by their diagnosis or they don’t want children. However, some women are extremely concerned about whether treatment will affect their chances of becoming pregnant in future. If you haven’t yet started or completed your family, preserving your fertility can be a priority.

It’s important to discuss any fertility issues with your specialist team before you begin treatment as you’ll need to be referred to a fertility specialist. You should be fully informed about the possible effects of any treatment on your fertility and ways of trying to preserve fertility before your treatment starts.

It’s often possible to have fertility preservation to freeze embryos, or in some cases eggs, for use in the future. You can ask your specialist or breast care nurse to refer you to a fertility clinic to discuss these options.

For more information about talking to your specialist team about fertility and possible ways of preserving it, see our booklet *Fertility issues and breast cancer treatment*.

The Human Fertility and Embryology Authority (HFEA) provides information on fertility services and clinics in the UK. See www.hfea.gov.uk for more information.
What do national guidelines recommend?

The National Institute for Health and Care Excellence (NICE) is an independent organisation responsible for providing evidence-based national guidance on effective ways to prevent, diagnose and treat ill health. NICE guidance only applies to England.

Assessment and treatment may be different in Wales, Scotland or Northern Ireland and your specialist team can tell you more about this.

NICE guidelines for assessing and treating people with fertility issues recommend that women with breast cancer should:

- have the chance to discuss the impact of cancer and its treatment on future fertility with their cancer team at the time of diagnosis
- be offered appropriate procedures to preserve fertility if their breast cancer treatment may lead to infertility, as long as they're well enough to have the procedures, this won't worsen their condition and there's enough time before cancer treatment begins.

The usual criteria for assessing whether someone can have fertility treatment shouldn't apply to people with cancer.

‘With hindsight, I sometimes wish I had thought more about what it might mean to lose my fertility. At the time I was so afraid for my daughter that having another baby was out of the question.’

Tamsin