

Breast cancer in younger women: coping with a diagnosis at 45 or under

breast
cancer
care



This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**



This publication is designed for you to dip in and out of the various sections, depending on what is relevant to you. You might want to come back to different topics later on.

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Introduction

This booklet is for younger women who have been diagnosed with breast cancer. It's been written by Breast Cancer Care, with input from younger women who have had breast cancer.

Inside you can read about some of the common issues faced by women who are diagnosed at a younger age, such as relationships, body image, fertility and pregnancy.

All the quotes are from women who have had breast cancer themselves and are likely to have been through many of the same experiences as you.

We hope this booklet will provide you with information and support from the time you're diagnosed, throughout your treatment and care.

You can order or download any of the Breast Cancer Care publications mentioned in this booklet at breastcancercare.org.uk/publications, or by calling our Helpline on **0808 800 6000**.

We know the needs of younger women with breast cancer are often different to those of older women, and want to make sure you receive care and support that is appropriate and relevant to you. For this reason we have put together our **Standards of care for younger women with breast cancer** – you can find these at the end of the booklet on page 35.

Breast cancer in younger women

Breast cancer is not common in younger women. However, it is the most common cancer in women under 40. The table below shows the average number of new cases of breast cancer between 2012–2014 (latest statistics available when this booklet was printed) for women aged up to 44. It's estimated every year in the UK around 5,600 women aged 45 or younger are diagnosed with breast cancer.

Age	Average new cases reported per year 2012–2014
15–19	3
20–24	32
25–29	226
30–34	626
35–39	1,264
40–44	2,777

Source: Cancer Research UK, cruk.org.uk/cancerstats, accessed January 2017

Being told you have breast cancer

Being diagnosed with breast cancer can be a shock, and you may struggle to take in what you're being told. This can be particularly difficult for women who didn't realise it was possible to get breast cancer at a young age. You may leave the hospital appointment feeling overwhelmed and full of questions. You may be completely numb from the shock. You might feel confused and disorientated, and your mind may race ahead with worries about what's going to happen to you.

These feelings of worry and uncertainty are normal, but it might help to talk to a friend, relative or breast care nurse for support.

Having breast cancer at a young age often involves making choices about your future sooner than you expected. You may feel bombarded with new information and faced with some difficult decisions to make. It's important to ask your specialist team about anything you don't understand, and it can be useful to take a friend or family member with you to your appointments. You might like to take notes, and some people even record the discussion on their phone (with permission), so they can come back to it later.

Our **Primary breast cancer resource pack** has information to help you understand your diagnosis, test results and the treatments available. The pack also includes questions you might want to ask your breast care team.

Breast cancer and you: coping with diagnosis, treatment and the future is a booklet looking at the emotional issues you may face following a diagnosis of breast cancer, and during and after treatment.

'I wasn't aware that young women could get breast cancer. I felt very alone and lonely, and very different to my friends who were getting married and having babies at that time.'

Jenny

'I felt quite isolated, even when waiting on that first day to have the mammogram. Most women there were much older than me – I didn't see anyone my age or younger in the waiting area.'

Janet

Telling people

The thought of telling people about your breast cancer might make you feel anxious, and you may worry about how they will react. It is likely to be a shock to them, particularly as they may not expect it to happen to someone of your age.

It can also be hard for you to talk about the details of your diagnosis. You might feel you don't have all the information to give people just yet, and there might be questions you can't answer. However, talking about your cancer can help you cope with what's happening and start to think beyond the diagnosis. It can also make it easier for people around you to support you.

You may prefer to only tell a few close people, or ask others to help you pass the information on. Who you tell and how you tell them is up to you.

There's no right or wrong way to tell someone that you have cancer, but these tips may help.

Who? Only tell who you want to. You might only want to tell those close to you at first. If you don't want them to pass it on to anyone else, be clear about this.

Where? Choose the time and place that works for you, when you feel comfortable and where you are less likely to be distracted.

What? It can help to tell people the basic facts about your diagnosis and treatment options, and let the conversation progress naturally.

You might find yourself overwhelmed or surprised by the reaction of others. Sometimes people unintentionally say insensitive or hurtful things, or simply become silent – this is usually because they feel awkward or don't know how to help or what to say.

Get some help. Your breast care team can help you think about what to say to people, or you may want a close friend or relative by your side when you break the news. Asking someone you trust to tell other people may take away the burden of having to keep going over the same ground. On the other hand, it may be that the more you talk about it, the easier it gets.

Consider other methods of telling people. Most close family and friends would probably prefer to hear the news in person, but sometimes it's easier or more practical to share the news over the phone. Some even prefer to tell people by email, to allow them to process what they are being told before discussing it further. This might also be easier for you if you feel too emotional to have a conversation about it.

'I decided to tell everyone by text literally within an hour of being diagnosed while I waited for a chest x-ray. I asked for no phone calls because I knew if I had to speak to people on the phone I would break down in tears. I then later called my parents and my brother and sister in the evening, when we had all had a bit of time to let it sink in.'

Rebecca

You can also give people information to read, such as a copy of our **Treating primary breast cancer** booklet, to help them understand the treatments you're having.

'In the end I told a handful of close friends and family and asked them to let other people know as that was easier for me to deal with.'

Janet

'The hardest was telling my mum. She didn't know I had found a lump, as she was going through breast cancer treatment at the time and I didn't want to worry her. She doesn't live near me so I had to tell her over the phone.'

Sarah

Talking to family and friends

When you tell those close to you that you have cancer they may react in different ways. Some will feel upset and cry, some will feel very shocked and others may struggle with how to talk to you.

You may feel under pressure to put on a brave face and stay cheerful to make the people around you feel better. But if you are worried about your future, sharing this can help you to cope. You don't need to stay strong at all times or protect other people's feelings. Often being honest about your feelings makes it easier for you and those close to you to cope.

Sometimes we expect people close to us to know exactly what to do and say. If people aren't being as sensitive as you'd like, it's probably because they are feeling overwhelmed, frightened and helpless. Equally, it can feel like people are avoiding talking to you about your cancer, but

they might just be worried about upsetting you. You may find it helps to talk to people about how you're feeling, and what they can do to help.

Sometimes people with no experience of cancer will withdraw from you and this can be hard. Some people distance themselves and are in denial about what is happening, which can be frustrating. This might stop you feeling able to talk to those close to you, particularly if you have a partner who reacts in this way.

There may also be times when you don't want to talk about your diagnosis. Let your family and friends know if you need a break from discussing your cancer.

Think about how different friends and family can help you, such as who is good to talk with and who can help you with cooking and shopping. They will probably want to help you but might not know how, and giving them direct tasks can make it easier.

'I think people felt like they couldn't bore me with what they felt were little problems, but I told them I wanted to hear about these things as I still wanted to be the same friend to them as I had been before cancer.'

Michelle

Talking to your children

Many younger women who are diagnosed with a serious illness say their first thoughts are about their children. Deciding when and what to tell them may be one of the most challenging things you have to face. It's often best to be open and honest so it's less frightening for them, even if they don't fully understand. Many children can sense when something's going on, and it can be very confusing and stressful for them if they are not included. It's likely they will imagine a situation that's very different from the reality. Keeping secrets is also tiring, and can be difficult to maintain – there's a risk that if you don't tell them, they will find out another way.

For more information, see our booklet **Talking with your children about breast cancer**. If you have young children, our picture book **Mummy's Lump** can be helpful. We have a booklet **Breast cancer and your child's school** to help you communicate with your child's school about your diagnosis and treatment. We also have a comic book **Medikidz explain breast cancer** for 8–15 year-olds.

'My breast care nurse had said to be honest as children get more anxious if they hear whispering behind closed doors.'

Janet

'We didn't say it was life-threatening – but we didn't make promises we couldn't keep about me getting better, either. We just said that I had a bad lump in my booby which the doctors would take away, that I would go on some special strong medicine to make sure it didn't come back and that would make my hair fall out, and that we would do everything we could to help me get better.'

Rebecca

Treating breast cancer in younger women

Most younger women are recommended a combination of treatments. These may include:

- surgery
- chemotherapy
- radiotherapy
- hormone (endocrine) therapy
- ovarian suppression (stopping the ovaries from working either temporarily or permanently)
- targeted therapies (also called biological therapies)

Your specialist team will consider many different factors when deciding the best treatments for you, and the order in which they are given. You can read more about the different treatment options in our booklet **Treating primary breast cancer**. We also have booklets on **Chemotherapy for breast cancer**, **Radiotherapy for primary breast cancer** and on individual hormone therapies and targeted therapies.

You may also be asked to take part in a clinical trial. You can find out more about the trials that are available through the UK Clinical Trials Gateway. Their details are at the end of this booklet.

Bisphosphonates

These drugs are sometimes used to reduce the risk of primary breast cancer spreading to the bones or elsewhere in the body. They are unlikely to be recommended unless your periods have stopped (post-menopausal). This is because the benefits of using them before the menopause are less clear. See 'Menopausal symptoms and the possibility of early menopause' on page 27.

Fertility and pregnancy

Your fertility and breast cancer

Some breast cancer treatments can affect your ability to become pregnant in the future. You may be single or in a relationship; you may not be sure if you want children; or you may be about to start a family. Whatever your situation, it's important to consider the effect of treatment on your fertility before it begins.

While your main concern is probably treating your breast cancer, if having children of your own is important to you then fertility preservation can usually be offered before starting treatment. It's important to discuss any concerns you have with your breast care team early on – they should offer you a referral to a fertility specialist to discuss your options.

Chemotherapy can damage the ovaries, reducing the number and/or quality of eggs. This will depend on the type of chemotherapy drugs used, the dose, your age and your current fertility. Women over 35 having chemotherapy are more likely to lose their fertility by having an early menopause (the time when a woman stops having periods and she's no longer able to get pregnant). Even if you don't go through the menopause and your periods return after chemotherapy, the menopause is still likely to happen sooner (up to 5–10 years earlier) than if you hadn't had chemotherapy.

If your breast cancer has receptors within the cell that bind to the hormone oestrogen (known as oestrogen receptor positive or ER+ breast cancer), you will be offered hormone treatment for up to 10 years. Because of the length of time hormone treatment is taken for, the side effects may hide the start of a natural menopause. It may only be when you finish taking it that you realise you have reached the menopause.

It can be difficult to make a decision about fertility preservation because there is a lot of uncertainty, and you might have to think about children earlier than you planned. You may feel under pressure to make a decision quickly. However it's important to talk about your fertility before treatment for breast cancer starts, to help you plan the most appropriate

treatment for you. There are several fertility preservation options, which are explained in more detail in our booklet **Fertility and breast cancer treatment**.

'I had heard that chemo could affect fertility and I didn't want to be that statistic. So, I started asking questions to ensure I could give myself the best possible chance of having a family. My hospital was hugely supportive.'

Jackie

'I've never wanted children and I was lucky that my husband felt the same. I did struggle with the potential loss of fertility at the end of active treatment which was a shock to me and made me question all that I felt. It was a really tough few months but I saw a counsellor at my local Maggie's centre who helped me see that I was grieving for the loss of choice.'

Jenny

Contraception during treatment

Generally, women are advised not to get pregnant while having treatment for breast cancer. You can discuss methods of contraception with your specialist team.

Women having breast cancer treatment are usually recommended to use non-hormonal methods of contraception, such as condoms, a coil (a type that doesn't contain hormones) or a diaphragm.

Coils containing hormones, such as the Mirena and Jaydess coil, work as a contraceptive by releasing a small amount of the female hormone progesterone. There's limited information about the safety of these coils and breast cancer – currently, the manufacturer doesn't recommend using them in women with a hormone receptor positive breast cancer. However, some oncologists may consider it. You can discuss this with your specialist team.

The contraceptive pill is not commonly advised after a diagnosis of breast cancer. This is because it contains hormones. The morning-after pill can be used in emergencies as it's a single dose of hormones and unlikely to affect your breast cancer.

Even if you have no periods, you can still get pregnant. Generally, you should assume you could still get pregnant unless you haven't had a period for at least a year after completing your treatment if you're 40 or over, or two years if you're under 40. However, this varies for each person. You may be offered a blood test to check your hormone levels.

Diagnosed during pregnancy

Being diagnosed with breast cancer during pregnancy is rare, and you can feel very alone. Finding out you have breast cancer can cause many different emotions, including shock, fear, sadness and anxiety, at a time that is usually considered to be a happy one.

Most women will be able to continue with their pregnancy while having breast cancer treatment. However, some women choose to have a termination. The decision to terminate a pregnancy is a very personal one. It can be made only by you, or you and your partner if you have one, following a discussion with your specialist team and obstetrician.

Our booklet **Breast cancer during pregnancy** addresses issues such as pregnancy, breastfeeding and treatment options. You can talk to others who have been diagnosed during pregnancy on the private Younger Breast Cancer Network Facebook group (see page 38).

The Royal College of Obstetricians and Gynaecologists (RCOG) has a guideline called Pregnancy and breast cancer for patients and Pregnancy and breast cancer (Green-top Guideline No. 12) for healthcare professionals. You can find them by searching on the RCOG website rcog.org.uk

Considering pregnancy after breast cancer

For many women, deciding whether to try to get pregnant after a diagnosis of breast cancer is difficult. If you're able to become pregnant and have a baby after your breast cancer treatment, there's no evidence that this will increase the risk of the cancer returning. There's also no evidence that there are any health risks for children born after breast cancer treatment.

Many specialists advise women to wait for at least two years before becoming pregnant. This is because the possibility of the cancer coming back can lessen over time, and you may be at greatest risk in the first two years after diagnosis.

Waiting for this long may not be appropriate for every woman. If you're thinking about getting pregnant, talk to your specialist. They can help you make an informed choice. You may want to discuss your own individual risk of the cancer coming back as well as other relevant factors, including your age, what treatment you have had and any that's ongoing.

If you're offered hormone therapy, it's usually taken for between 5 to 10 years, by which time you may be facing a natural menopause. Hormone therapy is not given to women who are pregnant or breastfeeding, so some women choose to take a break from hormone treatment if they want to try to get pregnant.

If the length of time taking hormone therapy concerns you, talk to your specialist team. If you're planning to get pregnant after you have finished taking hormone therapy, it's best to wait at least two months to allow time for the drug to leave the body completely.

There is currently a trial called the POSITIVE trial (Pregnancy Outcome and Safety of Interrupting Therapy for Women With Endocrine Responsive Breast Cancer) looking into the safety of interrupting hormone treatment to try to get pregnant. The women in this trial are encouraged to start taking hormone treatment again after the break to try for a baby.

Generally, women are not recommended to get pregnant for at least four to six months after chemotherapy treatment.

The targeted therapy trastuzumab (Herceptin) is normally given for a year and isn't thought to affect fertility. However, you should avoid becoming pregnant while taking it and for at least seven months after treatment has finished. This is because of the possibility of harm to a developing baby.

If your ovaries have been damaged by your breast cancer treatment, it may be possible to become pregnant using eggs donated by other fertile women. The egg is fertilised with sperm from a partner or donor and the embryo transferred to the womb of the woman hoping to become pregnant.

Some women choose other ways to grow their family such as adoption, fostering or surrogacy. There are organisations providing information and support on page 42.

Breastfeeding

If you've had breast surgery and/or radiotherapy, you may have problems breastfeeding from the affected breast. Breastfeeding from a breast previously exposed to radiotherapy can cause mastitis (infection) and this can be difficult to treat. However, many women are able to feed from the unaffected breast. If you have questions about breastfeeding, talk to your specialist team or your midwife.

Family history and breast cancer

Having breast cancer at a young age may mean there is an increased risk that an altered breast cancer gene runs in your family. Around 5% of women with breast cancer have inherited an altered gene. The most common altered genes associated with breast cancer are BRCA1 and BRCA2.

While most cases of breast cancer are not inherited, if you've been diagnosed with breast cancer known as triple negative you may be offered a referral to find out if you're eligible for genetic testing.

Most young women with breast cancer haven't inherited an altered gene.

Genetic testing

If you're concerned about your family history, talk to your breast care team. They may refer you to a family history or genetics clinic for further assessment. If the assessment shows you're at high risk, you will be offered genetic counselling and testing.

You should be referred for family history risk assessment if:

- you or one close relative has had breast cancer before the age of 40
- you or one close relative has had breast cancer in both breasts (bilateral breast cancer)
- you have had breast cancer known as triple negative
- you and one close relative have had breast cancer
- you have close relatives who have had breast cancer and others who have had ovarian cancer
- a male relative has had breast cancer
- you are of Ashkenazi Jewish ancestry

You might also be referred if your family has had a number of different cancers.

See our **Family history, genes and breast cancer** booklet for more details.

Relationships

A diagnosis of breast cancer is likely to have a big impact on your relationships with family, friends and loved ones.

‘It put a strain on some of my relationships with friends, some didn’t know what to do or say and kept away really, but most were really supportive and offered to help with cooking, cleaning, etc.’

Janet

Your relationship with your partner

How your diagnosis affects your relationship will probably depend on your personalities, your life experiences and how long you have been together. Often relationships are strengthened, but for some a breast cancer diagnosis can test a relationship to its limits. Your partner is likely to be distressed and feel very anxious. It can help to talk openly about your fears and what impact cancer and treatment has on both of you. This can help you both.

‘My husband and I are much closer. I think as we share a common experience that none of our friends or wider family can understand – he understands some of my fear about it coming back, and the “scanxiety”.’

Jenny

If you are single

If you are single when you're diagnosed with breast cancer it can be difficult to cope on your own, particularly if you live alone and are used to being independent. Most women will reach out to family members and friends for support, but it might be that they don't live nearby or that it isn't practical to have regular contact with them. Or it might just be that there isn't anyone you feel close enough to or comfortable with to talk about how you are feeling.

If you don't have anyone to talk to there are various support groups that have been helpful to other women. Breast Cancer Care's Younger Women Together event is an opportunity to talk about your thoughts and feelings with other younger women with breast cancer, and take part in workshops on relevant topics. If you would prefer to talk to someone one to one, our Someone Like Me service can match you with someone who has had a similar experience to you, who you can then talk to via email or phone. Lots of women find the private Facebook group Younger Breast Cancer Network (YBCN) an invaluable place to talk to other women and exchange ideas and support.

You can find more information about these resources on page 37 of this booklet.

Dating and new relationships

If you aren't in a relationship when you are diagnosed with breast cancer, you may worry about dating again after your diagnosis. You might be worried about how your breast cancer will affect your relationship with a future partner. A lot of women worry about when and how to tell a new partner that they have had cancer – there is no set answer to this and you will probably just know if and when the time is right.

You may also worry about how someone else will react to the physical effects of your cancer and treatment, such as mastectomy scars or a reconstructed breast. You might feel unsure about being intimate with a new partner and anxious about their reaction.

It can help to discuss this with them first to try and take away some of the pressure. Everyone is different and some people will take longer than others to feel comfortable sharing aspects of their diagnosis with a new partner, but it is important to move at a pace that is comfortable for you.

Body image and sexuality

Breast cancer and its treatments can cause changes to your body and the way you look, which can be particularly difficult for younger women. For example, after surgery you'll be left with some scarring. You may lose your hair if you have chemotherapy. Many women also put on weight during or after treatment.

'My long hair and breasts I felt were part of my femininity and appeal and not having those really knocks your confidence.'

Janet

Even though the effects of treatment are often temporary, they can still be very upsetting, and you may feel less confident in your appearance and how other people see you. If you're in a relationship you might be anxious about how your partner will react to these changes; if you are single you may worry about dating and the impact of your breast cancer on a new relationship.

Our booklet **Your body, intimacy and sex** outlines how these changes can alter your body confidence, and how they may affect sex and intimacy. If you have a mastectomy, you might find it useful to read our booklets **Breast reconstruction** and **Breast prostheses, bras and clothes after surgery** to help you consider the different options.

'I really hated towards the end of my treatment when I was losing my eyelashes and eyebrows. I felt very washed out and like I didn't look like me, which I found very upsetting. It did get better and I love my new short hair, which I would never have had the confidence to cut if I hadn't have been forced to!'

Sarah

Menopausal symptoms and the possibility of early menopause

The menopause is the time when a woman stops having periods and is no longer able to get pregnant. This usually happens naturally between the ages of 45 and 55, with 51 being the average age.

Sometimes in younger women, breast cancer and its treatments can bring on an early menopause. This may be distressing if you were hoping to have children of your own, and can feel like you are aging prematurely. Some women choose to have fertility preservation treatment to try and protect their chances of having children in the future (see 'Your fertility and breast cancer' on page 17).

Treatments such as chemotherapy and hormone therapy can result in menopausal side effects. These can include hot flushes, night sweats, vaginal dryness, joint pain, poor concentration and mood swings. Talk with your specialist or breast care nurse if you experience these symptoms – they may be able to help you manage them, or refer you to a specialist menopause clinic for further advice and support.

Even if you don't go through the menopause and your periods return after chemotherapy, the menopause is likely to happen sooner (up to 5–10 years earlier) than if you hadn't had chemotherapy.

For more information, see our **Menopausal symptoms and breast cancer** booklet.

Osteoporosis

Some treatments like chemotherapy and hormone treatment can affect your bones, which can increase your risk of developing osteoporosis in the future. Osteoporosis means 'porous bones' and is when bones become thinner and more likely to break. An early menopause before the age of 45 can lead to low levels of the hormone oestrogen and this can be a risk factor for osteoporosis. It's usually diagnosed with a bone density scan (often called a DEXA scan).

In pre-menopausal women, taking tamoxifen may cause a slight reduction in bone density. This is unlikely to lead to osteoporosis unless ovarian suppression is given as well. However, your risk may be higher if you're 45 or under and your periods have stopped for at least a year.

If your specialist team has a concern about your risk of osteoporosis they may suggest a DEXA scan to check your bone health before you start treatment. For more information see our booklet **Osteoporosis and breast cancer treatment**.

Financial and practical support

If you are diagnosed with breast cancer when you are young, this is likely to be at a very busy stage of your life. You may have an active social life with lots going on, you may be starting to build a career or you might be buying your first home.

‘A breast cancer diagnosis as a younger woman hits you at the most productive time of your life, when relationships are still to be formed, when families are being created and careers are in full throttle. Suddenly, you are knocked on to a different track and you are alone, you become very isolated.’

Victoria

Coping with a breast cancer diagnosis and treatment can make it especially difficult to juggle other responsibilities, particularly looking after children. It can be hard not to feel guilty and inadequate if you can no longer take care of them in the same way you used to. You may feel you’re not being a good parent because you can’t do the things you did before your diagnosis, or that you and your children are missing out.

Trying to manage these responsibilities can feel like you don’t have time to be ill, but there is help available. You can find out more on the ‘Finances and practicalities’ section of our website

breastcancercare.org.uk

Benefits and breast cancer

Breast cancer can affect your financial security during and after treatment. This can be something else to worry about at an already stressful and difficult time, but there is support in place to make it easier.

The benefits system is there to help, though it can be difficult to navigate. The amount of financial help that you are entitled to will depend on the impact your cancer has had on you and your financial circumstances.

You may wish to seek advice from a benefits adviser at Macmillan Cancer Support, Maggie's, or Citizens Advice. Turn2us is a charity that helps people to access welfare benefits, charitable grants and support services. Contact details for these organisations are listed at the end of the booklet.

Work and breast cancer

One of your concerns might be the impact of breast cancer on your day-to-day job. You may worry about taking time off for appointments and treatment, and what your rights are at work. You don't have to tell your employer that you have cancer but it may help them to be supportive and flexible. You have the right for any information you do provide about your breast cancer to be kept private and only discussed with other colleagues with your permission.

Your rights at work

The Equality Act protects people with breast cancer from any discrimination relating to employment, including the recruitment process. For the purposes of the Act, anyone who has or has had cancer is classed as disabled. Employers are required to make reasonable adjustments to help employees either work during treatment, return to work, have time off for medical appointments or continue their treatment and recovery.

Some women choose to carry on working, either full time or part time, during treatment. You may find that working during your treatment gives you satisfaction and helps you focus on something other than the cancer. How much work you feel you are able to do during your treatment, if any, will depend on your health, the type of work you do, how far you have to travel and the side effects you experience from treatment.

Returning to work

Going back to work after a break of a few weeks or months can be difficult. For many women, going back to work can help them return to some kind of 'normality'. If you have taken time off while receiving treatment you can create a 'return to work' plan with your employer to ease yourself back in. You might also consider a phased return to work, where you slowly build up to your normal hours.

Some women feel their current job role no longer suits them, and decide to look for a new one.

For more information and support about work and cancer see the 'Breast cancer and employment' pages on our website [breastcancercare.org.uk/information-support/breast-cancer-employment](https://www.breastcancercare.org.uk/information-support/breast-cancer-employment)

'My cancer diagnosis definitely changed my perspective on life, and after my return to work I changed my job so that it was less stressful and pressured.'

Michelle

Fear of your cancer coming back

If you've been treated for primary breast cancer, it's natural to worry about recurrence (when breast cancer comes back) or secondary breast cancer (when breast cancer cells spread to other parts of the body).

You can find out more about follow-up after treatment and signs and symptoms of recurrence in our booklet **After breast cancer treatment: what now?**

Some events may prove particularly stressful – the days or weeks leading up to your check-ups, the discovery that a friend or relative has been diagnosed with cancer, or the news that someone you met while having treatment is ill again or has died.

If you're finding it difficult to cope, you can talk to other women on our online Forum breastcancercare.org.uk/forum You can also read our tips on managing anxiety on our website breastcancercare.org.uk/managing-stress-anxiety



Moving forward after breast cancer

The end of treatment can be a strange time and many people find it difficult. You may feel nervous about no longer having regular contact with your specialist team, you might find it hard to get back to old routines, or you simply might still be trying to process what has happened to you.

Breast Cancer Care produces a **Moving Forward resource pack** containing information on a wide range of topics that might be relevant to you after treatment. You can order a copy from our website.

‘I think once your active treatment is over and your hair starts growing back and you’re back at work everyone expects you to be “back to normal”.’

Janet

Standards of care for younger women with breast cancer

To help ensure the needs of younger women are not overlooked, we have developed **Standards of care for younger women with breast cancer**. They include the care and support that all younger women with breast cancer should receive, and the important topics you may want to discuss with your breast care team. These standards were developed in consultation with younger women with breast cancer and breast healthcare professionals.

You might want to take the standards of care with you when you meet your breast care team or breast care nurse.

The following describes the minimum standards that should apply to younger women with breast cancer.

Treatment and care

1. You should receive treatment and care that is sensitive to your concerns as a younger woman. This means talking to you about issues that are particularly relevant to younger women, such as fertility.
2. It is important to have a detailed family history taken. Your team may refer you to a family history or genetics clinic for assessment – you will be offered genetic counselling and testing if you're considered at high risk of carrying an altered breast cancer gene.

Planning treatment

3. You should be informed about the risk of an early menopause and be given support for coping with menopausal side effects of treatment. These can include physical and emotional symptoms, such as changes to body confidence, sexual wellbeing and mental function (including concentration, memory and decision-making).
4. Your breast care team should make you aware that some treatments can affect your bones, and tell you about ways to try and minimise this.

Addressing fertility

5. Soon after your diagnosis, your specialist team should discuss the possible impact of treatment on your fertility. You will also be given advice about contraception and pregnancy after treatment. If you're pregnant when diagnosed with breast cancer, you should be referred to a specialist with expertise in treating women diagnosed during pregnancy.
6. You should be offered a referral to a fertility specialist (even if you have no partner) to discuss the options for trying to preserve fertility before starting chemotherapy or hormone treatment. This referral shouldn't depend on local funding arrangements.

You will be given information about the chances of success from fertility treatment and the possible impact of delaying breast cancer treatment.

Getting support

7. Your breast care team should give you access to tailored information and local and national support. This will include the chance to meet or talk to other younger women with breast cancer online, on the phone or face to face.
8. You should get support and information on talking with children about breast cancer and options for communicating with your child's school, if appropriate.
9. It is important you have access to expert financial and employment advice, including information about benefits and rights at work, coping with loss of income during treatment and the effect on your mortgage and insurance.
10. Your specialist team will talk to you about how you are feeling and offer you psychological support if needed. You may also want to discuss your concerns with a skilled counsellor and get help to move forward after treatment.

Where to find more support

At Breast Cancer Care we have a number of services designed specifically for younger women.

Younger Women Together (various locations across the UK)

Younger Women Together is a free two-day event for women aged 45 or younger who have been diagnosed with primary breast cancer in the past three years. Over the two days you will have the opportunity to meet other young women in a similar situation and share your experiences, thoughts and feelings. You can expect guest speakers, workshops and wellbeing sessions, covering topics such as treatment, menopausal symptoms, breast reconstruction, fertility and diet. The sessions are led by experienced healthcare professionals or subject experts.

Someone Like Me

You may prefer to talk to someone on a one-to-one basis via phone or email. Breast Cancer Care can put you in touch with another young woman who has been in a similar situation and is trained to offer support through our Someone Like Me service.

You could also attend one of our Moving Forward courses for information, support and professional guidance on adjusting to life after treatment.

You can find out more about any of our services via our website, or by calling our Helpline on **0808 800 6000**. Alternatively you can contact our team who coordinates these events on **0345 077 1893**.

Younger Breast Cancer Network (YBCN)

The Younger Breast Cancer Network (YBCN) is a private Facebook group set up by younger women who've had breast cancer. It allows you to chat privately with other younger women from the UK and Ireland. The group has over 2,600 members. You can join if you have a Facebook profile, by searching for 'Younger Breast Cancer Network'. You will need to message the main Facebook page and one of the administration team will help you join the group.

Friends and family can offer support, but you may also want to talk to someone who is specially trained in helping people with emotional problems. This could be a counsellor linked to your GP's practice or hospital, or a psychiatrist or clinical psychologist at your hospital who works with cancer patients. Your specialist team or breast care nurse can advise you on how to get further help.



breast
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breast cancer and you: breast care



When you have breast cancer, you often have a lot of questions. Our Breast Cancer Care team will help you understand the treatments, side effects and options you have over a long and we have the support you need.

For more support and information, call our free helpline on 0800 11 11 11 or visit www.breastcancer.org.uk

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Breast Cancer Care
100, The Quadrant, London SE1 1UL
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www.breastcancer.org.uk

Useful organisations

Clinical trials

UK Clinical Trials Gateway

Website: ukctg.nihr.ac.uk/clinical-trials

Provides information to help people make informed choices about taking part in clinical trials, including guidance on how trials work and details of current trials.

Cancer and long-term illness

Ellie's Friends

Website: elliesfriends.org

Ellie's Friends is a directory of free and discounted services or products for adults living with cancer.

The Osborne Trust

Website: theosbornetrust.com

Trust for children aged 16 and under who has a parent (or parents) with cancer. Provides access to recreational activities during the parent's (or parents') treatment.

Shine Cancer Support

Website: shinecancersupport.co.uk

Shine Cancer Support supports young adults in their 20s, 30s and 40s living with any type of cancer diagnosis. Shine creates tailored events and get-togethers allowing people to meet with others in a relaxed environment.

Premature (early) menopause

The Daisy Network

Website: daisynetwork.org.uk

Email: info@daisynetwork.org.uk

The Daisy Network is a support group for women who have experienced a premature menopause. Members of the network can share their experiences with one another and find further information about premature menopause and its effects.

Fertility preservation

Human Fertilisation and Embryology Authority (HFEA)

Website: hfea.gov.uk

Email: enquiriesteam@hfea.gov.uk

Telephone: 020 7291 8200

This organisation monitors and licenses all fertility clinics in the UK. It produces a list of centres providing fertility preservation as well as information about the different procedures.

Breast cancer during pregnancy

Mummy's Star

Website: mummysstar.org

Email: info@mummysstar.org

Mummy's Star is a charity for women and their families affected by cancer during pregnancy or shortly after a birth.

Adoption, fostering and surrogacy

Adoption UK

Website: adoptionuk.org

Provides information about adoption and support for adoptive families.

British Association of Adoption & Fostering

Website: baaf.org.uk

Provides information on adoption and fostering, and works with everyone involved with adoption and fostering across the UK.

Surrogacy UK

Website: surrogacyuk.org

Surrogacy UK was created by experienced surrogate mothers. They wanted to form an organisation that reflected their experience of what makes surrogacy work.

Body image and self-confidence

Look Good Feel Better

Website: lookgoodfeelbetter.co.uk

Telephone: 01372 747 500

Look Good Feel Better is a cancer support charity providing free services (such as pamper and make-up days) for women experiencing the visible effects of cancer treatment.

Odyssey Challenging Cancer

Website: odyssey.org.uk

Email: info@lgfb.co.uk

Odyssey is a charity that supports people with cancer to overcome certain challenges. The challenges are based mainly outdoors.

Family history

Guidelines for people with a family history of breast cancer (England)

National Institute for Health and Care Excellence (NICE) –
Familial breast cancer (CG164)

nice.org.uk/Guidance/CG164

BRCA Umbrella

Website: brcaumbrella.ning.com

A social network (including a blog, forum and local support group network) for people at high risk of breast cancer, BRCA gene carriers, and their family and friends.

Financial and practical support

Citizens Advice

Website: citizensadvice.org.uk

The Citizens Advice service helps people resolve their legal, financial and other practical issues by providing free, independent and confidential advice.

Macmillan Cancer Support

Website: macmillan.org.uk

Helpline: 0808 808 0000

Macmillan offers a wide range of support including information, support centres, online communities and a benefits advice line.

Maggie's centres

Website: maggiescentres.org

You can get confidential advice about benefits by contacting a Maggie's Benefits Adviser at your local Maggie's centre or online.

Turn2us

Website: turn2us.org.uk

Turn2us is a national charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services.



4 ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone who knows what it's like or want to read more about breast cancer, here's how you can.



Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at **forum.breastcancercare.org.uk**



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at **breastcancercare.org.uk**



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you. Visit **breastcancercare.org.uk/in-your-area**

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate by post

Please accept my donation of **£10/£20/my own choice of £**

I enclose a cheque/PO/CAF voucher made payable to
Breast Cancer Care

Donate online

You can give using a debit or credit card at
breastcancercare.org.uk/donate

My details

Name _____

Address _____

_____ Postcode _____

Email address _____

We might occasionally want to send you more information about our services and activities

Please tick if you're happy to receive email from us

Please tick if you don't want to receive post from us

We won't pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG,
Chester House, 1-3 Brixton Road, London SW9 6DE



About this booklet

Breast cancer in younger women was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



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For a large print, Braille, DAISY format or audio CD version:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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