

BREAST CANCER IN YOUNGER WOMEN



COPING WITH
A DIAGNOSIS
AT 45 OR
YOUNGER

BREAST
CANCER
NOW

The research
& care charity

THIS INFORMATION IS BY BREAST CANCER NOW.

Steered by our world-class research and powered by our life-changing care, Breast Cancer Now is here for anyone affected by breast cancer, the whole way through, providing support for today and hope for the future.

Our breast care nurses, expertly trained staff and volunteers, and award-winning information is all here to make sure anyone diagnosed with breast cancer gets the support they need to help them to live well with the physical and emotional impact of the disease.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancernow.org](https://www.breastcancernow.org)**

**BREAST
CANCER
NOW** The research
& care charity

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INTRODUCTION

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

It may be worthwhile to show this booklet to your family and friends to help them understand how you might be feeling.

Here you can learn 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 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's appropriate and relevant to you. For this reason we have put together our Standards of care for younger women with breast cancer, which you can find on page 8.

We hope this 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 Now publications mentioned in this booklet at **breastcancernow.org/publications**, or by calling our Helpline on **0808 800 6000**.

BREAST CANCER IN YOUNGER WOMEN

Breast cancer is not common in younger women. It's estimated that nearly 6,000 women are diagnosed aged 45 or younger in the UK each year.

The table below show the average number of new cases of breast cancer between 2014–2016 (using latest statistics available when this booklet was printed), for women aged up to 44.

Age	Average new cases reported per year 2014–2016
15–19	2
20–24	35
25–29	258
30–34	717
35–39	1,466
40–44	3,009

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

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. Ensure you receive treatment and care that is sensitive to your concerns as a younger woman.
2. Have a detailed family history taken to assess inherited cancer risk. If appropriate, you should be referred to a cancer genetics service for counselling and told about genetic testing.

Planning treatment

3. Ask about the risk of irregular periods or early menopause as a result of some treatments and be advised on how to cope with these and other effects of treatment. This could include changes to body confidence and sexual wellbeing, as well as your concentration, memory and decision-making.
4. Be aware that some treatments could affect the health of your bones and discuss with your treatment team possible ways to minimise this.

Addressing fertility

5. Talk to your treatment team about the possible effect of treatments on your fertility and be advised about contraception and pregnancy after treatment. If you were diagnosed when pregnant, you should ask to be referred to a specialist with expertise in treating women diagnosed during pregnancy.
6. Ask for a referral to a fertility specialist, if you hope to have children in the future, to discuss options for trying to preserve fertility before starting chemotherapy or hormone treatment. Every breast clinic should have a process for referring women promptly to a fertility specialist. The referral should not depend on local in vitro fertilisation (IVF) funding arrangements. The fertility specialist should tell you about the chances of success from fertility treatment and the possible impact of delaying breast cancer treatment.

Getting support

7. Seek out specialist information and support. This includes meeting or talking to other younger women in a similar situation online, on the phone or face to face.
8. If appropriate, get support and information on talking with children about breast cancer and communicating with your child's school.
9. Seek out expert financial and employment advice. This could include information about benefits and rights at work, coping with loss of income during treatment, and implications for mortgage and insurance.
10. Have your emotional wellbeing assessed and get psychological support if needed.

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 did not realise it was possible to get breast cancer at a young age. You can 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 can feel bombarded with new and difficult information and faced with some hard decisions to make. At your hospital appointments, it may be helpful to:

- Take a family member or friend
- Take notes about your treatment
- Record your appointment on your mobile phone (ask permission first)
- If preserving your fertility is important to you, ask for a referral to a fertility specialist

Our **Treating primary breast cancer** booklet and **Primary breast cancer information pack** have information to help you understand your diagnosis, test results and the treatments available. The pack 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.

Secondary breast cancer

Secondary breast cancer is when the cancer cells from the breast have spread to other parts of the body such as the bones, lungs, liver or brain.

Secondary breast cancer can be treated, but cannot be cured.

If you have been diagnosed with secondary breast cancer, our **Secondary breast cancer information pack** may be useful.

'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 was always the youngest person on the ward. I didn't meet anyone around my age while going through my chemotherapy. It was hard as I found it difficult to connect with anyone. I also found that people felt sorrier for me because I was younger.'

– Hattie

Telling people

The thought of telling people about your breast cancer might make you feel anxious, and you may worry about how they'll react. It's likely to be a shock to them, particularly as they did 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 do not have all the information to give people just yet, and there might be questions you cannot 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 do not 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're 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. Before the conversation it could be helpful to decide how much information you want to share. It's ok to tell people that after a certain point you no longer want to talk about your breast cancer.

You might find yourself overwhelmed or surprised by the reaction of others. Sometimes people unintentionally say insensitive, hurtful or incorrect things, or simply become silent – this is usually because they feel awkward or do not 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. Others prefer to share the information by messaging family and friends or posting it on social media. This might also be easier for you if you feel too emotional to have a conversation about it.

You can also give people information to read, such as our previously mentioned information, to help them understand the treatments you're having.

'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

'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 often 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 can feel under pressure to put on a brave face and stay cheerful to make the people around you feel better. But if you're worried about your future, sharing this can help you to cope. You do not need to stay strong at all times or try to 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 are not being as sensitive as you'd like, it's probably because they're 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 do not want to talk about your diagnosis. Let your family and friends know if you need a break from talking about 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 day-to-day activities. They'll probably want to help you but might not know how, and giving them direct tasks can make it easier.

Talking to your children

Many younger women who are diagnosed with a serious illness say their first thoughts are about their children. Mothers might feel guilty and anxious about what they'll say and how their children will react. You may be afraid of upsetting them or getting upset in front of them.

Deciding when and what to tell your children 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 do not fully understand. Many children can sense when something's going on, and it can be very confusing and stressful for them if they're not included. It's likely they'll 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 do not tell them, they'll 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. Talking with your children's school or nursery can also help provide stability and support at a time of change at home.

'My children knew something was up and I didn't want them to feel we were keeping anything a secret. My mum was also with us at the time.'

– Sarah

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 biological therapy
- Bisphosphonates (may be offered with ovarian suppression or if the ovaries have been removed)

Your treatment team will consider many different factors when deciding the best treatments for you, and the order in which they're given. We have information in print and online about the different treatment options.

You may also be asked to take part in a clinical trial. You can find out more about the trials that are available on the Be Part of Research or Cancer Research UK websites. Their details are listed at the end of the booklet.

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 the breast cancer, if having children of your own in the future is important, then fertility preservation can often be offered before starting treatment. Discuss any concerns you have with your breast care team early on – they should offer you a referral to a fertility specialist to discuss the option of trying to preserve your fertility.

Chemotherapy can damage the ovaries, reducing the number and quality of eggs. This will depend on the type of chemotherapy drugs used, the dose given, your age and what your fertility is like before any treatment. Women aged 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 your periods return after chemotherapy, the menopause is likely to happen sooner (up to 5–10 years earlier) than if you had not 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 therapy for up to 10 years. Due to the length of time taking hormone therapy, its side effects may hide the signs of a natural menopause. It may only be when you finish taking it that you realise you have reached the menopause.

It can be hard to make a decision about fertility preservation because there's a lot of uncertainty, and you might have to think about children earlier than you planned. You may feel you need to make a decision quickly but 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, pregnancy and breast cancer**. The Human Fertilisation and Embryology Authority (HFEA) has further information about fertility preservation. Their contact details are listed in 'Useful organisations' at the end of this booklet.

'I'd urge anyone...

...facing breast cancer to just ask. It's OK to look to life beyond treatment. It's OK to take hormones in a controlled environment for a limited time. It's OK to want to be a mother. And, it's OK to not feel confident or OK about the process. It's big. It's frightening. But ask me if I'd do it again and I'd say absolutely!

– 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 breast cancer treatment. You can discuss methods of contraception with your treatment team. Any hormone therapy given as part of your treatment should not be thought of as a contraceptive.

Women having breast cancer treatment are usually recommended to use non-hormonal methods of contraception, such as condoms, female condoms (Femidoms), a copper coil (that does not contain hormones) or a diaphragm.

Coils containing hormones, such as the Mirena and Jaydess coils, 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 does not recommend using them in women with a hormone receptor positive breast cancer. However, some oncologists may consider it. You can discuss this with your treatment team.

The contraceptive pill is not given after a diagnosis of breast cancer as it contains hormones. However, 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 are not having periods, you can still get pregnant. Generally, you should assume you could still get pregnant unless you have not 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 is a general guide and 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 or soon after giving birth is rare, and women diagnosed at this time 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's usually happy.

Many women can continue 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 treatment team and obstetrician.

Our booklet **Breast cancer during and after 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 (YBCN) Facebook group. You can also get support from Mummy's Star, a charity for women and their families affected by cancer during pregnancy or shortly after birth (see 'Useful organisations' on page 37).

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 currently no evidence that you're at increased risk of the cancer returning. There's also no evidence to date 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. 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've already received and any that's ongoing.

If you're offered hormone therapy, it's usually taken for between five to ten years, by which time you may be facing a natural menopause. Some women choose to take a break from hormone therapy if they want to try to get pregnant.

If the length of time taking hormone therapy concerns you, talk to your treatment team. If you're planning to get pregnant after you've 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's 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 therapy to try to get pregnant. The women in this trial are encouraged to start taking hormone therapy again after the break to try for a baby. This trial is currently not recruiting in the UK.

The targeted therapy trastuzumab is normally given for a year and is not thought to affect fertility. However, you should avoid becoming pregnant while taking trastuzumab 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 donated eggs. 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, while others enjoy life without children. See 'Useful organisations' for more information about this on page 37.

For more information see our booklet **Fertility, pregnancy and breast cancer**.

Breastfeeding

If you have had breast surgery or radiotherapy, you may have problems breastfeeding from the affected breast. Breastfeeding from a breast previously treated with 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 are unable to breastfeed, you may need to look at alternatives such as formula or screened donor milk. Talk to your treatment team or midwife if you have any questions about breastfeeding.

FAMILY HISTORY AND BREAST CANCER

Breast cancer at a younger age may mean there's an increased risk of having an altered breast cancer gene. Around 5% of women with breast cancer have inherited an altered gene. The most common inherited altered genes associated with breast cancer are BRCA1 (BReast Cancer1) and BRCA2 (BReast Cancer2). Inheriting an alteration in another gene called TP53 (tumour protein p53) also increases the risk, although this is much rarer.

While most cases of breast cancer are not inherited, if you've been diagnosed with breast cancer known as triple negative you should be offered a referral to a genetics clinic to discuss genetic testing, regardless of your family history.

Most young women with breast cancer have not 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'll 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 have close relatives who had breast cancer and others who had ovarian cancer
- A male relative has had breast cancer
- You're of Ashkenazi Jewish ancestry

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

See our website breastcancer.org for more information about family history, genes and breast cancer.

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 may 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.

Our booklet **When your partner has breast cancer** provides information and support for people whose partner has breast cancer.

'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

'We were planning our wedding...

...when I was diagnosed. I didn't think my partner would want to marry me now that I had lost a breast and might not be able to have children. But he said he loved me for me. We have now been married 11 years and I believe that cancer made us stronger.'

– Kelly

If you are single

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

If you do not have anyone close there are various support groups that have been helpful to other women. Breast Cancer Now'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 a person 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 in the 'Where to find more support' section on page 35.

I went to a Younger Women Together event that was the most incredible weekend of my life. It was nice to feel normal.

– Samantha

Dating and new relationships

If you're not in a relationship when you're 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's no set answer to this and you'll 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's important to move at a pace that you're comfortable with.

'I started dating again...

...after I finished treatment and was open with new partners about my situation. It wasn't always easy to bring up the conversation, but I decided that if anyone was put off by my diagnosis, they weren't the right person for me anyway. Everyone I met was surprisingly understanding about it.'

– Laura

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 scarring and 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 could make you 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 or if you're 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.

Look Good Feel Better is an organisation offering free workshops to help people deal with the visible side effects of cancer treatment. Visit their website lookgoodfeelbetter.co.uk for more details.

'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 did not 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 had not 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're aging prematurely. Some women choose to seek 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 do not 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 had not had chemotherapy.

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

OSTEOPOROSIS

Some treatments for breast cancer can affect your bones, which can increase your risk of developing osteoporosis. Osteoporosis means 'porous bones' and is when bones become thinner and more likely to break. An early menopause before the age of 45 means 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.

Drugs such as aromatase inhibitors (anastrozole, letrozole and exemestane) can lower the amount of oestrogen in the body and increase the risk of osteoporosis.

If your treatment team has a concern about your risk of osteoporosis they may suggest a DEXA scan to check your bone health before you start treatment.

National Institute for Health and Care Excellence (NICE) guidance for DEXA scans

NICE recommends that people with early invasive breast cancer (cancer that has the potential to spread to other parts of the body) should have a DEXA scan to assess bone density if they're not having bisphosphonate treatment for breast cancer and they:

- Are starting aromatase inhibitors
- Have treatment-induced menopause
- Are starting ovarian suppression treatment

Follow-up DEXA scans may be recommended every two years for some people.

For more information see our booklet **Osteoporosis and breast cancer treatment**.

FINANCIAL AND PRACTICAL SUPPORT

If you're diagnosed with breast cancer when you're 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 planning to go travelling.

'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, families are being created and careers are in full throttle. Suddenly, you're knocked on to a different track and you're 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 make you feel like you do not have time to be ill, but there's help available. You can find out more on the 'Financial support when you have breast cancer' section of our website **breastcancer.org**

'I felt guilty...

...about having cancer. I couldn't do as much with my children as I normally would and thought they were missing out. However, they have come through it positively. I would suggest that people accept help and lower their expectations of themselves for a while during treatment.'

– Julia

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's 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're 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 want to, or have to, continue working during some of your treatment or you might want to take time off. Many people worry about taking time off for appointments and treatment, and what their rights are at work. You do not have to tell your employer that you have cancer but it could help them to be more 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

Most employers will be understanding and your rights as an employee are protected by the Equality Act 2010. This 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're 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. This may be due to the continued side effects of treatment, such as fatigue and having trouble concentrating.

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 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 **breastcancer.org**

'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

Nearly everyone who has been treated for breast cancer worries that it might come back. At first, every ache or pain can worry you. But, as time passes, you may come to accept minor symptoms for what they are in most cases – warning signs of a cold or flu or the result of overexerting yourself.

After a diagnosis of breast cancer many people will naturally start to think about what their prognosis (outlook) might be. People vary greatly as to how much information they want to know, some would rather not think about it while others would like to know as much as possible. Speak to your treatment team if you want to know more about your prognosis.

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 breastcancer.org/forum You can also read our tips on managing anxiety on our 'Managing stress and anxiety' pages on our website breastcancer.org

MOVING FORWARD AFTER BREAST CANCER

The end of treatment following a primary breast cancer diagnosis can be a strange time and many people find it difficult. You may feel nervous about no longer having regular contact with your treatment 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.

We all deal with such anxieties in our own way, and there are no easy answers. But keeping quiet about them and not wanting to bother anyone is probably not the most helpful for you. Just as talking about your diagnosis and treatment may have helped you through the early days, talking about your fears and worries may help you later on. See our **Moving Forward** book for more information on coping with these worries.

'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

If you have had a diagnosis of secondary breast cancer and are having ongoing treatment, see our website for further information and support, as well as details about our secondary support events.

WHERE TO FIND MORE SUPPORT

At Breast Cancer Now 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'll have the opportunity to meet other young women in a similar situation and share your experiences, thoughts and feelings in a safe place. 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.

Younger Women with Secondaries Together is a free two-day event for women aged 45 or younger who have been diagnosed with secondary breast cancer. The event is a chance for you to meet other women in a similar position. As well as whole-group sessions, you'll be able to choose a number of break-out groups led by experts and specialists. Topics include current research and trials, sexuality and intimacy, palliative care and sessions where you can explore the impact a life-limiting diagnosis has had on different areas of your life.

Someone Like Me

You may prefer to talk to someone on a one-to-one basis via phone or email. Breast Cancer Now can put you in touch with another young woman who has had primary breast cancer and 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 coordinate 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. The group has over 3,000 members. You can join if you have a Facebook profile, by searching for 'Younger Breast Cancer Network'. You'll need to message the main Facebook page and a member 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 treatment team or breast care nurse can advise you on how to get further help.

USEFUL ORGANISATIONS

Clinical trials

Be Part of Research

bepartofresearch.nih.ac.uk

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 Research UK

cancerresearchuk.org

Cancer and long-term illness

Ellie's Friends

elliesfriends.org

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

Shine Cancer Support

shinecancersupport.org

Shine Cancer Support helps 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.

The Osborne Trust
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.

Premature (early) menopause

Daisy Network
daisynetwork.org

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)
hfea.gov.uk

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

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

adoptionuk.org

Provides information about adoption and support for adoptive families.

CooramBAAF

corambaaf.org.uk

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

Surrogacy UK

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

lookgoodfeelbetter.co.uk

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

odyssey.org.uk

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

Family history

BRCA Umbrella

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.

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

Financial and practical support

Citizens Advice

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

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

maggies.org

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

Trekstock
[trekstock.com](https://www.trekstock.com)

Trekstock delivers practical and social support programmes tailored to the needs of young adults with a cancer diagnosis, to give them a better chance of living well through and beyond cancer.

Turn2us
[turn2us.org.uk](https://www.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.

FOUR WAYS TO GET SUPPORT

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



Speak to our nurses or trained experts. Call our free Helpline on **0808 800 6000** (Monday to Friday 9am–4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it's like to have breast cancer.



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.breastcancer.org**



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



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 **breastcancer.org/in-your-area**

SUPPORT FOR TODAY HOPE FOR THE FUTURE

We believe that we can change the future of breast cancer and make sure that, by 2050, everyone diagnosed with the disease lives – and is supported to live well. But we need to act now.

If you found this booklet helpful, use this form to send us a donation.

Donate online

Donate using your debit or credit card breastcancernow.org/donate

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 Now

Name _____

Address _____

_____ Postcode _____

Email address _____

Telephone _____

Keeping in touch with Breast Cancer Now

We'd like to tell you ways you can help further, including through donating, fundraising, campaigning and volunteering, and send you updates on our research, the support we provide, breast health information and our wider work to achieve our aims.

If you already hear from us, we will continue to contact you in the same way. If you don't already hear from us, please tick the box if you are happy to be contacted by:

- Email
 Mobile messaging

Please return this form to Breast Cancer Now, Freepost RTSC-SJTC-RAKY, Fifth Floor, Ibx House, 42–47 Minories, London EC3N 1DY

How we use your information

From time to time, we may contact you by telephone and post to keep you updated on our work and ways you can help. You can change the way you hear from us at any time by emailing us at supporterengagement@breastcancernow.org or calling us on 0333 20 70 300.

To help us to work more efficiently, we may analyse your information to make sure you receive the most relevant communications, and to target our digital advertising. This may include using publicly available information. You can ask us to stop this at any time, by contacting us using the above contact details.

You can read more about how we will use your information on our website at breastcancernow.org/privacy, or contact us if you'd like a paper copy.



ABOUT THIS BOOKLET

Breast cancer in younger women was written by Breast Cancer Now'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 health-info@breastcancer.org



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health-info@breastcancer.org



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Phone 0345 092 0808
Email health-info@breastcancer.org

BREAST CANCER NOW

The research
& care charity

At Breast Cancer Now we're powered by our life-changing care. Our breast care nurses, expertly trained staff and volunteers, and award-winning information make sure anyone diagnosed with breast cancer can get the support they need to help them to live well with the physical and emotional impact of the disease.

We're here for anyone affected by breast cancer. And we always will be.

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

Breast Cancer Now

Fifth Floor,
Ibex House,
42-47 Minories,
London EC3N 1DY
Phone: 0345 092 0800
breastcancernow.org



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