

# Breast cancer and you: diagnosis, treatment and the future





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# Introduction

This booklet is for anyone dealing with a diagnosis of breast cancer and its treatment. It discusses some of the emotional issues that may arise in the early weeks and months. You may also want to read our booklet **Treating breast cancer**, which describes the range of treatments you may be offered.

This booklet deals mainly with primary breast cancer (breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm). If you have been diagnosed with secondary breast cancer (when cancer cells from the breast have spread to other parts of the body) you may find our **Secondary breast cancer resource pack** helpful.

Younger women (those who have not yet reached the menopause) may find it particularly useful to read our **Younger women with breast cancer** booklet as this looks at the issues that are specific to this group.

Although we refer to 'women' throughout the text, men who have been diagnosed with the disease may also find the information relevant and helpful. Our publication **Men with breast cancer** has been written specifically for men and covers all aspects of breast cancer from a male perspective.

When you have finished treatment you may want to read our resource pack **Moving Forward**. This pack looks at some of the common concerns people have once they have finished their hospital-based treatment.

We hope that this booklet will address many of your concerns, but if you have further questions or want more information, you can call our free Helpline on **0808 800 6000** (Text Relay **18001**). Breast Cancer Care's website has a wide range of Discussion Forums for people with breast cancer. We can also put you in touch with one of our trained volunteers if you would like to know how others in your situation have been affected. More details can be found in the back of this booklet.



# Diagnosis and the early days

**Most women can remember clearly how they felt when they were first told they had breast cancer. Whatever your initial feelings, you will probably go on to experience many different emotions.**

You may be frightened that you are going to die or be uncertain about what the future holds. You may feel shocked or angry and ask 'why me?' or 'what have I done to deserve this?' You may feel relieved that the cancer has been found and is going to be treated.

You may feel determined not to let the cancer take over your life or you may feel disbelief because you don't feel ill. You might be anxious about your treatment or sad because your life is changing. On some days you may feel hopeful, on others very low or anxious.

How you feel is individual to you. There's no list of right or wrong feelings to have and no order you might feel them in. It may help to take time to rest, eat a healthy diet, keep active if you are able to and, when you can, do something you enjoy.

The way you feel about your cancer and how it has affected you and your body will change over time. The concerns you have when you are diagnosed can be quite different from those at the end of treatment and different again years later.

How you react to your breast cancer may depend not only on you but also on those around you or your cultural background. Some women feel they must keep putting on a brave face for family, friends and even for the doctors and nurses looking after them. Others prefer to let their feelings show and draw strength and support from people close to them.



**'My partner was there at the initial "blunt" diagnosis so I did not have to tell him.'**

**Sue**

Most people will meet a specialist breast care nurse during the early days of diagnosis and treatment. They are there to offer support and information to you and your family. Often they will be able to spend time with you, helping you understand your treatment options and supporting you as you go through treatment.

Some women want to learn everything they can about their breast cancer and what it means for their future. They want to know all the treatment options and to decide for themselves what to do next. Others prefer to leave it to their specialist team to decide the best approach to treatment.

Whatever you decide to do, the main thing is that you have as much information as you want and feel comfortable with the decisions you have made. Thinking about questions in advance can help you ensure you get the information you want from your specialist team. See the 'Further support' section on page 37 for suggestions on how to get the information and support you need.

**'I was on my own, and couldn't really understand why they thought it might be a good idea to contact my husband. I think I was bewildered and didn't take in all the information.'**

**Eithne**

**'First time round I had absolutely no idea as there is no history of breast cancer in my family. I had one-year-old twins and everything was just fine and dandy in my life - how unprepared I was for this shock! Luckily my husband was with me and we were told together (I wondered why they were waiting for him to arrive) in the consultant's office at the hospital where I had returned to have the results of the biopsy.'**

**Frances**



**'[I was told] at the hospital with my husband. I had been waiting for 10 days. It helped having someone with me for support. I was in total shock. Part of me knew but I had talked myself into believing I hadn't got it. I thought it was the end and I was going to die. I was so scared.'**

**Lisa**

# Telling people

**Talking about your cancer may be a way of dealing with what has happened, so that you can start to think beyond the diagnosis.**

You may find it difficult to talk openly about your cancer, especially at first. Telling people the basic facts about your diagnosis and options for treatment can be a good way to begin and may lead naturally to talking about how you are feeling. It can also make it easier for the people around you to support you. You may decide it suits you better to tell only a few people. Who you tell and how you tell them is up to you.

Many people will find it hard to know what to say. If you can bring the subject up first it may help put them at ease. If you feel strongly about how you want to deal with things, let your treatment team, family and friends know so they can best respond to your needs.

If you tell everyone you know, you might find yourself overwhelmed or surprised by their reactions. Sometimes you may find yourself having to manage how others feel about your news and even end up reassuring them, which may affect how you feel towards them. People may say insensitive or hurtful things – this is usually because they feel awkward or don't know how to help.

People may tell you about similar experiences they had or heard about. It may be that some stories will make you feel more worried, while others will make you feel reassured.

**'My late husband was devastated when he heard the news - I remember him saying "why you"? My friends and family were very upset for me - and I felt I had to be brave for everyone else even though inside I was screaming NO!'**

**Heather**

**'Family and friends were very supportive but my marriage broke up as my husband had a breakdown and could not cope with my illness.'**

**Rachel**

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 becomes. If you're finding it difficult to explain certain things think about giving people booklets on the topic. For example, you may prefer to give friends and family a copy of our booklet **Treating breast cancer** to help them understand some of the treatments you may be having.

If you have younger children, deciding what to tell them may be one of the most challenging things you have to face. It's probably best to be open and honest as it can be less frightening for them to know what's going on, even if they don't fully understand. You might find these Breast Cancer Care publications useful.

- **Talking with your children about breast cancer** may help you decide what to tell them and how best to do it.
- **Mummy's Lump** may help you explain breast cancer if you have younger children.
- **Breast cancer and your child's school** may help you communicate with your child's school about your diagnosis and treatment.

'Initially my husband didn't seem to take in what I was telling him, both times, but he was supportive. (Just not good at waiting around in clinics or hospital wards.) My children were grown and not at home, but were supportive and kept in touch more than usual, helping out for short periods when my husband was away following a couple of my chemotherapy sessions.'

Cheryl

'The hardest person to tell was my mum, partly because my dad had died seven months earlier and she was now living alone. My partner and I drove down to see her on the Saturday and stayed overnight. On the Sunday morning my brother visited under some pretence and it was then that I told my mum.'

Perlita

## What about work?

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If you are working you may be concerned about telling your employer. How much you want to tell your employer depends on how you feel. You may feel you want to continue working during some of your treatment or you may want to take time off until you have reached a certain point in your treatment. Some types of treatment are tiring (see the section on 'Fatigue' on page 21) and you may have to take some time off work for medical reasons. Most employers will be understanding but whatever you decide, your rights as an employee are protected by the Equality Act.

For information and support about work and cancer see the breast cancer and employment pages on the Breast Cancer Care website [www.breastcancercare.org.uk/breast-cancer-information/impact-breast-cancer/finances-practicalities](http://www.breastcancercare.org.uk/breast-cancer-information/impact-breast-cancer/finances-practicalities) Macmillan Cancer Support also offers information on work and cancer. Visit their website for more details [www.macmillan.org.uk](http://www.macmillan.org.uk)

'The chance of a phased return really helped. I had a lot of energy when I first went back, but found it hard to sustain it. I dropped to four days a week recently.'

Eithne

'When I finished treatment, I made plans for returning to work. Within a month of completing radiotherapy I was back at work on a phased return. Going back to work after such a long time (six months) away was scary. I felt positive about the future.'

Perlita



'I was less happy with the support or lack of it at work. I was an adult education tutor, and my manager failed to obtain cover for the relatively short period I had off work with the DCIS, which meant that I probably returned to work after radiotherapy sooner than I should have.'

Cheryl



# Finding out more

Everyone has different information needs. You may want to learn everything you can about breast cancer and what it means. Knowing about the options for treatment can help you decide what to do next if you are offered a choice. Or you may choose to leave it to your specialist team to decide the best approach to your treatment and what information you need, it's up to you.

It can be very difficult to take everything in when you first hear you have cancer. Often you may only remember small bits of what has been said to you. You may need time and help to get the facts straight, understand what they mean and to ask questions that are important to you. You may also need your family and friends to give you breathing space to take in what's happening.

Any information you receive should be accurate and useful for you. A treatment that is right for one woman with breast cancer may not be right for another. The people who have the most information about your cancer are those in the specialist team looking after you. If you have questions, it may help to make a list of them and take them with you.

You or someone close to you can take notes during your appointment to help you remember what has been said. Our **Primary breast cancer resource pack** contains a number of questions which may be helpful for you to use when talking to your specialist team.

Ask whoever you feel most comfortable with – your specialist, your breast care nurse, or someone else in your specialist team. If they don't know the answer they should be able to find it out for you.

Most cancer outpatient clinics provide a variety of information, so it's worth asking what's available. Breast Cancer Care has information on all aspects of breast cancer and its treatment and you can call our Helpline on **0808 800 6000** for additional information and support. You can also use the Ask the Nurse email service on our website and a specialist nurse will respond to your question.

There's lots of information available, especially on the internet. Some websites are excellent sources of information, but others are less reliable and can be misleading or confusing. The Breast Cancer Care website [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) is a good place to start.

'I took a digital recorder to the appointment at the hospital. The medical professional was initially curious as to why I wanted to record the session. However, everything I had read suggested that it is hard to retain the detail of what is discussed when you have just been told you have cancer.

'I therefore recorded the diagnosis and subsequent discussion about surgery. My partner and I listened back to the recording some time later and were surprised at the difference between what we thought had been said and what had actually been said.'

Perlita

# Making decisions about treatment

Once your breast cancer has been diagnosed and you have had time to take this in, you and your doctors will want to start treatment. Your specialist team will advise you about your treatment, any options available and the advantages and disadvantages of each. You can then take some time to talk things over before you make any decisions.

That doesn't mean you need to rush your decisions about what to do. A few days spent making sure you have all the information you need about your treatment won't make any difference to the outcome and may help you to feel more in control of what's happening to you.

If you're unclear about something ask to have it explained again. You may feel overwhelmed with a lot of new information and it can be useful to take someone with you to appointments who can listen too and help you remember what was said.

Talk to whoever you feel comfortable with – it might be your partner, a family member or a close friend, or your breast care nurse. Breast Cancer Care's Helpline team can discuss your treatment and any options you may have been given and also refer you to other organisations and resources for information and help. The Ask the Nurse email service as well as the Discussion Forums on our website may also be helpful to you in making decisions. See the 'Further support' section on page 37 for more details.

Most people are recommended a combination of therapies which can be given in different orders. These may include:

- surgery
- radiotherapy
- chemotherapy
- hormone therapy
- targeted therapies.

The different treatment options are discussed fully in our booklet **Treating breast cancer**. You may also be asked to take part in a clinical trial. For more information about clinical trials see our website.

Some women may think about not having one, or any, of the treatments offered. This may be for personal or religious reasons, because they think the treatment will do them no good or that it will seriously affect their quality of life, or they may simply be frightened. Even if you think you don't want to accept the treatments being offered, think carefully about the options available to you before making a final decision.

Talking to your breast care nurse or GP (local doctor) may help you reach a decision that's right for you.

*'When I was originally diagnosed, the medical professional pointed out that some women in my position decide to have a mastectomy, although she was recommending a wide local excision and breast conservation. At that stage I did not entertain the idea of a mastectomy. It was only some months later, after I'd completed my surgery and treatment, that I started to think a bilateral mastectomy might be a good idea.'*

*'This was because my younger sister had been diagnosed with breast cancer in both breasts and with a more aggressive form (triple negative) than I had. My mother had died of breast cancer 30 years earlier. I opted for a bilateral mastectomy with reconstruction which took place two years after my original surgery.'*

Perlita

# The effects of treatment

The treatments you have for your breast cancer are likely to affect how you look and feel in some way. It's normal to be concerned about how you look. Wanting to look and feel good isn't vanity, it's part of being human. On some days we feel better about ourselves than on others – whether or not we have cancer.

Many of us buy clothes, wear make-up, treat ourselves to a special day out or a holiday to make ourselves look and feel good. Deep down we may know that who we are is far more important than how we look. However, that can be hard to hang onto when you're feeling unwell and vulnerable.

Some of the effects of treatment may be prevented or minimised, some will be temporary, but a few may not go away. It's normal to feel upset or angry about changes to your body during and after breast cancer treatment and it can be difficult to adjust to these changes.

Talking to your breast care nurse about these changes and how they are making you feel can help. They may suggest further support. It may help to talk to someone who has been in a similar situation. The Breast Cancer Care Helpline can put you in touch with a trained volunteer who has had a similar experience to you.

**'Hair loss was difficult, I am quite a pragmatic person, and didn't expect to be sentimental about losing my hair, but wept when it was falling out in the shower. I coped with my lovely wig, and wore a selection of scarves and hats to cope. As soon as the hair started to grow back, I was happy to go around looking as if I'd had a short crop.'**

**Eithne**

## Changes to your appearance

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Most women have some form of surgery as part of their treatment. Whether you have breast-conserving surgery (usually referred to as wide local excision or lumpectomy) or the entire breast removed (mastectomy), the first time you look at your body after the operation can be difficult. The area is likely to be bruised and swollen, but this will improve over time. Getting information about your operation and what to expect afterwards can help prepare you. Reading our booklet **Your operation and recovery** may help.

You may be given the opportunity to look at your scar before you leave hospital. Some women prefer to do this alone or with a nurse, others like to have a partner, friend or family member with them. Whatever you decide, try not to leave it too long before you look as the delay may make it harder.

**‘The surgery healed well and has left very little scarring. Although the affected breast is now smaller than the other my partner is “not bothered” about it.’**

**Sue**

**‘The cancer diagnosis did not worry me but losing the breast took time to come to terms with.’**

**Rachel**



**‘I have been wearing a prosthesis for nearly five years and find it OK now to deal with. However, I find the mastectomy bras very expensive and normal bras are not ideal for prostheses.’**

**Heather**

For some women, surgery doesn't affect how they feel about themselves, but many others find the changes difficult to accept. For example, you may feel very self-conscious if you are in a communal changing room, particularly at first. Some women feel lopsided or incomplete. Your confidence and self-esteem may be affected and you may feel unfeminine or unattractive.

The way we feel about ourselves can be closely linked to the way we look, and many women want to restore their natural appearance after breast cancer surgery. Some women feel that breast reconstruction can improve their outlook and enhance the quality of their lives after a mastectomy. Others feel just as comfortable wearing a prosthesis (an artificial breast form used to restore shape when some or all the breast has been removed). Some women decide not to have reconstruction or wear a prosthesis. It really is your choice. You may find it useful to read our booklets **Breast reconstruction** and **A confident choice: breast prostheses, bras and clothes after surgery** to help you consider the available options.

Depending on your treatment you may see other changes in your appearance such as skin changes, hair loss, weight loss or weight gain. Even though most of the effects may be temporary, they can be very upsetting and change the way you feel about yourself, not least because they can be an outward sign of having cancer.

In most cases something can be done to help you manage these problems. Your chemotherapy nurse will advise you if you are likely to lose some or all of your hair and can order a wig for you in advance. Alternatively, you may decide to use hats or scarves to cover your head. For more information see our **Chemotherapy for breast cancer** and **Breast cancer and hair loss** booklets.

**'I didn't lose a breast, but despite wide local excision to both breasts I am noticeably lopsided, sometimes more than others. I usually put a bit of padding in one bra cup to make this less noticeable. It hasn't stopped me from wearing swimming costumes though.'**

**Cheryl**

A close-up portrait of a woman with shoulder-length, straight, light brown hair and bangs. She has a gentle smile and is looking slightly to the right of the camera. She is wearing a bright orange top and a black necklace with white beads. The background is a soft, out-of-focus green and blue, suggesting an outdoor setting.

I had a lumpectomy first time round so I didn't lose a breast. I am still fairly conscious of my scar near my armpit and the "dent" in my breast that shows if I am not wearing a bra, but otherwise, thank goodness for gel bras and chicken fillets!

Frances

## Lymphoedema

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Another possible side effect of treatment is lymphoedema.

Lymphoedema is a swelling caused by a build-up of fluid that may occur following surgery or radiotherapy for breast cancer. If someone develops lymphoedema after breast cancer treatment it most commonly affects the arm, hand or breast/chest area on the same side as the treated breast.

If you develop lymphoedema, your breast care nurse or lymphoedema specialist will be able to advise you about different treatments and how to care for your arm and skin. This may include doing a range of exercises and wearing a compression sleeve. For more information see our booklet **Living with lymphoedema after breast cancer treatment**. If you would like to read more about reducing the risk of lymphoedema, see our factsheet **Reducing the risk of lymphoedema**.

## Fatigue

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Fatigue is something that many women experience at some point during or after their treatment. It can last for weeks, months or even a few years in some cases. Fatigue is different from normal tiredness – it's more extreme and unpredictable and doesn't go away with normal rest or sleep. It can affect you both physically and emotionally and have an impact on how you feel and cope with everyday life.

You may be able to identify a pattern to your fatigue and plan activities around this (there's a fatigue diary to download on the Breast Cancer Care website). Where possible, try to take things easy and don't be too hard on yourself if you can't do as much as you used to. Pace yourself if you can; for example, by taking up offers of help with shopping, transport, childcare or housework.

If you work full time, you might be able to ask to work part time for a while or rearrange your hours. Research has found that for many people, regular, gentle exercise such as walking can really help improve the feelings of fatigue and can be built up gradually, even if at first it feels impossible. It's also important to make time for yourself to relax.

Try to continue with a normal sleep routine, drink plenty of fluids and make the most of the times when your appetite is good – include meals and snacks that give you energy such as bananas or nuts. If you are concerned about your appetite or weight control you may wish to ask to see a dietitian.

**‘Chemotherapy was the hardest – the constant feeling of being sick, the fatigue, insomnia and loss of “control” was really hard to deal with. I felt very angry but had to keep it in and be brave.’**

**Heather**

Some people also find that complementary therapies can be helpful in managing fatigue.

It’s worth telling your doctor or nurse how you feel as sometimes the cause of fatigue can be treated, for example iron supplements may be prescribed for anaemia.

You can get more information about dealing with fatigue by calling the Breast Cancer Care Helpline or using the Ask the Nurse email service on our website. Macmillan Cancer Support also produces a booklet on cancer-related fatigue and how to cope with it. For more details see the ‘Further support’ section on page 37.

## Menopausal symptoms

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'I started having hot flushes when I was on chemotherapy. I would wake up wet on my chest, my neck, my thighs, and my head. I would just go back to sleep. Fortunately, the hot flushes were short-lived and they soon stopped.'

Perlita

Breast cancer treatments such as chemotherapy and hormone therapy can cause menopausal symptoms. These are often more intense than when the menopause happens naturally and can have a considerable impact on how you feel.

You may experience symptoms such as hot flushes, night sweats, vaginal dryness, poor concentration and a general feeling of not being on top of things, though you can get help with most of these symptoms. Even if you have been through a natural menopause before you had breast cancer, you may experience menopausal symptoms again as a result of hormone therapy. For more information, see our booklet **Menopausal symptoms and breast cancer**.

Some breast cancer treatments, such as chemotherapy, can affect fertility – this may be temporary or permanent. If you want to have children, or haven't yet completed your family, this can be a devastating prospect and particularly hard to bear when you are already dealing with breast cancer. If this is happening to you, remember that you don't have to cope on your own. Your cancer specialist or breast care nurse, as well as Breast Cancer Care's Helpline, can support you and guide you on the specialist help available. For more information, see our factsheet **Fertility issues and breast cancer treatment**.

'As for hot flushes, I felt (and do now) that they were not flushes as such, but that my body's thermostat was broken and I got hotter, and hotter and hotter. A "Chillow" helped with this and the painful feet!'

Eithne

'The hot flushes from the tamoxifen were the worst for me – usually at night time which meant my sleep pattern was often disturbed – so I found in the beginning I had a few naps.'

Heather

## Sex and intimacy

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You may find that you lose interest in sex which can be related to the physical and emotional effects of treatment. Pain or numbness after surgery, tiredness, vaginal dryness and changes to body image can all affect how you feel about intimacy and sex. Talking to your breast care nurse or GP may help to work out any physical problems that can be treated. For more information, see our booklet **Your body, intimacy and sex**.

Sometimes partners also have difficulty dealing with what is happening. They may become distant or cope by being very matter of fact. This doesn't mean that they don't care or are rejecting you, but they may not know what to do. You and your partner may find it useful to read our booklet **In it together: for partners of people with breast cancer**.

Talking to each other about how you both feel may be enough. In some cases emotional or sexual problems can arise which may be more difficult to sort out. If this happens, you may want to seek help either together or separately, such as counselling. Your breast care nurse or GP will be able to advise you on counselling services or refer you to a sex therapist, or you could contact an organisation like Relate. See the 'Further support' section on page 37 for more information.

Don't be afraid to talk to your specialist or breast care nurse about any problems you have, psychological or physical, as there is usually help available.

**'Fortunately, I still have feeling in my breast tissue. My partner still finds me attractive and still desires me. However, we have both lost so much as a result of the cancer-related surgery.'**

**Perlita**

# Worries and fears

It is natural to be anxious when you are dealing with a potentially life-threatening illness. Stress and tension can make you touchy and irritable, may stop you eating and sleeping properly, make your muscles tense and your heart race. Concentrating may become difficult.

Realising that there is a problem and going in search of help are two big steps in the right direction. Friends and family can offer support, but you may also want to talk to someone who is specially trained in helping people deal with emotional problems. This may 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. There are a variety of approaches that may be used to help you. Your treatment team or breast care nurse can advise you on how to access further help.

You may be recommended practical techniques, some of which you can learn and practise by yourself. These can help you feel more in control of your life.

## Managing anxiety

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'Once the news stopped getting worse and I had a treatment plan, my anxiety was greatly reduced. I was anxious about chemotherapy, though, and tried to avoid reading about problems with it. Some women on the forum were wonderful in offering realistic reassurance and tips for getting through it all. I kept on with my normal interests and activities (aside from going to work) as much as I could.'

**Cheryl**

Stress and anxiety can make you feel nervous, worried and tense. These feelings can range from being a bit uneasy to a continuing sense of dread and sometimes you may feel panicky and frightened. Stress and anxiety can affect your appetite (stopping eating or comfort eating) and your sleep patterns. Physical signs of stress and anxiety can include muscle tension, tightness in the chest, and a racing heart rate. In some cases anxiety can become so overwhelming that it leads to panic attacks, causing further fear and worry.

If you are experiencing stress and anxiety you might want to talk to someone about how you're feeling. This could be your breast care nurse or GP (local doctor) and they can advise you if more specialist psychological help would be beneficial. Talking to someone who has had a similar experience may also help. You can do this through a local support group or with Breast Cancer Care's One-to-One Support service. There are various techniques and talking therapies specifically designed to help you cope at a difficult time.

- **Distraction:** involves learning to focus on the things around you so that you can shut out negative thoughts.
- **Relaxation, visualisation and meditation:** can be used separately or together to reduce stress and tension, relax the mind and body and help improve wellbeing.
- **Yoga and meditation.**
- **Counselling:** one-to-one counselling takes place in a private and confidential setting. You will be able to explore a range of feelings such as anger, anxiety and grief which can be related to your cancer diagnosis, making them easier to understand and cope with.
- **Cognitive behavioural therapy (CBT):** can help you to change patterns of thinking and behaviour that may be stopping you from moving forward. Unlike some techniques, it focuses on problems and difficulties you are having in the 'here and now'. Instead of exploring causes of your distress or symptoms in the past, it looks for ways to improve your state of mind in the present.

If you think you might benefit from these techniques, your breast care nurse, local cancer information centre or GP will be able to advise you on how to access them.

There are lots of techniques to help with anxiety and you may need to try a few before you find one (or a combination of techniques) that's right for you. Complementary therapies may also help with side effects from breast cancer treatment. In some areas these are available through your local cancer unit. See our **Complementary therapies** booklet for more details.

## Low mood

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**‘On my sister-in-law’s advice, I went to my doctor and she agreed that it was indeed anxiety I was suffering from – and I am now on some medication (low dose) to boost my serotonin levels. I feel much more normal now.’**

**Frances**

Some women find that they become depressed because of their breast cancer diagnosis or the treatment for it. It’s hard to deal with a life-threatening illness and you may find yourself stuck, unable to get beyond thinking that you are going to die or that you will not live to see your children or grandchildren grow up. You may feel that all the enjoyment has gone out of life and you can’t imagine things getting better.

Realising that there is a problem and getting help is the most important thing you can do. While it’s normal to feel low during your treatment, if you find that negative thoughts are interfering with your life, if they don’t go away within a few weeks, or if they keep coming back, it may indicate that you are depressed.

You may find your habits change and you are sleeping or eating more or less than normal. You may feel numb, empty or helpless. You may experience strong feelings of guilt or a lack of self worth. You may lack energy and struggle to do what you normally do, even just getting up in the morning. You may not want to spend time with others, even close family and friends and may be very irritable or find yourself crying at the slightest thing.

You don’t have to ignore these feelings and struggle on. Many people find it hard to admit that they are feeling depressed, or finding it hard to cope, and that they need professional help. It may feel difficult to seek professional advice but there are many effective therapies that can help with low mood and depression.

‘Talking’ treatments such as cognitive behavioural therapy (CBT) can be very helpful and are becoming more widely available either through your GP or at the hospital where you are being treated. Further information about accredited therapists and their methods are available from the organisations listed in the ‘Further support’ section on page 37.

You may be recommended a course of anti-depressant medication. It usually takes between two to six weeks before you notice the effects and start to feel better, although it may take longer to feel the benefits. You may need to take medication for four to six months, or longer. Taking anti-depressants doesn't mean you will become dependent on them, but they can be an extra support during a particularly difficult period.

Your cancer specialist, breast care nurse or GP will be able to talk to you about depression and what support and treatment might be appropriate, and you can also call the Breast Cancer Care Helpline or visit our website to get more information.

## Support groups

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For some women, meeting with other people who are in a similar situation can help to decrease feelings of anxiety, isolation or fear. Breast cancer support groups can provide a sense of community, an opportunity to share your experiences and learn different ways of dealing with problems.

Support groups aren't for everyone. You may prefer to talk to someone on a one-to-one basis. Breast Cancer Care can put you in touch with someone who has been in a similar situation and is trained to offer support. You may find attending one of our Information Sessions or Moving Forward courses (see page 39), another way to meet people who have had similar experiences.

To find out about a support group in your area or for information on one-to-one telephone support, ask your breast care nurse, contact your local cancer information centre or phone Breast Cancer Care's Helpline.

Breast Cancer Care also runs Discussion Forums and regular Live Chat sessions on our website.

These services let people affected by breast cancer give and receive support, share information and talk about their experiences. For more information, see 'Further support' on page 37.

## Worries about breast cancer in your family

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When women are diagnosed with breast cancer they are often worried about whether this will increase the risk of breast cancer for family members. Your diagnosis does not necessarily mean that family members have a significantly higher risk of developing breast cancer.

The majority of cases of breast cancer happen 'by chance' as opposed to being inherited. If you feel worried about this, talk to your cancer specialist who can advise you further. They may refer you to a family history clinic or genetics clinic if your family history suggests a genetic cause. See our **Breast cancer in families** booklet for more details. Family members can also talk to their GP if they are concerned.

**'Initially I wasn't concerned about cancer coming back. After my elder sister's diagnosis five years after mine I'm less sure/confident about it and any implications that may arise from it. It's still very new so I'm still dealing with it. I try not to dwell on it too much and try to look forward.'**

**Sue**



'Few people talk about the continued presence of cancer in your life post-treatment. Fortunately, my partner and I have continued to talk about cancer, about how it has impacted on our lives and continues to do so, and we continue to have these conversations, even now two and a half years post-treatment.'

Perlita

# Moving forward

The end of treatment can be a strange time. Although you'll be glad it's over, it may seem like an anti climax.

## The end of treatment

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You may feel nervous about no longer having regular hospital visits or frequent contact with your specialist. Allow yourself time to rest, recuperate and adjust. This can sometimes take longer than expected, despite the desire to put it all in the past.

Once the treatment has finished, you and the people close to you may be expecting things to get back to normal. But that is often easier said than done. After what you've been through, it may not be easy to go back to working or looking after the family as if nothing has happened – you may feel that things may have changed.

For example, if you work, new systems may have been introduced while you were away. If you have a partner or children at home, they may be less dependent or have adopted a different routine.

You may need to learn how to enjoy yourself again such as planning ahead for outings, holidays and visits to family and friends.

There will be times when your mind wanders and you think about your cancer and its treatment. If there have been permanent changes in the way you look or feel, you may continue to feel sad about this and you don't have to push such thoughts away. It can take a long time to get used to the changes that have taken place and to adjust to life after your breast cancer treatment.

Even though you may have follow-up appointments after your diagnosis, it is important to be breast aware after your treatment. You should check your breast or scar area from time to time, just as anyone who hasn't had breast cancer is encouraged to do. You will need to become familiar with the shape, texture and feel of your breast or chest wall following your initial treatment and report any changes to your hospital team or GP.

'Friends and family expected me to just pick up where I had left off – it was very difficult trying to explain that I had changed – this experience had taken a year of my life and I was not the same!'

Heather

'Most people assumed that I was “cured” and had no further problems. My husband alternates between this and telling me not to do things he considers too heavy for me now.'

Cheryl

'At the end of treatment I had a meltdown for at least two days because all of a sudden I was on my own. What if the cancer came back? Who would be checking up on me? Every pain I felt post-treatment would be followed by me questioning: “Is it cancer again?”'

Heather

'I was scared that people weren't checking me as regularly. I felt now what? Where do I go from here?'

Lisa

## Worries about it coming back

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Nearly everyone who has been treated for cancer thinks about whether it really has gone away or whether it might come back. At first, every odd 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 over-exerting yourself – just those ups and downs we all get. However, because breast cancer can spread to other parts of the body it is important to contact your specialist if you have any symptoms which don't improve over several weeks and have no obvious cause.

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, the news that someone you met while having treatment is ill again or has died.

We all deal with such anxieties in our own way, and there are no easy answers. But keeping quiet about them, not wanting to bother anyone, is probably not the best approach. 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.

**'I think about it nearly every day. I try to forget but it isn't easy. I try to live every day as if it is my last but it's not easy as you get back on the old treadmill of work, family etc. I feel it will always be there and hate checking myself in case there is a lump.'**

**Lisa**

**'I think it is important not to forget what the experience of having cancer was like, as I have learned so much from the experience, as well as lost so much. It would be easy for me to tell myself that having had risk-reducing surgery the cancer will not come back.'**

**'However, such an approach is short-sighted and I recognise that I still need to check myself for signs of a recurrence or a new primary tumour. I also need to ensure that I exercise regularly and eat a healthy diet.'**

**Perlita**

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 specialist team if you want to know more about this.

You may find it helpful to read our booklet **Your follow-up after breast cancer: what's next?** This discusses what happens at the end of treatment and looks at some of the concerns you may have about follow-up appointments. Moving Forward is our dedicated programme of services for those living with and beyond breast cancer, including a **Moving Forward** information pack and local face-to-face events. Call our Helpline or see our website for details.

'I try very hard not to [think about the cancer coming back]. When I let my guard down, I do panic and worry about it. I acknowledged the five year marker in my head. I have had one or two random medical issues, and went to the GP to allay my fears.'

Eithne

# What next?

Months or years after your breast cancer, those who know you well will not have forgotten that you had cancer. But it won't come up in everyday thoughts and conversations, as it once did. It doesn't mean that family and friends don't care, just that life has moved on for all of you. People you meet after your cancer diagnosis may not be aware that you had the disease, and it's up to you to decide what you want to tell them.

Meeting someone new who you might want a sexual relationship with may be a concern. You may worry about whether, how and when to tell them you have had breast cancer or about how they may react to the way your body looks. Like any new friendship, you give and accept information slowly as you build trust between you. But holding back too long can cause problems as well. If you are finding it difficult, you might try working out what you want to say beforehand, or even practising with someone else first.

Many people say that having cancer, a heart attack or other serious illness changes their attitude to life. It makes them take a step back and think about what they are doing and what is important to them.

Having breast cancer will have had an effect on you and those around you and it may take time to come to terms with all that has happened to you. Survival rates are improving all the time with people living longer and leading full lives after being diagnosed with breast cancer.

**'I want to do so much yet feel I am tied to routines. I am no longer bothered about little things in life and people irritate me when they go on about trivial things. I try not to argue over silly things. Life is too short.'**

**Lisa**

**'I completed treatment at the end of March 2010, returned to work on a phased return from the end of April 2010. Then, when the phased return came to an end in mid-June I went with my partner to San Francisco for San Francisco Pride. When we booked the holiday back in the April, I felt quite panicky at the thought of travelling so far. By June, I felt fine about going away.'**

**Perlita**

‘I am more inclined to have a “this isn’t a dress rehearsal” attitude and frequently tell people to go for things as “you’re a long time dead!” I treasure my family and friends and the support they gave me.’

Eithne

‘Sadly two years after my diagnosis my husband was diagnosed with liver cancer and died within four months of diagnosis. So the past five years have been a real challenge in trying to be happy and staying happy. I take each day as it comes and realise that I can’t predict the future and I have to make my life count for something and be the best mum and dad I can be for my son. I have also had friends who I met at the Younger Women’s Forum have secondaries and pass on – so I am mindful that life is a gift – and I am lucky to be still here.’

Heather

# Further support

Being told you have breast cancer can be a very anxious, frightening and isolating time. There are people who can support you so don't be afraid to ask for help if you need it. If you let other people know how you feel and the kind of support you need, particularly your family and friends, they can be more supportive.

Some people find it helpful to discuss their feelings and concerns with their breast care nurse or specialist. If you feel you'd like to talk things through in more depth over a period of time, a counsellor or psychologist may be more appropriate.

**'Breast cancer does not mean the end, it is a journey but you will get there with support and care from family and friends and amazing organisations like Breast Cancer Care. It's OK to cry – you don't have to be brave all the time.'**

**Heather**

Breast Cancer Care is also here to support you. See below for more details on the information and support we can offer you.

## Breast Cancer Care

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From diagnosis, throughout treatment and beyond, our services are here every step of the way. Here is an overview of all the services we offer to people affected by breast cancer. To find out which may be suitable for you call our **Helpline** on **0808 800 6000** or contact one of our centres (details in the inside back of this booklet).

### Helpline

Our free, confidential Helpline is here for anyone who has questions about breast cancer or breast health. Your call will be answered by one of our nurses or trained staff with experience of breast cancer. Whatever your concern, you can be confident we will understand the issues you might be facing, and that the information you receive is clear and up to date. We will also let you know where else you can go for further support.

## Ask the Nurse

If you prefer not to talk directly, we can answer your questions by email instead. Our Ask the Nurse service is available on the website – complete a short form that includes your question and we'll get back to you with a confidential, personal response.

## Website

We know how important it is to understand as much as possible about your breast cancer. Our website is here round the clock giving you instant access to information when you need it. As well as clinical information, you'll find real life experiences and a daily newsblog on stories about breast cancer in the media. It's also home to the largest online breast cancer community in the UK, so you can share your questions or concerns with other people in a similar situation.

Our map of breast cancer services is an interactive tool, designed to help you find breast cancer services in your local area wherever you live in the UK. Visit [www.breastcancercare.org.uk/map](http://www.breastcancercare.org.uk/map)

## Discussion Forum

Through our Discussion Forum you can exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns online. Our dedicated areas for popular topics should make it easy for you to find the information you're looking for. The Discussion Forum is easy to use and professionally hosted. If you're feeling anxious or just need to hear from someone else who's been there, it offers a way to gain support and reassurance from others in a similar situation to you.

## Live Chat

We host weekly Live Chat sessions on our website, offering you a private space to discuss your concerns with others – getting instant responses to messages and talking about issues that are important to you. Each session is professionally facilitated by a moderator and a specialist nurse.

## One-to-One Support

Our One-to-One Support service can put you in touch with someone who knows what you're going through. Just tell us what you'd like to talk about (the shock of your diagnosis, understanding treatment options or how you feel after finishing treatment, for example), and we can find someone who's right for you. Our experienced volunteers give you the chance to talk openly away from family and friends.

## Information Sessions and Courses

We run Moving Forward Information Sessions and Courses for people living with and beyond breast cancer. These cover a range of topics including adjusting and adapting after a breast cancer diagnosis, exercise and wellbeing, and managing the long-term side effects of treatment.

## Lingerie Evenings

For more confidence when choosing a bra after surgery, come along to a Lingerie Evening. Join other women who have had breast cancer for a practical guide to what to look for in a bra, an opportunity to be fitted and a chance to see how the lingerie looks on volunteer models who have all had breast cancer themselves.

## HeadStrong

We can help you prepare for the possibility of losing your hair due to cancer treatment. We'll talk through how to look after your hair and scalp and show you how to make the most of alternatives to wigs, so you leave feeling that you've found something that works for you.

## Information Resources

We produce free Information Resources for anyone affected by breast cancer, including factsheets, booklets and DVDs. They are here to answer your questions, help you make informed decisions and ensure you know what to expect. All of our information is written and reviewed regularly by healthcare professionals and people affected by breast cancer, so you can trust the information is up to date, clear and accurate. You can order our publications from our website or our Helpline. They are also available to download as PDFs (or in some cases as e-books) at

[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

## Specialist support

We offer specific, tailored support for younger women through our Younger Women's Forums and for people with a diagnosis of secondary breast cancer through our Living with Secondary Breast Cancer meet-ups.

## Further reading

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### Coping with fatigue

This booklet looks at cancer-related fatigue and ways of coping with it.

### Work and cancer

This booklet looks at how cancer and its treatments can affect your ability to work.

Both available from Macmillan Cancer Support

## Useful addresses

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### Cancer organisations

#### Macmillan Cancer Support

89 Albert Embankment  
London SE1 7UQ

General enquiries: **020 7840 7840**

Helpline: **0808 808 0000**

Website: **[www.macmillan.org.uk](http://www.macmillan.org.uk)**

Textphone: **0808 808 0121** or **Text Relay**

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. It also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

## Other organisations

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#### Anxiety UK

Zion Community Resource Centre  
339 Stretford Road  
Hulme, Manchester M15 4ZY

Telephone: **08444 775 774** (open Monday to Friday 9.30–5.30)

Admin/office line: **0161 226 7727**

Email **[info@anxietyuk.org.uk](mailto:info@anxietyuk.org.uk)**

Website: **[www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)**

Anxiety UK is a national organisation for those affected by anxiety disorders, run by people affected by anxiety disorders supported by a high-profile medical advisory panel. Anxiety UK works to relieve and support those living with anxiety disorders by providing information, support and understanding via an extensive range of services.

### British Association for Behavioural and Cognitive Psychotherapies (BABCP)

Imperial House  
Hornby Street  
Bury BL9 5BN

Telephone: **0161 705 4304**

Fax: **0161 705 4306**

Email: **[babcp@babcp.com](mailto:babcp@babcp.com)**

Website: **[www.babcp.com](http://www.babcp.com)**

The BABCP is the lead organisation for cognitive behavioural therapy in the UK. It has almost 7,000 members – including nurses, trainees, counsellors, psychologists and psychiatrists. The BABCP is the only organisation which accredits cognitive behavioural therapists.

### British Association for Counselling and Psychotherapy (BACP)

BACP House  
15 St John's Business Park  
Lutterworth  
Leicestershire LE17 4HB

Telephone: **01455 883300**

Email: **[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)**

Website: **[www.bacp.co.uk](http://www.bacp.co.uk)**

BACP aims to promote counselling and psychotherapy and raise standards. It produces a directory of counsellors and psychotherapists, also available online, and will send a list of counsellors and psychotherapists in your area.

### Look Good...Feel Better

West Hill House  
32 West Hill  
Epsom  
Surrey KT19 8JD

Telephone: **01372 747 500**

Email: **info@lgfb.co.uk**

Website: **www.lookgoodfeelbetter.co.uk**

Look Good Feel Better is a cancer support charity, providing practical free services for women and teenagers suffering from the visible side effects from cancer treatment.

### Lymphoedema Support Network

St Luke's Crypt, Sydney Street,  
London SW3 6NH

Information and Support Line: **020 7351 4480**

Email: **adminlsn@lymphoedema.freeserve.co.uk**

Website: **www.lymphoedema.org**

National organisation providing information and support to people with lymphoedema. Provides a variety of materials including factsheets and alert bracelets for people living with, or at risk of, lymphoedema. Also campaigns for better awareness of lymphoedema within the medical profession and for appropriate standards of treatment and ongoing care for everyone affected.

### Mind

15-19 Broadway  
London E15 4BQ

Telephone: **020 8519 2122**

Infoline: **0300 123 3393**

Email: **contact@mind.org.uk**

Website: **www.mind.org.uk**

Mind is an organisation for people who are concerned about their mental and emotional health. Its services include a confidential helpline, drop-in centres, counselling and a range of publications offering coping strategies for life.

## Relate

Premier House, Carolina Court,  
Lakeside, Doncaster DN4 5RA

Telephone: **0300 100 1234**

Email: [enquiries@relate.org.uk](mailto:enquiries@relate.org.uk)

Website: [www.relate.org.uk](http://www.relate.org.uk)

Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face to face, by phone and through their website.

## United Kingdom Council for Psychotherapy (UKCP)

2nd floor, Edward House,  
2 Wakely Street, London EC1V 7LT

Telephone: **020 7014 9955**

Email: [ukap.org.uk](http://ukap.org.uk)

Website: [www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)

UKCP is a regulatory and standard-setting body for psychotherapists and can provide you with a list of UKCP accredited psychotherapists in your area.

## Women's Health Concern

4-6 Eton Place  
Marlow  
Buckinghamshire SL7 2QA

Telephone advice line: **0845 123 2319**

Office phonenumber: **01628 890 199**

Email: [admin@thebms.org.uk](mailto:admin@thebms.org.uk)

Website: [www.womens-health-concern.org](http://www.womens-health-concern.org)

Women's Health Concern is a charitable organisation which aims to help educate and support women with their healthcare by providing unbiased, accurate information.

## Notes

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## Find out more

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We offer a range of services to people affected by breast cancer. From diagnosis, through treatment and beyond, our services are here every step of the way.



SM39

SM25

SM23

SM24

SM36

SM34

To request a free leaflet containing further information about our services, please choose from the list overleaf, complete your contact details and return to us at the **FREEPOST** address or order online at [www.breastcancercare.org.uk/publications](http://www.breastcancercare.org.uk/publications)

## Donate today

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To make a donation please complete your details overleaf and return to us with your cheque/PO/CAF voucher at the **FREEPOST** address: **Breast Cancer Care, FREEPOST RRRKZ-ARZY-YCKG, 5-13 Great Suffolk Street, London SE1 0NS**

Or to make a donation online using a credit or debit card, please visit [www.breastcancercare.org.uk/donate-to-us](http://www.breastcancercare.org.uk/donate-to-us)

## I'd like more information

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Please send me:

- Diagnosis and treatment: support for you (SM39)
- Support for people living with and beyond breast cancer (SM23)
- Support for younger women with breast cancer (SM24)
- Support for people living with secondary breast cancer (SM25)
- Best foot forward: being active after breast cancer (SM36)

## I'd like to donate

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

- I enclose a cheque/PO/CAF voucher made payable to Breast Cancer Care.  
(Please don't post cash.)

Or to make a donation online using a credit or debit card, please visit  
[www.breastcancercare.org.uk/donate-to-us](http://www.breastcancercare.org.uk/donate-to-us)

**Thank you for your kind donation.**

## My details

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Name

Address

Postcode

Email address

From time to time we may wish to send you further information on our services and activities.

- Please tick if you are happy to receive emails from us
- Please tick here if you do not want to receive post from us

Breast Cancer Care will not pass your details to any other organisation or third party.

I am a (please tick):

- person who has/who has had breast cancer
- friend/relative of someone with breast cancer
- healthcare professional
- other (please state)

Where did you get this Breast Cancer Care publication?

Please return this form to **Breast Cancer Care, FREEPOST RRRKZ-ARZY-YCKG,  
5-13 Great Suffolk Street, London SE1 0NS**

This booklet can be downloaded from our website, **[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)** where you can also find the titles we produce as e-books. Publications are available in large print, Braille, audio CD or DAISY format by request on **0845 092 0808**.

This booklet has been produced by Breast Cancer Care's clinical specialists and reviewed by healthcare professionals and people affected by breast cancer. If you would like a list of the sources we used to research this publication, email **publications@breastcancercare.org.uk** or call **0845 092 0808**.

### **Centres**

#### **London and the South East of England**

**Telephone** 0845 077 1895

**Email** [src@breastcancercare.org.uk](mailto:src@breastcancercare.org.uk)

#### **Wales, South West and Central England**

**Telephone** 0845 077 1894

**Email** [cym@breastcancercare.org.uk](mailto:cym@breastcancercare.org.uk)

#### **East Midlands and the North of England**

**Telephone** 0845 077 1893

**Email** [nrc@breastcancercare.org.uk](mailto:nrc@breastcancercare.org.uk)

#### **Scotland and Northern Ireland**

**Telephone** 0845 077 1892

**Email** [sco@breastcancercare.org.uk](mailto:sco@breastcancercare.org.uk)

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please visit [www.breastcancercare.org.uk/donate-to-us](http://www.breastcancercare.org.uk/donate-to-us)



Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call our free Helpline on **0808 800 6000** (Text Relay **18001**).

Interpreters are available in any language. Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.

### **Central Office**

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