

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 elsewhere in the body). If you have been diagnosed with secondary breast cancer (breast cancer that has spread to another part of the body) you may find our booklet **Secondary breast cancer** 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 the disease 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, require more information, or would like to know how others in your situation have been affected, you can call our free Helpline on **0808 800 6000** (Text Relay **18001**). Breast Cancer Care's website also has a wide range of Discussion Forums for people with breast cancer. For further support, we can put you in touch with one of our trained volunteers. More details can be found in the back of this booklet.

Diagnosis and the early days

Most women can vividly remember 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. Some people say that having cancer makes them feel unclean. It can also make you feel guilty about being a burden to others.

You may feel determined not to let the cancer take over your life or you may feel disbelief because you don't feel ill, 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 must have them in.

'I was in a total state of disbelief. This couldn't be happening to me. I didn't feel ill. It was a dream I was going to wake up from and my life would be the same as before.'

Louise

More and more women are living long and full lives after breast cancer treatment. 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 can depend not only on you but also on those around you. 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.

It is important to continue to look after yourself. Take time to rest, eat a well-balanced diet and keep active if you are able to.

‘I felt a little bit like I was in a daze at first. It didn’t really sink in. It helped to have my husband there so that he was fully aware of what was happening and could support me.’

Margaret

‘My husband was with me and seeing his reaction was the worst moment imaginable. His face turned grey in front of me. Having him there was both a help and a hindrance, I was barely holding myself together but to watch him was so much worse, but then I couldn’t imagine going through it alone.’

Susan

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 doctors 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 for your doctor in advance can help you ensure you get the information you want.

See the ‘Further support’ section on page 47 for suggestions on how to get the information and support you need.

‘I had a gut feeling they would tell me I needed surgery but I never thought about a mastectomy. That was the shock, not that I had cancer.’

Mary

‘I found a lump on my right breast but I thought it was a cyst – I never thought cancer was possible as I have no family history. I was a very healthy 40 year old.’

Amanda B





Telling people

Talking about your cancer is 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.

Some 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 medical team, family and friends know so they can best respond to your needs.

If you tell everyone you know, however, you might find yourself overwhelmed or surprised by their reactions. 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.

'Friends were very supportive. A friend of a friend who had been through the same treatment wrote me a lovely letter and gave me advice about coping with treatment. My good friend said she'd come wig shopping with me if I needed her to.'

Eithne

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 later. People may say insensitive or hurtful things – this is usually because they feel awkward.

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 more supported.

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 are finding it difficult to explain certain things you might consider 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.

‘One friend offered to inform others of the situation, so that I didn’t have to keep telling the same story over and over again and then dealing with everyone’s reactions. That was particularly helpful.’

Helen



‘My husband and I invited the family over for dinner and told them during the course of the evening so that everyone knew at the same time.’

Kim

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.

‘I didn’t speak to friends or colleagues for about two weeks – I couldn’t. My husband was great and took over the task of telling those who needed to be told. Eventually I came through the shock and was able to talk about it. The reactions varied. Some friends were vague and distant. Others rose to the occasion and were there for me.’

Susan



‘I told everyone by text as soon as I left the hospital as I didn’t want to have to tell them face to face as I thought that would be upsetting for me. I had loads of texts and phone calls all day from people and everyone was very supportive.’

Kayla



If you are working, how much you want to tell your employers 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 27) and you may have to take some time off work for medical reasons. Whatever you decide, your rights as an employee are protected by the Equality Act.

Breast Cancer Care has produced the EMPLOY Charter to provide employers with guidance on best practice in supporting staff members who have breast cancer. The charter also points out the legal employment rights of cancer patients and the employers' responsibilities under equality law in the UK.

You may find it useful to give your employers this charter and the booklet, **The EMPLOY Charter – Information for employers**, when discussing your diagnosis with them.

'My boss is one of the best. He suggested the company's medical insurance company and agreed to fully support my treatment and told me not to worry about my job or salary.'

Miao



Finding out more

It can be very difficult to take everything in when you first hear you have cancer. You may need help to get the facts straight and to ask the questions that are important to you. You may also need your family and friends to give you breathing space to take in what is happening.

It is important that any information you receive is accurate and applies to you. A treatment that is right for one woman with breast cancer may not be right for another. There is a lot of information available, especially on the internet, but while some websites are excellent sources of information, others are less reliable. The Breast Cancer Care website www.breastcancercare.org.uk is a good place to start.

The people who have the most information about your cancer are those in the specialist team looking after you. You might want to take notes during your appointments. If you have questions, it may help to make a list of them, with the most important ones at the top. 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 booklets and factsheets 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.



Making decisions about treatment

Once your breast cancer has been diagnosed and you have had some time to absorb this news, you and your doctors will want to start your treatment. Your doctors or breast care nurse 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 a decision.

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 are unclear about something it is ok to 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 staff can discuss your treatment and any options you may have been given and 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 help you to make your decision. See the 'Further support' section on page 47 for more details.

Most women are recommended to have 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. See our factsheet **Clinical trials** for more information on these.

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, do think carefully about the options available to you before making a final decision.

The effects of treatment

The treatments you have for your breast cancer are almost certain to affect how you look and feel in some way. 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. Feeling upset or angry about changes to your body during and after breast cancer treatment is perfectly normal and it can take you a long time to adjust to them.

Don't be afraid to ask for reassurance from those who care about you. Talk about your fears and try not to distance yourself from people. Tell them whether you want them to touch you, hug you or just be with you.

'When you think about what is going to happen at the start of chemo it all seems incomprehensible and you don't know how you will bear it. In reality you take on a day at a time and gradually do get through.'

Amanda H

Changes to your appearance

Most women have some form of surgery as part of their treatment. Whether you have a lump removed (called a lumpectomy or wide local excision) or the entire breast removed (mastectomy), the first time you look at your body after the operation may not be easy. The area is likely to be bruised and swollen, but this will improve over time. Getting plenty of information about your operation beforehand can help prepare you. See the 'Further support' section on page 47.

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. The more you delay, the harder it may be.

'I went through the surgery and then came the hard problem of getting new clothing to suit the new me.'

Yvonne



'Surgery didn't bother me at all. I saw it as a way of getting rid of the "thing" inside me and the quicker the better.'

Susan

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 lop-sided or incomplete. Your confidence and self-esteem may be affected and you may feel unfeminine or unattractive.

Because the way we feel about ourselves can be closely linked to the way we look, many women want to restore their natural appearance after breast cancer surgery. Some women feel that breast reconstruction has improved their outlook and enhanced 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 of the breast has been removed). Some women decide not to have reconstruction or wear a prosthesis. It really is your choice. If you are considering any of these options you may find it useful to read our booklets **Breast reconstruction** and **A confident choice: breast prostheses, bras and clothes after surgery**.

'Having an immediate reconstruction was a massive boost to my confidence. Apart from when I was in theatre, I was never without two breasts.'

Mary

'I was resigned to the outcome and my partner has always said "they took away all the bad bits and left all the good bits" and he makes me feel just as attractive as before.'



Janet

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 are an outward sign of having cancer.


In most cases something can be done to help you deal with 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 or choose to cut your hair short. For more information see our **Chemotherapy for breast cancer** and **Breast cancer and hair loss** booklets.

'I lost all my hair but I just thought I'd rather lose my hair for the next few months and then I can have my life back.'

Kayla

'Although devastated at the loss of my hair I was surprised at how I adjusted to wearing bandanas and a wig, and watching as my hair, eye lashes and eye brows slowly returned.'

Louise



'I did not have a reconstruction as I had radiotherapy to come. I could not bear to take off the steri-strips; it took days before I could face doing it. I still look at my body without a breast and can't quite believe it.'

Amanda H

Lymphoedema

Another possible side effect is lymphoedema – a swelling (usually to the arm but it can also affect the treated breast) caused by a build-up of lymph fluid in the tissues as a result of damage to the lymph system because of surgery and/or radiotherapy.

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**. If you would like to read more about reducing the risk of lymphoedema, see our factsheet **Reducing the risk of lymphoedema**.

‘The fatigue wiped me out. Unless you’ve experienced it you can’t understand how it makes you feel. I explained it as being unable, physically or mentally, to even read a book, and waking up as tired as when you went to bed.’

Kim

Fatigue

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 for some women. Fatigue is different from normal tiredness – it is more extreme and unpredictable and doesn’t go away with normal rest or sleep. It can really make a difference to how you feel and how you cope with everyday life.

You may be able to identify a pattern to your fatigue and plan activities accordingly. 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, you might be able to work part-time for a while or rearrange your hours. Research has found that gentle, regular exercise such as walking can really help improve your feelings of fatigue and can be built up gradually, even if at first it feels impossible. Drink plenty of fluids and make the most of the times when your appetite is good. Try to eat regular meals and include snacks which give energy boosts such as nuts and bananas. If you are concerned about your appetite or weight control you may wish to ask to see a dietician.

It’s worth telling your doctor or nurse how you feel as there are ways in which the fatigue may be treated.

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 47

Menopausal symptoms

Breast cancer treatments such as chemotherapy and hormone therapy can cause menopausal symptoms. These are generally temporary but sometimes they can be permanent. The symptoms are often more intense than when menopause occurs 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, such as counselling. For more information, see our factsheet **Fertility issues and breast cancer treatment**.

'I get hot flushes from tamoxifen which are both embarrassing and unpleasant. I try and deal with it by dressing in layers and always having a hankie to hand.'

Jane

'I hate the weight gain as a result of hormone treatment, which has also brought me into an early menopause.'

Carolyn

Sexuality and intimacy

You may find that you lose interest in sex, partly because of how you feel generally but also because of the physical side effects of some treatments, such as vaginal dryness. For more information, see our booklet **Sexuality, intimacy and breast cancer**.

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 (local doctor) will be able to advise you on counselling or you could contact an organisation like Relate. See the 'Further support' section on page 47 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.

'My husband was initially worried to come too close to me after the surgery as he was frightened of hurting me, but this soon passed.'

Kim

'I have found that as time has gone on my self-image has improved, it's been a gradual thing. I am more self-conscious in front of my husband and I have changed the way I dress, and cover up more.'

Amanda H



'I was very bad at concentrating. Sleeping was a problem. I felt tired all the time and tender in my arm. I took anti-depressants for a while.'

Yvonne

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. Sometimes anxiety can become so overwhelming it leads to panic attacks, causing further fear and worry.

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 specialist 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.

'Since being diagnosed three years ago I have trouble concentrating, sleeping and suffer tiredness. My right side is still weak and I find it difficult to do gardening and decorating.'

Amanda B

Managing anxiety

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 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 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 or GP will be able to advise you on how to access them.

Remember that there are many others and you may need to try a few before you find one that is right for you. Complementary therapies may also help with side effects from breast cancer treatment. See our **Complementary therapies** booklet for more details.

'I walked most days to keep active. I did lots of nice things with friends and family, went out to lunch from time to time, and to museums. I watched lots of films, and read and wrote a little.'

Eithne

'As I was off work for a year I got involved in voluntary work when I could and this helped as it gave me an alternative focus.'

Amanda H

Low mood

Some women find that they become depressed because of breast cancer. This can happen at any stage during your treatment or even some time after treatment is finished. It is 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 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 is 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 couple of weeks, or if they keep coming back, it may indicate that you are clinically 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. There's nothing to be ashamed of in admitting that you are feeling depressed, or finding it hard to cope, and that you need professional help. Some people may find it particularly hard to seek professional advice but it can help to relieve these symptoms and allow you to regain control of your life.

There are many effective methods to help with depressed mood (see page 33). 'Talking' treatments such as CBT can be very helpful and are becoming more available either through your GP or the cancer centre where you are being treated. Further information about accredited therapists and their methods can be obtained from the organisations listed in the 'Further support' section on page 47.

While many people do not like the idea of taking tablets, a short course of anti-depressant medication may be recommended. 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 and breast care nurse 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

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 is 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 or phone Breast Cancer Care's Helpline.

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

You also have the option to join others who have had breast cancer in our Telephone Support Groups. These are one-hour group sessions which run for up to eight weeks.

These services let people affected by breast cancer give and receive support, share information and talk about their experiences. For more information, see the 'Further support' on page 47.

'I was worried what the future held but found the support group and relaxation sessions at my local cancer charity centre to be really beneficial. I also had a couple of useful counselling sessions.'

Kim



Worries about your family

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 could also talk to their GP if this is worrying them.





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

You may feel nervous about no longer having regular hospital visits or frequent contact with your specialist. It is important to give 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 – 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. Plan ahead for outings, holidays and visits to family and friends; reward yourself for making progress.

'The majority of people think that when the treatment's all over you'll get back to how you were before cancer, but it isn't like that. You'll always have that little nagging worry in the back of your mind.'

Kim

Even though you may have follow-up appointments for several years 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.

'The feeling was that the safety net had been taken away but there is elation that your life is no longer ruled by hospitals and appointments. Normality can be restored, even if it is a new normality.'

Susan

'I wasn't anxious during treatment as you are always focussed on the next hospital appointment. I got anxious after, worrying if it would come back or not, and will be referred to a clinical psychologist soon. I feel there should be more help at the end of treatment as that is very hard.'

Kayla

'My husband and I went on a romantic holiday to Venice as a reward to ourselves and each other for getting though everything together, and as a celebration too.'

Helen

Has it really gone?

Nearly everyone who has been treated for cancer has niggling doubts about whether the disease really has gone away or whether it might come back. At first, every odd ache or pain can frighten 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.

Moving Forward is our dedicated programme of services for those living with and beyond breast cancer, including a Moving Forward information pack, local events and telephone services. Call our Helpline or see our website for details. You may also 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

'Every now and then I have a wobble but I try and fill my life with friends, plenty of exercise and make a positive effort to get on with my life. It doesn't always work but I try!'

Susan



'I was diagnosed three weeks after I ran the London marathon in 2007. Running it again three years later for Breast Cancer Care was a real turning point. I don't think I'll ever leave it totally behind but I can distance myself from it a bit more now.'

Amanda H

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 since your cancer 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 with whom you might have a sexual relationship may be a concern. You may worry about 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.

'My life is different – it's richer and more satisfying. Cancer can put other problems into perspective.'

Irene

'Since being diagnosed with breast cancer three years ago I've become a volunteer for various cancer organisations and help with campaigns and fundraising. I have used my illness in a positive way and turned my life around.'

Amanda B

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

We all have ideas and plans that never quite get to the top of the list – to travel, to learn a new skill, or to do something you've only ever dreamed of. But with your treatment behind you, you might want to make one or two of those dreams a reality.

'I don't think you'd be human if you didn't worry just a little every now and again about the cancer returning, but I don't dwell on it. I remain positive about the future and think about the many women I know who had cancer 20, 30 or 40 years ago and are still here.'

Kim

'You have to keep moving forward, not continually looking over your shoulder but that can be hard to do sometimes. Allowing yourself the odd bad day means there are far more good ones.'

Helen



'I love life and am much more inclined to just do things, rather than thinking about them as I used to do. I seize the day: if I want to go on holiday I go! If I fancy seeing a play or film or exhibition, I don't spend time wondering how I'll fit it in... I go for it!'

Eithne

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

Breast Cancer Care

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 living with and beyond breast cancer.

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 members 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.

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 Services Map www.breastcancercare.org.uk/map is an interactive tool, designed to help you find breast cancer services in your local area, wherever you live in the UK.

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 your feelings 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.

Telephone Support Groups

Telephone Support Groups offer the chance to be part of a regular support group that you can join easily by phone. The group is professionally run to provide a safe place where you can share experiences and gain support from others in a similar situation. A specialist nurse is also on hand to answer any questions you may have.

Discussion Forums

Through our Discussion Forums 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 Forums are easy to use and professionally hosted. If you're feeling anxious or just need to hear from someone else who's been there, they offer 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 and there's a specialist nurse on hand to answer questions.

Ask the Nurse

If you find it difficult to talk about breast cancer, 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.

Information and Support Sessions and Courses

We run Moving Forward Information and Support Sessions for people living with and beyond breast cancer. These sessions cover a range of topics including adjusting and adapting after a breast cancer diagnosis, exercise and keeping well, and menopause. In addition, we offer Lingerie Evenings where you will learn more about choosing a bra after surgery.

We also offer a HeadStrong service where you can find alternatives to a wig and meet other people who understand the distress of losing your hair. Our Younger Women's Forums, Living with Secondary Breast Cancer courses and SECA support groups for people with secondary breast cancer are also here to offer specific, tailored support.

Information Resources

Our free Information Resources for anyone affected by breast cancer include 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 using our order form, which can be requested from the Helpline. All our publications can also be downloaded as PDFs from our website

Other organisations

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**

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. Over the phone, its cancer support specialists can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and are there if someone just wants to talk. Its website features expert, high-quality information on cancer types and treatments, emotional, financial and practical help, and an online community where people can share information and support. Macmillan also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

General organisations

Anxiety UK

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

Telephone: **08444 775 774**
(open Monday to Friday 9.30am–5.30pm)
Admin/office line: **0161 226 7727**
Email: **info@anxietyuk.org.uk**
Website: **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)

Victoria Buildings, 9-13 Silver Street
Bury BL9 0EU

Telephone: **0161 797 4484**
Fax: **0161 797 2670**
Email: **babcp@babcp.com**
Website: **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: **0870 443 5252**
Email: **bacp@bacp.co.uk**
Website: **www.bacp.co.uk**

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

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/lsn**

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**
MindinfoLine: **0845 766 0163**
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**
Website: **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: **info@psychotherapy.org.uk**
Website: **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 478 473**
Email: **info@womens-health-concern.org**
Website: **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.

Further reading

Coping with fatigue

Macmillan Cancer Support

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

Notes

Find out more

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.



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

Donate today

We hope you found this publication useful. We are able to provide our publications free of charge thanks to the generosity of our supporters. We would be grateful if you would consider making a donation today to help us continue to offer our free services to anyone who needs them.

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

I'd like more information

Please send me:

- Support for people recently diagnosed with breast cancer (SM21)
- Support for people having treatment for breast cancer (SM22)
- 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)

I'd like to donate

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

Thank you for your kind donation.

My details

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 RRKZ-ARZY-YCKG,
5-13 Great Suffolk Street, London SE1 0NS**

A large print version of this booklet can be downloaded from our website, www.breastcancercare.org.uk
It is also available in Braille or on audio CD on request by phoning **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.

Centres

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Telephone 0845 077 1895

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Telephone 0845 077 1894

Email cym@breastcancercare.org.uk

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Telephone 0845 077 1893

Email nrc@breastcancercare.org.uk

Scotland and Northern Ireland

Telephone 0845 077 1892

Email sco@breastcancercare.org.uk

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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 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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www.theinformationstandard.org