



personal experience professional support

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**.

Younger women with breast cancer



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A large print version of this booklet can be downloaded from our website, www.breastcancercare.org.uk. It is also available on audio CD or in Braille on request. Call 0845 092 0808 for more information.

lavender trust
at breast cancer care

The Lavender Trust at Breast Cancer Care raises money specifically to fund our information and support for younger women. We are the only fund in the UK dedicated to addressing the particular needs of this age group.

For more information about how you can help, see www.lavendertrust.org.uk or call 0845 092 0800.



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Introduction

This booklet looks specifically at the different issues, feelings and experiences you may have as a younger woman diagnosed with breast cancer. You may also find it useful to read our booklet **Breast cancer and you: diagnosis, treatment and the future** which looks at emotional issues for people with a breast cancer diagnosis at any age.

Breast cancer is not common in younger women (women who have not yet reached the menopause). Most breast cancers occur in women over the age of 50, so being diagnosed with breast cancer at a young age can be a very isolating experience. The thought of having cancer may never have crossed your mind, or it might be something you thought only happened to older people.

We hope that this booklet will address many of your concerns. If you have further questions, require more information, or would like to know how others in your situation have been affected, see the *Beyond this booklet* section on page 39.

As a younger woman with breast cancer you may find yourself facing a number of issues and concerns that are different to those experienced by older women. To make sure your needs are not overlooked, we have developed our 'Standards of care for younger women with breast cancer', which are listed on page 44. It may be useful to take the standards with you when you meet with your breast cancer specialist or breast care nurse.



Your diagnosis

Your feelings

Being told that you have breast cancer can come as a huge shock and it may be particularly unexpected because of your younger age. You may find it difficult to take in your diagnosis or you may question if it is really true. You might have little knowledge or information about breast cancer and feel unprepared to make decisions about your treatment. Having breast cancer at a young age might also mean making choices about your future sooner than you would have otherwise. At times you may feel a loss of control over what is happening in your life.

A diagnosis of breast cancer can lead to a range of complex emotions including feelings of isolation, anxiety, anger and fear of dying. These are all common and natural emotions.

Everybody responds differently and you may experience some, all or none of these feelings at different stages of your diagnosis and treatment. The time leading up to a breast cancer diagnosis can be difficult, especially if you have had a long wait for tests and results.

'My immediate reaction was immense shock, then fear. My sister was with me when I was told and took charge, asking lots of questions about what treatment lay ahead for me. Having an extra pair of ears there really helped.'

Jackie

'On the day of diagnosis no one actually told me that I had breast cancer, just that I had two malignant tumours and needed a mastectomy. It took weeks to sink in that I actually had breast cancer.'

Amy

'I couldn't believe it when I found out. I had no idea I could get it with me being so young. I felt like I wasn't in the room and I was watching a film of someone else getting told.'

Kayla

'I had a holiday booked to Australia and decided that I would still go – the consultant said it made no difference delaying surgery for three weeks. So I took my lump on holiday, which was how I viewed it, and it gave me time to come to terms with what had happened and to relax without having too much fuss.'

Vanessa

Telling other people

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

You might be the first person among your family, friends or work colleagues to be diagnosed with cancer and those close to you may also need time to deal with the impact of your diagnosis. They may respond in a number of ways. For example, a parent or partner may offer you constant help, advice and support, even if you feel you need some space or time alone. On the other hand, some people may distance themselves from you. For more information on how your diagnosis may affect your relationships with other people, see the *Relationships* section on page 23.

If you have children, deciding what to tell them may be one of the most difficult 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. Children may imagine the worst, or that they have done something wrong, so you may be able to reassure them. There is no one right way of telling them and so much depends on their age and your specific family situation. Our booklet, *Talking with your children about breast cancer*, may help you decide what to tell them and how best to do it. Our picture book, *Mummy's Lump*, might be useful when talking about your cancer diagnosis to young children.

'Telling my parents was really difficult. No child wants to have to tell their parents that they have a potentially life-threatening illness.'

Helen

'I told most people by text so I didn't have to explain it to them face to face.' **Kayla**



'I told people as I prefer to be open and honest about my diagnosis. People acted differently – only two friends didn't respond. Most were shocked but extremely supportive.'

Alison

'I found it very hard telling people initially as I couldn't compose myself. As soon as I started saying "cancer" I would burst into tears.' **Claire**

Familial (hereditary) breast cancer

Hereditary or family-linked (familial) breast cancer is when a faulty gene is inherited from a parent, increasing an individual's risk of developing breast cancer. It is not common – only 5-10 per cent of all breast cancers are hereditary. Certain factors may point towards a genetic link. These include several relatives on the same side of the family having breast cancer or ovarian cancer, or a close relative having breast cancer in both breasts. Being diagnosed with breast cancer under the age of 40 can also suggest a genetic link. However, it is important to remember that the vast

majority of breast cancers are not due to inherited (genetic) factors and many women overestimate their risk of developing breast cancer due to their family history.

Some younger women diagnosed may have a family experience of breast cancer, have been to a family history clinic, a specialist cancer genetic clinic or had genetic testing. If this is the case for you, your diagnosis may have brought up other issues and your treatment may remind you of the experiences of others. There might be concerns about it occurring in other family members, or any children you have or may want to have.

If you are worried about family-linked breast cancer, speak to your breast care nurse or cancer specialist who will be able to discuss referring you to a specialist cancer genetic clinic. If you are already under the care of a family history clinic you may want to contact them to talk about any concerns or issues.

If you would like more information about family-linked breast cancer you may find our **Breast cancer in families** booklet useful. The National Institute for Health and Clinical Excellence (NICE) has also produced an information booklet for

women at risk of familial breast cancer, *Women with breast cancer in the family – understanding NICE guidance – information for women at risk of familial breast cancer, their families and the public.* See the *Finding out more* section on page 41 for details.



'As soon as I found a lump I guessed that it might be breast cancer as I have a family history (paternal grandmother (in her 50s) and mother (in her 40s)). Nevertheless I was surprised at having it so young (30) and angry at the timing.' Adele

Treatment-related issues

There are many different types of treatment for breast cancer and younger women may be offered any or all of the following: surgery, radiotherapy, chemotherapy, hormone therapy, targeted therapy (such as Herceptin) and ovarian suppression or ablation (temporarily or permanently stopping the ovaries from working or removing them altogether). Your specialist team will discuss with you what treatment best suits your cancer and your personal circumstances and in what order it should be given. Your treatment will then be individually planned. If you would like to know more about treatments for breast cancer, see our booklet **Treating breast cancer**.

Although treatments vary from person to person, there are certain issues that will be relevant to many younger women. Some of these issues may be relevant to you now, later on or not at all.

'It is all so much information in such a short time. You do not really have time to think everything through, you just try and make the best decision in a short period of time.' Hester

Fertility

Your specialist's main aim is to treat your breast cancer while causing the fewest possible side effects. However, some of the treatments you may be offered can have an impact on your fertility.

Women who are overwhelmed by their diagnosis, or who do not want children, may not raise the issue of temporary or permanent fertility. Others can be extremely concerned about their chances of becoming pregnant in future. If you have not yet started or completed your family, preserving your fertility may be a priority.

Some breast cancer treatments cause infertility. This may be temporary or permanent depending upon your age and the treatment you are receiving. If fertility is a concern for you, it is important that you are fully informed about the side effects of any treatment, and of possible ways of preserving your fertility. You can ask your specialist or breast care nurse about the different choices available to you. Chemotherapy and ovarian suppression can affect your fertility, and taking tamoxifen may delay your plans for trying to get pregnant. It is not yet known how Herceptin (trastuzumab) may affect fertility. For more information, see our factsheet [Fertility issues and breast cancer treatment](#).



'I was so frightened that I was going to die that being infertile from any drugs or treatment at the time was not an issue for me. That changed later on.'
Claire

'I was frightened about having chemotherapy and the chance that I could be infertile afterwards as I have not yet had children. I'm sad I wasn't able to have some eggs frozen before treatment started.' Jackie

Chemotherapy

Cancer cells grow in a disorderly and uncontrolled way and chemotherapy works by destroying these cancer cells as well as other cells which divide quickly. Younger women with breast cancer are generally offered chemotherapy.

Chemotherapy causes changes within the ovaries that stop eggs being released, which can lead to infertility. Most women's periods will stop or become irregular during chemotherapy and whether they return will depend upon the type of drug(s) used, the dose given and your age. The risk of permanent infertility is greatest if you are over 35 years of age.

For more information on chemotherapy see our [Chemotherapy for breast cancer](#) booklet.

Tamoxifen

Tamoxifen is a hormone treatment that you may be given if your breast cancer is oestrogen receptor positive (ER+). This means that the cancer is stimulated by oestrogen, which encourages the cancer cells to grow. The drug partly works by blocking the effect of oestrogen on breast cancer cells, stopping them growing.

If your cancer is oestrogen receptor negative (ER-) the cancer cells are not stimulated by oestrogen. This means that your cancer would not respond to hormone therapy and so there would be no benefit in taking hormonal drugs like tamoxifen.

Tamoxifen is usually taken for five years and does not directly affect your fertility. However, it does not act as a contraceptive and it is still possible to become pregnant while taking it, although you will be advised not to do so. You may need to use some form of non-hormonal contraception, such as a condom or Femidom. Due to the length of time that it can be taken for (and because its side effects can include menopausal symptoms), tamoxifen may mask the onset of the natural menopause. It may only be when you

finish taking it that you realise you have started your menopause. If you want to have children then taking tamoxifen for the full five years is an issue you can discuss with your specialist team. For more information see our [Tamoxifen](#) factsheet.

Ovarian suppression and ablation

Ovarian suppression and ablation are other types of treatments that may be offered if your breast cancer is oestrogen receptor positive. These treatments stop the ovaries from working (making oestrogen) either permanently or temporarily and can be achieved in one of three ways: radiotherapy or surgery (known as ovarian ablation) and hormone treatment (ovarian suppression).

Radiotherapy is given to the ovaries over a period of a few days. This will gradually stop the ovaries from producing oestrogen. Surgical removal of the ovaries, unlike radiotherapy, achieves immediate ovarian suppression. The effect of both radiotherapy and surgery is permanent.

Alternatively, a hormone drug called Zoladex (goserelin) can be given as

Physical effects

injections. It stops the ovaries from producing oestrogen and its effect only lasts for as long as it is given (although it may take a while for your periods to return to normal after you stop taking it – sometimes up to six months or more).

The type of ovarian ablation or suppression you choose will depend upon your personal circumstances and your medical history.

For more information see our **Ovarian ablation and suppression** and **Zoladex** factsheets.

Diagnosis during pregnancy

Some women are diagnosed with breast cancer during pregnancy or shortly after giving birth and this can lead to many different and complex emotions which

can be overwhelming. The breast cancer itself does not behave differently during pregnancy. Breast cancer develops over time and is not triggered by pregnancy.

The treatment offered to you if you are pregnant will depend on the type and extent of your breast cancer and at what stage of your pregnancy it is diagnosed. Your treatment team will include breast cancer specialists and an obstetrician (a doctor responsible for your pregnancy). Most breast cancer treatments can be given during pregnancy. In some circumstances, your doctors may discuss terminating your pregnancy to receive certain treatments, or you may feel you are unable to concentrate on anything but your breast cancer and its treatment, and choose to have a termination.

For more information, see our factsheet **Breast cancer during pregnancy**.

Treatments for breast cancer can change how you feel physically and how you look. Some of the changes you experience may impact on different areas of your life. It is important to remember that many of these changes will be temporary and there are different approaches that can help you to get through this time.

'The real effect on me, especially at work, was the hot flushes from taking tamoxifen. Trying not to suddenly undress in front of everyone was difficult.' **Claire**

Menopausal side effects

Some treatments for breast cancer can cause side effects usually associated with the menopause. Chemotherapy, tamoxifen and ovarian suppression can all result in menopausal symptoms which may affect your quality of life to varying degrees. You may experience symptoms such as hot flushes, hair thinning, night sweats, vaginal dryness,



fatigue, poor concentration and mood swings. They can have a considerable effect on how you feel and be particularly difficult to adjust to if you are experiencing them at a younger age than you expected to.

Being young and taking tamoxifen can mean that the symptoms are more intense than if you were going through the menopause naturally. Don't be afraid to talk to your specialist or breast care nurse about any physical or emotional problems.

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

Body image

Breast cancer treatments can sometimes change the way your body looks and how you feel about yourself. You may become less confident doing normal day-to-day things you might have taken for granted in the past. You may feel self-conscious about going out in public, for example to the pub or out for a meal. It may be difficult to use public changing areas in clothes shops or at the swimming pool.

Other people may respond to you differently because of changes to how you look. For example, if you have children they can be self-conscious about being seen with you if you have lost your hair or are wearing a wig because of chemotherapy treatment. Certain drugs can make you gain weight. This can change the way you look and you may not feel comfortable with these changes. Other people's reactions are sometimes unexpected and upsetting and it can take time to adjust.

Some issues may be quickly resolved, but others might be more complex and take longer. If you are feeling a general loss of confidence or are concerned about how you look and feel, you may find it useful to talk to a counsellor. Whatever your feelings there are people who will be able to advise and support you during this period. For more information, see the *Beyond this* booklet section on page 39. Your breast care nurse or GP (local doctor) will be able to refer you to a qualified practitioner in your area.

If you are feeling low about your appearance, there are many things you can do to help you look and feel better about yourself. These are described on pages 15 and 16.

'The surgery has impacted on my body image, and initially on my confidence, but that gets easier over time and with support.' Jackie

'I get very self-conscious when I'm at the gym getting changed, as one breast is obviously smaller, having had a lump and surrounding tissue removed. I forget at times when buying clothes now that I can't wear certain things, which is annoying and frustrating.' Claire

Hair loss

Hair loss can be one of the most distressing physical side effects of breast cancer treatment. Your breast care nurse or 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, which can then be cut and styled by your own hairdresser. You can also have your hair cut short before starting treatment so that any hair thinning is less noticeable.

Our booklet **Breast cancer and hair loss** includes practical information on wigs and other headwear, and advice on various ways of tying scarves.

Our *HeadStrong* service provides information and support to people experiencing hair loss as a result of cancer treatment and gives them the opportunity to try a range of scarf-tying techniques, hats and hairpieces. Contact your local Breast Cancer Care centre (listed at the back of this booklet) to see if there is a *HeadStrong* service near you.

'Hair loss wasn't really a big issue for me, although I was upset from time to time when strangers would point and stare.' Gillian

'My hair started falling out after about two weeks. This was unbelievably distressing as I'd wake up in the morning and find my pillow covered in hair.' Vanessa

Breast reconstruction, prostheses and clothes after surgery

The way we feel about ourselves can be closely linked to how we look and many women want to restore their natural appearance after breast cancer surgery. Some women feel that breast reconstruction after a mastectomy has improved their outlook and enhanced their quality of life. Others feel just as

comfortable wearing a prosthesis (an artificial breast form). 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**.

Courses promoting health and wellbeing

You may benefit from joining a programme which offers complementary therapies and gives advice on appearance and self-image to people with cancer. Many hospitals have 'Look Good... Feel Better' programmes which offer informal beauty workshops for women undergoing treatment for any type of cancer. Ask your breast care nurse if there is one in your area. We also run courses to help and support women in improving their sense of wellbeing. See the *Beyond this booklet* section or contact your local Breast Cancer Care centre (listed at the back of this booklet) for further details.



'Clothes have become more of an issue – trying to find fashionable tops/bras/swimming costumes that don't make it obvious that you're wearing a prosthesis can be a challenge! There's always a solution, it might just take a while to find it!' **Helen**

Sexuality

You may find that your sex life changes during and after your treatment. You may feel insecure about your sexuality and your sexual relationships. This can include how you feel about kissing, cuddling, touching, other intimate contact and intercourse. It is important to remember that not everyone will experience problems.

Different treatments may affect you in different ways. Pain following surgery may limit intimacy and sexual intercourse or you may feel uncomfortable with how you look. On a physical level, chemotherapy might reduce your sexual desire or make you feel too unwell to even think about

sex or any kind of intimacy. Radiotherapy may make your breast or chest area too tender to touch, or a lack of sensation in the breast following surgery may alter your feelings and your sense of satisfaction. An early menopause and infertility may also have an effect on your sexuality and can often be linked with sexual problems. Any of these changes may affect your feelings about yourself as a woman.

Whether or not you are experiencing problems, there may be a time of readjustment for you and your partner before you both feel comfortable being intimate again. This may mean exploring together how you feel about being held or touched; for example if your breast or chest area is tender you may find a change of position can help. Whatever your situation, try to talk to each other about how you are feeling. If you are having problems you might find it helpful to talk to your breast care nurse, who may be able to suggest practical solutions, for example a vaginal lubricant if intercourse is uncomfortable.

Some women find that their partners may temporarily lose interest in them sexually or even reject them. This can be particularly difficult to deal with at a time when you need to feel reassured and cared for. However, it may be your

'Our sex life was non-existent for three months after surgery but that was my choice. It was a little frightening and difficult to accept that my husband still wanted me. He was and still is very patient and understanding. I think we are closer now having come through this together.' **Christine**

'I had hot flushes and a dry vagina. I was totally uninterested in sex.' **Claire**

partner's way of trying to be sensitive to your feelings. They might be waiting for you to initiate intimacy when the time is right for you. If possible, talk to your partner about how you feel and if these problems can't be resolved, you may both benefit from discussing them with a counsellor.

If you are single, you may not feel you can meet a new partner or start a sexual relationship. You may be worried about what and when to tell a prospective partner about your breast cancer, or worry how they may react if you are feeling less confident about your body image. When meeting new people it is important to build up a sense of trust. You may feel that there will never be a right time to tell a new partner about your

cancer, but as you become more comfortable in someone's company you may feel able to talk about how you feel.

After your treatment finishes you may find that your sexual relationship returns as before, or you become more sexually active because of a new love of life. However, if you continue to experience difficulties you might find it useful to contact a specialist organisation or a counsellor to discuss your feelings. Your breast care nurse or GP will be able to advise you on what is available in your area.

For more information, see our booklet **Sexuality, intimacy and breast cancer**.

Contraception

Whatever stage of treatment you are at, it is important that you use contraception. Depending on your type of breast cancer, you may be advised to avoid a hormone-based contraceptive such as the pill. This will mean using a barrier method such as a condom or Femidom. Even though you may not have had a period this does not necessarily mean that you cannot get pregnant. See our factsheet on **Fertility issues and breast cancer treatment** for more information.



Psychological and emotional effects

Although your experience of diagnosis and treatment for breast cancer will be individual to you, certain feelings and reactions are common among many younger women throughout the course of their treatment and after it has finished. These can include a sense of loss, uncertainty about the future, worry and low mood. Understanding the different reactions you may experience can help you adjust to what is happening to you.

'I feel less able to "cope" than I did before cancer. Things get on top of me more easily.' Amy

A sense of loss

A feeling of loss is common in younger women diagnosed with breast cancer. Loss can be felt in many different ways and it can be both physical and psychological. Feeling tired or not being as strong is a physical loss of wellbeing. This may mean that you are unable to do everyday tasks and can lead to you feeling frustrated and that things are beyond your control.

It is common to feel a loss of confidence in your health and have a heightened

awareness of your body. For example, you may worry that any ache or pain is a sign that the cancer has come back or has spread. You may also feel that you have lost the opportunity to achieve goals you have set yourself. If you were studying or saving towards buying a house your plans may now be delayed. You may find it takes time before you are able to do all of the things you did before your breast cancer, such as playing a favourite sport or socialising.

At times you may feel an overwhelming sense of loss. You may think that treatment and the way you are feeling may never end. You may be unable to imagine a time when you are well again. It can be reassuring to know that many women experience these feelings and

find ways of coping and adapting to their changed situation. Talking about how you are feeling with your family, friends and healthcare professionals can help you find solutions that are right for you.

'I did find it hard in the beginning to cope with the loss. I saw a psychologist and that really helped me cope with the emotions I was going through. I found it easier to just say what I felt and how I felt, without having to think that I will upset someone.' Hester

Uncertainty about the future

Breast cancer is a potentially life-threatening illness which will almost certainly have made you think about your own death. Other people your age will be getting on with their lives and may not have given any thought to serious illness. This may make you feel angry and cheated that it has happened to you, or sad and anxious that your life has changed so much. It may make you feel different from your friends and you may be frightened about the cancer coming back. If you have children you

may be concerned you will not be there to see them grow up.

It is important to remember that these feelings are perfectly normal. Living with this uncertainty and fear may not be easy to begin with, however you may find that over time these feelings lessen and you develop ways of coping with them as they arise. Attending a support group or talking to someone who has been diagnosed with breast cancer may help. See the *Beyond this* booklet section on page 39 for more ways to get the support you need.



'I am of course nervous about my cancer returning – there is no escaping the fact that a breast cancer diagnosis changes the landscape of your life. However, I find that as time goes by I manage most of the time to adopt the attitude that everything is fine and I am healthy until I am told otherwise.' Susan

'I will never forget the sheer panic that I felt at the thought of not seeing my children grow up.' Marcia

Worry and low mood

It is perfectly natural to feel anxious about your diagnosis and treatment. You may feel a sense of unease related to a specific aspect of treatment (like being unwell after chemotherapy) or anxious because of a loss of control over everything that is happening to you. It can make you tense, fearful and unable to concentrate. You may find that you are short-tempered or unable to sleep.

Feelings of anxiety are common for many women with breast cancer. Remember that this is an experience that is completely new and one for which you have not been prepared. You may only feel anxiety in the short term and once your treatment is over you may find some of these feelings disappear. If you continue to feel anxious over a period of time it may help to talk to someone about it. Recognising that you are anxious is an important step. Talking to friends and family may help but you may also want to talk to someone who is

professionally trained in helping people with these feelings.

Sometimes feelings of anxiety can also be linked with lowered mood and depression. Younger women with breast cancer can feel low for many reasons. For example, you may no longer feel you fit the image you had of yourself or you may be afraid of making plans for the future. Feeling sad, low and lacking in energy may be difficult to recognise as anxiety or depression because the symptoms can be very similar to the side effects of treatments. During the course of your treatment your body will use a lot of energy so you may feel more tired than usual, particularly as treatment goes on. This tiredness or fatigue may affect what you feel able to do.

If you would like to talk to someone who can provide professional help with any of these feelings there may be a counsellor you can see linked to your local GP surgery. Alternatively, your breast care nurse may be able to suggest a psychiatrist, psychologist or counsellor based at your hospital. There are different ways of treating anxiety and depression, including counselling, cognitive and other forms of psychological therapy and anti-depressant drugs.

Our booklet, **Breast cancer and you: diagnosis, treatment and the future**, gives more detail on anxiety and depression and some techniques which may help you to cope with these thoughts and feelings. You can also contact our helpline for more support and information.

'I found that my emotions were all over the place in the early days and I would get very teary. This did improve and I now have lots and lots of good days – I can't remember when my last bad day was, so that must be good!'
Jackie

'Initially after the operations I was very emotional and would cry for no reason. As time went on, I became stronger and the "black days" became less frequent.'
Alison



Relationships

The diagnosis and treatment of your breast cancer is almost certain to have an impact on those close to you. How well they adjust can influence how you cope during this time.

Partners

If you have a partner, you may find the roles within your relationship change. Some partners become overly protective while others may take on an almost parental role. They may feel they need to find out everything they can about your breast cancer, or remain positive at all times which does not allow you to discuss any negative thoughts or difficult issues. Others may cope by continuing with life as if nothing has happened.

For some partners, it may not be the diagnosis they find most difficult but the new role they find themselves in. For example, it may become your partner's job to manage the home or get children ready for school whereas before it was yours. It is important to recognise that this may create difficulties in your relationship. On the other hand, it can also bring you closer together. However your partner responds it is important that you both try to talk about your concerns.

You may both find our booklet **In it together: for partners of people with breast cancer** useful.

'I am a lot closer to my partner now. We have faced this together and are stronger for it. I have distanced myself from my parents, though. I find their worrying stressful.'
Katey

'My husband had time off work to look after me and our son. He became our son's main carer, which I resented.'
Adele



'After a rocky start following diagnosis, things are very good with my partner. During the whole thing we still laughed, shouted, joked and cried (well I did!).'
Gillian

'I honestly feel my relationships all round have solidified and realise how lucky I am to have such good support around me. My husband and I are inseparable and make the most of every day together.' Sharon

Children

You may find that the relationship between you and your children also changes. Children can respond in many different ways depending upon their age and character. For example, a younger child may become clingy and not want to leave the house or go to school. Alternatively, teenagers may distance themselves from the family and home. Relationships can be especially difficult between mothers with breast cancer and their teenage daughters. They may be worried about you or scared they may be at risk of developing breast cancer too.

You may feel that you are not being a good parent because you are unable to do the things you did before your diagnosis and that you and your children are missing out. Physically and mentally you may find that you are unable to do all the things you would like to do as a mother. It is important to keep in mind

that there will be a time when you are able to become more involved again.

If you have young children, you may find it helpful to show them our picture book, **Mummy's Lump**. This provides a simple way to raise difficult subjects, such as diagnosis, going into hospital, treatments and hair loss. Our booklet, **Talking with your children about breast cancer**, also explains what children of different ages can understand about a serious illness like cancer and features case studies from families who have been in this difficult situation.



'We tried to keep life as normal as possible for Amy's (our daughter's) sake so it didn't affect her life too much... We tried to involve her as much as possible... She would ask lots of questions which we always tried to answer honestly.' Jayne

Family and friends

Family and friends' responses may vary considerably and they can have both a positive and negative effect on you. However, they are often a good source of both practical and emotional support, from cooking you a meal to being people you can talk to honestly.

You may also find that your relationships with family and friends change. For example, a parent might suddenly want to do everything for you. Although they may be doing what they feel is best, this can be frustrating, particularly if you established your independence years before. Try to talk to them about how you feel and perhaps suggest things they can do that you would find supportive. If this is not possible, then perhaps someone close to you may be able to talk to them about how you are feeling.

Some people may react in a way that makes you feel unsupported. Your friends may have had little experience of a life-threatening illness and what it means, and may not be able to respond to your needs. For example, they may not be able to understand your uncertainty about the future or that you sometimes feel too ill to go out.

Your focus will have changed and sometimes a friend you felt you could rely on is not there for you. You may find that some people distance themselves from you. They may be frightened and have difficulty understanding what is happening to you or feel unsure about what to say or do.

'I felt more distant with my friends as for months I had only chemo going through my head and was not doing normal things that 21 year olds do.'

Kayla

'I only found out a year later how difficult it really was for my family and friends, and they told me how they struggled through it all. I just wish that they'd told me at the time.' Hester

If you are on your own

Some women may not have as much support as they would like or need. They may live alone or their family and friends may not be close by. If you are in this situation you may find it more difficult to cope emotionally and practically.

It can be a lonely and frightening experience, but you don't have to

manage completely on your own. You may find it difficult to ask, but even people you don't know very well are often willing to help. They may be neighbours, colleagues, friends of friends or members of local community groups. There may be everyday things they can do, like shopping, cooking or driving you to and from hospital appointments. Your breast care nurse, specialist or GP may also be able to tell you about other sources of practical support.



'Take time to talk to people you meet in shops, neighbours, etc, and you'll be amazed at how rewarding it is. It makes you feel more part of the community if you've been feeling isolated.' **Vanessa**

Finding support

Making contact with other young women who are in a similar situation can help reassure you that what you are feeling and experiencing is not unusual. This can help you feel less isolated and you may find it easier to say exactly how you feel, without needing to protect the feelings of others. There are different ways of getting this type of support and you will need to decide which is best for you. A couple of suggestions are given below and the *Beyond this* booklet section on page 39 provides details of services we offer to support you.

'I was lucky enough to meet two younger women during treatment and we were able to support each other and look on the bright side!' **Helen**

'The online discussion forums were a godsend for quite some period after diagnosis. They offered not only support but information (something that I have greatly benefited from and still do).' **Adele**



'I think the worst thing anyone can do when faced with cancer is try and cope alone. Friends, family, support groups, hospital staff, all are willing to help and support in any way they can.' **Amy**



'I found it very depressing being surrounded [by older women] in the self-help groups, nice though they were. I was desperate to meet and talk to people of my own age with similar problems.' **Helen C**

'I have been attending a young women's group since my operation and find our monthly meetings recharge my batteries. [It helps] just to have someone to talk to who you know understands 100% how you feel.' **Christine**

Support groups

There are a small number of support groups specifically for women diagnosed with breast cancer at a younger age. To find out if there is a younger women's support group near you:

- talk to your breast care nurse
- contact our helpline on 0808 800 6000 (for Typetalk prefix 18001)
- or look at our website, www.breastcancercare.org.uk

There might be a breast cancer support group near you for women of all ages. This may be suitable for some women, but others may find it isolating if it is mainly attended by older women with different issues. You might want to contact the group before attending to get an idea of how it runs and to see if it is right for you.



'It meant a lot to be able to relate to someone with the same issues as me – I certainly felt less unique in what I was going through.' **Marcia**

Professional support

You may prefer to speak to someone who is specially trained in helping people cope with emotional problems. Your GP may be able to refer you to a counsellor linked to their practice. Your cancer specialist or breast care nurse may also be able to talk to you about counselling services available at the hospital where you are being treated, or those in your area.

'With hindsight I did need to talk to someone but I didn't realise it at the time.' **Claire**

'I just wanted to talk to someone from the outside, not a family member or a friend, as I found it easier to just say what I felt and how I felt, without having to think that I will upset someone.' **Hester**



Practical issues

Being a younger woman diagnosed with breast cancer can raise a number of practical issues for you during your treatment or at a later date.

Childcare

Taking care of a child is a big responsibility at the best of times. Being diagnosed with breast cancer may make childcare more difficult. You may have problems organising childcare when you are visiting the hospital or recovering from treatment. A delayed hospital appointment may mean that you end up running late to collect your child from nursery or school.

Sometimes people close to you will be able to help. You may find asking for help difficult, but often people are happy to do so because it makes them feel useful. Your child's school might have an after school club or you may be able to pay for childcare. Your health visitor or GP may be able to recommend services or schemes within your area. Talk to your breast care nurse or see our factsheet **Breast cancer and childcare** for details of useful organisations.

'We lived on a farm so life became a little difficult for six weeks, as I was not allowed to drive after my surgery. My sister came to stay for the first two weeks and then my mum came for two weeks. The last two weeks friends took my children to after school activities and brought them home.'

Christine

Study and employment

If you have had to take time off because of treatment, returning to work or study may be a way of regaining some sense of normality. You may want to build up to working again gradually; perhaps you can negotiate with your employer to work fewer hours or part time. Some women find it difficult to return to the same environment or simply do not want to. It is common to re-think careers or re-prioritise goals after being diagnosed with a serious illness, so you may decide to change jobs, embark on a new course of study or do something else that you have always wanted to.

Another concern may be what to tell future employers and how they may respond to the fact you have had breast cancer. If a new employer requires information regarding your medical history, it is important to tell them about your breast cancer. Many employers have an equal opportunities policy, which means they should not discriminate against you because of your diagnosis. If you experience difficulties at work that relate to your diagnosis or treatment, your specialist may be willing to write to your employer to clarify any concerns they may have. Alternatively, it may be worthwhile speaking to a union representative, if you have one, or to your local Citizens Advice Bureau (CAB). New laws under the Disability Discrimination Act came into force in December 2005, increasing the protection for people who have cancer. You can get more information on this from your local CAB, or from the Department of Work and Pensions website, www.dwp.gov.uk

We have developed a charter for employers which provides a guide to their legal responsibilities to employees who have breast cancer. You can find out more about this at www.breastcancercare.org.uk/employ or contact our helpline to order a copy of the **EMPLOY Charter**.

Finance

Breast cancer can impact upon your financial security both during and after treatment. This can be an additional worry at an already stressful and difficult time. You may depend upon your wage to pay your rent or mortgage and for other financial commitments.

If you have a mortgage and are concerned about your situation, talk to your lender to see if they can work out a different payment scheme or defer your payments for a few months. There are also state benefits you may be able to claim. Talk to your breast care nurse or a social worker at the hospital to find out more about these. They will be able to tell you if there are any specific grants you can apply for in your area. Also, your local CAB will also be able to advise you of your entitlements or you can call the Macmillan Benefits Helpline on 0808 801 0304.

For more information, see our **Breast cancer and benefits** factsheet.



'It has had a massive impact on me financially. I am self-employed and haven't worked for a year. Sorting out benefits was very stressful at a time when I felt I couldn't cope with much more to worry about. I wasn't insured as I was 27 and thought nothing would happen to me!' Katey

Insurance

Being diagnosed with cancer may mean you have difficulty obtaining insurance both during and after your treatment, whatever your age. This will include car, travel and medical insurance. As a younger woman who has had breast cancer you may have difficulty getting life insurance or face large or increased premiums. Check any existing policies that you have to see if they are affected by your diagnosis, or you may have medical insurance or an income protection policy that comes into effect because of your illness.

To find out more about financial issues and insurance contact CancerHelp UK (see *Cancer organisations* at the back of this booklet) who produce information specific to cancer patients on these subjects. You may also find our factsheet **Breast cancer and travel insurance** useful.



Further issues

Many women see completing treatment as the start of getting their life back, although you may need some time to adjust. It is common to feel the end of treatment is an anticlimax, or to be unsure about what happens next. You may find that you are different in some ways or that your priorities have changed after your treatment has finished.

Pregnancy after breast cancer

Deciding whether or not to have a baby can be a difficult decision to make and may give rise to many different emotions. Some women feel that having a baby is an end to the cancer and a new beginning or a chance to start living again. Others worry that if they get pregnant it might make the cancer come back, although there is no evidence to support this.

You may not have considered having children before you were diagnosed. You may not have planned that far ahead or you may have been trying to have a child at the time. Whatever your situation, you will generally be advised to wait two years after your diagnosis before becoming pregnant. You may feel this is too long to wait or worry that you may be too old to have children once you have finished your treatment. It is

advisable to talk to your specialist team about your particular concerns and circumstances.



'My husband and I will try and have a family in four years, once my hormonal treatments are all in the past.' Hester

Permanent infertility

As discussed earlier, it is important to talk about the possibility of an early menopause and permanent infertility with your specialist before starting

The future

treatment. It may be possible to have fertility treatment to freeze embryos, or in some cases eggs, for use in the future after your treatment has finished.

Your specialist can do tests after your treatment is complete to help confirm if this has caused an early menopause. For more information, see our **Fertility issues and breast cancer treatment** factsheet.

Finding out that your cancer treatment has made you infertile can be devastating. Infertility means a loss of choice about having a child. It may change how you feel about yourself as a woman and you may feel intense grief at the loss your cancer has caused you.

It may be upsetting when someone you know gets pregnant or be difficult welcoming a new baby into your family or circle of friends when you are trying to deal with your own loss. You may be angry or sad at what has been taken away from you, or feel guilty for having these thoughts.

Don't be afraid to ask if you need some support in coping with infertility. People cope in different ways and you may find you need specialist support to help you come to terms with any grief you are experiencing. Your breast care nurse may be able to help you find a suitable

organisation or a counsellor who focuses on infertility issues. There are also some useful addresses listed at the back of this booklet.

Osteoporosis

Osteoporosis is thinning of the bone that can lead to an increased risk of fracture. Although it usually occurs in older women who have been through the menopause, it is also an issue for younger women who have had treatment for breast cancer. This is because oestrogen plays an important part in keeping bones strong and without it they will be weakened. If you have been made post-menopausal by your treatment, your oestrogen levels will be lowered and your risk of osteoporosis may have increased. Taking tamoxifen protects against osteoporosis by slowing down bone thinning.

If you are concerned about the possibility of osteoporosis, you may want to talk to your specialist about it. If appropriate, there are scans which can check bone density and treatments that can help maintain bone strength.

For more information, see our **Osteoporosis and breast cancer** leaflet.

Your experience of breast cancer may continue to affect you for some time following treatment. Situations may arise which remind you about it when you least expect it. Follow-up appointments may bring back fears and worries about the cancer returning. However, time may also bring a greater understanding of what has happened to you and the best way to deal with these situations. This perspective may mean that you want to give more time to doing things that are important to you, like spending time with friends and family or treating yourself every now and then.

You may find that your breast cancer is no longer a big part of your everyday life, but an experience which has shaped you and your outlook. People do manage to look forward, make new plans and resume ones that had to be put on hold.

Having a diagnosis of breast cancer does change your life. Its effects can be both positive and negative but many women find that they come through this experience with a different outlook and a renewed feeling for life.



'I feel positive about the future, although there is always a chance that it could come back I am not going to let that get me down or dwell on it; what will be will be....' Wendy



'I appreciate the smallest things now. Life in my head is completely different now; if I get a cold I will not moan about it, if my hair does not sit right, I don't care, I'm just glad I have hair.' **Kayla**

'I plan to take a degree and plan to become a teacher, something I have always wanted to do. I don't want to return to how everything was before cancer, I want to learn from this and grow as a person.' **Amy**

'I do fear the cancer coming back, but think about it less and less often now. I just think to myself that if it does, then I will deal with it then. I certainly intend on being around so I can spoil my nephew!'
Jackie

Beyond this booklet

Further support from Breast Cancer Care

Free telephone helpline 0808 800 6000 (Text Relay prefix 18001)

Our helpline provides information and support for anyone affected by breast cancer. Everyone on our helpline either has personal experience of breast cancer or is a breast care nurse. The team comes from a variety of backgrounds, so callers get to talk to someone who understands the issues they're facing.

The team is able to talk about clinical, medical and emotional issues surrounding breast cancer and breast health. Everyone on the helpline has an excellent knowledge of breast cancer issues and receives regular information on new developments. They can talk through the complexities of different treatments to help you understand your options and explain the best way for you to get treatment.

Volunteer support

Many people who have breast cancer find it helpful to talk to someone who

has been in a similar situation. Our peer support service puts you in touch with someone who has personal experience of breast cancer and has been trained to listen and offer emotional support. You can talk to someone at any stage – whenever you feel it would help. Call our helpline or visit our website for more information about this free service.

Telephone support groups

We offer free and confidential telephone support groups for people with breast cancer. They are facilitated by a professional therapist and a specialist nurse and are individually tailored to cover different aspects of breast cancer. They aim to give you the opportunity to express your feelings and share your experiences with others who may have been in a similar situation. For more information, call our helpline or visit our website.

Younger women's forums

Our **Younger women's forums** are two-day residential programmes for women aged between 20 and 45 who have been diagnosed with breast cancer.

The programme includes medical updates, information on diet, lifestyle and complementary therapies, and discussion groups specific to younger women's needs. It gives participants the opportunity to learn more about breast cancer and to meet other women in a similar situation in a supportive atmosphere. To find out about forums in your area contact your nearest Breast Cancer Care centre (details at the back of this booklet).

Courses and activities

We run courses and activities for people with breast cancer, which aim to provide information and support and give people the chance to meet others in a similar situation. For more information about these events, contact your nearest Breast Cancer Care centre or call our helpline.

Online forums and Live chat

Our website hosts discussion forums covering all aspects of the disease and its treatment. This service is available 24 hours a day and allows you to talk to people in a similar situation to you and to share your thoughts and feelings.

All forum users post their messages and responses at any time, however the regular Live chat sessions take place among users who are all logged on at the same time. They are hosted by our staff or a clinical specialist and give you the opportunity to discuss anything related to your diagnosis. Visit www.breastcancercare.org.uk for more details.

Ask the nurse

This is another service on our website. You can email a question on any breast cancer or breast health issue and our team of nurses will reply within promptly. The service is strictly confidential.

Publications

We produce a wide range of publications providing information for anyone affected by breast cancer. All of our publications are regularly reviewed by healthcare professionals and people affected by breast cancer. You can order our publications by using our order form, which can be requested from our helpline. All our publications can also be downloaded from our website.

Finding out more

Further reading

Breast cancer: answers at your fingertips

Emma Pennery, Val Speechley and Maxine Rosenfield
Class Publishing, 2009
ISBN 978 185 959 1987

Comprehensive and reassuring answers to over 350 questions asked by real people about all aspects of breast cancer.

Women with breast cancer in the family – understanding NICE guidance

National Institute of Clinical Excellence (NICE), 2006

Copies of this booklet can be ordered from the NICE publications order line: 0845 003 7783, quoting reference number N1131 or from the NICE website, www.nice.org.uk

Cancer organisations

CancerHelp UK

Email: publications@cancer.org.uk
Website: www.cancerhelp.org.uk

A free, web-based information service for people affected by cancer that is part of Cancer Research UK. Produces information on specific cancers and treatment, as well as on practical issues.

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840
Helpline: 0808 808 00 00 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.

Other organisations

British Association for Counselling and Psychotherapy (BACP)

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

Telephone: 01455 883300
Email: bacp@bacp.co.uk
Website: www.counselling.co.uk

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.

Citizens Advice

Telephone: 020 7833 2181 (to find a local Citizens Advice service)
Website: www.citizensadvice.org.uk

Provides free advice and information on a wide range of issues, including benefits, housing, money advice and consumer complaints. To find your nearest office, look in your local telephone directory or visit their website.

The Daisy Network

PO Box 183
Rossendale BB4 6WZ (include a SAE)

Recorded information line: 0845 122 8616
Email: daisy@daisynetwork.org.uk
Website: www.daisynetwork.org.uk

Voluntary support group for women who experience a premature menopause. Exchange of information on IVF, HRT and ways to have a family through egg donation, surrogacy or adoption. Provides informal telephone support by members and a quarterly newsletter.

Infertility Network UK (I N UK)

Charter House
43 St Leonards Road
Bexhill-on-Sea
East Sussex TN40 1JA

Telephone: 0800 008 7464
Email: admin@infertilitynetworkuk.com
Website: www.infertilitynetworkuk.com

Provides support, counselling and information, and promotes awareness of infertility issues.

National Osteoporosis Society (NOS)

Camerton
Bath BA2 0PJ

Telephone: 01761 471771/0845 130 3076 (general)
Helpline: 0845 450 0230 (medical enquiries)
Email: info@nos.org.uk
Website: www.nos.org.uk

A national charity dedicated to improving the diagnosis, prevention and treatment of osteoporosis. Provides information sheets and booklets and has a list of support groups.

Standards of care for younger women with breast cancer

These standards provide information about key issues you may want to discuss with the health professionals involved in your breast cancer treatment and care. They also advise on the kind of information and support you should be given access to as a younger woman with breast cancer. The standards have been developed in conjunction with younger women with breast cancer as well as breast cancer specialists.

It may be useful to take the standards with you when you meet with your breast cancer specialist or breast care nurse.

As a younger woman with breast cancer you should:

- 1** receive treatment and care from **health professionals who are sensitive to the specific issues** and concerns that you may face as a younger woman with breast cancer
- 2** have the opportunity to be **put in contact with other younger women** who have been diagnosed with breast cancer and be told about long-term sources of support for younger women
- 3** be offered the opportunity to discuss some of the complex life decisions you may be facing in a **supportive environment with a skilled counsellor**, especially if you are having difficulty coping with making major life decisions sooner than you expected
- 4** be given an **explanation of the risk of menstrual irregularity or early menopause** as a result of some treatments; you should also be given advice on coping with an early menopause or the menopausal side effects of treatment
- 5** be given a full explanation during initial treatment discussions about the **possible impact of treatment on fertility**, including advice about contraception and pregnancy after treatment
- 6** if appropriate, be given full information about **any possibilities for preserving fertility**, including information about the chances of success from fertility treatment and the possible impact of delaying breast cancer treatment
- 7** be offered **counselling if you are diagnosed with breast cancer during pregnancy or within a year of giving birth** to help you cope with the situation; if you have to be treated with chemotherapy during pregnancy you should have access to a specialist with experience in this area
- 8** be **fully informed of the potential impact some treatments may have on your bone health** and advised of possible management strategies to minimise this impact
- 9** have as full a **family history taken as possible** with respect to cancer risk; if appropriate, you should be offered a referral to a genetic service for testing and counselling

continues on next page

continued from previous page

10 be supplied with information about any **local sources of support to help you with childcare arrangements** during your hospital visits or recovery

11 be given the opportunity to be put in touch with **specialist advisers to discuss the financial implications associated with breast cancer**, including employment rights, state benefits, coping with a loss of income and implications for mortgage and insurance.

Would you like more information?

To find out more about Breast Cancer Care and the free services we offer, please fill in your details below and return this slip to:

**Breast Cancer Care, FREEPOST RRRKZ-ARZY-YCKG,
5-13 Great Suffolk Street, London SE1 0NS**

Your details

Name: _____

Address: _____

Postcode: _____

Email: _____

please tick if you are happy to receive emails from us

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) _____



Please complete reverse of page

Please let us know where you got this Breast Cancer Care publication.

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

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

Please tick here if you don't want to hear from us.

free helpline 0808 800 6000

www.breastcancercare.org.uk

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For all breast cancer or breast health concerns call our free, national helpline on **0808 800 6000** (for Text Relay prefix **18001**) or visit **www.breastcancercare.org.uk**

Confidentiality is maintained between callers and Breast Cancer Care.

Donations from the public make it possible for us to provide publications like this one free to people affected by breast cancer. If you would like to make a donation, please send your cheque to: Breast Cancer Care, RRKZ-ARZY-YCKG, 5-13 Great Suffolk Street, London SE1 0NS. Or donate via our website at www.breastcancercare.org.uk

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Email sco@breastcancercare.org.uk

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Email cym@breastcancercare.org.uk

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