

BREAST CANCER  CARE

Sexuality, intimacy and breast cancer

LARGE PRINT



Breast Cancer Care is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer. Every year we respond to over two million requests for support and information about breast cancer or breast health concerns. All our services are free.

We are committed to campaigning for better treatment and support for people with breast cancer and their families.

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Introduction

This booklet is for any woman who has breast cancer and would like more information on how it may affect her sexuality and sexual wellbeing.

Talking about sex and sexuality can be hard. You may find it a difficult enough subject to discuss with your partner or a close friend, let alone someone involved in your treatment. It may be the first time that you've really thought about the whole issue and what it means for you. Additionally, you may be from a background or culture in which sex and sexuality are rarely discussed.

The subject may not be mentioned by your treatment team, so if you do have worries you may feel it's difficult to raise them. If this is the case for you, this booklet may help you to talk about your concerns, not only to your treatment team but also to those close to you.

Women can be affected in many different ways after their diagnosis of and treatment for breast cancer. These effects can be both physical and emotional. Around half of all women who have breast cancer will experience some changes in how they feel sexually or in their sex life. These can occur in the weeks and months after treatment or years after treatment is finished.

However, it's important to remember that not everyone will experience problems. Indeed, some women find that their sex lives improve because they've been in a situation that's made them really think about their sexuality, and some feel closer to their partners because of their experience of cancer.

Although the information in this booklet is relevant if you have secondary breast cancer (cancer that has spread to another part of the body; also called metastases), not all of the symptoms, treatments and issues associated with secondary breast cancer are included. For more information you may want to read our **Secondary breast cancer** booklet.

Sex and sexuality

Your sexuality is unique to you, and involves how you feel about yourself both physically and emotionally. Your sexuality concerns how you feel about your body, and may involve how you look, how you relate to others or your role in life – for example, wanting to feel close to or care for other people. How you see yourself sexually can also be influenced by your background and past experiences, and cultural or religious beliefs.

'I feel my sexuality is a central part of who I am, and it therefore influences all aspects of my life. This includes how I dress, what I read, the music I listen to, the films I watch, the friends I make.' Maggi

'To me sexuality isn't just about sex, it's part of how we relate to people all the time, from being tactile and touching casually to more intimate kissing and stroking – and of course more explicit sexual contact!'

Madeleine

Sexuality can also be about sexual preference – for example, whether you see yourself as gay, straight or bi-sexual. It concerns how you feel about intimate contact, such as kissing, cuddling and touching as well as penetrative sex. For many people sexuality is a combination of some or all of these factors.

Sexuality is an important part of some people's overall identity while for others it assumes less importance. Our feelings about sexuality can also change at different times of our lives. Everyone is different and there's no right or wrong way to feel about sex and your sexuality.

The term 'sex' can also mean different things to different people. In this booklet sex is used to refer to any aspect of sexual or intimate contact with men or women, not just to the physical act of having sex.



'My breasts represented the very core of my sexuality. I was indeed very proud of my 34DD breasts, especially since my husband has always been a breast man.'

Margaret

Women's sexual response

A woman's sex life will change throughout her life regardless of whether or not she has been diagnosed with breast cancer. It may be affected by her menstrual cycle or by larger life events such as pregnancy or the menopause (when your periods have stopped). As we grow older the way we express ourselves sexually may change due to our health or other factors, such as worry or stress. All of these factors may have an effect on your desire for sex and intimacy.

Understanding how the body responds physically during sex is an important factor in a woman's sexuality. This is known medically as the female sexual response. Knowing how your body responds sexually may make it easier to understand your own personal situation and any problems you may be experiencing.

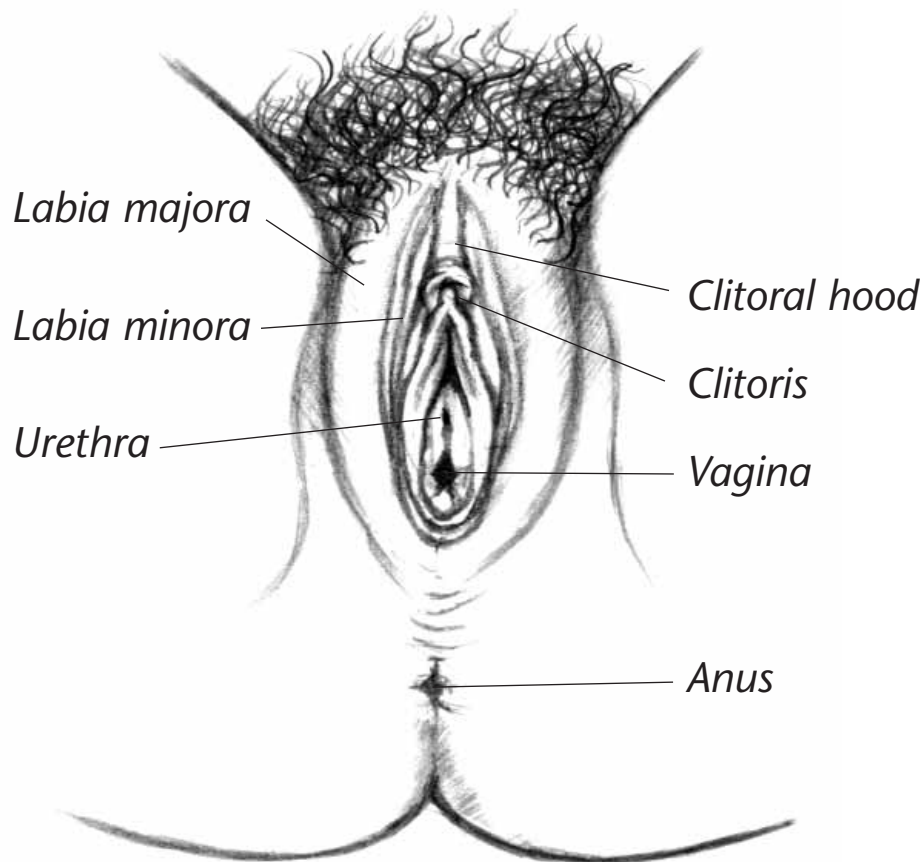
Female genitalia

The external female genitalia are known as the vulva and consist of:

- the **labia majora** – two folds of skin, tissue and fat, containing glands which produce a fluid that keeps the vulva moist. At puberty hair grows in this area
- the **labia minora** – two smaller folds of skin and glands
- the **clitoris** – corresponds to the penis in the male. It contains tissue and sensitive nerve endings, and most women feel sexual pleasure when it's stimulated

- the **clitoral hood** – the skin and tissue that covers the clitoris
- the **vagina** – shaped like a flattened tube in its resting state, the vagina expands when a woman is sexually aroused and extends during penetrative sex
- the **urethra** – the opening through which urine is passed from the bladder
- the **anus** – the opening to the rectum, which contains sensitive nerve endings.

Female genitalia



Female sexual response is made up of three stages that affect the whole body as well as the genital area.

- **Sexual interest/desire** – Sexual interest or desire is the first step in the process and is very important. When you experience desire blood starts flowing to the genital area. This can happen simply if you're with someone you are attracted to or more directly by having your erogenous zones (areas that give you sexual pleasure) touched or stimulated. Your blood pressure and pulse rate will increase and breathing becomes faster. The vulva also becomes lubricated.
- **Sexual arousal and orgasm** – When this excitement and stimulation increases there are more changes in the genital area. The outer and inner lips of the vagina increase in size. As the blood continues flowing to the area the vaginal lips open out, making it easier to reach the vagina and clitoris. If this arousal and stimulation continues orgasm can be reached. This is the release of sexual tension. It involves contractions of the muscles in the pelvis and sometimes elsewhere in the body.
- **Resolution** – This is where the body returns to its pre-arousal or resting state.

'However you feel about your sexual relationship during cancer treatment is natural. It is an individual thing – don't spend important time comparing yourself to others or worrying about it.' **Joyce**

Many women don't reach orgasm every time they have sex; for some just enjoying the sensations of arousal gives them the sexual satisfaction they are looking for.

As stated earlier, desire (sometimes referred to as libido) plays a vital role in sexual response. However, many women being treated for breast cancer find their desire for sexual contact decreases, either because of the side effects of treatment, or because they feel they can't concentrate on anything other than their diagnosis and treatment. Your feelings about your breast cancer and how it may have affected your body image may also have an effect on your sexual desire.

Of course sexual desire is only one of the many reasons women choose to be sexually intimate. Other reasons include showing their partner that they love them, to feel close to or loved by their partner, or to get pregnant.

Being diagnosed and treated for breast cancer may mean that it's difficult for you to enjoy sex in the way you used to. This may be for a variety of reasons connected to how you feel mentally and physically about your illness. In the next section we look at the different aspects that may affect your sense of sexual satisfaction.

'I'm very lucky in that Rob has been great about my new body, although I feel if he hadn't been I wouldn't be with him. We both know that my sexuality and I exist beyond my breasts and that having two breasts does not define me as a sexual being.' Maggi

Breast cancer and your sexuality

Being diagnosed with a life-threatening illness will almost certainly affect how you feel about sex and your sexuality. At a time when you're dealing with so much you may not feel like expressing yourself sexually; or you may want to have sex to give you a feeling of normality during what is an uncertain time. Some women say their desire for intimacy increases but not necessarily for sexual intimacy. Additionally, the treatments you receive may have an effect on your sexual desire and sexuality.

The following issues may be relevant to you now, at a later date or perhaps not at all. If you'd like to know more about the treatments given for breast cancer, see our **Treating breast cancer** booklet.



'After surgery, because of the tenderness of the chest area, of course there is a period when physical contact is the last thing on your mind! In fact a lot of time in bed is spent avoiding contact. Also, I felt I needed to keep my body totally to myself, to protect it until my wound healed – I don't know why, I just felt this way!' Joyce

'My expression of sexuality is very dampened and therefore I feel rather a sexual nonentity at the moment but I am working at it. I have absolutely no libido – I think due to the menopause – and this is a big problem, really.' **Anne**

Experts think that sexual response may be affected or disturbed in three ways. These are pain (in the genital area or elsewhere in the body), anxiety and fear around intimacy,

or having too much on your mind so that you can't really think about sex. However, there are also other factors specific to breast cancer and its treatment that may have an impact on your sexual response.

Pain and discomfort

Treatments for breast cancer may cause a level of pain or discomfort, so you may experience pain for a number of different reasons. If you are in pain you may feel that you want to concentrate on feeling well again and don't have the energy or desire for sex.

Being treated for breast cancer will nearly always mean you have some form of surgery, which may also include breast reconstruction.

'Where previously I felt pleasure when my breasts and nipples were touched, I now feel pain and a numb sensation.'

Madeleine

'Even after 19 months I still have pain from radiotherapy. It is being dealt with but this has affected so many things that I can or can't do and being touched in this area is strictly no go.' **Judith**

It may be difficult to touch or hug someone if the wounds from your surgery are still healing or if the area around the scar is uncomfortable.

If you've gone on to have radiotherapy, the area being treated may be tender during treatment and for a little while after the treatment ends, and may feel too painful to be touched. This can be upsetting if it means you can't be as physically close to your partner as before, even if it is only for a short time.

'I didn't have any problems sexually or otherwise during my first course of chemotherapy, which was put down to the fact that I was so fit and healthy (apart from the cancer, that is!). Life went on much as before until the latter stages when tiredness tends to interfere with your life a little. After surgery, I had a second course of chemotherapy and encountered a lot more side effects and tiredness, which just about obliterated any sex life.' **Joyce**

'The radiotherapy made me feel really tired for months afterwards and with going back to work and a small child I really didn't have the energy for anything else.' **Anne**

Painkillers can help with any discomfort you're feeling, although having to think about taking these before having sex and being intimate may change how you feel about the experience. However, you may find it reassuring to know that any pain you experience from surgery or radiotherapy should lessen as the area heals.

Alternatively, a change of position during sex or being intimate may also help – for example, one that puts less pressure directly on to your chest.

A pictorial version of *The Kama Sutra* contains many sexual positions and can be useful for those wishing to experiment. If you or your partner feel a little nervous about doing something different you can experiment by taking the book to bed and practise with your clothes or underwear on. This will allow you to find out which positions are comfortable and physically possible – and can also be enjoyable.

'We remained very intimate and physically close but I did not want sexual intimacy as I felt too ill and fragile. Also I didn't feel wildly sexually attractive as a sweating, bald-headed, one-breasted woman with mouth ulcers and sore gums!' **Andrea**

Fatigue

Fatigue is extreme tiredness that doesn't go away with rest or sleep and is a common side effect of cancer treatment. It can get worse as treatment goes on and can also continue once treatment has finished. The treatments most likely to cause fatigue are chemotherapy and radiotherapy, although surgery and hormone therapies can also affect your energy levels.

'During the chemotherapy I was dog-tired and not wanting any sex, but I needed a lot of intimacy and cosseting which was forthcoming.' **Anne**

If you're feeling fatigued you may not want to have sex at all or you may want to take a less active role. This may take a little adapting to if you've always taken a very physical part in lovemaking. It's important to realise what your current limits are and not push yourself too much. Try not to be too hard on yourself if you can't be as physically involved as you may have been before your treatment.

These feelings of fatigue will gradually lessen over time and you may then feel you have more energy to put into your sex life.



‘Tamoxifen brought on some menopausal symptoms including vaginal dryness. We overcame this by using lubricant jelly. Another side effect of tamoxifen, which seemed to be ignored by the medical professionals, was the weight gain that occurred – I put on about a stone and a half. Despite doing a lot of exercise, I found it really difficult to lose the weight and this had a negative effect on the way I felt about myself. Through dieting I have now managed to lose this weight and feel much better both physically and sexually.’ Elaine

Menopausal symptoms

Menopausal symptoms are a common result of treatments for breast cancer. Treatments can either stop the effectiveness of female hormones or stop their production altogether. The treatments most likely to produce these symptoms are chemotherapy, hormone therapy or ovarian ablation or suppression (stopping the ovaries working either permanently or temporarily).

As a result, you may experience some or all of the following symptoms; hot flushes, tiredness, mood swings, hair thinning, loss of elasticity in the vaginal wall or vaginal dryness. These

menopausal side effects vary from one person to another.

Side effects of treatment and menopausal symptoms can contribute to many women feeling different about themselves and their bodies. For example, during arousal you may feel less sensation, which means it can take longer to orgasm. Or you may simply feel too tired to have any interest in sex, perhaps as a result of symptoms like night sweats.

Women who experience these symptoms during their natural menopause may be given hormone replacement therapy (HRT). However, HRT is not generally recommended for women with breast cancer because of the hormones it contains. It remains uncertain whether HRT increases the risk of recurrence after an initial diagnosis of breast cancer. The vast majority of women who are taking HRT at the time of their diagnosis will be advised to stop the treatment straightaway. This may mean they will have menopausal symptoms before having any breast cancer treatment.

'The menopausal symptoms were sudden for me as I chose oophorectomy [removal of the ovaries]. The tamoxifen had already dried out my vagina – so although I had the energy to make love, it was uncomfortable, so rather off-putting. I have found that using lubricants before lovemaking has really helped and my sex life is looking up, which is lovely for us both.' **Anne**

Younger women being treated for breast cancer often experience menopausal symptoms due to chemotherapy or ovarian ablation and suppression. This menopausal state may be temporary or permanent. Although the symptoms are the same as those experienced with a natural menopause, initially they can often be more severe. Having these symptoms at a younger age can make someone feel older than they really are, which can have a negative effect on how they feel sexually.

If you are experiencing menopausal symptoms that are having an impact on your quality of life there may be some ways to help relieve them. For more information see our **Menopausal symptoms and breast cancer** factsheet.

Vaginal dryness

Treatments that alter the level of the hormone oestrogen in your body can cause vaginal changes, such as dryness and/or irritation, which can make penetrative sex painful. They can also have an effect on sexual desire and feelings of arousal. Vaginal dryness is a very common menopausal symptom in women who have had treatment for breast cancer and one that can be very distressing.

‘I have vaginal irritation when I have any sexual encounter, either masturbating or with someone else, and lubricants don’t really help.’ **Madeleine**

Pain or discomfort can reduce sexual feelings and desire. However, there are things that can help. Once you know that penetration is not going to be painful or that discomfort can be reduced to a minimum you may find that your desire for sex increases.

'Menopause due to chemotherapy has caused vaginal dryness. I use KY Jelly but have some initial slight pain on penetration which soon passes as the tissues stretch.' **Kate**

The most common treatment suggested for vaginal dryness is HRT, although (as mentioned above) HRT is not generally advised for women with breast cancer. However, some specialists will consider prescribing locally acting hormone treatments such as oestrogen cream that can be applied to the vagina/vulva for short periods of time. The exact amount of oestrogen absorbed into the rest of the body from these treatments is not fully known so it may be useful to discuss their use with your cancer specialist.

'Vaginal dryness has been a problem and can be quite painful at times, but we have managed this by taking more time over having sex, which is quite nice.' **Margaret**

There are also some simple, practical steps you can take that don't involve using hormones. Try wearing loose-fitting cotton underwear and avoiding tight-fitting trousers, as this is less likely to irritate the vaginal area. It may also help to avoid perfumed soaps or bath products.

You can also try to relieve the symptoms with vaginal moisturisers and lubricants. Vaginal moisturisers such as Replens MD or Senselle (both available from chemists) may be used every few days. If you experience discomfort during sex it may be helpful to apply a water-based personal lubricant such as KY Jelly, Pasanté TLC/Light Lube or Astroglide, or a natural lubricant such as Sylk. These products don't generally cause vaginal irritation and are fine to use with condoms.

Body image and self-esteem

How you think about your body and the way you see yourself is known as your body image. Our body image changes constantly throughout our life and illness can affect how we feel about our body image and may give rise to feelings that affect self-confidence.

You may have a very different view of your body after your diagnosis and treatment from the one you had before it. Your breast cancer will have left you with visible reminders of your experience, either temporary ones or permanent ones. This may include surgery scars, changes to the skin after radiotherapy, hair loss during chemotherapy or

'I've never been a big fan of my body, always felt too fat, etc. Having a mastectomy/breast cancer has only made me feel better about my body. I have had a breast reduction on the remaining side as I was very large and there was such a difference. Now I have had the reduction, I am very happy not to wear a prosthesis. It has made me think very much about body image and how sad I feel when I read women feel they are no longer a woman if they have mastectomies, and that we are encouraged to have reconstructions rather than seeing ourselves in a positive light.' Maggi

regrowth after. You may also have put on or lost weight as a result of some of your treatments. All this can make you feel like your body has 'let you down' and you may lose confidence in the way you look.

It may take some time to be comfortable with these changes. You may not feel sure of yourself or how others see you, and may avoid situations where you have to cope with other people's responses to how you now look. This can affect your self-esteem – how you feel about yourself, how you present yourself to other

'I feel less desirable and fear others' responses to me with no clothes on. Sexual attractiveness-wise I feel as though I'm in a different category now and am quite often wary of sexual contact.' Madeleine

people and your overall feelings of wellbeing.

Because our body image and self-esteem play an important part in how we feel about our sexuality and our relationships with others, changing feelings around your body image and self-esteem can affect how you feel sexually. Having low or damaged

self-esteem can result in problems in your sexual relationship. This may be because you feel unhappy or uncomfortable with your body. Some women may try to avoid sexual situations. Others find ways of adapting,

'I didn't make love at all until completing all the chemo and radiotherapy and by then the tamoxifen had kicked in so I can only recall things being quite sore, though they got worse after the menopause. I found it very hard to relax at first as I was very self-conscious of my breast and to be honest I did not really want sex more than a few times in the first two years. I made love to give pleasure to my husband.' **Anne**

'I think I know my body much better than before I had breast cancer. At first I was very conscious of the surgery and scarring, worrying if it would show. Also I put on quite a bit of weight. As time has gone on those worries have gone, I have lost the weight and I feel good about my body once more.' **Elaine**



'I lost a lot of weight through changing my diet. I also became more health conscious and therefore felt much better about my body.' Andrea

perhaps by wearing underwear or nightwear to cover a particular area of the body, or getting into bed before their partner so they don't have to undress in front of them.

You may also be concerned about how your partner now sees you. However you may feel about your body, don't assume that your partner feels the same way. Sharing feelings with your partner, being honest and talking openly can help in understanding each other. If you can explain to your partner how you feel, however awkward or difficult this is, they will be more able to respond to your needs.

Finding new ways of continuing to be intimate with your partner may help you to adjust to your altered body until you reach a point where you feel more comfortable.

It's worth bearing in mind many women adapt to a changed body image over time and continue to have fulfilling relationships and lives after breast cancer, while some people may benefit or need support from a professional counsellor.

'I was previously very proud of my appearance and worked hard keeping it that way (gym three times a week!). I now feel that no matter how hard I work out, or how good I may look on the surface, underneath, I know I have changed. This makes me a little sad, but I'll get over it. I am definitely feeling less self-confident ... apart from the hair thing, I think I also put this down to knowing that one of my 38D breasts is gone forever, although I do have a brilliant contact prosthesis.' **Joyce**

Breast reconstruction

Some women feel a breast reconstruction helps them to adjust to the changes to their body as a result of breast surgery. A woman may choose breast reconstruction for reasons related directly to her body image, self-esteem and sexuality. Reconstruction can often be done at the same time as a mastectomy (immediate reconstruction), or months or even years later (delayed reconstruction).

Some studies have shown that immediate breast reconstruction can help women to come to terms with the changes in their bodies and how they feel sexually. Some women feel a reconstruction helps them to feel more confident overall. However, other women feel comfortable with their change in body image, and don't want to have more surgery so soon after their breast cancer surgery.

'Since reconstruction I feel better – not that I didn't feel feminine – I just feel balanced, accepted, better to look at for others and myself.' Jenny



'Neither of us feel that reconstruction is necessary for us to have a good sex life. I know people find it cosmetically very good but I don't want another big operation, nor do I want even more scars on my body than I have already. For me, it isn't worth it. I like my body as it is with the only invasive surgery being that needed to save my life.' **Kate**

Some women go ahead with a reconstruction as they feel it will make a difference to their partner, while others may think it could mend the problems in a sexual relationship. Having a reconstruction for these reasons may not be the best way to resolve any problems. It's important that any decision you make about having a reconstruction is right for you.

Most women who have breast reconstruction are satisfied with the result but there are some whose

experience will not be as positive. It's important to realise that breast reconstruction can only reconstruct a breast shape – it can't bring back your breast or the sensations of the breast and nipple.

If you're considering a reconstruction you may find it useful to read about different options in our **Breast reconstruction** booklet.

Lymphoedema

Lymphoedema is a swelling caused by a build up of lymph fluid in the tissues that can be a side effect of breast cancer treatment. It occurs in some degree about a quarter of women who have surgery to the lymph nodes (glands) in the armpit. Having radiotherapy to the armpit area can also increase the risk of developing this condition. The swelling can occur in the chest area where you had your surgery as well as in the arm, hand or fingers on that side of your body. The amount of swelling you have can vary. For more information see our **Reducing the risk of lymphoedema** factsheet.

Having lymphoedema can affect you both physically and emotionally. Some of the physical side effects may include tightness, stiffness and discomfort in the affected area. All of these symptoms can make you feel differently about your body. Developing lymphoedema can mean that you have to adapt to yet another change in your body image and appearance.

If you have lymphoedema you may have to use a lymphoedema sleeve, which can be a visible sign that something is different about

'Life is beginning to resume some kind of normality, although there is the need for Joyce to continue indefinitely with exercise and lymph drainage techniques to prevent lymphoedema. This can be time-consuming and sometimes a bit tedious if left until bedtime!' James, Joyce's husband

you. Wearing a sleeve may make you feel you have to change the way you dress – for example, no longer wearing sleeveless tops or dresses. Being conscious of the swelling can make you anxious about intimacy and sex. It may also restrict you physically and you might find you need to make changes in your sexual relationship to accommodate this, perhaps trying different sexual positions to relieve weight or pressure on the affected area.

Lymphoedema is a long-term condition, which means that while it can be controlled with appropriate treatment, it will never completely go away. Controlling your lymphoedema may help to restore your confidence in your appearance as well as enable you to resume the level of sexual activity you want. If you're in this situation, ask your specialist about lymphoedema treatments. For more information see our **Living with lymphoedema after breast cancer surgery** booklet.

Anxiety

Feelings of anxiety are common for many women with breast cancer. This anxiety may be only short term, or may continue for some time after your treatment is over. If you are worried about your treatment or about the future you may find it difficult to relax enough to enjoy sex or even think about it. Tension and anxiety can also reduce a

'I worried about whether my Keith would feel the same way about me as he had before. There seemed to be a need to really prove that we could still maintain a really strong sexual relationship.' **Elaine**

woman's ability to become aroused and reach orgasm, so you and your partner may want to explore techniques that help you both relax.

You may be worried about initiating intimacy, or concerned that your partner no longer finds you attractive. You may be fearful that your relationship can no longer be what it was or anxious about how you approach new relationships.

All of these feelings are normal and it may take some time before they lessen or disappear completely. Talking to your partner about how you feel might ease some of these worries. It may also help to talk to a close friend or family member about the concerns you have. Sometimes just speaking about your worries can help ease them and give you some possible solutions. Sharing your feelings with others helps them understand your anxiety and makes you feel less alone with your worries.

Sometimes, though, it can be hard to talk to your partner, or family and friends, so you may find it useful to speak to someone who's not involved in your life, such as a professional counsellor.

‘Emotionally I tried to convince myself that it didn’t matter that I had lost my breast – a small price to pay for my life, I thought. But I was deluding myself and the full impact of my loss didn’t become apparent until 15 months later when I became quite depressed I wasn’t me any more.’ **Margaret**

Depression

Some women diagnosed with breast cancer may become depressed. This can happen either during treatment or after it’s finished. It may be related to an overwhelming sense of anxiety, although this is not always the case.

Depression can make you feel sad, low and lacking in energy. If you are depressed you may have problems sleeping and have no appetite. You may have no interest in day-to-day life and struggle just getting up in the morning. It’s often difficult to diagnose depression in people with cancer, as some of the side effects of treatment and fatigue are similar to the symptoms of depression.

Being depressed can mean you lose interest in sex or find it less pleasurable. If your symptoms of depression continue you may need to seek specialist help. Try talking about how you feel with someone in your treatment team or your GP. They may be able to recommend different ways of helping you through this time. For example counselling, therapy and drug treatments can all be effective in treating depression – although it may be worth bearing in mind that some anti-depressant drugs can reduce sexual desire and may also make reaching orgasm more difficult.

Fertility

Younger women with breast cancer may experience uncertainty around whether their fertility will return after treatment finishes. They may have to face the prospect of permanent infertility. If you are in this situation, it can be devastating, particularly if you have yet to start or complete your family. You may also feel isolated from your peers and unable to share your sense of loss with others.

Being infertile may affect how someone who is pre-menopausal (still having periods) feels sexually and as a woman. There is information about early menopause and permanent infertility in our Younger women with breast cancer booklet and our **Fertility issues and breast cancer treatment** factsheet.

Intimate relationships

If you are in a relationship you may find that it changes. It's important to remember that changes may be positive or negative, and that some things will be easier to deal with than others. These changes may be difficult to talk about with your partner and it may take some time to resolve them.



'My husband tells me I look beautiful. I can't go with that – I feel that my body is less attractive now – although I am not ashamed and don't hide it – at first I'd prefer to make love in a vest but now I'm relaxed enough to go without.'

Anne

'What had been a quite important part of our lives suddenly seemed to pale into insignificance compared to fighting for survival. I suddenly didn't have space in my life for anything other than getting well again. My husband was devastated at my diagnosis and initially changed into a protective, in fact over-protective, individual.' Joyce

'The person I'd had a 14-year relationship with couldn't cope with my cancer diagnosis and disappeared. That was extremely hard but fortunately my female partner of 25 years – I'm bi-sexual – was rock solid. It's been hard for me to talk about what's happened because although lots of people have more complicated relationship setups, we seldom talk about them explicitly.' **Madeleine**

The quality of a relationship, both generally and sexually, before breast cancer is likely to have a large bearing on how a couple cope with the experience of a diagnosis and

'My husband has not been able to cope with my breast cancer and has never seen my scar and does not want to. Obviously my body is a turn-off.' **Judith**

treatment. Breast cancer may not always cause problems but it can often aggravate existing ones.

'Andrea lost a lot of weight which made her feel better about her body. I enjoyed Andrea's liking for her new body image.'
Philipa, Andrea's partner

If you had problems in your relationship before having breast cancer these will not necessarily have gone away. Your illness will almost certainly make you re-evaluate many things in your life, including your relationship. Some people may decide that they no longer want to stay in a relationship where they are unhappy. Others may feel they need the security of their relationship even if it isn't an entirely happy one. Being able to talk openly about your situation can mean that together you are able to find solutions. This may be a gradual process but avoiding problems altogether may make them more difficult to resolve in the long run.

Women who had a good relationship before their diagnosis often find the experience brings them and their partner closer. Together they have the strength and resources to carry on and overcome whatever difficulties breast cancer brings. This is not always the case, though, and even good relationships can be tested by a diagnosis of breast cancer.

'After surgery there was an initial shock at the sight of the wound and scar, and the loss of a large, beautiful breast. This feeling was of course only temporary, and the main feeling since has been one of tenderness.' **James, Joyce's husband**



'I find it difficult to connect now. My new relationships have been with people who haven't had cancer – and they don't really understand.' *Madeleine*

Dealing with something like cancer will change a relationship during the course of the illness and may be particularly difficult if the relationship is new. If you're in the early stages of a relationship you may find that you are discussing important issues much sooner than you would have liked.

If you're not in a relationship you may find the thought of forming a new one a bit daunting. You may no longer have the same confidence in yourself and how you

appear to others. Beginning an intimate sexual relationship may also bring on feelings of anxiety – for example, about telling someone you've had surgery for breast cancer.

Whatever your situation – whether you are currently single, in a relationship or embarking on a new one – beginning a sexual relationship again may make you very anxious and uncertain. If you were in a relationship before your diagnosis you may be worried about your partner comparing things to how they were before. If you're in a new relationship you may be concerned about how your new partner will react to your body. It may take time for you to feel physically well enough or able to cope emotionally with resuming any form of sexual activity.

It's important to remember that each person's intimate and sexual relationships will be unique. Getting back into sex will be a gradual process that you should try and take at your own pace. Things may well be different and you may need to adapt to your new situation. However, if you and your partner are willing to work at it and communicate supportively with one another, there's no reason why your sexual relationship shouldn't be satisfying and fulfilling for you both.

Partners

An illness like breast cancer not only affects the life of the person diagnosed but also the lives of those who are close to them, especially partners. Couples facing cancer can both feel emotional distress, and when both partners are under stress the relationship often becomes strained.

If you have a partner, they will also face a time of readjustment following your diagnosis and treatment. How your partner responds to you sexually may be influenced to a degree by how they reacted to your breast cancer.

Some partners may take on an overly-protective role, which means they try to do everything for you and protect you from any further distress. They may not want to mention or initiate sex for fear of upsetting or hurting you. Some partners simply need time to accept what's happened. Others cannot come to terms with their partner's breast cancer and may emotionally push them away or even reject them, temporarily or permanently. This rejection may be difficult to deal with at a time when you feel vulnerable.

'I felt there was little change in her body; the changed appearance of the breast that had been operated on was really minimal. But I did have a fear of her being hurt by contact, and that is a fear which persists.' **Keith, Elaine's partner**

'Sex has been off the menu from the time of diagnosis and has been ever since.' **Judith**

Try talking to your partner about how you feel. They in turn may then be able to explain to you a little more about how they are feeling. You may both be making assumptions about how the other feels without realising it.

Your partner may find it helpful to read our **In it together: for partners of people with breast cancer** booklet.

New partners

If you weren't in a relationship when you were diagnosed, or your relationship ended after your diagnosis, meeting someone new may mean telling them about your breast cancer. Deciding when and how to do this can be difficult. You may feel there isn't a right time to talk about this or be unable to find the words. But as you get to know someone and feel more comfortable with them, you may find it easier to talk about all aspects of your life, including your breast cancer.

'I would always advise women to tell a potential partner at the start of a relationship as it is rather unfair to strip off and say, "look at me!". Men I have been involved with have never been frightened, to my knowledge, possibly because I have always prepared them by telling them about my surgery. They are usually fascinated and very kind in their reaction and actions.' **Jenny**



'If I could meet someone new who was caring and loving, I feel at the moment I would love to enter into an intimate relationship just to know that someone could love me for who I am.'

Judith

When you feel the time is right to tell your new partner they may respond in a number of ways. They may initially be shocked and take a little time to adjust to this news. They may have their own anxieties and fears around cancer and what it means to them. Or your new partner may be very accepting of your history and recognise that your experience of breast cancer is now part of who you are.

Getting back to sex

Even though your sexual activity may have decreased or stopped completely during and after your treatment, you may want to try and maintain a level of closeness with your partner. You may not feel like having sex but you may be happy holding hands, hugging, kissing or finding your own ways of being intimate. Taking turns giving each other a massage or taking a bath or shower together can be a pleasing and bonding way to spend time together. Sexual activity can also include touch and other signs of affection that don't always lead to penetrative sex but still result in pleasure.

When you feel ready to increase your level of sexual activity, you may want to think about making some time specifically for you and your partner, free from distractions. The way you communicate with each other at this time is very important. Both of you need the opportunity to talk about how you are feeling. It may not always be easy to talk about sex and you may find it easier to talk somewhere that you both feel comfortable, perhaps away from the bedroom.

'First sexual experiences after treatment were good as far as I remember, surprisingly so, but I think I was thinking I must make the most of things in case I don't survive this.' **Kate**



'We tried to talk about why some things didn't work any more. At times I felt attention to either of my breasts was not desirable. I can only describe it as an electrical circuit that did not quite work – with sensation gone from one breast and nipple I didn't quite feel the connection. I've learnt to live with it. I just need attention to the areas that do work.' Jenny

Your concerns about the effect breast cancer has had on your sexuality will be unique to you and your circumstances. Any of the changes you've experienced may affect your confidence and feelings about yourself as a woman. You may also be anxious about your first sexual experience following your diagnosis, or worried things will not be the same as before. Additionally, if you were pre-menopausal at your diagnosis you may be worried about having to find a new type of contraception and the possible risk of getting pregnant. All of these worries are normal and to be expected. It may take time for your confidence to return and for you to feel comfortable having sex again.

It's important for you to feel you can still be part of a sexual relationship without making comparisons to what things were like before. You and your partner will need to find ways of adapting to the changes resulting from your breast cancer, and this can take time, patience and effort from both of you.

Taking things slowly at first may help. Think about what kind of level of intimacy you feel comfortable with and how much energy you have. There may be practical things to consider, such as making a comfortable area for yourself or taking painkillers if still necessary.

It may also be worthwhile thinking about what would give you confidence at this time. You may wish to create a relaxed, comfortable atmosphere with soft lighting and music. Burning aromatherapy oils can promote an atmosphere of sensual awareness, an accompaniment to an atmosphere of intimacy and sensuality. Some women may

'At first I worried Andrea's scar hurt her and worried about hurting her arm where she had the lymph nodes removed. In sexual terms, I love Andi and it is not an issue that she has had a mastectomy'. **Philipa, Andrea's partner**

'I miss the sensual feelings that have been taken away from me. That in turn produces feelings of loss. My existing breast and its feelings are immensely important to me.' **Jenny**



‘Early sexual experiences after treatment were relaxing, a little cautious, different in that familiar comfortable positions had to be changed due to the sensitivity of my chest wall and under my arm. But I’ve always seen change as a good thing and this was no exception.’ Maggi

not feel comfortable naked and choose to wear soft lacy camisoles, others to wear a prosthesis and bra to bed. Remember, what’s important is what you are comfortable with and what helps you feel less anxious, even if this may take away a sense of spontaneity.

For some women the breasts are a very erogenous zone. If having your breasts

stimulated was an important part of your sex life, losing a breast or changes to a breast through surgery and radiotherapy may have a big impact on your sexual satisfaction. This sense of loss may be shared by your partner if they gained sexual pleasure from the look or feel of your breasts. You and your partner may want to change your focus to other areas of the body and explore other erogenous areas to help you feel sexually satisfied. Some women find sex toys, such as vibrators and clitoral stimulators, helpful in finding out more about what gives pleasure.

The effects of your treatment may mean that you need to think about trying different sexual positions. This may be because of pain or discomfort or because you don't want the focus to be on a particular part of your body. If your chest is tender or you have a permanent access line for chemotherapy you may want to avoid positions where either you or your partner are lying directly on top of one another.

'Early sexual experiences after treatment were very intense. There was hardly any time at all when we had to suspend sexual activities; it was an immense relief to have sex and it felt like an indication that some kind of normality was returning.' **Keith, Elaine's partner**

For some couples, trying different positions may be a new experience. You may want to try lying face to face with your partner or perhaps a 'spoons' position (with your partner lying behind you) if you're concerned about putting pressure on your chest area. Trying new

'The first intercourse after surgery was very tender because I felt Joyce had had enough to cope with without further invasion.' **James, Joyce's husband**



'Sex after I started treatment was tentative – it was almost like sex for the first time with my husband, yet we have been married for 34 years. We needed to rethink our lovemaking – foreplay could no longer be the same as it had been before my surgery.' Margaret

positions may take a little getting used to but it may also be enjoyable.

If vaginal dryness means that penetration is painful, as well as using moisturisers and lubricants you might look at other ways of having sex such as mutual masturbation or oral sex. However, it's worth bearing in mind that chemotherapy can cause mouth ulcers, soreness and vaginal irritation during treatment and for several weeks after.

It's thought that chemotherapy drugs can't pass into semen or vaginal fluids but there may be a theoretical risk of this as chemotherapy drugs can be excreted through blood and

body fluids. Most hospital specialists will advise using barrier or protection methods such as wearing a condom for a few days after chemotherapy treatment is given.

It's particularly important that women who were pre-menopausal at their diagnosis use contraception to avoid pregnancy during their chemotherapy treatment.

If you're worried about any of these aspects of chemotherapy, talk to your specialist or breast care nurse who'll be able to advise you.

Masturbation

Masturbation and sensual touching, both with a partner and on your own, can help remove anxiety associated with sex and can be a helpful starting point for people resuming sexual activity. Although masturbation is often treated as taboo it's both entirely normal and extremely common.

If you're masturbating with your partner, try and start slowly without any expectations and begin with non-sexual cuddling, taking gradual steps and relearning how to give each other pleasure. The single most important factor in resolving sexual difficulties is open, honest communication between you both.

Masturbating on your own can be a good way of finding out what's okay and what's not. Explore your body to discover where and how you like to be touched, find out how responsive your body is to certain sensations and learn how you can be sexually aroused. If you have a partner you can share your discoveries with them to make sex as fulfilling as possible.

Professional help

If you're concerned about any issues relating to your sexuality that you want help in resolving it may be worthwhile talking to your oncologist, breast care nurse or GP in the first instance. Even if it's been a while since you finished your treatment your breast care nurse will still be a useful point of contact. She may be able to help with some of the difficulties you are experiencing – for example, issues around reconstruction, vaginal dryness or concerns about menopausal symptoms.

In some instances you may need specialised help and sometimes it can be easier to talk to a healthcare professional than someone close to you. This may mean you, or you and your partner, seeing a counsellor or a therapist who deals specifically with sexual issues. Your GP or breast care nurse should be able to help arrange this for you. The majority of cancer patients who experience sexual problems don't need long-term therapy but you may find it useful to talk to someone about a particular problem or at a particular point in your treatment or recovery.

Looking ahead

Treatment for breast cancer causes change in you and how you feel about yourself. It may take some time for you (and your partner if you have one) to come to terms with these changes. You may feel a sense of loss for what has been taken away from you or angry that your sexual life has changed so much.

Some women, though, find that experiencing a life-threatening illness like cancer makes them want to embrace life fully and they put more energy and enthusiasm into their sex lives because of this.

'What Andrea went through brought us closer together especially because we talked about everything, including our worries, fears and feelings about our relationship.' **Philipa, Andrea's partner**

'We became closer, I came to understand more clearly how much she meant to me and that resulted in more honesty in the relationship. We knew that we were facing a big challenge and we did that together. It felt like a dreadful period, but it also felt as though a bond had been created by it.' **Keith, Elaine's partner**

Everyone's feelings about their sexuality and sex lives are different and it's important to remember there's no wrong or right way to feel. Being honest with yourself and with those close to you can help you understand both how you feel about your breast cancer and how it has affected your sexuality.

'It was after the diagnosis that we were finally able to be totally honest about how we felt about one another. It felt really good to be able to openly discuss these feelings and it brought us much closer together, we finally realised how much we loved each other. I know it was a really difficult time for Keith as well; not only was he really worried about me, and what would happen to me, but he also had to put up with my desperate lows.' **Elaine**

Having breast cancer will have changed many aspects of your life, including your sexuality. However, many women come through this experience and go on to have a greater understanding of their own sexuality as well as enjoyable and rewarding sexual relationships.

'I read a book that had a line in it which was a quote from a woman saying, "Of course it affects your sex life, of course it does." This preyed on my mind before I had the mastectomy and one person I knew quoted it to me and told me categorically that it was going to ruin my sex life. This was absolute rubbish and whilst I accept that some people may have problems, I really want people to know that it does not have to be a problem and sex can still be good after breast cancer.' **Kate**

Beyond this booklet

Further support from Breast Cancer Care

Free telephone helpline 0808 800 6000 (for Typetalk 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 daily 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. Breast Cancer Care's 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. You can also contact our centres to access these services (contact details on the inside back cover of this booklet).

Online discussion forums and Live chat

The Breast Cancer Care 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 Breast Cancer Care 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 the Breast Cancer Care website. You can email a question on any breast cancer or breast health issue and our team of specialist nurses will reply within two working days. The service is strictly confidential.

Publications

Breast Cancer Care produces 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.

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.

Further reading

Leslie R Schover

Sexuality and Fertility after Cancer

John Wiley & Sons, 1997

ISBN 0 471 18194 3

A book for cancer patients to help them learn to enjoy sex again and make informed choices about pregnancy after cancer treatment. American.

Sarah Litvinoff

Sex in Loving Relationships

Vermillion, 2001

ISBN 0 09 185668 X

A guide produced in association with Relate that looks at all aspects of sex in relationships. Includes practical tasks and quizzes as well as case histories.

Miriam Stoppard

Healthy Sex

Dorling Kindersley, 2003

ISBN 0 7513 6984 5

A guide with pictures including advice on sex and lovemaking for men and women.

Suzi Godson

The Sex Book

Cassell Illustrated, 2002

ISBN 1 84403 511 5

A frank and straightforward book about all aspects of sex – including masturbation, sex toys and sexual health – for both women and men.

Anne Hooper

The Kama Sutra

Dorling Kindersley, 2000

ISBN 0 75130 799 8

Contains descriptions and drawings of different sexual positions.

www.bbc.co.uk/relationships

Gives general advice on relationships and sex.

www.cancerhelp.org.uk

Includes a section on sex, sexuality and cancer.

Useful addresses

Cancer organisations

Cancerbackup

3 Bath Place

Rivington Street

London EC2A 3JR

Office: 020 7696 9003

Freephone helpline: 0808 800 1234 (Mon-Fri, 9am-7pm)

Email: info@cancerbackup.org

Website: www.cancerbackup.org.uk

Cancerbackup is a national information and support charity for people affected by cancer. Services include a helpline, staffed by specialist cancer information nurses, a website, cancer information booklets and local information centres. All Cancerbackup services are free to people affected by cancer.

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

Telephone: 020 7840 7840

Macmillan CancerLine: 0808 808 2020

Textphone: 0808 808 0121

Email: cancerline@macmillan.org.uk

Website: www.macmillan.org.uk

Macmillan Cancer Support is helping people who are living with cancer through the provision of immediate practical and emotional support. Specialist services include Macmillan nurses and doctors, cancer centres, a range of cancer information and direct financial help. The Macmillan CancerLine provides information and emotional support. Textphone available.

General organisations

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

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.

British Association for Sexual and Relationship Therapy (BASRT)

PO Box 13686

London SW20 9ZH

Telephone: 020 8543 2707

Email: info@basrt.org.uk

Website: www.basrt.org.uk

The national specialist charity for sexual and relationship therapy. Can provide a list of accredited therapists in your area.

Relate

Central Office: Herbert Gray College

Little Church Street

Rugby

Warwickshire CV21 3AP

Telephone: 0845 456 1310

Email: enquiries@relate.org.uk

Website: www.relate.org.uk

The UK's largest relationship counselling organisation. Qualified counsellors work in locations throughout England, Wales and Northern Ireland. To find your nearest centre call or see the website. Also produces information leaflets and books.

Central Office

Breast Cancer Care

5–13 Great Suffolk Street
London SE1 0NS
Telephone 0845 092 0800
Fax 0845 092 0820
Email info@breastcancercare.org.uk

Centres

Breast Cancer Care Scotland

Telephone 0845 077 1892
Email sco@breastcancercare.org.uk

Breast Cancer Care Cymru/Wales

Telephone 0845 077 1894
Email cym@breastcancercare.org.uk

Breast Cancer Care North & Midlands

Telephone 0845 077 1893
Email nrc@breastcancercare.org.uk

Breast Cancer Care London & South

Telephone 0845 077 1895
Email src@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 Typetalk prefix 18001) or visit www.breastcancercare.org.uk.

Breast Cancer Care relies on donations from the public to provide its services free to clients. 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.