My body, myself
Altered body image, intimacy and sex after breast cancer

A policy report by Breast Cancer Care
Foreword

Diana Jupp,
Director of Services,
Breast Cancer Care

People who use our information and support services often tell us that their breast cancer diagnosis and treatments have affected their self-confidence and the way they view their bodies.

We also hear how a negative self-image can in turn have a devastating impact on their social and intimate relationships.

I am proud that Breast Cancer Care is here to support people through information, support and bringing people together so that they can work towards building confidence after breast cancer.

I am also proud that we are highlighting the often unspoken issue of altered body image after breast cancer, through this policy report and through our body image awareness campaign.

One way that we are raising awareness is via a short film and a series of adverts featuring Jill, Heather and Ismena, who talk about their experience of body image after breast cancer. These adverts aim to raise awareness of the issues and the free information and support we provide: www.breastcancercare.org.uk/body

The needs of people directly affected by breast cancer are at the heart of this report and everything we do. Here you will read direct quotes from our Breast Cancer Voices (people affected by breast cancer who share their experience and expertise to inform our work). What they have in common is a powerful call to action: body image matters after breast cancer, and addressing body image and intimacy concerns should be as important as effective clinical treatment.

‘I feel that my self-image and confidence has been the hardest part of cancer to overcome and that myself and other patients would benefit from and appreciate improved support in this area.’

Lisa, 30

We know there is no simple ‘one size fits all’ solution and different people have different needs at different times. But there are things that can help, such as talking to others in a similar situation, information and support about treatment side effects such as menopausal symptoms, and being referred to psychological or sex therapy services.

Our goal is that everyone should have access to the information and support they need, when they need it, to help them cope with altered body image and its legacy after breast cancer.

Through our information and support services and through the recommendations we are making in this policy report, we are making progress towards this goal.
Acknowledgements

Thank you to the people affected by breast cancer who shared their experiences with us to create this report. Thank you also to the Breast Cancer Voices who make up our Body Image Reference Panel that has helped inform this report.

Thank you to our Body Image Advisory Group* for guiding the focus of this report and reviewing drafts of our recommendations.

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This report was prepared by Policy and Campaigns Manager Lizzie Magnusson and Campaigns and Involvement Co-ordinator Emma Lavelle, Breast Cancer Care 2014
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Our body image adverts

www.breastcancercare.org.uk/body

We’ve produced a short film and three adverts featuring women talking about their experiences of body image after breast cancer and showing their mastectomy scars. Appearing across the UK, they aim to raise awareness of the issues and the free support we provide.

We’ve also been asking people affected by breast cancer to write a letter to their body to share on our website their feelings about their body and what has helped them cope with these feelings.

A letter to my body

Dear body,

When I was first diagnosed it didn’t really sink in. I was on my own for that appointment and my nurse kept asking if I was OK, expecting me to burst into tears. She even suggested I ring my husband, but there was no signal in the hospital.

Over the next few weeks I put you through all the tests they do. I had the surgery and then the radiotherapy. All the time, I didn’t even think about cancer.

The radiotherapy made the scar on the nipple invert, causing a hole which I could only dry and wash with a cotton bud, and you bled a bit. My surgeon told me he would close the hole but it would mean losing my nipple.

I was OK with this (or so I thought) joking with him and my nurse that at 62 I didn’t think I was going to be breastfeeding again. What I didn’t realise was I wasn’t likely to be having sex again either. My husband had not wanted sex since my diagnosis. Before I went for the first operation he said it didn’t bother him what I looked like afterwards. It didn’t matter to him if I had a mastectomy or not, he said.

Breast cancer treatments also stopped my hair from holding hair dye, so I am now grey.

The tamoxifen I was put on caused you – my body – to put on weight, but that was better than the side effects of the first two drugs my oncologist put me on. You’ve finally started to lose the weight, one stone so far and another one to go.

My breast nurse has been very understanding. I realise there are women a lot worse off than me and I hate bothering her with trivial things. Needless to say, she told me off for thinking like that.

She referred me to a psychologist and suggested a referral to a plastic surgeon, as the loss of the nipple has really affected me. I find I cannot look at you in the mirror and my husband stays ‘asleep’ while I get dressed and comes to bed after me. I have also burst into tears at my last appointments at the clinic and at the prosthesis fittings.

I bought stick-on nipples, a leaflet I picked up at the clinic. Having these means I can wear some of my unpadded post-surgery bras – one goes on the prosthesis. It doesn’t solve the no sex problem, though, and it has been over two years now. He even finds it hard to hug me, and I do miss it all. If I talk to him about it he just rolls his eyes, almost saying I’m talking rubbish. He doesn’t see the tears as he never comes into the appointments with me.

Jane
Introduction

‘Expressing sexuality remains important to many people with cancer, regardless of age, and can be fundamentally compromised by the condition and its treatment. Cancer has an impact on intimate relationships, can cause specific sexual dysfunction, and affects how people perceive their sexual identity through, for example, a changed body image. Because sexuality is an issue that many people – health and social care professionals and patients – find difficult to address, there can be a failure to offer or seek information and support.’

Improving Supportive and Palliative Care for Adults with Cancer (NICE, 2004)

A breast cancer diagnosis and breast cancer treatments can bring changes related to a person’s body image and sexuality, which in turn can have a devastating impact on intimate relationships.

A report published by the All Party Parliamentary Group on Body Image (APPGBI) in 2012 emphasises the devastating impact a negative body image can have on someone. The report states that in the UK ‘body image dissatisfaction is high and on the increase and is associated with a number of damaging consequences for health and wellbeing’ (APPGBI, 2012).

Defining the term ‘body image’ can be difficult because it means different things for different people, but as an organisation, Breast Cancer Care holds with the definition coined by Sarah Grogan. It provides a simple but inclusive description of the term that is easy to identify with: ‘...a person’s perceptions, thoughts and feelings about his or her body’ (Grogan, 2008).

About a half a million people are alive today following a diagnosis of breast cancer (Maddams et al, 2009). Breast Cancer Care is able to provide information and support related to altered body image, intimacy and sex after breast cancer – an area of long-term cancer care we know is underrepresented. We are campaigning for support and information about altered body image, intimacy and sex to be available to everyone affected by breast cancer as an essential and integral part of their cancer treatment and care.

Impact on intimate relationships

This report offers an overview of the key issues involved in altered body image after breast cancer, with a particular focus on changes in sexual and self-identity, and the impact these changes can have on intimate relationships, both existing and new.

We make recommendations on how NHS services in England, Scotland and Wales can best support people affected by breast cancer in relation to altered body image, intimacy and sex.

Until recently the cancer policy agenda had been dominated by a focus on clinical outcomes and improving cancer survival. Recently, however, there has been a shift in the focus towards a more holistic and longer-term approach, looking at the care provided for people living with or beyond cancer. This approach recognises that cancer care needs to be more than providing effective clinical treatment. It should also focus on other aspects of a person’s life and wellbeing, including self-image, social interactions and intimate relationships, sometimes well after treatment has ended.

We are campaigning for altered body image and intimacy concerns to be consistently recognised as part of this holistic, person-centred approach to cancer policy and cancer care.

We examine altered body image, intimacy and sex after breast cancer under the following five headings.

- My body, myself – six statements for breast cancer services, see p8.
- The impact of altered body image, see p9.
- Access to information and support, see p16.
- Recommendations for service improvements, see p20.
- National standards, public policy and guidance, see p28.

Evidence base for this report

- Literature review (mainly 2006 until the present day) on altered body image, intimacy and sex after breast cancer.
- Analysis of focus groups held between 2009 and 2011 with people affected by breast cancer.
- Feedback from women affected by breast cancer, healthcare professionals and other experts on our Body Image Advisory Group* (see p4).
- Feedback from our Body Image Reference Panel of 14 women affected by breast cancer.
- Previous Breast Cancer Care reports on challenging inequalities in cancer care, particularly the inequalities that exist for people from black and minority ethnic backgrounds, older people, and lesbian and bisexual women.
- Personal stories from people affected by breast cancer gathered in 2013.

‘Body changes can occur quickly or over a long period of time. They can affect the way you think and feel about your body (body image), which can affect your self-confidence. You might also worry that people will treat you differently because of a change to your body. Concerns about your body can occur at any time. Some people will focus on just getting through their treatment and won’t think about its impact until much later.

‘Changes to your body may seem more important after you leave hospital, at the start of another type of treatment or after finishing treatment. Some people may feel that they “don’t recognise themselves” or that they “lose themselves”:’

NHSInform (Scotland) – Cancer Zone, Coping with body changes

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My body, myself – six statements for breast cancer services

These statements summarise the information and support that people who use our services have identified as necessary to address concerns about altered body image, intimacy and sex.

We’ve developed them with people directly affected by breast cancer, healthcare professionals and other experts through our Breast Cancer Voices, Body Image Advisory Group and Body Image Reference Panel. We address each statement in Recommendations for service improvements (see p20).

1. I want to be treated as a whole person. I want issues relating to changes to my body, and concerns about intimacy and sex to be taken seriously, assessed and addressed as an essential and integral part of my treatment and ongoing care for primary or secondary breast cancer.

2. I want to be listened to as an individual. I do not want assumptions to be made about how I feel about my body, intimacy and sex based on my relationship status, age, gender, religious background, ethnicity, disability or sexual orientation.

3. I want to be able to access specialist information about altered body image, intimacy and sex throughout my breast cancer treatments and after treatment has ended. I want this information to include practical ideas. I may want this information in a language other than English.

4. I want to know about and be referred to services in the NHS and voluntary sector that offer support with altered body image, intimacy and sex. These services should be available to me regardless of where I live.

5. I may want to be able to get in touch with other people affected by breast cancer to talk about changes to my body and to share coping strategies.

6. I may want my partner to be involved in the support I receive about body image, intimacy and sex or to receive information specifically designed for partners.

The impact of altered body image

‘There is currently a variation in the provision and quality of psychological approaches and services offered to patients with cancer. For example, women with breast cancer may need support due to traditional symbols of feminine sexuality being challenged by treatments: loss of a breast(s), changes to breasts, loss of hair and, for some younger women, fertility issues.’

Living with and beyond cancer: taking action to improve outcomes (National Cancer Survivorship Initiative, 2013)

Breast cancer treatments affect those parts of the body and bodily functions that are particularly associated with femininity and female desirability (such as breasts, fertility and hair).

For men diagnosed with breast cancer, it can be distressing to be diagnosed with a condition commonly seen as a ‘feminine disease’ (Donovan and Flynn, 2007). As such, treatments can have a particularly negative (and sometimes long-term) impact on a person’s self-image, sexual identity and intimate relationships (Arroyo et al, 2011; Fallbjörk et al, 2012).

Breast cancer treatments can also have an impact on sexual functioning in women and men, with side effects such as low sexual desire and vaginal dryness in women. It may lead to temporary or permanent infertility (Panjari et al, 2011; Breast Cancer Care, 2011 and 2013). Sexual dysfunction and changes to fertility can have devastating consequences for a person’s self-esteem and self-image and for their intimate relationships, existing and new.

There is a wide spectrum of altered body image experiences and feelings after breast cancer, with everyone’s experience personal to them. For example, one study describes the different personal meanings of having a mastectomy as ranging from ‘No big deal’ to ‘Losing oneself’ (Fallbjörk et al, 2012). The possible changes in body image after breast cancer can be loosely grouped as affecting a person physically, psychologically and socially. These headings are broad and their content often overlaps. Some examples of the impact of altered body image after breast cancer under these headings follow.

‘...more needs to be done to promote help for women and for these issues to be taken seriously. After all, there is enough to cope with emotionally with a cancer diagnosis without also feeling that there is nobody to talk to about body image issues, and that it is somehow selfish or vain to worry about them.’

Rachel, 47
Physical impact

This refers to changes in bodily appearance and related practical issues. Examples of the physical impact of breast cancer treatments include the list below.

- Loss of breast(s) or breast tissue through surgery for breast cancer or breast cancer risk-reducing surgery. This could be breast-conserving surgery, otherwise referred to as lumpectomy or wide local excision – in which the cancer is removed along with a margin of normal breast tissue – or mastectomy, in which all the breast tissue including the nipple area is removed.
- Asymmetry in appearance, for example after the removal of breast tissue on one side, or asymmetry after breast reconstruction.
- Difficulties and lack of choice in finding and buying suitable and attractive bras and swimwear and lack of access to specialist post-surgery bra fitting. Difficulties and lack of choice in finding and buying attractive clothing, particularly summer or evening wear of choice in finding and buying suitable and attractive bras and swimwear and lack of access to specialist post-surgery bra fitting.
- Scarring from surgery – for both tumour removal and breast reconstruction – and from radiotherapy.
- Total or partial body hair loss caused by chemotherapy and hair regrowth issues. Hair can grow back different from the hair before treatment, either permanently or temporarily.
- Skin changes after some treatments, such as skin discolouration or dry skin. This may be a particular issue for black and Asian people.
- Menopausal symptoms as a side effect of breast cancer treatment. Including hot flushes and vaginal dryness.
- Some chemotherapy and hormone therapies used in the treatment of breast cancer can bring about an early menopause and can cause temporary or permanent infertility. Chemotherapy can affect sperm production, leading to temporary or permanent infertility in men.
- Weight gain as a side effect of breast cancer treatment.
- Lymphoedema, when the arm, hand or breast area swells because of damage to the lymphatic system caused by surgery and radiotherapy.
- Secondary breast cancer (where the cancer has spread to another part of the body) can result in many different physical symptoms including pain. Symptoms depend on where the cancer has spread to in the body.

What people tell us

'I had a lumpectomy three years ago and have noticed that my breast on that side is smaller and the nipple sticks out more. The breast is also about 2cm higher than the non-treated breast.'

Susan, 69

'For me the biggest change was being flat chested on my right side following my mastectomy. This has really taken some adjusting to. It is easier to cope with in winter than summer. I have also found I am gaining confidence with my choice of clothes: prior to the breast cancer I liked low-cut tops; now I am much more conservative but do try and look nice as it makes me feel so much better. I had a single mastectomy so being “lopsided” has also taken some getting used to.'

Jennifer, 41

'Although I had an immediate reconstruction, I was never fully comfortable with it and felt I needed to adjust my clothing to hide it. I was also concerned about the weight gain from tamoxifen, but managed to get this under control once I stopped taking it.'

Mairead, 58

'Lorna, 45

'I feel OK about my body when I have clothes on but feel self-conscious about the changes when I don’t have clothes on. I was glad to get rid of the tumour. However, I didn’t realise that a lumpectomy would change the shape of my breast as it has done.'

Susan, 69

'My main concern was always to get rid of the cancer. Unfortunately, the breast went with it but I don’t think losing the breast affected me as much as accepting the new breast, if that makes sense. The old one could go, it was diseased and could have killed me – the new is different; it’s heavy, it’s numb but often painful and it had no nipple for a long time.'

Jasmin, 44

'I found the whole experience of preparing for hair loss, and the build-up to it, to be a very distressing and traumatic time.'

Susan, 53
Psychological impact
This refers to changes in emotional wellbeing, including difficulties with anxiety and depression. Examples include the points below.

- Feelings of permanent and temporary loss and associated depression, anxiety and feelings of grief. People often use the word ‘loss’ to describe a lack of something physical and notional or spiritual after breast cancer. This includes loss of: breast/s and breast tissue, nipple/s, hair during chemotherapy; skin sensation where surgery has taken place; fertility through cancer treatments; confidence; a sense of femininity or masculinity; a sense of self or clear identity; a sense of wholeness or bodily integrity; a sense of attractiveness or sensuality.

- Feeling less confident or self-conscious because of self-awareness of changes in body or appearance.

- Feelings of being incomplete or a fraud and connected feelings of depression, anxiety and shame, such as feeling ‘less of a woman’ or ‘less of a man’.

- Changes in sexual identity, including feeling less attractive or unattractive, experiencing changes to traditional symbols of femininity and feminine desirability through breast cancer treatments, such as the breast(s), hair and, for some younger women, fertility. For men diagnosed with breast cancer, living with the stigma of a ‘woman’s disease’ can challenge sexual identity.

- Changes in self-identity and confusion about identity, such as feelings of being ‘less feminine’ or ‘less masculine’. This can include feeling as though the identity of ‘cancer patient’ or ‘cancer survivor’ dominates other feelings about how you see yourself or are seen by others.

- Reminder of the cancer diagnosis. Altered appearance can be a positive reminder of successful treatments. However, it can also be a negative reminder of the cancer diagnosis and associated fear of cancer recurrence, or a reminder that a person is living with secondary breast cancer (breast cancer that has spread to another part of the body and can be controlled but not cured).

- Loss of trust in the body. Some women talk of their body having let them down after being diagnosed with breast cancer and feeling that they have no confidence in their body anymore. This can be a particular issue for women with secondary breast cancer (where the cancer has spread to another part of the body).

What people tell us

‘I am still working out how I feel about the changes my body has undergone. Do I feel maimed? Or am I a new Amazon woman, one-breasted and beautiful?! I don’t know.’

Tamsin, 43

‘When I lost my breast I lost my sexuality. I don’t feel feminine or whole and I feel angry and sad that this has happened.’

Kate, 50

‘When I went to a lingerie shop there was a beautiful set of cream lace lingerie. I felt ashamed to be looking at it and I still feel a sick lump in the pit of my stomach that someone like me could look at it.’

Sarah, 44

‘Following my mastectomy I also clearly remember waking up in recovery and being so aware that my breast had gone, it felt so empty. No-one had talked to or prepared me for this feeling. I cried for hours post-op.’

Jennifer, 40

‘I do miss my real breasts as they are such a big part of being a woman.’

Natalie, 43

‘I am so pleased that the cancer has been taken away but grieve for the loss of the breast I had.’

Tracy, 49

‘Another big thing is the loss in trust of my body, especially after being diagnosed with secondaries last July. The treatment for this has turned into a watch-and-wait but the diagnosis really was such a shock and it will take time to learn to trust my body and that every twinge is not a new recurrence or cancer.’

Vicky, 33
Social impact
This is about changes in how people respond to the social environment and changes in social and intimate relationships. Examples include the points below.

- **Changes in a person’s role within the family, with a partner and with friends.** This can include the reactions of others to bodily changes caused by breast cancer treatments. It can involve feeling that the identity of ‘cancer patient’ or ‘cancer survivor’ dominates other feelings about how you see yourself or are seen by others, or feeling as though an intimate relationship has been replaced with the roles of ‘carer’ and ‘patient’.

- **Changes in sexual functioning after breast cancer treatments,** such as vaginal dryness, which can cause pain or discomfort during sex, reduced libido, loss of orgasm and orgasm intensity, discomfort from scarring, the impact of fatigue (a common treatment side effect) and lack of sensation in breasts.

- **Challenges to existing intimate relationships.** This can be linked to feelings of unattractiveness or the impact of the physical side effects of treatment on sexual functioning. It might be linked to difficulties in talking as a couple about breast cancer, or a partner’s response to an altered body image and its impact on the relationship.

- **Challenges in forming new relationships.** For example, feeling anxious about revealing a breast cancer diagnosis to a new partner or unable to start a new intimate relationship because of concerns over not feeling sexually attractive or sexual dysfunction.

- **Being unable to return to paid employment or having to take time off from employment due to body image issues, or feeling less confident in a job role.**

- **Finding it distressing to use communal changing rooms** in sports facilities and clothes shops.

- **Social isolation or changes in social interactions due to lack of self-confidence and concerns that appearance changes will reveal a breast cancer diagnosis to others.**

### What people tell us

- **Self-confidence has plummeted!** … People say, “Wow haven’t you done well, you look great” etc, but inside I feel that I look freaky, the way I dress has changed … I just want to blend into the background.

  **Elaine, 45**

- **He [my partner] was much more upset about it than me and initially could not look at my scar. He also wanted me to have reconstruction, which I did not want.**

  **Janet, 43**

- **Prior to being with my new partner, I was very worried about meeting someone as I felt like a freak.**

  **Natalie, 43**

- **I do not like looking at myself anymore and believe my husband doesn’t either as he waits for me to go to bed and to get up. We no longer have any intimacy.**

  **June, 61**

- **I think it is important to acknowledge the impact that your changes in body image have on children. I let both of my children look at my mastectomy wound when they wanted to, and they both took this in their stride. It was my hair loss during my chemo that they struggled with.**

  **Jennifer, 41**

- **Once my breasts had healed, I believe it was difficult for him [my partner] to touch my breasts... We talked and gradually he was able to touch and kiss my breasts.**

  **Irene, 57**

- **I had a mastectomy at age 38. I couldn’t bear to look at myself having been mutilated, much less have anyone else look. Sexual relationships were then off the agenda for good. I am now aged 71.**

  **Anon, 71**

- **I still really care about my appearance. I worry about my breasts and how numb they are and how the long menopause [brought on by breast cancer treatments] has affected my sexual feelings.**

  **Lorna, 45**

- **We have grown apart because of the mastectomy. We have no sex life, I have no libido and now we have no marriage. I can’t ever imagine being intimate with anyone again.**

  **Kate, 50**

- **Our physical relationship has suffered... the physical discomfort of the side effects and surgery, tiredness and feeling very unattractive.**

  **Karen, 52**
Access to information and support

There are several barriers for breast cancer services to overcome in order to address altered body image, intimacy and sexual concerns effectively.

Altered body image and changes in sexuality affect different people in such different ways that a standard approach isn’t appropriate – a range of information resources and service referral options is needed.

Altered body image and concerns about intimacy and sex can remain silent issues in cancer care, with patients and healthcare professionals sometimes reluctant to talk about them. Also, altered body image and intimacy concerns can arise long after treatment and hospital-based appointments have ended so that the people affected may feel that they don’t know where to turn to access the specialist support they need. These barriers are explored further below.

Assessment of individual needs

‘I wasn’t offered any support. I was told about changes to my body but wasn’t offered support. I actually find it difficult to discuss certain issues and haven’t contacted anybody.’

Jasmin, 44

Everyone diagnosed with breast cancer (whether primary or secondary breast cancer) should have their needs assessed through a holistic needs assessment tool, such as the Distress Thermometer. The outcomes of this assessment should be regularly reviewed as needs may change.

It is important that no assumptions are made about who will be affected by altered body image, intimacy and sexual concerns, and that people’s individual feelings are explored. Some research has examined the hypothesis that body image after breast cancer is a particular concern for younger women. However, other studies suggest that body image is also important for many older women, particularly for those concerned about appearance pre-treatment (Figueiredo et al, 2010).

A recent parliamentary report into older age and breast cancer (Age is just a number) noted the importance of not overlooking the intimacy and body image needs of older people with breast cancer. The report recommends holistic needs assessment for older patients that looks at needs concerning ‘information about body image, prosthetics after surgery and intimacy and relationship issues.’ It goes on to say: ‘Several studies have found that many older breast cancer patients are not offered this information as it is sometimes assumed that they are not as concerned as younger women about these issues’ (APPG Breast Cancer, 2013).

‘My breast care nurse referred me to a clinical psychologist who really did help me. I was able to talk openly about how I felt. The psychologist helped me reframe my thoughts – for example we talked a lot about attractiveness, and this really helped me to look forward and start accepting my new look. I also read the leaflets from Breast Cancer Care on intimacy and sexuality, which I found useful.’

Jennifer, 40

People affected by breast cancer are sometimes reluctant to raise issues of altered body image, intimacy and sex with healthcare professionals or family and friends. This can be because they fear these issues will be seen as trivial, or because they feel embarrassed or have concerns over privacy. In addition, some healthcare professionals feel ill-equipped to respond effectively to these concerns.

Training and resources for healthcare professionals

- Breast Cancer Care’s Nursing Network – including the November 2013 edition of Nursing Network News, which contains information on supporting people on issues of altered body image, intimacy and sex.
- Macmillan Cancer Support’s LearnZone web-based tools for healthcare professionals.
- The PLISSIT model (Annon, 1976) of including the topic of sexuality in healthcare (Brandenburg, 2011; Katz, 2005):
  - P = permission: giving patients permission to raise sexual concerns
  - LI = limited information: giving limited factual information
  - SS = specific suggestions: making specific suggestions, tailored to the individual patient’s needs
  - IT = intensive therapy: referral when appropriate to intensive therapy.

Breast Cancer Care has developed a prompt list to help people with breast cancer identify the issues they want to bring up with a healthcare professional, discuss with our Helpline or email to our Ask the Nurse service. Your body, your concerns: a prompt list for discussions can be used in conjunction with a wider holistic needs assessment tool. The list aims to empower people affected by breast cancer to ask for information and support on body image and intimacy issues. As well as being reproduced here (p38), it is available on our website and as part of the patient information booklet, Your body, intimacy and sex.

For information on Breast Cancer Care services and information see p36.
Support could be practical (such as prosthesis fitting or lymphoedema management) or emotional (such as a support group or one-to-one counselling). The format of information and support will depend on the person’s needs and preferences, but might involve:

- giving a patient a copy of an information booklet
- referring to a support group or other peer support opportunity
- referring to a voluntary sector service, such as a Breast Cancer Care Lingerie Evening, or a Relate or Relationships Scotland service
- referring to a specialist NHS service such as gynaecology, psychology or psychiatry.

People should also be given clear information about how to access support if hospital appointments have ended (for example, by contacting a voluntary sector organisation, their GP or by getting back in touch with a breast care nurse).

The value of peer support

“I’ve been helping others... realise that they can still wear lovely underwear and there is a sexual life after cancer. This is a vital role and, in my opinion, is better given by someone who’s gone through the experience rather than a health professional.”

Tina, 52

Peer support opportunities can be valuable in coping with the impact of altered body image. Focus groups conducted by Breast Cancer Care in 2011 to inform the development of our services found that women placed great value on peer support for body image and intimacy issues, both before and after treatment. The focus group participants preferred support in a group setting, although some women also valued one-to-one support via the telephone.

The value of exercise

Physical exercise can also help improve mental wellbeing and manage treatment side effects, such as weight gain and extreme fatigue (Macmillan Cancer Support, 2012). Healthcare professionals should consider talking to patients about the benefits of exercise and signposting to appropriate physical exercise opportunities (such as Breast Cancer Care’s Best Foot Forward walking groups) that can also offer the chance to meet and talk with other people affected by cancer.

Inclusive services

Information and support services and resources must be sensitive to diverse backgrounds and communities.

Assumptions should not be made that a patient is heterosexual, and breast cancer information should use images and language inclusive of lesbian, gay and bisexual people (Breast Cancer Care, 2011c).

It is also important that breast cancer information and support is culturally sensitive (sensitive to different ethnic and religious needs) and that literature contains images that are ethnically diverse. Another positive step is making information available in community languages other than English. People should be given information about local voluntary organisations (where available) appropriate to their ethnic and cultural background.

People from black, Asian and minority ethnic groups (BAME) may have distinct body image concerns after breast cancer that should be recognised in their cancer care.

Breast Cancer Care and King’s College, London’s Better Access, Better Services project conducted focus groups with 20 Asian and African Caribbean women diagnosed with breast cancer. The project found variations in access to appropriate support services, with some women having problems in obtaining breast prostheses that matched their skin colour or finding wig services that catered to the hair needs of black women. One African Caribbean woman in the study reported great difficulty in finding a lymphoedema sleeve that matched her skin tone (Blows et al, 2009b).

A study by researchers at the Centre for Appearance Research (University of the West of England, Bristol) concluded that while BAME women expressed similar body image concerns that have been documented among Caucasian women affected by breast cancer, there are also unique body image concerns specific to BAME women. For example, some BAME women in the study were dissatisfied with the limited range of cosmetic aids (wigs, scarves, prostheses and cosmetics) and felt that they did not meet their cultural needs (Patel et al, 2010). A study led by the Black Health Initiative (BHI) into hair loss and wig services in Leeds found that black women can feel put off using hair loss services if accompanying wig catalogues only picture white women (BHI et al, 2012).

Men diagnosed with breast cancer can find it challenging their sense of masculinity and it can be distressing and stigmatising living with a disease mainly associated with women (Donovan and Flynn, 2007). It may be helpful to offer photographs of men after a mastectomy and gender-specific information on side effects of treatments, such as chest hair loss after radiotherapy (Williams et al, 2003).

The need for specialist information and support, and the forms this might take, is defined further in the recommendations section of this report, overleaf.
Recommendations for service improvements

Working with our Breast Cancer Voices and our Body Image Advisory Group and Reference Panel, Breast Cancer Care has developed a set of statements for breast cancer services relating to body image, intimacy and sex. The statements summarise the support people want in order to address sex and intimacy issues, and to help them rebuild confidence in their bodies following a breast cancer diagnosis.

We have also developed corresponding recommendations for breast cancer service improvements, set out in the tables that follow. The recommendations are aimed at health policy-makers, service commissioners and planners, and healthcare professionals involved in cancer care.

Overarching recommendation: national breast cancer clinical guidelines and national cancer policy/strategy documents should include recommendations for assessing and addressing needs and concerns about body image, intimacy and sex as an essential and integral part of breast cancer treatment and care.

Our recommendation
Everyone diagnosed with breast cancer should have a holistic needs assessment that includes questions on altered body image, intimacy and sex.

<table>
<thead>
<tr>
<th>My body, myself – statements for breast cancer services</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. I want to be treated as a whole person. I want issues relating to changes to my body and concerns about intimacy and sex to be taken seriously, assessed and addressed as an essential and integral part of my treatment and ongoing care for primary or secondary breast cancer.</td>
<td>Everyone diagnosed with breast cancer (whether primary or secondary breast cancer) should have their needs assessed through a holistic needs assessment tool, such as the Distress Thermometer. This assessment should be carried out by a breast care nurse or other healthcare professional involved in that person’s cancer care at the start of treatment and regularly reviewed as directed by the patient. For primary breast cancer patients who attend follow-up appointments, this assessment should also be reviewed at follow-up appointments to identify any ongoing needs.</td>
</tr>
<tr>
<td>2. I want to be listened to as an individual. I do not want assumptions to be made about how I feel about my body, intimacy and sex based on my relationship status, age, gender, religious background, ethnicity, disability or sexual orientation.</td>
<td>Breast Cancer Care has developed Your body, your concerns: a prompt list for discussions (see p38) for use in conjunction with holistic needs assessment tools. This is a prompt list of potential body image and intimacy concerns to help people identify which concerns they wish to raise with their healthcare professional or with Breast Cancer Care’s Helpline, and to help them feel confident that these concerns are a valid part of their cancer care.</td>
</tr>
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</table>

Healthcare professionals should have access to training and resources to equip them with the skills and knowledge to address these issues. Breast Cancer Care has produced information for breast care nurses on providing support and information. This is available through Breast Cancer Care’s Nursing Network.
### Our recommendation

As guided by the outcomes of a holistic needs assessment, patients should be given specialist practical information or referred to reliable sources of information created for people affected by breast cancer about changes to their body and self-image, and concerns about relationships, intimacy and sex.

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### My body, myself – statements for breast cancer services

<table>
<thead>
<tr>
<th>Description</th>
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<tr>
<td>In order to ensure that each person is making informed treatment choices and is prepared for possible consequences of treatment, people diagnosed with breast cancer (whether primary or secondary breast cancer) should be given information about:</td>
</tr>
<tr>
<td>• the changes they may experience in their appearance</td>
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<tr>
<td>• their feelings about their bodies</td>
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<tr>
<td>• their intimate relationships.</td>
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Also, about how they might cope with these feelings and changes. Images in such information should reflect the diversity of people affected.

The person affected should be made aware of how to access information at any point (for example, by contacting a named breast care nurse or Breast Cancer Care’s Helpline). For primary breast cancer patients, information should also be given at follow-up appointments about any potential ongoing issues or concerns.

The information given should be identified by the outcomes of regularly reviewed holistic needs assessments. The individual person’s preferences should guide the form this information takes. It should include practical ideas about coping with challenges or difficulties. Information should be available in languages other than English. This could be written information in the form of a booklet from a reliable source or by referral to a trusted website. It could be information given in a conversation with a healthcare professional or signposting to Breast Cancer Care’s Helpline or email Ask the Nurse service. There should be specialist information available written by and for people from minority ethnic groups.

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### My body, myself – statements for breast cancer services

<table>
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<tr>
<th>Description</th>
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<tbody>
<tr>
<td>Information should be available on:</td>
</tr>
<tr>
<td>• breast surgery, breast reconstruction and nipple tattooing, including photographs representing different ethnic communities</td>
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<tr>
<td>• coping with menopausal symptoms and weight gain</td>
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<tr>
<td>• preventing and managing lymphoedema</td>
</tr>
<tr>
<td>• relationships (existing and forming new ones), intimacy and sex after breast cancer – for example Breast Cancer Care’s information booklet <em>Your body, intimacy and sex</em></td>
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<tr>
<td>• skin changes, including discolouration and the different skin changes women from different ethnic groups might experience</td>
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<tr>
<td>• effective and safe lubricants for vaginal dryness and pain</td>
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<tr>
<td>• how exercise can improve mood and self-esteem</td>
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<tr>
<td>• examples of psychological approaches to cope with low self-esteem and negative self-image</td>
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<tr>
<td>• breast prostheses, bras and clothing after breast surgery, for example Breast Cancer Care’s information booklet <em>A confident choice</em>.</td>
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People should 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.
Our recommendation
Each breast unit should establish referral pathways to relevant NHS and voluntary sector services that can offer support and information on the altered body image, intimacy and sexual issues raised through holistic needs assessments.

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<tr>
<th>My body, myself – statements for breast cancer services</th>
<th>Description</th>
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<tr>
<td>4. I want to know about and be referred to services in the NHS and in the voluntary sector that offer support on issues about altered body image, intimacy and sex. These services should be available to me regardless of where I live.</td>
<td>Breast units should refer people with breast cancer (whether primary or secondary breast cancer) to relevant specialist information and support services, as guided by the outcomes of regularly reviewed holistic needs assessments. Information should be given about local, regional and national services. This might be:</td>
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<tr>
<td></td>
<td>• a Breast Cancer Care service</td>
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<td></td>
<td>• a local voluntary sector specialist support service</td>
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<td>• a hospital-run service</td>
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<td></td>
<td>• a Relate or Relationships Scotland service</td>
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<td></td>
<td>• a Look good… feel better workshop</td>
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<td></td>
<td>• a referral to NHS clinical psychology and psychiatric services</td>
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<td></td>
<td>• a referral to NHS gynaecology services</td>
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<td></td>
<td>• a local breast cancer support group. These include practical and emotional support services on:</td>
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<td></td>
<td>• managing hair loss and regrowth (including wig-fitting services with access to wigs in colours and textures suitable for black and Asian people)</td>
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<td></td>
<td>• managing treatment side effects including menopausal symptoms and lymphoedema (including lymphoedema sleeve fitting, with sleeves available in diverse skin tones)</td>
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My body, myself – statements for breast cancer services

Continued from p24

<table>
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<tr>
<th>Description</th>
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<tbody>
<tr>
<td>• breast prosthesis fitting (including prostheses in colours suitable for black and Asian clients) and advice on choosing post-surgery bras (such as Breast Cancer Care’s Lingerie Evenings) and clothing</td>
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<tr>
<td>• coping with low self-esteem, loss of confidence and changes in self-image</td>
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<tr>
<td>• sex therapy and relationships counselling, culturally appropriate counselling, family therapy</td>
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<tr>
<td>• sexual health services</td>
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<tr>
<td>• exercise opportunities, such as Breast Cancer Care’s Best Foot Forward walking groups.</td>
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People affected by breast cancer should have the option of being referred to a fertility specialist to discuss the options for preserving fertility both before starting chemotherapy or hormone treatment and afterwards.

Everyone affected by breast cancer should be given information about how to access support and information after treatment and hospital appointments have ended, for example through Breast Cancer Care’s Helpline and website.
### My body, myself – statements for breast cancer services

#### Description

<table>
<thead>
<tr>
<th>5. I may want to be able to get in touch with other people affected by breast cancer to talk about changes to my body and to share coping strategies.</th>
</tr>
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<tbody>
<tr>
<td>People identified through holistic needs assessments as potentially benefitting from support on body image and intimacy issues should be given information about or referred to peer support services such as face-to-face group support services, online discussion forums or one-to-one peer support. Examples include:</td>
</tr>
<tr>
<td>- hospital-based support groups and voluntary support groups expert in supporting particular ethnic or cultural groups</td>
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<tr>
<td>- the online discussion Forum and Live Chat on Breast Cancer Care’s website</td>
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<tr>
<td>- Breast Cancer Care’s face-to-face services</td>
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<tr>
<td>- Breast Cancer Care’s telephone-based and email-based one-to-one support service with trained volunteers with experience of breast cancer.</td>
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</table>

### My body, myself – statements for breast cancer services

#### Description

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<tr>
<th>6. I may want my partner to be involved in the support I receive about body image, intimacy and sex or to receive information specifically designed for partners.</th>
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<tbody>
<tr>
<td>Guided by the outcomes of regularly reviewed holistic needs assessments, people affected by breast cancer should be made aware of the specialist information and support available for partners. Examples include:</td>
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<tr>
<td>- Breast Cancer Care’s information booklet for partners <em>In it together</em></td>
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<tr>
<td>- referral to NHS clinical psychology services</td>
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<tr>
<td>- referrals to couples and family counselling</td>
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<tr>
<td>- referral to services available for couples or individuals at a local Relate Centre or a Relationships Scotland service.</td>
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</table>

[www.relate.org.uk/find-your-nearest-service/index.html](http://www.relate.org.uk/find-your-nearest-service/index.html)

[www.relationships-scotland.org.uk/find-a-local-service](http://www.relationships-scotland.org.uk/find-a-local-service)
Policy, guidance and standards – England and Wales. See also ‘England only’ p30 and ‘Wales only’ p31


1.2.3 All patients with breast cancer should be offered prompt access to specialist psychological support and, where appropriate, psychiatric services.

1.5.1 Discuss immediate breast reconstruction with all patients who are being advised to have a mastectomy, and offer it except where significant comorbidity or (the need for) adjuvant therapy may preclude this option. All appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally.

1.13.3 Ensure that all patients with early breast cancer who develop lymphoedema have rapid access to a specialist lymphoedema service.

1.14.6 Patients treated for breast cancer should have an agreed, written care plan, which should be recorded by a named healthcare professional (or professionals), a copy sent to the GP and a personal copy given to the patient. This plan should include:

- contact details for support services, for example support for patients with lymphoedema.


1.4.1 Healthcare professionals involved in the care of patients with advanced breast cancer should ensure that the organisation and provision of supportive care services comply with the recommendations made in ‘Improving outcomes in breast cancer: manual update’ (NICE cancer service guidance [2002]) and ‘Improving supportive and palliative care for adults with cancer’ (NICE cancer service guidance [2004]), in particular the following two recommendations.

- ‘Assessment and discussion of patients’ needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as diagnosis; at commencement, during and at the end of treatment; at relapse; and when death is approaching).’

- ‘Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of “key worker” for individual patients.’

1.5.4 Provide patients with lymphoedema with at least two suitable compression garments. These should be of the appropriate class and size, and a choice of fabrics and colours should be available.

1.5.5 Provide patients with lymphoedema with clear, written information and the contact details of local and national lymphoedema support groups.

Policy, guidance and standards – England and Wales. See also ‘England only’ p30 and ‘Wales only’ p31

NICE Improving Supportive and Palliative Care for Adults with Cancer (2004)

10.7 Expressing sexuality remains important to many people with cancer, regardless of age, and can be fundamentally compromised by the condition and its treatment. Cancer has an impact on intimate relationships, can cause specific sexual dysfunction, and affects how people perceive their sexual identity through, for example, a changed body image. Because sexuality is an issue that many people – health and social care professionals and patients – find difficult to address, there can be a failure to offer or seek information and support.

10.13 The rehabilitation needs of patients should be assessed at key points in the patient pathway, using an assessment tool agreed across the Cancer Network.

12.13 Family members and carers should be offered the opportunity for their needs for support and information to be assessed separately from those of patients, particularly at stages in the patient pathway acknowledged as especially demanding and when extra help might be needed. Cultural and ethnic preferences on family involvement should be taken into account.

NICE Clinical Guideline 156 – Fertility: Assessment and treatment for people with fertility problems (2013)

1.16.1.2 At diagnosis, the impact of the cancer and its treatment on future fertility should be discussed between the person diagnosed with cancer and their cancer team.
Policy, guidance and standards – England only. See also ‘England and Wales’ p28

NICE Quality Standard Breast Cancer (QS12)

Quality statement 3: Breast-conserving surgery
People with early breast cancer undergoing breast-conserving surgery, which may include the use of oncoplastic techniques, have an operation that both minimises local recurrence and achieves a good aesthetic outcome.

Quality statement 4: Mastectomy
People with early breast cancer who are to undergo mastectomy have the options of immediate and planned delayed breast reconstruction discussed with them.

Quality Statement 9: Clinical follow-up
People having treatment for early breast cancer are offered personalised information and support, including a written follow-up care plan and details of how to contact a named healthcare professional.

Definition:
- Information about the possible psychosocial impact of breast cancer, including anxiety, depression, altered body image, sexuality and relationships.

Improving Outcomes: A Strategy for Cancer (Department of Health, 2011)

5.3 Although there have been significant improvements in support for people living with and beyond cancer, more needs to be done so that cancer survivors have the care and support they need to live as healthy a life as possible, for as long as possible. We want to see improvements in the outcomes which are particularly relevant for people living with and beyond cancer, such as:

- Reducing the proportion of people who report unmet physical or psychological support needs following cancer treatment

5.17 The NCSI (National Cancer Survivorship Initiative) has developed a series of principles which should underpin support provided to people living with and beyond cancer. These principles are based on the model of care for people with long term conditions and include that following cancer treatment people should be offered:

- A personalised, risk stratified pathway of care, following assessment and care planning. The assessment will include needs associated with the individual, the disease and the treatment. The pathway will include an end of treatment record summary shared between the cancer centre and primary care team and the care plan will be co-ordinated so that it addresses the full range of needs of those with co-morbidities.

- People living with and beyond cancer often have specific support needs which, if left unmet, can damage their long-term prognosis and ability to lead an active and healthy life. These needs can include information about treatment and care options, psychological support, access to advice on financial assistance and support in self-managing their condition.

National Cancer Survivorship Initiative – Living with and beyond cancer; taking action to improve outcomes (2013)

5.4 To improve this step in survivorship all patients should be offered:

- Information about their cancer, and their support and treatment options, including the short- and longer-term consequences of treatment.
- Support in making decisions that are appropriate for them.

6.21 All patients should be offered a Holistic Needs Assessment. The assessment may require input from a range of doctors, nurses and allied health professionals (such as dieticians, physiotherapists, occupational therapists, and speech and language therapists) depending on the nature of a patient’s problems. These assessments can be delivered in a number of ways, one being dedicated clinics.

Policy, guidance and standards – Wales only. See also ‘England and Wales’ p28


Actions – Local Health Boards to assess the clinical and non-clinical needs (such as information needs on accessing financial, emotional and spiritual help) of people following a diagnosis of cancer and draw up and implement a care plan to be reviewed regularly.


Standard no. 3.2 Written information in a language and format appropriate to the patient should be offered to each new cancer patient. This should cover:

b. Detail of treatment options, specific local arrangements including information about the MDT (multidisciplinary team) and support services and whom the patient should contact if necessary.

c. Details of local self-help/support groups and other appropriate organisations.

Standard no. 5.2 Written referral pathways should be drawn up by the breast cancer MDTs in collaboration with primary care which detail the patient journey from whichever point patients access the system.


Standard no. 2.1 Cancer rehabilitation should be a core consideration of all cancer MDTs whether cancer site specific, specialist palliative care or community based to ensure that patients at any stage from diagnosis to end of life are identified, referred and assessed for rehabilitation measures as necessary.

Standard no. 3.2 Written referral pathways to access cancer rehabilitation services should be drawn up by the CNRAG (Cancer Network Rehabilitation Advisory Group) in collaboration with primary, secondary and voluntary sector providers which detail the patient journey from whichever point the patient accesses the system. These pathways should include clear transfer of care arrangements from inpatient and outpatient settings once a patient is transferred to their preferred location.
Diagnosis

Checklist for provision of information – surgery or mastectomy.

Women with invasive breast cancer who are undergoing breast surgery should be offered the choice of breast-conservation surgery or mastectomy.

Checklist for provision of information – Treatment

- Explain the surgical options available, including reconstruction if appropriate. Patients may wish to know about how they will look and feel after surgery.
- Discuss practical issues around breast prostheses and bras, if appropriate.
- Discuss side effects and how they can be managed. Let the patient know that not all people will react to the same treatments in the same way.
- Provide practical advice on hair loss, such as where to obtain a wig.
- Have information leaflets available and details of where other sources of support can be found.

Checklist for provision of information – Follow up

- Practical and psychological support may be needed for patients for many years following treatment.
- Provide details of where patients can receive support, advice and information on life after cancer/survivorship.


Standard Statement 3a

Patients are fully informed of the different options for treatment and involved in decision-making to the extent they wish. Clear lines of communication are maintained between the staff in the breast unit and the primary care team.

Essential criteria 3a.3

Written information leaflets (including information about local support groups) are available for all patients (including those with disabilities and those requiring translation services).

Scottish Government, Better Cancer Care (2008)

Psychological support

Care systems, protocols or pathways should be developed to ensure that psychological needs are actively considered as a part of planning care. This is particularly important for patients who need reconstructive care due to changes in their physical appearance caused by treatment.

NHS Boards and regional cancer networks will be encouraged to ensure that all patients with cancer have an assessment of their psychological care needs and that tailored responses are developed as part of personal care plans. This work should be developed in partnership with the voluntary sector and with specialist psychological care practitioners such as clinical health psychologists and liaison psychiatrists.

Conclusion and next steps

Breast Cancer Care recognises that breast cancer can alter a person’s body image and challenge their self and sexual identity, wellbeing and relationships.

Through timely assessment of concerns and prompt referral to specialist services and resources, people affected by breast cancer can be supported to make steps towards positive body image. We know that there are many examples of good practice in supporting people affected by breast cancer on these issues – we want to make sure that this is available to everyone who needs it.

We will be meeting with healthcare professionals, cancer policymakers, and service planners and commissioners in England, Scotland and Wales to discuss how we can work together to take forward the recommendations from this report.

In summary, Breast Cancer Care is calling for:

- consistent recognition in national and regional guidelines of the need to address concerns about altered body image, intimacy and sex as an essential part of breast cancer treatment and care
- everyone diagnosed with breast cancer to have a holistic needs assessment that includes questions on altered body image, intimacy and sex
- each breast unit to establish referral pathways to relevant NHS and voluntary sector services that can offer support and information on issues about altered body image, intimacy and sex, including services providing peer support opportunities
- each breast unit to have the resources to provide (or signpost to) specialist information created for people affected by breast cancer about changes to their body and self-image, and concerns about intimacy and sex
- people affected by breast cancer and their partners to be offered or referred to specialist information or support services designed for partners.

Breast Cancer Care
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Breast Cancer Care (2011a) Men with breast cancer, London: Breast Cancer Care


Breast Cancer Care (2011c) Lesbian and bisexual women and breast cancer, London: Breast Cancer Care, ESRC knowledge exchange programme RES-192-22-0111

Breast Cancer Care (2013) Your body, intimacy and sex, London: Breast Cancer Care


NHSSinform (Scotland) Cancer Zone: coping with body changes, available at www.nhssinform.co.uk/cancer/lifeaftercancer/bodychanges [Accessed 1 Nov 2013]


NICE (2004) Improving Supportive and Palliative Care for Adults with Cancer, London: NICE


NICE (2011) NICE Quality Standard Breast Cancer (QS12), London: NICE


Hair loss advice
Our free HeadStrong service can help prepare you for the possibility of losing your hair because of cancer treatment.

Lingerie Evenings
For more confidence when choosing a bra after surgery, join other women who have had breast cancer at one of our Lingerie Evenings.

Moving Forward
We run free four-week programmes, examining some of the issues that may affect people moving forward after breast cancer.

Best Foot Forward
Short walks for people of all abilities with other people who have had breast cancer.

Secondary breast cancer
We run monthly meet-ups in 12 locations across the UK to give you the opportunity to meet other people living with secondary breast cancer.

Younger women
Breast cancer is not common in younger women. Being diagnosed at a young age can sometimes be a very isolating experience. We provide expert information, free services and publications for younger women with breast cancer.

Find support
Publications
www.breastcancercare.org.uk/publications

Your body, intimacy and sex
Looking at the physical and emotional changes as a result of breast cancer and its treatment that can alter how you feel about your body, and how these changes can affect sex and intimacy.

Your body, your concerns: a prompt list for discussions
To help you identify your body image and intimacy concerns for discussion with healthcare professionals such as your breast care nurse or GP, or in a phone call with our Helpline. It is published in this report and available free on our website and as part of the Your body, intimacy and sex booklet.

A confident choice
Having breast surgery can have emotional as well as physical implications, particularly when dealing with changes in appearance. Balancing shape with a well-fitting bra and breast prosthesis can help restore confidence. This free booklet covers this and other clothing concerns following surgery.

Body image
We provide a range of information on our website about changes to your body.

In it together: for partners of people with breast cancer
Packed with useful tips and information, this free publication offers practical help for everyone whose partner has been diagnosed with breast cancer.

Services
www.breastcancercare.org.uk/services

Helpline
Our free, confidential Helpline is here for anyone who has questions about breast cancer or breast health. Your call will be answered by one of our nurses or trained staff with experience of breast cancer. Call 0808 800 6000.

One-to-one support
Our one-to-one support service can put you in touch with someone who knows what you’re going through, by phone or email.

Publications
www.breastcancercare.org.uk/publications

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Your body, your concerns
A prompt list for discussions

Talking about changes to your body, sex and intimacy can be difficult. But addressing your concerns is an important part of your breast cancer treatment and care. This list may help you discuss these topics with your healthcare professional (perhaps your breast care nurse or GP) or in a phone call with Breast Cancer Care’s Helpline. Tick the topics you would like to talk about, ask for more information about, or find specialist services about. Have the list with you when you talk to your healthcare professional. You may also want to make a list of the treatments you’ve had or are having.

I want to talk about or be directed to relevant information or specialist services about the issues I have ticked.

- Operation scars
- Reconstruction
- Radiotherapy skin changes
- Prostheses, bras, clothes and swimwear
- Menopausal symptoms
- Lymphoedema
- Hair loss/hair regrowth
- Weight gain/weight loss
- Regaining confidence in my appearance
- Vaginal dryness/discomfort or pain during intercourse
- Pain, numbness and sensitivity after surgery
- Contraception (compatible with my breast cancer treatment)
- Loss of desire
- Changes to how I experience orgasm
- Low energy (fatigue)
- Worries about starting a new relationship
- Changes in my relationship with my partner after breast cancer
- Accessing relationship counselling or sex therapy
- Support or information for my partner
- Coping with the loss of my fertility and its impact on my relationship
- Low mood/depression

Any other issues about my body and intimacy
Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer.

Our clinical expertise and emotional support network help thousands of people find a way to live with, through and beyond breast cancer.

Visit www.breastcancercare.org.uk or call our free Helpline on 0808 800 6000.

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