

The EMPLOY Charter

Breast Cancer Care's guide to best practice in the workplace



Information about breast cancer

The following pages provide a brief introduction to breast cancer and breast cancer treatments. You can find further information about all aspects of breast cancer on our website, www.breastcancercare.org.uk, in our publications or by calling our free and confidential helpline on **0808 800 6000** (for Typetalk prefix **18001**). Our trained nurses are also available by email to offer specialist information on breast cancer and health issues through our 'Ask the Nurse' service. See our website for more information.

Breast cancer

Breast cancer is the most common cancer in the UK. More than 44,300 women and around 300 men were diagnosed with breast cancer in the UK in 2004. Due to earlier detection and improved treatment survival rates for breast cancer are improving. It is estimated that around 172,000 women are living in the UK who have been diagnosed with breast cancer in the last 10 years.

Breast cancer starts when a single cell in the breast begins to divide and grow in an abnormal way. Breast cancer is not one single disease and there are several types of breast cancer. It can be diagnosed at different stages of development and can grow at different rates. Breast cancer is a complex disease and it is difficult to predict what course it will take.

The term primary breast cancer describes breast cancer that is only found in the breast area. Secondary, or metastatic, breast cancer occurs when breast cancer cells spread to other parts of the body. When breast cancer spreads, for example, to the bones, it is called secondary breast cancer in the bone. A diagnosis of secondary breast cancer means that the cancer cannot be cured. However it can be treated and controlled, sometimes for years, and it is important to note that some people with a diagnosis of secondary breast cancer may feel well and be symptom free for a long time.

For more information see our **Secondary breast cancer** booklet (http://www.breastcancercare.org.uk/content.php?page_id=5258).

'Alongside the physical aspect of my secondary [breast cancer] diagnosis, the psychological and emotional side was enormous and I knew I couldn't cope with the external stress of work alongside what was going on for me.'

Breast cancer treatments

For more information about all breast cancer treatments, see our **Treating breast cancer** booklet (http://www.breastcancercare.org.uk/content.php?page_id=670).

'In general, I think employers need to know that treatments affect everyone differently... that some people want to be supported to work and some don't or aren't able to work. It's not a case of "you're either sick or not sick", it's much more complex.'

It is important to highlight that different individuals will follow different treatment plans. Many factors are involved in working out an individual patient's treatment plan, including:

- the person's age
- the individual's general health
- the type of breast cancer and its stage (the extent of the spread of a cancer and the size of a tumour)
- patient choice.

The emotional impact of a diagnosis of breast cancer will also vary between individuals and patients will experience different physical and emotional reactions to treatment.

Treatment for breast cancer may involve any or all of the following: surgery, chemotherapy, radiotherapy, hormone therapy, and targeted therapy. The order of the treatments can differ from person to person.

Surgery

This is usually the first treatment for people with primary breast cancer, with some of the breast tissue (breast-conserving surgery or lumpectomy) or all of the breast tissue (mastectomy) being removed.

Recovery time after breast surgery can vary from person to person and depends on many factors. These include the type of procedure undertaken, the general health and medical background of the person and the type of work the individual is returning to, for example office-based or manual labour.

As well as time off work for the operation and recovery, individuals will need time off for related outpatient appointments, both before and after the surgery. The number of appointments will, again, depend on the individual circumstances. After a mastectomy some women choose to wear a prosthesis (an artificial breast form) and will need to attend a prosthesis fitting service for one or two appointments.

For more information see our booklets **Your operation and recovery** (http://www.breastcancercare.org.uk/content.php?page_id=714) and **A confident choice: breast prostheses, bras and clothes after surgery** (http://www.breastcancercare.org.uk/content.php?page_id=3487).

Some women may choose to have a breast reconstruction, either at the same time as their breast surgery or at some point in the future. Reconstruction can involve major surgery and has to be considered carefully. Reconstruction can be an important part of treatment and may help emotional recovery and wellbeing. Reconstructive surgery will usually take longer to recover from physically than breast-conserving surgery or a mastectomy and additional outpatient appointments, both before and after the procedure, may be needed. After some types of breast reconstruction surgery an employee may not be able to carry out repetitive lifting or certain manual handling tasks for several months.

For more information see our **Breast reconstruction** booklet (http://www.breastcancercare.org.uk/content.php?page_id=663).

Chemotherapy

The aim of chemotherapy is to destroy any cancer cells that may have spread from the breast to other parts of the body. Chemotherapy is usually given after surgery and before radiotherapy in primary breast cancer (although it can be given before surgery). It usually starts three to four weeks after surgery, giving the body some time to recover from the effects of the operation. It may also be given as a stand alone treatment in secondary breast cancer.

Chemotherapy for breast cancer is usually given as a series of treatments every two to four weeks over a period of four to six months. This can vary, depending on the type of breast cancer and the combination of drugs used. The gap between courses of treatment gives the body time to recover from any short-term side effects that might occur. Chemotherapy is normally given as an outpatient but individuals will probably be at the hospital for most of the day. Patients will also need to attend outpatient and blood test appointments during their chemotherapy treatment.

Chemotherapy affects people in different ways. The side effects can depend on the patient's individual situation and the specific drugs being used. Two people receiving the same combination of drugs may feel completely different during the course of their treatment. Some people experience very few side effects and are able to continue with their usual activities while others find their lives are affected to varying degrees. Some of the most common side effects are susceptibility to infection, nausea and vomiting, sore mouth, mouth ulcers, tiredness and hair loss or thinning. For more information about hair loss, see our **Breast cancer and hair loss** booklet (http://www.breastcancercare.org.uk/content.php?page_id=658).

'There was one morning when I had a 9am external meeting and I woke up at 7am to find all my hair on the pillow. I certainly hadn't factored in enough time that morning to deal with an emotional hair crisis and it was the most difficult thing to get into a 'wig mindset' in time to get to work – all the time feeling very self-conscious about the wig.'

For more information about chemotherapy see our **Chemotherapy for breast cancer** booklet (http://www.breastcancercare.org.uk/content.php?page_id=664).

Radiotherapy

Radiotherapy is the use of high energy x-rays to destroy cancer cells. Radiotherapy treatment can be used in a number of different ways but is often used after surgery to try to get rid of any remaining cancer cells in the breast and to reduce the chances of the cancer from returning. It is usually given daily, Monday to Friday, for a total of three to six weeks as an outpatient. It is important that treatment continues as planned and that individuals do not miss any appointments. Radiotherapy may be given on an inpatient basis for secondary breast cancer patients. Radiotherapy is a specialised treatment which is not available in every hospital. This means individuals may have to travel some distance to receive treatment.

'The impact of chemotherapy and radiotherapy made me feel so tired I was physically and mentally unable to work. I had to travel 45 minutes to and from the hospital each day for radiotherapy. I was tired so could not work.'

Radiotherapy to the breast does not usually make people feel unwell. However, the body does use a lot of energy over the course of treatment, so people may feel more tired than usual. This may affect what they feel able to do. The journey to hospital can be tiring in itself. Some people find they can manage their daily tasks as usual and may continue to work full-time. Others need more time to rest and may need to take time off.

For more information see our **Radiotherapy** factsheet (http://www.breastcancercare.org.uk/content.php?page_id=706).

Hormone therapy

If someone's breast cancer is stimulated to grow by hormones (hormone receptor positive breast cancer) they will be offered hormone therapy. Nearly all hormone therapies are taken as tablets over several years. Hormone therapies include tamoxifen, Femara (letrozole), Aromasin (exemestane) and Arimidex (anastrozole). Zoladex (goserlin) is a hormone treatment given by injection.

Side effects from hormone therapy treatment include menopausal symptoms such as hot flushes, night sweats and mood swings. Some people experience joint pains. People affected may need to make changes to their working patterns to deal with these side effects, depending on their individual circumstances.

For more information see Breast Cancer Care's factsheets on individual hormone therapy drugs (http://www.breastcancercare.org.uk/content.php?page_id=5257).

'My oncologist put me on a monthly injection of hormone treatment to shut my ovaries down. This stops the production of oestrogen which feeds the cancer. I am therefore having an early menopause with all the side effects including hot flushes. I get tired at work'

Targeted therapy

Currently the best known targeted therapy is Herceptin (also known as trastuzumab). Herceptin is given as a drip into a vein in the arm or hand. People receive this treatment as an outpatient, usually once a week or once every three weeks for up to one year. It will also be necessary for patients to have heart tests during Herceptin treatment.

The side effects of Herceptin will vary from person to person but can include flu-like symptoms, nausea and diarrhoea. Again, the individual affected may need to make changes to their working patterns to help cope with these side effects.

For more information see our **Herceptin (trastuzumab)** factsheet (http://www.breastcancercare.org.uk/content.php?page_id=696).

The emotional impact of breast cancer

It is important not to underestimate the possible emotional or psychological impact of a diagnosis of primary or secondary breast cancer and breast cancer treatment. Not everyone's reaction is the same, but people can feel upset, frightened or have difficulty adjusting to what is happening to them. These feelings can occur during treatment or after treatment is completed. A diagnosis of breast cancer can continue to have an emotional impact some years later. Anxiety about losing a job or not being supported by your employer can make this even worse. Many people find that talking to a counsellor, psychiatrist or psychologist or attending a support group helps them. These appointments may fall within normal working hours.

'A diagnosis of cancer knocks you out emotionally.'

For more information see our booklet **Breast cancer and you: Diagnosis, treatment and the future** (http://www.breastcancercare.org.uk/content.php?page_id=661).

Fatigue

Fatigue or tiredness is a common side effect of breast cancer and its treatment. People may feel tired or exhausted some or all of the time, often without the energy to complete even simple, everyday tasks. It is usual to feel tired during treatment. However, some people can still feel tired and lacking in energy for several months after treatment has finished. Fatigue can also fluctuate. It may be a continuous problem or something that affects people at different times over a number of years. This may be due to sleep problems, ongoing treatment or psychological issues. Although most people recover their energy in six months to a year after treatment, some people find that fatigue is ongoing.

A common symptom of secondary breast cancer is fatigue. This can have a significant impact on an individual's ability to cope with their illness and treatment. It can also affect everyday activities and may necessitate a change to working hours and the introduction of flexible working.

'I was very tired a lot, but my company were very supportive and allowed me to dictate my hours etc. I felt very much in control and if I was too ill to work, I didn't. I was lucky that during my treatment everyone was supportive.'

For more information, see Cancerbackup's booklet **Coping with fatigue** (Cancerbackup, London 2002, ISBN 1904370233). This booklet looks at cancer-related fatigue and ways of coping with it. To order, visit www.cancerbackup.org.uk

Lymphoedema

Lymphoedema is caused by a build-up of lymph fluid in the tissues following breast surgery or radiotherapy. It is thought to affect around one quarter of people who have surgery for breast cancer to some extent. It can occur in the weeks or months following treatment or sometimes years later. It is a long-term condition which means that, while it can be controlled, it will never completely go away.

Lymphoedema affects people in different ways. The most common symptom is swelling of the arm, including the hand and fingers. Swelling can also affect the breast or chest area. The skin may feel stretched, making it difficult to move the arm. Some people find the swelling results in aching, heaviness or a pins-and-needles sensation. Some people may experience symptoms such as heaviness or aching of the arm but no swelling. For a few people, the swelling will restrict movement and this can make some jobs and activities difficult.

The symptoms of lymphoedema usually respond very well to treatment and this means that in most cases it can be well managed. A patient may need to attend ongoing appointments with a lymphoedema specialist for advice, support and, if appropriate, for measuring and fitting specific hosiery (compression sleeve).

Employees experiencing lymphoedema may need to have their job descriptions reviewed and some reasonable adjustments made to their role, such as removing some manual handling tasks or supplying equipment so that the employee can continue to carry out tasks that could involve lifting or stretching their arms.

For more information see our **Living with lymphoedema after breast cancer treatment** booklet (http://www.breastcancercare.org.uk/content.php?page_id=666).

'I work as a receptionist. For me, lymphoedema and wearing a sleeve are the only outward signs of my cancer.'

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

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