Moving Forward: 
for people living with and beyond 
a diagnosis of primary breast cancer
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This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We’ve been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who’ve been there. We also offer local support across the UK.

From the moment you notice something isn’t right, through to treatment and beyond, we’re here to help you feel more in control.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk
What is Moving Forward?

Breast Cancer Care’s Moving Forward services and information are here for anyone who has had a diagnosis of primary breast cancer, helping you approach life after treatment with more confidence.

This Moving Forward pack contains information that may be useful to you after treatment for primary breast cancer.

For some people, the last hospital-based treatment is the goal they focus on, and getting there can feel like a real achievement. But some people also feel isolated, low or anxious when their regular hospital appointments stop.

You may be experiencing ongoing side effects of treatment, thinking about going back to work or worrying about the cancer coming back.

After treatment has ended, the healing process, both physical and emotional, can take months or sometimes years.

We hope this information pack will help you move forward with more confidence and support you through the process.

Who is Moving Forward for?

This information pack is for anyone who is coming to the end of or has finished their hospital-based treatment for primary breast cancer.

Whether you’ve just finished your treatment or your diagnosis of breast cancer was a few years ago, this pack contains information that’s relevant to you. You may also find it useful to show the pack to your family or friends to help them understand how you might be feeling.
While we mainly refer to women throughout the pack, men who have had breast cancer may also find much of it useful.

How do I use Moving Forward?

Moving Forward is designed to be easy to dip in and out of. And while you may want to read the whole pack, you can just take what’s useful to you, your family and friends and leave the rest. How you use Moving Forward is entirely up to you.

You may want to read about certain topics in more detail. Breast Cancer Care has publications and online content on many of these subjects. Where relevant, we’ve included the names of other publications which you can order or download from our website www.breastcancercare.org.uk, or order using the form on page 143.

Look out for this symbol:

The ‘Further support’ section on page 139 also outlines Breast Cancer Care’s range of services and support for people living with and beyond breast cancer.

Breast Cancer Care’s Moving Forward courses

Finishing active treatment for breast cancer can be an unexpectedly challenging time, bringing a mix of emotions. You might feel relieved that the hospital appointments are over but also under pressure to get back to ‘normal’ and worried about how to adjust to life after your diagnosis.

Our free Moving Forward courses can help. Over four weeks we look at the issues that you may be facing at this time, from the physical side effects of treatment like fatigue to how you’re feeling about your relationships and the future. Because the courses are run in partnership with NHS hospitals, there is expert guidance on hand to answer the questions that are most important to you, and meeting up regularly also
means you’ll get to know other people who are in a similar situation and understand how you’re feeling. You can also find out more about the other support we provide and services which are available locally.

Topics covered may include: healthy eating, exercise, managing menopausal symptoms, lymphoedema, cancer fatigue, intimacy and relationships, and adjusting and adapting after a diagnosis of breast cancer.

For more details, visit our website or call 0345 077 1893.

‘I felt quite isolated and confused at the end of treatment and I signed up for a four-week Moving Forward course organised by Breast Cancer Care at the New Victoria Hospital in Glasgow. It was absolutely excellent and I thoroughly enjoyed meeting other ladies who had been through similar treatment.’

Catriona
Keeping a diary

Some people find keeping a diary of how they’re feeling helps them recover after breast cancer.

Recording your feelings, both good and bad, can help you make sense of them and identify the cause. As time goes on, looking back through your diary may help you see signs that you’re recovering from your experience, both physically and emotionally.

It’s up to you how often you write in your diary, what you include and where you write it. You could use a diary, a notebook or a computer.

Read more about keeping a diary on the next page.

Below are some things you may want to record.

<table>
<thead>
<tr>
<th>Topic</th>
<th>What to record</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue (extreme tiredness) and sleep problems</td>
<td>How fatigued you feel each day on a scale of 1 to 10, where 1 is no fatigue and 10 is needing to rest or sleep most or all of the day. How much sleep you’ve had, what time you went to sleep and when you woke.</td>
</tr>
<tr>
<td>Pain</td>
<td>How bad any pain is on a scale of 1 to 10, where 1 is no pain and 10 is the worst pain you’ve ever felt. How often pain occurs, how long it lasts and when it’s better or worse. Where the pain is, whether it’s in one or several places, or spreads. What the pain feels like, for example a stabbing, nagging or burning sensation. What makes the pain worse and what has relieved it in the past, for example pain relief.</td>
</tr>
<tr>
<td><strong>Menopausal symptoms</strong></td>
<td>Any menopausal symptoms you experience, such as hot flushes. You may want to discuss them with your breast care nurse or GP (local doctor).</td>
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<td>------------------------</td>
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<tr>
<td><strong>Mood</strong></td>
<td>How you’re feeling. This can help you come to terms with what you’ve been through and to make sense of your feelings. Write as much or as little as you like, as often as you choose.</td>
</tr>
<tr>
<td><strong>Ongoing treatments</strong></td>
<td>Any treatments you’re having. This will help you identify any patterns between having treatment and any side effects you experience.</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td>What sort of exercise you’ve done, how long you exercised for and how difficult you found the exercise.</td>
</tr>
</tbody>
</table>

If any of the side effects of your treatment are affecting your daily life, or if you’re concerned about any of the issues above, contact your breast care nurse or GP.
Call our Helpline on 0808 800 6000
Managing the effects of treatment

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Breast Cancer Care’s publications contain more information on the topics covered in this section. You can order or download a copy from our website, or use the order form at the end of this pack.
You may like to read:

• Breast cancer and hair loss
• Complementary therapies
• Fertility and breast cancer treatment
• Living with lymphoedema after breast cancer
• Menopausal symptoms and breast cancer
• Osteoporosis and breast cancer treatment
• Reducing the risk of lymphoedema
• Younger women with breast cancer.
Introduction

Breast cancer and its treatments can cause a number of side effects – such as fatigue (extreme tiredness) and hot flushes – which can stop you feeling that you’re moving forward. For some people the side effects are a constant reminder of their breast cancer. For others, these ongoing effects leave them feeling very low and they may struggle to cope.

This section outlines some of the side effects you may have as a result of your treatment and possible solutions that may help you manage them.

We have a range of booklets and online information on the drugs used to treat breast cancer. To find out more call the Helpline on 0808 800 6000 or visit the website.
Menopause and menopausal symptoms

The menopause is a natural event for all women. Menopause refers to a woman’s final menstrual period. The average age of a natural menopause for women in the UK is around 52 years, with symptoms usually lasting from several months to a number of years. However, treatment for breast cancer can cause an earlier menopause in younger women and a return of menopausal symptoms in women who have already been through the menopause.

What treatments cause menopausal symptoms?

Chemotherapy can cause menopausal symptoms in pre-menopausal women because their ovaries, which produce oestrogen, are affected by the treatment. For some women this may cause an earlier, more sudden menopause. Symptoms are often more intense than when the menopause occurs naturally. Periods can also stop temporarily during chemotherapy and menopausal symptoms may continue until regular periods return.

Menopausal symptoms can also be caused by hormone (endocrine) therapy or ovarian suppression (preventing the ovaries from making oestrogen, either permanently or temporarily). Hormone therapy will only be prescribed for people whose breast cancer has receptors within the cell that bind to the hormone oestrogen and stimulate the cancer to grow (known as oestrogen receptor positive or ER+ breast cancer).

What symptoms might I have?

Menopausal symptoms are very common among women treated for breast cancer, although some have few or no symptoms. Some of the more common symptoms include:

- hot flushes
- night sweats
- vaginal dryness
- palpitations
- mood changes
• joint pain
• changes to skin and hair.

Less common symptoms include:
• putting on weight, particularly around the waist
• problems sleeping
• anxiety and irritability or having problems with memory or concentration
• a crawling sensation under the skin.

The changes you notice in your body may be gradual but for some women symptoms such as hot flushes can start suddenly.

How severe the menopausal symptoms are and how long they last varies. Some women have very few symptoms at all. For others they can be very distressing and interfere with everyday life. You may feel they are a constant reminder of cancer or feel frustrated that they have been caused by your cancer treatment. But you may get used to them and find they improve in time.

Managing menopausal symptoms

Lifestyle changes, drugs and therapies may help reduce menopausal symptoms and make them easier to manage.

You can find out more about menopausal symptoms as well as tips on how to manage them in our booklet Menopausal symptoms and breast cancer.

Some people use complementary therapies to help manage menopausal symptoms but there’s very little reliable research into these. So it’s hard to judge how useful complementary therapies are. You should discuss complementary therapies with your specialist team before trying them.

For more information about complementary therapies, see page 93. You may also like to read our booklet Complementary therapies.
Different treatments work for different people and it can be trial and error until you find something suitable. If you decide to try something new, talk to your specialist, breast care nurse or GP (local doctor). You may also be referred to a specialist menopause clinic if there is one in your local area.

‘About one month after I started taking tamoxifen, I began to have serious night sweats. This was not simply a little sweaty but as if someone had poured liquid over me, and I had to change the linen at least once every night. I began to think I might not be able to cope with tamoxifen, but as quickly as the sweats began, they ended after three weeks.’

Catriona
When your hair grows back

If you lost your hair because of chemotherapy, it will almost always start to grow back once your treatment is over, and sometimes it may even start to grow back before you finish treatment. In a small number of people, hair loss may be permanent.

When your hair grows back it may be weak and fragile or softer to begin with, but over time the condition and texture of hair becomes stronger. Other hair such as eyebrows and eyelashes may grow back at different rates – everyone is different.

Sometimes, hair grows back differently to how it was before treatment, for example:

- the colour may change
- the texture may be different
- it may be curlier
- it may be straighter.

This change may only be temporary but for some it will be permanent. For some women, having hair grow back differently to what they are used to can be very difficult. You may feel it is another change to your appearance that you need to cope with especially if, in the short term, you’re not able to treat or style your hair in the way you always have.

As your hair grows back you may find that your scalp is very dry, sensitive and scaly. If this is the case, there are special treatments that can help to repair and moisturise your scalp, and reduce dryness and scaliness.

Until your hair is long enough to shampoo, an aqueous cream (available from the chemist) may be suitable for cleansing and moisturising the hair and scalp. Once your hair is long enough, you can begin to use a gentle shampoo and conditioner.

While your hair is growing back, you should continue to treat it with care.

- It’s best to avoid perming, colouring or using chemical products on your hair for six months to a year after the end of treatment, as your hair may still be weak.
- If you do want to colour your hair, ask your hairdresser for advice on the best products for your hair.
• Avoid hair extensions that are woven in for several months after your hair has begun to grow back as the new hair will be very delicate and liable to break easily.

For more information about caring for your hair and scalp when your hair grows back, see our Breast cancer and hair loss booklet.

People vary in how comfortable they are going outside when their hair is growing back. Wigs, scarves and other headwear are available if you choose to wear them, until your hair is longer.

**Finding a suitable salon**

Macmillan Cancer Support and TONI&GUY salons have developed a training programme that aims to ensure people affected by cancer have access to a salon in their area where a trained professional can provide specialist support and advice on hair care. For more information, see toniandguy.com/charity/strength-in-style

The charity My New Hair lists a national network of independent salons and professionals who offer a wig styling service for people affected by cancer who are experiencing hair loss. For more information, see www.mynewhair.org
Pain

Some treatments for breast cancer can cause pain while you are having them or for some time afterwards. People may experience pain in different areas of their body, for example the joints or across their scar and shoulder. For most people this will be manageable but for some people it can be longer lasting and affect day-to-day life.

Pain after breast surgery or reconstructive surgery

You’re likely to have some pain or discomfort after surgery but everyone’s experience is different. After breast surgery, the area around your operation site(s) may continue to feel sore and your arm may feel stiff for several weeks, or longer if you have had breast reconstruction. But this should gradually improve over time.

Nerve pain

Many people experience pain, numbness and a burning sensation as a result of temporary damage to the minor nerves under the arm (axilla) and scar area. This should settle within the first few weeks or months after surgery. However, for a few people the pain continues.

Some people have phantom breast pain (pain that feels as though it’s coming from the breast even though it has been removed). These can all be the result of damage to the nerves.

Contact your breast care nurse if you’re concerned about any ongoing pain.

Joint pain

If you are taking hormone (endocrine) therapy, particularly aromatase inhibitors such as exemestane, anastrozole or letrozole, you may experience pain or stiffness in your joints. This is usually mild and can be relieved by gentle exercise and muscle strengthening and/or anti-inflammatory drugs. For more information about exercise, see page 85.

In some cases the pain can be severe and affect day-to-day activities and sleep patterns. If you experience pain like this, it’s important to contact your specialist team to discuss the pain, pain relief options or
the possibility of changing to another hormone therapy. Do not stop your hormone therapy before you have discussed doing so with your specialist team.

What can be done to relieve the pain?

How much your pain affects your day-to-day life will determine the treatment you may need to relieve it. If the pain is interfering with everyday tasks and affecting your sleep, it can be an added source of anxiety at a time when you’re hoping to move forward in your recovery.

You may find it helpful to take regular pain relief using anti-inflammatory drugs, either in tablet or topical (applied to the skin) form. Other drugs may also be prescribed such as a low-dose antidepressant or drugs usually used to treat people with epilepsy. These have been found to be helpful with certain types of pain. Different types and strengths of pain relief are available and what you are given will vary according to your needs. Some hospitals run special clinics for people with persistent pain that is difficult to relieve.

For some people, restarting their arm and shoulder exercises (if for any reason you have stopped) may help, and for others gentle heat such as taking a warm bath may ease the pain.

A course of physiotherapy may also help with arm and shoulder movement and your breast care nurse will usually be able to refer you for this.

If you have pain around your shoulder, armpit or over your scar that doesn’t improve with time or pain relief, talk to your specialist team.

‘The joint pain was at its worst during chemo in my hands and fingers and I had to get my mum to massage them all the way through week one. There has been a fair amount of joint pain on and off through the tamoxifen but now I am on exemestane and Zoladex that has gone down a lot to only the odd flare-up.’

Catriona
Fatigue (extreme tiredness)

Fatigue is different from normal tiredness and is more extreme and unpredictable. Often it’s not improved by a good night’s sleep. Most people experience fatigue at some point during or after their treatment and it can last for weeks or even months. Being fatigued can make a lot of difference to how you feel and how you cope with everyday life.

How does fatigue differ from normal tiredness?

People with fatigue have no energy at all and find it difficult to do simple everyday tasks. For this reason it can affect independence and quality of life. Everyone’s experience of cancer fatigue is different. Knowing what your limits are and not expecting too much of yourself may help you cope better.

Why does fatigue occur?

Most of the treatments used for breast cancer can contribute to fatigue.

- **Surgery** – many people experience a temporary feeling of tiredness after surgery. This may be due to the stress placed on your body and the time required to heal. For some people it can be more significant and last longer. Sometimes people won’t have recovered before the effects are made worse by further treatments.
- **Chemotherapy** can cause altered eating patterns, lowered resistance to infection, and anaemia (too few red blood cells in the body), which can all cause or worsen fatigue.
- **Radiotherapy** – travelling back and forth to the hospital can make you feel increasingly tired and the treatment can cause fatigue because of the way it affects your body. Often this tiredness starts or gets worse after the radiotherapy has finished.
- **Hormone (endocrine) treatments** can bring about changes to the body’s metabolism (the chemical balance of the body) and this can lead to a number of side effects including fatigue.
- **The emotional effects of your diagnosis throughout your treatment**, including anxiety, poor sleep patterns and depression, can all contribute to fatigue.
- **The side effects of any other medications used throughout your treatment** such as anaesthetic drugs, pain relief, anti-sickness drugs, sleeping tablets and antidepressants can also make you feel very tired.
What can I do to manage fatigue?

Where possible, try to take things easy and don’t be hard on yourself if you can’t do as much as you used to.

You may find the following tips helpful.

• Tell your doctor or nurse how you feel as sometimes the cause of the fatigue can be treated. For example, iron supplements may be prescribed for anaemia.
• Make sure you have plenty of rest between your daily activities, but try to limit naps to less than an hour so that you sleep at night.
• Aim to do small amounts of activity or light, such as walking, each day.
• Set priorities and structure your day so that your expectations are realistic.
• Use relaxation techniques to relieve tension.
• Drink plenty of fluids as dehydration can make you tired.
• Make the most of the times when your appetite is good, choosing healthy, high-energy foods such as wholewheat pasta.
• Prepare and plan for activities that will require a lot of energy by resting beforehand.
• Accept offers of help from others where possible.
‘You learn that through all treatment and beyond you have a finite reserve of energy and so you have to be selective about how to use it, and then listen to your body when it tells you that reserve is used up.’

Catriona

‘In the early years the fatigue was bad, as though someone had put my body in a vat of lead. It is nearly eight years now since diagnosis and I still have fatigue but to a much lesser extent. I tend to cat/power nap once or twice a day.’

Androulla
Problems sleeping

Disturbed sleep is a common and often distressing problem for people with breast cancer. Sleep patterns often become disrupted around the time of diagnosis but this can continue after treatment.

You may feel guilty for feeling tired, or frustrated that your sleep pattern did not return to normal immediately after treatment ended.

In most cases sleep patterns do eventually return to normal.

What causes sleep problems?

The main causes of sleep disruption are stress and anxiety resulting from your diagnosis and side effects of treatment.

- Anxiety can be related to many things. It could be uncertainty about the future or worries about relationships with friends and family and their expectations of you. Feeling anxious can stop you from getting to sleep or cause you to wake early.
- Your sleep pattern may have changed while you were having chemotherapy.
- Changes in your daily routine can also affect your sleep. Being diagnosed with breast cancer affects what you do on a daily basis. You may have stopped working during treatment and started getting up later which disturbs your regular sleep pattern.
- You might be experiencing night sweats because of the onset of menopause or a return of menopausal symptoms due to taking hormone (endocrine) therapies. Getting back to sleep after a night sweat can be difficult, especially if you have to change your bedclothes.
- You may have less energy and be doing less exercise. Being less active can affect your sleep patterns.

What can I do to improve my sleep patterns?

The following tips may help you get a good night’s sleep.

- Go to sleep and wake up at regular times.
- Do something relaxing before bedtime.
- Create a dark, comfortable sleep environment.
- Avoid watching television or working in the bedroom.
- Get plenty of natural light during the day.
• Try to limit naps to less than an hour.
• Limit your amount of caffeine-containing drinks, such as tea, coffee and cola.
• Do some regular exercise, but not within three hours of bedtime.

A lot of people believe that if they have a bad night’s sleep they should go to bed especially early the next night, but this can make the problem worse. It’s important to get into a routine of going to bed and getting up at the same time every day. Look at how much sleep you get on average each night and go to bed at a time that allows you to get the sleep you need.

For people who have difficulty sleeping, the bedroom can become a place of stress and anxiety, which can make it harder to get to sleep. Strengthening the link between your bedroom and sleeping can help. For example, try to avoid using the bedroom for other activities such as watching television. Turn the light off when you go to bed and switch off any devices like your mobile phone. If you are not asleep within 15 minutes after lying down get out of bed and, if possible, go to another room until you feel tired enough to go back to bed.

What treatments are available?

It may be difficult for some people to return to their old sleeping pattern. Sleeping tablets are another possible short-term option and you can discuss this with your GP (local doctor) or breast care nurse.

Talking therapies such as counselling or cognitive behavioural therapy (CBT) can be useful. CBT for insomnia (difficulty getting to sleep or staying asleep) can help change thoughts and behaviours that contribute to sleep problems.

If you think you might benefit from counselling or CBT, discuss these with your GP or breast care nurse.

Some people find activities such as yoga, mindfulness and using relaxation techniques help them to relax and aid sleep. For more on this, download or order our Complementary therapies booklet.
‘Since finishing active treatment, I have had spells of disturbed sleep mainly due to post-surgery pain or discomfort. I have taken medication for sleep and pain for about a year, which has helped a lot, and am due to review this with my GP soon.’

Cheryl

‘I wake up two or three times a night.’

Amanda
Lymphoedema

Lymphoedema is swelling of the arm, hand or breast/chest area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of surgery or radiotherapy to the lymph nodes under the arm (axilla) and surrounding area. Lymphoedema can be a distressing side effect of breast cancer and its treatments.

When does lymphoedema occur?

Lymphoedema may develop soon after surgery or radiotherapy, but can also occur many years later and may be triggered by infection or injury to the arm, hand or breast/chest area.

Lymphoedema is a long-term condition, which means that once it has developed it can be controlled but it is unlikely to ever go away completely. It affects people in different ways. The most common symptom is swelling of the arm, which can include the hand and fingers. The skin feels stretched, making it difficult to move the arm. Swelling can also affect the breast, chest, shoulder, and the area on the back behind the armpit. Some people feel tightness in the arm without the arm appearing swollen, and the arm may also feel heavy and uncomfortable.

Who is at risk?

Anybody who has had surgery or radiotherapy as part of their treatment for breast cancer may develop lymphoedema at some time in their life. However, only the arm, hand, fingers, breast and chest wall on the same side as the affected breast are ‘at risk’.

People who have a sentinel lymph node biopsy have a reduced risk of developing lymphoedema compared to people who have surgery where a greater number of lymph nodes are removed. The vast majority of people who develop lymphoedema after breast cancer and its treatment have only mild to moderate symptoms.

Evidence suggests that being overweight can increase your risk of developing lymphoedema due to added strain on an already impaired lymphatic system.
A wound infection, cording (cord-like structure under the skin in the arm causing pain and restricted movement) or seroma (collection of fluid under the skin near the scar) after breast surgery slightly increase the risk of developing lymphoedema in the future.

Radiotherapy is an additional risk factor for people who have had surgery to their lymph nodes.

Most people who have had the lymph nodes under their arm removed don’t develop lymphoedema. However, it’s important to be aware of the risk.

**How can I reduce my risk of developing lymphoedema?**

While it’s not known exactly what causes lymphoedema, damage to the skin or injury to your ‘at risk’ arm can lead to cellulitis (an infection of the skin and underlying tissue), which can increase your risk of developing lymphoedema. Although there is limited scientific evidence about how best to reduce the risk of lymphoedema, the following tips may help.

- Try to use your arm normally. Gentle exercise such as walking or swimming is important for lymph drainage and will keep your joints supple.
- Look after the skin on your arm. Wash it every day and avoid using very hot or cold water or soaps that dry out the skin. Dry your arm and hand thoroughly and use an unperfumed moisturising cream to help keep the skin supple and moist.
- Try to avoid cuts, scratches, insect bites or stings on your arm or hand. Wear protective gloves when gardening or washing-up, and take care when sewing. Use insect repellent when appropriate. If your skin is damaged, treat it promptly, cleaning it and applying antiseptic.
- Avoid biting your nails. Use a nail file and take care to avoid damage to the cuticles when cutting your nails, as this can allow bacteria to enter and cause infection.
- Avoid getting sunburnt. Use a sunscreen with a high sun protection factor (SPF), and remember to apply it even under clothing as it is possible to become sunburnt through some clothes.
- Take care when removing underarm hair – an electric razor or depilatory cream are safest as they are less likely to damage the skin (if using a depilatory cream, use with caution after patch testing).
• Avoid constriction around the arm and armpit from tight-fitting bras, sleeves, jewellery or heavy shoulder bags.
• Try not to strain with activities such as pushing or pulling, digging the garden or lifting heavy objects such as shopping bags.
• During long flights, train journeys, car or bus trips, try to gently exercise your arm as much as possible, and ensure you get up and move about.
• Try to maintain a healthy body weight by doing regular exercise and following a balanced diet.

Taking blood from the ‘at risk’ arm

As a precaution in the past, you may have been told to avoid having blood taken, having injections, or having your blood pressure taken from the arm on the same side as your breast cancer treatment.

Recent evidence has suggested that these procedures may not increase your risk of developing lymphoedema, provided they are done correctly and under clean conditions. However, your specialist may still recommend taking these precautions to reduce the risk of infection.

Our booklet Reducing the risk of lymphoedema contains more information as well as further tips for reducing your risk. If you have developed lymphoedema you may find our booklet Living with lymphoedema after breast cancer useful.

What symptoms should I look out for?

If you notice either of the following symptoms, contact your breast care nurse or specialist team as soon as possible:

• swelling of your arm, hand, fingers, breast or chest area
• a feeling of tightness or heaviness in the affected side.

If you’re no longer in touch with your specialist team, you should see your GP (local doctor) to explain your concerns and they can refer you to the hospital.
If your arm, breast or chest area suddenly becomes red, tender and hot, with increased swelling or a rash, or if you have flu-like symptoms, you may have developed an infection. These symptoms need urgent attention from your GP and you will probably need to start a course of antibiotics.

If you do develop lymphoedema, it should respond well to treatment and can be controlled and improved in most cases, especially if treatment is started when the symptoms are mild.

Having lymphoedema can be uncomfortable and can affect your ability to do some daily activities and sports. It can also affect your body image and self-esteem, and be a constant reminder of your breast cancer diagnosis. See the section about body image on page 62 for more information on coping with this.

‘It bugs me that I have to wear a compression sleeve on my arm for lymphoedema, but hey! That’s a small price to pay for getting through breast cancer!’

Kim
Bone health and osteoporosis

Bone health is important throughout life. It becomes more important as we get older or if illness or treatments increase the risk of bone problems. Around the age of 35, we start to lose bone density as part of the natural ageing process and this can lead to osteoporosis.

What is osteoporosis?

Osteoporosis literally means ‘porous bones’ and is a weakening or thinning of the bone. As the bones become fragile they can break (fracture) with little or no force. Often osteoporosis isn’t found until the time of this first fracture. Although osteoporosis cannot be cured, treatments are available to try to keep bones strong and less likely to break.

How can breast cancer treatment affect bone health?

Both women who haven’t yet gone through the menopause (pre-menopausal) and women who have gone through the menopause (post-menopausal) may have an increased risk of osteoporosis related to breast cancer treatment.

Chemotherapy

Chemotherapy can affect the function of the ovaries, causing an early menopause in some women. This means less oestrogen is produced which can reduce bone density.

Women aged 45 or under whose periods have stopped for at least a year as a result of treatment may also be at risk of osteoporosis, even if their periods restart.

Some research has shown that post-menopausal women who have chemotherapy may notice greater loss of bone density than they would have had without chemotherapy.
Ovarian suppression
Ovarian suppression is when the ovaries are removed, or temporarily or permanently stopped from working. This means there’s less oestrogen in the body to stimulate the cancer to grow, which can also reduce bone density. Ovarian suppression can be done using a type of hormone therapy, surgery or radiotherapy.

Tamoxifen
Tamoxifen can be given to both pre-menopausal and post-menopausal women. It blocks the effect of oestrogen which helps stop breast cancer cells from growing.

In pre-menopausal women, taking tamoxifen may cause a slight reduction in bone density. This is unlikely to lead to osteoporosis unless ovarian suppression is given as well. However, your risk may be higher if you’re 45 or under and your periods have stopped for at least a year.

In post-menopausal women, taking tamoxifen slows down bone loss and can reduce the risk of osteoporosis.

Aromatase inhibitors
Aromatase inhibitors (including anastrozole, letrozole and exemestane) are mainly used to treat breast cancer in post-menopausal women. These drugs reduce the amount of oestrogen circulating in the body, which can reduce bone density.

Some pre-menopausal women have an aromatase inhibitor at the same time as ovarian suppression. Having these two treatments can reduce bone density.

The likelihood of developing osteoporosis while taking aromatase inhibitors also depends on how healthy your bones were before your breast cancer treatment.

What can I do to maintain bone health?
Exercise can help keep your bones strong and reduce the risk of developing osteoporosis.

Regular weight-bearing exercise helps to stimulate growth and strength of the bones. Good weight-bearing exercises include taking a brisk walk, skipping, aerobics, tennis, dancing and weight training. You should consult your specialist team before starting any new exercise.
routine. See page 85 for more information about exercise after treatment.

It’s essential to eat a balanced diet to give you the nutrients that are important for strong, healthy bones. Include sources of calcium in your diet, such as dairy foods like milk, cheese and yoghurt. You can find out more in the section on ‘Eating for bone health’ (see page 82).

Drinking too much alcohol and smoking can have a damaging effect on bones.

For more information on how to keep your bones healthy, see our booklet Osteoporosis and breast cancer treatment.
Can I still become pregnant after treatment?

It’s difficult to predict exactly how your fertility will be affected by cancer treatment. Generally, you should assume you could still get pregnant unless you haven’t had a period for at least a year after completing your treatment if you’re 40 or over, or two years if you’re under 40. Even if your periods haven’t started again, you may still be producing eggs and could become pregnant. However, if your periods have returned this doesn’t necessarily mean that your fertility hasn’t been affected.

How can fertility be affected?

Having cancer treatment may mean you have to think about your fertility sooner than you had planned. This is because some breast cancer treatments can affect your ability to become pregnant in the future. This can depend on your age and the type of treatment. Some women will have been referred to fertility specialists before starting their treatment.

Hormone (endocrine) therapy

If you have been offered tamoxifen, this is usually given for five years or longer. You’ll be advised not to get pregnant while taking it as it may harm a developing baby. If you want to have children and you’re in your late 30s or early 40s, taking tamoxifen for five years or more may be an issue you want to discuss with your specialist team.

Chemotherapy

Chemotherapy can cause infertility in women who have not been through the menopause (pre-menopausal). It can affect the functioning of the ovaries, reducing the number or quality of eggs.

Chemotherapy can also cause your periods to stop (amenorrhoea). This may be temporary or permanent. In general the younger you are when having treatment, and particularly if you’re under 35, the more likely it is that your periods will return. Women over 35 are more likely to lose their fertility by having an early menopause.

Even if your periods return after chemotherapy, the menopause is likely to happen sooner (up to 5–10 years earlier) than it would have done if you hadn’t had chemotherapy. This may mean you have a shorter time
than normal to try to get pregnant. If your periods do return, it doesn’t necessarily mean your fertility has been unaffected, so it’s important to speak to your oncology specialist if you have any concerns. For more information on chemotherapy, see our Chemotherapy for breast cancer booklet.

How will I know if my fertility has been affected?

After your treatment has finished, there’s no totally reliable way of checking how it has affected your fertility. You may not be able to find out straight after your treatment has finished if you are still fertile.

If your periods have remained normal or returned after stopping, it’s likely that you will be able to get pregnant, depending on your age. However, the return of your periods doesn’t necessarily mean your fertility has been unaffected, so it’s important to speak to your specialist if you have any concerns.

If your periods haven’t returned, you may need to contact your hospital team or GP who can then refer you to see a specialist (gynaecologist).

To check if your ovaries are working, your specialist will ask about your periods, whether they’ve started again and whether you have any menopausal symptoms. A series of blood tests to check the levels of a hormone called FSH (follicle stimulating hormone) may be taken. Your level of oestrodiol (female sex hormone) may also be measured. The results of these may show whether you have gone through the menopause. Sometimes a blood test will also be taken to check the level of a hormone called AMH (antimullerian hormone) as this may give more accurate information about how your ovaries are working. An ultrasound scan of the ovaries may also be helpful and is offered in some centres.

Pregnancy after breast cancer

Some specialists advise women to wait for at least two years before becoming pregnant. This is because the possibility of the cancer coming back can lessen over time, and you may be at greatest risk of it returning in the first two years after diagnosis.
Waiting for this long may not be appropriate for every woman. If you’re thinking about getting pregnant before the two-year period is up, talk to your specialist. They can help you make an informed choice.

Facing permanent infertility

Some women who’ve had breast cancer treatment will face the possibility of permanent infertility. This can be devastating and difficult to come to terms with, especially if it comes at a time when you were planning to start a family or before you have completed your family. It may change how you feel about yourself as a woman and you may feel intense grief at the loss your cancer has caused you.

If you’re concerned about any issues relating to your fertility, you may find it helpful to talk through your feelings with a specialist infertility counsellor. Your breast care nurse, specialist team or GP should be able to arrange this for you. Whatever your feelings, remember that you don’t have to cope on your own.

There is further information on temporary and permanent infertility in our booklets Fertility and breast cancer treatment and Younger women with breast cancer.

Breast Cancer Care’s Someone Like Me service may also be able to put you in touch with someone who has had a similar experience. For more information call the Helpline on 0808 800 6000.

Our Younger Women Together events involve two days of support and information for women aged up to 45 who have been diagnosed with breast cancer in the past three years. Sessions relate specifically to the needs of younger women, recognising issues that are important to you. For more information call the Helpline or visit the Breast Cancer Care website.
The following organisations can help people who are coping with infertility:

- Infertility Network UK – www.infertilitynetworkuk.com
- The Daisy Network – www.daisynetwork.org.uk

‘My husband and I have never wanted children, however at the end of treatment I struggled with the knowledge that it was no longer my choice.’

Jenny

**Contraception after breast cancer**

If you’re sexually active with a man, it’s important to discuss contraception with your specialist team. They may refer you to a family planning clinic or your GP (local doctor) who can advise you on the most appropriate contraception for you. Women having treatment for breast cancer (including the hormone treatment tamoxifen) are recommended to use non-hormonal methods of contraception, such as condoms, Femidoms or a diaphragm.

You should use reliable contraception during and after treatment.

It may also be possible to use a coil (IUD). However, you would need to discuss this with your specialist as not all types are suitable for women with breast cancer.

The contraceptive pill is less commonly advised after a diagnosis of breast cancer. This is because the hormones in the contraceptive pill could possibly stimulate any remaining breast cancer cells. However, the morning-after pill can be used in emergencies as it’s a single dose of hormones and is unlikely to affect your breast cancer. Speak to your specialist team if you have any concerns.
Further support
Breast Cancer Care

Publications
Breast cancer and hair loss
Complementary therapies
Fertility and breast cancer treatment
Living with lymphoedema after breast cancer
Menopausal symptoms and breast cancer
Osteoporosis and breast cancer treatment
Reducing the risk of lymphoedema
Younger women with breast cancer

To order or download a copy, visit www.breastcancercare.org.uk/publications or use the quick order form included in this pack.

Younger Women Together
Our Younger Women Together events offer two days of support and information for women aged up to 45 who have been diagnosed with breast cancer in the past three years. For more information call the Helpline or visit the Breast Cancer Care website.
Other organisations

Menopause organisations

Menopause matters
Website: www.menopausematters.co.uk

Menopausematters.co.uk is an independent, clinician-led website. It aims to provide easily accessible, up-to-date, accurate information about the menopause, menopausal symptoms and treatment options, including hormone replacement therapy (HRT) and alternative therapies, so that women and healthcare professionals can make informed choices about menopause management.

The Daisy Network
PO Box 71432
London SW6 9HJ

Website: www.daisynetwork.org.uk
Email: info@daisynetwork.org.uk

Voluntary nationwide support group for women who experience a premature menopause.
Fertility organisations

Human Fertilisation and Embryology Authority
Finsbury Tower
103–105 Bunhill Row
London EC1Y 8HF

Tel: 020 7291 8200
Website: www.hfea.gov.uk
Email: enquiriesteam@hfea.gov.uk

Licenses and monitors UK fertility clinics and all UK research involving human embryos, and provides impartial and authoritative information to the public.

Infertility Network UK (I N UK)
Charter House
43 St Leonards Road
Bexhill on Sea
East Sussex TN40 1JA

Tel: 0121 323 5025
Website: www.infertilitynetworkuk.com
Email: admin@infertilitynetworkuk.com

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

British Lymphology Society (BLS)
24 Kiniths Crescent
West Bromwich B71 4BX

Tel: 01452 790178
Website: www.thebls.com

BLS members consist of healthcare professionals, as well as others who are directly involved in the management of lymphoedema. BLS promotes awareness of lymphoedema and establishes standards of treatment and long-term management of the condition. Its website includes a directory of lymphoedema clinics around the country.

The Lymphoedema Support Network
St Luke’s Crypt
Sydney Street
London SW3 6NH

Tel: 020 7351 4480 (support) / 020 7351 0990 (administration)
Website: www.lymphoedema.org
Email: admin@lsn@org.uk

The Lymphoedema Support Network (LSN) is a national patient-led charity that provides information and support to people with lymphoedema. It runs a telephone helpline, produces a quarterly newsletter, self-help videos and a wide range of factsheets. It works to raise awareness of lymphoedema and campaigns for better national standards of care.
### Osteoporosis organisations

**National Osteoporosis Society**  
Camerton  
Bath BA2 0PJ

Telephone helpline: 0808 800 0035  
Website: www.nos.org.uk  
Email: info@nos.org.uk

The National Osteoporosis Society is the only national charity dedicated to improving the prevention, diagnosis and treatment of osteoporosis. Services include a telephone helpline, written information and a network of support groups across the UK.

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### Hair loss organisations

**My New Hair**  
PO Box 626  
Durham DH1 9LJ

Website: www.mynewhair.org  
Email: info@mynewhair.org

Provides public advice, and supports a national network of independent salons and professionals who provide a wig styling service for people affected by cancer and medical hair loss.

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**Strength in Style**  
Website: toniandguy.com/charity/strength-in-style

Macmillan and TONI&GUY have developed a hair care available on the high street for people affected by cancer. Consultants undergo an intensive training programme to help them deal with the emotional and practical issues surrounding hair loss and thinning due to cancer treatment.
Cancer organisations

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840
Helpline: 0808 808 00 00
Website: www.macmillan.org.uk

Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer, and their carers and families. It also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

Further reading

Coping with fatigue
Macmillan Cancer Support, 2015
be.macmillan.org.uk
(also available on CD)

Colin A. Espie, 2006

ISBN 978-1845290702
Call our Helpline on 0808 800 6000
Signs and symptoms of the cancer coming back (recurrence)

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Continuing to be breast aware 51
Types of recurrence 52
Who to contact if you have a concern 55
Coping with fear of recurrence 56
Further support 58
Breast Cancer Care’s publications contain more information on the topics covered in this section. You can order or download a copy from our website, or use the order form at the end of this pack.

You may like to read:

• Breast cancer in families
• After breast cancer treatment: what now?
Introduction

Most people worry about the cancer coming back (recurrence). These worries are normal, and the fear and anxiety usually lessens with time. Knowing how to continue to be breast and body aware after treatment and the symptoms you should report can help you manage your feelings of uncertainty.

This section explains what happens after hospital-based treatment, what you need to look out for, the different ways cancer can return and what to do if you have a concern.
Follow-up appointments

How you are followed up will depend on your individual needs and on the arrangements at the hospital you have been treated in. You’ll probably find your contact is more frequent at first, becoming less so as time goes on.

Most people are followed up at the hospital and will have regular appointments with their surgeon and oncologist. Some people are given a choice of being followed up by their GP (local doctor) or a combination of hospital and GP appointments. In some areas you may be reviewed by the breast care nurse unless there are any particular concerns. In other areas follow-up appointments will be over the phone and you would only need to visit the breast clinic if there’s any concern or symptom that you or your doctor feel should be checked out.

Your follow-up appointments will focus on how you are feeling so you can explain any problems, symptoms or treatment side effects, for example any pain, stiffness, menopausal symptoms or fatigue. This is also your opportunity to ask questions. Many people find writing their questions down beforehand helps them get the best out of the appointment.

If you attend in person you can take someone with you. You may have a physical examination that includes your breast and/or chest area as well as any other area of concern. You may be referred to another healthcare professional for advice, for example a physiotherapist if you are having problems with arm movement.

This follow-up period usually lasts around five years.

Open access

Some people won’t be given any regular follow-up appointments but have open access to the breast clinic if they have concerns or symptoms and would like to be seen by a doctor or nurse at the hospital. If you are offered this sort of follow-up you should be given the details of who to contact.
Follow-up after clinical trials

If you’ve taken part in a clinical trial during your treatment, your follow-up may vary depending on which trial you’ve been part of. The research nurse will be able to give you a better idea of how you will be followed up.

Will I have any regular tests?

After your hospital-based treatment, continue to look and feel for changes (see page 51). You will also be invited to have regular mammograms (breast x-rays). If you’ve had breast-conserving surgery (also known as wide local excision or lumpectomy) you’ll have a mammogram on both breasts. If you’ve had a mastectomy, with or without reconstruction, you will only have a mammogram on your other breast.

The time between mammograms may vary depending on the hospital where you have your follow-up. Most hospitals will follow the recommendations set out by NICE (National Institute for Health and Care Excellence), an independent organisation responsible for producing evidence-based guidance on effective ways to prevent, diagnose and treat ill health.

For more information see our booklet After breast cancer treatment: what now?

‘I felt anxiety as I was certain [the doctor] was going to tell me the cancer had come back. I had convinced myself it had come back despite having no signs or symptoms and so I was relieved to get it over with.’

Caroline
‘I was anxious about the [follow-up] appointment and continued to be throughout my follow-up clinics over the years. While you’re certain all is OK, you definitely have a spring in your step when you’re told it really is all fine. However, it’s also reassuring to have an expert check you over, especially in the neck and shoulder area that’s hard to check yourself.’

Kim
Continuing to be breast aware

Whether you’ve had breast-conserving surgery or a mastectomy (with or without reconstruction), it is important to be aware of any changes to the breast, chest or surrounding area after your treatment, even if you’re still having follow-up appointments or regular mammograms.

After treatment for breast cancer it can be difficult to know how your breast or scar area should feel, particularly as the area can change over time as it repairs and heals. Immediately after surgery and in the weeks that follow people can experience pain and sensations such as burning and numbness in the scar area and under the arm (axilla). The area may feel lumpy, numb or sensitive.

You will need to get to know how it looks and feels so you know what is normal for you. This will help you feel more confident about noticing changes and reporting them early to your GP (local doctor) or breast care nurse. It’s also important to be aware of any new changes in the other breast and surrounding area, and to report these as soon as possible to your hospital team.

What to look for

Changes to look and feel for in the breast, chest and under the arm:

- change in size or shape of the breast
- redness or a rash on the skin and/or around the nipple
- nipple discharge
- swelling in your chest, in your armpit or around your collarbone
- lump or thickening that feels different
- change in skin texture such as puckering or dimpling
- your nipple becomes inverted (pulled in) or changes its position or shape
- pain
- swelling in the upper arm.
Recurrence

Recurrence is the term used to describe breast cancer that has returned following treatment.

At the time of your diagnosis and after surgery, tests will have been done to find out the type of breast cancer you had. The results are used to plan your individual treatment to ensure it is as effective as possible in reducing the risk of the breast cancer coming back.

While most people have no further problems, sometimes breast cancer can come back. This can either be local recurrence or locally advanced breast cancer (also called regional recurrence).

Local recurrence

This is when the breast cancer has come back in the chest/breast area, in the skin near the original site or scar, but has not spread to other parts of the body. Local recurrence is treatable.

If you notice any changes in the skin around your scar line or chest area, contact your breast care nurse or specialist.

Locally advanced breast cancer (also called regional recurrence)

This is when the breast cancer has come back and has spread to the tissues and lymph nodes (glands) around the chest, neck and under the breastbone. How regional recurrence is treated will depend on what treatments you had previously, but could include surgery, radiotherapy and drug treatments.

If you notice any changes around the scar line or in your breast, chest, armpit or around your collarbone, contact your breast care nurse or specialist.
A new primary breast cancer

Sometimes a new primary breast cancer (breast cancer that has not spread beyond the breast or the lymph nodes under the arm) can develop, either in the same side after breast-conserving surgery or in the opposite breast. People who have breast cancer in one breast are at slightly higher risk of developing a new primary breast cancer on the other side. This would be treated as a new cancer and is not recurrence.

Secondary breast cancer

Treatment for primary breast cancer aims to prevent the cancer coming back or spreading, but some people will develop secondary breast cancer. Secondary breast cancer occurs when breast cancer cells spread from the first (primary) cancer in the breast to other parts of the body. You may hear this referred to as metastatic breast cancer, metastases, advanced breast cancer, secondary tumours, secondaries, or stage 4 breast cancer.

Secondary breast cancer is most likely to develop in the bones, lungs, liver or brain. One or more areas of the body can be affected. A diagnosis of secondary breast cancer means that the cancer can be treated but it can’t be cured. As treatments have improved more and more people are living longer after a diagnosis of secondary breast cancer.

Symptoms of secondary breast cancer

It’s difficult to list all the symptoms of secondary breast cancer but it’s important to report any symptoms you have that are new and persistent and have no obvious cause to your doctor or breast care nurse.

Many symptoms of secondary breast cancer may be the same as those of other conditions. For example, aches and pains in the bones may be
due to ageing, arthritis or treatment side effects. Breathlessness and coughs can be symptoms of a cold or flu-type illness. If you have any persistent or unexplained symptoms, the best thing to do is to talk to your doctor or breast care nurse.

**Symptoms you may want to report**

- Pain in your bones (for example in the back, hips or ribs) that doesn’t improve with pain relief or persists for more than one to two weeks and is often worse at night.
- Unexplained weight loss and a loss of appetite.
- A constant feeling of nausea.
- Discomfort or swelling under the ribs or across the upper abdomen.
- Feeling constantly tired.
- A dry cough or a feeling of breathlessness.
- Severe or ongoing headaches.
- Altered vision or speech.

Some of these symptoms, such as tiredness and loss of appetite, can be normal side effects that many people experience after cancer treatment. But if symptoms don’t improve, your specialist team may decide to investigate the many possible causes.
Who to contact if you have a concern

During follow-up

Many people find calling their breast care nurse can be an easy way to discuss any concerns in between their follow-up appointments. They may make you an earlier appointment if you need to see your specialist sooner.

If you have any new symptoms that are worrying you, you can see your GP between appointments for advice.

Alternatively, you can phone the hospital and ask for an earlier appointment.

After follow-up

After you have been discharged from your follow-up appointments, your GP may be your main contact to get concerns checked quickly. If they think you need to be seen at the breast clinic they can refer you. When speaking to your GP, make sure they know about your breast cancer, particularly if you were diagnosed some time ago.

Alternatively, you may still be able to contact the breast care nurse or hospital you were discharged from.
Coping with fear of recurrence

Nearly everyone who has been treated for cancer worries about it coming back. At first, every ache or pain can frighten you. But, as time passes, you may come to accept minor symptoms for what they are in most cases – warning signs of a cold or flu or the result of over-exerting yourself.

Some events may be particularly stressful – the days or weeks leading up to your check-ups, the discovery that a friend or relative has been diagnosed with cancer, or the news that someone you met while having treatment is ill again or has died.

We all cope in our own way, and there are no easy solutions. But keeping quiet because you’re worried about bothering people is probably not the best approach. Talking about your fears relating to recurrence may help.

The wellbeing section on page 77 has more information on how to cope with anxiety or low mood as well as details of where you will find support if these feelings are getting on top of you.

‘The concerns have not lessened, but I’ve found it important to try and manage them by getting on with other things in my life.’

Catriona

‘I did worry in the first year or so but not any more. I focus on being grateful for each day that I wake up cancer-free. I know that there will always be a possibility of recurrence but I have read and understood enough to know that worrying won’t make things better; only worse.’

Androulla
Worries about a family history of breast cancer

Women diagnosed with breast cancer are often worried about whether this will increase the risk of breast cancer for family members, especially daughters. A diagnosis is unlikely to mean family members have a significantly higher risk of developing breast cancer. The majority (more than 90%) of cases of breast cancer happen ‘by chance’ and are not inherited. If you are worried about this, you can speak to a member of your specialist breast care team who may be able to refer you directly to a genetic counsellor or clinical geneticist.

For more information see our booklet Breast cancer in families.
Further support
Breast Cancer Care

Publications
Breast cancer in families
After breast cancer treatment: what now?
To order, or download a copy, visit www.breastcancercare.org.uk/publications or use the quick order form included in this pack.
You and your relationships

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Your relationships 65
Your sex life after breast cancer 68
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Breast Cancer Care’s publications contain more information on the topics covered in this section. You can order or download a copy from our website, or use the order form at the end of this pack.

You may like to read:

• Breast prostheses, bras and clothes after surgery

• In it together: for partners of people with breast cancer

• Your body, intimacy and sex

• Talking with your children about breast cancer.
Introduction

Illness can affect how you feel about yourself and your self confidence. Your breast cancer treatment may have left you with reminders of what you have been through and a sense of loss for how things were before. These may be temporary or permanent and can include surgical scars, a change in weight or feelings of anxiety.

This section describes feelings you may have about your body and identity, your relationships and your sex life following treatment for breast cancer. It also contains further sources of support and information.
Changes to the way you look and feel

How you think about your body and the way you see yourself is known as your body image. Body image changes constantly throughout life. Illness can affect how the body functions and how you see yourself, which may in turn affect self-confidence.

For many people, appearance can have a big impact on body image. Any changes to your body resulting from breast cancer and its treatment can have a lasting effect on how you feel about yourself.

Getting used to the changes that have taken place, and adjusting to life after breast cancer, can take time. It’s natural to feel that you need to grieve for what’s been lost.

You may be anxious about your appearance after surgery. Some people find it difficult to look at their scars or are unhappy about the shape of their breast/chest after surgery and radiotherapy. You may also worry that you won’t be able to wear the same clothes. However, with time, most people become more confident in knowing what works for them and what feels comfortable.

You may feel you can no longer trust your body or you may be comfortable with any changes your body has undergone. Your body image and how you feel about yourself after a breast cancer diagnosis is a very personal thing.

If you had low self-confidence before your breast cancer diagnosis, it may take longer to overcome any lasting changes from treatment. Talking to your breast care nurse or GP (local doctor) about your concerns can help.

If you wear a prosthesis

If you wear a prosthesis (an artificial breast form used to restore shape when part or all of the breast has been removed), it can help to have a well-fitting, supportive bra when you’re being fitted for your permanent or replacement prosthesis. The person fitting your prosthesis will help you choose one that matches the shape and size of your natural breast and advise you about bras that will hold it comfortably and securely in place.
Loss of self

You may feel that life as you knew it has been disrupted by the diagnosis of breast cancer and that you have lost a sense of who you are. It’s not uncommon for people to feel their body has let them down or that they need to exert some control over their lives at a time when they feel unsure about the future and the changes in their body. During this time you may experience a number of emotions from anger and fear, to shock and disbelief.

Feeling you have lost your identity at times can affect a number of areas of your life. Finding it difficult to work and maintain relationships can be challenging and this can add to the feelings of loss you’re experiencing. Your sexuality and how attractive you feel may also have been affected by breast surgery or menopausal symptoms caused by hormone treatment or chemotherapy.

Relating to people around you

The way you relate to others can be affected as you recover. Those around you may be eager for you to return to the person they knew before you were diagnosed. If you’re struggling with a loss of identity, you may find it difficult to relate to others and for them to relate to you. This in turn can make you feel very isolated and alone and you might feel the need to avoid situations where you have to deal with others’ responses to you.

Many people experience these types of issues. Try to identify the area that is having the biggest impact and make some gradual changes.

Sharing your feelings with your healthcare team or a counsellor can help you feel more confident and comfortable with yourself. You may
find it useful to ask those close to you to read this pack to help them understand the issues you may be facing. This may help you to talk to them about how you are feeling.

‘I don’t like to see myself naked in the mirror yet. I say yet as I keep improving on it and keep looking at it but I am not comfortable with what I see.’

Caroline

‘It took me some time, about three months, after the surgery to have a really good look at my breasts and especially the scars. Bizarrely I now think my smaller operated breast looks great, and I am considering having a reduction on the healthy breast as I am very lopsided.’

Catriona
Your relationships

When treatment has finished, you and the people close to you may expect things to start to get back to normal. However, for many people this isn’t easy. If you’re having trouble with this after treatment you should continue talking to those close to you about your concerns.

Family, friends and colleagues

Family and friends’ responses to your diagnosis and your situation can vary considerably. Your friends may have little experience of a life-threatening illness and what it means, and they may not be able to respond to your needs. Some people may react in a way that makes you feel unsupported.

How you deal with any changes in your relationships depends on how much you want to talk about what you have been through. Talking openly about your cancer may make it easier for the people around you to respond to your needs. Alternatively, you may be happy not to talk about your breast cancer experience with those outside your immediate family or specialist team.

If you have children

After your treatment has finished, your children may expect their ‘old’ mum back. Make sure they have a realistic expectation about your energy levels, how involved you can be and where you may still need their help or understanding. Continue talking with your children about your experience of breast cancer even after treatment has finished.

Children tend to be more comfortable when they know what’s happening and what to expect. You may want to talk to them about any fears they may have for you, your partner (if you have one) or their own future. The age of your children will affect how you communicate with them and their expectations of you after treatment has finished.
For more information you can order our booklet *Talking with your children about breast cancer* and our children’s book *Mummy’s Lump*.

**If you have a partner**

If you are in a relationship you may find that the roles within your relationship change. These changes may be positive or negative, and some things will be easier to cope with than others. It may be difficult to talk about them with your partner and it may take some time to resolve them. Or you may feel your relationship is stronger as a result of facing breast cancer together.

**How your relationship may change**

The roles you and your partner had before your breast cancer diagnosis may change. Depending on how your partner reacted to your breast cancer experience, they may have become more independent or taken on the role of carer during your treatment.

Once treatment has finished your partner may have adjusted to their new role and want to continue this way. Or they may want to revert back to how things were before, moving on or pretending nothing happened. However your partner responds, it’s important that you both try to talk about any concerns or fears.

Your partner might like to read our booklet *In it together: for partners of people with breast cancer*. 
If you have problems with your relationship

How your relationship was before breast cancer is likely to have a large bearing on how you cope as a couple with the diagnosis and treatment. Breast cancer may not cause problems but it can aggravate existing ones. If you had problems in your relationship (generally or sexually) before having breast cancer, it’s likely these will not have gone away. Your illness will almost certainly make you re-evaluate many things in your life, including your relationship.

Some people decide that they no longer want to stay in a relationship in which 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’re able to find solutions. This may be a gradual process, but avoiding problems altogether can make them more difficult to resolve in the long term.

‘Your sex life after breast cancer’ on page 68 describes how treatment may affect your sex life. It also explains the potential effects on your partner and how future partners may react.

‘I told very few friends about my condition. I think my family understood that recovery was likely to be long. It took me some time to understand how my friends might react to the diagnosis and for sure there were lots of different reactions, not all of which were helpful to me.’

Catriona

‘[My partner] was brilliant and showed a side of him I had never seen before. As well as being strong and concerned, he was practical, tolerant of my moods and surprisingly good as a nurse!’

Mary
Your sex life after breast cancer

People can be affected in many different ways after their breast cancer diagnosis and treatment. The effects can be 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 changes can occur in the weeks and months after treatment or years later.

Altered feelings about 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.

You may also be concerned about how your partner now sees you. However you feel about your body, don’t assume that your partner feels the same way.

The section on ‘Loss of self’ on page 63 explains in more detail some of the feelings you may be having.

Talking about sex

Some people find it difficult to talk about sex. You may feel awkward discussing it with your partner or friends. It may be the first time that you’ve really thought about the issue and what it means for you. You may also be from a background or culture in which sex is rarely talked about.

Sharing feelings with your partner, being honest and talking openly can help you understand each other. If you can explain to your partner how you feel, however awkward or difficult this is, they may be more able to respond to your needs.

Your specialist team may not mention sex or intimacy, making it harder for you to raise any questions or concerns. But your breast care nurse or GP should be able to talk to you about any issues you have or refer you on to other professional help.
How your partner may react

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 feel emotional distress and when both partners are under stress, the relationship often becomes strained. However, some couples find that intimacy improves during this time.

Your partner may 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 or intimacy 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 can be particularly difficult to deal with at a time when you feel vulnerable.

How future partners may react

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.

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 and recognise that your experience of breast cancer is now part of who you are.

When you start a new relationship, you and your partner will decide on the right time to have sex for the first time. Having breast cancer may affect how you feel about when the right time is for you. Talking with your partner about your feelings will help with any anxiety you are feeling about this.
Getting back to sex and intimacy

Even if your sexual activity decreased or stopped completely during and after your treatment, you may want to maintain a level of closeness with your partner.

Sexual activity can include touch and other displays of affection that don’t always lead to oral or penetrative sex, but still result in pleasure. When you feel ready to increase or resume sexual activity, you may want to make some time specifically for you and your partner, free from distractions. It may help to consider what you and your partner now expect from intimacy and sex and explore new ways of sharing sexual pleasure. 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. Some people recommend getting started by writing down what you like about each other and practising talking about these positives.

How your sex life may change

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. Other side effects of treatment, such as menopausal symptoms, can affect your sex life. For information, see the section on ‘Managing the effects of treatment’ (page 10).

If it’s been a while since you last had sex, talk to your partner before you get intimate, when it could be more difficult to say how you feel. This gives you the chance to talk things through, and help your partner understand how you might be feeling.

Your concerns about the effect breast cancer has had on your sex life will be unique to you and your circumstances. Any of the changes you’ve experienced may affect your confidence and feelings about yourself. You may also be anxious about your first sexual experience following your diagnosis, or worried things will not be the same as before. It can also be difficult to start doing things differently when the usual ways of being sexual with a partner no longer work.
For some women the breasts are very sensitive to sexual stimulation. 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. You may experience areas of numbness and sensitivity, or loss of sensitivity. This sense of loss may be shared by your partner if they gained sexual pleasure from the look or feel of your breasts.

**Coping with changes to your sex life**

You and your partner may want to change your focus to other areas of the body and explore other areas sensitive to sexual stimulation (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.

It’s important for you to feel you can still be part of a sexual relationship without comparing things now to how they were before. You and your partner may 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. It may take time for your confidence to return and for you to feel comfortable having sex again.

Loss of libido, vaginal dryness and pain are common problems experienced by women having treatment for breast cancer and these can make it more difficult to have sex.

Our booklet *Your body, intimacy and sex* describes these issues in more detail and offers some possible solutions (see ‘Further reading’).
‘I’m in a new relationship now and the breast cancer and scars have no bearing to our sex life. My new partner is not concerned by the scars, which makes them less important to me too.’

Gill

‘Breast cancer combined with the menopause isn’t great! My husband is considerate and patient but I do feel guilty and I miss the sex life we used to have.’

Susan
Further support

Breast Cancer Care

Publications
Breast prostheses, bras and clothes after surgery

In it together: for partners of people affected by breast cancer

Your body, intimacy and sex

Talking with your children about breast cancer

To order, or download a copy, visit www.breastcancercare.org.uk/publications or use the quick order form included in this pack.

Someone Like Me
Sometimes it can feel like no one really understands how you feel. Our Someone Like Me service matches you to a trained volunteer who has had breast cancer too and who has experience of the issues you’re facing – whether that’s going back to work, struggling with relationships old or new, or any other concerns you have. Chatting over the phone, where and when it suits you, means you can ask any questions you like and talk openly without worrying about the feelings of the person listening. Call 0345 077 1893 or email someoneilikeme@breastcancercare.org.uk. Some of our volunteers can also chat via email – check our website to read more about them.
Other organisations

College of sexual and relationship therapists (COSRT)
The Administrator
COSRT
PO Box 13686
London SW20 9ZH

Tel: 020 8543 2707
Email: info@cosrt.org.uk
Website: www.cosrt.org.uk

The national specialist charity for sexual and relationship therapy with over 30 years of experience.

FPA pleasure
Website: www.fpapleasure.co.uk

The sexual health charity FPA has launched a website that has information, advice and opinion pieces covering topics such as sexual pleasure and wellbeing and talking with your partner about sex.

Relate
Tel: 0300 100 1234
Website: www.relate.org.uk

Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through their website.
Further reading

riprap
Website: www.riprap.org.uk
A website for children and young people who have a parent with cancer.
Your wellbeing

Introduction  79
Healthy eating  80
Physical activity  85
Dealing with anxiety  89
Low mood and depression  90
Complementary therapies  93
Further support  94
Breast Cancer Care’s publications contain more information on the topics covered in this section. You can order or download a copy from our website, or use the order form at the end of this pack.

You may like to read:

• Complementary therapies

• Diet and breast cancer.
Introduction

The term ‘wellbeing’ can mean different things to different people, but it might be described as feeling content, physically and emotionally well or having a sense of control. Breast cancer and its treatment can affect your wellbeing. You may feel upset more frequently or have difficulty relaxing.

Your experience of having breast cancer may make you want to take particular care of different aspects of your physical and emotional wellbeing. For example, you may decide to pay more attention to the food you eat or you may want to make time to do something you enjoy that will help you relax. If you’ve put on weight as a result of treatment, you may now want to start or return to regular exercise.

You may feel that now your hospital-based treatment has finished, you should be able to move on with your life, but instead you’re still experiencing many different emotions.

If there have been permanent changes to the way you look or feel, you’ll probably need some time to grieve for what has been lost. This is perfectly natural and you don’t have to push these thoughts away. It can take a long time to get used to the changes that have taken place and to adjust to life after breast cancer.

This section outlines how diagnosis and treatment for breast cancer can affect your wellbeing and the different things you can do to help improve it.
Healthy eating

Eating healthily is important for everyone, but when you’ve had breast cancer you may become even more aware of what you eat and drink. You may have experienced a loss or increase in appetite or your tastes may have changed during treatment. You may have put on weight or you may want to find out if diet can play a role in your recovery and future health.

What is a balanced diet?

To achieve a healthy, balanced diet, you should eat a variety of foods from each of the four main food groups every day. The eatwell plate shows the different types of foods we should eat and in what proportions, including:

- plenty of fruit and vegetables
- plenty of bread, rice, potatoes, pasta and other starchy foods – choose wholegrain varieties whenever you can
- some milk and dairy foods
- some meat, fish, eggs, beans and other non-dairy sources of protein.
In addition to this, you should:

- avoid having sugary foods and drinks too often
- avoid eating fatty foods too often
- drink alcohol only in moderation.

Unless you’re having problems recovering from treatment, supplements such as iron or multivitamins are not needed. As supplements have the potential to do harm as well as good, talk to a dietitian or your specialist team before taking them.

**Alcohol**

Drinking within the recommended guidelines is not thought to have any effect on the risk of breast cancer recurrence. But regularly drinking more than the recommended amount of alcohol may increase the risk. It’s recommended that men and women shouldn’t drink more than 14 units of alcohol a week, and that this should be spread evenly over three days.

For more information and advice on cutting down on alcohol, see the NHS Change4Life website [www.nhs.uk/change4life](http://www.nhs.uk/change4life)

Some people find that a glass of wine before a meal can improve their appetite. However, if you’re worried about putting on weight, remember that alcohol is high in calories.

**If you’ve put on weight**

Some people put on weight during and after treatment, which can be distressing. We put on weight when the amount of calories we eat is more than the amount of calories we burn through normal everyday activities and exercise.

Weight gain may be due to:

- the side effects of some drugs, which increase appetite
- your body retaining fluid
- being less active than usual
- natural or early menopause which makes you more likely to put on weight, particularly around the waist.

It can be helpful to check what your ideal weight should be with your GP or practice nurse, who can also offer advice about healthy eating.
If you want to lose weight after treatment, aim for a realistic weight loss of about 0.5–1kg (1–2 pounds) a week until you reach your ideal healthy weight. The following tips may help.

- Reduce your portion sizes.
- Eat at least five portions of fruit and vegetables a day.
- Choose wholegrain varieties of bread, pasta and cereals.
- Use lower-fat dairy foods, such as skimmed or semi-skimmed milk or lower-fat cheese such as feta, reduced-fat cheddar or cottage cheese.
- Go for lean cuts of meat and trim off as much fat as possible.
- Include beans and pulses in your diet.
- Limit the amount of alcohol you drink.
- Keep biscuits, cakes, chocolate and crisps for occasional treats.
- Take care when eating out, and remember that takeaways can be high in fat and calories.

Maintaining a healthy weight through a combination of healthy eating and physical activity (see pages 80 and 85) could help reduce the chance of breast cancer coming back.

**If you’ve lost weight**

If you’ve lost weight during your treatment, some simple changes to your diet can help. To maintain or put on weight, you need to take on more calories and more protein. The following tips can help.

- Add extra oil, butter, margarine or cheese to savoury dishes.
- Make hot drinks with milk rather than water.
- Avoid low-fat or so-called ‘healthy option’ foods.

Your GP can prescribe high-protein or high-energy drinks and soups if you need extra help to gain weight.

Recording your weight on a monthly basis may help a doctor or dietitian see the pattern in your weight change.

**Eating for bone health**

Some breast cancer treatments, such as chemotherapy or hormone therapies, can affect your bones, which can increase your risk of osteoporosis (see page 31).
It's important to get enough calcium, which is vital for healthy bones, from your diet. Our main source of calcium is dairy produce. Dairy foods that are rich in calcium include milk, cheese and yoghurt.

If your diet doesn’t include dairy foods, make sure you eat other calcium-containing foods such as:

- fish with edible bones such as sardines
- green leafy vegetables such as broccoli and curly kale
- pulses, beans and seeds such as kidney beans, green beans or baked beans
- nuts and seeds
- calcium-fortified cereals
- dried fruit such as apricots or figs
- okra.

Vitamin D is needed to help your body absorb calcium. The best source is sunlight, which your body uses to make this vitamin in your skin. Other sources of vitamin D include oily fish, margarine and breakfast cereals such as bran flakes.

Some women choose to adopt a dairy-free diet after a diagnosis of breast cancer. However, there’s no evidence that this reduces the risk of breast cancer recurrence.

**What are alternative diets?**

Some people who’ve had breast cancer consider following an alternative diet. This may be because they believe an alternative diet could reduce the risk of cancer coming back.

Alternative diets usually encourage eating or avoiding certain types of food.

There’s no conclusive scientific evidence that eating an alternative diet will stop the cancer coming back.

Evidence shows that maintaining a healthy weight, exercising and eating a balanced diet have benefits for people who’ve had breast cancer. Alternative diets can often be very restrictive, expensive and sometimes do not provide you with the nutrients you need, which may result in other conditions such as anaemia (lack of red blood cells) or osteoporosis.
If you’re thinking about changing your diet or want to find out more about different diets, you may find it helpful to talk to your specialist team or a dietitian.

Our Diet and breast cancer booklet has more information on healthy eating after breast cancer treatment.

‘I am much more conscious about what I eat. I started to keep a food diary, and that enabled me to cut out some of the junk.’

Catriona

‘I have tried hard to bring my weight down. I found the tamoxifen seemed to give me a huge appetite so it was hard to get rid of weight. I have changed my diet as I was very much a cheese and bread addict!’

Androulla
Physical activity

Being physically active (or exercising) during and after treatment for breast cancer can be difficult, especially if you have side effects such as fatigue, or you feel unwell.

But regular physical activity has many benefits, and there’s evidence to show that being active and maintaining a healthy weight after treatment may reduce the risk of breast cancer coming back.

Regular physical activity can:

• help avoid or reduce some side effects of cancer treatment – such as fatigue, weight gain, osteoporosis and lymphoedema
• improve your long-term health, reducing the risk of heart attacks and strokes, and may reduce the risk of the cancer coming back
• help your mental wellbeing by reducing anxiety, stress, depression and improving your overall mood
• prevent or reduce the loss of muscle tone and aerobic fitness that can happen during treatment.

Before you start any exercise, discuss it with your GP or breast care nurse, and then begin gently and build up gradually. If you’ve had reconstruction surgery, check with your specialist team when you can start exercising and which exercises are safe.

How much exercise should I do?

It’s recommended that adults should do at least 150 minutes (2 hours 30 minutes) of moderate-intensity activity a week. You can split this however you like. For example, you could do 30 minutes of activity on five days a week, or if you want to do shorter periods of activity, you could do 10 minutes three times a day on each of these days. You should build up to this amount gradually, especially if you’re not used to exercising.

Moderate-intensity activity should make your heart beat faster. You’ll feel warmer and breathe slightly harder, but you should still be able to hold a conversation.

Any amount of activity is better than none; if you struggle to do 150 minutes, start by trying to reduce the time you spend sitting down or being inactive and gradually increase this over time.
What type of activity should I do?

Some examples of moderate-intensity activities are:

- brisk walking
- cycling
- hiking or hill walking
- water aerobics or swimming
- gardening or housework
- dancing.

A combination of different types of activity can be more interesting, and will exercise different parts of your body.

If you’re new to exercise, you should build up your activity levels gradually. There are many ways to include physical activity in your daily routine. The following tips may help.

- If you enjoy walking, try to increase the amount of time you walk for and the number of times you walk each day. You could also try increasing your pace as your energy returns. A pedometer (or pedometer app for your phone) can help you monitor your progress.
- Energetic housework can help increase your daily activity levels.
- If you drive to work or the shops, park your car a little further away and walk the rest.
- Get off the bus a stop earlier than you need to and walk.
- Use the stairs instead of taking the lift.
- Try to sit less and stand more, for example when talking on the phone.

Setting realistic goals and keeping a record of how much activity you do may help you stay motivated.

Our Eat well, keep active after breast cancer DVD contains an exercise class that is suitable for people who have had treatment for breast cancer. This class is tailored to people of all fitness levels, whether you exercise regularly or are just beginning. You can order the DVD on our website at www.breastcancercare.org.uk/publications, or by calling the Helpline on 0808 800 6000.

Muscle-strengthening activities

As well as activities like walking, aim to do muscle-strengthening activities at least twice a week. Ask someone in your treatment team for advice on when you can begin doing muscle-strengthening activities.
These activities can help strengthen your muscles after treatment, and include:

- sitting to standing
- squats
- press-ups against the wall
- lifting light weights, such as tins of food or small bottles of water
- gardening
- activities that involve stepping and jumping such as dancing
- using fitness equipment such as a static bike or cross trainer
- yoga or Pilates.

**Physical activity if you have osteoporosis**

If you’ve been diagnosed with osteoporosis, avoid high-impact exercises such as jumping, running, jogging or skipping. A special exercise programme may be recommended if you’re at high risk of breaking a bone (fracture). Ask your specialist team for advice.

According to the National Osteoporosis Society, walking, dancing, low-impact aerobics, cross training machines and stair climbing are all good examples of exercises that can help slow bone loss.

**Physical activity if you have lymphoedema**

It’s thought that exercise doesn’t cause or worsen lymphoedema and may even lessen symptoms. The type of exercise that’s best for you depends on the severity and cause of your lymphoedema, and whether you have any other medical conditions, such as heart disease or arthritis. Speak to your lymphoedema specialist for more information.

Flexibility exercises can minimise skin scarring and joint contractures (shortening of a muscle or tendon) that may obstruct the lymph flow. There is ongoing research into many types of exercise for people with lymphoedema. However, Pilates, yoga, Tai Chi, Qigong and swimming might be of benefit.

Always wear any compression garments you’ve been given while exercising as they help increase lymph and blood flow (compression garments shouldn’t be worn while swimming).
‘In the early years (it’s now nearly eight), I found it very tiring to walk, jog, etc and got tired quickly. I could only manage to go shopping in one store. Now I can walk/jog a lot and manage half a dozen stores easily before I get tired.’

Androulla

‘Due to the fatigue, I struggled with my horse riding for some time, as it just wore me out. Luckily I had a great friend who would do all the preparation work for me, so I just turned up, rode and then went home. I do about the same level of physical activity now that I did before.’

Kim
Dealing with anxiety

Stress and anxiety can make you feel nervous, worried and tense. These feelings can range from being a bit uneasy to a continuing sense of dread and sometimes you may feel panicky and frightened. Stress and anxiety can affect your appetite (stopping eating or comfort eating) and your sleep patterns. Physical signs of stress and anxiety can include muscle tension, tightness in the chest, and a racing heart rate. In some cases anxiety can become so overwhelming that it leads to panic attacks, causing further fear and worry.

If you’re finding it difficult to move on after treatment has finished, you might want to talk to someone about how you’re feeling. This could be your breast care nurse or GP (local doctor), who can advise you if more specialist psychological help would be beneficial. Talking to someone who has had a similar experience may also help. You can do this through a local support group or with Breast Cancer Care’s Someone Like Me service. For more details see page 140.

There are various techniques and talking therapies specifically designed to help you cope at a difficult time.

- Distraction involves learning to focus on the things around you, or a hobby or interest, so that you can shut out negative thoughts.
- Relaxation, visualisation, mindfulness and meditation can be used separately or together to reduce stress and tension, relax the mind and body and help improve wellbeing.
- One-to-one counselling takes place in a private and confidential setting. You will be able to explore feelings such as anger, anxiety and grief which can be related to your cancer diagnosis, making them easier to understand and cope with.
- Cognitive behavioural therapy (CBT) can help you to change patterns of thinking and behaviour that may be stopping you from moving forward. Unlike some techniques, it focuses on problems and difficulties you’re having in the ‘here and now’. Instead of exploring causes of your distress or symptoms in the past, it looks for ways to improve your state of mind in the present.

If you think you might benefit from these techniques, your breast care nurse or GP may be able to advise you on how to access them.

You can also visit the Anxiety UK website or call their helpline (see page 95 for details).
Low mood and depression

Depression is a common condition which can have a broad range of symptoms, from feeling continuously low in spirits to having no will to live.

Depression can be a normal response to trauma and a way of coping, but as you adjust to what has happened, you will gain energy and your mood should improve.

Some people become depressed because of the impact of breast cancer and this can happen at any stage during diagnosis and treatment, or after treatment has finished.

This can be made worse by having fewer hospital trips or none at all because you may miss the reassurance of being seen by your specialist team. People close to you may expect you to carry on with the life you had before breast cancer.

How to recognise depression

If negative thoughts are interfering with your life and don’t go away within a few weeks or keep coming back, it may indicate that you’re depressed.

If you or the people close to you are worried because you have any of the following signs, you should talk to your GP (local doctor) or hospital team, who can refer you to a counsellor, psychiatrist or psychologist for help and support:

- loss of enjoyment and interest in everyday things and experiences
- loss of interest in your appearance
- persistent thoughts such as ‘I can’t be bothered’ or ‘What’s the point?’
- withdrawing from others (not going out or socialising)
- feeling more tearful and irritable than usual
- difficulty concentrating
- difficulty sleeping or wanting to sleep all the time
- loss of appetite or overeating
- feeling very low in mood or even suicidal.
You don’t have to ignore these feelings and struggle on. Realising that there is a problem and getting help is the most important thing you can do.

There’s nothing to be ashamed of in admitting that you’re feeling depressed, or finding it hard to cope, and that you need professional help. Some people find it particularly hard to seek professional advice but it can help to relieve these symptoms and allow you to regain control of your life.

**What might help?**

Anxiety and depression are natural reactions to the experience of breast cancer. Emotional support from your family and friends and healthcare professionals can help at this time.

**Talking therapies**

Professional support such as counselling or cognitive behavioural therapy (see page 89) can also be of benefit and your breast care nurse or your GP will be able to direct you to services in your area.

**Antidepressants**

Antidepressant drugs may be recommended to treat symptoms of depression. It usually takes up to six weeks before you notice the effects and start to feel an improvement in mood, although it may take longer to feel the full benefits. Antidepressants can be an extra support during a particularly difficult time.

**Sources of support**

Joining a cancer support group to meet others with a similar experience may be helpful. You can search for support groups near you on the Macmillan Cancer Support website.

You can also call our Helpline on **0808 800 6000** for information and support. Alternatively, you can email a Breast Cancer Care nurse through the Ask our Nurse service on our website. All emails are treated confidentially. Visit [www.breastcancercare.org.uk/atan](http://www.breastcancercare.org.uk/atan) to submit a short form that includes your question and a nurse will reply.
Samaritans provides confidential non-judgemental emotional support, 24 hours a day, for people experiencing feelings of distress or despair. You can call them on 116 123 or email jo@samaritans.org

You can find more information about depression on the NHS Choices website www.nhs.uk

The Mental Health Foundation has more information on talking therapies that you may find helpful. See ‘Further support’ on page 94 for more details.

‘I found it difficult to cope with the diagnosis without going through some significant low periods.’

Catriona

‘As I had tried to carry on as normally as possible all the way through treatment, I don’t think anyone really knew how I was feeling. I think I played everything down.’

Gill
Complementary therapies

Some people use complementary therapies alongside conventional medical treatments. They are different from alternative therapies, which are used instead of conventional treatments.

If you want to have a complementary therapy, speak to your specialist team first. There’s very little reliable research into complementary therapies, so it’s hard to judge how useful they are and whether they could affect your breast cancer treatment. Doctors may advise you to avoid certain complementary therapies (particularly herbal remedies) if there’s a chance they may affect how well your breast cancer treatment works.

Types of complementary therapy

Popular types of complementary therapies include:

- acupuncture
- aromatherapy
- healing and energy therapies
- herbal medicine
- homeopathy
- hypnotherapy
- massage
- mindfulness
- reflexology
- shiatsu and acupressure
- yoga, Tai Chi and Chi Gung.

For more information, see our Complementary therapies booklet.

‘[Something] that helped me deal with the chemo were complementary therapies, especially massage for my very sore feet and the sore arm I had from the cannula. Reflexology helped a lot.’

Eithne
Further support
Breast Cancer Care

Publications
Complementary therapies

Diet and breast cancer

To order, or download a copy, please visit www.breastcancercare.org.uk/publications or use the quick order form included in this pack.
Other organisations

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

Helpline: 08444 775 774
Website: www.anxietyuk.org.uk
Email: info@anxietyuk.org.uk

Provides information and support to people with anxiety disorders through a range of services, including one-to-one therapy.

The Haven
Head Office
Effie Road
London SW6 1TB

Tel: 020 7384 0099
Website: www.thehaven.org.uk
Email: info@thehaven.org.uk

Provides support, information and complementary therapies to help anyone affected by breast cancer. Its services are free of charge to anyone affected by breast cancer. Also produces Haven at Home DVD and audio podcasts of some therapies.
Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840
Helpline: 0808 808 00 00
Website: www.macmillan.org.uk
Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. It also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

Maggie’s Centres
20 St. James Street
London W6 9RW (London office)

Tel: 0300 123 1801
Website: www.maggiescentres.org

Maggie’s provides free practical, emotional and social support to people with cancer and their family and friends.
The Mental Health Foundation is a leading UK charity that provides information, carries out research, campaigns and works to improve services for anyone affected by mental health problems, whatever their age and wherever they live.

Mind
15–19 Broadway
London E15 4BQ

Tel: 020 8519 2122
MindinfoLine: 0300 123 3393
Email: contact@mind.org.uk
Website: www.mind.org.uk

Mind is an organisation for people who are concerned about their mental and emotional health. Its services include a confidential helpline, drop-in centres, counselling and a range of publications offering coping strategies for life.
Samaritans
Freepost RSRB-KKBY-CYJK
PO Box 9090
Stirling FK8 2SA

Tel: 116 123
Email: jo@samaritans.org
Website: www.samaritans.org

Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair.
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Breast Cancer Care’s publications contain more information on the topics covered in this section. You can order or download a copy from our website, or use the order form at the end of this pack.

You may like to read:

• Breast prostheses, bras and clothes after surgery.
Introduction

When you’re dealing with the physical and emotional effects of having breast cancer, money or work might be the last things on your mind. But being diagnosed with breast cancer can have a financial impact you may not be aware of straight away. For example, you may have to take time off work or reduce your hours, or you may have to pay increased childcare costs or meet the cost of travelling to hospital.

This section outlines some of the financial and practical issues you may face, such as claiming benefits, travelling abroad or going back to work. It also suggests possible sources of help and support.

The benefits system can be complicated and subject to change. Therefore, rather than explaining different benefits in detail, we have suggested where you can go to get up-to-date and expert advice.
Health costs

Prescription charges

In Wales, Scotland and Northern Ireland, prescription charges have been abolished.

Exemption certificates for people living in England

People in England being treated for cancer are entitled to all their prescriptions free of charge. To show you’re eligible for free prescriptions you need to apply for an exemption certificate (FP92A) from your GP or hospital.

The certificate means that you will not have to pay any charges for prescriptions for five years. You can renew your application after five years if you’re still having treatment for:

- cancer (includes tamoxifen or other hormone therapies and lymphoedema garments)
- the effects of cancer (includes pain relief and effects directly related to cancer that did not exist before the cancer diagnosis such as a change in mental health)
- the side effects of cancer treatment (includes all side effects of chemotherapy or late effects caused by radiotherapy).

If you have to pay a prescription charge while you’re still waiting for your exemption certificate, you should ask the dispenser for an NHS receipt (FP57). This is also a refund claim form.

People aged 60 and over do not have to pay NHS prescription charges in England and do not need to apply for the certificate.

Getting a new breast prosthesis

NHS patients do not have to pay for their prostheses. Your prosthesis will have a guarantee but the length of this can vary. Some prostheses may last for three or more years before they need replacing, which may be longer than the period of the guarantee. The NHS will replace your prosthesis when it is damaged or worn out or if you have changed shape or size due to gaining or losing weight.

You can have a reassessment if your prosthesis is no longer a good fit, even if it’s still in good condition. You can also be reassessed in other
specific circumstances such as if you have problems with your wound healing or with scar tissue, or if you need surgery on your other breast.

You can contact your breast clinic to arrange a prosthesis reassessment and fitting, or ask your GP (local doctor) for a referral to the breast clinic or prosthesis fitter if you no longer attend scheduled follow-up visits. New prosthesis styles are developed frequently, so when you need a replacement it’s a good idea to have a reassessment rather than directly replacing the one you already have. If the style you like is not in stock, the fitter can usually order it.

If you have private health insurance, check if your scheme covers the cost of your prosthesis. If it doesn’t, you may be able to get one from the NHS in the same way that NHS patients would apply for a replacement.

For more information see our booklet Breast prostheses, bras and clothes after surgery.
Financial help and benefits

Many people with breast cancer don’t claim benefits because they’re unaware of what they’re entitled to, are too embarrassed to ask for help, or find the system complicated.

Whether you’re entitled to certain benefits depends on your individual circumstances.

If you’re unable to work because of your breast cancer or your treatment for breast cancer, you may be able to get Statutory Sick Pay (SSP). You can speak to your employer or human resources department about this.

Finding out what you may be entitled to

The benefits system can be confusing, so it’s a good idea to get help to find out what you may be entitled to. Friends or relatives may be able to help with questions about benefits. You can also talk to your breast care nurse, someone at your GP surgery, or be referred to a social worker or welfare adviser at the hospital.

Macmillan Cancer Support

Macmillan Cancer Support produces a booklet called Help with the cost of cancer. This outlines the benefits and financial help available to people affected by cancer, as well as information on benefits available for carers, help with housing costs, children’s needs and transport. You can order a free copy from their website be.macmillan.org.uk or by calling their helpline on 0808 808 00 00.

You can also call their helpline to speak to a welfare rights adviser, who can provide information about benefits for people affected by cancer and their families and carers.

GOV.UK

You can find out more about benefits on the government information website www.gov.uk

To get an estimate of what benefits and tax credits you could get, and find out about claiming specific benefits, see the GOV.UK website www.gov.uk/benefits-calculators
Citizens Advice (CA)
Citizens Advice is a good place to go for general guidance about benefits. You can find information on their website www.citizensadvice.org.uk, where you can also download factsheets about specific benefits and find your local Citizens Advice.

Who can claim?
Several factors are taken into account when assessing whether you’re eligible for benefits. Some benefits depend on your income and savings, and those of your partner. These are called means-tested benefits. Benefits can also be based on the level of National Insurance you have paid (called contributory).

If you think you may be eligible for certain benefits, it’s important to apply as soon as you feel able because many benefits can’t be backdated.
Working after breast cancer

Your rights at work

People with cancer are protected at work by the Equality Act 2010. The Equality Act (which replaced the Disability Discrimination Act in England, Scotland and Wales) protects employees from being discriminated against because of their disability.

For the purposes of the Act, anyone who has or has had cancer is classed as disabled. Employers are required to make reasonable adjustments to help employees return to work, to have time off for medical appointments or continued treatment and recovery.

You can find more detailed information about your rights at work on the Macmillan Cancer Support website.

The Disability Discrimination Act (DDA) will continue to protect people living in Northern Ireland.

Returning to work

When treatment has finished, you may be keen for life to start getting back to normal. Returning to work after a breast cancer diagnosis can be a very positive step and helps some people move forward.

If you took time off or reduced your working hours during your breast cancer treatment, returning to your previous work pattern can be difficult for a number of reasons. You may be surprised or disappointed that it isn’t as easy as you imagined.

When and whether you decide to return to work will depend to some extent on what your job involves and your financial situation. If your job is physically or mentally stressful, you may need more time before you feel ready to return.

You may want to discuss returning to work with your doctor, occupational health or human resources department and your manager.

Do I have to tell my employer about my cancer?

You don’t have to tell your employer any details of your diagnosis and treatment if you don’t want to.
How much information you give about your breast cancer to those involved with your return to work is a personal decision. However, you have the right for any information given to be kept private and only discussed with other people with your permission.

Remember, your employer has a duty to make reasonable adjustments to your role or your working environment to help you do your job. If you don’t tell them about your diagnosis and treatment, it may be difficult for them to know what adjustments to make.

**Do I have to tell a new employer about my diagnosis?**

Many people worry that giving information about their cancer diagnosis when applying for a new job may affect their chances of success. If you are being or have been treated for breast cancer, the Equality Act 2010 protects you against any discrimination relating to employment – including during the recruitment process.

Under the Equality Act, employers are not permitted to ask questions about candidates' health during the recruitment process. This includes asking if you have a disability. Information regarding your health can be asked for by an employer, if it is relevant to the job or is to be used as part of equal opportunities monitoring.

Once you’ve been offered a job, an employer can then ask for information about your health. If you’re asked directly it’s important you answer truthfully. Giving false or incomplete information could mislead your employer. However if they decided to withdraw the job offer, this must be done for reasons that are non-discriminatory.

**Giving up work**

Some people choose to stop working altogether after a diagnosis of breast cancer. This may be for health reasons or because the experience of having breast cancer has made them reassess what’s important. However, giving up work is not an option for everyone and your circumstances may mean it’s not possible for you to do this.

Giving up work for good means you also give up any rights and benefits linked to your job such as pension rights. So if you’re planning to stop
working it’s important to get independent employment advice before you make any decisions.

Macmillan Cancer Support has more information about how cancer and cancer treatments may affect your employment: www.macmillan.org.uk

For employment advice you can contact Acas through its website www.acas.org.uk/contact or call their helpline on 0300 1230 1100.

‘I had a phased return, at a location closer to home. I was still having Herceptin at this time, and I was tiring easily. My colleagues were very supportive, but I don’t feel that my employers were.’

Gill

‘I found going back to work very hard as it was a new job and very unfamiliar. Having said that I was phased in and also my boss was wonderfully supportive. I have since changed jobs several times; I’ve learnt what I can manage and a fast/noisy/stop-start environment doesn’t suit me, nor does five days a week. I aim for three days only.’

Androulla
Travelling abroad

If you’re travelling abroad, having breast cancer won’t necessarily affect your arrangements. But planning things in advance can help ensure your trip goes more smoothly.

Travel insurance

Some people have difficulty getting travel insurance after a diagnosis of breast cancer. If you do have problems, it can be frustrating and may make you feel that you are being penalised for something beyond your control. However, there are some companies that specialise in providing cover for people who have had cancer.

Be aware that your travel insurance will not cover you for any claim relating to your breast cancer and its treatment or any other pre-existing medical condition if you don’t inform the insurance company about it when you buy the policy.

Breast Cancer Care does not approve specific insurance companies or products because they change on a daily basis. However, you can find recommendations for insurance companies from people affected by breast cancer on our online Forum [forum.breastcancercare.org.uk](http://forum.breastcancercare.org.uk) (see the ‘Work, finance and travel’ section in the category called ‘Living with and beyond breast cancer’).

You can also find information on the Macmillan Cancer Support website [www.macmillan.org.uk](http://www.macmillan.org.uk)

Medication

If you’re taking tablets, such as tamoxifen, it’s a good idea to pack more than you’re likely to need in case of travel delays. Carry your medication in your hand luggage so it doesn’t get lost. A summary of your medical details may also be helpful.

Air travel and prostheses

It’s safe to fly with a prosthesis as aircraft cabins are pressurised.

If you pack your prosthesis in your luggage, some small air bubbles may appear in the back of your prosthesis. This is because the luggage
hold is not pressurised. These small bubbles will disappear shortly after you’re back on the ground and will not harm your prosthesis.

Some airports use body scanners as part of their security procedures and some of these will reveal a prosthesis. Where body scanners are in use, a random sample of travellers is selected to be scanned, so there’s a high chance you won’t be scanned.

A member of security staff can conduct a body search after viewing someone’s scan. However, a breast prosthesis does not inevitably lead to a body search. The Department for Transport advises people wearing an external breast prosthesis to notify security staff before being scanned. Although this may be awkward or embarrassing, it will mean you’re less likely to be searched than if you haven’t declared it. It may also be helpful to carry a letter from your GP or specialist team, confirming your situation.

You can find out more information about breast prostheses and body scanners on our website, or by reading our booklet *Breast prostheses, bras and clothes after surgery*.

**Radiotherapy and skincare**

If you’ve had radiotherapy, the skin in the treated area may be more at risk from the sun. Therefore, make sure that the skin in the treatment area is covered or apply a high-factor sun cream when you’re out in the sun, even when treatment is finished.

**Travelling if you have lymphoedema**

There’s no reason why having lymphoedema should stop you enjoying holidays, but extra care may be necessary.

- If you’ve been fitted with a compression garment, wear it during your journey.
• Wear loose, comfortable clothes when travelling.
• Make sure jewellery or watches aren’t too tight.
• Use a suitcase on wheels rather than one you carry and ask for help when moving luggage around.
• Keep your hand baggage light and try to carry it on your back rather than your shoulder.
• Try not to sit for too long in one position. Take regular breaks if travelling by car or move around if you’re travelling by air. Gentle exercises can also be carried out while sitting to promote lymph flow.
• A high-factor sunscreen applied regularly is essential to prevent sunburn if you are going somewhere hot. Loose cotton clothes with long sleeves will also protect your swollen arm from the sun.
• Wash your skin after swimming in the sea or in a pool to get rid of the salt from the sea and chemicals from the pool.
• Use mosquito repellent every day, particularly in the evening and at night. Mosquito bites can become infected and are very uncomfortable.
• Before you travel, talk to your GP or lymphoedema specialist about taking antibiotics with you (in case you develop an infection in the swollen area).
• Try to avoid extremes of temperature – getting too hot then too cold, or too cold then too hot.

**Travel vaccinations**

If you’re planning to travel somewhere that requires vaccinations, discuss your plans with your specialist team first.

**Live vaccinations**

Live vaccinations – which contain tiny amounts of live virus or bacteria – are not recommended during chemotherapy or for six months afterwards. This is because they could cause serious infections.

Live vaccinations include:

- measles
- rubella
- yellow fever
- typhoid (tablets)
- tuberculosis (BCG).
Inactivated vaccinations
While inactivated vaccines are safe after treatment, they may be less effective if you have a weakened immune system. This may be the case in the first six months after chemotherapy.

Inactivated vaccines include:

- cholera
- diphtheria, tetanus and polio
- hepatitis A and B
- flu
- Japanese encephalitis
- meningococcal meningitis
- typhoid (injection)
- tick-borne encephalitis
- rabies.
Further support

Breast Cancer Care

Publications
Breast prostheses, bras and clothes after surgery

To order, or download a copy, visit www.breastcancercare.org.uk/publications or use the quick order form included in this pack.
Other organisations

Age UK
1-6 Tavistock Square
London WC1H 9NA

Advice line: 0800 169 2081
Website: www.ageuk.org.uk

Age UK can offer advice on a wide range of benefits. Contact the advice line or visit the website to find out details of your nearest office.

Citizens Advice
Website: www.citizensadvice.org.uk

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

GOV.UK
Government information website www.gov.uk is the place to find out about government services. You can find information about benefits and financial support, get an estimate of what benefits and tax credits you could get, and find out about claiming specific benefits.
Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840
Helpline: 0808 808 00 00
Website: www.macmillan.org.uk
Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. It also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

Further reading

Work and cancer, 2013
Macmillan Cancer Support

Self-employment and cancer, 2014
Macmillan Cancer Support

Help with the cost of cancer, 2015
Macmillan Cancer Support

Tel: 020 7840 7840
Website: be.macmillan.org.uk
Call our Helpline on 0808 800 6000
Introduction

Many people find it useful to see how others in a similar situation have moved forward after treatment for breast cancer. Four women have shared their stories with us.

As you move forward after your treatment, we will continue to be here for you. On page 139 you’ll find an outline of the services we offer to people affected by breast cancer.

We would love to stay in touch with you. You may also reach a point where you would like to help others through their breast cancer diagnosis and treatment. This is hugely beneficial to our service users and we hear from many of our volunteers that it helps them too. This section also describes the different ways you might like to get involved in our work and events.
Moving Forward: your stories

The following stories highlight how four women who’ve had breast cancer have moved forward after treatment.

Everyone’s experience of moving forward after breast cancer is different. How you react, both physically and emotionally, may be different to someone else who had a similar diagnosis and treatment. But speaking to someone who has been through it can help.

However long ago your diagnosis was, Breast Cancer Care can put you in touch with someone who understands how you are feeling. For more information, see ‘Further support’ on page 139.
Running my way to recovery

Amanda Humphry was diagnosed with breast cancer in 2007 at the age of 44. Like many people, she found the end of her hospital-based treatment to be a time of mixed emotions.

I found a lump and was referred to the breast clinic ‘just to be on the safe side’. I was assured that it was just a cyst, and told not to lose sleep over it. I didn’t worry even when they wanted to do a biopsy. I was about to run my first London Marathon so that was a big focus for me at the time. When I went for the biopsy results I didn’t take my husband, but luckily a friend came with me. I was completely thrown by the diagnosis. I knew when I went in that something was wrong because the breast care nurse came in with us – that was a bit of a giveaway!

I started chemotherapy almost straightaway, then had a mastectomy and lymph node removal on one side, followed by radiotherapy. I was then on tamoxifen for five years, followed by two years of letrozole. I experienced menopausal symptoms: sweats, tiredness, mood swings, interrupted sleep patterns, and I hated it. Being suddenly menopausal made me feel like I had become old, whereas before I had always felt young. People often said how young I looked for my age, but that didn’t happen anymore. I felt like the last bit of my youth had been taken away from me.

Finishing treatment

The end of treatment was weird. I was glad to have finished, although I felt very insecure that I would not be seeing hospital staff so much. Everyone else thinks you’re better and back to normal, but you feel completely different. Some friends understood. My husband Nick was my rock. I feel he went through just as much as I did as he watched me go through all the treatment and then beyond. The people I can really talk to understand how much the experience has affected me, but for more casual friends it is ‘out of sight, out of mind’ now.

I found that follow-up appointments can be an anxious time. It is nice to know that you are being checked out, but at the same time all the feelings come flooding back and I hate going to the hospital.

I had a whole year off work as I was a primary school teacher and could not feel I could cope with doing such a demanding job alongside the
treatment and emotional trauma. I felt I needed all my energy and time to fight the cancer. I was anxious about how I would feel, and how other people would be when I went back to work and I found it hard to adjust to getting back at first.

**Step by step**

I had a four-week phased return. My colleagues were supportive and very kind – especially when I was off. After a while we didn’t mention it so much and I was just back to being one of the team again. I became a job-sharer and worked three days a week as I found I was just getting too tired. I felt that during my cancer treatment I got off a big treadmill, but then I just jumped straight back on again once it was over. Six years after my cancer I decided to leave teaching altogether, and I now have a much less demanding job, which gives me a better work-life balance. It was a hard decision, and took a long time to make. I needed to be a long way past the cancer to be able to make such a big decision comfortably.

I did change my diet a little bit and I try to be healthy – but I had always been a healthy eater and exercised regularly anyway. I fought hard to get back to a similar level of fitness to before I was diagnosed. I still train several times a week and I’m more confident in my body now.

Having a self-supporting (adhesive) breast prosthesis has also helped hugely. However, I still get a shock when I look in the mirror and see a flat space where my breast should be. But I chose not to have reconstruction as I didn’t want any more surgery, and I also did not want to have an implant. I am still happy with that decision eight years later.

I don’t think about cancer so much now, but the fear of recurrence has not gone away, and I found this especially so when I came off all the medication after seven years. I wondered if that was the only thing stopping the cancer coming back, and I felt very nervous about it at first. Some women I met through a support group and from doing charity fundraising have had recurrences or died and I find that terrifying. I also feel guilty sometimes because when I hear that someone else has it, I feel so sad for them but also glad that it’s not me. That seems a mean thing to admit!

Sometimes having breast cancer seems like a dream or a movie I have seen – I can’t quite believe it all happened to me. It made me stop
and think about what I wanted from life and what was important, but I’d rather not have had it. I went through a fairly long period of feeling very down several years after I finished my treatment, and I think this was when what had happened finally hit me. I wasn’t expecting to feel like that, I thought that I would just leave it all behind and move on! Eight years later I feel like I am back to myself again, and from this perspective I can appreciate how far I have come.

My aims now are to stay healthy and happy, take up the opportunities life offers me, make time for myself and my family – just to enjoy life and make the most of it. One of my goals was to run the London Marathon again, which I have done – twice more! It was a fantastic feeling.

Listen to your body and make time for yourself to do what you enjoy. Spend time with the people who mean the most to you, and don’t be reluctant accept the emotional and practical help they offer. Never give up hope, never be afraid to ask for help, cry when you need to and don’t feel guilty for doing so, it is part of healing.

‘Everyone else thinks you’re better and back to normal, but you feel completely different.’
Call our Helpline on 0808 800 6000
**Share and share alike**

For Gillian Munday, the end of treatment was a confusing time. She found that talking to someone else who understood how she was feeling helped her to make sense of her emotions and to regain confidence.

When I was 36 and my daughter was three, I found a lump in my right breast. I was diagnosed with breast cancer. I had the lump removed, four cycles of chemotherapy and six weeks of radiotherapy.

I plunged deep into a cycle of appointments. Everything else stayed in the background, which was good at the time, as my mind needed something to hold onto while everything seemed to be spinning around. I became just as fearful once I finished treatment. Suddenly there was no one looking after me and telling me what to do next, and I began to feel shaky about the future. I tried to steady myself with a family holiday, to draw a line under it, but everything had happened so quickly, it took a while to catch up emotionally.

I’d had a stroke in my 20s. I led an active, healthy lifestyle so I put it down to bad luck, but then getting breast cancer made me feel I must have been doing something wrong. It really knocked my self-confidence and left me feeling pretty ashamed and vulnerable. I’d lost my hair through chemotherapy and the image in the mirror just wasn’t me. I felt that I was putting on a show, having all these rituals before I could leave the house for an appointment or going to meet a friend – before I could feel a part of society. It’s easy to pretend that you’re in control, but I was losing sense of who I was on all levels.

**Finding the right approach**

For me, it’s not brave to go through cancer – it’s something everyone in that position has to get on with. I’ve always been forward-thinking, wanting to plan ahead and leap into the future. With breast cancer, all that suddenly comes to a halt. I realised I just needed to get better, so I had to almost close down parts of myself; the most important thing was (and will always be) my family.
Back on track

I wanted to get to the crux of what was bothering me. I had my family and friends, but I needed to speak to someone else who had had breast cancer when they were still relatively young. I had two friends my age who were both diagnosed with breast cancer at the same time as me, but it was hard as we didn’t want to burden each other; sometimes we wanted to talk about anything but cancer.

I felt that I had to get as much information as possible, so I visited Breast Cancer Care’s website. I found out about their Someone Like Me service and they put me in touch with a trained volunteer who had been in a similar situation.

When we spoke, the main thing that struck me was that she was really calm, and she helped create a bit of calm in me. I did most of the talking and she did a lot of listening. She helped me establish what was bothering me, and talking to her gave me hope that I’d be able to deal with my situation in a way that I felt was true to me.

I understood that breast cancer was something she’d experienced and moved through. It was now part of her and she was getting on with her life. It took some time to make peace with the fact that it wasn’t my fault. She gave me hope that one day I could be in that position, instead of feeling devastated.

After treatment, I got back to my regular yoga practice. As well as helping improve movement in my right shoulder area, it helped (and continues to help) me process some of the anguish and spiritual questions that sometimes bubble up unannounced.

It’s so easy to take on more and believe you can handle everything, and that saying no is almost not an option. I learned that I had to give more priority to my wellbeing. After I finished treatment the wheels came off, but I know that they’re back on now and are even better than before. That wouldn’t have happened without Someone Like Me. I’m still not sure she realises how much she helped.
Talking about your breast cancer can churn up all sorts of emotions that you thought you’d dealt with, so having someone willing to discuss them really helped me. My relationship with my husband and daughter has always been great but now we are even closer. It’s often really hectic in the week with our careers and her many activities, but we all have a renewed understanding for each other; we try even more to carry each other’s hearts with care.

‘Suddenly there was no one looking after me and telling me what to do next, and I began to feel shaky about the future.’
Call our Helpline on 0808 800 6000
Cheryl Thornett, 64, felt relieved when her hospital treatment came to an end, but two years later she was diagnosed with breast cancer for the second time. Cheryl found Breast Cancer Care’s Moving Forward courses useful in helping her move on after treatment.

I’ve had lots of lumps in the past that weren’t cancer. But when I did get cancer, there was no lump to feel. In 2008 I was diagnosed with DCIS after a screening mammogram. I was very shaken to learn that I had a tumour, and had a lumpectomy and radiotherapy. Two years later, my second routine check-up revealed a small but invasive cancer. I had more surgery, followed by chemotherapy, radiotherapy and hormone therapy.

After my first lot of hospital treatment was over, I felt relieved and very lucky. The second time, I also felt relieved, though a little less lucky than before. I feel guilty at times, because others are less fortunate than me with their treatment, side effects and outlook.

Moving Forward courses

Several months after active treatment had finished, it seemed that I wasn’t regaining health or energy anymore. Pain was still a problem. Things even seemed to be going backwards, and I knew I needed help. People who had been on Moving Forward courses said they were really helpful, and after some emails and phone calls, I managed to get a cancellation place at a hospital not too far away. The speakers were all excellent, very well informed and willing to change their plans for a session to meet the needs of the friendly women present. Some had had breast cancer themselves. Thanks to the lymphoedema nurse, I know common sense ways to reduce the risk of getting lymphoedema.

Another speaker explained the physical ups and downs we were all going through, and post-cancer fatigue and how to deal with it. A clinical psychologist talked about the emotional trauma of cancer and the importance of finding safe ‘places’ and people in our lives to regain our former confidence. He helped me formulate what help to ask my
GP for. We also had good tips about diet and exercise, more pleasant because of the friendly social setting, and plenty of information to take away.

Support from family and friends

When my treatment finished, quite a few people assumed that I was ‘cured’ and ‘back to normal’. My family and some friends were more understanding and continued to offer support. Some took the trouble to ask how I was getting on and whether I still needed help and support.

My grown children were good at keeping in touch and being thoughtful during the more recent treatment. The two who are in the UK stayed with me a couple of times when my husband was away just after a chemotherapy session, and phoned to make sure I was OK.

My husband, like many men, isn’t very demonstrative, but took over some household jobs, drove me to appointments and treatment sessions, bought berries and satsumas for me to nibble, and so on. A friend who has had adult leukaemia sent me regular sympathetic and entertaining emails.

Getting back a sense of wellbeing

I’d never felt particularly strong or athletic, and I’ve had back problems since I was a child, but I thought I was healthy. In some ways, I still am, since my heart and lungs are OK, but I don’t yet feel healthy in the same way.

Having breast cancer definitely wasn’t a good experience, but it could have been a lot worse. I got through it and learned that I am stronger and can be more stoic than I had thought. Medically, I had good treatment, but sometimes things were more stressful than necessary due to organisational hitches. I also wish there was more provision for women (and men) with breast cancer in my area in terms of support, pain relief and management, relaxation therapy and so on.

I hope to continue to recover strength and a sense of wellbeing. I don’t want to be defined by cancer, but I do want to contribute to improved treatment and support for others. I’m still exploring my life and role after retirement, because I’m not finished yet. I wrote a regular blog for Breast Cancer Care’s online magazine, Vita. Maybe I’ll write a book too. Now most of my time is taken up being Church Secretary while we haven’t
got a minister. I hope someday to be a granny, but that may take a while, so I’ve just got to keep going in the meantime.

Recovery may be slower and more difficult than you hope, but most of us get there in the end. Don’t try to fit to others’ expectations and don’t push yourself too much, especially at first. Learn what’s right for you. Ask for help if you need it – there are no medals for suffering in silence or even suffering loudly.

And try to get on one of Breast Cancer Care’s Moving Forward courses – they’re really helpful.
A wonderful support

Snober Bhangu MBE was diagnosed with breast cancer in 2000 aged 56. After moving forward from her own experience she decided to help other women affected by breast cancer. She has been a volunteer for Breast Cancer Care for over eight years.

It’s now 15 years since I was diagnosed with breast cancer. My breast cancer was found through a routine mammogram when I was 56. I had not felt a lump because it was tucked away and very small. I had a lumpectomy and took tamoxifen for five years.

After my initial treatment I wanted to give something back and do something to help others. I had wonderful support and encouragement from my family, friends and healthcare professionals but I know that not everyone has the same support. I wanted to do something to help them.

I’m an independent, strong person and when I was diagnosed I was able to make well-informed decisions about treatment options and remained in control. However, there were times when I felt isolated and on my own; I was trying to protect my family from how I was feeling because I didn’t know how they would react.

Two years after my diagnosis I became a volunteer for Breast Cancer Care and trained to offer support for the Someone Like Me service. I started by supporting women by phone who want to speak to someone who has had a similar experience of breast cancer and who understands what they’re going through. I think that when you talk to a stranger who is on the same journey as you it’s easier to open up and share your fears.

I’ve given support to a number of people. I feel good about helping them and it’s rewarding to think that through speaking to me those women feel reassured that they are not on their own.

‘I’ve moved on and through my rewarding and uplifting work as a volunteer with Breast Cancer Care, I have been able to put my fears behind me and I enjoy living a very normal, healthy and happy life.’
Shared experiences

For some people, their experience of breast cancer is something that they want to keep private. I want to be open about my experience and talk about it in the hope that it will help other women. I also completed some breast awareness training to raise the profile of the Breast Health Promotion team, and now hold regular workshops in the community to teach people about breast health. I tell them about how to be breast aware by looking for signs and symptoms, the risk factors involved and the benefits of leading a healthy lifestyle. I also talk quite openly about my own cancer journey and encourage them to go for routine breast screening.

I’ve also been a media volunteer for Breast Cancer Care. This has meant doing interviews for magazines about my experience of having breast cancer to try to encourage people to be breast aware.

The end of treatment can be a difficult time. For me personally, when I came to the end of my course of tamoxifen after taking it for five years, I lost my confidence for a bit. I felt I was protected while I was swallowing this little pill every morning and when that stopped it was as if that reassurance had been taken away from me. That left me feeling very insecure. Fortunately that didn’t last too long.

Now I don’t really think about having breast cancer on a daily basis. I’ve moved on and through my rewarding and uplifting work as a volunteer with Breast Cancer Care, I have been able to put my fears behind me and I enjoy living a very normal, healthy and happy life.

Get involved with Breast Cancer Care

If you are interested in becoming a volunteer for Breast Cancer Care, you can find out about the volunteer roles that are available in your area by visiting www.breastcancercare.org.uk/volunteer There are many ways you can help support people affected by breast cancer, including fundraising, volunteering in one of our offices, or helping to spread the breast awareness message by delivering workshops. It can be a very rewarding experience both for you and the people you meet in your volunteer role.
Moving forward: your words

We asked people who have had a diagnosis of breast cancer what they would like to say to people who have just finished their hospital-based treatment.

‘Don’t rush to get back to “normal life” whatever that might be for you. Pace yourself and find ways to have “time out” or “quiet space”. I believe the mind more than the body needs to heal from the shock of the diagnosis and the trauma of the treatment. Just be kind to you!’

Androulla

‘Think positively. You will return to normal. Do not panic if it seems to be slow progress. You are still the same person as you were before.’

Ann

‘Don’t be scared, grab life back in your control with both hands and enjoy the fact that now you get to choose what happens – it isn’t the cancer choosing for you.’

Caroline
‘Be kind to yourselves, do not Google, listen to your body.’

Susan

‘Keep positive, access counselling support if you need it, take up offers of Moving Forward courses, and if you are affected by fatigue, just remember it will go and don’t beat yourself up about it when you have to rest. You’ve made it this far, so you are a strong person, well done!’

Kim
Further support

Breast Cancer Care
From diagnosis, throughout treatment and beyond, our services are here every step of the way. Here is an overview of all the services we offer to people affected by breast cancer. To find out which may be suitable for you call our Helpline on 0808 800 6000.

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. Whatever your concern, you can be confident we will understand the issues you might be facing, and that the information you receive is clear and up to date. We will also let you know where else you can go for further support.

Ask our Nurse
If you prefer not to talk directly, we can answer your questions by email instead. The Ask our Nurse service is available on the website www.breastcancercare.org.uk/atn – complete a short form that includes your question and we’ll get back to you with a confidential, personal response.

Website
We know how important it is to understand as much as possible about your breast cancer. Our website is here round the clock, giving you instant access to information when you need it. As well as clinical information, you’ll find real life experiences and regular blogs addressing breast cancer in the news. It’s also home to the largest online breast cancer community in the UK, so you can share your questions or concerns with other people in a similar situation.

Forum
Through our Forum you can exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns online. Our dedicated areas for popular topics make it easy for you to find the information you’re looking for. The Forum is easy to use and professionally hosted. If you’re feeling anxious, or just need to
hear from someone else who’s been there, there is always someone online 24/7, 365 days a year. Visit forum.breastcancercare.org.uk

Someone Like Me
Sometimes it can seem like no one really understands how you feel. Our Someone Like Me service matches you to a trained volunteer who has had breast cancer too and who has experience of the issues you’re facing – whether that’s going back to work, struggling with relationships old or new, or any other concerns you have. Chatting over the phone, where and when it suits you, means you can ask any questions you like and talk openly without worrying about the feelings of the person listening. Call 0345 077 1893 or email someoneilikeme@breastcancercare.org.uk Some of our volunteers can also be contacted via email – check our website to see their profiles and read more about them.

Moving Forward courses
Finishing your hospital-based treatment for breast cancer can be an unexpectedly challenging time, bringing a mix of emotions. You might feel relieved that the hospital appointments are over, but also under pressure to get back to ‘normal’ and worried about how to adjust to life after your diagnosis.

Moving Forward courses can help by focusing on the issues that you may be facing at this time, such as healthy eating, exercise, managing menopausal symptoms, lymphoedema, cancer fatigue, intimacy and relationships, and adjusting and adapting after a diagnosis of breast cancer. You’ll get to know other people who are in a similar situation and who understand how you’re feeling. Check our website for details or call 0345 077 1893 to find your nearest services.

Information resources
We produce free information for anyone affected by breast cancer, including booklets, e-books and online information. Our resources are here to answer your questions, help you make informed decisions and ensure you know what to expect. All of our information is written and reviewed regularly by healthcare professionals and people affected by breast cancer, so you can trust the information is up to date, clear and accurate. You can order our publications from our website www.breastcancercare.org.uk/publications or our Helpline.
Younger Women Together
At these two-day residential events, you will meet other women under the age of 45 and find out more about topics such as the medical management of breast cancer in younger women, fertility after treatment and breast surgery and reconstruction, with plenty of opportunity to ask questions. Discussion groups on topics such as intimacy and sexuality, relationships and communication help you to explore the impact your breast cancer has had on these areas of your life. Support is also available throughout the event from our Younger Women’s Nurse, and from trained Someone Like Me volunteers who have all experienced breast cancer as younger women.

‘You are not on your own with this disease. Use the services of Breast Cancer Care whenever you need to and do try and talk to as many others as possible who have been through breast cancer.’

Catriona
Getting involved

Breast Cancer Voices

You can make a real difference to the support and care available for people affected by breast cancer by becoming a Breast Cancer Voice. It is a unique and powerful way to make a positive, lasting impact for people today and into the future.

Give as much time and energy as you would like by choosing the opportunities that appeal to you. From campaigning on important issues to taking part in an awareness-raising photoshoot, we’ll offer you a range of ways you can take action.

If you have any questions or would like more information about Breast Cancer Voices, we’d love to hear from you. Contact us at voices@breastcancercare.org.uk

Volunteering

The work that we do would not be possible without our volunteers.

We're always looking for motivated people who want to get involved and make a difference. From helping to deliver support services, to supporting our sporting and challenge events so they run smoothly, there are lots of ways you can help. Some people like to stay behind the scenes: we also welcome people to help in our offices, and even have some really easy tasks you can do from your own home.

Whether you have a few hours to spare every week or would like to spend a day helping at a special event near you, do something amazing and make today the day you volunteer.

See more at www.breastcancercare.org.uk/get-involved or call us on 0114 263 6120 for more information and an application pack.
Find out more

Breast Cancer Care publications
To order any of Breast Cancer Care’s publications, tick the boxes below next to the titles you want and send this page to the address overleaf.

Alternatively, all our publications are free to order or download from our website [www.breastcancercare.org.uk/publications](http://www.breastcancercare.org.uk/publications), or call our Helpline on [0808 800 6000](tel:08088006000)

Managing the effects of treatment
- Breast cancer and hair loss BCC54
- Fertility and breast cancer treatment BCC28
- Living with lymphoedema after breast cancer BCC5
- Menopausal symptoms and breast cancer BCC18
- Osteoporosis and breast cancer treatment BCC75
- Reducing the risk of lymphoedema BCC15
- Younger women with breast cancer BCC66

Signs and symptoms of the cancer coming back (recurrence)
- Breast cancer in families BCC32
- After breast cancer treatment: what now? BCC169

You and your relationships
- Breast prostheses, bras and clothes after surgery BCC123
- In it together: for partners of people with breast cancer BCC120
- Your body, intimacy and sex BCC110
- Talking with your children about breast cancer BCC50

Your wellbeing
- Complementary therapies BCC55
- Diet and breast cancer BCC98
Call our Helpline on 0808 800 6000

Name: 

Address: 

Postcode: 

We will not pass on your details to any other organisation or third party.

Please send to: Breast Cancer Care, PO Box 33, Ross-on-Wye HR9 9WA

Keep in touch

We’d like to keep in touch with you by sharing information and keeping you up to date about our services.

Vita magazine

Our free quarterly lifestyle magazine and website for people affected by breast cancer is full of real-life stories, health and wellbeing features, hot topics and recipes.

Subscribe to Vita magazine at vita.org.uk

Facebook and Twitter

Like us on Facebook www.facebook.com/breastcancercare or follow us on Twitter @BCCare for the latest news and campaigning and volunteering activity.
We’re here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate by post
Please accept my donation of £10/£20/my own choice of £
I enclose a cheque/PO/CAF voucher made payable to Breast Cancer Care

Donate online
You can give using a debit or credit card at www.breastcancercare.org.uk/donate

My details
Name ________________________________
Address ________________________________
__________________________________________________________________________
__________________________________________________________________________
Postcode ______________ Email address ________________________________

We might occasionally want to send you more information about our services and activities

☐ Please tick if you’re happy to receive email from us
☐ Please tick if you don’t want to receive post from us

We won’t pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, 5–13 Great Suffolk Street, London SE1 0NS
About this booklet

Moving forward resource pack was written by Breast Cancer Care’s clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.

For a full list of the sources we used to research it:

Phone 0345 092 0808
Email publications@breastcancercare.org.uk

You can order or download more copies from www.breastcancercare.org.uk/publications

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Phone 0345 092 0808
Email publications@breastcancercare.org.uk

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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone’s experience is different.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk

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