

Open Access Follow-up (OAFU) for Breast Cancer

Information for patients

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Cancer Care Line Telephone Number: 01227 86 86 66

Important Notice

If there is any change of your address, telephone number, or GP, please tell us on the above contact telephone number as well as telling your GP

What is this booklet about?

This booklet has been written to give you information about our Open Access Follow-Up programme for breast cancer patients. It tells you how your follow-up will be organised, has information on recovery and possible side effects of breast cancer treatment, how you can look after yourself in the future, and what symptoms you should report to the Breast Care Team.

It is a reminder of your conversation with the Breast Clinical Nurse Specialist (CNS) and a way of showing you where more help is available. More detailed information about all these subjects is available through Macmillan or Breast Cancer Now (the breast cancer support charity).



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What is Open Access Follow-Up (OAFU)?

Open Access Follow-Up (OAFU) is a new type of follow-up. It is where routine, clinical examination type appointments are replaced by a system where patients can call us when they have a problem; they do not have to come to hospital at times when they are feeling well and are symptom free.

In the past, patients who had completed their treatment for early breast cancer were seen for follow-up by their consultant team in the hospital. Although some patients found these appointments useful and reassuring, many patients found coming to the hospital a source of great anxiety and not particularly helpful. There is also good evidence to show that following up patients in this way does not prevent cancer returning and does not increase the life expectancy of patients.

With Open Access your care will remain the same. You will remain under the care of the hospital for at least five years after your treatment has stopped, and continue to have mammograms every year, for at least five years (see page 10). The difference will be that you no longer have to come into hospital for your breast clinic appointments if you are well, your mammograms do not show any problems, and you are free of symptoms.

Many hospitals across the country have changed the way patients are followed up after breast cancer treatment. We are moving away from a 'one size fits all' approach towards recognising that you can manage your own health.

What happens next?

Once you have received this booklet, you will no longer be given routine follow-up clinic appointments. This means you do not have to come to a clinic appointment if you are well, your mammograms do not show any problems, and you do not have any symptoms. You are in control.

Routine appointments with a doctor are replaced by a system where you can call us if you have a concern. You can then be seen in the clinic, if necessary. After five years (if you are age 50 or older), you will be discharged back to your GP and continue to have regular mammograms through the National Breast Screening Programme. From this point on, if you have any concerns or notice anything unusual, you will need to go back to see your GP.

Your GP will have received a letter and information about your follow-up plan. Your GP will still be responsible for your general health and can give you advice and support, as well as continuing to support your family and carers.

When should I be seen in the Breast Clinic and how do I arrange an appointment?

- You may be asked to attend the breast clinic if your follow-up mammogram shows any changes which need further investigation. Should there be a need for you to attend the breast clinic for further tests, your Breast Care Team will contact you to let you know.
- You should arrange a review with a member of the Breast Care Team if you have concerns about any of the following issues:
 - possible side effects from your chemotherapy or radiotherapy treatment
 - your on-going hormonal treatment
 - new changes in your breasts, chest wall regions, neck, or under your arm
 - new medical symptoms that you are worried could mean a spread of your breast cancer.

To arrange a review, please contact your Breast Care Team on the Cancer Care Line 01227 86 86 66. A Breast Care Nurse Specialist will contact you within two working days to discuss your concern and, if necessary, arrange a clinic appointment with your consultant. We will aim to see you within two weeks of your telephone call.

Cancer Care Line Telephone Number: 01227 86 86 66

Recovery and possible side effects of breast cancer treatment

Recovering from breast surgery

- **Is it normal to still get aches and pains in my breast or chest several months after my surgery?**

Many patients continue to get aches and pains in their breast or underarm area for many months after their surgery. These can be made worse by radiotherapy and can continue for a year or more. If, however, you develop a new pain that gets worse over two to three weeks then contact the Breast Care Team to arrange a review.

- **Why do I have a strange sensation on the inside of my arm?**

This is usually due to surgery interfering with the nerves in the under arm area, resulting in a changed sensation (often numbness) affecting the underside of your upper arm. It can be either temporary or permanent.

- **My scar feels hard and lumpy. Is this normal?**

Yes, after any operation, the scar may feel hard and lumpy due to the healing process and scar tissue forming. If this happens, gently massaging your scar with a moisturising cream can help to break down the hardened area and even out the scar line (use whichever moisturising cream you usually use). Any new lump in or around your scar should be checked by your surgeon.

- **What is this tight 'pulling' sensation stretching down my arm?**

This is known as 'cording' and it is a common problem after an operation. It is thought to be caused when the lymph vessels harden and tighten due to the surgery (particularly surgery to the arm pit). This side effect can either settle by itself or be encouraged to 'ease' by massaging and stretching the affected area.

- **Can I wear deodorant?**

Yes, there are no proven studies to suggest otherwise.

- **My arm is swollen, is this normal?**

Some patients, who have had surgery to remove lymph nodes from their arm pit (axillary node clearance), develop a swelling of this arm in the weeks or months following their surgery. This is known as lymphoedema (see page 9) and is due to disruption of the normal channels that the lymph fluid flows through away from the arm. If your arm swells up many months or even years after your original surgery, you should contact the Breast Care Team to arrange a review by your consultant.

Recovering from breast surgery free resources

- Your operation and recovery booklet
- Exercises after breast surgery booklet

Booklets available to order or download from the Breast Cancer Now web site [breastcancernow.org/information-support/publications/download-order](https://www.breastcancernow.org/information-support/publications/download-order) or ask your Breast Care Nurse for a copy.

Recovering from chemotherapy

- **How long will I feel tired for?**

Almost all patients feel very tired by the end of their chemotherapy. This can get worse if they are receiving radiotherapy. Your tiredness should have started to improve one to two months after your last cycle of chemotherapy and then steadily improve. However, it can take at least six months before your energy levels return to normal. Some patients still feel tired 12 to 18 months after the end of their treatment.

- **When will my hair grow back and when can I dye it?**

Most patients find that their hair starts to grow back three to four weeks after their last chemotherapy session. Hair grows slowly to begin with and can be quite thin and 'fluffy', but over time the hair thickens up and after six months most patients will have a good head of hair again.

As your new hair will be rather delicate, it is recommended you wait six months before using chemicals, permanent, or semi-permanent dyes on your hair. However, it is safe for you to use herbal or non-permanent dyes while you are waiting.

- **Why have I put on weight?**

It is quite common for patients who have had chemotherapy for breast cancer to gain some weight during their treatment. The chemotherapy drugs themselves do not cause weight gain but the steroid tablets that are used as anti-sickness tablets can increase your appetite. Many patients also find that their diet changes whilst they are having chemotherapy and that they do less exercise than usual because of the tiredness chemotherapy can cause.

- **When will I recover feeling in my fingers or toes?**

If you have developed pins and needles or numbness of your fingers or toes during your chemotherapy treatment, this should gradually improve in the weeks and months after the end of your treatment. However, you may find that to start with it gets worse after your last treatment before it starts to get better. A small number of patients may find that feeling in their fingers or toes remains permanently changed.

- **Are there any long term side effects of chemotherapy?**

There is a very low risk that one of the commonly used chemotherapy drugs can affect the heart muscle. Please discuss this with your oncology consultant if you have any concerns. There is also a very low risk that a patient's treatment with chemotherapy for early breast cancer can develop a different, unrelated cancer years later.

Recovering from chemotherapy free resources

- Chemotherapy for Breast Cancer booklet
- Breast cancer and hair loss booklet

Booklets available to order or download from the Breast Cancer Now web site [breastcancernow.org/information-support/publications/download-order](https://www.breastcancernow.org/information-support/publications/download-order) or ask your Breast Care Nurse for a copy.

Recovering from radiotherapy

- **How long will radiotherapy side effects last for?**

Radiotherapy causes side effects which happen during treatment and tend to peak at the end or up to two weeks after finishing treatment. Most skin reactions resolve and completely heal by four to six weeks after radiotherapy.

Up to half of patients treated may experience rib tenderness or shooting pains in their breast. These generally settle within a few months of radiotherapy treatment but they can appear again every now and again over the long term.

Many patients feel tired both during and after radiotherapy. This is usually worse if you also had chemotherapy. Tiredness tends to improve about six weeks after completing radiotherapy but patients can often take several months to recover.

- **When can I go out in the sun?**

Take sensible precautions in the sun and avoid getting sunburnt. The treated area may be more sensitive and should be covered. High factor suncream should be used (at least factor 20).

- **Will I get any long term side effects from my radiotherapy?**

Long term effects are rare but can happen in a small percentage of people. There may be a change in the appearance of your skin, with the skin within the treatment area being darker and firmer to the touch, and your breast may be smaller in size.

After a mastectomy, the chest wall can feel tight and there may be permanent skin changes, if there was a severe skin reaction.

People who have had breast reconstruction with implants may experience contraction of the capsule around their implant. Occasionally, it is necessary to remove or exchange the implant.

There is a slightly increased risk of rib fracture in the treated area and a small risk of heart damage after treatment to the left side. Occasionally, radiotherapy can cause inflammation of a small area of lung tissue. There is also a very small risk of a second cancer developing in the treated area as a result of radiotherapy.

Recovering from radiotherapy free resources

- Radiotherapy for Primary Breast Cancer booklet

Booklets available to order or download from the Breast Cancer Now web site [breastcancernow.org/information-support/publications/download-order](https://www.breastcancernow.org/information-support/publications/download-order) or ask your Breast Care Nurse for a copy.

Hormonal therapy

- **Why do I take hormone tablets?**

If your breast cancer was sensitive to the hormones oestrogen and/or progesterone, you will have probably started a course of anti-hormonal treatment. Taking anti-hormone therapy, for a hormone-sensitive breast cancer, will significantly reduce the risk of your cancer returning, in addition to the other treatments you have already had. These are usually taken for five to 10 years. Towards the end of your OAFU, your Breast Care Team will discuss the risks and benefits of continuing your tablets or changing to a different one. You and your GP will be told if you are to continue any anti-hormone therapy and for how long.

You do not have to pay for hormone tablets as you are entitled to free prescriptions. If you do not already have a medical exemption certificate, ask your GP or speak to your Breast Care Team.

There are two main types of anti-hormone therapy:

1. Tamoxifen is an anti-oestrogen and it acts by blocking oestrogen receptors on tumour cells. Tamoxifen is prescribed for pre-menopausal women and some post-menopausal women. Most male breast cancers are hormone-dependent, so oestrogen-blocking treatments including Tamoxifen are often used.

2. Anastrozole (Arimidex), **Letrozole** (Femara), and **Exemestane** (Aromasin) are all aromatase inhibitor drugs and work by switching off the enzyme that make oestrogen in the body. These drugs are only suitable for post-menopausal women.

- **What side effects may I experience?**

Not everyone will experience side effects from these tablets but all of them can sometimes cause menopausal-type symptoms such as hot flushes and night sweats. It is important not to stop your treatment without telling your GP or breast care nurse. If side effects cannot be controlled, there may be an alternative anti-hormone tablet you can try or your consultant oncologist can discuss with you the risks and benefits of stopping the treatment.

Tamoxifen is associated with a small risk of blood clots and can also rarely cause abnormal thickening of the lining of the womb, which can show itself as post-menopausal vaginal bleeding. You must tell your doctor if you experience any post-menopausal vaginal bleeding whilst on Tamoxifen.

Possible side effects for men taking Tamoxifen include headaches, nausea (feeling sick), hot flashes, skin rash, fatigue (feeling tired), sexual dysfunction, and weight and mood changes.

Anastrozole, Letrozole, and Exemestane can cause aching and stiffness of the joints and are also associated with thinning of the bone (osteoporosis). Your bones will be monitored for signs of this with a baseline bone density scan (see page 11).

If your periods stop as a result of taking anti-hormone therapy, please let us know by contacting the Cancer Care Line to speak to your breast care nurse. You may be advised to change to a different anti-hormone tablet.

- **Are menopausal symptoms normal?**

Yes. Many women who receive treatment for breast cancer develop menopausal symptoms. These can be due to the effect of chemotherapy or hormone therapies on your own hormone levels, or simply due to stopping your usual hormone replacement therapy. Hot flushes and night sweats are the most common menopausal symptoms, but many women also notice weight changes, vaginal dryness, changes in libido,(sex drive), and mood swings.

- **Can I use hormone replacement therapy?**

Hormone replacement therapy (HRT) is not recommended for women who have been treated for breast cancer as it may increase your risk of the disease returning (particularly if your breast tumour was sensitive to oestrogen), or increase your risk of developing a second breast cancer. However, very occasionally women who are at very low risk of cancer returning and are experiencing severe menopausal symptoms that are affecting their quality of life, may decide that the benefits of HRT outweigh the risks. This is a decision that should always be made after a discussion with your consultant surgeon or consultant oncologist.

If you are suffering from vaginal dryness, vaginal lubricants such as Replens MD or KY-Jelly can be helpful. If these do not solve this problem then a topical oestrogen cream may be helpful. This should be discussed with your consultant, GP, or breast care nurse.

- **Can I take herbal therapies to help?**

Some 'natural' remedies, such as Black Cohosh and Red Clover, are advertised as relief for menopausal type symptoms. However, these contain plant oestrogens (phyto-oestrogens) and are not recommended for use by patients who have had breast cancer. Evening Primrose Oil is safe to use and some patients do report that it is helpful for menopausal symptoms, although, there is no scientific evidence to prove this. There is no good evidence for the use of vitamin E for hot flushes and vitamin E supplements may be harmful, especially for people with heart disease.

- **What else can I do?**

Tell your breast care nurse or GP if your menopausal symptoms are troubling you. Several prescription drugs can help with reducing hot flushes and your doctor will be able to discuss the potential benefits and side effects of these medications with you. Alternatively, some patients find relaxation based complementary therapies such as acupuncture, hypnotherapy, massage, or aromatherapy helpful for their symptoms.

Hormonal therapy free resources

- Tamoxifen booklet
- Anastrole (Arimidex) booklet
- Letrozole (Femara) booklet
- Exemestane (Aromasin) booklet
- Menopausal Symptoms and Breast Cancer Treatment booklet

Booklets available to order or download from the Breast Cancer Now web site breastcancernow.org/information-support/publications/download-order or ask your Breast Care Nurse for a copy.

Lymphoedema

Lymphoedema is swelling caused by a build-up of fluid in the body's tissue. The swelling usually affects the arm and can affect the hand, fingers, breast, chest, shoulders, or the area of the back behind the armpit. It can occur as a result of damage to the lymphatic system, usually as a result of treatments such as surgery or radiotherapy to the lymph nodes in the armpit. Lymphoedema only affects the side of the body that was treated.

Who is at risk?

You may be at risk of lymphoedema if you:

- have had surgery to your lymph nodes, with a greater risk if you have also had radiotherapy to your lymph nodes
- are overweight
- have limited movement in your arm; or
- have had cellulitis (a sudden infection of the skin and the tissue underneath it).

Most people who have had lymph nodes under their arm removed do not develop lymphoedema. However, it is important to be aware of the risk and quickly deal with any swelling that develops.

What are the symptoms of lymphoedema?

- Swelling, mainly in the arm but sometimes in the hand, fingers, breast, chest, shoulders, or back.
- Tightness in the above mentioned areas of the body
- Discomfort, dull aches, heaviness, and tingling and/or numbness in the above mentioned areas of the body.
- Dry skin in the above mentioned areas of the body.
- Arm stiffness/limited movement.

What can I do to reduce my risk of lymphoedema?

- Maintain a healthy body weight.
- Use your 'at risk' arm sensibly and exercise regularly. Refer to the Breast Cancer Now leaflet **Exercises after breast cancer surgery**. Check with your GP or breast care nurse before starting or returning to other forms of exercise.
- Reduce your risk of infection by providing as much protection as possible to your skin on the above mentioned areas of your body. If you notice any signs of infection (redness, heat, swelling, tenderness/pain) speak to your GP or breast care nurse as soon as possible as you may need antibiotic treatment.
- Try to avoid having blood tests, blood pressure readings, and intravenous fluids in the arm on the treated side of your body; although, there is no strong evidence this will cause lymphoedema.
- Take care when travelling. During long flights or car journeys try gentle arm/shoulder exercises such as clenching/unclenching your fist and shrugging your shoulders. Use insect repellent, carry antiseptic cream, and possibly ask your GP for a course of antibiotics in case you need them.

If you notice swelling that is not going away, please contact your breast care nurse via the Cancer Care Line. Most people with lymphoedema have mild to moderate symptoms which can be managed with help and advice from your breast care nurse. If your lymphoedema is severe, you can be referred to a specialist lymphoedema service.

Early diagnosis of lymphoedema makes it easier to treat and it can often be controlled and relieved.

Lymphoedema free resources

- Reducing the risk of lymphoedema booklet
- Living with lymphoedema after breast cancer booklet
- Exercises after breast cancer surgery leaflet

Booklets available to order or download from the Breast Cancer Now web site breastcancernow.org/information-support/publications/download-order or ask your Breast Care Nurse for a copy.

Cancer Care Line Telephone Number: 01227 86 86 66

What happens in the future with my mammograms?

All patients who have had breast cancer have regular follow-up mammograms. This is because a small number of people will develop a new cancer in the other breast or another cancer in the same breast (recurrence).

If you had a **lumpectomy (wide local excision)** to remove your breast cancer, you will be invited for a mammogram every year for five years after surgery.

If you have had a **mastectomy** to remove your breast cancer (with or without reconstruction) we will only do a mammogram on the remaining breast.

If you receive an invitation to attend for a National Breast Screening Programme mammogram during this time, please cancel this appointment by contacting the East Kent Breast Screening Unit directly on 01227 78 30 00 and let them know you are having follow-up after breast cancer.

This section is for women only:

- If you are under 50 in five years' time, you will continue to have mammograms every year, under our care, until you reach 50. Then you will be discharged to your GP and transferred to the NHS Breast Screening Programme for three yearly mammograms.
- If you are 50 or over in five years' time, we will discharge you to your GP and we will encourage you to continue regular mammograms through the NHS Breast Screening Programme. You will be invited automatically every three years but can request more regular mammograms by contacting the East Kent Breast Screening Unit directly on 01227 78 30 00.
- If you have been assessed as being at increased risk because of family history or genetic testing, you may need to have yearly mammograms for longer. Your Breast Family History Nurse will discuss this with you.

How do I get my mammogram results?

After your mammogram, you should receive your result by letter within two weeks. We will also let your GP know the result. The letter will tell you when your next mammogram is due. Once you have completed at least five years (or longer dependant on your age), you will receive your last mammogram result letter telling you that you are being discharged from our care. If you have not received your mammogram result letter within four weeks, please contact the Cancer Care Line on 01227 86 86 66.

Sometimes, after having treatment for breast cancer, we can see changes on your mammogram. If this happens we will send you a letter asking you to come back for further tests.

What happens if I am asked to come in for further tests?

If you receive a letter asking you to come to hospital for further tests, it is because we need more detailed information.

Changes on your mammogram can be caused by a number of things, including treatments such as surgery or radiotherapy. Not everyone needing further tests has a recurrence of their breast cancer, but further tests may be needed to rule this out or to see if you have a different breast problem.

The further tests might include more mammograms, an ultrasound, and maybe a biopsy. If a biopsy is needed, the results can take up to two weeks to come back. We will arrange your follow-up once your further test results are available.

What are DEXA scans? and, why do I need one?

If you are having anti-hormone treatments, such as Anastrozole, Letrozole, or Exemestane, you may have had or will need to have checks of your bone density (a DEXA scan). These may also be recommended if your periods stopped early because of your treatment. Your breast consultant surgeon, consultant oncologist, or breast care nurse will have told you if these are needed.

DEXA scans tell us if you have or are developing bone thinning which could lead to a condition called osteoporosis. This can increase the risk of you having a broken bone (fracture) with only minor injuries or falls.

Once you have had your first DEXA scan, your breast consultant will write to your GP with the result, you will also receive a copy of the letter. If your scan shows evidence of osteoporosis, your GP will be advised to prescribe you with some bone supplement medication and a repeat DEXA scan will be arranged for you in two years' time.

Lifestyle changes, particularly exercise and diet, can help reduce your risk of osteoporosis. Your breast care nurse or GP can give you information and advice about what you can do to keep your bones healthy.

DEXA scans and bone health free resources

- Osteoporosis and Breast Cancer Treatment booklet

Booklets available to order or download from the Breast Cancer Now web site breastcancernow.org/information-support/publications/download-order or ask your Breast Care Nurse for a copy.

Concerns about cancer returning, staying breast aware, and general health awareness

Am I cured and what are the chances of my cancer returning?

You will find that most doctors do not use the term cured, as this implies that they can give you a 100% guarantee that your breast cancer will never return. Unfortunately, we can never make this promise to any patient. The risk that your breast cancer will come back is different for every patient. However, by having the treatment recommended by your surgeon and oncologist you have minimised your personal risk of having any further problems from breast cancer, as much as possible. It is entirely natural to feel anxious that your breast cancer may return and we recognise that this can make you feel very uncertain about your future and lead to difficulties in getting on with life. Some people find it useful to have some additional support in dealing with these feelings and might benefit from counselling.

How do I stay breast aware?

Although mammograms are a good screening test, they will not find all breast cancers. Being breast aware is an important part of caring for yourself.

You should examine your treated breast or scar line after a mastectomy, as well as your untreated breast. If you have had a reconstruction, you should still examine your skin and scar line. Your treated breast or chest wall will have changed and may change more as your body heals. For example, it is common to feel tenderness and a burning or numbness in the scar area and under your arm. You may also have a lumpy scar.

We recommend that you examine your breasts once a month. Try to get used to the shape, texture, and feel of your breast or chest wall so you know what is normal for you. You will then feel more confident about noticing any changes.

What changes should I call the Breast Care Team about?

- A lump, thickening, or swelling in your breast or skin after a mastectomy.
- A lump, thickening, or swelling above your collarbone, in your neck area, or in your armpit.
- A change in how your skin/nipple feels, a dimple, puckering or pulling, areas of redness, or spots near your scar line.
- Discharge coming from your nipple or a rash around your nipple.
- A change in the size or shape of your breast that is not related to a change in your weight.

There is no right or wrong way to examine yourself. Get used to looking at and feeling your breasts, chest, and armpits regularly; perhaps in the bath or shower, or when you apply moisturiser. Your breast care nurse can give you a leaflet and advice about how to examine yourself.

If you have any concerns or worries about your breasts you can call the Cancer Care line on 01227 86 86 66. The nurse may be able to reassure you but will advise you if you need to see your GP or attend the clinic. If you are advised to attend the Breast Clinic for a clinic review, you do not need a new referral from your GP. We will arrange the appointment for you within two weeks.

Staying breast aware free resources

- Know your breasts and Quick guide leaflet
- Touch, Look, Check leaflet

Booklets available to order or download from the Breast Cancer Now web site breastcancernow.org/information-support/publications/download-order or ask your Breast Care Nurse for a copy.

General health awareness and symptoms to report

Everyone will experience other health problems from time to time, such as coughs, back ache, or stomach upsets. But when you have had breast cancer, it is common to worry that a health problem is linked to your breast cancer or that the cancer has come back.

Although we have listed some of the things that can be caused by breast cancer returning somewhere else in the body, these symptoms are very general. All of them can be due to other health conditions and some can be normal after cancer treatment, for instance, tiredness or lack of appetite.

It is also possible that symptoms are a side effect of treatment. Some side effects of treatment will go away at the end of treatment but others can take longer to improve.

It takes time to get used to what is normal for you. If you notice something new, that is not going away and you cannot explain, it is important to contact either your GP or your Breast Care Team for advice.

New, persistent symptoms to report might include:

- Weight loss or a loss of appetite
- Pain in your bones, for instance hips, back, or ribs
- Feeling sick
- Pain or swelling under your ribs or in the upper tummy area
- Tiredness
- Pins and needles, weakness or numbness in your arms or legs
- Severe headaches
- Swelling in your hand or arm on the treated side
- Dry cough or breathlessness.

Although it is important to be aware of health changes, it is not helpful if you are constantly worried or anxious about your health. If you find that you are constantly checking yourself for symptoms or feeling very anxious, please speak to your GP or contact your Breast Care Team, as more support is available.

Getting back to normal

• **Feelings and emotions after treatment**

Everyone has different feelings when they finish treatment. Some people are relieved that they can get back to normal, others are worried about what might happen in the future. You may feel isolated because you have had much less contact with the hospital or be relieved that your treatment is finished.

It is normal to feel upset or angry that your body has changed. You may find that your confidence is affected. It is also normal to feel low, or anxious, and uncertain sometimes, or to worry about the cancer coming back.

Your experience may change the way you see life, how you think about things, and it may change your priorities. You may find new interests or want to make changes to improve your health. The way you feel about cancer and how it has affected you will change over time. The concerns you have now will be different in a few years.

If you start to feel that your mood is interfering with your life, that you are finding it difficult to adjust to the changes, or you are finding it difficult to cope, please contact your GP or the Cancer Care Line for advice about more support.

There is no right or wrong way of living with and beyond breast cancer. Some people prefer not to talk, while others like to get support from talking about their experience. There is a range of support available including talking therapies, support groups, treatments, or complimentary therapies such as stress reduction or mindfulness. There is also support online from website forums and apps you can download. Please ask your breast care nurse for the leaflet **Further help and support for breast cancer patients**.

- **Managing changes in breast shape or size**

Changes in the shape or size of your breast can happen as a result of surgery or sometimes after radiotherapy.

If you feel your breasts are unequal in shape or size (asymmetry) you might want to consider a bra insert (prosthesis) or further surgery to correct the appearance of your breast. You can get advice about your choices by contacting your breast care nurse through the Cancer Care Line or book an appointment to be fitted for a breast prosthesis. Please ask your breast care nurse for the leaflet **Further help and support for breast cancer patients**.

- **Breast reconstruction**

If you have had a mastectomy and decided against reconstruction, you might want to think about it again at a later time. Dependant on your treatment, you may need to wait a while before being considered for breast reconstruction surgery. If you would like to discuss breast reconstruction in the future, please contact your breast care nurse through the Cancer Care Line 01227 86 86 66.

- **Returning to work**

If you work and have not yet returned, you can do whenever you feel ready to. When you do return, remember that it may be a big shock to the system to begin with. It may be useful to return to work in a 'phased' manner, increasing your working hours over a few weeks. Returning to work may give you a sense of normality and routine. You may also have friends and a social life through work which are important to you. Some people may find that returning to work is not for them or they may wish to try something different.

- **Can I travel abroad?**

Once you have completed your hospital-based treatment, there is no reason for you not to travel abroad. Sometimes patients have difficulties getting travel insurance if they have been treated for breast cancer but there are insurers who specialise in the cover of patients who have had cancer.

- **Should I exercise?**

Most patients feel tired for a number of weeks or months after they have had treatment for breast cancer. We recommend that once you have completed your treatment, you try to gradually increase your daily activity with the aim of trying to build up to at least three 20 minute sessions of moderate activity each week, such as a brisk walk.

- **What diet should I follow?**

Enjoying a healthy diet, avoiding putting on too much weight, and doing a moderate level physical activity is important if you have had breast cancer. There are conflicting theories about diet and cancer, which can be confusing. Most experts would agree that healthy eating means eating a balanced, varied diet that provides all the nutrients you need.

Evidence suggests that keeping a healthy weight, as well as keeping up a moderate level of physical activity can improve breast cancer survival and overall survival. This advice is also suitable for people who do not have cancer and can be followed by members of your family. It may reduce the chances of getting heart disease and diabetes as well as certain types of cancer.

- **Can I drink alcohol?**

There is no need to avoid alcohol completely. However, a number of research studies have shown that drinking a lot of alcohol may be linked with a slight increase in the risk of breast cancer. We would always advise that you should not drink in excess of the Department of Health's recommendations (no more than two to three units of alcohol per day, where a unit of alcohol equals a small glass of wine).

- **What about sex?**

Cancer has many effects and your treatment may have affected your physical ability to give and receive sexual pleasure. It may have changed how you feel about your body and you might find it difficult to talk to your partner about this. Your partner may also have concerns but talking to each other may help with this. Making love might not be the same as it was before your diagnosis and you may have to find ways of adapting to the changes. It can help to take things slowly at first. Some practical ways to help might include trying different positions and using vaginal lubricants if dryness is a problem. Your breast care nurse will be happy to discuss any of these issues with you.

- **What should I do about contraception?**

We recommend that you avoid pregnancy for at least two years after chemotherapy ends and for the whole time you are being treated with hormonal therapies. Women who have been treated for breast cancer should not use oral contraceptive pills (the combined pill or mini pill) or hormonal implants. Your GP will be able to advise you about suitable contraceptive methods which include barrier contraceptives (such as condoms and the cap) and intra-uterine devices (the coil).

Free resources from Breast Cancer Now (BCN) and Macmillan Cancer Support (MCS)

- After breast cancer treatment, what now? booklet (BCN)
- Breast prostheses, bras and clothing after breast cancer surgery booklet (BCN)
- Breast reconstruction booklet (BCN)
- Work and cancer booklet (MCS)
- Travel and cancer booklet (MCS)
- Have safe sex booklet (MCS)
- Exercises after breast surgery leaflet (BCN)
- Stay healthy: exercise booklet (MCS)
- Diet and breast cancer booklet (BCN)
- Eat a healthy diet booklet (MCS)
- Drink less alcohol booklet (MCS)
- Your body, intimacy and sex booklet (BCN)

Booklets available to order or download from either the Breast Cancer Now web site [breastcancernow.org/information-support/publications/download-order](https://www.breastcancernow.org/information-support/publications/download-order), the 'Information' tab at [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or ask your Breast Care Nurse for a copy.

Complimentary therapies

Some people like to use complimentary therapies alongside their medical treatment. Common ones include herb and vitamin supplements, acupuncture, aromatherapy, reflexology, or massage. If you are thinking about using something like this, please check with your breast care nurse to make sure it will not have an effect on any ongoing treatments you are having. Your Breast Care Team can refer you to The Harmony Trust, a charitable organisation who can offer free complimentary and supportive therapy sessions to cancer patients. Examples are aromatherapy, massage, Reiki, and reflexology.

- **The Harmony Trust**

Web: theharmonytherapytrust.org.uk

Telephone: 01795 66 30 50

Email: ttht2010@gmail.com

Health and wellbeing

Many people ask if there is something they can do to keep healthy and reduce the chance of their cancer returning. It is also common to look for ways to cope and adjust after treatment. The most important things you can do are to keep a healthy weight, be active, eat healthily, cut down on alcohol, and stop smoking.

Many areas hold events delivering information about having a healthy lifestyle. These events also include information about ways to keep well emotionally, complimentary therapies, and local resources of support. For further information on events that may be suitable for you, please visit macmillan.org.uk

Patient feedback suggests that the Breast Cancer Now Moving Forward events (see below) are invaluable, particularly if you are struggling to get back to 'normal' after treatment for breast cancer.

Breast Cancer Now 'Moving Forward Course'

The Breast Cancer Now charity offer free Moving Forward events to patients who have completed any hospital based treatment for their breast cancer (surgery, chemotherapy, and/or radiotherapy).

Adapting to life after treatment can often be difficult and you might need some support. Whether you are experiencing side effects of treatment, wondering how to adopt a healthier lifestyle, or finding it hard to make sense of your breast cancer experience, the Breast Cancer Now award-winning Moving Forward courses are here for you.

These courses are run in partnership with NHS Hospitals. The course usually takes place over half a day for three or four weeks. They are delivered by a range of expert speakers and aim to provide information, support, and professional guidance on how to cope with and adjust to life after breast cancer treatment. Topics covered may include: healthy eating, exercise, managing menopausal symptoms, lymphoedema, cancer fatigue, and intimacy and relationship issues.

The course is open to people who have had a primary breast cancer diagnosis and have finished their hospital based treatment. We ask that you are free to attend every week of the course.

If you wish to attend, please speak to your breast care nurse/breast support worker who can refer you. Or for further information contact 0345 077 18 93 or visit breastcancernow.org/information-support/support-you/moving-forward

Free resources

- Complimentary Therapies, Relaxation and Wellbeing booklet
- Moving Forward, for people living with and beyond breast cancer booklet

Booklets available to order or download from the Breast Cancer Now web site breastcancernow.org/information-support/publications/download-order or ask your Breast Care Nurse for a copy.

Cancer Care Line Telephone Number: 01227 86 86 66

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation