



**East Kent
Hospitals University
NHS Foundation Trust**

Your breast cancer follow-up and support

Information for patients from the Breast Cancer Care team

Important notice: if there is any change to your address, telephone number, or GP, please contact us to let us know. Also, let your GP know.

Contact details

- **Cancer Care Line** (for all breast cancer concerns and further / ongoing support)
Telephone: 01227 868666
- **Breast Cancer Open Access Follow-up (OAFU)** (for patients on Open Access Follow-up)
Helpline: 01233 616632

East Kent Hospitals' Breast Cancer Care Follow-up and Support team

- Breast Clinical Nurse Specialists
- Breast Support Workers

What is this booklet about?

This booklet has been written to give you information about your annual follow-up with your consultant team. It includes the following advice and support.

- How your follow-up will be organized, including details of your annual check-ups for a total of at least 5 years.
- Information on your recovery.
- The possible side effects of breast cancer treatment.
- How you can look after yourself in the future.

- What symptoms you should report to the Breast Care Team.
- Resources showing you where more help is available.

More detailed information about all these subjects is also available online through Macmillan (<https://www.macmillan.org.uk/>) or Breast Cancer Now (<https://breastcancernow.org/>) (the breast cancer support charity).

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What happens next?

Once you have completed most, if not all, of your active (hospital-based) treatment, you should have:

- a copy of this booklet; and
- an appointment for a post-active treatment review with our Breast Cancer Care team. This appointment may be face-to-face or over the telephone.

At this appointment, you will be provided with the following.

- Confirmation of your follow-up pathway, including any appointments / surveillance breast imaging. See next section for further information about your follow-up.
- How you will get surveillance breast imaging results.
- How to manage the side effects of your treatment.
- Health and wellbeing information.
- Further supportive information, including details of Breast Cancer Now's Moving Forward Courses.
- When and how to contact the Breast Cancer Care Team.

Your GP will still be responsible for your general health. They can give you advice and support, as well as continuing to support your family and carers.

Your follow-up

After completing any active (hospital-based) treatment, you will continue follow-up / surveillance for a total of at least 5 years. This will be under your breast surgeon / Breast Cancer Care team.

How you are followed-up after treatment finishes, depends on your individual needs. You may have regular appointments, but you will usually be offered annual surveillance breast imaging. This will depend on the type of surgery you have had.

Follow-up without clinic appointments, known as Open Access Follow-up (OAFU)

Patients may not be offered annual face-to-face breast surgical follow-up clinic appointments after active (hospital-based) treatment ends. This is known as Open Access Follow-Up (OAFU).

OAFU is where annual face-to-face follow-up appointments are replaced by a system where you can **contact us via our Breast Cancer Open Access Follow-up Helpline 01233 616632 if there is a concern**. You do not have to come to hospital at times when you are feeling well and are symptom free. However, you will still be invited for annual surveillance imaging (mammograms) for at least 5 years under our care. Please see the **What happens in the future with my surveillance breast imaging (mammograms)?** section later on in this booklet.

If you do have a concern, a breast care nurse specialist will arrange a face-to-face breast clinic appointment. You will be booked for a physical examination within 2 to 3 weeks. The examination will include examining your breast(s) or chest area, as well as any other area(s) of concern. If there are any concerns, imaging may be arranged for sooner than your planned surveillance mammogram.

If your clinical examination and imaging are normal, you will likely remain on OAFU.

If there are any other concerns, you may be referred to another healthcare professional.

Why has OAFU replaced routine face-to-face follow-up appointments?

In the past, patients who had completed their treatment were seen for follow-up by their breast consultant surgical 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 a face-to-face setting:

- does not prevent cancer returning; and
- does not increase the life expectancy of patients.

With OAFU, your care will remain the same. You will remain under the care of the hospital for at least 5 years after your breast surgery. You will continue to have mammograms every year, for a total of 5 years. If you are under 50 years of age after the 5 years, your annual mammograms will continue until you turn 50.

The difference will be that you will not have to come into hospital for breast clinic appointments if:

- you are well
- your annual mammogram does not show any problems; and
- you are free of symptoms.

If you have concerns at any time, please contact the Breast Cancer Open Access Follow-up Helpline 01233 616632.

Follow-up with planned clinic appointments / consultant-led follow-up

You may be offered planned breast clinic appointments with members of your breast surgeon's team. This depends on your individual needs.

- **What happens at planned follow-up appointments?**

If attending in person, you may have a physical examination. A physical examination will include examining your breast(s) or chest area, as well as any other area(s) of concern.

Any surveillance breast imaging will still take place annually. However, these will not happen at your follow-up appointment, as it will depend which month the mammogram is due. Should there be any clinical concerns, imaging may be arranged sooner.

If there are any other concerns, you may be referred to another healthcare professional.

If you have concerns at any time, please contact the Breast Cancer Care team via the Cancer Care Line 01227 868666.

- **Follow-up after clinical trials**

If you have taken part in a clinical trial during your treatment, your follow-up will depend on which trial you have been part of. Your research nurse will give you information on how you will be followed up.

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

- You may be asked to come to the Breast Clinic if your follow-up mammogram shows any changes which need further investigation. If you need to attend the Breast Clinic for further tests, your Breast Care team will contact you to let you know.
- Please 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 endocrine (anti-hormone) tablets.
 - New or persistent changes in your breasts, chest wall regions, neck, or under your arm. For further information, please go to the section below **Concerns about cancer returning: staying breast aware**.
 - New and persistent physical symptoms that you are worried could mean a spread of your breast cancer. For further information, please go to the section below **General health awareness and symptoms to report**.

To arrange a review, please contact a breast care nurse via the appropriate contact telephone number on the front of this booklet. If necessary, a breast care nurse specialist will arrange a clinic appointment with your consultant. We will aim to see you within 2 to 3 weeks of your telephone call.

- **Staying breast and body aware after a breast cancer diagnosis / treatment: free resources**

- Changes to be Aware of After Breast Cancer leaflet
- Know your breasts and Quick guide leaflet
- Touch, Look, Check leaflet

The above booklets are available to order or download from Breast Cancer Now.

(<https://breastcancernow.org/information-support/publications/download-order>) Or ask your breast care nurse for a copy.

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?**

Yes. 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. However, if you develop a new pain that gets worse over 2 to 3 weeks, 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 your under arm area. It can result 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 (<https://leaflets.ekhuft.nhs.uk/scar-massage/html/>) 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. It 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, contact the Breast Care team to arrange a review with your consultant.

- **Recovering from breast surgery: free resources**

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

The above resources are available to order or download from Breast Cancer Now. (<https://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?**

Most patients feel very tired by the end of their chemotherapy. This can get worse if you are receiving radiotherapy. Your tiredness should start to improve 1 to 2 months after your last cycle of chemotherapy, and then steadily improve. However, it can take at least 6 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 3 to 4 weeks after their last chemotherapy session. Hair grows slowly to begin with and can be quite thin and 'fluffy'. Over time hair thickens up, and after 6 months most patients will have a good head of hair again.

Your new hair will be rather delicate, so wait 6 months before using chemicals, or 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 their diet changes whilst they are having chemotherapy. They also do less exercise than usual, due to the tiredness caused by chemotherapy.

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

Some patients develop pins and needles or numbness in their fingers or toes during their chemotherapy treatment. If you have this, it should gradually improve in the weeks and months after your treatment has finished.

You may find that 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

The above booklets are available to order or download from Breast Cancer Now. (<https://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. The side effects tend to peak at the end or up to 2 weeks after finishing treatment.

- Most skin reactions resolve and completely heal 4 to 6 weeks after radiotherapy.
- Up to half of patients treated may have rib tenderness or shooting pains in their breast. These generally settle within a few months of radiotherapy treatment. However, 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 6 weeks after completing radiotherapy, but patients can often take several months to recover.

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

After breast cancer treatment, especially after radiotherapy, you must take sensible precautions in the sun. **Do not get sunburnt.**

Use a high SPF sunscreen all over. Make sure it offers broad-spectrum protection (both UVA and UVB). Reapply it regularly. Your treated area may be more sensitive, so please make sure this is covered with sunscreen.

A minimum SPF of 30 is recommended, but SPF 50 or higher is preferable for long-term sun exposure.

You should also consider using mineral sunscreens. These sunscreens provide a physical barrier against the sun's rays, and are often recommended for sensitive skin.

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

Long-term effects are rare, but can happen in a small number of people.

- There may be a change in the appearance of your skin. The skin within the treatment area may be darker and firmer to the touch. Your breast may be smaller in size.
- After a mastectomy, your chest wall can feel tight. If there was a severe skin reaction, you may have permanent skin changes.
- If you had breast reconstruction with implants, you may experience contraction of the capsule around your implant. Occasionally, we may need to remove or exchange the implant.
- There is a slightly increased risk of rib fracture in the treated area.
- There is 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

The above booklet is available to order or download from Breast Cancer Now. (<https://breastcancernow.org/information-support/publications/download-order>) Or ask your breast care nurse for a copy.

Immunotherapies (also known as targeted or biological therapies)

- **Why was I prescribed immunotherapy?**

Targeted therapies are a group of drugs that can block the growth of some breast cancers. The most widely used targeted therapies are for people with HER2 positive breast cancer. Only people whose cancer is HER2 positive will benefit from this type of treatment.

Targeted therapies for HER2 positive breast cancer include **Trastuzumab (Herceptin)** and sometimes **Pertuzumab**. The duration of this treatment may vary. Depending on the type of breast cancer you have, **other targeted (biological) therapies** may have been offered.

Please contact the relevant Oncology Department / Chemotherapy Unit if you have any concerns, questions or need further information regarding targeted (biological) therapies. The contact details for these departments can be found at the end of this booklet.

Bisphosphonates

- **Why was I prescribed bisphosphonates?**

Bisphosphonates are sometimes given to slow down or prevent bone loss in people who have, or are at risk of osteoporosis. Osteoporosis is when bones lose their strength and become more likely to break.

Osteoporosis can happen as part of the natural ageing process. However, some treatments for breast cancer can increase your risk of getting osteoporosis. In the treatment of primary breast cancer in postmenopausal women, bisphosphonates can reduce the risk of breast cancer recurring in the bones. This depends on the type of breast cancer you have.

Where appropriate, bisphosphonates are currently prescribed for between 2 and 5 years. The benefits of using bisphosphonates before the menopause to reduce breast cancer spread are less clear. They are not prescribed for this reason in younger pre-menopausal women.

Endocrine (anti-hormonal therapy)

- **Why do I need to take anti-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 tablets are usually taken for 5 to 10 years. At your follow-up appointment, 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 these 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. For more information, see the leaflet **Free prescriptions for patients with cancer diagnosis**.
(<https://leaflets.ekhuf.t.nhs.uk/free-prescriptions-for-patients-with-cancer-diagnosis/html/>)

There are two main types of anti-hormone therapy

- **Tamoxifen** is an anti-oestrogen. 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.
- **Anastrazole (Arimidex), Letrozole (Femara), and Exemestane (Aromasin)** are all aromatase inhibitor drugs. They 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. However, all of these tablets can 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. Your consultant oncologist can discuss with you the risks and benefits of stopping treatment.

- **Tamoxifen** is linked to a small risk of blood clots.
- It can also rarely cause abnormal thickening of the lining of the womb, which can show itself as post-menopausal vaginal bleeding. Whilst on Tamoxifen, you must tell your doctor if you have any post-menopausal vaginal bleeding.
- Possible side effects for men taking Tamoxifen include:
 - headaches
 - nausea (feeling sick)
 - hot flashes
 - skin rashes
 - fatigue (feeling tired)
 - sexual dysfunction; and
 - weight and mood changes.
- **Anastrazole, Letrozole, and Exemestane** can cause aching and stiffness of the joints. They are also associated with thinning of the bone (osteoporosis). Your bones will be monitored for signs of this with a baseline bone density scan. For more information, see the **What are DEXA scans?** section on this leaflet.
- 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 anti-hormone therapies on your own hormone levels. Or, they can simply be due to stopping your usual hormone replacement therapy (HRT). Hot flushes and night sweats are the most common menopausal symptoms. Many women also notice weight changes, vaginal dryness, changes in libido (sex drive), and mood swings.

- **Can I use hormone replacement therapy (HRT)?**

Hormone replacement therapy (HRT) is not recommended for women who have been treated for breast cancer. 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 may decide that the benefits of HRT outweigh the risks, if they are:

- at very low risk of cancer returning; and
- are experiencing severe menopausal symptoms that are affecting their quality of life.

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 can be helpful. If these do not help, try a topical oestrogen cream. If you have questions or concerns, please speak to your consultant, GP, or breast care nurse.

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

Some 'natural' remedies are advertised as relief for menopausal type symptoms. These remedies include Black Cohosh, Red Clover, and Sage tablets. However, these contain plant oestrogens (phyto-oestrogens) and are not recommended for use by patients who have had breast cancer. Always check with a breast care nurse before starting any herbal remedies / supplements.

Evening Primrose Oil and Star Flower Oil are safe to use. Some patients report that these are 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. 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. Some patients find relaxation based complementary therapies helpful for their symptoms. These therapies include acupuncture, hypnotherapy, massage, and aromatherapy. These therapies may be available via The Harmony Therapy Trust. (<https://theharmonytherapytrust.org.uk/>)

Several prescription drugs can help with reducing hot flushes. Your doctor will be able to discuss the potential benefits and side effects of these medications with you.

You may be referred to a menopause clinic. Speak to your breast care nurse for further information.

- **Hormonal therapy: free resources**

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

The above booklets are available to order or download from Breast Cancer Now. (<https://breastcancernow.org/information-support/publications/download-order>) Or ask your breast care nurse for a copy.

Further supportive information for those affected by menopause and cancer, is available on the **Menopause and Cancer** web site. (<https://menopauseandcancer.org/>)

Lymphoedema

- **What is lymphoedema?**

Lymphoedema is swelling caused by a build-up of fluid in the body's tissue. The swelling usually affects the arm. It can also affect the hand, fingers, breast, chest, shoulders, or the area of the back behind the armpit. Lymphoedema can occur as a result of damage to the lymphatic system. It is 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:

- 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
- 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 and tightness, mainly in the arm. However, sometimes patients also have this in their hand, fingers, breast, chest, shoulders, or back.
- 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**. (<https://breastcancernow.org/information-support/publications/download-order>) 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, please speak to your GP or breast care nurse as soon as possible. Signs of infection can include redness, heat, swelling, and tenderness / pain. If you have an infection, you may need antibiotic treatment.
- Try to avoid having blood tests, blood pressure readings, and intravenous (IV) fluids in the arm on the treated side of your body. However, 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 and unclenching your fist and shrugging your shoulders. Use insect repellent, carry antiseptic cream. Ask your GP for a course of antibiotics in case you need them.
- If you notice swelling that is not going away, please contact a breast care nurse. 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

The above resources are available to order or download from Breast Cancer Now. (<https://breastcancernow.org/information-support/publications/download-order>) Or ask your breast care nurse for a copy.

What happens in the future with my surveillance breast imaging (mammograms)?

Patients who have had breast cancer will have annual surveillance mammograms. These will be organised by the patient's treating team every year, for at least 5 years. This is because a small number of people will develop a new cancer in the other breast or another cancer in the same breast (called recurrence).

- If you had a **lumpectomy (wide local excision)** to remove your breast cancer, you will be invited for a mammogram every year for at least 5 years after surgery. Please continue to self-examine your breasts approximately once a month. Report any changes to your Breast Care Team.

- 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. Please continue to self-examine your mastectomy scar and your remaining breast, approximately once a month. Report any changes to your Breast Care Team.
- If you had **bilateral mastectomies** (removal of both breasts), you do not need a mammogram each year. Please continue to self-examine your chest wall area. Report any changes to your Breast Care Team.

If you receive an invitation to attend for a National Breast Screening Programme mammogram during this time, please cancel this appointment. You can do this by contacting the East Kent Breast Screening Unit on 01227 783000. Tell them 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. Once you reach 50, you will be discharged to your GP and transferred to the NHS Breast Screening Programme for mammograms every 3 years.
- If you are 50 or over in five years' time, we will discharge you to your GP. We will encourage you to continue regular mammograms through the NHS Breast Screening Programme. You will be invited automatically every 3 years, but can request more regular mammograms by contacting the East Kent Breast Screening Unit directly on 01227 783000.
- 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 a few weeks. We will also let your GP know your results.

When you have completed annual mammograms for at least five years (or longer, depending on your age), you will receive your last mammogram result letter. This letter will tell you that you are being discharged from our care. If you have not received your mammogram result letter within 4 weeks, please contact the Breast Care team.

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

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

If you are contacted 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. However, 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 2 weeks to come back. We will contact you once your further test results are available.

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

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

DEXA scans tell us if you have or are developing bone thinning (osteopenia), which could lead to a condition called osteoporosis. This can increase your risk of breaking a 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 receive a copy of this letter. If your scan shows evidence of osteopenia / 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 2 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

The above booklet is available to order or download from Breast Cancer Now.

(<https://breastcancernow.org/information-support/publications/download-order>) Or ask your breast care nurse for a copy.

Concerns about my cancer returning, and staying breast aware

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. 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 additional support to help deal 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.

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. For example 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, contact a breast cancer nurse using the appropriate number on the front of this booklet. 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 2 to 3 weeks.

Staying breast and body aware after breast cancer diagnosis / treatment: free resources

- Changes to be aware of after breast cancer leaflet
- Know your breasts and Quick guide leaflet
- Touch, Look, Check leaflet

The above leaflets are available to order or download from Breast Cancer Now.

(<https://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 example 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 example hips, back, or ribs
- Feeling sick
- Pain or swelling under your ribs or in your 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.

For further information, please read the **Changes to be aware of after breast cancer** leaflet.

(<https://breastcancernow.org/download-and-order-publications/changes-to-be-aware-of-after-breast-cancer-bcn402>)

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.

Please contact the Breast Care team via the appropriate telephone number on the front of this booklet, or speak to your GP, if:

- you start to feel that your mood is interfering with your life

- that you are finding it difficult to adjust to the changes; and / or
- you are finding it difficult to cope.

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**.

(<https://leaflets.ekhft.nhs.uk/further-help-and-support-for-breast-cancer-patients/html/>)

- **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 and request a fitting appointment for a free breast prosthesis, by contacting the Breast Care team via the appropriate telephone number on the front of this booklet.

- **Breast reconstruction**

If you have had a mastectomy and decided against reconstruction, you might want to think about it again at a later time. Dependent 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 a breast care nurse via the appropriate telephone number on the front of this booklet.

- **Returning to work**

If you work and have not yet returned, you can return 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.

- **Sun protection**

After breast cancer treatment, especially after radiotherapy, you must take sensible precautions in the sun. **Do not get sunburnt.**

Use a high SPF sunscreen all over. Make sure it offers broad-spectrum protection (both UVA and UVB). Reapply it regularly. Your treated area may be more sensitive, so please make sure this is covered with sunscreen.

A minimum SPF of 30 is recommended, but SPF 50 or higher is preferable for long-term sun exposure.

You should also consider using mineral sunscreens. These sunscreens provide a physical barrier against the sun's rays, and are often recommended for sensitive skin.

- **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. Aim to build up to at least 150 minutes sessions of moderate activity each week, spread throughout the week, such as brisk walking.

For help and advice on returning to exercise, go to the **Everyday Active** web site.
(<https://www.everydayactivekent.org.uk/hints-and-tips/how-much-is-enough-physical-activity-guidelines/>)

- **What diet should I follow?**

If you have had breast cancer, it is important to:

- enjoy a healthy diet
- avoid putting on too much weight; and
- do a moderate level of physical activity.

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 advice that you do 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.

Making love might not be the same as it was before your diagnosis. 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 2 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. These methods 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)
- 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)
- Have safe sex booklet (MCS)
- Your body, intimacy and sex booklet (BCN)

The above resources are available to order or download from either the Breast Cancer Now (<https://breastcancernow.org/information-support/publications/download-order>) web site, the Macmillan (<https://be.macmillan.org.uk/be/s-4-order-information.aspx>) web site, or ask your breast care nurse for a copy.

Some people like to use complimentary therapies (such as herb and vitamin supplements) alongside their medical treatment. **Always check with your breast care nurse, to make sure these 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 include aromatherapy, massage, Reiki, reflexology, and acupuncture.

- The Harmony Trust (<https://theharmonytherapytrust.org.uk>)
Telephone: 01795 663050
Email (harmony@thtt.org.uk)

If you wish to be referred, please contact your Breast Care team on 01227 868666.

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.

For help and support with your health and wellbeing, please go to the **One You Kent** web site.
(<https://www.kentcht.nhs.uk/service/one-you-kent/>)

Macmillan can also provide support guidance on health and wellbeing. Contact their helpline on 0800 808 0000 or visit their web site. (<https://www.macmillan.org.uk/cancer-information-and-support/get-help/wellbeing>)

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.

Look Good Feel Better

Look Good Feel Better are a UK-wide specialist cancer support charity. They focus on helping people to manage the cosmetic and physical impact of their cancer treatment. The charity hold regular face-to-face (usually held in Herne Bay and Romney Marsh) and online wellbeing workshops and classes, for people living with and beyond cancer.

Patients can book onto a workshop via the **Look Good Feel Better** web site.
(<https://lookgoodfeelbetter.co.uk/>)

Pink Ribbon Pilates

"Stay active, motivated and supported at whatever stage of breast cancer survivorship". Free to attend Pilates class for women in East Kent. Every Monday at 9am, Ashford.

- **Pink Ribbon Pilates**

Contact Jan on 07342 956678

Web (<https://www.pinkribbonpilates.info/>)

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. Hospital-based treatment includes surgery, chemotherapy, and / or radiotherapy.

Adapting to life after treatment can often be difficult, and you might need some support. The Breast Cancer Now award winning Moving Forward courses are here for you, 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.

These courses are run in partnership with NHS Hospitals. The course usually takes place over half a day, over two consecutive Fridays. 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 both sessions of the course.

If you wish to attend, please speak to the Breast Care team on 01227 868666. Or you can self-refer and / or find out more information via the **Moving Forward** web site (<https://breastcancernow.org/support-for-you/moving-forward>) or call 0800 800 6000.

Free resources

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

The above booklets are available to order or download from Breast Cancer Now.

(<https://breastcancernow.org/information-support/publications/download-order>) Or ask your breast care nurse

for a copy.

Useful apps

- Breast Cancer Kent: Patient Journey App (<https://www.breastcancerkent.org.uk/about-us/patient-journey-app/>)
- Breast Cancer Now: BECCA the breast cancer support app (<https://breastcancernow.org/support-for-you/becca>)
- CALM App (<https://www.calm.com/>) for meditation and sleep.
- Headspace (<https://www.headspace.com/>) for meditation and mindfulness.

Further information and support

There are many other organisations / charities that offer support and information. For a comprehensive directory of these, please visit the **Cancer Care Map** web site. (<https://www.cancercaremap.org/>) Or for further help, please contact your Breast Cancer Care Team on 01227 868666.

Contact details

- Cancer Care Line (all breast cancer concerns and further / ongoing support)
Telephone: 01227 868666
- Breast Cancer Open Access Follow-up (for patients on Open Access Follow-up)
Helpline: 01233 616632
- Breast Surveillance Imaging (mammogram) appointment queries
Telephone: 01227 864306 option 6
- Chemotherapy, immunotherapy, bisphosphonate queries / concerns:
 - Cathedral Day Unit
Telephone: 01227 783096
 - Celia Blakey Unit
Telephone: 01233 616194
 - Viking Day Unit
Telephone: 01843 234488
- Hospital switchboards
 - Kent and Canterbury Hospital, Canterbury
Telephone: 01227 766877
 - Queen Elizabeth the Queen Mother (QEQM) Hospital, Margate
Telephone: 01843 225544

- William Harvey Hospital, Ashford
Telephone: 01233 633331

What do you think of this leaflet?

We welcome feedback, whether positive or negative, as it helps us to improve our care and services.

If you would like to give us feedback about this leaflet, please fill in our short online survey. Either scan the QR code below, or use the web link. We do not record your personal information, unless you provide contact details and would like to talk to us some more.

Giving feedback about this leaflet



<https://www.smartsurvey.co.uk/s/MDOBU4/>

If you would rather talk to someone instead of filling in a survey, please call the Patient Voice Team.

- **Patient Voice Team**

Telephone: 01227 868605

Email (ekhuft.patientvoice@nhs.net)

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhufit.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhufit.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring 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 has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhufit.nhs.uk/patient-information>).

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