

# Following treatment for breast cancer



Providing support for patients and their families

## Who is this information for?

This information is for patients in our breast Open Access programme. The Open Access programme has been designed by our team to support you after treatment. This type of follow-up means that:

- You, the patient, are in control.
- Your normal routine is not disrupted by hospital appointments.
- You can quickly gain access to the Breast Unit if you need to.

It is based on evidence that shows that there is no advantage to regular follow-up in hospital for people who are well after breast cancer treatment.

## How can I contact the Open Access service?

To provide individualised follow-up care we offer a telephone helpline service called the Breast Care Helpline.

The aim of the telephone service is to provide helpful advice and allow you to have rapid access back to the Breast Team as required. You can call us to talk about any new symptoms that you are concerned about, or other issues related to your breast cancer.

The telephone service is an answer machine service. You will be asked to leave your name and telephone number and our support worker will call you back. The messages are picked up daily Monday to Friday, 9am-3pm, (excluding Bank Holidays).

All calls are reviewed by a clinical nurse specialist in breast care who will offer advice, appointment or investigations as necessary.

### **Breast Care Helpline:**

**01273 696955 extension 4111 (Monday to Friday, 9am-3pm)**

## How often will I have mammograms?

Current recommendations are for annual mammograms for five years after diagnosis. People who have had breast cancer are at risk of developing a further breast cancer in the same breast (recurrence), or a new cancer in the other breast.

Mammograms can detect cancer before it is able to be felt, either by you or a health care professional. For the majority of women, mammograms are the recommended way of checking for breast cancer.

## How will I receive my mammogram results?

You will receive your mammogram results by letter. This will normally take two weeks. If you do not receive your results within one month please contact the Breast Care Helpline.

## Will I still need to have mammograms through the NHS Breast Screening Programme, as well as my regular annual mammograms?

No. An NHS breast screening invitation is sent every three years to all women between the ages of 50 and 70 years. If you have recently had treatment for breast cancer and receive this invitation, please cancel the appointment. You can inform the NHS Breast Screening Unit that you are receiving regular mammograms at the hospital.

## What happens after my annual mammograms stop?

- **If you are over 50 years:** after five years of follow-up at the hospital, you are advised to attend the National Breast Screening Programme. This means that you will receive mammograms every three years through your local screening service.
- **If you are aged under 50 years:** after five years of follow-up at the hospital, we will recommend that you continue with annual mammograms at the hospital until invited for routine screening. You will then be offered mammograms every three years through your local NHS Breast Screening service.
- **If you are aged 70 years or over:** after five years of follow up, you may not routinely be called for screening. However you can continue to have mammograms every three years by requesting an appointment. Please contact your local NHS Breast Screening Unit. Their contact details are:

**East Sussex: 01273 664966**

**West Sussex: 01903 239757**

Alternatively, you can ask your GP to arrange this.

## Will I have to take anti-hormone therapy?

Some people with hormone sensitive cancers are prescribed anti-hormone tablets, also known as endocrine therapy.

Anti-hormone therapy choices include Tamoxifen, Letrozole, Anastrozole and Exemestane.

You will usually be recommended these tablets for at least five years. Some people may be advised to continue with their tablets for longer. Once you have completed five years of medication we will write to you and your GP and confirm if tablets should stop, continue or be switched.

You will not have to pay for tablets as you are entitled to free prescriptions. A medical exemption certificate is available from your GP surgery or breast unit.

Treatment recommendations change and develop all the time. If there are major changes in the way we prescribe hormone medication we will write and tell you about this and what it may mean for you. We may request that you return to clinic to discuss this further.

## **Will I need to have bone density (DEXA) scans?**

People taking an aromatase inhibitor ( Letrozole, Anastrozole, or Exemestane) may need a bone density scan (DEXA scans). These scans can tell us if you are at risk of osteoporosis (bone thinning). We will let you know how these will be booked.

Patients who have received bisphosphonates (bone strengthening tablets or injections) as part of their breast cancer treatment will not usually need to have bone density scans.

Regular weight-bearing exercise (e.g. Walking) as well as a diet high in calcium will help to maintain bone health. During your open access telephone consultation you should receive information about how to look after your bones.

## Will I experience any side effects from my treatment?

Everyone is different. Some people will have no side effects whilst others may experience some difficulties.

All treatments have the possibility of side effects and some may last longer than others. Below are some of the common side effects you may experience:

- Breast discomfort or tenderness
- Menopausal side effects
- Fatigue
- Lymphoedema.

## Will I experience any side effects from my hormone medication?

You may experience side effects that are particular to the drug you are taking.

For example, Tamoxifen can cause a vaginal discharge. Tamoxifen can also cause thickening of the uterus (womb). This will present as clear or opaque and odourless. This is common and not serious. However, if your periods have stopped and you experience unexpected vaginal bleeding you should contact the Breast Care Helpline as you may need to be referred to a gynaecologist.

Aromatase inhibitors such as Letrozole can sometimes cause joint stiffness and pain. This joint stiffness is often worse after rest (e.g. in the morning after sleep).

The lack of oestrogen can also lead to vaginal dryness, particularly during sex. Anti-hormone medication can cause other menopausal symptoms, most commonly hot flushes.

If you are experiencing side effects with your medication please contact the Breast Care Helpline for support and advice.

## Do I still need to use contraception?

Even though you may not be having regular periods, you may still be able to get pregnant. Effective contraception is important. After breast cancer hormonally based contraception such as the pill is usually not recommended. Your GP or practice nurse will be able to recommend a local family planning centre where you can discuss your individual needs.

If you need to discuss your fertility or the possibility of future pregnancy please contact the Breast Care Helpline number **01273 696955 Ext. 4111**

## What is the risk of the breast cancer returning?

Survival rates for breast cancer are improving all the time. Modern breast cancer treatment has high success rates.

However, breast cancer can sometimes return. The risk of breast cancer recurrence reduces over time, although sadly we cannot be absolutely certain that a breast cancer will never recur.

Breast cancer can return:

- In the treated breast (local recurrence)
- In the nearby area under your arm, above your collarbone or neck area (regional recurrence)
- Elsewhere in the body (distant recurrence also known as metastatic or secondary breast cancer)

It is important that you are aware of what to look out for and what to do if you have concerns.

## How can I be 'breast aware'?

Being 'breast aware' is an important part of caring for your body. It means getting to know how your body looks and feels, so you know what is normal for you. You can then feel more confident about noticing changes.

We know that after breast cancer treatments it can take some time to become familiar with your body. However, the better we know our bodies the quicker we notice what is normal or not. If something feels different for you, please contact the Breast Care Helpline.

There is no right or wrong way to get to know your breasts. Try to get used to the way your breasts look and feel. You can do this monthly, in the bath or shower, when using soap or body lotion. The following website may be helpful:

<https://breastcancernow.org/information-support/have-i-got-breast-cancer/signs-symptoms-breast-cancer>

## What signs and symptoms should I look out for?

Everyone can have aches and pains but, after a breast cancer diagnosis, you may be more aware of them and may be concerned that pains are related to cancer.

Included below are some symptoms you should report to your G.P or the helpline number. If you experience any of these symptoms it does not necessarily mean that your cancer has returned as they can be caused by many other conditions, but it may mean that you should have a check-up with the breast team.

### Please contact us if you experience:

- A lump or a swelling in your breast, or in the skin after a mastectomy, above your collarbone, in the neck area or under your arm
- Any skin changes including dimpling, puckering, redness or raised spots on your breast or mastectomy scar
- Nipple discharge
- If you develop lymphoedema (affected side arm swelling)
- Any new, on-going pain in any part of your body, especially in your back or hips, that does not improve with painkillers and which is often worse at night
- Pins and needles and / or a loss of sensation or weakness in your arms or legs
- Unexplained weight loss and loss of appetite
- A constant feeling of nausea
- Discomfort or swelling under your ribs or across your abdomen
- A persistent dry cough or a feeling of breathlessness
- A persistent hoarse voice
- Severe headaches - usually worse in the morning.

## Who can I talk to about breast reconstruction and prosthesis?

If you wish to discuss reconstruction at any time after a mastectomy then please contact us via the helpline number.

In some cases surgery can correct unequal breast sizes and you can be seen in clinic if you wish to discuss this. If you had radiotherapy, we will advise you to wait at least a year after completion of radiotherapy. It is natural for breasts (treated and untreated) to change over time.

If you need advice about your prosthesis, need a replacement, or advice about getting a bra to fit, then please contact the Breast Care Helpline.

## Who can I talk to about my feelings and emotions?

Everyone will have different feelings when they no longer need to see their medical team regularly. Some people feel relieved and start to get their lives back to normal. Other people may be concerned about what can happen in the future and be anxious about losing contact with their hospital team. Most people worry about the cancer coming back. This is very normal and usually these anxieties lessen with time.

While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If you are finding it difficult to cope, you may find that one of the local support groups, Macmillan Horizon Centre, or national support organisations such as Breast Cancer Now or Macmillan Cancer Support may be beneficial. Their contact details can be found at the back of this booklet.

## How can I stay healthy after my treatment?

After treatment people often want to know what they can do to stay healthy. You may have some questions about diet, exercise and general well-being. We understand that your need for support does not end when treatment finishes, so we are working with Breast Cancer Now to provide a Moving Forward course. This is a programme of information sessions to help you adjust and adapt after a diagnosis.

The Moving Forward course runs for half a day each week over four weeks. You will need to be available for, and commit to attending, all four weeks of the course. For more information please contact the Breast Care Helpline.

## Useful contacts

### Breast Care Helpline

**01273 696955 Ext. 4111** (Monday to Friday, 9am-3pm)

### Prosthesis fitting service

**01273 696955 Ext. 4111** (Monday to Friday, 9am-3pm)

### To change a mammogram appointment

**01273 696955 Ext. 3730**

### Breast Cancer Now

Free Helpline **0800 800 6000**

**[www.breastcancer.org](http://www.breastcancer.org)**

### Macmillan Cancer Support

Free helpline **0808 808 0000**

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

### The Macmillan Horizon Centre

2, Bristol Gate, Brighton, BN2 5BD

**01273 468770**

**[www.macmillan.org.uk/horizoncentre](http://www.macmillan.org.uk/horizoncentre)**

This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

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#### Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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