

A large, stylized pink ribbon graphic is positioned diagonally across the page, set against a solid blue background. The ribbon is composed of several overlapping, curved segments in various shades of pink, from light to dark.

**NHS**  
University Hospitals  
Coventry and Warwickshire  
NHS Trust

**NHS**  
George Eliot Hospital  
NHS Trust

**NHS**  
South Warwickshire  
NHS Foundation Trust

# Open Access Follow Up After Treatment for Primary Breast Cancer

# Oncology and Cancer Services

## Open access follow up after treatment for primary breast cancer

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### **Open access follow up after treatment for primary breast cancer**

The open access follow up programme has been specially designed by the breast unit to support you when you have completed your treatment. It is a type of follow up, where you, the patient, are in control. It means that your normal routine will not be disrupted by regular hospital appointments; instead you can quickly gain access to the breast care team and hospital if there is a need. It is based on evidence that there is no advantage to regular, fixed time follow up in hospital for well women or men, after treatment for breast cancer. Research has shown that having routine regular outpatient follow up appointments does not help prevent cancer returning or identify any new problems; in fact many patients feel that regular follow up visits to the hospital can create anxiety. However, if you are taking part in a clinical trial you may be seen regularly for a longer period of time e.g. Up to 10 years. This booklet describes what happens now that you have transferred from the hospital clinics to a self-management, patient initiated, follow up pathway. It will explain ways in which you can continue to access support and advice about your health.

### **Follow up Mammograms and Bone Density Scans**

Those who have had breast cancer have a small, increased risk of developing a further cancer in the same breast (recurrence) or a new cancer in the other breast. Mammograms (breast x-rays) can often detect breast cancer or precancerous changes before they can be felt, either by you or a health care professional.

After breast conserving surgery (lumpectomy/wide local excision therapeutic mammoplasty) you will have a mammogram on both breasts. If you have had a mastectomy you will have a mammogram on your remaining breast.

If you have had both breasts (bilateral reconstruction), you will not require mammogram screening of the reconstructed breast.

For a small number of women mammography may not be appropriate and other options will be discussed with you, if this is the case.

**If you are aged over 50 years:** After five years of annual follow ups, you will be invited to the National Breast Screening Programme.

## Patient Information

Attendance is strongly recommended/advised; you will undergo a mammogram every three years through your local screening service.

**If you are aged under 50 years:** When five years of follow ups is completed we will recommend that you continue with annual mammograms until you are invited for screening every three years through your local NHS Breast Screening service.

**If you are aged 71 years or over:** You will not be automatically called for routine screening. However you can opt to continue three yearly mammograms under the NHS Breast Screening Programme by requesting an appointment. Please contact your local NHS Breast Screening Unit or GP to arrange this. Please see contact numbers at the back of the booklet

## Results of Mammograms

After your mammogram your results will be available via your GP within two weeks. If you cannot access your results within one month of having your mammogram, please contact the breast screening unit. Please see contact numbers at the back of this booklet.

Sometimes, after having treatment for breast cancer, mammograms are not as easy to read; therefore we may recall you so we can carry out further assessment or investigations. We will contact you by telephone or by letter if this is the case.

## DEXA Scans and Bone Health

After the menopause as oestrogen levels fall, women's bones often become less strong. When you are taking an aromatase inhibitor such as Letrozole, Anastrozole, or Exemestane this process may be speeded up. You will have regular bone density scans (DEXA scans) as discussed with you by your Consultant. These scans can tell us if you are at risk of developing symptoms of bone thinning which could lead to a condition called osteoporosis. Treatment usually comprises of a bisphosphonate drug in combination with calcium and vitamin D supplements.

Regular exercise, such as walking, as well as eating a diet high in calcium will help to maintain bone health. Information can be found on the Breast Cancer Now website or the Macmillan website-contact information at the back of this booklet.

## Patient Information

### **Your Cancer Medication – Anti-Hormone Therapy (Endocrine Therapy)**

Patients with hormone receptive cancers are prescribed anti-hormone tablets, also known as endocrine therapy. Anti-hormone therapy includes Tamoxifen, Letrozole, Anastrozole and Exemestane. You will be advised to take these tablets for either five or ten years. Once you have completed the first five years, we will write to you and your GP to confirm if the prescription should stop, continue or be switched. Your Treatment Summary will confirm the date you started your anti-hormone medication and the date you will complete it. If you haven't heard from us as you near the end of the fourth year of your hormone treatment please contact your breast care nurse.

Some patients are recommended to change their tablets after two or three years. For example, if you reach the menopause (your periods may be masked by tamoxifen) the team will sometimes advise you switch to another anti-hormone treatment. We will inform you if this is the case.

Some younger patients may be recommended to have a monthly or 3 monthly injection of Goserelin to induce menopause. If this is the case your oncologist will have discussed the risks and benefits with you and the details included in your treatment summary

You will not have to pay for hormone treatment tablets as you are entitled to free prescriptions. A medical exemption certificate is available from <https://www.nhsbsa.nhs.uk/exemption-certificates/medical-exemption-certificates>. This will need renewing after five years if treatment continues.

Treatments do change and develop all the time. If there is a change in the way we prescribe anti-hormone medication, we will write and tell you and what this may mean for you. You may be referred back to your GP or breast care nurse to discuss further.

### **Possible side effects of Anti-Hormone Medication**

You may experience side effects that are particular to the drug you are taking. We haven't listed all the side effects. It is very unlikely that you will have all of these side effects, but you might have some of them at the same time.

## Patient Information

How often and how severe the side effects are can vary from person to person. They also depend on what other treatment you are having. For example, your side effects could be worse if you are also having other drugs. If buying any products over the counter, interactions should be checked by a Health Care Professional.

If you are a patient receiving or have previously received Tamoxifen you may experience abnormal gynaecological symptoms, like vaginal bleeding, or menstrual irregularities, vaginal discharge and pelvic pain or pressure. These should be promptly investigated. You may need to be referred to a specialist doctor - a gynaecologist.

Less serious side effects such as hot flushes may also occur. Please contact either your GP or your breast care nurse if you are worried.

Tamoxifen can also cause a very small risk, less than 10%, of you developing a blood clot Deep Vein Thrombosis (DVT) that could possibly travel to your lungs. If you experience pain, redness, swelling or warm to touch in either of your calves or shortness of breath attend A&E immediately.

There is research that suggests some drugs – including the antidepressants Paroxetine and Fluoxetine may cause Tamoxifen to be less effective, but this isn't certain. If you are prescribed these whilst you are taking Tamoxifen please tell your GP.

Aromatase inhibitors such as Letrozole, Anastrozole and Exemestane can sometimes cause joint stiffness and pain, as well as vaginal dryness which some women may find uncomfortable and could affect your sex life. These tablets can also cause your bones to become weaker and more likely to break (osteoporosis).

If you are experiencing side effects from the medication that are impacting on your quality of life please contact either your breast care nurse or your GP, who will be able to offer further support and advice. Switching to an alternative medication may be helpful in these circumstances.

## Breast Awareness

It is important to remain breast aware after your treatment. Breast awareness is an important part of caring for your body. It means getting

## Patient Information

to know how your breasts look and feel, so you know what is normal for you. You can then feel more confident about noticing any changes.

We know that after having treatment for breast cancer it can take some time (up to two years) for changes to settle and for you to become familiar with your treated breast. However, you know better than anyone how your breasts look and feel normally, so if you notice a change, contact your breast care nurse on the numbers at the back of the booklet or see your GP.

There is no right or wrong way to examine your breasts. Try to get used to the way your breasts look and feel. You can do this around once a month, in the bath or shower, when using soap or body lotion. There is really no need to change your everyday routine. You can find leaflets and websites, which may be helpful. See back of this booklet.

### **You should report**

- Any new lumps in the breast area or under the arm on either side or on neck or collar bone
- Bleeding from the nipple
- Change in the shape or outline of the breast
- Swelling of the arm or breast also described as lymphoedema
- Puckering of skin (peau d'orange)
- Inverted nipple

### **Signs and Symptoms**

Everyone has aches and pains at times, but when you have had breast cancer, you may be more aware and concerned that any new pain is related to cancer. Included below is a summary of symptoms that you should report to either your Breast Care nurse or your GP if they develop. 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 common conditions, but it is advisable to get them checked out:

- Breathlessness not associated with a cold or chest infection
- A new pain which is persistent anywhere in the body, that lasts for more than two weeks

## Patient Information

- Any other new symptom which last for more than two weeks
- Sudden 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 being sick (nausea)
- Discomfort or swelling under your ribs or across your tummy area (abdomen)
- A persistent dry cough
- Severe headaches - usually worse in the morning.
- Altered vision or speech
- Any yellowing of the white of your eyes or skin (jaundice)
- Dizziness and balance issues

## If Breast Cancer Returns

A recurrence or a new cancer can be frightening, but it is important to remember that if breast cancer returns, it can usually be treated.

It is important to know that survival rates for breast cancer are improving all the time and that modern breast cancer treatment is usually very successful.

For the majority of people the risk of the breast cancer returning reduces over time

The risk of recurrence for hormone receptor positive breast cancer continues for 20-25 years or more, gets less over time.

For triple negative and HER two positive cancers the risk decreases faster, becoming very low after five years.

It is important that you are aware of what to look out for and what to do if you become concerned. 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)
- Sometimes in the other breast
- Elsewhere in the body – in the bones, lungs, liver or brain (distant recurrence) also known as metastatic breast cancer or secondary breast cancer)

## Patient Information

### **Breast Reconstruction and Prosthesis**

If you have had a mastectomy and decided against reconstruction but change your mind at a later date, please contact your breast care nurse who can refer you back to clinic to discuss this further.

If you had radiotherapy, we will advise you to wait at least a year for surgery after completion of radiotherapy, but this will be on an individual basis and may be offered after 6 months. In some cases surgery can be offered to correct unequal breast sizes and the breast care nurse can also refer you back to clinic if you wish to discuss this further. It is natural for breasts (treated and untreated) to change over time. If you require any information about your prosthesis including replacement, please contact your breast care nurse.

### **Feelings and Emotions**

Everyone will have different feelings about completing their treatment. Some people feel relieved that they can start to get their lives back in order; others may be concerned about what can happen in the future and feel anxious about losing contact with the hospital where they received their treatment. Most people worry about the cancer coming back. This is very normal and mostly these anxieties lessen with time.

Realising there is a problem and getting help is the most important thing you can do.

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, speak to your breast care nurse, who will discuss your concerns. A referral for counselling may be helpful. It may also help to contact a local or national support organisation such as Breast Cancer Now, Macmillan Cancer Support, or Breast Cancer Haven. Also think about signing up for the Moving Forward course or HOPE course. These Contact details can be found at the back of this booklet.

### **Life After Treatment and How I Can Help Myself**

What can I do to help myself?

- Eat a healthy, well balanced diet
- Take regular exercise
- Avoid large amounts of alcohol

## Patient Information

- Maintain a healthy weight
- Look after mental wellbeing
- Stop smoking

## Other Areas of Support That Can Be Accessed

### Hope Course:

An informal course which runs for a 3 hour session once a week for a total of six weeks. This enables patients with any cancer to share their experiences and gain confidence and build resilience following treatment. Please see back of booklet for details of booking.

### Moving Forward Course:

This is coordinated by Breast Cancer Now Charity for breast cancer patients only and consists of a three hour session once a week for four weeks. Please see numbers at back of booklet to apply for a place.

### Haven Breast Cancer – Solihull.

Provide complementary personalised programmes of support to anyone affected by breast cancer 0121 7269570  
[westmidlands@breastcancerhaven.org](mailto:westmidlands@breastcancerhaven.org)

### Macmillan Cancer Support 0808 808 0000

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

## Our Commitment to You

You will not lose contact with our service because you have been transferred to self-management initiated follow up. If you have any specific issues or problems you wish to discuss then use the relevant contact details at the back of this booklet for the hospital where you were treated.



## Patient Information

### Hormone Treatment

You have been prescribed

TAMOXIFEN 20mg orally daily,	Yes	No
ANASTRAZOLE 1mg orally daily	Yes	No
LETROZOLE 2.5mg orally daily	Yes	No
EXEMESTANE 25mg orally daily	Yes	No

You should stop taking this: \_\_\_\_\_ month \_\_\_\_\_ year

ZOLADEX - Subcutaneous

Start: \_\_\_\_\_ Completed: \_\_\_\_\_

### Bisphosphonates

ZOLEDRONIC ACID 6 MONTHLY X4 TREATMENTS

Start: \_\_\_\_\_ Completed: \_\_\_\_\_

Your next Mammogram is due: \_\_\_\_\_

and should be done in \_\_\_\_\_ (month) for the next 5 years.

Patient Information

## **University Hospitals Coventry and Warwickshire (UHCW) NHS Trust**

### **Useful Contacts**

#### **Oncology breast care secretaries**

Prof Poole – 02476 967497

Dr Kechagioglou/Dr Boiangiu – 02476 967518

Dr Mcavan – 02476 967484

Surgical Breast Care Nurse Service: Monday - Friday 9-5pm –  
02476 967089

Oncology Breast Care Nurse Service: Monday - Friday 8-4pm –  
02476 967473

If your call cannot be answered please leave a message on the answer  
phone. Remember to leave your name AND contact details.

Messages are checked regularly throughout the day

#### **Mammogram appointments**

If you need to change your follow up mammogram appointment  
please call – 02476 967200.

#### **Other Areas of Support**

Cancer information service at UHCW Main entrance – 02476  
966052

Breast Cancer Now Support, including Moving Forward Course:

[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) – 0808 800 6000

Hope Course: booking contact Cancer Information Service at  
UHCW – 02476 966052

## Patient Information

Penny Brohn, Living Well with Cancer: they provide support and practical advice and offer free residential overnight stays at their Centre in Bristol - Call 00303 3000118

Coventry Breast Cancer Support Group: Myton Hospice Coventry, just as you enter the grounds for main UHCW hospital. Meet the first Wednesday of the month except January 7.30-9.30pm all welcome

## **George Eliot NHS Trust**

### **Useful Contacts**

Surgical Breast Care Nurses – 024 7686 5181

Oncology Breast Care Nurse – 0787 659 0687

Living with and Beyond

Cancer Specialist Nurse – Rebecca Bourne – 0734 105 5424

Breast Care Secretaries – 024 7686 5116

Monday - Friday 9-5pm

If your call cannot be answered please leave a message on the answer phone. Messages are checked regularly throughout the day remember to leave your name and contact details

Mammogram Appointments

If you need to change your follow up mammogram appointment please call – 02476 865458

## Patient Information

### **Other Local Support Available**

Walk and Talk Support Group: A friendly, group where people meet, have a walk in the Riversley park in Nuneaton and and go for a drink afterwards if they wish.

We meet every Tuesday at 1.30pm. Contact – 0787 659 0687 for more information.

The Oasis Centre: Based at the hospital, the Centre offers people various complementary therapies such as aromatherapy, massage and relaxation free of charge

Contact the Oasis Centre - 02476 86 5046 to book a place

Breast Cancer Now Support – 0808 800 6000 - [www.breastcancer.org.uk](http://www.breastcancer.org.uk) including booking a place on Moving Forward course

Cancer Information Support at GEH – 02476 15 3201

HOPE: course booking contact Cancer Information Service – 02476 153201

Penny Bohn, Living Well with Cancer: they provide support and practical advice and offer free residential overnight stays at their Centre in Bristol. – Call 00303 3000118

## **South Warwickshire Foundation Trust (SWFT)**

### **Useful Contacts**

Breast Care Nurse Service: Monday - Friday 8.30-4.30pm – 01926 495321 ext 4503

If your call cannot be answered please leave a message on the answer phone. Remember to leave your name and contact details. Messages are checked regularly throughout the day.

## Patient Information

### **Mammogram Appointments**

If you need to change your follow up mammogram appointment please call – 01926 600007 option 8 – Mon/Weds/Fri

### **Support Available**

Breast Cancer Now Support: – 0808 800 6000 - [www.breastcancer.org.uk](http://www.breastcancer.org.uk) including booking a place on Moving Forward course

Macmillan Cancer Information Support Centre's at Warwick Hospital, Aylesford Unit – 01926 495321 Ext 8214

Stratford Hospital, Rigby Unit – 01789 205831 Ext. 5871

HOPE: course booking contact Cancer Information Support on above numbers

Penny Bohn, Living Well with Cancer: they provide support and practical advice and offer free residential overnight stays at their centre in Bristol. – 00303 3000118

The Trust has access to interpreting and translation services. If you need this Information in another language or format please contact 024 7696 7238 and we will do our best to meet your needs.

The Trust operates a smoke free policy

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