



# A guide to...

## Open Access Follow-up Treatment for Breast Cancer

*Patient and Carer Information*

### How to contact us

Breast Unit  
St Albans Hospital  
West Hertfordshire NHS Trust  
Waverley Road  
St Albans  
Hertfordshire  
AL3 5PN

Breast Care Telephone number: **01727 897 562**

If you need this leaflet in another language, large print, Braille or audio version, please call **01923 217 198** or email [westherts.pals@nhs.net](mailto:westherts.pals@nhs.net)



Author	Kerrie Vaughan/Michelle Sorley
Department	Cancer Services
Ratified Date / Review Date	Nov 2020 / Nov 2023
ID Number	17-1079-V1



## **Contents**

Introduction	2
Treatment summary	2
Future mammograms	3
Results of mammograms	3
The NHS Breast Screening Programme	3
After five years of annual follow up mammograms	3
Contacting the NHS Breast Screening Service	6
Your cancer medication	7
Possible side effects of hormone medication	8
Dexa scans and bone health	10
Possible side effects of treatment	10
Contraception	11
If breast cancer returns	11
Breast awareness	12
Signs and symptoms	13
Summary of symptoms	13
Breast reconstruction and prosthesis	15
Feelings and emotions	15
The open access telephone service	16

## **Introduction**

The open access follow-up programme has been 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 when you need to. The programme is based on evidence showing that there are no advantages to regular, fixed-time follow-ups in hospital for well women after treatment for breast cancer (NICE 2009).

## **Treatment summary**

The treatment summary provides information about your diagnosis and treatment as well as how your follow-up care will be organised. This includes:

- the dates of your future mammograms, if needed
- the dates which you started and should complete your anti-cancer medication
- the dates of bone density (DEXA) scans if recommended for you
- some of the common side effects of treatment
- if breast cancer returns; signs and symptoms to report to us
- being breast and body aware
- services available to patients who have completed treatment
- further help and support and how to contact the breast care team.

## ***Future mammograms***

People 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 before it can 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. Our current recommendations are that you should have annual mammograms for five years following your diagnosis, or until you reach the age at which the National Breast Screening Programme starts. These mammograms will be organised by West Hertfordshire Hospitals Trust. For a small number of women, mammography may not be appropriate and we will discuss the other options if this is the case.

## ***Results of mammograms***

After your mammogram, you will receive your results letter within two weeks. The results letter will also contain the time and date of your next appointment. For this reason it is important to make sure that the hospital has your correct address and telephone number. If you do not receive your results within one month of having your mammogram, please contact us.

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 assessments or investigations. We will contact you by telephone or by letter if this is the case.

## ***The NHS Breast Screening Programme***

A screening invitation is sent every three years to all women between the ages of 50 and 70 years. Age extensions are currently being rolled out nationally to start screening at 47 years and continue until 73 years. If you have recently undergone treatment for breast cancer and receive an invitation to attend for a screening mammogram during the time you are attending the hospital, please cancel the appointment with the NHS Breast Screening Unit, telling them that you are receiving regular mammograms at the hospital following treatment for breast cancer.

## ***After five years of annual follow up mammograms***

### ***If you are aged over 50 years***

After five years of follow up at West Hertfordshire Hospitals Trust you will be invited to and should attend the NHS Breast Screening Programme. 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 we will recommend that you continue with annual mammograms at West Hertfordshire Hospitals Trust 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***

You may not be automatically called for routine screening. However you can continue to receive three yearly mammograms under the NHS Breast Screening Programme by requesting an appointment and it is recommended that you do this. Please contact your local NHS Breast Screening Unit or GP to arrange this.

***Your cancer medication – hormone therapy***

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

Anti-hormone therapy will include Tamoxifen, Letrozole and other medications such as Anastrozole and Exemestane. You will be on these tablets for five to ten years. Once you have completed the first five years we will write to you and your GP and confirm if the prescription should stop, continue or be switched.

Your treatment summary will confirm the date you started your hormone medication and the date that you will complete five years of hormone therapy. If you have not heard from us as you near the end of your hormone treatment, please contact the open access nurse practitioner.

A change in your tablets may be recommended after two or three years. For example, if you become menopausal (your periods stop) the team might advise that you are switched over to a different anti-hormone treatment. We will tell you if this is the case.

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, hospital pharmacy or local chemist.

Treatments do change and develop all the time. If there are major changes in the way we prescribe hormone medication during the time you are on it, we will write and tell you about this and what it may mean for you. You may be invited to return to clinic to discuss this further.

***Possible side effects of hormone medication***

You may experience side effects that are particular to the drug you are taking. For example, as a result of taking Tamoxifen the lining of your womb may become thicker which can then cause you to develop vaginal discharge. This is common and not serious. However, if your periods have stopped and you experience unexpected vaginal bleeding, please contact either your GP or the breast care nurses. Your GP may refer you to a gynaecologist.

Aromatase inhibitors such as Letrozole, Anastrozole and Exemestane can sometimes cause joint stiffness and pain. Keeping as active as possible can often help to reduce this.

Vaginal dryness is a common side effect of hormone medication, in particular the aromatase inhibitors such as Letrozole, Arimidex and Exemestane. There are a number of treatments that can help with vaginal dryness including vaginal moisturisers and lubricants. These can be prescribed by a doctor, bought in a chemist or ordered online.

If you are experiencing side effects of medication such as menopausal symptoms, joint ache or vaginal dryness, please contact your open access nurse practitioner who will be able to offer further support and advice.

### ***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 (arimidex) or Exemestane, this process may be accelerated. You may need one or more bone density scans (DEXA scans). These scans can tell us if you are developing bone thinning which could lead to a condition called osteoporosis. Your treatment summary will state if these are needed. Sometimes they are organised by West Hertfordshire Hospitals Trust and sometimes by the GP. We will let you know how these will be booked.

If your periods have stopped early because of your treatment, you may also need bone density scans. This can also be arranged by us or more commonly by your GP. Your treatment summary will state if these are required. Regular exercise such as walking, along with a diet high in calcium, will help to maintain bone health.

### ***Possible side effects of treatment***

All treatments (surgery, chemotherapy, radiotherapy and hormone therapy) have the possibility of some side effects and some of these can last longer than others. Not everyone will experience side effects and some patients may experience more difficulty with them than others. Below are some of the common side effects you may experience:

- breast discomfort or tenderness
- menopausal related side effects
- fatigue
- lymphoedema (swelling).

### ***Contraception***

Even though you may not be having regular periods, you may still be able to get pregnant. Effective contraception is important. Depending on the type of breast cancer you had, you may be advised to avoid hormone based contraception such as the pill. Your GP or practice nurse will be able to recommend a local family planning centre where you can discuss your individual needs. It is advised that you should not get pregnant for two years following treatment.

## ***If breast cancer returns – signs and symptoms***

It is important to know that survival rates for breast cancer are improving all the time (NICE 2009) and that modern breast cancer treatment is usually very successful.

However, breast cancer can sometimes return. There is no maximum time span as to when this can happen but for most people the risk reduces over time. It is important that you are aware of what to look out for and what to do if you become concerned about anything.

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)
- in the other breast (rarely)
- elsewhere in the body (distant recurrence also known as metastatic breast cancer or secondary breast cancer).

For further information on survival rates, please see the Cancer Research UK website via

*[www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/survival](http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/survival)*

## ***Breast awareness***

Being breast aware is an important part of caring for your body. It means getting 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) to become familiar with your treated breast. However, the better we know our bodies, the quicker we notice what is normal or not normal for us. If something feels unusual to you, please contact the nurse practitioner.

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 around once a month, in the bath or shower, when using soap or body lotion. There is no need to change your everyday routine.

You can find leaflets and websites which may be helpful; your breast care nurse can recommend some if you wish.

You know better than anyone how your breasts look and feel normally, so if you notice a change, contact the open access nurse practitioner.

## ***Signs and symptoms***

Everyone has aches and pain, but when you have had breast cancer, you may be more aware of them and may be concerned that any pain is related to cancer.

Below is a summary of symptoms that you may wish to report to the open access breast nurses, should 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 may mean that you should get them checked out by the breast team.

Having 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.

## ***Summary of symptoms***

Please contact us if you experience:

- a lump or a swelling in your breast, in the skin after a mastectomy, above your collarbone or 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
- lymphoedema (affected side arm swelling). Or if you experience:
- any new, ongoing 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 upper abdomen
- a dry cough or a feeling of breathlessness
- severe headaches, usually worse in the morning.

## ***Breast reconstruction and prosthesis***

If you have had a mastectomy and decided against reconstruction but change your mind at a later date, please contact us to discuss delayed reconstruction. If you have had radiotherapy, we will advise you to wait at least a year after completion of radiotherapy. In some cases surgery can be offered to correct unequal breast sizes – the nurse practitioner can 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 need advice about your prosthesis or bra fittings, please contact us.

## ***Feelings and emotions***

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

Realising that 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, your nurse practitioner may be able to arrange an appointment for counselling. It may also help to contact a local or national support organisation such as Breast Cancer Care or Macmillan Cancer Support. Please see their contact details on page 17.

## ***The open access telephone service***

Once you have entered the open access follow up programme, you should call the open access breast nurse about any new symptoms that you are concerned about or other issues you may have. 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.

## ***Our commitment to you***

If the breast nurse feels the symptoms you are experiencing may represent a new cancer diagnosis or be related to your previous cancer diagnosis, an appointment will be arranged at one of our clinics. If necessary, further investigations may be organised and an outpatient appointment will be arranged to receive the results.

For patients continuing to experience side effects of treatment, there are a number of other clinics and support services which you can be referred or signposted to.

Sometimes, verbal advice (via the telephone service) may replace the need for an outpatient appointment. In these cases, a written letter will be sent to you and your GP. We hope that this enhances and promotes your ability to care for yourself once treatment has been completed and enables you to benefit from the team's expertise as required.

The telephone service is open Monday to Thursday, 9am-5pm and Friday 9am-4pm) may be answered by a Macmillan support worker or a breast nurse. If your call is not answered immediately please leave your name, hospital number and detail that you are calling the open access follow up with a short message and your call will be returned by the end of the working day.



## ***Finally***

If you are worried about something to do with your breast cancer, or the treatment that you have had for it, please contact the breast nurses. They would rather see you with something that turns out to be nothing, than for you to be at home worrying. They are there to help you, so please call if you have any questions or concerns.