

Open access follow-up after treatment for primary breast cancer

Breast Unit



Patient Information

Open access follow-up after treatment for primary breast cancer

Patient name:

Hospital number:

This information is for patients in our breast open access follow-up programme

The Open Access Follow-up (OAFU) 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 when you need to. It is based on evidence showing that there is no advantage to regular, fixed time follow up in hospital for well women after treatment for breast cancer.

This information is a summary of the consultation and is for you to keep

The **Treatment Summary** included gives 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 applicable to you
- some of the common side effects of treatment
- if breast cancer returns; signs and symptoms to report to us or your GP
- 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

Information about the Open access programme will also be sent to your GP.

Your future mammograms

People who have had breast cancer are at 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 detect breast 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. Our current recommendations are that you should have annual mammograms for five years following diagnosis or for younger women until the age of 50 years. Following 5 years of OAFU, patients will be discharged to their GP. A further five years mammograms post OAFU will be requested on behalf of your GP by the Advanced Nurse Practitioner (ANP)/Breast Care Nurse (BCN) and will be done at Ashford and St. Peter's Hospitals NHS Foundation 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 month and year of your next mammogram appointment. The exact date will be communicated to you by a phone call from radiology shortly before the actual mammogram. 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 the OAFU telephone helpline provided at the back of this leaflet. Following discharge from OAFU, results of further 5 years of mammogram will be sent directly to your GP and you can receive your results by contacting your GP surgery.

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 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 after treatment for breast cancer.

After your annual mammograms

- If you are aged over 50 years: after five years of follow up at the hospital and a further 5 years of mammogram requested on behalf of your GP, you are advised to attend the National Breast Screening Programme and 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 within 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 and a further 5 years of mammogram requested on behalf of your GP, 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 or GP to arrange this.

Anti-hormone therapy

Some 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 Arimidex and Exemestane. You will usually be on these tablets for five years, although some patients may be advised to continue with their tablets for a longer period of time. Once you have completed five years of hormone medication 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 you will complete your hormone therapy. If you haven't heard from us as you near the end of your hormone treatment please contact the Open access telephone helpline.

Some patients will change their tablets at some point during their treatment. For example, if you become menopausal (your periods stop) the team will sometimes advise that you are switched over to another anti hormone treatment. We will have told you this if this is the case. If you are one of these people the date in which you are due to switch to another medication is confirmed on your Treatment Summary. A blood test to measure the hormone levels in your blood may be required before switching to another medication. If this is the case we will write and let you know.

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 your Clinical Nurse Specialist (CNS).

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. We may request that you return to clinic to discuss this further.

DEXA scans and bone health

When you are taking an aromatase inhibitor such as Letrozole, Arimidex or Exemestane 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. 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 be arranged by us or more commonly by your GP. Your Treatment Summary should tell you if these are required.

Regular exercise such as walking as well as a diet high in calcium will help to maintain bone health. During your open access consultation you will have received verbal and written information about how to look after your bones. Please contact our open access telephone helpline if you require further information.

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

If you have had chemotherapy, you may possibly experience some long term side effects such as fertility issues, effects on the heart and altered sensation in your fingers and toes (peripheral neuropathy).

If you have a concern about any of these side effects, please contact our open access telephone helpline or your breast care nurse for advice and support

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 Open access telephone help line. You may need to be referred to a gynaecologist.

There is some research that suggests some drugs – including the antidepressants paroxetine (Seroxat®) and fluoxetine (Prozac®) – may cause Tamoxifen to be less effective, but this isn't certain. If you are prescribed these please tell us.

Aromatase inhibitors such as Letrozole can sometimes cause joint stiffness and pain, as well as vaginal dryness which some women find uncomfortable.

We will have given you a separate advice sheets about these. If you do not have these you can ask us for another copy. If you are experiencing side effects of medication please contact our Open access telephone helpline for further support and advice.

Younger women

Younger women may have different needs at the end of treatment. There is a booklet from Breast Cancer Care called Younger women with breast cancer. This book covers issues which may be important to you such as:

- How treatment may affect your fertility
- What happens when you are diagnosed with breast cancer during pregnancy
- The impact a breast cancer diagnosis can have on your body image and sexuality and how this may impact upon relationships as well as practical advice about contraception

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. The general advice is that you should not get pregnant for two years.

If breast cancer returns - signs and symptoms

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.

However, breast cancer can sometimes return. There is no maximum time span as to when breast cancer can return 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)
- (rarely) in the other breast or
- elsewhere in the body (distant recurrence also known as metastatic breast cancer or secondary breast cancer)

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 not normal for you, please contact the Open Access telephone 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 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. Your breast care nurse can recommend you to 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 telephone helpline.

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. Included below is a summary of symptoms that you may want to report to either the open access telephone help line or your GP 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.

Getting 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 you may want to report:

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
- if you develop lymphoedema (affected side arm swelling)

Or if you experience:

- 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 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 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 and you can be seen 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 getting a bra to fit, 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. Most people 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 breast care nurse may be able to arrange an appointment for one to one support or counselling. It may also help to contact a local or national support organisation such as Breast Cancer Care or Macmillan Cancer Support. Their contact details can be found at the back of this booklet.

The Open access telephone service:

Once you have entered the open access follow-up programme you should call us to talk 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. A Macmillan support worker will also be available to offer information support over the phone once you have completed treatment.

Our commitment to you:

If the breast care nurse feels that you should be seen back in one of our clinics because of any symptoms you are experiencing, we will make sure that you are offered an appointment within seven days of telephoning us. If necessary, further investigations may be organised and an out-patient appointment arranged to receive the results. Sometimes, verbal advice may replace the need for an outpatient appointment and may be supported by correspondence 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 – Friday, 9am- 5pm and will be answered by a Macmillan support worker. If your call is not answered immediately please leave your name, hospital number and a short message and your call will be returned by the end of the working day.

Life after treatment

Once treatment is over people often want to know what they can do to stay healthy. You may have questions about your diet, exercise and general well-being which we would be happy to address. Some of the specialist services we offer focus on:

- stress management and general relaxation
- counselling and support
- lymphoedema
- menopausal side effects, including acupuncture for hot flushes
- fertility issues
- sexuality issues
- body image issues
- Look good feel better work shops

Welfare and benefits advice

If you are experiencing housing, employment, immigration, financial or welfare benefits issues, you can get help by contacting the welfare and benefits advisor. The telephone number is included at the end of this booklet.

If there are other issues which concern you that are not offered here, please discuss them with your breast care nurse who will be able to advise you on where to get help and support and information if you need it.

Finally

If you are worried about something to do with your breast cancer, or the treatment that you have had for it, please contact your key worker or breast care nurse. 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.

Useful Contacts:

Open access telephone helpline

01784-884762

Breast care nurses/ Clinical Nurse Specialist

Ashford Hospital **01784 884411**

St. Peter's Hospital **01932 722771**

Lymphoedema Service

Faith Cockroft 01932 722771 or 01932 722684

Prosthesis Fitting

St. Peter's Hospital **01932 722771**

To change a mammogram appointment

Ashford Hospital **01784 884477 or 01784 884473**

Ashford Breast Cancer Support Group

Pat Morrison 01784 252344

Carole Edmonds 01784 455670

The Mulberry Centre

Tel: 0208 321 6300

www.themulberrycentre.co.uk

The Fountain Centre, St. Luke's Cancer Centre

Tel: 01483 406618

www.fountaincentre.org

CREST Cancer Support Charity

Tel: 01784 446298

www.crestcancer.org.uk

Welfare and Benefits Advisor

Macmillan Welfare Rights

Tel: 01483 230849

Email: macmillan@guildfordcab.org.uk

Runnymede and Spelthorne Citizens Advice Bureau

Advice Assessment Telephone: 01932 827187

Mon-Fri from 10:00am -12:30pm

Guildford Citizen Advice Bureau

Tel: 01483 576699

www.guildfordcab.org.uk

Look Good. Feel Better Work Shops:

Contact Fountain Centre on 01483 406618

Breast Cancer Care

Free Helpline: 0808 800 6000

www.breastcancercare.org.uk

Macmillan Cancer Support
Free helpline: 0808 808 0000
www.macmillan.org.uk

The London Haven: Breast cancer support Centre
Effie Road, SW6 1TB
Tel: 0207 384 0000
www.thehaven.org.uk

The Brigitte Trust
Tel: 01306 881816
Website: <http://www.brigitte-trust.org/>

Maggie's: Cancer caring centres
Charing Cross Hospital
Fulham Palace Road
London, W6 8RF
Tel: 0207 386 1750
www.maggiescentres.org

The Jarvis Breast Screening Unit
Stoughton Road
Guildford, Surrey
Tel: 01483 783211

The Ashford and St. Peter's Hospitals Switchboard
Tel: 01932 872000

Further Information

We endeavour to provide an excellent service at all times, but should you have any concerns please, in the first instance, raise these with the Matron, Senior Nurse or Manager on duty.

If they cannot resolve your concern, please contact our Patient Experience Team on 01932 723553 or email patient.advice@asph.nhs.uk. If you remain concerned, the team can also advise upon how to make a formal complaint.

Author: Regina Santos

Department: Breast Clinic

Version: 1

Published:

Review:



We can provide interpreters for a variety of languages, information in larger print or other formats (e.g. audio) - please call us on 01932 723553.

To use the Text Relay service, prefix all numbers with 18001.

اگر نیاز به ترجمہ دارید، لطفاً با شماره 01932 723553 تماس بگیرید.

ने उदाहृ उतनमे ची लेउ वै उं विरथा वरवे ढिस नंघर उे डेन वरवे: 01932 723553

اگر آپ اس کا اردو زبان میں ترجمہ چاہتے ہیں، تو براہ کرم اس فون نمبر 01932 723553 پر رابطہ کریں

Se precisa de uma tradução por favor contacte: 01932 723553

আপনার অনুবাদের দরকার হলে এখানে যোগাযোগ করুন : 01932 723553

यदि आपको अनुवाद की ज़रूरत है तो कृपया इस नंबर पर फोन करें: 01932 723553

Jeżeli chcemy, aby te informacje w innym języku, proszę zadzwonić 01932 723553

Ashford Hospital
London Road
Ashford, Middlesex
TW15 3AA
Tel: **01784 884488**

St. Peter's Hospital
Guildford Road
Chertsey, Surrey
KT16 0PZ.
Tel: **01932 872000**

Website: www.ashfordstpeters.nhs.uk