

---

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

---

**Breast Unit**

**Patient Information**





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

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 when you need to. It is based on evidence showing that there is no advantages 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 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 The Royal Marsden 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 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 assessment 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 after 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 the hospital you will be invited and should 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:** 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.

## Contacting the NHS Breast Screening Service

If you want to cancel appointments, check when they will be screening in your area following your five years of annual mammograms (or longer if under fifty years of age) or self-refer for breast screening if over 73 years of age you can telephone the National Office and be provided with the telephone number for your local NHS Breast Screening Unit.

## 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 (arimidex) 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 you will complete five years of hormone therapy. If you haven't heard from us as you near the end

of your hormone treatment please contact the open access nurse practitioner.

Some patients will change their tablets after two or three years. 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.

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 open access nurse practitioner. 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 whilst you are taking Tamoxifen please tell your open access nurse practitioner.

Aromatase inhibitors such as Letrozole, Anastrozole and Exemestane can sometimes cause joint stiffness and pain, as well as vaginal dryness which some women find uncomfortable. If you are experiencing side effects of medication 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, a woman's bone 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 tell you if these are needed. Some times they are organised by the hospital 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 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 your open access nurse practitioner if you require further information.

## 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

The Royal Marsden NHS Foundation Trust has a rehabilitation service which gives you access to dietitians, physiotherapists, counsellors, psycho-sexual therapists and occupational therapists that have experience in helping people manage the side effects

of treatment. The open access nurse practitioner will be able to discuss these problems with you and arrange referral to other staff as required.

## Younger women

Younger women may have different needs at the end of treatment such as:

- the impact of treatment upon your fertility
- becoming pregnant after treatment
- issues related to body image and sexuality and how this may impact upon relationships
- 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 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 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 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. Included below is a summary of symptoms that you may want to report to either the open access nurse practitioner 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 anew 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 lymphedema (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 pain killers 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 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 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 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. 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 the open access nurse practitioner 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 nurse practitioner 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 a written letter 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 Friday, 9am-5pm and may 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, 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

**Spring into Action:** is a clinic organised by the physiotherapists and dietitians which offers individual advice about making positive changes to levels of physical activity and/or diet after cancer treatment. If you wish to attend you can self-refer and the telephone number is included at the end of this booklet. The clinic takes place in Chelsea and Sutton on alternate Tuesdays.

**Make a change, live well:** is a health and well being event for patients who have completed treatment for cancer and is organised by our Macmillan support worker. This event takes place every three months and you will be invited to this.

If you would like further information on services available to patients upon completion of treatment please ask us.

## **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 the open access nurse practitioner who will be able to advise you on where to get help and support and information if you need it.

## **Medicines Information Service**

This service provides support for patients who have any questions about medicines, including complementary medicines, vitamins supplements and medication you have been prescribed by a doctor. The phone number for this service is included at the end of this booklet.

## **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 nurse practitioner. 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 nurse practitioner**

Sutton and Chelsea

Tel: 020 7811 8114

Email: *oafu@rmh.nhs.uk*

### **Macmillan one to one support worker**

Sutton and Chelsea

Tel: 020 7352 8171 (ext. 4506)

Email: *oafu@rmh.nhs.uk*

### **Breast care nurses**

Sutton           Tel: 020 8661 3027

Chelsea          Tel: 020 7808 2813

### **Lymphoedema Service:**

Sutton           Tel: 020 8661 3504

Chelsea          Tel: 020 7808 2981

### **Medicines Information service**

Tel: 020 8770 3821

### **Nutrition and Dietetic Service (including Spring into Action Clinic)**

Sutton           Tel: 020 8661 3066

Chelsea          Tel: 20 7811 8194/2431

### **Physiotherapy Service**

Sutton           Tel: 020 8661 3098

Chelsea          Tel: 020 7808 2821

### **Occupational Therapy Service**

Sutton           Tel: 020 8661 3090

Chelsea          Tel: 020 7808 2336

### **Prosthetics team**

Sutton           Tel: 020 8661 3079

Chelsea          Tel: 020 7808 2811

## **Outpatients**

Sutton Tel: 020 8661 3430

Chelsea Tel: 020 7811 8194/2431

## **RDAC (Rapid Diagnostic & Assessment Centre) Administrator**

Sutton Tel: 020 8661 3828

Chelsea Tel: 020 7808 2467/8

## **To change a mammogram appointment**

Sutton Tel: 020 8661 3589

Chelsea Tel: 020 7808 2467

## **Social Work reception**

Sutton Tel: 020 8661 3382

Chelsea Tel: 020 7808 2481

## **The Welfare and Benefits Advisor**

Sutton Tel: 020 8642 6011

Chelsea Tel: 020 7808 2484

## **Chaplains**

Sutton Tel: 020 8661 3074

Chelsea Tel: 020 7808 2818

We can also put you in touch with our hospital multi- faith chaplains who would be happy to talk to you about any spiritual issues you may have.

## **Look Good.....Feel Better Work Shops**

Tel: 020 7808 2949 (available for up to one year after finishing treatment)

## **Breast Cancer Care**

Free Helpline: 0808 800 6000

Website: [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

## **Macmillan Cancer Support**

Free Helpline: 0808 808 0000

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

**The London Haven: Breast cancer support centre**

Effie Road, SW6 1TB

Tel: 020 7384 0000

Website: [www.thehaven.org.uk](http://www.thehaven.org.uk)

**Maggie's: Cancer caring centres**

Charing Cross Hospital

Fulham Palace Road

London, W6 8RF

Tel: 020 7386 1750

Website: [www.maggiescentres.org](http://www.maggiescentres.org)

**The South East Cancer Help Centre**

2 Purley Road (Tesco Development)

Purley, CR8 2HA

Tel: 020 8668 0974

Website: [www.sehc.org.uk](http://www.sehc.org.uk)

**Pauls Cancer Support Centre**

20-22 York Road

London, SW11 3QA

Tel: 020 7924 3924

Website: [www.paulscancersupportcentre.org.uk](http://www.paulscancersupportcentre.org.uk)

**The Macmillan Butterfly centre**

Epsom Hospital

First Floor Bradbury Wing

Tel: 01372 735 456

Website: [www.epsom-sthelier.nhs.uk](http://www.epsom-sthelier.nhs.uk)

**NHS Cancer Screening Programme**

Fulwood House

Old Fulwood Road

Sheffield S10 3TH

Tel: 0114 271 1060

Email: [info@cancerscreening.nhs.uk](mailto:info@cancerscreening.nhs.uk)

**The Jarvis Breast Screening Unit**

Stoughton Road

Guildford

Tel: 01483 783211

**SW London Breast Screening**

The Rose Centre

St George's Hospital

London

Tel: 020 8725 2723

**West London Breast Screening**

Charing Cross Hospital

Tel: 020 3313 6644

**The Royal Marsden Switchboard**

Sutton           Tel: 020 8642 6011

Chelsea           Tel: 020 7352 8171

**The Royal Marsden Help Centre – PALS  
(Patient advice and liaison service)**

Tel: 0800 783 7176

Email: *patientcentre@rmh.nhs.uk*

## Notes/Questions:

## Notes/Questions:

## References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Freephone: 0800 783 7176

Email: [patientcentre@rmh.nhs.uk](mailto:patientcentre@rmh.nhs.uk)

No conflicts of interest were declared in the production of this booklet

Published April 2014. Planned review April 2017

© The Royal Marsden NHS Foundation Trust xx-xxxx-xx

Life demands excellence

