
Open access follow up treatment for breast cancer

Patient and Carer Information



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Introduction

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. The programme is based on evidence showing that there are no advantages to regular, fixed time follow up 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 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.

This information is a summary of the group session and is for you to keep.

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. 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 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 The Royal Marsden 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 The Royal Marsden 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

Please contact your local unit. You can find your local centre online using the following web address:

www.nhs.uk/service-search/breast-screening-services/locationsearch/325

- if you wish to cancel appointments
- to check when they will be screening in your area following your five years of annual mammograms (or longer if under 50 years of age)
- to self-refer for breast screening if over 73 years of age.

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 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.

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 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 open access nurse practitioner. 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 The Royal Marsden 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. 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 (swelling).

The Royal Marsden has a rehabilitation service which provides 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 issues 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 fertility
- becoming pregnant after treatment
- issues related to body image and sexuality and how this may impact upon relationships
- advice about contraception.

Bisphosphonate treatment

Some individuals will be recommended a bisphosphonate treatment. This is usually given as a drug called Zometa or Zoledronic acid which is given as an infusion every six months for three years. If your oncology team has recommended this, they will have discussed it with you in the clinic prior to you receiving this booklet. It is important that your dental health is good and regular dental checks are recommended whilst on this treatment.

There is a separate booklet available which outlines the treatment and side effects in more detail. *Bisphosphonates in early breast cancer* should be available from your Breast Care Nurse or the PALS Help Centre at The Royal Marsden at both Chelsea and Sutton.

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 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

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 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.

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
- lymphedema (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 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 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 within two weeks of telephoning us. 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 Friday, 9am-5pm and may be answered by a Macmillan support worker or a nurse practitioner. 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 wellbeing 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* workshops.

Spring into Action

Is a clinic organised by 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. Please see the contact details on page 16. The clinic takes place at both Chelsea and Sutton on alternate Tuesdays.

Welfare and benefits advice

If you are experiencing issues with housing, employment, immigration, financial or welfare benefits, you can get help by contacting the welfare rights advisor. Please see contact details on page 17.

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.

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 7811 8114

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

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

Sutton Tel: 020 8661 3066

Chelsea Tel: 020 7808 2814

Physiotherapy Service

Sutton Tel: 020 8661 3098

Chelsea Tel: 020 7808 2821

Occupational Therapy Service

Sutton Tel: 020 8661 3090

Chelsea Tel: 020 7808 2830

Prosthetics team

Sutton Tel: 020 8661 3079

Chelsea Tel: 020 7808 2811

Outpatients

Sutton Tel: 020 8661 3430

Chelsea Tel: 020 7811 8194/2431

To change a mammogram appointment

Sutton Tel: 020 8661 3589

Chelsea Tel: 020 7808 2467

Welfare rights 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 Workshops

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

Website: www.lookgoodfeelbetter.co.uk/workshops-near-me/

Breast Cancer Care

Free Helpline: 0808 800 6000

Website: www.breastcancercare.org.uk

Macmillan Cancer Support

Free Helpline: 0808 808 0000

Website: www.macmillan.org.uk

The London Haven: Breast cancer support centre

Tel: 020 7384 0099

Website: www.breastcancerhaven.org.uk/london

Maggie's: Cancer caring centres

Charing Cross Hospital

Tel: 020 7386 1750

The Royal Marsden, Sutton

Tel: 020 3982 3141

Website: *www.maggiescentres.org*

The South East Cancer Help Centre

Tel: 020 8668 0974

Website: *www.sechc.org.uk*

Pauls Cancer Support Centre

Tel: 020 7924 3924

Website: *www.pauls.org.uk*

The Macmillan Butterfly Centre

Epsom Hospital

Tel: 01372 735 456

Website: *www.epsom-sthelier.nhs.uk*

NHS Cancer Screening Programme

Tel: 0114 271 1060

Email: info@cancerscreening.nhs.uk

The Jarvis Breast Screening Unit

Stoughton Road

Guildford

Tel: 0333 200 2062

SW London Breast Screening

The Rose Centre

St George's Hospital

London

Tel: 020 8725 4868

West London Breast Screening

Charing Cross Hospital

Tel: 020 3758 2024

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 and questions

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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

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.



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