

Information about supported self-management (SSM) after treatment for breast cancer

Breast Care Centre

Information for patients

Produced: Sep 2023

Review: Sep 2026

Leaflet number:2004 Version:2.3

What is supported self-management?

Now that you have completed your treatment for breast cancer you have been referred for supported self-management. This offers you support and education to help you take charge of your health and wellbeing. It provides follow-up after treatment for breast cancer.

What are the benefits of supported self-management?

Routine clinic visits and investigations often cause anxiety and stress for individuals who are well following their treatment. Other hospitals have found that SSM allows patients to put their cancer experience behind them and focus on getting back to their normal lives. They tend to worry less about results and clinic appointments and also avoid the inconvenience that these visits may cause. It allows you (the patient) to take control - you can quickly gain access to the team when you need to. It is based on evidence showing that there is no advantage to regular, fixed-time follow-up in hospital after treatment for breast cancer is completed.

Any concerns that you have can be dealt with quickly. Routine follow-up appointments can sometimes delay us finding out about problems as people tend to wait for their appointment before raising any concerns.

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 most women, mammograms are the recommended way of checking for breast cancer. 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 University Hospitals of Leicester NHS Trust (UHL). For a small number of women mammograms may not be appropriate and we will discuss the other options if this is the case.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

Results of mammograms

After your mammogram, you will receive your results by letter. It is therefore 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 on 0116 258 3644.

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

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 ring the Breast Screening Office for advice on 0116 258 3644.

After five years of mammograms

If you are aged over 50 years: after five years of follow-up at the hospital you will have mammograms as part of the National Breast Screening Programme and have 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 Programme.

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 Programme

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, please ring the Breast Screening Office for advice on 0116 258 3644.

Your cancer medication - endocrine therapy

Patients with hormone-sensitive cancers are prescribed anti-hormone tablets, also known as endocrine therapy. Endocrine therapy includes tamoxifen, letrozole, anastrozole and exemestane. You will be on these tablets for five to ten years depending on which medication you are prescribed.

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 to something else. Your last clinic letter (or treatment summary if available) should confirm the date you started your endocrine medication and the date you will complete five years of endocrine therapy.

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, or your Breast Care Nursing Team.

Endocrine therapy

Treatments change and develop as new information from research studies becomes available. If there are major changes in the way we prescribe endocrine 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 have an appointment to discuss this further.

Possible side effects of endocrine 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 Nursing Team. 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 is not certain. If you are prescribed these whilst you are taking Tamoxifen please tell your doctor or GP.

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 GP for advice.

Dexa scans and bone health

After the menopause, oestrogen levels fall and this can reduce the strength of women's bones. When you are taking an aromatase inhibitor such as letrozole, anastrozole or exemestane this process may be speeded up. You may need one or more bone density scans (DEXA scans) in the few years after your breast cancer. These scans can tell us if your bones are becoming less strong and thinning, called osteopenia, which could lead to a condition called osteoporosis. Your Treatment Summary will tell you if these scans are needed. These are organised by the hospital or by your GP. We will let you know how these will be booked.

You may also need bone density scans if your periods have stopped early because of your treatment. This can be arranged by us or more commonly by your GP. Your Treatment Summary should tell you if these are required.

Regular weight-bearing 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 the Breast Care Nursing Team if you require further information. If needed, they will then seek advice from your oncologist or surgeon.

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 and not at all while on endocrine therapy.

Possible side effects of treatment

All treatments (surgery, chemotherapy, radiotherapy and hormone therapy) have possible 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.

Looking after yourself

Survival rates for breast cancer are improving all the time and today's breast cancer treatment is usually very successful.

However, breast cancer can sometimes return. There is no maximum timespan 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 us. 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. Ask your Breast Care Nursing Team if you are unsure.

You know better than anyone how your breasts look and feel normally, so if you notice a change, contact the Breast Care Nursing Team using the contact details on page 7.

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 your Breast Care Nursing Team 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 may mean that you should get them checked out.

If your cancer comes back it can be frightening, but it is important to remember that if breast cancer returns, it can usually be treated.

Signs and symptoms

Please contact us if you have:

- 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 (swelling) in the arm on the same side as your operation
- any new 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 and has lasted longer than two weeks.
- any new pins and needles and/or loss of sensation or weakness in your arms or legs
- unexplained weight loss and loss of appetite
- a constant feeling of nausea (sickness) for more than two weeks
- discomfort or swelling under your ribs or across your upper abdomen for longer than one week
- a dry cough or a feeling of breathlessness for more than three weeks.
- severe headaches - usually worse in the morning—which do not get better with rest and last longer than ten days.

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 referred 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 Clinical Nursing Team can signpost you to counselling services. It may also help to contact a local or national support organisation such as Breast Cancer Now or Macmillan Cancer Support. Their contact details can be found at the back of this booklet.

Our commitment to you

If the Breast Care Nursing Team feels that you should be seen in one of our clinics because of any symptoms you are experiencing, we will make sure that you are offered an appointment within fourteen days of telephoning us. If necessary, further investigations may be organised and an out-patient appointment arranged to receive the results. This may be with either the breast surgery or oncology team. 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.

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 talk about. 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
- Moving Forward and HOPE courses for patients who have completed treatment
- Benefits that you may be able to claim

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 Care Nursing Team. They would rather help 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.

Importantly, this service is not for acutely unwell patients, so if you feel suddenly very unwell, please seek urgent medical attention through your GP, A&E, or the 111/999 services.

Group Health and Wellbeing Support

We will send you an online presentation, via a link, one year after discharge from your surgeon. You will be shown how to be body and breast aware including specific symptoms you should report without delay to your Breast Care Nursing Team. In person sessions are also available. Please let us know if you would prefer an in person session, and this can be arranged.

Some people will still be having active treatment one year later, if this is the case we will contact you to change your appointment accordingly.

Contacting the Breast Care Nursing Team

Please contact the open access number 07855173531 or

mailbox: uhl-tr.breastopenaccessmailbox@nhs.net in the event of any questions or concerns. This will be checked weekly.

Please ensure you leave your name, date of birth, hospital number (if you have it) and the best way to contact you back. This will usually be a phone number.

One of the Breast Care Nursing Team will call you back to talk through the symptoms or concerns that you have and decide with you whether you need to be brought back to clinic initially for a clinical review and a decision about any tests needed. We may in many cases be able to resolve your query without you having to come in.

You can alternatively contact us with any non-urgent queries by scanning the below QR code or copying the URL into your web page on your computer or laptop.

Scan the below to contact the **Breast Cancer Remote Monitoring team** at University Hospitals of Leicester:



<https://accurx.nhs.uk/p/RWEBRM>

This is for non urgent requests, for urgent help please call 111 or 999

Importantly, this service is not for acutely unwell patients, so if you feel suddenly very unwell, please seek urgent medical attention through your GP, A&E, or the 111/999 services.



Other useful contacts

Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary, LE1 5WW

Telephone: 0116 258 6189
Email: uhl-tr.cancerinformationcentre@nhs.net
Website: www.uhleicester.nhs.uk/

Breast Cancer Now

Telephone: 0808 800 6000
Website: www.breastcancer.org

Macmillan Cancer Support

Freephone: 0808 808 00 00
Website: www.macmillan.org.uk

Local support and information

There are local organisations, including support groups, that may offer you the support and information you are looking for. Please ask your Breast Care Nursing Team for details or contact the Macmillan Information and Support Centre (details above).

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿੱਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net