

Patient Initiated Follow-up programme

Information and advice for patients

Breast Unit

What is patient initiated follow-up? (PIF)

Research has shown that having regular outpatient follow-up does not help prevent cancer returning or identify any new problems and many patients find the follow-up visits cause a lot of anxiety.

Patient initiated follow-up puts the patient in control. More emphasis is now placed on self-awareness and easy access to the Breast team. If you have any concerns or problems, please ring the Breast Care Nurses. They will discuss your concerns over the phone and if necessary they will arrange a hospital appointment for you. You will still attend for your planned mammograms if you require them.

Symptoms you may want to report

Many patients ask what symptoms they should report to us. The majority of patients have no further problems after they complete their treatment and live to an old age without any cancer related problems.

The following guide suggests what symptoms to seek further advice about. If you have any of the following symptoms for more than 3 weeks which are getting worse rather than better, please contact Breast Care Nurse.

- New changes in your breast (s) & scars e.g. lumps or skin nodules
- Swelling of the arm/hand on the side of the breast cancer
- Lumps around the collar bone, neck or armpit
- Unexpected vaginal bleeding or spotting (if on hormone tablets)
- New Persistent back or bone pain which is unrelieved with regular painkillers
- A New dry cough or a feeling of breathlessness

Your feelings

Everyone will have different feelings when they no longer need to be seen regularly by their medical team. Some people feel relieved that they can start getting their lives back to normal. Others may be concerned about what can happen in the future and are anxious about losing contact with the hospital.

Most people worry about the cancer coming back. This is perfectly normal and usually lessens with time. If you are finding moving on difficult, you may want to talk to your Breast Care Nurse, GP or if needed, one-to-one support or counselling can be arranged.

You can talk to someone who has been through a similar experience through the breast Cancer Peer Support Service or a local support group. Your Breast Care Nurse will be able to provide you with these contact details.

Breast Awareness

It is important to be breast aware after your treatment. Being breast aware means knowing how your breasts feel and look. If you notice any changes that aren't normal for you please contact your Breast Care Nurse.

Mammograms

Following your treatment, you will be invited to have regular mammograms (breast x-ray). If you have had a mastectomy, a mammogram will be done on the other side. After a lumpectomy or wide local excision you will have mammograms on both breasts. A complete breast reconstruction does not need a mammogram.

Mammograms will be done in the Breast Unit for a total of 5 years after your surgery (or until you reach the age of 50 if your cancer was diagnosed before the age of 45 years). Your mammogram will usually be done around the same month each year.

If you receive an invitation to attend routine breast screening (usually done on a mobile van) during the 5 year period we are doing hospital mammograms, please cancel the screening appointment.

Your follow-up mammograms will be around the same month each year:

From _____ / _____

Until _____ / _____

After your final planned mammogram, we would advise you to have mammograms with the National Breast Screening Programme. You can ring them on 0121-507-4967 to let them know you wish to have breast screening mammograms and they will then call you every 3 years between the ages of 50 to 70 years old. If you are over 70 years old then you can still request 3 yearly screening mammograms if you wish, but you will not automatically be recalled. We will give you information on how to arrange screening after your final mammogram with us.

At the end of your mammographic follow-up you will be discharged from our care, back to the care of your General Practitioner. After this, if you develop any problems, your GP will need to refer you back to us.

Hormone treatment

If you have been prescribed hormone tablets to take (Tamoxifen, Anastrozole, Exemestane, Letrozole), you will need to take these until:

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These tablets are normally taken for a minimum of 5 years. Some patients may need to take these tablets for a longer period. Some women need to change tablets after 2-3 years, especially if they have gone through the menopause (the change). Whilst on certain tablets we may advise you need a regular bone density scan to look for any signs of bone thinning.

After 5 years of treatment we will contact you to let you know if you need to stop the tablets or if we would recommend you continue for longer. You will be advised about your individual plan by either the surgical or oncology team.

What support can my Breast Care Nurse offer?

Your Breast Care Nurse will be known to you since your diagnosis and she can provide you with specialist advice, support and information. The Breast Care nurse service is available to you at any point, whilst you are having mammograms under our care.

If your first treatment is an operation, one of our Cancer Support Workers will ring you to offer a "holistic needs assessment" at around 3 months after your diagnosis. This provides an opportunity for you to talk about any concerns or issues you may have. If you have chemotherapy as your first treatment, this assessment will be offered by the hospital where you are receiving treatment.

At around 6-9 months, a breast care nurse will ring again to discuss your care, any concerns, problems treatment side effects etc. This is called an End of Treatment Consultation.

Please be reassured your Breast Care Nurse team are available at any time during your journey to discuss issues including new symptoms, problems with tablets, prosthesis advice, to discuss breast reconstruction or to provide advice and support.

Clinical trials

If you are taking part in a clinical trial you may be seen in clinic regularly for a longer time period.

Contact details

You can contact our Breast Care Nurse team on 0121 507 4976

Monday - Friday, 9:00am - 4:00pm

You can also contact our Surgical Secretaries on:

0121 507 4593 / 0121 507 5961 / 0121 507 5111 Monday - Friday, 8.30am - 4.30pm

If your call cannot be answered please leave a message on the answer phone. Messages are checked regularly.

Mammogram appointments

If you need to change your follow-up mammogram appointment please call 0121 507 4967 option 2.

When you need to re-enter the National Screening Programme please call 0121 507 4967 option 1.

Further information

Below is the list of support groups that might be of interest:

Breast Cancer Now

0808 800 6000

<https://breastcancernow.org/>

Macmillan Cancer Support

0808 808 0000

www.macmillan.org.uk

Sources used for the information in this leaflet

- National Institute for Health and Care Excellence (2018). *Early and locally advanced breast cancer* [NICE Guideline 101]. [Online]. London: NICE. Available at: <https://www.nice.org.uk/guidance/ng101> [Accessed: 26th June 2023]
- Montgomery, D. A., Krupa, K., & Cooke, T. G. (2007). Follow-up in breast cancer: does routine clinical examination improve outcome? A systematic review of the literature. *British journal of cancer*, 97(12), 1632–1641. <https://doi.org/10.1038/sj.bjc.6604065>

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