

New model of follow-up after breast cancer treatment

Information for primary care

Although the pathway has changed we will still provide continued care and support for your patients when they need it. We call this supported self management on the road to recovery.

Why are we sending you this information

Because from this year, follow-up for breast cancer patients with a low risk cancer changed. Such patients are likely to be post menopausal and have had treatment with surgery, radiotherapy and endocrine therapy. Younger patients and those who have had chemotherapy as part of their treatment will at present continue under current regular review.

What is the 'Living with and beyond' programme?

This is a new way of follow-up for patients who are at low risk of recurrence of their breast cancer. Patients will remain under the care of the breast team for five years but will not be under 'active follow-up'. Patients will be seen for the first year after treatment starts so that we can help them with most of the adverse effects of their treatments. After this they are discharged to monitor themselves and can call us when they have a problem. This way they don't have to come to hospital at times when they are feeling well and have no concerns.

Why have we made this change?

National guidance suggests that with the medical model of routine follow-up appointments with regular clinical examination for these patients is not effective at managing their symptoms, or concerns or picking up recurrences which are usually detected by the patients themselves. It can also be a poor experience for patients. Traditional follow-up is often a source of anxiety and can lead to patients delaying reporting symptoms if the next routine appointment is not too far away. Patient supported self-management allows patients to be more in control of their own recovery and to ask for help when they need it.

Is patient supported self-management only happening in Northumbria Healthcare?

Many different trusts are now establishing and following such a programme of patient supported follow-up.

What information has been given to your patients so far?

Patients will have been seen regularly during the first year of their cancer follow up. In that time they will have had:

Holistic needs assessments on a minimum of two occasions - at diagnosis and at the end of their primary treatment.

A treatment summary completed detailing their therapies and documenting the short-term adverse effects that they have experienced and the ways in which these have been treated. There will also be information on potential long-term side effects and how these can be managed by patients themselves and closer to home in the community. The treatment summary will detail any medication that you will have to prescribe for your patients and any tests that you might need to arrange for them.

Wellbeing events Patients will have attended two of these before being discharged. These educational events support patients to manage their condition and to actively participate in their recovery, giving them necessary information to promote and maintain positive lifestyle changes, detect possible changes early and to find further help and support when they need it.

Will patients still have regular mammograms?

Yes, patients will continue to have regular mammograms annually for five years as now, if clinically appropriate. After this time they will return to the standard NHS breast screening programme unless they are under 50 years when annual mammograms will continue until 50 years of age when they will then join the NHS breast screening programme. We will write to patients and their GPs with mammogram results.

And bone density scans?

If your patient requires bone density scans these will be arranged at diagnosis and two yearly thereafter until five years. We will write to patients and GPs with the results of their bone density scans. After five years further bone density scans will need to be requested from primary care as now.

Patients will still be able to access breast care

If they have any concerns or problems and will be encouraged to do so via the breast helpline. This can be accessed by telephoning 0344 811 8111 and asking for the breast helpline. This will be available from 10am-12 midday and 2pm-4pm daily and patients will be called back by one of our breast care nurse team within one working day. If it is felt that investigations or a review appointment is required then these will be arranged as appropriate.

Primary care cancer review

You will still be required to undertake this review but you will have much more information about your patient from the treatment summary which you will receive at the end of the patients' surgery and radiotherapy treatment.

Changes that patients should report

The following is a reminder of the symptoms and signs that might suggest a spread or return of the patient's breast cancer and which may need further investigation. Patients should contact the breast helpline if these occur.

- A lump or swelling in the breast, in the skin or under the arm in the axilla or in the neck. This includes lumps which appear to be involving or close to any scars from previous surgery
- Any skin changes occurring in the skin over the remaining breast tissue, chest wall or under the arm or on the neck. This might be areas of redness, puckering or raised thickened spots
- Discharge from the nipple or nipple in-drawing

- Any thickening of the skin over the breast, axilla or arm which might be lymphoedema
- Persisting pain in any bones or joints or any part of the body which does not settle after a few days or which does not settle with painkillers
- Discomfort or swelling in the upper abdomen of below the ribs
- A persisting dry cough or breathlessness
- Persisting weight loss or loss of appetite which is unplanned or unexplained
- Persisting feelings of nausea
- Headaches which are severe and which seem worse on waking in the morning
- Any neurological symptoms which might be due to an underlying spinal cord compression:
 - pins and needles
 - loss of sensation and numbness in the arms, legs or face
 - weakness in the arms, legs or face

These symptoms might suggest that the patient requires assessment in emergency care for urgent review and perhaps MRI. The emergency care department will then decide if the local spinal cord co-ordinator should be contacted directly.

Please encourage your patients to contact the breast care nurses via the breast helpline for any symptoms or signs that might suggest a recurrence or spread of their cancer or with any symptoms which might represent an adverse effect from their previous treatment which they are not able to manage for themselves.

You can also contact this number if you have any concerns regarding your patients' care or for advice regarding new symptoms or signs (unless these might suggest spinal cord compression when a direct referral to the emergency care department for urgent review should be made.)

Breast helpline

0344 811 8111

Available: 10am-12 midday
& 2pm-4pm

Messages will be collected and responded to within one working day.