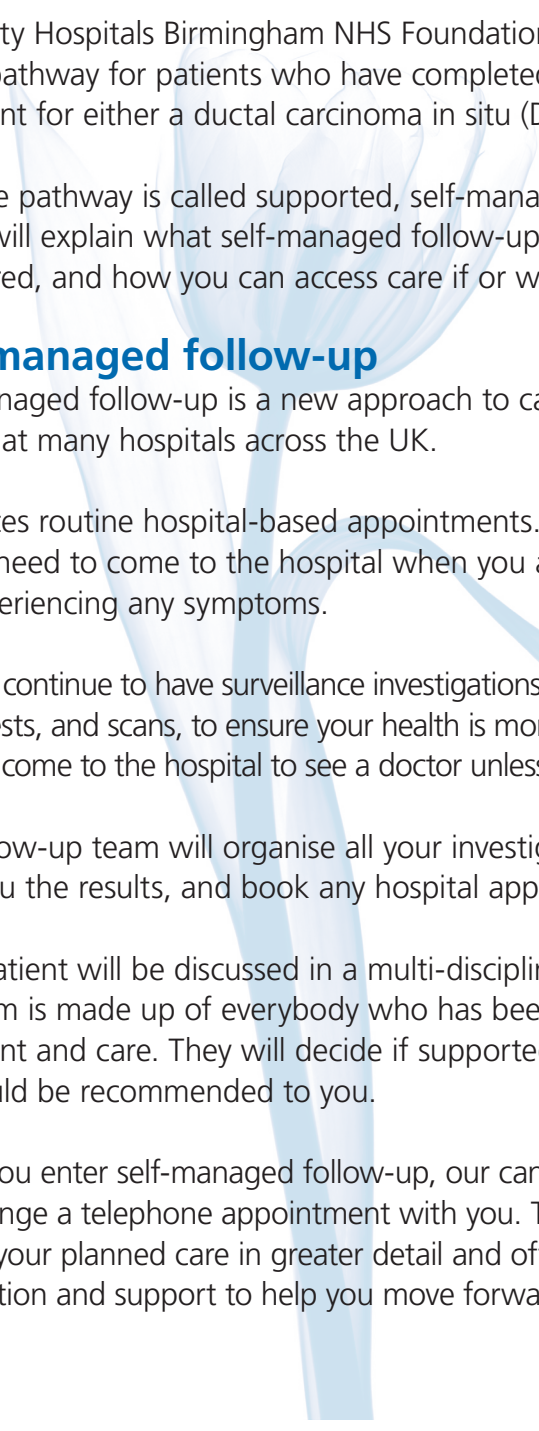




**Information about supported  
self-managed follow-up for  
patients with breast cancer or  
ductal carcinoma in situ (DCIS)**

**Building healthier lives**

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University Hospitals Birmingham NHS Foundation Trust has put in place a care pathway for patients who have completed their hospital-based treatment for either a ductal carcinoma in situ (DCIS) or breast cancer.

The care pathway is called supported, self-managed follow-up. This leaflet will explain what self-managed follow-up is, how you will be monitored, and how you can access care if or when needed.

## **Self-managed follow-up**

Self-managed follow-up is a new approach to care, which is being offered at many hospitals across the UK.

It replaces routine hospital-based appointments. This means that you do not need to come to the hospital when you are feeling well and not experiencing any symptoms.

You will continue to have surveillance investigations, such as mammograms, blood tests, and scans, to ensure your health is monitored, but you will not need to come to the hospital to see a doctor unless you have any concerns.

The follow-up team will organise all your investigations and scans, send you the results, and book any hospital appointments as needed.

Every patient will be discussed in a multi-disciplinary team meeting; this team is made up of everybody who has been involved in your treatment and care. They will decide if supported self-managed follow-up should be recommended to you.

When you enter self-managed follow-up, our cancer support workers will arrange a telephone appointment with you. This appointment will discuss your planned care in greater detail and offer you additional information and support to help you move forward from your diagnosis.

# Follow-up care for patients who have had breast cancer or DCIS

## Mammograms

After a diagnosis of DCIS or breast cancer, you have a slightly increased risk of developing a further problem in the same breast (if you still have breast tissue on that side) or a new problem in your other breast.

To monitor you, we will arrange for you to have a mammogram annually for five years, starting 12 months after your surgery.

You will receive the results of your mammogram in the post. If these results are normal; the team will inform you via letter and arrange your next mammogram for the following year.

If something requires further investigation, you will receive a letter with information about what to expect next. Sometimes, after breast cancer treatment, mammograms are not as easy to interpret. If this is the case, we may need to bring you back for further assessment.

If you have any queries about any of your appointments, please contact the follow-up team.

# The NHS Breast Screening Programme

The NHS Breast Screening Programme is a national programme offering mammographic surveillance to women aged 50 to 70. These mammograms are offered every three years. This service is separate from the follow-up care you are receiving at your treating hospital, meaning you may be invited for a screening mammogram while still receiving follow-up care for your DCIS or breast cancer. You should not have a screening mammogram whilst in follow up for your breast cancer.

If you receive an invitation from the National Breast Screening Programme while you are in follow-up, please contact the NHS screening team on the telephone numbers provided on the invitation letter. They will arrange for your screening mammograms to commence after your hospital follow-up has ended.

**If you are under 50 years of age:** We will arrange your annual mammograms at the hospital until you reach the age of 50.

**If you are aged 70 or over:** You will not automatically be called for routine breast screening. However, you are eligible have mammograms at your request. Please get in touch with your local breast screening unit to arrange these. The contact details for local breast screening units are listed at the end of this leaflet. Your GP can tell you which screening service covers your area

## Hormone therapy

If your cancer was hormone-sensitive, you will have been prescribed anti-oestrogen tablets, also known as hormone therapy or endocrine therapy.

Examples of anti-oestrogen tablets include:

- Tamoxifen - usually used in pre-menopausal women or men with breast cancer.

The following are known as aromatase inhibitors (AI) and are usually for post-menopausal women:

- Exemestane
- Anastrozole
- Letrozole

You will need to take these tablets for the next five to 10 years. Your GP will provide you with a repeat prescription for these. You should continue to take these tablets to reduce the risk of your cancer returning. If you are struggling with the side effects of your hormone therapy, please make an appointment to come and see us, as it may be possible to adjust your treatment. Please do not stop taking your medication before discussing it with your team.

Your treatment summary will confirm the date you started taking your hormone medication and the date you should stop taking it. If you are unsure about the type or duration of hormone therapy you have been prescribed; please get in touch with the follow-up team.

## Bone health

If you have been prescribed an aromatase inhibitor (AI), there is a risk that you may develop osteoporosis (bone weakening) in the future.

We will arrange for you to have a DEXA scan at the start of your AI treatment to check your bone strength. If the results of this scan are normal, we will only need to repeat it if you have been advised to take the AI for more than five years.

If your DEXA scan results are abnormal, you may need repeated DEXA scans throughout your AI treatment. In addition, you may be prescribed some additional medications such as calcium and vitamin D supplements or a group of drugs called bisphosphonates. Examples of bisphosphonates include:

- Zolendronic acid (Zometa)
- Ibandronic acid (Bondronat)
- Disodium pamidronate (Acredia)
- Sodium clodronate

You must continue to take these medications if prescribed, until you are told otherwise to maintain your bone health.

Regular exercise and a healthy diet can also help to maintain your bone health.

## Expected after-effects of breast cancer treatment

Breast cancer treatments (surgery, chemotherapy, radiotherapy, hormone therapy) can cause long-term side effects. Some of the common side effects include:

- Breast discomfort and tenderness
- Menopausal-related side effects
- Fatigue
- Problems sleeping
- Lymphoedema

Please contact the follow-up team if you are concerned or need further support with these side effects.

## Self-examination and changes in health

It is important to remain breast aware. Whilst most people who have completed treatment for breast cancer have no further problems, sometimes a breast cancer can come back.

Whether you have had breast-conserving surgery or a mastectomy (with or without reconstruction), it is important to be aware of any changes to the breast, chest or surrounding areas after your treatment.

Changes to look and feel for in the breast, chest and under the arm:

- Change in the size or shape of your breast
- Rashes or redness on the skin or nipple
- Discharge from the nipple
- Swelling in your chest, armpit or around your collarbone
- A lump
- Thickening of the skin that feels different
- Changes in the texture of the skin such as puckering or dimpling
- Nipple inversion (where the nipple is pulled inwards)
- Changes in the shape or position of the nipple
- Pain

Other symptoms you may want to report:

- Unexplained weight-loss
- Pain in your bones that doesn't improve with pain relief, particularly if this is persistent and worse at night.
- A persistent feeling of nausea
- Feeling constantly tired
- New discomfort or swelling under your ribs or across your upper abdomen
- Feeling breathless
- A dry, persistent cough
- Altered vision or speech
- Headaches that do not improve with pain relief and are persistent
- Abnormal vaginal bleeding

Please do not hesitate to contact the follow-up team if you experience any of these symptoms.

## Periods, fertility and contraception

### Pre-menopausal women

Breast cancer treatment can make your periods irregular or cause them to stop altogether, either temporarily or permanently. However it may still be possible for you to become pregnant. It is therefore important that you use effective contraception. Hormone-based contraceptives are not usually recommended. You should discuss your options with your GP or practice nurse.

You may be keen to start a family once you have completed your breast cancer treatment. If you plan on becoming pregnant, discussing this with your oncologist beforehand is essential, as they will need to advise you regarding medications, potential risks, etc.

If you have difficulties becoming pregnant after your cancer treatment you may be referred to a fertility team for further assessment and investigation.



## **Pre and post-menopausal women**

Some breast cancer treatments can cause abnormal vaginal bleeding. Please report any unexpected bleeding to your follow-up team. Other side effects from treatment can include vaginal dryness and a reduced interest in sex. You can speak, in confidence, to the follow-up team, who can advise and support you with any of these issues.

## **Reconstruction**

You should have had the opportunity to discuss breast reconstruction with your surgeon (if applicable). If you have concerns regarding your surgery or scars or you wish to explore breast reconstruction options, please get in touch with the follow-up team, who will arrange a surgical appointment for you.

## **Prostheses**

If you have had a mastectomy or you have some asymmetry after a lumpectomy, you should have been fitted with a breast prosthesis. If you have not, please contact the follow-up team who will arrange a fitting appointment for you.

Breast prostheses may need replacing in the future if they show signs of wear and tear or if you lose or gain weight. If you need a new prosthesis, please contact the follow-up team, who can arrange a replacement.

## Ongoing support

The treatment you have received for breast cancer or DCIS may have caused a lot of disruption in your life. You may continue to have physical or emotional needs even after your treatment has finished.

The breast cancer follow-up team will continue to support you, so please do not hesitate to contact us if you are worried about anything. The team contact details are listed below.

## Useful telephone numbers

### The Breast Cancer Follow Up Team

Email: **breastcancerfollowup@uhb.nhs.uk**

### Queen Elizabeth Hospital

Cancer Support Worker: **07502714347**

Clinical Nurse Specialist: **07502689749**

Telephone: **0121 371 8060**

Telephone: **0121 371 7647**

### Solihull and Good Hope Hospitals

Cancer Support Worker: **07825 243 493**

Breast Cancer Follow up team: **0121 424 4034**

Health information centre: **0121 424 5616**

**The Patrick Room** (Queen Elizabeth Hospital cancer centre information room): **0121 371 3537**

### NHS Breast Screening Services:

- South Birmingham (Queen Elizabeth site) : **0121 335 8050**
- Warwickshire, Coventry and Solihull: **0247 696 7200**
- Hereford and Worcestershire: **01527 488 055**
- Dudley and Wolverhampton: **01384 244 177**
- City, Sandwell and Walsall Breast Screening Service: **0121 507 4967**

## Useful links

### **Breast Cancer Now:**

[www.breastcancernow.org.uk](http://www.breastcancernow.org.uk)

General enquiries and supporter care: 0333 20 70 300

Support services: 0345 077 1893

Email: [hello@breastcancernow.org](mailto:hello@breastcancernow.org)

### **Macmillan Cancer Support:**

[www.Macmillan.org.uk](http://www.Macmillan.org.uk)

Tel: 0808 808 0000 (8am to 8pm, seven days a week)

### **Cancer Research UK:**

[www.cancerresearchuk.org/about-cancer/breast-cancer](http://www.cancerresearchuk.org/about-cancer/breast-cancer)

### **NHS website:**

[www.nhs.uk/conditions/breast-cancer](http://www.nhs.uk/conditions/breast-cancer)

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email **[interpreting.service@uhb.nhs.uk](mailto:interpreting.service@uhb.nhs.uk)**.

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**Breast Care**  
University Hospitals Birmingham NHS Foundation Trust

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