



**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 new care pathway for patients who have completed their hospital-based treatment for ductal carcinoma in situ (DCIS) or breast cancer.

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

Supported self-managed follow-up

Supported 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 follow-up appointments. This means that you do not need to come to hospital when you are feeling well and not experiencing any symptoms. Instead, you can contact the team at the hospital who are looking after you and arrange to see them as and when you need to.

You will continue to have all the necessary investigations such as mammograms, blood tests and scans which are needed to monitor you safely.

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.

You will then have an appointment with your consultant and/or clinical nurse specialist (CNS) who will discuss supported self-managed follow-up with you and you will decide together if this is the right thing for you.

At the end of the consultation you will receive a treatment summary letter which will have details of everything you discussed at the consultation, including how to contact the hospital if you have concerns.

A copy of this letter will be kept on your hospital records and shared with your GP. You will be seen by your GP for a cancer care review where your GP will discuss the information from the treatment review with you.

Your follow-up schedule will be entered onto a computer system which will help the hospital support you. A member of the team known as a clinical support worker will book appointments for your scans and tests. They will also send you the results of these and will book an appointment to be seen at the hospital if you need it.

Living well and moving forward

The treatment you have received may mean that you continue to have physical or emotional needs. Your team will continue to support you with any concerns or help you might need.

You will be invited to attend a health and wellbeing programme run by healthcare professionals who work at the hospital. The programme focusses on self-supported management and covers topics such as fatigue, physical activity, nutrition and emotional wellbeing.

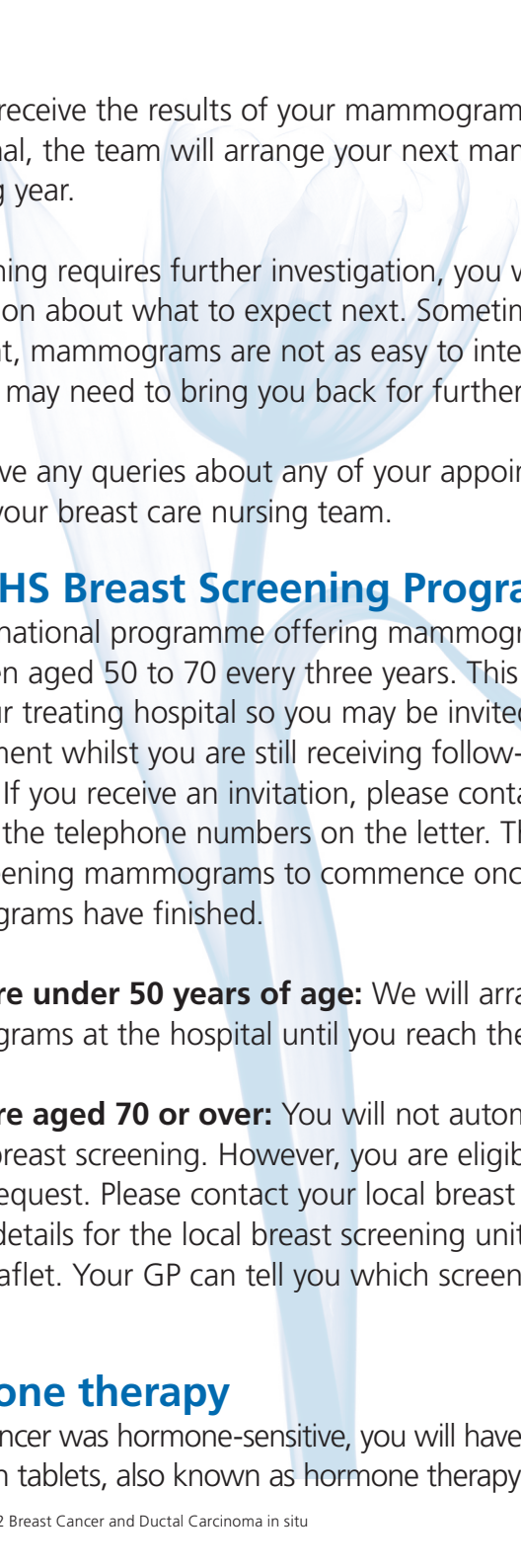
At your treatment review, you will also be given information about services, programmes, local groups and charities that can help support you.

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 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 are normal, the team will 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 your breast care nursing team.

The NHS Breast Screening Programme

This is a national programme offering mammographic surveillance to women aged 50 to 70 every three years. This is a separate service from your treating hospital so you may be invited for a screening appointment whilst you are still receiving follow-up care from the hospital. If you receive an invitation, please contact the NHS screening team on the telephone numbers on the letter. They will organise for your screening mammograms to commence once your follow-up mammograms have finished.

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 contact your local breast screening unit. The contact details for the 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

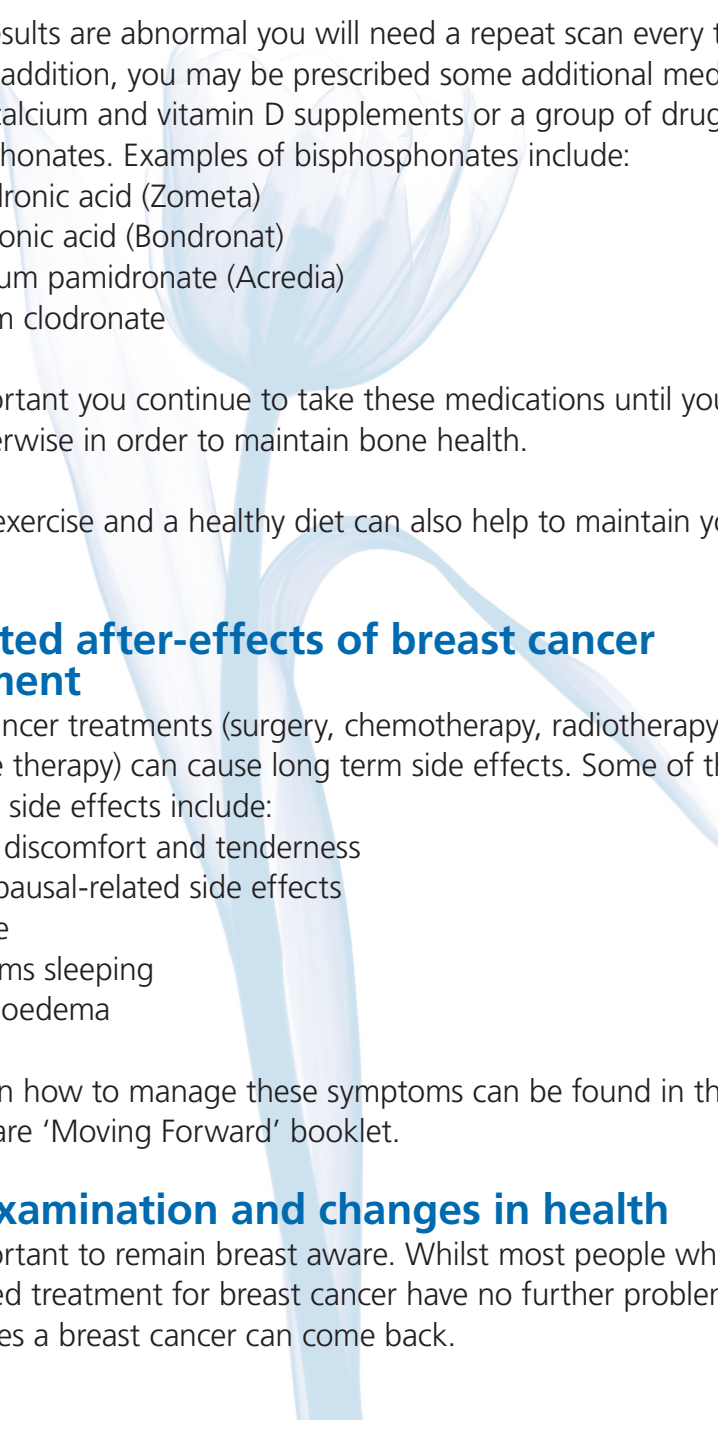
You will need to take these tablets for the next five to 10 years. Your GP will provide you with a repeat prescription for these. You should continue to take these tablets to reduce the risk of your cancer returning. If you are struggling with the side effects of your hormone therapy, please make an 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 your hormone medication. This will also tell you if you should stay on the same tablet or if we have suggested switching to another. Having more than one type of tablet can be beneficial to some women. This may depend on whether you are still having periods or if these have stopped. If you are unsure about the type or duration of hormone therapy, please contact your hospital team.

Bone health

There is an increased risk of you developing osteoporosis (bone weakening) if you take one of the aromatase inhibitor (AI) medicines.

A DEXA scan is used to monitor your bone health. This is usually performed when you start taking the medication. If the results of this are normal, you will only need a repeat scan after five years if you are going to continue taking the medicines for longer (up to ten years may be recommended).



If your results are abnormal you will need a repeat scan every two years. 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

It is important you continue to take these medications until you are told otherwise in order to maintain 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

Advice on how to manage these symptoms can be found in the breast cancer care 'Moving Forward' booklet.

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

It is important to seek advice if you are concerned about any symptoms you have noticed. Please contact your team or your GP- you will not be wasting anyone's time.

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. The general advice is that you should wait two years after completing your treatment before you attempt to get pregnant.

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 this to your team straight away. Other side effects can include vaginal dryness and a reduced interest in sex. Please speak in confidence to your breast care team who can advise you.

Reconstruction

Breast reconstruction includes a range of techniques to reconstruct a breast following mastectomy or improve the cosmetic outcome following a 'lumpectomy' – or wide local excision. Radiotherapy can have an effect on the breast tissue, so it is not recommended to have surgery for at least six months if you have had this treatment.

Please discuss your options with the specialist nurses who can advise regarding possible corrective procedures or prosthetics. They can arrange for you to see the plastic surgery team if you wish to proceed.

Prostheses

If you have had a mastectomy or you have some asymmetry after a lumpectomy, then you can be fitted with prosthesis. These may need replacing if they show signs of wear, or you lose or gain weight. Clinics are offered on different days and different sites, so please call for advice.

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 care nursing teams will continue to support you so please do not hesitate to contact us if you are worried about something.

The team contact details are listed below. We ask you to contact the cancer support workers in the first instance. They can help with many concerns. However if you need to speak to a specialist nurse or hospital doctor, then they can arrange this for you.

Useful telephone numbers

The Breast Cancer Follow Up Team

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

Cancer Support Worker: **07502714347**

Clinical Nurse Specialist: **07502689749**

Telephone: **0121 371 8060**

Telephone: **0121 371 7647**

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

Health information centre (Solihull Hospital): **0121 424 5616**

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**

Useful links

There is a wealth of information online – here are some good sources of information:

Breast Cancer Now:

www.breastcancernow.org.uk

General enquiries and supporter care: 0333 20 70 300

Support services: 0345 077 1893

Email: hello@breastcancernow.org

Macmillan Cancer Support:

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

NHS website:

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**.

Breast Care
University Hospitals Birmingham NHS Foundation Trust
