



## **Breast Department**

# **Information for Breast Patients on the Patient-Led Follow-up Pathway (Open Access)**

On completion of your treatment for breast cancer you will be part of open access follow-up. This is called the Patient-Led Follow-up Pathway (PLFU). The open access pathway means that you will be self-managing with the support of the Breast PLFU Team.

**Telephone Number:**

**01305 255160**

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## Introducing Patient-Led Follow-up

The Patient-Led Follow-up programme (PLFU) enables your Breast PLFU Team to support you after you complete treatment. It means that your normal routine will not be disrupted by regular hospital appointments, and you will be able to have control over contacting the Breast PLFU Team and attending an appointment if and when you need to. This type of follow-up is based on evidence showing that there are no advantages to patients who have the traditional style of annual follow-ups for a number of years.

This booklet will provide you with all the information you should need to contact the breast unit and arrange appointments if you need them. The booklet also contains information we think you may find useful as you recover from treatment. Not everything in this booklet will be relevant to your care as an individual, so please refer to the contents page to find the information you need.

You will have an End of Treatment appointment with a member of the Breast PLFU Team. This may be a Breast Clinical Nurse Specialist or a Cancer Support Worker specialising in breast cancer. This will be around three months after completing your final treatment, which may be surgery, radiotherapy or chemotherapy. Following this appointment, you will be provided with a Treatment Summary which covers the individual details of your type of breast cancer, and the treatments you have received and may still be receiving. A copy of this will also be sent to your GP.

If you have any concerns or queries, or feel that you require an appointment (this may be face to face or telephone), the number you need to contact is: 01305 255160. It is likely that you will have to leave a message on the answering machine, but we will get back to you within 24-48 hours. If you leave a brief message saying you are on PLFU, with your name, date of birth and hospital or NHS number, we can access your details more easily. Your GP can also call on this number if they have a concern or query regarding your care.

### When should I be seen by the Breast PLFU Team?

You should contact the Breast PLFU Team about any new symptoms that you are concerned about or other issues you may have. Please contact the Breast PLFU Team if you have any concerns about the following issues:

- Your ongoing hormone therapy
- Side effects from chemotherapy or radiotherapy
- New changes in your treated (or non-treated) breast, chest wall region, neck, collarbone or armpit
- Swelling to arm/hand
- Any symptoms that you are worried could be a sign that breast cancer has spread to another part of your body (see page 9)
- Questions about breast reconstruction
- Anxiety related to your cancer diagnosis that impacts your day to day life.

## **Your Future Mammograms**

People who have had breast cancer have a slightly increased risk of developing a further cancer (recurrence), or a new cancer, in either breast. Mammograms (breast X-rays) can often detect breast cancer before it can be felt, either by you or a health professional. For the majority of people, mammograms are the recommended way of checking for breast cancer. Some patients' cancer was not visible on mammography when they first presented with the disease, however, surveillance mammography is still the best investigation for following up this group of patients, as any recurrence or new cancer is most likely to show up on future mammograms. Ultrasound or MRI scans are not recommended for routine surveillance. If you have had a breast reconstruction, the other breast will be checked with a mammogram.

Our current recommendation is that you should have annual mammograms for five years following your diagnosis or surgery date. You should receive a mammogram appointment letter approximately one month before it is due. If you have not received this, please contact the Breast PLFU Team. The mammogram will be carried out at Dorset County Hospital at the Women's Health department in the East Wing.

If you were diagnosed under the age of 50, you will have yearly mammograms until age 50 (a minimum of five annual mammograms). After this, you will then come under the National Breast Screening programme. Your Breast Clinical Nurse Specialist will be responsible for requesting annual mammograms and this will be done after you have been given your results.

## **Mammogram Results**

You will receive a letter with the results approximately two to three weeks following the mammogram. If you are becoming anxious waiting for this results letter, please contact the Breast PLFU Team who will let you know your results over the phone if they are available. Your GP will also get a copy of this results letter. It is important that you update the hospital with any change of address. If you have not received the letter within a month of having your mammogram, please contact the Breast PLFU Team.

If there is any concern following your mammogram, we will recall you so we can carry out further assessment or investigations.

## **The NHS Breast Screening Programme**

A screening invitation is sent out every three years to all women between the ages of 50 and 70. If you have recently undergone treatment for breast cancer and receive an invitation to attend for a screening mammogram during your five-year follow up period, please cancel the appointment with the NHS screening unit, informing them that you are receiving regular mammograms at the hospital after treatment for breast cancer.

## **After Completing Five Years of Annual Follow-up Mammograms or Reaching Age 50**

If you are under 50 years of age, we recommend that you continue having annual mammograms at the hospital until invited for routine screening. You will then be invited for mammograms every three years until aged 70. After this age you can still request three yearly mammograms by calling the **Dorset Breast Screening Unit on 01202 665511 (Option 2)**. These will be carried out at your local screening unit and not Dorset County Hospital. It is important that you remain breast aware (see below), and if you notice any changes that are unusual for you, please speak to your GP as soon as possible.

## **Recovery after Surgery**

### **Is it normal to still get aches and pains in my breast/chest several months after surgery?**

Many people continue to get discomfort in their breast, underarm or around the mastectomy scar for many months, even years, after their surgery. This can be a normal consequence of surgery and/or radiotherapy. Some patients describe this as an intermittent 'stabbing pain'. However, if you develop a new pain that gets worse over two to three weeks, please contact us to arrange a review.

### **Why do I have a strange sensation on the inside of my upper arm?**

This is usually as a result of surgery affecting the nerves under the arm, resulting in changed sensation (often numbness). This can be temporary or permanent.

### **My scar feels hard and lumpy. Is this normal?**

After your operation, it is normal for your breast/scar to feel different. There may be fluid in the wound cavity (seroma), or bruising that can remain for some time, and also scar tissue formation. Gently massaging the area with moisturiser can help to soften it over time. If you notice any new lumps, please contact us so we can arrange review by one of the breast surgeons.

### **What is this tight 'pulling' sensation down my arm?**

This is known as cording and thought to be related to hardening and tightening of the lymph vessels following axillary surgery. This often feels like an elastic band being pulled. If you experience this, and it does not settle with the shoulder-stretching exercises or firm massage to the corded area, contact your Breast Care Nurses for further advice. Please refer to the Breast Cancer Now exercise leaflet in the pack that you will have been given by one of the Nurse Specialists in clinic. We can refer you to a specialist physiotherapist if required. This also applies to any restrictions in arm or shoulder movements that persist following surgery.

## **Swelling of the arm pit and/or breast or chest wall**

Surgery to the axilla can increase the risk of swelling in the arm pit or hand (Lymphoedema). If you have had an axillary clearance, (removal of all lymph nodes in the arm pit) you should have had an appointment after your operation with a Lymphoedema nurse specialist, for advice. If you have had a sentinel lymph node biopsy, (small sampling of lymph nodes in the arm pit) your risk will be much lower. After radiotherapy, swelling can also occur in the breast and this may also need review by the Lymphoedema nurses. If you develop any swelling, please contact your Breast PLFU Team and we can arrange appropriate review or advice. Even if swelling develops several years after treatment, it is important to seek advice.

## **Breast Reconstruction**

If you have had a breast reconstruction and notice any problems such as pain, skin changes or change in shape, please contact the Breast PLFU Team for advice.

Please contact the Breast Nurse Specialists if you would like information about a delayed breast reconstruction or to be referred to the Oncoplastic team at another hospital.

## **Recovering from Chemotherapy**

### **For how long will I feel tired?**

Tiredness or fatigue is the most common side effect reported by patients after having breast cancer treatment. It can be particularly severe after chemotherapy. It may go on for several months after completing treatment and can be slow to improve. Some patients feel that it takes at least a year for energy levels to return to normal. If you are struggling to cope with fatigue, please contact the Breast PLFU Team for management advice.

### **When will my hair grow back and when can I dye it?**

Your hair should start growing back three to four weeks after chemotherapy finishes. The hair grows slowly to begin with and can be quite fluffy and thin, but over time the hair thickens, and by six months, most people find that their hair should be growing well. As your new hair will be delicate, it is recommended that you wait around six months, or an inch in growth, before having chemical, permanent or semi-permanent dyes on your hair.

### **Why have I put on weight?**

Weight gain is commonly reported during and after breast cancer treatment and is thought to be due to a number of reasons. These include steroids used during chemotherapy to help prevent nausea, change of eating habit/appetite, reduction of physical activity levels and hormonal changes. If you would like support or advice to help increase your activity or make healthy changes to your diet, please contact the Breast PLFU Team.

## **I have numbness in my fingers and toes. How long will this last?**

This is called peripheral neuropathy and can be a side effect of chemotherapy where damage to the nerves occurs. It can take up to six months to improve, and very occasionally, it can be permanent.

## **Chemotherapy and fertility**

Chemotherapy can bring on the menopause earlier than it would have naturally occurred. This is more common if you are close to the menopause age when you start treatment. Some women find that their periods stop whilst they are having chemotherapy and do not come back.

## **Recovering from Radiotherapy**

Radiotherapy can cause soreness of the skin that has been treated, which includes the breast, chest wall, axilla and/or above the collarbone. This often peaks towards the end of treatment and in the two weeks following completion. Most skin reactions resolve and completely heal by four to six weeks after completing radiotherapy. Fatigue can also be a side effect of radiotherapy and this can take several months to settle. Pain in the treated area can also take months to settle.

## **Hormone Therapy**

Patients with hormone-sensitive breast cancers are prescribed anti-hormonal treatments in the form of tablets. This is also known as endocrine treatment, and includes the drugs Tamoxifen, Anastrozole, Letrozole and Exemestane. You will have been advised to take these tablets for a minimum of five years, and a small group of patients may benefit for up to 10 years. At five years, we will write to you and your GP to advise if this treatment is to continue or stop. Your Treatment Summary should also confirm the start date and planned duration of this treatment.

Some patients struggle with side effects of hormone therapy and may need to switch to an alternative type of tablet. It is useful to make a note of the brand of drug, as patients sometimes notice they tolerate different brands better than others. Please contact the Breast PLFU Team if you have any concerns relating to endocrine treatment.

Some patients will be recommended a change in tablets if they become menopausal during the five year follow-up. If you have not had a period for at least two years, and think this may be the case, please contact us for advice.

You are entitled to free prescriptions after a cancer diagnosis, so if you have not already organised this, contact your GP practise for an exemption certificate.

## **Possible side effects of Hormone Therapy**

### **Tamoxifen**

If you are pre or peri-menopausal, with an oestrogen-sensitive breast cancer, it is likely you are taking Tamoxifen. You may also be on Tamoxifen if you are post-menopausal with a non-invasive cancer (ductal carcinoma in situ or DCIS). Men with breast cancer may also take Tamoxifen. You may experience side effects from these tablets. With Tamoxifen, the lining of the womb can thicken, which can cause you to develop some vaginal discharge.

If you experience any post-menopausal bleeding whilst taking your Tamoxifen, it is important to contact your GP, as you may need to be referred to a gynaecologist. Tamoxifen is also associated with a slightly increased risk of developing clots in your veins (deep vein thrombosis or DVT). If you develop any calf swelling/pain, or shortness of breath, seek urgent medical advice. If you are scheduled for any other type of surgery whilst on Tamoxifen, we recommend that you stop the Tamoxifen prior to surgery. Please contact us to discuss. Some antidepressants (Paroxetine and Fluoxetine) may cause the Tamoxifen to be less effective, so you would need to discuss this with your GP.

### **Aromatase Inhibitors and DEXA Scans**

Aromatase inhibitors are hormonal tablets used for ladies who have been through the menopause. Common side effects of Aromatase inhibitors such as Letrozole, Anastrozole and Exemestane can include joint aches and stiffness and menopausal symptoms. A lower oestrogen level can affect the strength of your bones. If you are on this group of hormone-lowering tablets, and are not taking a type of medicine called a bisphosphonate (to protect the bones), you should be having your bone density checked with a DEXA scan. This scan should be done within a few months of starting hormone treatment, and then again at two-yearly intervals whilst taking these tablets. This is so that any bone thinning, which may lead to osteoporosis, can be detected and treated if necessary. Your Treatment Summary will tell you when these DEXA scans are due and if your baseline scan showed any abnormalities. If there is any bone thinning (Osteopenia) you will be advised to take calcium and Vitamin D supplements. If you have osteoporosis, then it is likely you will be advised to take a bisphosphonate such as Alendronic Acid. Your DEXA scans will be requested by Dorset County Hospital. We advise that you contact the breast team if you do not receive a scan date when your DEXA is due. Further information will be in your individual Treatment Summary. Your diet and physical activity are also important for maintaining good bone health. See the Moving Forward book for more advice. This will be sent to you following your end of treatment appointment with your Treatment Summary.

### **Managing Menopausal Symptoms**

Many women who receive treatment for breast cancer develop menopausal symptoms. This can be due to the effects of chemotherapy, taking endocrine treatment or stopping HRT (Hormone Replacement Therapy). Hot flushes and night sweats are the most common symptoms, but many women also notice vaginal dryness, weight changes, mood swings and changes in libido. Please contact the Breast PLFU team for advice on managing any of these symptoms. It is not recommended to take HRT when you have had a breast cancer diagnosis, as it may increase your risk of recurrence. If you are suffering with vaginal dryness, it is advised to avoid topical oestrogens where possible and try non-hormonal vaginal moisturisers such as 'YES' or 'Replens' which you can get from your GP/chemist or order online.



## **Fear of Cancer Returning**

It is important to remember that survival rates for breast cancer are improving all the time and that modern breast cancer treatments are usually very successful. However, breast cancer can sometimes return. There is no maximum time span as to when breast cancer can return, but for most people the risk reduces over time. It is important that you know 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) or mastectomy scar (even after breast reconstruction)
- In the nearby area under your arm, above your collarbone or neck area (regional recurrence)
- Elsewhere in the body (distant recurrence; also known as metastatic breast cancer or secondary breast cancer)

## **Breast Awareness**

Being breast aware means getting to know how your breasts look and feel so that you know what is normal for you. You will then be confident about noticing any changes. After surgery and/or radiotherapy, your treated breast or scar area will feel more lumpy and hardened. However, if something changes, or does not feel normal for you, please contact the Breast PLFU Team. There is no right or wrong way to check your breasts; in the bath or shower when using soap or body lotion is often a good time.

## **Body Awareness**

Everyone has aches and pains, but when you have had cancer, you may be more aware of them and be concerned that any pain is related to the breast cancer. Included below is a summary of symptoms that you should report to the Breast PLFU team or your GP should they develop. If you experience any of the following symptoms, it does not necessarily mean that your cancer has returned as they can be caused by many other common conditions, but it is worth discussing these.

Getting a breast cancer recurrence or new breast cancer can be frightening, but it is important to remember that if breast cancer returns, it can usually be treated.

## **Summary of Symptoms to Report**

Please contact us if you experience:

- A lump or swelling in your breast above your collarbone, neck area, under your arm or in the skin of your chest wall following a mastectomy
- Any skin changes, including dimpling, puckering, redness or raised spots on your breast or mastectomy/reconstruction scar
- Nipple discharge
- Lymphoedema (swelling to arm or hand) on the treated side
- Any new, ongoing pain in any part of your body, especially your back or hips that does not improve with pain killers and which is often worse at night
- Pins and needles and/or a loss in sensation or weakness in your arms or legs
- Unexplained weight loss or loss of appetite

- A constant feeling of nausea
- Discomfort or swelling under your ribs, or across your upper abdomen
- A dry cough or feeling short of breath
- Severe headaches – usually worse in the morning

## **Breast Reconstruction/Symmetrising Surgery/Prosthesis**

If you want to discuss delayed breast reconstruction options following a mastectomy, or need to discuss surgery for symmetry, please contact us on 01305 255160.

If you need a replacement breast prosthesis, or have any problems regarding this, please contact our breast administrator on 01305 254450.

## **Feelings and Emotions**

Everyone will have different feelings when they are told they no longer need to see the hospital team regularly. Some people feel relieved that they can start to get their lives back to normal, whilst others may be concerned about what may 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 there is a problem and getting help is the most important thing you can do. Whilst it is normal to feel low in mood from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If this is the case, or if you are finding it difficult to cope, your Breast PLFU Team can give you information about support services, including counselling. It may also help to contact a local or national support organisation such as Breast Cancer Now or Macmillan Cancer Support. Contact details can be found at the end of this booklet.

## **Optimising your Recovery and Health**

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 well-being which we would be happy to advise you on. Please contact the Breast PLFU Team if you wish to discuss any of the following:

- Weight management and healthy eating
- Becoming more active
- Complimentary therapies
- Counselling
- Support groups
- Financial advice
- Lymphoedema prevention and advice
- Managing menopausal symptoms
- Fertility issues
- Sexuality issues
- Delayed Breast reconstruction/Body image
- Look Good Feel Better (group session about make-up and skin care for patients having chemotherapy)
- Genetics

## Useful Contact Numbers:

We hope that you have found this information useful. If you have any questions or are worried about anything, please speak to the following Dorset County Hospital Staff:

<b>Breast PLFU Team:</b> (Breast Care Nurses/Cancer Support Worker)	<b>01305 255160</b>
<b>Prosthesis Appointments/Advice:</b>	<b>01305 254450</b>
<b>Lymphoedema Nurse:</b>	<b>01305 255370</b>
<b>Dorset Breast Screening Unit:</b>	<b>01202 665511 (option 2)</b>
<b>Macmillan Cancer Support:</b>	<b>0808 808 0000</b>
<b>Breast Cancer Now:</b>	<b>0808 800 6000</b>
<b>Cancer Research UK:</b>	<b>0808 800 4040</b>
<b>Haven Unit:</b>	<b>0300 012 0112</b>

## Support Groups:

**Axminster and Lyme Cancer Support:** 07512 279663  
Website: <https://axminsterandlymecancersupport.co.uk/contact>  
Email: [support@axminsterandlymecancersupport.co.uk](mailto:support@axminsterandlymecancersupport.co.uk)

**Cancer Matters Wessex:**  
Website: [Cancer Matters Wessex - Cancer Matters Wessex](#)

**Central Dorset Citizens Advice:** 03442451291  
1 Acland Road, Dorchester, Dorset DT1 1JW  
Website: [www.centraldorsetca.org.uk](http://www.centraldorsetca.org.uk)

**Dorset Cancer Care Foundation: Nikkie Davies-Thomas** 07593 890 879  
Website: <https://www.dccf.co.uk/>  
Email: [admin@dccf.co.uk](mailto:admin@dccf.co.uk)

**Living Tree Bridport:** 07341 916 976  
Website: <https://www.thelivingtree.org.uk/>  
Email: [thelivingtreedorset@gmail.com](mailto:thelivingtreedorset@gmail.com)

**Macmillan CAB for financial advice/grants:** 08454 9000 42

**Turn2us (UK charity for financial support):** 0808 802 2000

**C'Siders Weymouth & Portland Cancer Support Group:** 07430 695462  
(supporting C'Fit Cancer Rehabilitation Exercise Scheme)  
The Osprey Leisure Centre, Castletown, Portland, Dorset DT5 1BD  
Website: <http://csiders.org/>  
Email: [cfit@csiders.org](mailto:cfit@csiders.org)  
**Fishing for Life:** 01398 371244  
Peter Mullins [mullinsp44@gmail.com](mailto:mullinsp44@gmail.com)  
Email: [cfit@csiders.org](mailto:cfit@csiders.org)

## Lifestyle Support:

Live Well Dorset: 01305 233105  
Website: [www.livewelldorset.co.uk](http://www.livewelldorset.co.uk)

Stepping Out Bridport: 01308 427464  
Bridport Leisure Centre Brewery Fields, Bridport, Dorset DT6 5LN  
Website: <https://www.stepsoutbridport.co.uk/>

Steps to Wellbeing: 0300 790 6828  
Website: <https://www.steps2wellbeing.co.uk/>  
Email: [dhc.west.admin.s2w@nhs.net](mailto:dhc.west.admin.s2w@nhs.net)

Breast cancer now run a Moving Forward course for patients after treatment.

Moving Forward services and information are for anyone living with and beyond breast cancer, helping them approach life after treatment with increased confidence. The courses usually take place over two consecutive weeks and are delivered by a Moving Forward Facilitator, in partnership with NHS hospitals. Courses cover a range of sessions and topics delivered by expert speakers, supported by on-demand online resources.

How to sign up: Go to breast cancer now website- [www.breastcancernow.org](http://www.breastcancernow.org) and type in Moving Forward. There is an online sign-up form to complete. They will then contact you with course updates and information.

## About this leaflet:

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If you have feedback regarding the accuracy of the information contained in this leaflet, or if you would like a list of references used to develop this leaflet, please email [pals@dchft.nhs.uk](mailto:pals@dchft.nhs.uk)



**INTEGRITY | RESPECT | TEAMWORK | EXCELLENCE**

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