



## **Moving Forward – Your Guide to Self-Management after treatment for primary breast cancer Patient Information**

1 in 8 women will be diagnosed with breast cancer.

All ladies are different, and their treatment pathways will also vary. It is important that you fully understand what treatment you have had, why you have had this treatment and how the long-term effects may affect you

After you have completed all the active parts of your breast cancer treatment, such as surgery, radiotherapy or chemotherapy, and your breast surgeon or oncologist feels you are ready, you will no longer be given pre-scheduled follow-up appointments.

This information booklet has been put together for patients that are being discharged from routine hospital follow up. It is **based on evidence showing that there is no advantage to regular fixed time follow up appointments in hospital for women that are well and does not prevent cancer returning or increase life expectancy.**

This booklet will cover:

- 1) Recovery from surgery
- 2) Recovery from RT/Chemotherapy
- 3) Ongoing treatment (hormone therapy)
- 4) Lifestyle
- 5) Body image, intimacy and sex
- 6) Things to look out for and contact details

**This useful information has been put together by the Surgical Nurse team at The Primrose Breast Care Centre, University Hospitals Plymouth.**

## **Recovering from surgery**

Many women continue to get aches, pains and altered sensation in their breast and/or underarm area for months after their surgery. This can be made worse by Radiotherapy and can continue for a year or more. However, if the pain is worsening or a new pain that has been there 2-3 weeks or more then you should contact the breast care team to arrange a review.

Your scar will go through different stages of healing. It may at times feel hard and lumpy. Gentle massage of the scar can help to break down the tissue, and even out the scar line. If you notice any new lump in, or around the scar or any changes in your other breast, you should contact the breast care Centre (if within 6 months of your surgery) or your GP who can arrange for it to be checked by a breast surgeon.

When surgery takes place under the arm (axilla) the nerves are often interfered with, and nerves do not mend very well. This can result in altered sensation, often numbness in the underside of the upper arm. This can be temporary but can also be permanent. A tight or pulling feeling is often a common post-operative problem called "cording". It is thought to be caused when the lymph vessels harden and tighten as result of surgery. It may settle by itself, but usually requires some encouragement through massage and stretching of the area. This can be achieved by doing this yourself, but if you are having problems a referral to a physiotherapist can be completed either by the breast care team or your GP.

If you have had Radiotherapy your breasts may continue to change over the next year or more. The breasts may feel firmer and smaller, the skin may remain mildly discoloured and thicker. If you have had reconstruction, the effects of radiotherapy can vary from person to person, if you are concerned about the overall effect you are left with contact the breast care team who can refer you to the reconstruction specialist nurse for further advice.

You will see your surgeon or a specially trained breast care nurse a year following your surgery, where your wound will be checked and you can discuss how you feel about your new shape, and whether you would like a further consultation about reconstruction. You will also at this point start the first of your annual surveillance mammograms, which will continue for a minimum of 5 years, more if this doesn't take you up to the national screening age (47-71).

## **Recovery from Radiotherapy**

The side effects from radiotherapy can continue for several weeks after treatment has finished. The main side effects are tiredness, which can occur anytime, but don't be surprised if it happens after you have finished your radiotherapy.

Skin changes. Whilst having your treatment you may find that the area being treated turns pink/red and becomes tender. For the initial weeks after this may worsen before it gets better. The radiotherapy department will give you advice and guidance on how to manage this. It is important to always be aware that this area will always be more sensitive in the sun, so be sure to take care, and cover up.

Over the future months your breast may shrink and become firmer. Or it may swell. If you notice that the swelling increases, becomes more painful and or red you are welcome to come along to the drop-in clinic at the Primrose centre up to 6 months after your surgery for review as you may have something called lymphoedema. This can happen in the breast, and in the arm if you have had several lymph nodes removed and/or radiotherapy to the area. This is a manageable condition which can occur at any time but does require specialist review.

### **Lymphoedema**

You should have received information regarding the signs and symptoms of lymphoedema at the time of your surgery. It often presents as a swelling of the arm, or breast on operated side. The arm may feel heavy, and rings/watches may feel tight. If you notice any of these symptoms contact the breast care unit for further advice and possible referral to the specialist lymphoedema service based at St Luke's in Turnchapel.

### **Recovery from Chemotherapy**

One of the most common long term side effects of chemotherapy, and/or radiotherapy is fatigue. Fatigue is different from normal tiredness; it is more extreme and unpredictable. Most people will experience fatigue at some point, and it can last anywhere from days to months. The main reason that this occurs is an accumulation of treatments and their own individual side effects, as well the emotional and psychological impact of diagnosis. There are many ways to manage fatigue, please contact the Mustard Tree support centre for more information.

You may experience ongoing physical side effects from chemotherapy such as pain in the veins where your treatment was administered, or long-term neuropathic pain (pins and needles) in your fingers and toes. Regular massage and moisturising may help, but it maybe you need specific nerve pain relieving medication.

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## Ongoing risk reducing treatment (hormone therapy)

For patients that have had a hormone receptor positive cancer, you may see it referred to as ER+, You may be prescribed anti-hormone tablets or endocrine therapy. The reason for prescribing these tablets is to further reduce your risk of disease recurrence. Treatment includes tablets called Tamoxifen, Anastrozole (Arimidex), Letrozole and Exemestane. It will be explained to you by your Oncologist why you have been prescribed a particular one. It is usually recommended that you take your prescribed treatment for a minimum of 5 years, although studies continue, and you may be advised to continue for 10 years or longer.

Unfortunately, there aren't many treatments that don't come without side effects. The main side effects of all the tablets replicate those experienced during menopause, such as hot flushes, night sweats, weight gain and dryness of the skin. The evidence has shown that most side effects tend to improve after around three months so if you can try and persevere but if these side effects are particularly problematic speak to your breast care nurse.

Some "natural" remedies such as Black Cohosh and Red clover are often advertised as relieving menopausal symptoms, **but we do not recommend** ladies that are on hormone therapy for their breast cancer to take these. Evening Primrose can be helpful and is safe, and there are other alternative treatments which can be very effective such as ocular acupuncture/hypnotherapy, or ladycare magnet Tamoxifen is associated with a small risk of blood clots, and can also, although rarely cause abdominal thickening with a small link to endometrial cancers. You must inform your doctor if you experience any abnormal vaginal bleeding. Anastrozole, Letrozole and Exemestane, can cause joint stiffness and aching, and are also associated with thinning of the bones (osteoporosis).

After menopause as oestrogen levels fall, a women's bones can become weakened. When you take an aromatase inhibitor this process may be accelerated. Because of this you may have a bone density (DEXA) scan. These scans tell us if you are developing bone thinning which could lead to osteoporosis. Your treatment summary will tell you if you need this, and how frequent they need to be repeated.

Your bones will be monitored for signs of this whilst on treatment, in the way of bone density scans, and if there is any cause for concern you may be prescribed a bone strengthening infusion which is given in combination every 6 months on the chemotherapy unit through a cannula and takes around 20 minutes. Your oncologist will have discussed side effects of this treatment, but if you are having it is important to maintain good oral hygiene and should you require any dental treatment whilst receiving it you must let your dentist know you are on it, and the nurse administering it.

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## Lifestyle

Around 4 in 10 cancers in the UK could be prevented by lifestyle changes. Making these changes doesn't guarantee that you won't get cancer, but they will make it less likely and will improve your general health.

### **Physical Activity**

Physical activity has many benefits for people with breast cancer, from reducing fatigue to helping you regain a sense of control.

Regular physical activity can help maintain or improve your health during and after treatment, and can:

- Help avoid or reduce some side effects of cancer treatment – such as fatigue, weight gain, osteoporosis and lymphoedema
- Improve your long-term health, reducing the risk of heart attacks and strokes, and **may reduce the risk of the cancer coming back**
- Help your mental wellbeing by reducing anxiety, stress, depression and improving your overall mood
- Prevent or reduce the loss of muscle tone and aerobic fitness that can happen during treatment.
- Whilst it is recommended that everyone should try to do a certain amount of activity each week, some treatments for breast cancer can make you feel very tired or ill. If this is the case, don't worry about trying to do the recommended amount. Even a small amount of activity will have benefits.

As part of your discharge package, you will be referred to one of our support workers in the Mustard Tree who will be in touch regarding accessing a fully funded 4-week physical activity programme at Marjon University

## **Give up smoking**

If you smoke, giving up is the single most important thing you can do for your health.

In the UK about 1 in 5 cancers, and more than 1 in 4 cancer deaths, are linked to smoking. Breathing in other people's smoke (passive smoking) also increases your risk of developing cancer. If you are worried about passive smoking, talk to your doctor or practice nurse.

Help is available if you want to give up smoking. Ask your GP for advice, or contact your national stop smoking service below:

### **Keep to a healthy weight**

More than half of adults in the UK (61%) are overweight. Being overweight increases the risk of several cancers, including cancers of the pancreas, bowel, womb, and kidney. It can also increase the risk of breast cancer after the menopause and may lead to other health problems such as heart disease, high blood pressure or diabetes.

If you're overweight, getting to a healthy weight is one of the best ways to reduce your risk of cancer. Your GP or practice nurse can talk to you about the ideal weight for your height.

The best way to lose weight is by eating a healthy diet and being more physically active.

### **Eat a healthy diet**

A healthy diet can reduce your risk of cancer, particularly bowel cancer. It can also lower your risk of other health problems, such as heart disease and diabetes.

You should eat foods that are high in fibre, such as wholegrain bread and pasta, beans, and oatmeal. Try to eat five portions of fruit and vegetables every day.

Limiting how much salt, red meat, and processed meat you eat is also important. Processed meats are meats that have had preservatives added to them, or that have been preserved by salting, curing, or smoking. They include sausages, ham, and burgers.

### **Keep physically active**

Many studies have found that regular physical activity can reduce the risk of cancer.

You should try to do at least two and a half hours of activity each week. This can be split into 10-to-30-minute sessions throughout the week. You can increase these times as you get used to exercising.

You don't have to go to the gym to be active. Regular walking, cycling or swimming can be enough. During any activity, you should feel you are breathing quicker but still able to talk. Your pulse should be slightly faster than normal.

If you're not used to doing exercise, your GP can advise you on getting started.

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## **Limit how much alcohol you drink**

Drinking alcohol, especially more than the recommended limits, can increase your cancer risk. About 4 in 100 cancers in the UK are linked to alcohol.

Alcohol increases the risk of cancers of the mouth and throat. It is also linked to cancers of the bowel, liver and breast. In general, the more you drink, the higher your risk.

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over three or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary strength beer, lager or cider, one small glass (125ml) of wine or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at [Drinkaware](#).

## **Take care in the sun**

Spending some time outside in the sun helps you stay healthy. Our bodies use the UVB rays in sunlight to make vitamin D. This is important for bone health and reduces the risk of many illnesses, including cancer. But it's also important to protect your skin from burning, as this can increase your risk of skin cancers.

If you're going to be out in the sun for longer than a few minutes, use a suncream with a sun protection factor (SPF) of at least 30. You should wear loose, cotton clothes that cover your body, as well as a hat.

Avoid using a sunbed or sunlamp. If you want to look tanned, use fake tanning lotions or sprays.

## **Wellbeing**

You may well feel after your hospital-based treatments have finished a sense of anxiety or difficulty moving on with your life. This is perfectly natural, and it can take a long time to adjust to life after breast cancer. If you haven't already, you will receive an invite to a wellbeing event within 3 months of discharge/end of treatment. Where these worries can be discussed with other ladies experiencing the same feelings, and advice on coping techniques and additional support can also be offered. These could include complimentary therapies such as hypnotherapy, mindfulness and reflexology, to name but a few.

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## Body image, intimacy, and sex.

We know that breast cancer often brings with it body image and intimacy challenges. Breast cancer treatments mean physical changes, some of which can have a detrimental effect on self - esteem and intimate relationships.

Any changes to your body that you have experienced, for example after surgery, can affect your confidence and feelings about yourself. This in turn can affect how you feel about sex, how you relate to a partner, or how your partner relates to you. If you are in a relationship, you may find that it changes after a breast cancer diagnosis. Or you may be worried about starting a relationship in the future.

You may be anxious about your first sexual experience following your diagnosis, or worried that things will not be the same as before.

These worries are normal and it may take time for you to feel completely comfortable about having sex again.

You may not feel like having sex or being intimate at a time when you're dealing with breast cancer, or you may find that sex helps you feel more normal during an uncertain time.

Some of the ongoing treatments may cause you to experience some vaginal dryness. There are many over the counter creams available to help with this common problem. These include Replens, Silk, and Yes. If you have tried these but are still experiencing discomfort, please see your GP who will be able to help. **How breast cancer affects you sexually will be unique to you.**

The Mustard Tree has a sexual Psychotherapist who is available to talk confidentially and openly about these issues. She can see you individually, with your partner, or your partner alone. Please contact The Mustard Tree directly to access this service.

Even though you may not be having regular periods, you may still be able to get pregnant. Effective contraception is important. The type you use may be affected by the type of breast cancer that you have had, you may be advised to avoid hormone-based contraception, such as the pill. Your GP will be able to discuss your individual needs. Likewise, if you have any questions surrounding fertility you can discuss this with your GP, who can refer you to a specialist if required.

### **Breast reconstruction**

If when you had your breast surgery and didn't have immediate reconstruction, or it wasn't advisable for you at the time, but you would like to discuss your options at a later date, your GP will be able to refer you into the service at any point following discharge. You will see your surgeon, or one of the specialist nursing team at 12 months when you can also discuss this. We have a dedicated reconstruction nurse specialist who can help and advise you along the way. There are many different procedures available, not all of which may be appropriate but this can be discussed with you.

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## **Discharge from routine follow up.**

Everyone will have different feelings when they no longer have to see the medical team regularly. Many feel relieved that they can get back to their normal lives; others may feel anxious about losing contact with the hospital. Most people worry about their cancer coming back, this is very normal, and these worries should lessen over time.

If you are having trouble moving on, or these feelings are interfering with your enjoyment of life, then you may need to seek further support. The Mustard Tree and its triangle centers are open to you and your family for support and information, therapies, counselling and financial advice, as well as living well workshops, exercise programmers and dietary advice.

Your GP will be given a copy of the treatment summary you will have been given at your discharge clinic appointment, so they will be aware of the treatment you have had, and the side effects associated. **You should be called in to see your GP on completion of treatment for a Cancer Care Review.** If you haven't heard within 3 months please contact them as ask for this

**Once you have been discharged from routine follow up you should contact your GP with any new symptoms or clinical concerns. They will be able to re access the hospital services should they feel it is appropriate. If you are still within 6/12 months of your surgery you may be able to get help and advice via the nurse led drop in clinics held at the Primrose Unit on Mondays and Thursdays from 2-4, for emotional and psychological support please contact the Mustard Tree.**

**Reasons for seeing your GP could include;**

A new lump or changes in appearance in the skin of the breast, particularly around your scar, but also be aware of the skin under your arm, your collarbone and neck.

**Changes to report;**

- Dimpling
- Puckering
- Redness or raised spots
- Nipple discharge
- Lymphoedema
- Unexplained weight loss
- Shortness of breath or persistent cough
- Nausea or abdominal pain
- Headaches (severe/constant) or visual disturbances/loss of balance.
- Unexplained bone pain in one or more area
- Any weakness in arms/legs, or changes in power/sensation in arms/legs

There may well be a perfectly normal explanation for any of these symptoms, so please try not to become unduly worried. Things that come and go, we are not concerned about, but things that come and stay, you should let your GP know about. They can assess, and investigate if necessary and can also refer you to be seen back in one of our clinics.

**Surgical Nursing team  
The Primrose Breast Care Centre,  
01752431898**

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## Other use links

Changes to your body after treatment.

<https://www.primrosefoundation.org/bits-and-blogs/2021/4/19/changes-to-your-body-after-breast-cancer-treatment>

Life after treatment.

<https://www.primrosefoundation.org/bits-and-blogs/2021/4/19/life-after-treatment>