

The End of Treatment



What Happens Now?

Your guide to what comes after treatment for Breast Cancer/DCIS



UHNM Breast Care Team Breast Care Advice & Support Line: 01782 674077

My Next Steps

(Please bring this booklet with you to your end of treatment review)

I am being referred for:

Open Access Follow Up
End of treatment review due with Breast ANP
Traditional Clinical Follow Up
End of treatment review due with Breast ANP Next traditional follow up due:
Surgical Team
Oncology Team
I will continue to have appointments for:
Herceptin
Zoledronic acid infusions
Clinical trials
Oncoplastic (cosmetic) reviews
Other
My Breast Care Nurse (BCN) is

My Breast Advanced Nurse Practitioner (ANP) is

UHNM Breast Care Team

Breast Care Advice & Support Line 01782 674077

Open Monday to Friday, 9am – 4pm. Whether you are on Open Access Follow Up or Traditional Follow Up, calls to the number above are taken by a member of the Breast Care Team who can help with practical queries or help navigate you to the most appropriate member of the team to deal with your query or concern.

A message from us to you...

If you're reading this then you have recently finished your treatment for breast cancer/DCIS. We know that coming to the end of active treatment can bring with it a whole mixture of feelings. We've been there! Some people are just extremely relieved, some want to move on and not look back, others find they need a bit of time to process what they've been through. It can feel strange to suddenly not be scheduling your life around hospital visits or treatment days. Whatever you are feeling just know you are not alone.

We hope this booklet provides you with some insight into what comes next, some of the things we have found helpful, some answers to commonly asked questions, and who to contact for support.

If you have any further questions don't hesitate to contact your Breast Care Nurse or Breast Advanced Nurse Practitioner on the Breast Care Advice & Support Line or contact your local support group - you don't have to do this alone, there is lots of support out there!



From a breast cancer patient.....

"I had mixed feelings – I was apprehensive of what was to come but really happy to ring that bell and think 'that's it'...all being well. But I did also walk out of the hospital and think...what happens now?"

Contents



What Happens Now?

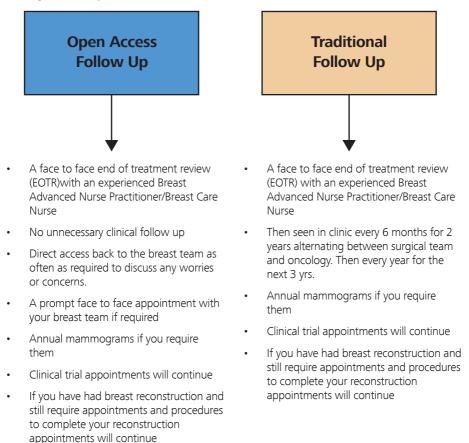
Your team will let you know which kind of follow up is most appropriate for you

"In the past", following treatment for breast cancer, patients were seen at regular intervals by their breast specialist team. Some patients found these pre-arranged appointments useful and reassuring, however many more found them a source of great anxiety and of little benefit, unless they had something specific to discuss. We call this **traditional follow up**.

Research has shown that having a regular outpatient follow-up does not help prevent cancer returning or increase life expectancy. There is now very strong evidence that symptoms and concerns are addressed more quickly if a patient reports them as they occur rather than waiting for a routine appointment.

Open access follow up puts you in control of your care by promoting self-awareness and giving you easy access to the Breast Care Team and breast services as often as you need if you have any queries or concerns

Following the end of your main treatment:



Your End of Treatment Review

Your end of treatment review appointment (EOTR) and holistic needs assessment (HNA)

Approximately three months after you have completed your treatment, whether you have had surgery alone or had either Radiotherapy, chemotherapy or a combination of the two, you will be seen in clinic by an Advanced Nurse practitioner(ANP)/Breast Care Nurse for an end of treatment review. If you are continuing on Herceptin/Zoledronic acid infusions you will still receive a review appointment at this time.

People often tell us that although finishing hospital-based treatment is a relief, they sometimes feel anxious about what's ahead. We understand your need for support doesn't end when treatment finishes and you may need some time to come to terms with all the changes that have taken place. For this reason, before your EOTR, you will be given a concerns checklist to complete. This will enable the Nurse/Practitioner to focus on any specific individual concerns/needs you have and they will be able to recommend/direct you to further support and advice if required.

You will be able to discuss how you feel you have recovered from surgery and treatment with the aim of helping you adjust to life after treatment and move forward with knowledge and confidence. You will also be offered advice regarding accessing courses and events to help you live well, with and beyond cancer (further information is provided at the end of this booklet) and to discuss healthy lifestyles. You will be advised how to carry out effective breast self-examination and how to be body aware including signs and symptoms to look out for that may need referral back to your GP or the Breast Care Team. You will have the opportunity to go through your treatment summary with your practitioner and you will be provided with a copy.

Your Treatment Summary

The Treatment Summary is a summary of the consultation and is for you to keep and will be shared with your GP. It gives information about your diagnosis and treatment as well as how your follow up care will be organised. This may include:

- The dates of your future mammograms
- The dates which you started and should complete your anti-hormone(endocrine) tablets, Herceptin and bone strengthening medication
- The dates of bone density (DEXA) scan
- Information that your GP will need to oversee your care
- A summary of the information discussed with you at your review appointment including any on-going side effects, any action that needs to be taken by your G.P. and any additional information provided
- Alert signs and symptoms to report to us or your GP that may require referral back to the Breast Care Team
- How to contact the Breast Care Team

Open Access Follow Up

What can I expect if I join Open Access Follow up?

- A face to face end of treatment review (EOTR) with an experienced Breast Advanced Nurse Practitioner/Breast Care Nurse
- Advice on how to carry out breast self-examination and how to be body aware
- An holistic needs assessment (HNA) based on your concerns and a written care plan if required
- A treatment Summary for you and your GP
- Advice regarding accessing courses and events to help you live well, with and beyond cancer
- Direct telephone access to the open access follow up team, as often as you need, to discuss any worries or concerns related to your diagnosis and treatment and your breast health
- Quick access back into see your breast specialist team if required
- Information about open access follow up and a copy of your treatment summary will also be sent to your GP.

When should I contact the open access follow up team?

The Open Access Follow Up Team is made up of Breast Advanced Nurse Practitioners, a breast navigator who answers and triages the help line calls and Breast Care Nurses

Once you have entered open access follow up you should call the open access follow up team for expert advice if you have concerns about any of the following issues:

- your on-going hormonal treatment
- possible side effects from your chemotherapy or radiotherapy treatment
- problems related to your original breast surgery or questions about breast reconstruction
- new changes in your breasts, chest wall region, neck or under your arm
- new medical symptoms that could represent a possible return of your breast cancer (see list of alert symptoms page)

How do I contact the Open Access Follow Up Team?

Call the Open Access Follow Up Team Breast Care Advice & Support Line 01782 674077 Monday to Friday, 9am – 4pm

Your GP can also use this number to contact us if they feel that you need to be seen by the Breast Care Team. If your call is not answered immediately please leave your name, date of birth your contact number and a short message on our answer phone. Your call should be returned by the end of the working day or the next working day if left after 4pm. If your ANP/BCN feels that you should be seen back in one of the breast clinics, we will make sure that you are offered an appointment within 14 working days of telephoning the team. If necessary, further investigations may be organised and an out-patient appointment arranged to receive the results. Sometimes, verbal advice may replace the need for an outpatient appointment and may be supported by a written letter to you and your GP. We hope that this will enhance and promote your ability to care for yourself once treatment has been completed and enable you to benefit from the team's expertise as required.

Managing Side Effects

From a breast cancer patient.....

"I just don't think I was aware of how the side effects can impact people, but it's good to know that you're not the only one, it's not just you who has been affected"

All treatments (surgery, chemotherapy, radiotherapy, anti-hormone (endocrine) therapy and targeted therapies such as Herceptin and zoledronic acid) have the possibility of some side effects and some of these can last longer than others. It is not unusual for cancer treatments to cause general changes in how you feel. You may:

- Be more tired/fatigued than usual for several months after treatment
- Have difficulty in concentrating or remembering things
- Have issues related to body image and sexuality and how this may impact upon relationships

Not everyone will experience side effects and some patients may experience more difficulty with them than others. Side effects are usually mild and get better over time. But some can be permanent. Your ANP/BCN will be able to discuss on-going side effects and changes with you and arrange referral to other specialists if required. The Macmillan booklet titled "Managing the Late Effects of Breast Cancer Treatment", which describes the possible effects of treatment and how they can be improved or managed and a Breast Cancer Now booklet on "Menopausal symptoms and breast cancer" are really useful resources available free from Macmillan Cancer Support and Breast Cancer Now. See websites at the back of this booklet

In the following sections you will find more specific information about the side effects relating to:



Recovering from surgery

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

Many women continue to get aches and pains in their breast or underarm area for many months after their surgery. These can be made worse by radiotherapy and can continue for a year or more. If, however, you develop a new pain that gets worse over two to three weeks then contact us to discuss.

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

This is usually due to surgery interfering with the nerves in the under arm area, resulting in a changed sensation (often numbness) affecting the underside of the upper arm. This altered sensation can be either temporary or permanent.

My scar feels hard and lumpy. Is this normal?

After an operation this may be due to the healing process and formation of scar tissue. Gently massaging the scar with a moisturising cream can help to break down the hardened area and even out the scar line (using whichever

moisturising cream you usually use). Any new lump in or around the scar should be checked by a breast ANP or surgeon.

What is this tight 'pulling' sensation stretching down my arm?

This is known as 'cording' and it is a common problem after an operation. It is thought to be caused when the lymph vessels harden and tighten due to the surgical procedure (particularly axillary (arm pit) surgery). This side effect can either settle by itself or be encouraged to 'ease' by massaging and stretching the affected area.

Can I wear deodorant?

Yes, once your scar has healed completely there are no proven studies to suggest otherwise.

My arm/breast is swollen. Is this normal?

Some women who have had surgery to remove lymph nodes from their armpit, (axillary node clearance) can develop swelling of this arm or breast or both in the weeks or months following their surgery. This is known as lymphoedema and is due to disruption of the normal channels that the lymph fluid flows through away from the arm. If your arm or breast is swollen, please contact the open access follow up team who can arrange for you to be reviewed and refer you to the lymphoedema clinic for assessment. If your arm/breast swells up many months or even years after your original surgery, you should contact the open access follow up team to arrange a review by your consultant.

Breast Reconstruction and prosthesis

If you have had a mastectomy and decided against reconstruction but change your mind at a later date, please contact the open access follow up team to discuss delayed reconstruction. If you had radiotherapy, we will advise you to wait at least a year after completion of radiotherapy. In some cases surgery can be offered to correct unequal breast sizes and your ANP/BCN can refer you back to clinic if you wish to discuss this further. It is natural for breasts (treated and untreated) to change over time. The normal life span of an external breast prosthesis (breast form) is approximately 3 years. If you need advice about your prosthesis or need a new one, please contact Royal Stoke University Hospital 01782 674201 or County Hospital 01785 886010

How long does a silicone implant last?

Modern implants do not need to be changed or replaced as a matter of routine. It may need changing for cosmetic reasons, for instance you gain or lose weight, have capsular contraction (formation of tough, fibrous tissue around the implant), have an infection (when it must be removed and replaced at a later date). It is very difficult to damage implants, only a severe chest injury, for instance a road traffic accident, could do this. So you can carry on with all your normal activities, including things like sports and air travel, without worrying that it will affect your implant.

Recovering from Chemotherapy

How long will I feel tired for?

Almost all patients will feel very tired by the end of their chemotherapy. This can get worse if they are receiving radiotherapy. Your tiredness should start to improve one to two months after your last cycle of chemotherapy and then steadily improve. However it can take at least six months before your energy levels return to normal and some will still feel tired 12 to 18 months after the end of their treatment.

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

Most people find that their hair starts to grow back three to four weeks after their last chemotherapy session. The hair grows slowly to begin with and can be quite thin, fragile and 'fluffy', but over time the hair thickens up and after six months there will be a good head of hair again As your new hair will be rather delicate, we recommend that you wait for six months before using chemical, permanent or semi-permanent dyes on your hair. However, it is safe for you to use herbal or non-permanent dyes while you are waiting.

Why have I put on weight?

It is quite common for patients who have had chemotherapy for breast cancer to gain some weight during their treatment. The chemotherapy drugs themselves do not cause weight gain but the steroid tablets that we use as anti- sickness tablets can increase appetite. Many patients also find that their taste and diet changes whilst they are on chemotherapy and that they do less exercise than usual because of the tiredness that it can cause.

When will I recover feeling in my fingers or toes?

If you have developed pins and needles or numbress of your fingers or toes during your chemotherapy treatment, this should gradually improve in the weeks and months after the end of your treatment. However, you may find that it initially gets worse after your last treatment before it starts to get better. A small number of patients may find that sensation in their fingers or toes remains altered permanently.

Are there any long-term side effects of chemotherapy?

There is a very low risk that one of the chemotherapy drugs that we commonly use can affect the heart muscle. Please discuss this with your oncology consultant if you have any concerns. There is also a very low risk that patients treated with chemotherapy for early breast cancer can develop different, unrelated cancer years later.

Can chemotherapy treatment affect my fertility and periods?

Chemotherapy for breast cancer can bring on the menopause earlier than it would have naturally occurred. This is more common if you are close to menopausal age when you start your treatment. Some women therefore find that their periods stop whilst they are having chemotherapy and never come back. If you do have a premature menopause as a result of chemotherapy, this will affect your ability to have children (fertility). Even if your periods resume there may be a reduced number of eggs and therefore fertility. For men receiving chemotherapy as part of breast cancer treatment this can affect sperm production which can lead to temporary or permanent infertility. If you have concerns about fertility then please discuss this with your Doctor or BCN.

After Herceptin

Targeted therapies such as Herceptin and some chemotherapy drugs can cause changes in the way the heart works. If heart problems happen during treatment with Herceptin they are usually temporary. This means they improve with medication and get better after treatment finishes. Most people will never experience any effect on the heart.

Recovering From Radiotherapy

How long will radiotherapy side effects last for?

Many patients feel tired both during and after radiotherapy. This is usually worse if you also had chemotherapy.

Tiredness tends to improve about six weeks after completing radiotherapy but it can often take several months to recover.

Radiotherapy causes acute side effects which occur during treatment, and tend to peak at the end or up to two weeks after finishing treatment. Most skin reactions resolve and completely heal by four to six weeks after radiotherapy though sometimes pigmentation (skin colour) persists much longer.

Up to half of patients treated may experience rib tenderness or shooting pains in the breast. These generally settle within a few months of radiotherapy treatment but they can continue on and off in the long term.

When can I go out in the sun?

If you have had radiotherapy as part of your treatment, the treated area may be more sensitive so you should take sensible precautions and avoid getting sunburnt. We would recommend using a high factor sun screen of at least factor 30+ and wear a hat and a long-sleeved shirt. It is important to remember that you can burn even through clothing if you are out in hot sun for a long time.

Will I get any long-term side effects from my radiotherapy?

If you have had part of your breast removed you may find your treated breast shrinks slightly over time. If this happens the breasts may be different sizes. A partial breast form can be fitted.

Long-term effects occur in a small percentage of people. There may be a change in the appearance of the skin, with the skin within the treatment area being darker and firmer to the touch, and the breast may be smaller in size.

After a mastectomy the chest wall can feel tight and there may be permanent skin changes if there was a severe skin reaction. People who have had breast reconstruction with implants may experience contraction of the capsule around the implant. Occasionally it is necessary to remove or exchange the implant.

There is a very slightly increased risk of rib fracture in the treated area though a more common finding is inflammation of the cartilage, this doesn't usually require any treatment. There is a small risk of heart damage after treatment to the left side. Radiotherapy causes inflammation of a small area of lung tissue which will become scarred. This does not usually lead to any symptoms. There is a very small risk of a second cancer developing in the treated area as a result of radiotherapy, predominantly in smokers. If you smoke it is worth giving up even at this stage.

What is Lymphoedema?

Lymphoedema often presents as swelling of the arm, breast or chest wall on the treated side. This can sometimes be made worse by radiotherapy treatment. Please also see information in your pack given to you at initial diagnosis. If you notice any swelling, contact the open access follow up team for further advice and possible assessment in the lymphoedema clinic.

Anti-Hormone (endocrine) and other Treatments

Why do I have to take anti-hormone tablets?

If your breast cancer was sensitive to the hormones oestrogen and /or progesterone we will generally recommend that you have a course of anti-hormonal therapy reatment for your breast cancer. Taking endocrine therapy, usually for five to ten years, will significantly reduce the risk of your cancer recurring, in addition to the other treatments you have already had.

Are there different types of anti-hormonal therapy?

There are two main types of hormone therapy:

Tamoxifen is an anti-oestrogen and it acts by blocking oestrogen receptors on breast cancer cells. Tamoxifen is prescribed for men, pre-menopausal women and some post-menopausal (gone through the change) women

There is some research that suggests some drugs – including the antidepressants paroxetine (Seroxat®) and fluoxetine (Prozac®) – may cause Tamoxifen to be less effective, but this isn't certain. If you are prescribed these whilst you are taking Tamoxifen please tell your ANP.

Arimidex (Anastrozole), Femara (Letrozole) and Aromasin (Exemestane) are all aromatase inhibitor drugs and work by switching off the enzyme that makes oestrogen in the body. They are often called Al's. These drugs are only suitable for post-menopausal women.

You will be on these tablets for five to ten years. If you accidentally run out of medication and cannot get a repeat prescription in time your community pharmacist can access your Summary Care Record containing your prescription medications and are usually able to prescribe between 5 and 30 days of medication to last you until you can get a repeat prescription from your GP. Once you have completed the first five years we will write to you and your GP and confirm if the prescription should stop, continue or be switched. Your Treatment Summary will confirm the date you started your hormone medication and the date you will complete five years of hormone therapy. If you haven't heard from us as you near the end of your hormone treatment please contact the Open Access Follow Up Team.

Some patients will change their tablets after two or three years. For example, if you become menopausal (your periods stop) the team will sometimes advise that you are switched over to an aromatase inhibitor. We will have advised you if this is the case.

You will not have to pay for tablets as you are entitled to free prescriptions. A medical exemption certificate should have been provided to you. Please ask your ANP/BCN if this is not the case. Treatments do change and develop all the time; if there are major changes in the way we prescribe anti-hormone medication during the time you are on it we will write and tell you about this and what it may mean for you. You may be invited to return to clinic to discuss this further. If you are experiencing side effects of medication please contact the open access follow up team who will be able to offer further support and advice.

What side effects may I experience?

All of these tablets can cause menopausal type symptoms such as hot flushes, vaginal dryness and night sweats. Tamoxifen is associated with a small risk of blood clots and can also rarely cause abnormal thickening of the lining of the womb, which can show itself as post-menopausal vaginal bleeding. You must inform your doctor if you experience any post-menopausal vaginal bleeding whilst on Tamoxifen.

Arimidex, Femara and Aromasin can cause aching and stiffness of the joints and are also associated with thinning of the bones (osteoporosis). Your bones will be monitored for signs of this with regular bone density scans. If you are getting troublesome side effects from your hormone tablets, please contact the open access follow up team or your BCN to discuss.

Bone density (DEXA – dual energy X-ray absorptiometry) scans and bone health

After the menopause as oestrogen levels fall, our bones often become less strong. When you are taking an aromatase inhibitor such as Anastrozole, (Arimidex®), Letrozole, or Exemestane or if your periods have stopped early because of your treatment, this process may be accelerated. To assess your bone strength (bone mineral density) we will request a baseline (at the beginning of treatment) bone density (DEXA) scan.

This is usually repeated around every 2 years whilst on treatment. These scans can tell us if you are developing bone thinning which could lead to a condition called osteoporosis. Your Treatment Summary will tell you if these are needed and when. If you are having Zoledronic acid infusions as part of your treatment you will not need a further bone density scan until after 12 months after your Zoledronic acid treatment has finished. DEXA will be organised by the open access follow up team and the results will be sent to your GP. Your GP should act on any recommendations regarding supplements if required.

Regular exercise such as walking as well as a diet high in calcium will help to maintain bone health. During your end of treatment review you will receive verbal and written information about how to look after your bones. Please contact the Open Access Follow Up Team if you require further information.

Managing menopausal symptoms

Many women who receive treatment for breast cancer develop menopausal symptoms. These can be due to the effect of chemotherapy or hormone therapies on your own hormone levels, or simply due to stopping your usual hormone replacement therapy. Hot flushes and night sweats are the most common menopausal symptoms, but many women also notice weight changes, vaginal dryness, changes in libido and mood swings.

Can I use hormone replacement therapy?

Hormone replacement therapy (HRT) is not recommended for women who have been treated for breast cancer as it may increase your risk of disease recurrence (particularly if your breast tumour was sensitive to oestrogen), or increase your risk of developing a second breast cancer. However, very occasionally women who are at very low risk of cancer recurring and are experiencing severe menopausal symptoms that are affecting their quality of life may decide that the benefits of HRT outweigh the risks. This is a decision that should always be made after a discussion with your oncologist or surgeon. If you are suffering from vaginal dryness, vaginal lubricants such as Replens MD or KY-Jelly can be helpful. If these do not solve this problem then a topical oestrogen cream may help. However, this should be discussed with your Consultant, ANP/BCN or GP.

Can I take herbal therapies to help?

Some 'natural' remedies, such Black Cohosh and Red Clover are often advertised for the relief of menopausal type symptoms. However these contain plant oestrogens (phyto-oestrogens) and are not recommended for use by women who have had breast cancer. Evening primrose oil is safe to use and some women do report that it is helpful for menopausal symptoms. However, there is no scientific evidence to prove this. There is no good evidence for the use of vitamin E for hot flushes and vitamin E supplements may even be harmful, especially for people with heart disease.

What else can I do?

Please discuss with your ANP/BCN via the Breast Care Advice & Support Line if your menopausal symptoms are troubling you. Several prescription drugs can be effective in reducing hot flushes and your doctor will be able to discuss the potential benefits and side effects of these medications with you. Alternatively, some women find relaxation-based complementary therapies such as acupuncture, hypnotherapy, massage or aromatherapy helpful for their symptoms. Medicines Information Service.

This national service provides support for patients who have any questions about medicines, including complementary medicines, vitamins supplements and medication you have been prescribed by a doctor. The phone number for this service is also included at the end of this booklet.

Other treatments

Bisphosphanates (bone strengthening drugs) such as Zoledronic acid are sometimes used to prevent breast cancer returning in bones. They can cause problems with the teeth and jaw. When your dentist is taking a medical history, be sure to inform them if you are taking, or have ever taken a bisphosphonate and in what forms and dosages. Maintain excellent oral hygiene to reduce the risk of infections and go for regular exam and cleaning appointments. Report any teeth concerns to your dentist. If you wear a denture that is causing you discomfort, ask your dentist to adjust it.

Staying Breast Aware

What is my chance of developing a cancer in my other breast?

We will arrange for you to have mammograms more regularly (usually every year) because your risk of developing cancer in your other breast is slightly higher than it would be if you hadn't had breast cancer. Unless you have an inherited genetic predisposition (such as BRCA1 or BRCA2 alteration) or strong family history, your risk will not be much higher than most people your age.

There is no evidence that removing your other breast (contralateral mastectomy) will enable you to live longer, unless you have an inherited genetic disposition or your risk has been assessed as very high by the genetics team.

Should I still examine my breasts and what should I do if I find a lump or notice a new change in my breast?

Being breast aware is an important part of caring for your body. It means getting to know how your breasts look and feel, so you know what is normal for you. You can then feel more confident about noticing any changes and reporting them early. 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, your mastectomy scar or the surrounding area (known as the chest wall) after your treatment even though you will be having regular mammograms. After treatment for breast cancer it can be difficult to know how your breast or scar should feel, especially as the area can change over time as it repairs and heals. Immediately after surgery and in the weeks that follow, you can experience pain and sensations such as burning and numbness in the scar area and under the arm (axila). The area around the scar may feel lumpy, numb or sensitive.

There is no right or wrong way to check for changes. Get used to looking at and feeling both sides of your breasts or your /scar and chest wall regularly. You should do this around once a month, in the bath or shower, when using soap or body lotion. There is really no need to change your everyday routine. Just decide what you are comfortable with and what suits you best. You will be sent a guide to Breast Awareness called "know your breasts" there is also a guide in this booklet, or use the Breast Cancer Now website at www.breastcancernow.org.uk. If you would prefer a video to watch you can use the following link https://player.vimeo.com/video/350305644

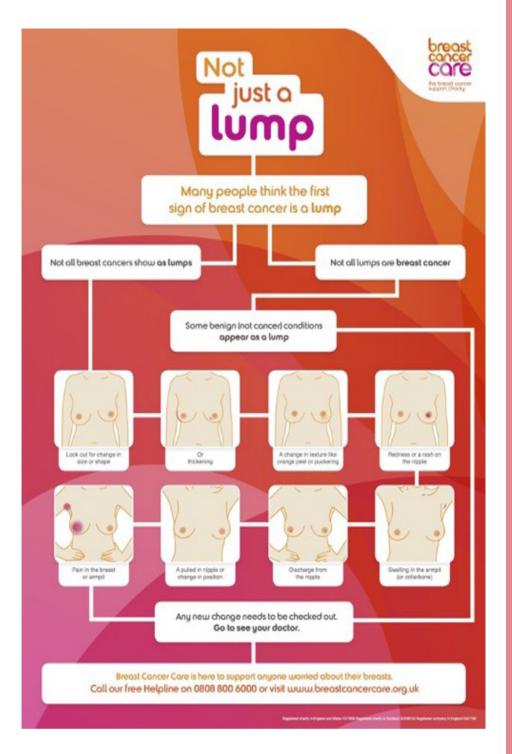
You know better than anyone how your breasts look and feel normally, so if you notice a change in either breast or your mastectomy scar, the area around your scar or your chest wall or something feels not normal for you, please contact your ANP/BCN via the Open Access help line for advice on 01782 674077.

Your future mammograms

People who have had breast cancer have a small increased risk of developing a further cancer in the same breast (recurrence) or a new cancer in the other breast. Mammograms can often detect breast cancer before it can to be felt, either by you or a health care professional. For the majority of women and men mammograms are the recommended way of checking for breast cancer.

Our current recommendations are that you should have annual mammograms for five years following your diagnosis, or until you reach the age at which the National Breast Screening Programme starts (aged 50yrs). If you have had breast conserving surgery (a wide local excision or mammoplasty) you will have a mammogram of both breasts. If you have had a mastectomy with or without reconstruction, you will only have a mammogram on your remaining breast.

Your mammograms will be organised by the Breast Care Department at UHNM and appointments are normally sent approximately one month in advance. For a small number of women mammography may not be appropriate and we will discuss the other options if this is the case.



My breast cancer wasn't seen on a mammogram

You may require extra investigations such as a breast MRI as well as your regular mammograms. This would need to be discussed and agreed by the Breast Care Team as per radiology and NICE guidelines

Results of mammograms

After your mammogram, you should receive your results letter within two weeks. For this reason it is important to make sure that the hospital has your correct address and telephone number. If you do not receive your results within one month of having your mammogram, please contact the open access follow up team.

Sometimes, after having treatment for breast cancer, mammograms are not as easy to read; therefore we may recall you so we can carry out further assessment or investigations. We will contact you by telephone or by letter if this is the case. For this reason it is important to make sure that the hospital has your correct address and telephone number. If you have any questions about your breast imaging appointment please call 01782 674200

The NHS Breast Screening Programme

A screening invitation is sent every three years to all women between the ages of 50 and 70 years. If you have recently undergone treatment for breast cancer and receive an invitation to attend for a screening mammogram during the time you are attending the hospital for yearly mammograms, please cancel the appointment with the NHS Breast Screening Unit, telling them that you are receiving regular mammograms at the hospital after treatment for breast cancer.

After five years of annual follow-up mammograms:

If you are aged over 50 years: after five years of follow up mammograms at the hospital you will be invited and should attend the National Breast Screening Programme and receive mammograms every three years through your local NHS breast screening service.

If you are aged under 50 years: after five years of follow up we will recommend that you continue with annual mammograms at the hospital until invited for routine screening. You will then be offered mammograms every three years through your local NHS Breast Screening service.

If you are aged 70 years or over: after five years of follow up you will not be automatically called for routine screening. However you can continue to receive three yearly mammograms under the NHS Breast Screening Programme by requesting an appointment and it is recommended that you do this. Please contact your local NHS Breast Screening Unit or GP to arrange this.

Family history

Women who remain at high risk due to a family history of breast cancer or who carry an altered BRCA gene may need to have regular tests for a longer period. You will be advised regarding this.

Contacting the NHS Breast Screening Service

If you want to cancel appointments, check when they will be screening in your area following your five years of annual mammograms (or longer if under 50 years of age) or self-refer for breast screening if over 73 years of age please call North Midlands Breast Screening unit on 0300 123 1463

Life After Cancer

Feelings and emotions

Everyone will have different feelings when they no longer need to see their breast specialist team regularly. Some people feel relieved that their treatment is over and they can start to get their lives back to normal, others may be concerned about what can happen in the future and may feel isolated or abandoned as you now have much less contact with the hospital. Most patients will also find that it takes rather longer than they expect to recover fully from their treatment.

You may have focused on getting through the treatment and only have time to reflect on the impact of your diagnosis and treatment once treatment has finished. It's possible family and friends have moved on and expect you to 'put it all behind you'. You may still be experiencing effects of hospital treatment or side effects from on-going treatment such as anti-hormone therapy, as well as trying to manage fears about whether the cancer could come back and worrying about every ache and pain. This is very normal and usually these anxieties lessen with time.

Where can I find support?

Everyone will find different ways of living with breast cancer after having treatment. There is no right or wrong way, just what works for you. Some people prefer not to talk about it, while others find it helpful to discuss and share their experience. Realising that if you think you have a problem, that getting help is the most important thing you can do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If you are finding moving on difficult you may want to talk to someone about your feelings. This could be your Breast Care Nurse, GP or if needed, one to one support or counselling can be arranged. You can talk to someone who has been through a similar experience through a local support group or national support organisation such as Breast Cancer Care or Macmillan Cancer Support. Details of local and national support are at the end of the booklet and are also available on the UHNM website http://www.uhnm.nhs.uk

UHNM Macmillan Cancer Support & Information Service

An NHS non-clinical service working in partnership with the national charity Macmillan Cancer Support (not to be confused with the local Douglas Macmillan Hospice) providing information resources, signposting and referral for a wide range of emotional, financial and practical support. No appointment or referral is required and we have a Macmillan Cancer Support Centre on both hospital sites open 10am-4pm or you can ring us on 01782 676333 or 01785 236075, Monday to Friday or email macmillancentre@uhnm.nhs.uk

What support can my Breast Care Nurse (BCN) continue to offer me?

Your Breast Care Nurse will be known to you since your diagnosis of breast cancer. All patients will continue to have access to the specialist advice, support and information that a Breast Care Nurse can offer. The Breast Care Nurse is available at any point in your care including this period following your discharge from regular hospital follow-up. You can contact your Breast Care Nurse via the Breast Cancer Advice and Support Line on 01782 674077.

When can I return to work?

You can return to work whenever you feel ready to do so. When you return, remember that it will be a big shock to the system to begin with. It can be very useful to return on a 'phased' return, increasing your working hours over a few weeks.

Can I travel abroad?

Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients can have difficulties getting travel insurance if they have been treated for cancer. The UHNM Macmillan Support and Information Centre, the Macmillan website and Breast Cancer Care have a list of insurers who specialise in the cover of patients who have had cancer and will be able to offer advice.

Should I exercise?

Most women feel tired for a number of weeks or months after they have had treatment for breast cancer. We recommend that once you have completed your treatment, you try to gradually increase your daily activity with the aim of trying to build up to three or more twenty minute sessions of moderate activity each week.

What diet should I follow?

Enjoying a healthy diet, avoiding excessive weight gain and maintaining a moderate level of physical activity is important if you have had breast cancer. There are conflicting theories about diet and cancer, which can be confusing. Most experts would agree that healthy eating means eating a balanced, varied diet that provides all the nutrients you need. Evidence suggests that maintaining a healthy weight and avoiding excessive weight gain can improve breast cancer survival and overall survival. There is also evidence that keeping up a moderate level of physical activity such as taking a daily half hour walk, is beneficial too.

For a healthy diet:

drink at least 8 glasses of water per day eat the right amount to maintain a healthy weight eat plenty of fresh fruit and vegetables eat plenty of foods rich in fibre and starch avoid eating too much fatty food avoid sugary food and drinks avoid alcohol or drink in moderation These guidelines are also suitable for people who don't have cancer and can be followed by

These guidelines are also suitable for people who don't have cancer and can be followed by members of your family. They may reduce the chances of getting heart disease and diabetes as well as certain types of cancer including breast cancer. A summary of the global evidence regarding Diet, Nutrition, Physical Activity and Cancer was produced in May 2018 by the World Cancer Research Fund. There is a lot of information available on healthy eating from organisations such as the Food Standards Agency and NHS Direct.

Can I drink alcohol?

There is no need to avoid alcohol entirely. However, a number of research studies have indicated that increased alcohol intake may be associated with a slight increase in risk of breast cancer. We would always advise that you should not drink in excess of the Department of Health's recommendations (no more than two to three units of alcohol per day, where a unit of alcohol equals a small glass of wine).

What about sex?

Cancer has many effects and your treatment may have affected your physical ability to give and receive sexual pleasure. It may have changed how you feel about your body, and you might find it difficult to talk to your partner about this. Your partner may also have concerns but talking to each other may help with this. Making love might not be the same as it was before your diagnosis and you may have to find ways of adapting to the changes. It can help to take things slowly at first. Some practical ways to help, include trying different positions and using vaginal lubricants if dryness is a problem. Your ANP/BCN will be happy to discuss any of these issues with you.

What should I do about Contraception?

Even though you may not be having regular periods, you may still be able to get pregnant. We recommend that you should avoid pregnancy for at least two years after chemotherapy and for the duration of treatment with anti- hormonal therapies. Effective contraception is important. Women who have been treated for breast cancer should not use oral contraceptive pills (the combined pill or mini pill) or hormonal implants. Your GP or practice nurse or family planning clinic will be able to advise you about suitable contraceptive methods which include barrier contraceptives (such as condoms and the cap) and intra-uterine devices (the coil – without oestrogen).

Welfare and benefits advice

If you are experiencing housing, employment, immigration, financial or welfare benefits issues, you can get help by contacting the Macmillan Welfare and Benefits Team at Disability Solutions or the national Macmillan Cancer Support line. Telephone numbers are listed the end.

Dealing with worries about breast cancer returning

Am I cured?

You may hear words like 'cure' and 'all clear' in the press or on the TV but these might not be used by your specialist. Many people who have cancer want to know if they are 'cured'. The term 'cured' means there is no chance of the breast cancer coming back. While most people will be 'cured', it is virtually impossible to give a guarantee as each person is different. The term 'all clear' is also used sometimes and this means there's no sign of cancer after your treatment at that time. You may also hear the term 'remission'. This term is generally associated with other types of cancer, but again means there's no sign of disease at this time.

Your breast specialist team is more likely to speak in terms of your survival over time. They may talk about your percentage chance of surviving five or ten years and beyond. For breast cancer, five and ten year survival statistics are used as a way of describing how likely it is that the future will be good. Each person's risk of the cancer coming back varies. This depends on many factors, such as the size, type and grade of the cancer and whether the lymph nodes (glands) were affected. The risk of the cancer coming back (recurrence) is higher in the first few years and reduces as time goes on. But recurrence can happen even many years after treatment, which is why you still need to be aware of any changes. In the UK, the number of people surviving breast cancer has risen greatly over the past decade and most people diagnosed with primary breast cancer will not have a recurrence.

What is the chance of my breast cancer returning?

The risk that breast cancer will come back is different for every patient. However, by having the treatment recommended by your surgeon and oncologist you have minimised your personal risk of having any further problems from breast cancer as much as possible. Whilst most people have no further problems, sometimes breast cancer can come back. 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 are aware of what to look out for and what to do if you become concerned about anything.

New primary

Having breast cancer in one breast means you have a slightly higher risk of developing another breast cancer than someone who has never had breast cancer. A new primary breast cancer can occur either in the same breast after breast-conserving surgery, or in the other breast. This would be treated as an entirely new breast cancer.

Local recurrence

If breast cancer comes back in the chest or breast area, or in the skin near the original site or scar, this is called local recurrence. This doesn't mean the cancer has spread. Treatment for a local recurrence will depend on what treatment you had before, but could include surgery, radiotherapy and drug treatments and is till curative.

Locally advanced breast cancer (also known as regional recurrence)

If breast cancer comes back and spreads to the tissues and lymph nodes around the chest, neck and under the breastbone, this is called locally advanced breast cancer. Treatment will depend on what treatments you previously had, but could include surgery, radiotherapy and drug treatments. People who have locally advanced breast cancer are thought to have an increased risk of cancer cells spreading to other areas of the body. Treatments such as chemotherapy, anti-hormone and targeted therapies are given because they work throughout the whole body.

Secondary (metastatic) breast cancer

When breast cancer spreads to other parts of the body, it is called secondary breast cancer. This happens when breast cancer cells are carried away from the breast through the lymphatic system or the bloodstream. These cancer cells can then form secondary breast cancers in other parts of the body. You may also hear this called stage 4 or advanced breast cancer. Secondary breast cancer can develop anywhere in the body, but it's most likely to develop in the bones, lungs, liver and brain. It may affect just one area or more than one area of the body. Although Secondary breast cancer can't be cured it can often be controlled, sometimes for many years, and treatments are improving all the time.

Will I have any tests to check that the cancer hasn't returned?

You will continue to have regular follow-up mammograms. Research studies have shown us that doing regular blood tests, x-rays or CT scans on women who have no symptoms are not helpful in diagnosing recurrent breast cancer, cause unnecessary anxiety and does not improve overall survival. However, if you develop any new symptoms, the appropriate test or scan will be organised for you once you have been reviewed in the clinic.

I am constantly anxious that my breast cancer will return. What can I do?

It is entirely natural to feel anxious that your breast cancer will return and we recognise that this can make you feel very uncertain about the future and lead to difficulties in getting on with life. Talking this through with your BCN can help. Some people find it useful to have some additional support in dealing with these feelings and benefit from counselling. This may be available from your GP, or alternatively we can refer you to the Cancer Psychology Service for counselling.

What sort of symptoms will I get if my cancer returns?

Everyone has aches and pain, but when you have had breast cancer, you may be more aware of them and may be concerned that any pain is related to cancer. Included below is a summary of symptoms that you may want to report to either your ANP/BCN via the open access follow up team or your GP should they develop. If you experience any of these symptoms it does not necessarily mean that your cancer has returned as they can be caused by many other common

Page 22

conditions, but it may mean that you should get them checked out by the breast team. Getting a recurrence or a new cancer can be frightening, but it is important to remember that if breast cancer returns, it can usually be treated.

Alert signs and symptoms you should report

If you experience any new, unexplained, persistent symptoms that do not get better with time or treatment please contact us via the help line for advice.

Signs that may indicate a new primary or a local recurrence can include:

- A lump or a swelling in your treated breast, in the skin after a mastectomy, above your collarbone or in the neck area, or under your arm
- Any new skin changes including dimpling, puckering, nipple inversion, change in shape, redness or raised spots on your breast or mastectomy scar
- Blood stained nipple discharge
- New lymphoedema (arm or breast swelling) on the affected side

Signs and symptoms that may indicate secondary breast cancer can include:

- Unexplained vaginal bleeding or spotting important to report if taking Tamoxifen
- A persistent dry cough or a feeling of breathlessness
- Any new, on-going pain in any part of your body, especially in 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 of sensation or weakness in your arms or legs
- Unexplained weight loss and loss of appetite
- Discomfort or swelling under your ribs or across your upper abdomen
- A constant feeling of nausea
- Unexplained persistent headaches
- Altered vision or speech

Some symptoms such as tiredness and loss of appetite can be normal effects that many people experience after cancer treatment. But if these types of symptoms don't improve, your doctor or we may need to investigate the many possible causes. Do remember, however, that all of these symptoms can also be caused by other conditions that are completely unrelated to breast cancer, so please do not become unduly anxious while you're waiting for your review

Finally

If you are worried about something to do with your diagnosis, or the treatment that you have had, please contact the Breast Cancer Advice and Support Line to speak to your Open Access Follow-Up Team/ANP or your BCN. They would rather see you with something that turns out to be nothing, than for you to be at home worrying. They are there to help you, so please call if you have any questions or concern.

Support to live well, with and beyond breast cancer

There is no right or wrong way, just what works for you. Once treatment is over people often want to know what they can do to stay healthy. You may have questions about your diet, exercise, general well-being and your ANP/BCN will be happy to discuss. You may also be looking for support on how to adjust, adapt and cope after diagnosis and treatment and find a way of living with and beyond breast cancer. Health and well-being events can help provide this support. You will be given written information about local and national events and how to book attendance. See below for further information.

Moving Forward course offered by Breast Cancer Now working in partnership with UHNM

This is a course designed to help you adjust to life after treatment for breast cancer. It is also a chance to get to know others in a similar situation. It is free of charge and takes place 5 times per year in Stoke and Stafford and runs for half a day each week over 3 consecutive weeks.

Topics the course includes:

- Introduction to Moving Forward
- Lymphoedoma reducing the risks and management
- Managing Menopausal symptoms
- Activity and energy
- Cancer related fatigue
- Healthy eating
- Breast and body awareness
- Relationships and communication
- Adjusting and adapting complementary therapies

You will be given written information on this course at your post op visit and will be discussed again at your end of treatment review. If you wish to attend, with your permission, your ANP/BCN will pass your contact details to Breast Cancer Now who will send you an invite to the next course with a suitable date for you.

For more information contact Breast Cancer Now, telephone 0808 800 6000, www.breastcancernow.org

Look Good Feel Better (LGFB) work shops

LGFB is an international cancer support charity that helps boost the physical and emotional wellbeing of people undergoing cancer treatment. Their free confidence boosting face to face workshops are held locally (in Stoke on Trent, Stafford and Crewe but other locations are available throughout the UK, for women, men and young adults undergoing treatment for any type of cancer. Each group session is led by trained volunteers and is a chance to meet others in a similar situation, as well as learning useful skills and techniques to manage the side-effects of cancer treatment. They have lots of printed materials and online tutorials for those who are unable to attend one of our sessions or who would like some extra advice. Tel: 01372 747 500 Website: www.lookgoodfeelbetter

H.O.P.E Self-Management Programme

Do you want to enhance your resilience through these difficult times, rediscover strengths and increase your ability to cope? H.O.P.E is 'Help to Overcome Problems Effectively'.

The programme focuses on: Smarter goal setting, priorities and values, managing stress, coping with fatigue, living positively with fears for the future, finding things to be thankful for, character strengths, eating well, physical activity.

The online programme begins on : 5th September or 31st October 2022 and is provided by Macmillan Cancer Support. You are asked to commit to a minimum of 2 hours per week for 6 weeks, at a time to suit you, and have access to the internet via smartphone, tablet or PC. To sign up or find out more, please visit https://bit.ly/MAC-HOPE-2022

The face to face programmes are held locally in Stoke on Trent and Stafford and also run for 6 weeks - contact the Macmillan Cancer Support & Information Service at UHNM for start dates.

Support Groups and Other Support

Local Breast Cancer/Cancer Support Groups

Burntwood Support Group

3rd Wednesday every month 10am-12.30pm Burntwood Memorial Institute, Rugeley Road. Burntwood. WS7 9BE Pauline Walker 07779102272 Linda Griffith 07796122828

Butterflies Support Group

Starting 7pm monthly Stafford Constitutional Club Ltd 5 Lloyd Street, Stafford, ST16 3SA Alison Smith 01785 660193 Mobile 07522986272 alisonsmith99@ntlworld.com

Pinfold Pink Support Group

3rd Tuesday every month 4.30pm Penkridge Fire Station, Boscomoor Lane, Penkridge Janet Peel 01785 711124 janpeel2@sky.com Joan Proctor 07922006126 Margaret Hodson 01785 713090

Pink Sisters and Misters

2nd Monday every month 7-9pm The Bridge Centre, Birches Head Rd, Stoke-On-Trent ST2 8DD and also at 1 Sandon Rd, Meir, Stoke-On-Trent ST3 7DT Jackie Mackenzie 07786007315 pinksistersstaffs@gmail.com

Terrible Titties Support Group

1st Wednesday every month7pm -9pm Stafford Rugby Club, Blackberry Lane, Doxey Stafford, ST16 2TT 07366 923048 terribletitties@gmail.com

The Local Breast Surgery & Mastectomy

Support Group 2nd Tuesday every month Church of Nazarene Smithpool Road, Fenton, Stoke-on-Trent, ST4 4PB Betty 01782 388977 Mary 01782 634056 Jean 01782 329427 jjcape@yahoo.co.uk

TLC

3rd Monday every month 4:30 - 6:00pm Breewood Medical Centre, Kiddermore Green Road Stafford, ST19 9BQ Tina Gibbon 07541328068 tinasgibbon@aol.com

The Optimists Breast Cancer Support Group

3rd Monday every month Moorlands Hospital, Ashbourne Rd, Leek, ST13 5BQ Ann 01298 83362 Doreen 01538 360958 leekoptimists@gmail.com

S.L.I.M.B.S – Lymphoedema Support Group

Marjorie (secretary) 07752404636

Staffordshire Moorlands Cancer Support Group

Support and information for all cancers 3rd Tuesday of each month, 7.30pm onwards Cheadle Cricket Club, 225 Kingsway, Cheadle SK8 1LA Peter Oakden: 01538 754298 / 07971173358 Carmen Alcock: 01538 752661 / 07950707081 Shirley Whittall: 01538 754112 / 07731891569

Healing Voices

Choir for people affected by cancer Every Thursday 7.00pm to 9.00pm The Baptist Church, Sandon Rd, Stafford, ST16 3HW Mark Dalton: 07710 502355 info@healingvoices.org.uk

Useful Local Contact Numbers

Burntwood Support Group

3rd Wednesday every month 10am-12.30pm Burntwood Memorial Institute, Rugeley Road. Burntwood. WS7 9BE Pauline Walker 07779102272 Linda Griffith 07796122828

UHNM Breast Care Advice & Support Line 01782 674077

UHNM Switchboard

Tel: 01782 715444

Breast Screening Unit North Midlands Tel: 0300 123 1463

UHNM Macmillan Cancer Support & Information Centre

Provides cancer information, resources, fact sheets, signposting and referral for a wide range of emotional, financial and practical support including physical activity for people with cancer, advice about nutrition and support with well-being.

Royal Stoke Hospital 01782 676333 County Hospital 01785 236 075 macmillancentre@uhnm.nhs.uk

Macmillan Welfare Benefits service at Disability Solutions

Tel: 01782 638300 Email info@disability-solutions.net Web: www.disability/solutions.net

Lymphoedema Service UHNM Royal Stoke 01782 676688 or emaillymphoedemaclinic@uhnm.nhs.uk

Lymphoedema service Katherine House Hospice 01785 270800 or 270870

Dove Centre Counselling Service

The Dove Service works across Stoke-on-Trent and North Staffordshire offering counselling and support to those struggling with the impact of bereavement, significant loss, or life changing/limiting illness. The Dudson Centre, Hope St., Hanley, Stoke-on-Trent Tel: 01782 683155

Staffordshire and Stoke-on-Trent Wellbeing Service (IAPT)

Your choice of safe, convenient therapy – On-line, by phone or face-to-face Tel:03003030923 https://staffsandstokewellbeing.nhs.uk/

Useful National Contacts

Breast Cancer Now

For information & support. Also offers specific support for younger women, lesbian women and women with secondary breast cancer. Tel: 0808 800 6000 Website: www.breastcancernow.org

Breast Cancer Now app

The need for support doesn't end when treatment does. If you're struggling to find your 'new normal' after breast cancer BECCA, the Breast Cancer Care app, gives you information, support and inspiration to help you move beyond breast cancer, presented on easy-touse flashcards.

To download the BECCA app search for it on the Apple App Store or Google Play.

Macmillan Cancer Support Line

0808 808 00 00 Every day 8-8 www.macmillan.org.uk

Clinical Genetics Team – regional team

Lavender house Birmingham Women's Hospital Mindelsohn Way, Birmingham, B15 2TG Tel: 0121 335 8024 Email: genetics.info@nhs.net

Look Good Feel Better Work Shops

Offers various online and face to face workshops such as skincare, make up, nail care. Tel: 01372 747 500 www.lookgoodfeelbetter.co.uk

Lymphoedema Support Network (LSN)

The LSN provides information & support to people with Lymphoedema Tel: 020 7351 4480 www.lymphoedema.org/lsn

Penny Brohn UK,

Living well with cancer www.pennybrohncancercare.org

Books

We have a range of useful books that are available to loan – seethe list below. More recent publications are also available on line and from bookshops.breastcancernow.org.uk also recommend up to date books, just search by typing into their search box (top right) "top 10 books to read.

The Complete Guide to Breast Cancer: How to Feel Empowered and Take Control

Professor Trisha Greenhalgh, an academic GP, and Dr Liz O'Riordan, a Consultant Breast Cancer Surgeon, are not only outstanding doctors, but they have also experienced breast cancer first-hand. She started blogging about her experiences as a doctor and a patient (liz. oriordan.co.uk), and this led to her talking all over the world. She was nominated for a 'Woman of the Year' award in 2016, and has written this book with Professor Trish Greenhalgh, and describe it as the book you can trust to support you at every stage of your treatment - and beyond.

Professor Trisha Greenhalgh & Dr Liz O'Riordan 2018 ISBN: 9781785041877

The Breast Cancer Book

A personal guide to help you through it and beyond. Val Sampson & Debbie Fenlon ISBN 0-09-185613-2

The Secret C

Straight talking about cancer written for children Julie A. Stokes ISBN 0-9539123-0-2

Норе

Claire Shvili ISBN 0-75410-701-9

The Power of Positive Thinking

Norman Vincent Peale ISBN 0-7493-0715-3

All Woman - Life After Breast Cancer

Tania Farrell Yelland ISBN 1-84241-004-0

A Safe Place

A Journal for Women with Breast Cancer Jennifer Pike ISBN 0-8118-2267-2

Be a Survivor

V.Lange M.D. ISBN 0-9663610-0-8

Α	space	for	your	notes
---	-------	-----	------	-------
