

# Open access follow-up after treatment for breast cancer

Information for patients and carers



# Contents

Introduction to open access follow-up	3
The open access telephone service	3
Treatment summary	3
Patient education presentation	4
Future mammograms	4
The NHS Breast Screening Programme	5
Your cancer medications/treatments	6
Hormone therapy	7
Possible side effects of treatment	7-8
Menopausal symptoms	11-13
If breast cancer returns – signs and symptoms	13
Breast awareness	12
Summary of symptoms to report	14
Breast Reconstruction and Prosthesis	15
Feelings and emotions	15
Life after treatment	17
Useful contacts	19

# Introduction to (OAFU)

The open access follow-up programme has been specially designed by cancer specialists to support you when you have completed your primary treatment for breast cancer.

The programme is based on evidence demonstrating that for well people after treatment, there is no advantage to scheduling appointments at fixed intervals where you have to attend a hospital appointment.

Furthermore, research has shown that regular routine appointments do not help prevent cancer returning and specifically in identifying new problems. This approach is more likely to create anxiety for patients.

Open access follow-up involves you, as the patient, being in control of your follow-up care. It means that your day-to-day life will not be disrupted by regular hospital appointments; instead, you can quickly gain access to the breast team and hospital when you need to within your follow-up period.

The following sections provide a summary of what you can expect when on the open access follow-up pathway.

Once you have entered the OAFU pathway, you should call the open access contact number (01623 676174) between 8am-4pm, Monday to Friday, about any new symptoms that you are concerned about or other issues you may have. Messages are picked up periodically and you will receive a call back within 48 hours.

Concerns are reviewed by a senior nurse, surgeon or oncologist and appropriate rapid access back through the breast unit, investigations or signposting/referrals can be made.

## Treatment summary

At the end of your surgical treatment, you will receive a treatment summary alongside your post-operative results letter.

Your treatment summary provides information about your diagnosis and treatment(s), as well as how your follow-up care will be organised.

This includes:

- Your planned anti-cancer treatments following surgery.
- If a bone density (DEXA) scan is applicable.
- Some of the common side effects of treatment.
- Signs and symptoms to report to us, or your GP.

- Being breast/chest and body aware.
- Further help and support information.
- How to contact the breast team.

Your treatment summary will be copied to you and your GP, so they have access to information about your personalised pathway.

## Patient education presentation (OAFU workshop)

You will be invited to attend an end of treatment nurse-led presentation. This will be scheduled around six months from when you were moved onto the open access follow-up pathway.

This is held in the Breast Unit's Amazon Lounge on a Thursday morning where a nurse will discuss numerous topics to a small group of patients (this is a patient only workshop to allow for a secure environment to have open discussions).

If you would prefer not to attend the workshop, or following discussions with the surgeon or nurse it seems it would not be appropriate, you would be sent an end of treatment letter which would include a link / QR code to allow you to watch the presentation at home with an invitation to request a nurse telephone consultation should you feel this would be beneficial.

Topics discussed within the presentation are:

- **How open access works.**
- **Being breast/chest and body aware.**
- **What to expect following treatment.**
- **Signs and symptoms to report.**
- **Health and well being.**
- **Support services.**

## Future mammograms (if applicable)

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 can develop in the other breast. Mammograms (breast x-rays) can often detect breast cancer before it can be felt, either by you or a healthcare professional. For the majority of women, mammograms are the recommended way of checking for breast cancer. Mammograms will be organised by this Trust at the timepoints recommended

by the current national guidelines. Your personalised mammogram plan will be documented in your post-operative clinic letter and treatment summary. For a small number of women and men, mammography may not be appropriate.

## Results of mammograms

After your mammogram, you will 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 King's Mill Breast Screening team on telephone 01623 676008.

Sometimes, after having treatment for breast cancer, mammograms are not as easy to read, and we may recall you so we can carry out further assessment or investigations. We will contact you by telephone or letter if this is the case.

## The NHS Breast Screening Programme

A screening invitation is sent 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 the time you are attending the hospital, please cancel the appointment with the breast screening team.

### After five years of annual follow-up:

- **If you are aged over 50 years:** You will be invited and should attend the National Breast Screening Programme. Mammograms will be every three years through the local screening service.
- **If you are aged under 50 years:** We will recommend that you continue with annual mammograms until invited for routine screening as above.
- **If you are aged 70 years or over:** You may not be automatically called for routine screening. However, you can continue to receive three yearly mammograms under the NHS Breast Screening Service – contact the breast screening team or your GP to arrange this.

# Contacting the NHS Breast Screening Service

Please telephone 01623 676008 to:

- Cancel / reschedule appointments.
- Check when there will be screening in your area (please note this is only necessary when you have been discharged from the Breast Unit).
- Self-refer for breast screening if over 70 years of age.

## Your cancer medications / treatments

Following surgery, you may be offered chemotherapy, radiotherapy, bisphosphonate therapy, targeted therapy or hormone therapy. Your oncologist and treatment team will provide you with further information regarding this. These treatments can cause side effects which can continue / remain following completion of the treatment. Please make contact regarding any side effects with the numbers you have been provided.

Contact for the Oncology Team is the main hospital number (01623 622515) followed by the below extensions:

- Oncology secretaries' extension – 6217.
- Chemotherapy nurse extension – 3061 / 3872.
- Rapid Response at Nottingham City Hospital – 0115 9628066.
- Radiotherapy information support: 01159627976.
- Nottingham oncology home delivery pharmacy: 0115 8405867.

## Chemotherapy treatment

Some patients may go on to have post-operative (adjuvant) chemotherapy, or, you may have received pre-operative (neoadjuvant) chemotherapy and will continue with maintenance therapy. This will be discussed with you at your oncology appointment. The oncology service is run by Nottingham University Hospitals NHS Trust and the breast oncology team visit once a week to see King's Mill Hospital oncology patients. Treatments are given at either King's Mill Hospital, or Nottingham City Hospital.

# Radiotherapy treatment

If it would be of benefit, you may have been referred to the radiotherapy oncology team for post-operative radiotherapy. The radiotherapy team visit King's Mill Hospital once a week to review patients in advance of, and following their radiotherapy treatment.

The radiotherapy centre is based at Nottingham City Hospital. At your appointment with the oncologist you will be given a map along with information about radiotherapy.

# Hormone therapy

Patients with hormone-sensitive cancers are prescribed anti-hormone tablets, also known as endocrine therapy. Anti-hormone therapy includes tamoxifen, letrozole, anastrozole or exemestane (can also be known by their trade names). The tablets can be given for up to five or ten years depending on your diagnosis. If applicable, once you have completed five years, we will review your case with current guidelines and write to you and your GP if the prescription should be extended or the medication should be changed.

An injection called zoladex (goserelin) may also be given if you are pre or peri-menopausal and will be given in combination with one of the tablets. The injection is given into the lower stomach in the Breast Unit at King's Mill Hospital, the Newark Medical Daycase Unit or you can enquire with your GP surgery.

Your treatment summary will confirm if you will receive anti-hormone medication and whether it is advised that you take them for five or ten years.

You will not have to pay for tablets as you are entitled to free prescriptions for the duration. A medical exemption certificate is available from your GP surgery, hospital pharmacy, local chemist or breast specialist nurse (routinely given at diagnosis).

Treatments do change and develop all the time. If there are major changes in the way we prescribe 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.

# Possible side effects of hormone medication

You may experience side effects that are specific to the drug you are taking.

For example, as a result of taking tamoxifen, the lining of your womb may become thicker, which can then cause you to develop vaginal discharge. This is common and not serious. However, if your periods have stopped and you experience unexpected vaginal bleeding, please contact your GP or the open access helpline. You may need to be referred to a gynaecologist.

There is some research that suggests that some drugs, including anti-depressants paroxetine (Seroxat®) and fluoxetine (Prozac®) may cause tamoxifen to be less effective, but this is not certain. If you are prescribed these whilst you are taking tamoxifen, please tell your surgeon / oncologist or GP.

Aromatase inhibitors such as Letrozole, Anastrozole and Exemestane can sometimes cause joint stiffness and pain. Keeping as active as possible has been proven to help reduce the symptoms and walking or resistance based exercises will give the most benefit. Please ask the Breast Team about physiotherapy referrals to our 'Spring into Action' course, or the local cancer walking group.

Vaginal dryness is a common side effect of hormone medication, in particular the aromatase inhibitors. There are several treatments that can help with vaginal dryness including vaginal moisturisers and lubricants (such as Replens MD, Senselle or Hyalofemme). Oestrogen based moisturisers can be considered on an individual basis. If you are experiencing any side effects from your hormone therapy, please contact the open access helpline to arrange a discussion with one of the nurses.

It can sometimes be suggested to request a different brand of the medication via your pharmacy, or, we may suggest switching to one of the different tablets. As there are only four medications in this family of drugs, we may advise persevering and utilising other techniques or medications to manage symptoms over a period of time until you adjust to the medication. These are covered in the section about menopausal symptoms.

## **DEXA scans and bone health**

After the menopause, as oestrogen levels fall, women's bones often become less strong. When you are taking an aromatase inhibitor such as Letrozole, Anastrozole or Exemestane, this process may be accelerated. You may need one or more bone density scans (DEXA scans). These scans can tell us if you are developing bone thinning, which could lead to a condition called osteoporosis. Your treatment summary will state if these are needed. Sometimes they are organised by the hospital and sometimes by a GP.

If your periods have stopped early because of your treatment, you may also need bone density scans. These can also be arranged by the Breast Team, Oncology Team, or more commonly by your GP.

If you receive bisphosphonate therapy, your DEXA scans will continue after treatment is completed (usually after five years).

If the DEXA scan shows bone thinning, your GP will be informed, and you may be started on calcium or vitamin D supplements. You can help maintain your bone health by maintaining good nutrition, a diet high in calcium, a healthy body weight and taking part in gentle weight bearing exercise such as walking.

## Bisphosphonate therapy

Bisphosphonates are a group of medications that have been used to treat thin bones (osteoporosis) for decades. They control the cells that break down bone (osteoclasts) and allow the cells that rebuild bone (osteoblasts) to work better. As a result, they increase bone density and strength and thereby reduce the risk of fractures, especially at the wrist, hip, and spine.

Clinical studies have shown that breast cancers can recur in the bones, often many years later. Doctors think this could be because the chemicals that control bone turnover could also encourage the growth of breast cancer cells inside the bones.

These clinical trials found that bisphosphonates reduced the risk of breast cancer coming back in the bones. Not all patients have the same benefit though; greatest benefits were seen in natural or chemically induced post-menopausal women who have had their cancer completely removed.

Your treatment summary will explain if you are to receive bisphosphonates as part of your treatment. If so, you will receive further information from the oncology specialists.

## Targeted therapy (CDK 4/6 inhibitors)

CDK 4/6 inhibitors are a class of medicines used to treat certain types of hormone receptor positive, HER 2 negative breast cancers. They target specific proteins known as cyclin-dependent kinases 4 and 6 (CDK 4/6). Not all patients will require targeted therapy.

CDK 4/6 proteins control how quickly cells can grow, and in some breast cancers these proteins can become overactive. The aim of these treatments, if they will be beneficial to you, is to reduce the risk of the cancer returning.

During treatment which is given in tablet form as either the drug Abemaciclib or Ribociclib, you will have regular blood tests and review appointments with the Oncology Team.

The medication can come with some side effects, and it's important to highlight and discuss these at oncology appointments or via the Rapid Response Triage line: 0115 9628066.

## Possible side effects of treatment

All treatments (surgery, chemotherapy, targeted therapy, radiotherapy, bisphosphonates and hormone therapy) have the possibility of some side effects and some of these can last longer than others. Not everyone will experience side effects, and some patients may experience more difficulty with them than others. Below are some of the common side effects you may experience:

- Breast discomfort or tenderness
- Menopausal related side effects (hot flushes, vaginal dryness, changes in mood)
- Fatigue
- Joint pain
- Lymphoedema
- Peripheral neuropathy
- Numbness under your arm/across your scar
- Struggling emotionally
- Pain.

Through the Macmillan Cancer Information and Support Centre, the breast specialist nurses, or the Maggie's Centre (based at Nottingham City Hospital), a referral can be made for services such as dieticians, physiotherapists, counsellors, psychologists and occupational therapists that have experience of helping people manage side effects of treatment. There is also a specialist Late Effects clinic which runs at Nottingham City Hospital for patients with chemotherapy or radiotherapy related side effects, which you can be referred to by the breast specialist nurses.

## Lymphoedema

Lymphoedema is a swelling of the arm/breast/chest following treatment. If you have had breast surgery and lymph node removal, it is important to look after your arm and breast/chest area. You should take precautions to avoid cuts, scratches, irritations, burns and insect bites wherever possible.

It is important to check that any numb patches of skin are not injured.

There is no consistent evidence of increased risk of lymphoedema associated with medical procedures (e.g., blood tests, injections, intravenous medicines, and blood pressure measurement) on the treated side and the decision to perform medical procedures using the arm on the treated side should depend on the clinical need and the possibility of alternatives. In the first instance, we recommend not using the treated arm.

# Fertility, sexual relationships and contraception

If you are to receive chemotherapy or targeted therapy, you will be required to use barrier contraception. Chemotherapy can affect your ability to become pregnant, this should be discussed with the oncology team before starting treatment.

Following treatments, even though you may not be having regular periods, you may still be able to get pregnant. Effective contraception is important. Depending on the type of breast cancer you had, you may be advised to avoid hormone-based contraception such as the pill, implant or Mirena Coil. Your GP or practice nurse will be able to recommend a local family planning centre where you can discuss your individual needs. The general advice is that you should not get pregnant for two years following treatment.

There is support, advice and information available via Breast Cancer Now and Macmillan websites about sex and intimacy during and following breast cancer treatment.

## Menopausal symptoms

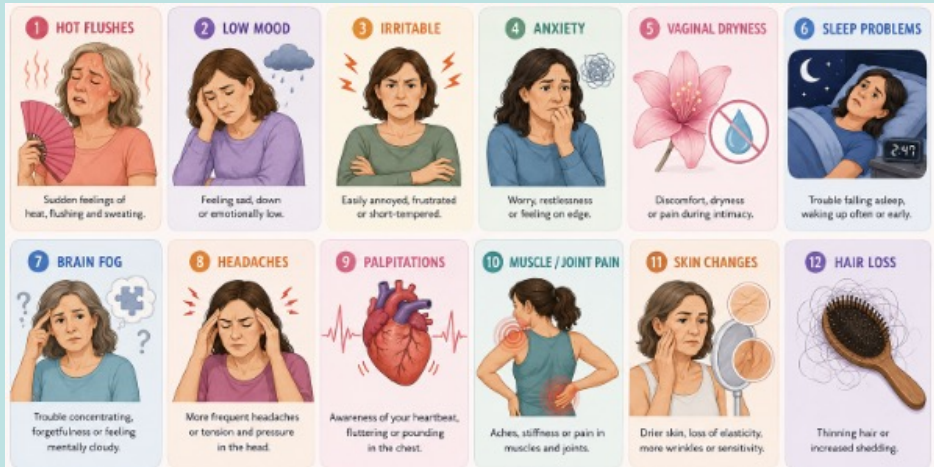
Some treatments for breast cancer can cause menopausal symptoms or can make the menopause start earlier. The menopause usually occurs between the ages of 45-55. There are many symptoms which you can experience which are due to the drop in hormone levels, and different ways these can be managed. Some of these are;

Menopausal symptom	Ways to manage
Hot flushes and sweats	<ul style="list-style-type: none"><li>- Avoiding hot drinks, caffeine, alcohol and spicy foods.</li><li>- Wearing thin layers of clothing</li><li>- Using fans</li><li>- Cognitive behavioural therapy (CBT)</li><li>- Mindfulness</li><li>- Medications.</li></ul>
Low mood, irritable, anxiety	<ul style="list-style-type: none"><li>- Talking therapies</li><li>- CBT</li><li>- Mindfulness</li><li>- Medications.</li></ul>

Menopausal symptom	Ways to manage
Vaginal dryness, itching, loss of libido, urinary symptoms	<ul style="list-style-type: none"> <li>- Topical vaginal moisturisers and creams</li> <li>- Oestrogen based creams (would need to be discussed with the breast team)</li> <li>- Talking therapies</li> <li>- Loose fitting cotton underwear.</li> </ul>
Sleep problems, brain fog, memory difficulties	<ul style="list-style-type: none"> <li>- CBT</li> <li>- Mindfulness</li> <li>- Sleep hygiene</li> <li>- Sleepio website (CBT)</li> <li>- Sleepstation website</li> <li>- Clementine app</li> <li>- Exercise.</li> </ul>
Headaches or migraines	<ul style="list-style-type: none"> <li>- Medications</li> <li>- Sleep hygiene</li> <li>- Hydration</li> <li>- Mindfulness</li> <li>- CBT.</li> </ul>
Palpitations	<ul style="list-style-type: none"> <li>- Medications</li> <li>- CBT</li> <li>- Mindfulness</li> <li>- Yoga.</li> </ul>
Muscle and joint pain, osteoporosis, weight gain	<ul style="list-style-type: none"> <li>- Exercise</li> <li>- Healthy weight</li> <li>- Healthy diet rich in calcium and Vitamin D.</li> </ul>
Skin changes, hair loss	<ul style="list-style-type: none"> <li>- Moisturisers</li> <li>- High factor sun cream</li> <li>- Medications, ointments and eyedrops</li> <li>- Vitamin D.</li> </ul>

Herbal treatments for menopause are not recommended as there is not enough study evidence on their effect on breast cancer risk. Some of these will also have plant-based oestrogens which should be avoided.

**Please discuss any concerns with the breast nurses.**



### Helpful online resources:

- <https://menopauseandcancer.org/>
- <https://www.cancerresearchuk.org/about-cancer/breast-cancer/living-with-menopausal-symptoms>
- <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/menopausal-symptoms-and-cancer-treatment>
- <https://futuresdreams.org.uk/breast-cancer-menopause-tips/>

## If cancer returns – signs and symptoms

It is important to know that survival rates for breast cancer are improving all the time and that modern breast cancer treatment is usually very successful.

However, breast cancer can sometimes return, or you can develop a new breast cancer. There is no maximum time span as to when this can happen, 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.

### Breast cancer can return:

- In the treated breast (local recurrence).
- In the nearby area under your arm, above your collarbone or neck area (regional recurrence).
- In the other breast.
- Elsewhere in the body (distance recurrence also known as metastatic breast cancer or secondary breast cancer).

## Breast/chest awareness

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.

We know that after having treatment for breast cancer it can take some time (up to two years) to become familiar with your treated breast. However, the better we know our bodies, the quicker we notice what is normal or not normal for us. If something feels unusual to you, please contact the breast specialist nurses.

There is no right or wrong way to get to know your breasts. Try to get used to the way your breast look and feel. You can do this around once a month, in the bath or shower, when using soap or body lotion. There is no need to change your everyday routine. You can find leaflets and websites which may be helpful (some of which will be listed at the end of this booklet).

You know better than anyone how your breasts look and feel normally, so if you notice a change, contact the breast specialist nurses.

## Signs and symptoms

Everyone has aches and pains, but when you have had breast cancer, you may be more aware of them and be concerned that any pain is related to cancer. Included below is a summary of symptoms that you may wish to report to either a Breast Specialist Nurse 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 conditions, but it may mean that you should get them checked out by the Breast Team.

Having 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.

## Summary of symptoms to report

### **Please contact us if you experience:**

- A lump or a swelling in your breast, in the skin or on the chest wall after a mastectomy, above your collarbone or in the neck area, or under your arm.
- Any skin changes including dimpling, puckering, redness or raised spots on your breast or mastectomy scar.
- Nipple discharge.
- Lymphoedema (affected side swelling).

Or if you experience:

- Any new ongoing 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.
- A constant feeling of nausea.
- Discomfort or swelling under your ribs or across your upper abdomen.
- A dry cough or a feeling of breathlessness.
- Severe headaches, usually worse in the morning.

## Breast reconstruction and prosthesis

If you have had a mastectomy and decided against reconstruction but change your mind at a later date, please contact us to discuss delayed reconstruction. If you have had radiotherapy, we will advise you to wait at least a year after completion of radiotherapy for the tissues to heal. In some cases, surgery can be offered to correct unequal breast sizes – the breast specialist nurses and support worker 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. If you need advice about your prosthesis or bra fittings, please arrange an appointment by contacting 01623 672273.

## Feelings and emotions

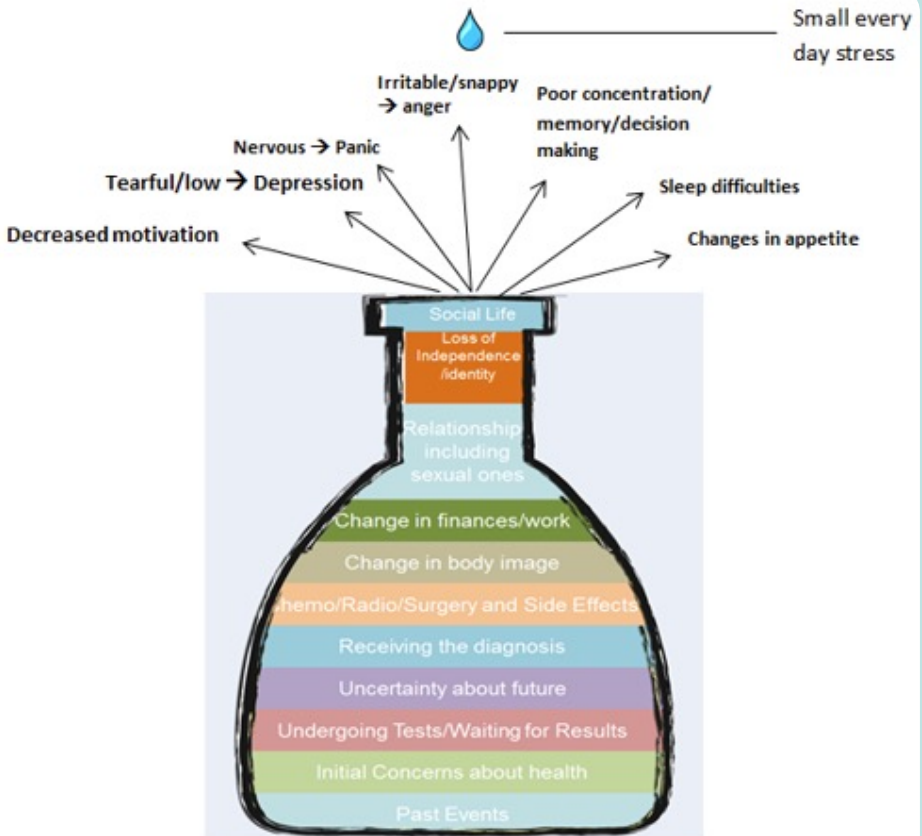
Everyone will have different feelings when they no longer need to see their medical team regularly. Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment. Many worry about the cancer coming back. This is very normal and usually these anxieties lessen with time.

Realising that there is a problem and 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 it difficult to cope, contact the breast specialist nurses as they can signpost or refer to talking/counselling services or your GP can refer you for cognitive behavioural therapy (CBT).

It may also help to contact a local or national support organisation such as Breast Cancer Care or Macmillan Cancer Support. Their contact details can be found at the back of this booklet.

The 'stress bottle' is a useful way to help you think about the stressful things that have happened, as well as any changes and loss in your life. Sometimes when you sit down and draw out your own stress bottle, you begin to see its not at all surprising that you feel stressed. Once the bottle is full, the smallest drop of everyday stress that tries to squeeze in (for example, dropping a plate in the kitchen) can lead to a 'bottle eruption'. It may be that in that moment you feel irritable, snappy, easily tearful, panicky or low. Its important to remember this eruption is simple a sign that your bottle is full.

It's unlikely that you will be able to empty your bottle completely, but you can develop coping strategies such as mindfulness to help empty some of the bottle.



# Our commitment to you

If the breast specialist nurse feels the symptoms you are experiencing could possibly represent a new cancer diagnosis or be related to your previous cancer diagnosis, an appointment will be arranged at one of our clinics within two weeks of telephoning us. If necessary, further investigations may be organised and an outpatient appointment will be arranged to receive the results. For patients continuing to experience side effects of treatment, there are other clinics and support services which you can be referred, or sign posted to following a discussion with the breast specialist nurses.

Sometimes, verbal advice (via the telephone service) may replace the need for an outpatient appointment. In these cases, an holistic needs assessment care plan will be sent to you with a copy to your GP. We hope that this enhances and promotes your ability to care for yourself once treatment has been completed and enables you to benefit from the team's expertise as required.

## Life after treatment

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 address. Some of the specialist services we can offer are:

- Mindfulness courses.
- Counselling and support.
- Lymphoedema services.
- Menopausal side-effects advice.

## Wellbeing courses

### Spring into Action

Spring into Action is a clinic organised by physiotherapists which offers individual advice about making positive changes to levels of physical activity and/or diet after cancer treatment. If you wish to attend, you can self-refer by contacting 01623 622515 extension 3221 or 6030 or speak to the breast specialist nurses.

### HOPE course

The 6-weekly Macmillan Help to Overcome Problems Effectively (HOPE) course concentrates on focusing and rediscovering inner strengths and resilience to help individuals cope emotionally, psychologically, and practically. Referrals can be made via the Breast Team or Macmillan Cancer Information and Support Centre.

## **Moving Forward course**

Facilitated by Breast Cancer Now in partnership with NHS hospitals, the course usually takes place over half a day for three or four weeks. It aims to provide information and support to cope with and adjust to life after breast cancer treatment. Topics covered may include; healthy eating, exercise, managing menopausal symptoms, lymphoedema, cancer fatigue and intimacy/relationships. You can self-refer via the website found at the end of this booklet, or via the breast specialist nurses on the open access line.

## **Maggie's Nottingham**

Located at Nottingham City Hospital Campus. Maggie's Nottingham offers a range of cancer support; from courses, casual classes, self-help, support groups and help with money worries, or just a calming space with friendly faces. Information is located at the end of this booklet.

## **Welfare and benefits advice**

If you are experiencing issues with housing, employment, immigration, financial or welfare benefits, you can get help by contacting the breast specialist nurses on the open access line or the Macmillan Information and Support Centre who can complete a referral to the Macmillan money and work advisors. Their contact details are at the end of this booklet.

## **Medicines information**


If you have any questions or concerns about medication started by your cancer doctors, please contact the breast specialist nurses for advice. If you have any questions or concerns regarding medications started by your GP or holistic/complementary medications, please contact your GP or a local pharmacist.

# **Finally**

If you are worried about something to do with your breast cancer, or the treatment that you have had for it, please contact the breast specialist nurses on the open access line. 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 concerns.

# Useful contacts

<b>Breast Unit open access line</b>	<b>01623 676174</b>
Breast team: Key workers/breast specialist nurse/ support worker	01623 622 515, extension 3884 CNS: Lisa Beccy Kim Yvonne Carolyn BCN: Nichola Sandra BCSW: Charlotte
Breast prosthetic/bras	To arrange a fitting appointment telephone 01623 672 273
Breast secretaries	01623 672 273
Breast screening team	01623 676 008
Late Effects Clinic (Nottingham City Hospital)	0115 962 7976 Email: lateeffects@nuh.nhs.uk
Macmillan Information and Support Centre	01623 622 515, extension 6499 Email: sfh-tr.cancer.info@nhs.net
Macmillan Money and Work/ Benefits Advice	0808 808 00 00
Maggie's Centre Nottingham	0115 924 6210 Email: nottingham@maggies.org
Oncology secretaries	01623 622 515, extension 6217
Physiotherapy	01623 622 515, extension 3221 or 6030

Support Information 	<b>Charity</b> Available to anyone and their family affected by breast cancer in Mansfield.	01623 672 273 <a href="http://www.amazonsgroup.org.uk/">http://www. amazonsgroup.org.uk/</a> 
--	---	--

## Support groups in the surrounding areas







<p>Nottingham Breast Institute City Campus</p>	<p>Meets on the 3rd Tuesday of the month.</p>	<p>Kate Holmes on 0115 923 3348 or Janet Briars on 0166 298 8937 Email: janmbriars@gmail.com</p>
<p>Cancer Patients and Carers Support Group, Queen's Medical Centre, Room C2505, C floor, South Block</p>	<p>Meets at 5.30pm on the 3rd Tuesday of the month. Information, support and befriending service.</p>	<p>Freda and Ken on 0115 9313541 Email: ccancerinfo@nuh.nhs.uk Facebook: Nottingham cancer patients and carers support group</p>
<p>Cancer Journey Nottinghamshire and Derbyshire</p>	<p>People with cancer and their carers.</p>	<p>Email: Sharon Steer cancerjourney@outlook.com</p>
<p>Newark Cancer Support Group</p>	<p>Support and friendship to anyone affected by cancer including family members and carers.</p>	<p>Email: newarkbcsg@gmail.com 01636706177 </p>
<p>Lincolnshire Cancer Support Groups Breast Cancer Support Groups</p>	<p>Grantham Boston Brigg and District Lincoln Grimsby Bosom Buddies Louth Embrace Breast Cancer</p>	<p>Jenny 01476530519 Margaret 01205750408 Michelle 07955770995 Joy 01427668699 Betty 01522809178 Sue 01472590188 Maddy 07800802660</p>




## Psychological and emotional support

	<p><b>Charity</b> Available to anyone affected by breast cancer.</p>	<p>0808 800 6000 <a href="https://breastcancernow.org/">https://breastcancernow.org/</a> </p>
<p>Bright Sky</p> 	<p><b>App / wellbeing</b> Confidential app with support and information for anyone in an abusive relationship.</p>	<p><a href="http://www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps">www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps</a></p>
 <p>CANCER RESEARCH UK</p>	<p><b>Charity</b> Available to anyone affected by cancer.</p>	<p><a href="https://www.cancerresearchuk.org/">https://www.cancerresearchuk.org/</a> </p>
<p>Counselling</p>	<p><b>Support</b> You can self-refer for talking therapies or counselling.</p>	<p><a href="https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/">https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/</a></p>
 <p>MAGGIE'S Everyone's home of cancer care</p>	<p><b>Charity / support</b> Based at Nottingham City hospital. Offers numerous drop-in and workshop services.</p>	<p><a href="mailto:nottingham@maggies.org">nottingham@maggies.org</a> 0115 924 6210 <a href="http://www.maggies.org">www.maggies.org</a> </p>
<p>Information Hub</p> 	<p><b>Charity / support</b> Located outside clinic 14 at King's Mill Hospital.</p>	<p>01623 622515, extension 6499 <a href="mailto:Sfh-tr.cancer.info@nhs.net">Sfh-tr.cancer.info@nhs.net</a> <a href="https://www.macmillan.org.uk/">https://www.macmillan.org.uk/</a> </p>

 <b>headspace</b>	<b>App / wellbeing</b> Science backed app in mindfulness and meditation.	<a href="http://www.headspace.com">www.headspace.com</a> <a href="http://www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps">www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps</a>
 <b>unmind</b>	<b>App / wellbeing</b> Mental health platform to improve wellbeing.	<a href="http://www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps">www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps</a>
	<b>App / wellbeing</b> Collection of positive practical support for working parents.	<a href="http://www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps">www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps</a>
#Stayalive 	<b>App / wellbeing</b> Suicide prevention resource to help keep people safe.	<a href="http://www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps">www.england.nhs.uk/supporting-our-NHS-people/support-now/wellbeing-apps</a>
	<b>Charity / support</b> For young adults affected by cancer.	Email: <a href="mailto:hi@shinecancersupport.org">hi@shinecancersupport.org</a> <a href="https://shinecancersupport.org/">https://shinecancersupport.org/</a>
	<b>Charity / support</b> A little lift, when you need it most.	01603 740361 <a href="mailto:hello@littlleifts.org.uk">hello@littlleifts.org.uk</a> <a href="https://www.littlleifts.org.uk">https://www.littlleifts.org.uk</a>
	<b>Charity / support</b> For anyone affected by cancer. Online group sessions and support. Based in Bristol.	0303 3000 118 <a href="mailto:clientsupport@pennybrohn.org.uk">clientsupport@pennybrohn.org.uk</a> <a href="https://www.pennybrohn.org.uk">https://www.pennybrohn.org.uk</a> 
<b>FUTURE DREAMS</b>	<b>Charity / support</b> No one should face breast cancer alone. Online support based in London.	020 4558 2950 <a href="mailto:info@futuresdreams.org.uk">info@futuresdreams.org.uk</a> <a href="https://futuresdreams.org.uk">https://futuresdreams.org.uk</a> 

## Living well advice and support

<p>Moving forward workshop</p> 	<p><b>Workshop</b> Provides information, support and guidance with how to cope with, and adjust to life after treatment.</p>	<p>To discuss and book onto the course: 0345 077 1893 <a href="https://breastcancernow.org/information-support/support-you/moving-forward">https://breastcancernow.org/information-support/support-you/moving-forward</a></p>
	<p><b>Charity / app / information/ support</b> Information on how to check your chest/ breasts and other helpful information.</p>	<p><a href="https://coppafeel.org/">https://coppafeel.org/</a></p>
	<p><b>Information</b> Good resource with evidence-based information regarding pain management.</p>	<p><a href="https://www.britishpainsociety.org/people-with-pain/">https://www.britishpainsociety.org/people-with-pain/</a></p>
<p><b>EATING PROBLEMS</b></p>	<p><b>Information</b> Macmillan information page with help and support for eating.</p>	<p><a href="https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/eating-problems">https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/eating-problems</a></p>
	<p>Home delivery of meals.</p>	<p><a href="https://www.wiltshirefarmfoods.com/">https://www.wiltshirefarmfoods.com/</a> 0800 077 3100</p>
	<p><b>Wellbeing app</b> More than 4 million people have used the app to start running.</p>	

	<p><b>Wellbeing app</b> Track and build up daily walks.</p>	
	<p><b>Wellbeing</b> NHS website for mindfulness.</p>	<p><a href="https://www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness/">https://www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness/</a></p>
<p><b>Body image</b></p>		
	<p><b>Information / support</b> For women wanting more information and support around reconstruction.</p>	<p><a href="https://keepingabreast.org.uk/">https://keepingabreast.org.uk/</a></p>
	<p><b>Information / support</b> Dedicated to supporting women who have had single or double mastectomy and chose not to have reconstruction.</p>	<p><a href="https://www.flatfriends.org.uk/">https://www.flatfriends.org.uk/</a></p>
	<p><b>Prosthetics / charity</b> Hand crafted woollen breast mounds.</p>	<p><a href="https://www.knittedknockersuk.com/">https://www.knittedknockersuk.com/</a></p>
	<p><b>Information / charity / support</b></p>	<p><a href="https://www.lymphoedema.org/">https://www.lymphoedema.org/</a> 020 7351 4480 admin@lsn.org.uk</p>
<p><b>Recovery</b></p>		
<p>Arm exercises app</p> 	<p><b>Information</b> Breast Axilla Postoperative Support app (BAPS Wales).</p>	<p>Download from android play or iOS</p>

<p>CARE Programme</p> 	<p><b>Wellbeing</b> Notts County FC working with Macmillan to deliver a rehabilitation exercise programme.</p>	<p>Tel: Josh Stevenson on 07534135670 josh.stevenson@nottscountyfitc.org.uk</p>
	<p><b>Charity / support</b> Helping people manage the side effects of cancer treatments to improve quality of life.</p>	<p><a href="https://www.canrehab.com/canrehab-trust/">https://www.canrehab.com/canrehab-trust/</a></p>
	<p><b>Wellbeing</b> Cancer exercise specialists working with Macmillan.</p>	<p><a href="https://safefit.nhs.uk/">https://safefit.nhs.uk/</a></p>
	<p><b>Wellbeing</b> NHS website of home workout videos.</p>	<p><a href="https://www.nhs.uk/better-health/get-active/home-workout-videos/">https://www.nhs.uk/better-health/get-active/home-workout-videos/</a></p>
	<p>Macmillan grants are one time payment which can be completed via the Macmillan pod or website.</p>	<p><a href="https://www.macmillan.org.uk/cancer-information-and-support/get-help/financial-help/macmillan-grants">https://www.macmillan.org.uk/cancer-information-and-support/get-help/financial-help/macmillan-grants</a> Tel: 0808 8080 000 Financialguidance@macmillan.org.uk</p>
	<p><b>Charity / support</b> Provides practical help to those struggling financially.</p>	<p><a href="https://www.turn2us.org.uk/">https://www.turn2us.org.uk/</a></p>

	<p><b>Charity / support</b> National Energy Action – supporting action against fuel poverty.</p>	<p>0191 261 5677 <a href="http://www.nea.org.uk">http://www.nea.org.uk</a></p>
	<p><b>Charity / support</b> Practical, local support and equipment.</p>	<p>0300 456 1914 <a href="http://www.redcross.org.uk">http://www.redcross.org.uk</a></p>
	<p><b>Charity / support</b> Help for parents with a child under the age of five.</p>	<p>0116 4645490 <a href="mailto:info@home-start.org">info@home-start.org</a> <a href="http://www.home-start.org.uk">http://www.home-start.org.uk</a></p>



## **Further sources of information**

NHS Choices: [www.nhs.uk/conditions](http://www.nhs.uk/conditions)

Our website: [www.sfh-tr.nhs.uk](http://www.sfh-tr.nhs.uk)

## **Patient Experience Team (PET)**

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

**King's Mill Hospital:** 01623 672222

**Newark Hospital:** 01636 685692

**Email:** [sfh-tr.PET@nhs.net](mailto:sfh-tr.PET@nhs.net)

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email [sfh-tr.PET@nhs.net](mailto:sfh-tr.PET@nhs.net).

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them. If you require a full list of references (if relevant) for this leaflet, please email [sfh-tr.patientinformation@nhs.net](mailto:sfh-tr.patientinformation@nhs.net) or telephone 01623 622515, extension 6927.

To be completed by the Communications office  
Leaflet code: PIL202606-03-OAFBC  
Created: August 2023 / Revised: June 2026  
Review Date: June 2028