Healthier Communities, Outstanding Care





Open Access Follow-Up after Treatment for Breast Cancer

Patient and Carer Information

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turn 208	Charity / support Provides practical help to those struggling financially	https://www.turn2us.or g.uk/
NEA	Charity / support National Energy Action – supporting action against fuel poverty	Tel: 0191 261 5677 http://www.nea.org.uk
BritishRedCross	Charity / Support Practical, local support and equipment	Tel: 0300 456 1914 http://www.redcross.or g.uk
H&ME START	Charity / Support Help for parents with a child under the age of 5	Tel: 0116 4645490 Email: info@home- start.org http://www.home- start.org.uk

Introduction

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.

Treatment Summary

At the end of your surgical treatment, you will have received a treatment summary (generated following your surgical postoperative results appointment).

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
- The timescales in which you started and should complete your anti-cancer medication
- o If a bone density (DEXA) scan is applicable
- Some of the common side effects of treatment
- o Signs and symptoms to report to us, or your GP
- Being breast 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.

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 in the other breast. Mammograms (breast x-rays) can often detect breast cancer before it can be felt, either by you or a health care professional. For the majority of women, 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. These mammograms will be organised by Sherwood Forest Hospitals NHS Foundation Trust. For a small number of women and men, mammography may not be appropriate.

CARE	Wellbeing	Tel: Josh Stevenson
Programme	Notts County FC	07534135670
	working with	Email:
Motherthant	Macmillan to deliver	josh.stevenson@notts
care	a rehabilitation	countyfitc.org.uk
Cancer And Rehabilitation Exercise	exercise	
	programme.	
	Charity / Support	https://www.canrehab.
		com/canrehab-trust/
	Helping people	com/carrieriab-trust/
CanRehab	manage the side	
• •	effects of cancer	
	treatments to	
	improve quality of	
	life	
ি SafeFit	Wellbeing	https://safefit.nhs.uk/
1001 Salerit	Cancer exercise	
	specialists working	
	with Macmillan	
	Wellbeing	https://www.nhs.uk/bet
Better Health Let's	NHS website of	ter-health/get-
Health Let's	home workout	active/home-workout-
	videos	videos/
do this	Videos	
MACMILLAN CANCER SUPPORT	Macmillan grants	https://www.macmillan.
CANCER SUPPORT	are one time	org.uk/cancer-
	payment which can	information-and-
	be completed via	support/get-
	the Macmillan pod	help/financial-
	or website	help/macmillan-grants
	3. 11000110	p/macrimari granto
		Tel: 0808 8080 000
		Email:
		Financialguidance@m
		acmillan.org.uk

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Body Image		
Keeping Abreast	Information /	https://keepingabreast.
Breast Cancer Reconstruction Support	Support	org.uk/
	For women wanting	
	more information	
	and support around	
	reconstruction	
S Elat ,	Information /	https://www.flatfriends.
Friends	Support	org.uk/
- TICHOS	Dedicated to	
	supporting women	
	who have had single	
	or double	
	mastectomy and	
	chose not to have	
	reconstruction	
Knitted	Prosthetics / Charity	https://www.knittedkno
Knockers UK ®	Hand crafted	ckersuk.com/
"Made with love and filled with lags."	woollen breast	
	mounds	
	Information / Charity	https://www.lymphoed
	/ Support	ema.org/
THE LYMPHOEDEMA		Tel: 020 7351 4480
SUPPORT NETWORK		
because lymphoedema matters		admin@lsn.org.uk
Recovery		
Arm Exercises	Information	Download from
App	Breast Axilla	android play or iOS
	Postoperative	
BAPS	Support App (BAPS	
	wales)	

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 Kings Mill Breast Screening team on: 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 (age extensions are currently being rolled out nationally to start screening at 47 years and continue until 73 years which may include your area). 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 Kings Mill Breast Screening team.

After five years of annual follow-up mammograms:

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.

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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 Kings Mill Screening Team or your GP to arrange this.

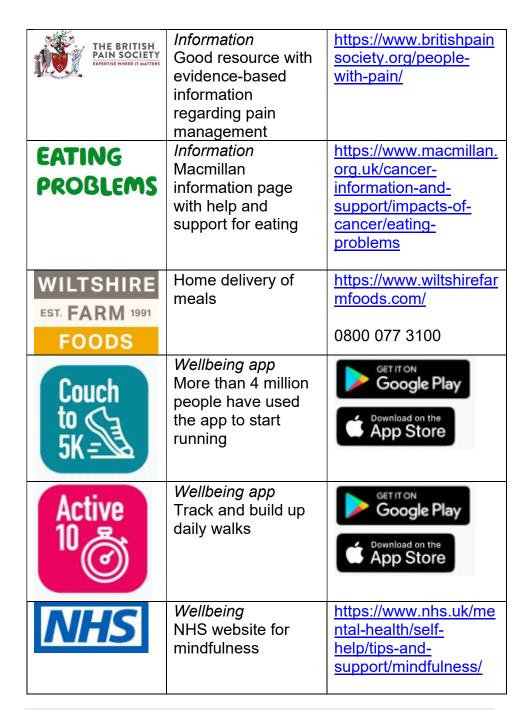
Contacting the NHS Breast Screening Service

Please contact 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 prescribed chemotherapy, radiotherapy, bisphosphonate therapy, targeted therapy or hormone therapy. Your Oncologist and treatment Nurses 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.



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CITYParents	App / wellbeing Collection of positive practical support for working parents	www.england.nhs.uk/s upporting-our-NHS- people/support- now/wellbeing-apps
#Stayalive	App / wellbeing Suicide prevention resource to help keep people safe	www.england.nhs.uk/s upporting-our-NHS- people/support- now/wellbeing-apps
shine CANCER SUPPORT	Charity / Support For young adults affected by cancer	https://shinecancersupporport.org/
Living Well Advic	e and Support	
BREAST CANCERNOW The research & care charity MOVING FORWARD WORKSHOP	Workshop Provides information, support and guidance with how to cope with and adjust to life after treatment	To discuss and book onto the course telephone: 0345 077 1893 https://breastcancernow.org/information-support/support-you/moving-forward
CoppaFeel!	Charity / App / Information/ Support Information on how to check your chest/breasts and other helpful information	https://coppafeel.org/

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

Oncology Secretaries' extension: 6217

Chemotherapy Nurse: 3061 / 3872

Rapid Response at Nottingham City Hospital: 0115 9628066

Hormone Therapy

Patients with hormone sensitive cancers are prescribed antihormone tablets, also known as endocrine therapy. Anti-hormone therapy will include tamoxifen, letrozole, anastrazole or exemestane (can also be known by their trade names). The tablets can be given for up to 5 or 10 years depending on your diagnosis. If applicable, once you have completed 5 years, we will review your case with current guidelines and write to you and your GP if the prescription should be extended.

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 every four weeks in the Breast Unit (administration at Newark or GP surgery can be assessed on an individual basis).

Your Treatment Summary will confirm if you will receive hormone medication and whether it is advised that you take them for 5 or 10 years.

Some patients will change their tablets after two or three years. For example, if you become menopausal (your periods stop), the

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team will sometimes advise you are switched to another antihormone treatment via your GP.

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 Nurse Specialist (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 (NICE, 2009). If you are prescribed these whilst you are taking Tamoxifen, please tell your Surgeon/Oncologist or GP.

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CANCER RESEARCH	Charity	https://www.cancerres
UK NESEARCH	Available to anyone	earchuk.org/
14 a 18 a 1	affected by cancer	
Counselling	Support	https://www.nhs.uk/me
	You can self-refer	ntal-health/talking-
	for talking therapies	therapies-medicine-
	or counselling	treatments/talking-
		therapies-and-
		counselling/nhs-
		talking-therapies/
	Charity / Support	nottingham@maggies.
MAGGIE'S	Based at City	org
Everyone's home of cancer care	hospital. Offers	0115 924 6210
	numerous drop in	
	and workshop	www.maggies.org
	services.	www.maggioo.org
Information Hub	Charity / Support	01623 622515 ext
MACMILLAN	Located outside	6499
CANCER SUPPORT	clinic 14 at Kings	Sfh-
	Mill Hospital	tr.cancer.info@nhs.net
	Willi 1 103pital	tr.caricer.imo@fins.net
		https://www.macmillan.
		org.uk/
	Ann / Mallhaina	
headspace	App / Wellbeing	www.headspace.com
	Science backed app in mindfulness and	variation along the tilt/s
		www.england.nhs.uk/s
	meditation	upporting-our-NHS-
		people/support-
		now/wellbeing-apps
	Ann / Mallhaine	
bnimnu 🛂	App / Wellbeing Mental health	
		www.england.nhs.uk/s
	platform to improve	upporting-our-NHS-
	wellbeing	people/support-
		now/wellbeing-apps

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Lincolnshire Cancer Support	Grantham	Jenny Hubbard 01476530519
Groups	Boston	Margaret Dooley
Breast Cancer Support groups	Brigg and District	01205750408
3 22/	Lincoln	Michelle Mundey 07955770995
	Grimsby Bosom Buddies	Joy- 01427668699
	Louth Embrace	Betty- 01522809178
	Breast Cancer	Sue Munday 01472590188
		Maddy West 07800802660
Psychological and Emotional Support		
Psychological an		
	Charity	0808 800 6000
BREAST		0808 800 6000 https://breastcancerno w.org/
BREAST	Charity Available to anyone	https://breastcancerno
BREAST	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now	https://breastcancerno
BREAST	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now created the app for peer support	https://breastcancerno w.org/ Get It on Google Play Download on the
BREAST	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now created the app for	https://breastcancerno w.org/
BREAST CANCERNOW The research & care charity	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now created the app for peer support during/following treatment App / wellbeing	https://breastcancerno w.org/ Getiton Google Play Download on the App Store www.england.nhs.uk/s
BREAST CANCERNOW The research & care charity	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now created the app for peer support during/following treatment App / wellbeing Confidential app	https://breastcancerno w.org/ Google Play Download on the App Store www.england.nhs.uk/s upporting-our-NHS-
BREAST CANCERNOW The research & care charity	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now created the app for peer support during/following treatment App / wellbeing Confidential app with support and information for	https://breastcancerno w.org/ Getiton Google Play Download on the App Store www.england.nhs.uk/s
BREAST CANCERNOW The research & care charity	Charity Available to anyone affected by breast cancer Application (App) Breast Cancer Now created the app for peer support during/following treatment App / wellbeing Confidential app with support and	https://breastcancerno w.org/ Google Play Download on the App Store www.england.nhs.uk/s upporting-our-NHS- people/support-

Aromatase inhibitors such as Letrozole, Anastrazole and Exemestane can sometimes cause joint stiffness and pain. Keeping as active as possible has been proven to help reduce the symptoms. 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 (Breast Cancer Now, 2017). 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.

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, Anastrazole 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, or more commonly by your GP.

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Regular exercise such as walking, along with a diet high in calcium, will help to maintain bone health.

If you receive bisphosphonate therapy, your DEXA scans will continue after treatment is completed (usually after 5 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, body weight and taking part in gentle weight bearing exercise contact the Breast Specialist Nurses if you would like an information sheet on suggested exercises).

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.

Support Information AMAZON BREAST SUPPORT GROUP	Charity Available to anyone and their family affected by breast cancer in Mansfield	01623 672273 http://www.amazonsgr oup.org.uk/
Support Groups i	n the Surrounding Ar	
Nottingham Breast Institute City Campus	Meets on the 3 rd Tuesday of the Month	Tel: Kate Holmes 0115 923 3348 or Janet Briars 0166 298 8937 Email: janmbriars@gmail.com
Cancer Patients and Carers Support Group QMC Room C2505 C floor South Block	17:30 on the 3 rd Tuesday of the month Information, support and befriending service.	Tel: Freda and Ken 0115 9313541 Email: cancerinfo@nuh.nhs.u k Facebook: Nottingham cancer patients and carers support group
Cancer Journey Nottinghamshire and Derbyshire	People with cancer and their carers.	Email: Sharon Steer cancerjourney@outloo k.com
Newark Cancer Support Group	Support and friendship to anyone affected by cancer including family members and carers	Email: nikiwhitbum@btinterne t.com Tel Niki 07803710640 Tel Kerry 07958297919

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Useful Contacts

Breast Unit:	01623 676174
Open Access Line	
Breast Team:	01623 622 515
Key Workers/Breast	Gill: Ext 3884
Care Nurse/ Support	Lisa: Ext 3946
Worker	Yvonne/Carolyn: Ext 3017
	Beccy: 3946
	Kersten: Ext 3946
	Charlotte: Ext 3884
Breast	To arrange a fitting appointment
Prosthetic/Bras	contact:
	01623 672273
Breast Secretaries	01623 672 273
Breast Screening	01623 676008
Team	
Late Effects Clinic	0115 9627976
(City Hospital)	lateeffects@nuh.nhs.uk
Macmillan Information	01623 622 515
and Support Centre	Ext: 6499
	sfh-tr.cancer.info@nhs.net
Macmillan Money and	01274 987 600
Work/Benefits Advice	financialguidance@macmillan.org.uk
Maggie's Centre	0115 924 6210
Nottingham	nottingham@maggies.org
Oncology Secretaries	01623 622 515
	Ext: 6217
Physiotherapy	01623 622 515
	Ext: 3221 or 6030

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 (Abemaciclib)

Abemaciclib is used to treat locally advanced or metastatic (spread to other places in the body) breast cancer. It is only used if tests show that the cancer cells have hormone receptor positive breast cancer (Oestrogen Positive / ER+), do not have HER receptors (HER2 negative) and the oncology team have agreed you are eligible for the treatment.

Abemaciclib is a type of targeted therapy drug called a cancer growth inhibitor. It comes in tablets that you take twice a day, every day without a break. It is given in combination with daily hormone therapy. During treatment, 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 affects you may experience:

- Breast discomfort or tenderness
- Menopausal related side effects (hot flushes, vaginal dryness, changes in mood)
- Fatigue
- Joint pain
- Lymphoedema

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.

Younger Women

Younger women may have different needs at the end of treatment such as:

- Understanding the impact of treatment upon fertility
- Becoming pregnant after treatment
- Issues related to body image and sexuality and how this may impact upon relationships
- Advice about contraception

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 Clinical Nurse Specialists 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.

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 located at the end of this booklet.

Contraception

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.

If Breast Cancer Returns – Signs and Symptoms

It is important to know that survival rates for breast cancer are improving all the time (NICE, 2009) 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 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.

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.

The telephone service is open Monday to Friday, 9am to 5pm and may be answered by a Support Worker, a Clinical Nurse Specialist or may go to the answering machine which is checked twice a day. If your call is not answered immediately, please leave your name, hospital number and a short message and your call will be returned within 2 working days.

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
- Fertility/sexual issues signposting
- Body image issues
- Look good feel better workshops
- Wellbeing courses

Wellbeing courses

Spring into Action

Spring into Action is a clinic organised by physiotherapists which offers individual advice about making positive changes to levels

The Open Access Telephone Service

Once you have entered the open access follow-up programme, you should call the open access contact number about any new symptoms that you are concerned about or other issues you may have. The aim of the telephone service is to provide helpful advice and allow you to have rapid access back to the Breast Team as required.

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 out-patient 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.

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.

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 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 arm 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. 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.