

## Being discharged from the breast clinic following treatment of breast cancer

### Introduction

For many years women with breast cancer were followed up for 5 to 10 years. However, recent evidence has shown that this is not the best care we can give. The change in practice has come from extensive research and has involved patient groups and expert opinion.

At your recent outpatient appointment with the Breast Team it will have been explained to you that you are transferring onto Patient Initiated Follow-up (PIFU).

This type of follow-up has been specially designed, so you are more in control. It provides you with direct access to guidance when you most need it. Your normal routine will not be disrupted by regular routine hospital appointments; instead you can quickly gain access to the Breast Team when you need to. It is based on evidence showing that there are no advantages to regular, fixed time follow-up in hospital for women and men that are well after treatment for breast cancer.

### Who to contact for support?

Your Breast Clinical Nurse Specialist will be known to you since your diagnosis of breast cancer. The Breast Clinical Nurse Specialist is available at any point in your care and is still available whilst you are on Patient Initiated Follow-up. If you have any concerns about any new symptoms or need advice and support, you can contact them on the help line provided. For all other concerns, or if you are feeling unwell, your GP remains your first point of contact.

### You should phone if:

- You have any symptoms that you are worried might be a sign that your cancer has come back.
- You are having ongoing problems after your treatment that you need help with.

If the Breast Clinical Nurse Specialist thinks you should be seen back in one of our clinics, because of any symptoms you are experiencing, they will arrange an appointment for you to be seen within two weeks. If necessary, further investigations may be organised and a further outpatient appointment arranged to receive the results. Sometimes, verbal advice may replace the need for an outpatient appointment.

### Please note

**The Breast Clinical Nurse Specialists are not in the office all the time, so please leave a message with your name and hospital number on the answer phone and you will be contacted within two days. This helpline is not for emergencies.**

### Helpline Numbers - Monday to Friday - 8.30am to 4.30pm

#### Conquest Hospital

Tel: **0300 131 4833** or **0300 131 4834**

Email: **esht.breastcnsconq@nhs.net**

#### Eastbourne DGH

Tel: **0300 131 4604**

Email: **esht.breastcnsedgh@nhs.net**

## Symptoms you may want to report

Most patients have no further problems or symptoms after they complete their treatment. Here is a guide to symptoms to seek further advice about:

- 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
- if you develop Lymphoedema (affected side arm swelling)

### Or if you experience:

- any new, on-going pain in any part of your body, especially in your back or hips, that does not improve with painkillers 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 awareness and future mammograms

It is important to remain breast aware after your treatment. Being breast aware means knowing how your breasts or chest looks and feels. If you notice any changes that aren't normal for you, please contact your Breast Clinical Nurse Specialist.

The current recommendation is women and men should have **annual** mammograms for **five years** following a diagnosis of breast cancer. After your recent appointment your consultant will have arranged these appointments for you with Radiology. The appointments will be sent to you in the post **every year** or through my health record/Patient Knows Best, if you have registered online for this. (Please see end of leaflet if you would like to know more about accessing appointment letters and test results, online).

After your mammogram, you will receive your results letter within **3 to 6 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 this timescale, please contact the Patient Initiated telephone helpline.

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 if this is the case.

An NHS breast screening invitation is sent every three years to **all** women who are registered with a GP and are between the ages of 50 and 71 years. If you receive an invitation to attend an NHS screening mammogram, during the time you are attending the hospital for mammograms, **please cancel the appointment with the NHS Breast Screening Unit**. Inform them you are receiving regular mammograms at the hospital, after treatment for breast cancer.

At the end of the 5 years you will be advised on when you will be offered future mammograms depending on your age and family history:

- If you are under the age of 50 we will arrange annual mammograms until the age of 49.

- If you are 71 or over you can self-refer to Brighton every 3 years. Please contact them on Tel: 01273 696955.
- If you have been advised by the Family History Risk Assessment Clinic to have annual mammograms up to the age of 59 please contact the Family History service on – Tel: 0300 131 5387 so these can be arranged.

## Anti-hormone therapy

Some patients with hormone sensitive cancers are prescribed anti-hormone tablets, also known as endocrine therapy. You will usually be on these tablets for five years, although some patients may be advised to continue with their tablets for a longer period. Once you have been on Patient Initiated Follow-up for five years, the Multi-disciplinary team will review your records and advise you of any changes to your medication.

You will not have to pay for tablets as you are entitled to free prescriptions. A medical exemption certificate is available from your GP Practice.

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. We may request that you return to clinic to discuss this further.

## DEXA scans

When you are taking an aromatase inhibitor such as Letrozole, Anastrozole or Exemestane 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. These scans need to be arranged through your GP. If your periods have stopped early because of your treatment, you may also need bone density scans. This can also be arranged by your GP. Regular exercise such as walking as well as a diet high in calcium will help to maintain bone health, see end of leaflet for exercise advice.

## Long term and late effects of treatment

If side effects of treatment do not go away, or if you develop late effects, you can contact the Breast Clinical Nurse Specialist; they can assess your symptoms and give you some advice on how to manage them.

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 as you may need to be referred to a Gynecologist.

To help avoid developing Lymphoedema, if you have had breast surgery and lymph-node removal, it is important to look after your arm. Lymphoedema is a swelling of the arm or hand. The following should be avoided to help you minimise your risk for its development. Avoid cuts, scratches, irritations, burns, wasp, bee and other insect bites. Don't have injections or blood given or taken on that side and avoid straining your arm or binding and squeezing the arm e.g. by a blood pressure cuff or tight clothing. If you notice any swelling in your arm, hand or chest, always ask your GP or nurse to check it. To rule out other causes and the earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully. It is also important to carry on with your arm exercises, shown to you by the Breast Clinical Nurse Specialist. Please see end of leaflet for more advice on arm care.

## Feeling unable to cope:

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, your Breast Clinical Nurse Specialist may be able to arrange an appointment for one to one support or counselling. You can also self-refer to this service and your close family members can also receive support or counselling through this service. Please see details at the end of the leaflet.

## Finally

If you are worried about something to do with your breast cancer, or the treatment that you have had for it, please contact your Breast Clinical Nurse Specialist. They would rather see you with something that turns out to be nothing, than for you to be at home worrying. There is some evidence that suggests cancer patients can feel very vulnerable when the active treatment stops, suddenly all the professionals around you disappear leaving you alone. It is important to build up a network of support around you; this can be achieved through support groups and exercise classes. At the end of this leaflet is a list of contacts and information where you can find other support.

Once you have been on Patient Initiated Follow-up for five years, the Multi-disciplinary team will review your records, if you have remained well and not required further interventions over that time they will discharge you from the hospital and Patient Initiated Follow-up to the care of your GP and practice team.

## Support and useful contacts

Contact for Clinical Nurse Specialists		
<b>Conquest Hospital</b>	<b>Breast Clinical Nurse Specialists</b> Juliette Twyman Louise Hunter Debbie Turnbull Cancer Support Worker: Claire Moor	<b>Tel:</b> 0300 131 4833 0300 131 4834 (with answerphones) <b>Email:</b> esht.breastcnsconq@nhs.net
<b>Eastbourne District General Hospital</b>	<b>Breast Clinical Nurse Specialists</b> Heather Driver Emma Robb Katy Hollobon Cancer Support worker: Claire Moor Volunteer: Jackie Gully	<b>Tel:</b> 0300 131 4604 (with answerphone)  <b>Email:</b> esht.breastcnsedgh@nhs.net
Body Image		
Mammogram Appointment to Cancel or reschedule	Please ring the appointment Centre 0300 131 4600 Monday to Friday - 8am to 6pm Saturday - 9am to 12pm	Or Cancel or reschedule your appointment on-line <a href="http://www.esht.nhs.uk/service/outpatient-appointment/cancel-or-reschedule-your-outpatient-appointment/">www.esht.nhs.uk/service/outpatient-appointment/cancel-or-reschedule-your-outpatient-appointment/</a>
<b>Arm Care</b>	This leaflet can help you regain arm and shoulder movement after breast cancer surgery. It has exercises for the different stages of your recovery and explains how to reduce your risks of lymphoedema. You need to follow this	<a href="http://www.breastcancernow.org.uk">www.breastcancernow.org.uk</a>  <a href="https://breastcancernow.org/information-support/publication/exercises-after-breast-cancer-surgery-bcc6">https://breastcancernow.org/information-support/publication/exercises-after-breast-cancer-surgery-bcc6</a>

	advice for life.	
Lymphoedema Service (Treatment for arm swelling due to surgery or radiotherapy to axilla (armpit) as part of cancer treatment)	<p>Healogics provide 4 elements of treatment, all of equal importance:</p> <ul style="list-style-type: none"> <li>• skin care</li> <li>• exercise,</li> <li>• compression therapy (bandages or hosiery) and or</li> <li>• Simple Lymphatic Drainage (a special type of massage).</li> </ul>	<p><b>Referral by GP or Breast Clinical Nurse Specialist</b> to Healogics who have NHS contracts to treat patients for Lymphoedema at their Centre in Eastbourne at their Centre in Hastings. They also see people privately</p> <p><b>Eastbourne Healogics</b></p> <p>Wound Healing Centre Wish Tower House, 1c Edward Road, Eastbourne, BN23 8AS</p> <p><b>Phone: 01323 735588.</b></p> <p><b>Hastings Healogics</b></p> <p>Wound Healing Centre Station Plaza Health Centre Station Approach Hastings TN34 1BA</p> <p><b>Phone: 01323 735588.</b></p> <p><b>Email for both:</b> info.healogicsUK@healogics.com</p>
Guidance on Pain	The British Pain Society - Provides contemporary guidance, supported by available evidence, on clinical and other pain matters.	<a href="http://www.britishpainsociety.org/people-with-pain/">www.britishpainsociety.org/people-with-pain/</a>
Younger Women with Breast Cancer book	<p>This book covers issues which may be important to younger woman such as:</p> <ul style="list-style-type: none"> <li>• How treatment may affect your fertility</li> <li>• What happens when you are diagnosed with breast cancer during pregnancy</li> <li>• The impact a breast cancer diagnosis can have on your body image and sexuality and how this may impact upon relationships as well as practical advice about contraception.</li> </ul>	<a href="http://www.breastcancernow.org.uk">www.breastcancernow.org.uk</a>
<b>Flat friends UK</b>	Flat Friends UK - is dedicated to supporting women who have had single or double mastectomy surgery without breast reconstruction, including those who may face such decisions now or in the future, due to either a breast cancer diagnosis or preventative surgery. We believe living without reconstruction is a	<a href="https://www.flatfriends.org.uk/">https://www.flatfriends.org.uk/</a>

	<p>positive outcome. We have a closed Facebook group which provides a safe, private, respectful and mutually supportive place for women to come together and talk about practical and emotional matters related to living flat, including clothing, cancer treatment and relationships in everyday life. Join us via our public page on Facebook, from which you can reach the closed group.</p>	
<b>Keeping Abreast</b>	<p>Keeping abreast recognises a great need for women, both newly diagnosed with breast cancer and facing the possibility of mastectomy, and also women further down the line who are also considering reconstructive surgery, to be able to meet and talk to other women who have been through similar experiences. This allows women make an informed choice about whether or not to proceed with breast reconstruction. They aim to provide information, support, practical help and advice for those considering breast reconstruction, including the opportunity to share the experiences of others. Also to enrich the quality of care for those recovering from breast reconstruction.</p>	<p><a href="http://www.keepingabreast.org.uk/">www.keepingabreast.org.uk/</a></p>
<b>Breast Prosthetic Fitting Conquest</b>	<p>The Orthotics Department have trained staff that will provide breast prosthesis. A clinic is held on alternative Friday mornings, by a representative from Silima, who will provide bra and prosthesis, fitting and advice.</p>	<p><b>Tel: 0300 131 4500 148547.</b> <b>You will need to ask your GP to write a letter to the Orthotic Office to request a new prosthesis.</b></p>
<b>Breast Prosthetic Fitting Eastbourne</b>	<p>A prosthetics fitting clinic is held once a month on a Friday in a private room in Paget House at Eastbourne District General, where a representative from Silima, will provide breast prosthesis and advice on appropriate bras. Appointments are always required for prosthetic fittings. Each appointment lasts for 20 minutes. Occasionally more than one appointment is necessary to get a correct fitting.</p>	<p>As you have been discharged from the clinic <b>your GP</b> will need to send a referral letter to the Breast Clinical Nurse Specialists who will arrange the appointment for you.</p>
<b>Knitted knockers</b>	<p>Knitted Knockers - are a UK charity that knit and crochet breast prostheses for women that have undergone a mastectomy or lumpectomy. Ladies that have undergone surgery are provided with silicone breast prosthesis by the</p>	<p><a href="http://www.knittedknockersuk.com/">www.knittedknockersuk.com/</a></p>



	<p>NHS, which some ladies have found to be uncomfortable, heavy and may rub against the scars left after surgery, causing rashes and pain. At Knitted Knockers UK we want women to know that there is a lightweight, 100% cotton alternative that takes the form of a real breast and is soft against the skin and is breathable. Each Knocker is Made with love and filled with hope, and we provide them FREE OF CHARGE to those ladies who need it. Aqua Knockers are also popular and allow ladies to swim in confidence.</p>	
<b>Breast Reconstruction Women</b>	<p>If you have had a mastectomy and decided against reconstruction but change your mind at a later date, please contact Breast CNS's 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 you can be seen back in clinic if you wish to discuss this further. It is natural for breasts (treated and untreated) to change over time.</p>	<p><b>Conquest Hospital - Email:</b> <b>esht.breastcnsconq@nhs.net</b></p> <p><b>Eastbourne DGH - Email:</b> <b>esht.breastcnsedgh@nhs.net</b></p>
<b>Men Chest Reconstruction</b>	<p>Sometimes surgery can be offered to create a new nipple, the surgeon might be able to create the shape of a nipple using the skin from another part of your body (a skin graft). You can be seen back in clinic if you wish to discuss this further.</p> <p>Other options include tattooing a new nipple and areola on to the chest. Or you can use stick on nipples. Your Breast Clinical Nurse Specialist can tell you where to get them</p>	<p><b>Conquest Hospital - Email:</b> <b>esht.breastcnsconq@nhs.net</b></p> <p><b>Eastbourne DGH - Email:</b> <b>esht.breastcnsedgh@nhs.net</b></p>
<b>Cancer Register</b>		
<b>Cancer Register</b>	<p>Cancer Register - Leaflet explaining the Cancer Register and how information on all cancers across England can be tracked and monitored to help with research</p>	<p><a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/770502/cancer_registration_information_leaflet_jan19.pdf">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/770502/cancer_registration_information_leaflet_jan19.pdf</a></p>

<b>Complimentary Therapies</b>		
<b>Holistic Therapists</b>	The Federation of Holistic Therapists (FHT) is the UK's largest professional association for therapists, ensuring high standards in therapy education and practice since 1962 below are some on line tips.	<a href="http://www.fht.org.uk/about-us">www.fht.org.uk/about-us</a>
<b>Meditation</b>	At a time when everything feels up in the air, it is important to put our own health and wellbeing at the top of our agenda. The ancient art of meditation can help decrease stress and lower blood pressure and is an easy practice to try at home. To get you started, we've put together a list of some free meditation practices to try.	<a href="https://blog.fht.org.uk/2020/03/30/meditation-to-try-at-home/">https://blog.fht.org.uk/2020/03/30/meditation-to-try-at-home/</a>
<b>Yoga Tips for Anxiety</b>	Leading yoga instructor and health and fitness specialist Hannah Barrett shares her expert tips to help with coronavirus anxiety.	<a href="https://blog.fht.org.uk/2020/04/08/yoga-expert-shares-tips-to-aid-anxiety/">https://blog.fht.org.uk/2020/04/08/yoga-expert-shares-tips-to-aid-anxiety/</a>
<b>Face Massage</b>	A simple face massage which can be practiced daily to achieve brighter skin and to help alleviate headaches.	<a href="https://blog.fht.org.uk/2020/04/20/fht-vice-president-mary-dalgleish-shares-simple-face-massage/">https://blog.fht.org.uk/2020/04/20/fht-vice-president-mary-dalgleish-shares-simple-face-massage/</a>
<b>Manage Stress</b>	Self-help techniques to reduce anxiety and boost your health and wellbeing	<a href="https://blog.fht.org.uk/2020/03/20/self-help-techniques-to-boost-your-health-and-wellbeing-at-home/">https://blog.fht.org.uk/2020/03/20/self-help-techniques-to-boost-your-health-and-wellbeing-at-home/</a>
<b>Hand Reflexology</b>	A mini hand reflexology treatment that you can apply to yourself anywhere, at any time, including in the comfort of your own home. It lasts just six minutes per hand and works different reflex points to help ease away stress and anxiety.	<a href="https://blog.fht.org.uk/2020/04/15/kate-mulliss-mfht-shares-a-hand-reflexology-video-for-stress-awareness-month/">https://blog.fht.org.uk/2020/04/15/kate-mulliss-mfht-shares-a-hand-reflexology-video-for-stress-awareness-month/</a>

## Sources of information

Surrey and Sussex Cancer Alliance, Breast Nurse Consultant, Clinical Nurse Specialists, Consultants: <https://www.england.nhs.uk/south-east/cancer-alliances/surrey-and-sussex-cancer-alliance/>

## Important information

This patient information is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

## Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: 0300 131 4731 (direct dial) or by email at: [esh-tr.patientexperience@nhs.net](mailto:esh-tr.patientexperience@nhs.net)



## Hand hygiene

The trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

## Other formats

**If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.**

**Tel: 0300 131 4434 Email: [esh-tr.AccessibleInformation@nhs.net](mailto:esh-tr.AccessibleInformation@nhs.net)**

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

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## Reference

The following clinicians have been consulted and agreed this patient information:  
Enter names and Job titles (at least one from each site if appropriate)

The Clinical Specialty/Unit that have agreed this patient information leaflet:  
Enter name here, if appropriate

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Responsible clinician/author: Lis Grimsey/Emma Robb

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