

Information for patients and visitors

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# **Breast Care Service Clinical Nurse Specialist Survivorship Team – Nurse Led Follow Up**

**Breast Care Survivorship Team**

**Telephone: Grimsby 03033 303192**

**This leaflet has been designed to  
give you important information  
about your follow up care.**



# Information for patients and visitors

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## Introduction

Dear Patient this leaflet has been produced to give you important information about your follow up care and how it has changed. Please retain this for your reference.

## Changes to Breast Care Follow Up

Medical research has identified that the previous traditional follow up for breast cancer patients has failed to address the wider needs of the patient. For example you may be finding it hard to return to a normal routine. Therefore a more patient - centered approach to follow up has been developed and implemented.

You have recently attended an outpatient appointment and have been reviewed by the surgical doctor or nurse practitioner who has referred you in to the nurse-led breast care survivorship programme.

Once entered into the breast care survivorship programme you will no longer be required to attend for routine clinical follow up appointments with the surgical doctor or nurse practitioner and will not require any further physical examinations. This will have been discussed with you prior to leaving the clinic.

You may not need to be seen by the oncology doctors (cancer doctors) once entered into the breast care survivorship programme, however this is a clinical decision and will be discussed with you by the Oncologist during your clinic appointment.

You will continue with annual mammography appointments (breast x-ray) if applicable. All patients will be invited to attend for yearly mammograms by post unless you have had a bilateral mastectomy (both breasts

removed) in this case mammography is not required.

Your nursing support "key worker" at this point will transfer from the Macmillan breast care nursing team to the breast care survivorship nursing team.

From here you will continue to be followed up as part of the breast care survivorship programme for a minimum of 5 years from the date of your cancer diagnosis (see exceptions).

## Mammography Appointments

You will continue to have yearly mammography appointments (if applicable) until you are discharged from the hospital breast care unit.

You should receive an appointment letter for your mammogram through the post four weeks prior to your mammography due date.

Mammography results will not be given on the day of the appointment, the results will be sent by post to your home address within three weeks.

You will not see the breast survivorship team at the mammography appointment.

## Years 1 and 2 of Survivorship

If you have completed active treatment (chemotherapy, radiotherapy, primary endocrine medication, Herceptin, surgery, medication only) in the last two years then you will be classed as in year 1 or 2 of survivorship dependent upon when your treatment ended.

People in Years 1 and 2 of survivorship will be invited to attend a planned clinic appointment with the breast care survivorship nursing team.

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This appointment will be within four weeks of being entered into the survivorship follow up programme by the surgical clinician.

### Years 3, 4 and 5 of Survivorship

If you have completed active treatment (chemotherapy, radiotherapy, primary endocrine medication, Herceptin, surgery, medication only) more than two years ago you will be classed as in years 3, 4 or 5 of survivorship dependent upon when your treatment ended. You will not routinely be seen in the survivorship clinic as research has shown that most patients have got back to some routine and normality at this point.

However, you will have access to and be able to receive support from the breast care survivorship nursing team throughout the remaining time that you are under the care of the hospital breast care unit.

If you have any concerns that you would like to discuss please contact the breast care survivorship team via telephone in the first instance on the number at the end of this booklet.

### What is nurse led breast care follow up?

The aim of nurse led follow up is to enable you to self-manage your health and wellbeing as much as possible and to effectively address any concerns you have which may be affecting your quality of life.

Concerns that impact on quality of life can be physical, emotional, spiritual or financial issues.

### What can we offer you?

We understand that when you are having frequent visits to the hospital you have regular contact with members of staff and

once you have completed treatment this can appear to stop.

We aim to provide a service where you feel supported, yet you are in control and can direct the level of support you require to meet your needs.

If you do not need to have any contact with us, that is fine.

We aim to offer a supportive and continuing link throughout your follow up period until you are discharged back to your GP's care.

Support provided may consist of:

- answering any questions you might have in relation to signs or symptoms you are worried about or experiencing
- Helping you talk through the things you feel are important to you or are worrying you
- Helping you understand and manage the potential long term side effects of your treatment
- Directing you to information and resources that are available to help you self-care

### What happens at a nurse led appointment?

The breast care survivorship team consists of breast care clinical nurse specialists (CNS) who have a wide range of clinical nursing experience particularly in the field of breast care and oncology.

Following the consultation with the breast survivorship team you will develop and agree a care plan.

The care plan will include detailed information that is individual to you about issues that are concerning you with tailored goals to try to address your needs.



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The care plan will include information about long term side effects of the treatment you have received, specialist services you have been referred to and any further advice you have been given.

You will receive a copy of your care plan within three weeks of your appointment and your GP will be sent a summary. Copies will also be kept within your medical notes. The information may be shared with other key persons involved in your care with your permission.

### Working Hours

The breast care survivorship specialist nurses work varying hours, however we are available Monday to Friday between the hours of 8.30am and 3.30pm, excluding bank holidays. We do not accept “drop in” appointments. If you have concerns outside of these hours please contact your GP or the services at the end of this leaflet.

We hold clinics in Scunthorpe and Grimsby and may on occasion provide home visits by mutual agreement.

The breast care survivorship team can be contacted via telephone on the number at the end of this leaflet.

If there is no one available to take your telephone call, a message can be left on the answer machine and we will endeavor to return your call within 48 hours.

### Completion of hospital based follow up

Most breast cancer patients remain under the care of the hospital breast service for a total of 5 years before being discharged back to the care of their GP and the NHS Breast Screening Programme for mammography. You will be given the opportunity to contact

the breast care survivorship team prior to being discharged back to your GP's care.

Patients who were of a young age when diagnosed will remain under the hospital breast care service for longer.

This is usually until the age of 50 years old when you would be eligible to attend the routine NHS breast screening programme.

### Frequently Asked Questions

#### Will I always remain in the breast survivorship programme?

The majority of patients will remain in the breast survivorship follow up programme, however you will be withdrawn if you have a recurrence of your cancer or if you enter a clinical trial that requires a physical examination.

In these instances you will still receive support by either a Macmillan breast care nurse, or a trial nurse who will liaise with the survivorship team if needed.

#### What if I am having reconstructive surgery?

Whilst undergoing reconstructive procedures you will be supported collaboratively by the clinician, the breast care survivorship team and / or the Macmillan breast care nurses until the reconstruction episode is completed.

You will not need to do anything as this will automatically happen, we will ensure you know who will be your main contact during these procedures.

#### Future Aesthetics or Reconstruction

Some patients may require aesthetic and reconstructive procedures after their hospital

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breast care follow up has finished. If you would like to be considered for any aesthetic procedure please telephone us on the number at the end of this leaflet as options can vary.

### Hormone Switch

The oncologist will advise how long the hormone blocking tablet needs to be taken for and for most patients that will be for five years. Hormone blocking tablets are also called “Endocrine Therapy” and include Tamoxifen, Anastrozole, Letrozole and Exemestane.

Some patients require a change known as a “switch” after 2 or 3 years.

If you are unsure whether this applies to you please contact us on the number at the end of this leaflet. If you know you are due a switch and have not received your appointment please contact the oncology secretary whose number is at the end of this leaflet.

Some patients are advised by the oncologist to take the hormone - blocking tablet for an extended period of time, usually 10 years.

If you are unsure please contact us on the number at the end of this leaflet.

### Family History / Genetics

The majority of breast cancer patients do not have a significant family history of the disease. You may have had your family history assessed at your initial clinical appointment. If you had a family history you will have been referred to the family history clinic and been told your estimated risk. You may even have been referred to specialist genetic clinics for further investigations. However if there is any change in circumstances or if you are unsure please

contact us on the number at the end of this leaflet.

### If you Require a New Prosthesis or Prosthesis Fitting:

Grimsby patients: contact the Pink Rose Suite reception on telephone: 03033 303955.

Scunthorpe patients: contact the Macmillan breast care clinical nurse specialists on telephone: 03033 305084.

### Being Breast and Body Aware

We recommend you continue to be breast and body aware. If you notice any changes please contact us. The following guidance may be helpful to you:

- Try to get used to looking at and feeling your breasts regularly
- Look for any signs of change on a monthly basis by looking at your breasts in the mirror with both arms down then raised above your head
- To feel for any changes put your arm above your head and use the flat of your hand to feel for any changes. You may find it helpful do this in the bath or shower as part of your everyday routine
- Examine your breasts and arm pit
- Do not examine yourself by pinching your breast between your fingers

### Changes to Look and Feel For:

- A change in size and shape
- Redness or a rash on the skin or around the nipple
- A lump or thickening that feels different from the rest of the breast tissue

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- A change in skin texture such as puckering or dimpling
- Any discharge that comes from the nipple without squeezing the breast
- Any changes in the nipple such as a change in shape, position or if it becomes inverted
- Swelling of the arm or hand
- Constant pain in the breast or armpit
- A change to the scar line

### Other Symptoms to Seek Advice On:

- Pain, particularly in the back or hip areas
- Persistent dry cough or feeling breathless for over 2 weeks
- Constantly feeling exhausted or experiencing nausea / sickness
- Sudden unexplained weight loss or loss of appetite
- Severe headaches, altered vision or dizziness
- Abdominal pain or swelling
- Yellowing in skin colour

### Can I Reduce My Risk?

Maintaining a healthy lifestyle and looking after your general health may help reduce your risk:

- Maintain a healthy weight
- Take regular exercise
- Eating a healthy well balanced and varied diet with plenty of fruit and vegetables and limit your intake of saturated fats

- Stop smoking
- Limit alcohol intake and do not exceed the recommended weekly amount

### Managing Your Physical and Psychological Wellbeing:

- Do what you enjoy and enjoy what you do. Aim for small goals initially
- Relaxation programmes and exercise
- Plan and pace your day, and take one day at a time
- Use aids if you need them to make life easier
- Take short naps or rest breaks if you need them balanced by regular exercise
- Have a routine for waking and sleeping
- Let others help you
- Try to let go of things that don't matter as much
- Join a support group
- Be kind to yourself
- Seek specialist advice when needed

### Courses Available

**Breast Care "Moving Forward Programme"** This course is for breast cancer patients who have finished treatment within the last two years and is run in partnership with Breast Cancer Care

**HOPE** course - helping overcome problems effectively. This course is run by Macmillan professionals and is available for patients who have had a diagnosis of any type of cancer.

**Macmillan Cancer Survivorship Support Team** - A service provided for patients in the Grimsby area who have completed treatment



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for any type of cancer who may require help, support or courses. They can be contacted directly on the following number:

Telephone: 01472 571276

Please contact us if you would like any further information about any of these courses.

### Local Breast Cancer Support Groups

**Bosom Family Support** - Scunthorpe  
Telephone 07861460754

**Bosom Buddies** - Grimsby Telephone  
01472 590188

**Embrace** - Louth Telephone 07800802660

**Brigg and District Breast Cancer Support Group** -PO Box 85, Brigg, North  
Lincolnshire, DN20 8WU  
[info@breastcancersupport-brigg.org.uk](mailto:info@breastcancersupport-brigg.org.uk)

### Useful Telephone Numbers

Diana, Princess of Wales Hospital  
Scarcho Road, Grimsby  
DN33 2BA  
Tel: 01472 874111

Pink Rose Suite Main Reception, DPoW:  
03033 303955

Breast Care / General Surgery  
Administration Team: 03033 306529  
Email: [nlg-tr.SAT1@nhs.net](mailto:nlg-tr.SAT1@nhs.net)

Oncology Secretary's Grimsby: 03033  
303013

Scunthorpe General Hospital  
Cliff Gardens  
Scunthorpe  
DN15 7BH  
Tel: 01724 282282

Secretary to Mr Vijh: Scunthorpe: 03033  
302292

Oncology Secretary's Scunthorpe: 03033  
302055

### Emergency

Out of hours, it is recommended that you contact your own General Practitioner or the GP Out of Hours service.

### Breast Cancer Care

**Helpline – 0808 800 6000 or visit**  
[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

**Breast Cancer Care “Someone Like Me”**  
**Telephone: 0345 077 1893 or email**  
[someonelikeme@breastcancercare.org](mailto:someonelikeme@breastcancercare.org)

**Breast Care Survivorship Team**  
**Pink Rose Suite**  
**Telephone: 03033 303192**

### Concerns and Queries

If you have any concerns / queries about any of the services offered by the Trust, in the first instance, please speak to the person providing your care.

**For Diana, Princess of Wales Hospital –** you can contact the Patient Advice and Liaison Service (PALS) on (01472) 875403 or at the PALS office which is situated near the main entrance.

**For Scunthorpe General Hospital –** you can contact the Patient Advice and Liaison Service (PALS) on (01724) 290132 or at the PALS office which situated on C Floor.

Alternatively you can email:  
[nlg-tr.PALS@nhs.net](mailto:nlg-tr.PALS@nhs.net)

### Northern Lincolnshire and Goole NHS Foundation Trust

**Diana Princess of Wales Hospital**  
**Scarcho Road**  
**Grimsby**  
**DN33 2BA**  
**01472 874111**



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Scunthorpe General Hospital  
Cliff Gardens  
Scunthorpe  
DN15 7BH  
01724 282282

Goole & District Hospital  
Woodland Avenue  
Goole  
DN14 6RX  
01405 720720

[www.nlg.nhs.uk](http://www.nlg.nhs.uk)

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