



Northern Cancer Alliance Aftercare guidelines for breast cancer patients treated with curative intent 2019 Stratified Follow up

Developed by Caroline Buchanan, CNS and the Breast Care Nursing Department at the Queen Elizabeth Hospital, Gateshead and adopted by the Northern Cancer Alliance.

Modified by the NCA Breast tumour pathway board.

Title:	NCA Follow up guidelines for all breast patients treated with curative intent				
Authors:	Caroline Buchanan, Breast Care Nurse Dr Tony Branson, Consultant Oncologist				
Circulation List:	Breast Tumour Board				
Prepared by	Kath Jones kath.jones3@nhs.net				
Version History:					
Date:	15.05.18	Version:	V1	Review Date:	May 2019
Date	03.09.19	Version:	V2	Review Date:	December 2019
Date	24.10.19	Version	V2.1	Review Date	December 2019
Date	04.12.19	Version	V2.2	Review Date	December 2019
Date	20/12/19	Version	V2.3	Review Date	January 2020
Date	03/02/20	Version	V2.4	Review Date	January 2020
Date	11/02/20	Version	V2.5	Review Date	January 2021
Date	11/02/20	Version	V3 final	Review Date	January 2021

CONTENTS

Introduction	3
Background	3
Stratified Follow Up Pathways	4
Eligibility Criteria	4
Process	5
Clinical Responsibilities and Roles	5
Advice	6
Information Booklet	8

INTRODUCTION

This document provides regional guidelines to Breast teams for aftercare for breast cancer patients. It is designed to complement existing national guidelines e.g. National Institute for Health and Care Excellence (NICE) and NCA breast cancer guidelines. This guideline does not override the individual responsibility of healthcare professionals in making decisions appropriate to the circumstances of the individual patient.

It is not anticipated that the guidelines will cover all clinical situations in all patients, but where unusual circumstances exist, it is expected that such treatments would be discussed in the appropriate MDT.

These guidelines were developed by the Breast Care Nursing Team at Queen Elizabeth Hospital, Gateshead and take into account NICE clinical guidelines, CG80 (NICE February 2009, April 2012) CG81 (June 2014) and CG164 (June 2013),

The guidelines will be reviewed on an annual basis. Where new treatments are introduced between revisions they will be added as an addendum to the current guideline.

BACKGROUND

There are more than 40,000 breast cancers diagnosed each year in the UK with one woman in nine developing breast cancer at some time during her lifetime. Between five and ten per cent of women with breast cancer have an inherited predisposition whilst eight of ten breast cancers occur after the menopause. The number of deaths from breast cancer in England peaked in the late 1980's and since then has been falling faster than in any other country. Therefore, there are more people living with and beyond breast cancer in England than ever before.

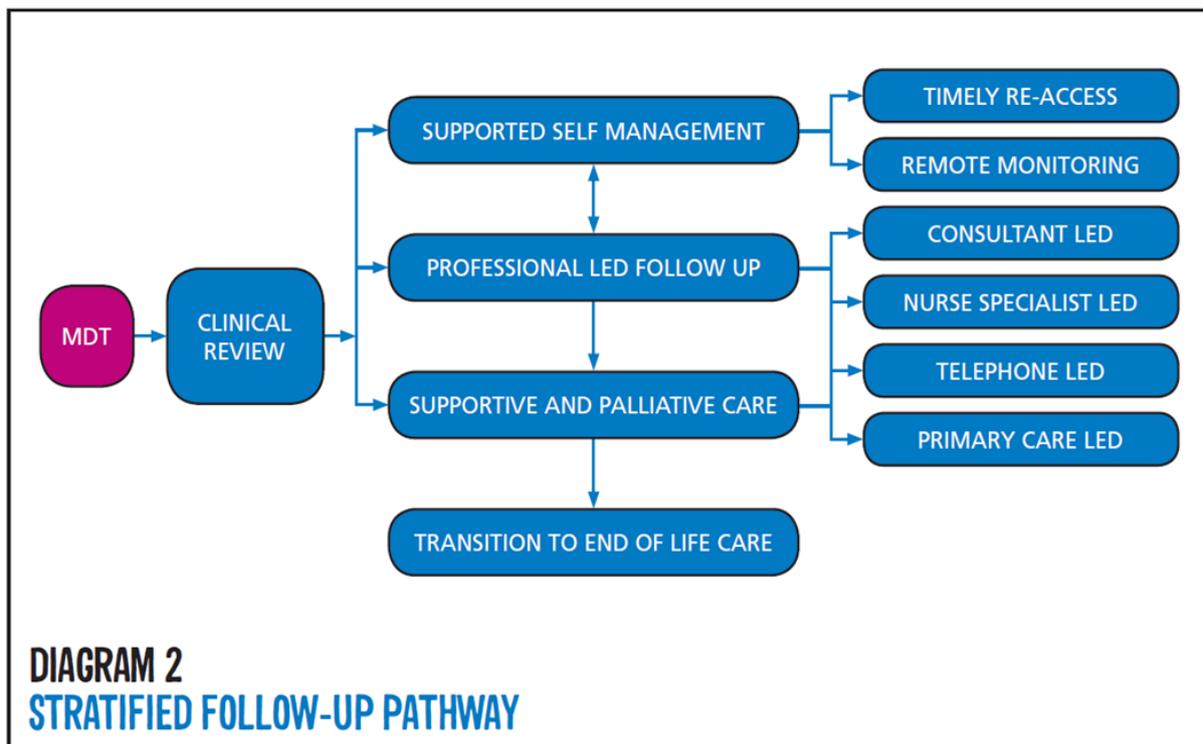
In July 2015 an Independent Cancer Taskforce published a report outlining 96 recommendations for improving cancer care and outcomes by 2020. Achieving World Class Cancer Outcomes - A Strategy for England 2015-20 set out six priority areas for action covering the whole patient journey of which number four is living with and beyond cancer. The aim of which is to ensure that by 2020 every person with cancer will have access to elements of the Recovery Package, and stratified pathways of follow-up care.

The NHS Operational and Planning Guidance 18/19 secured this vision placing requirements on Cancer Alliances to roll out stratified follow up pathways for breast, colorectal and prostate pathways across their footprint.

Although there is no evidence that routine follow up by a specialist increases long term survival, it is believed that many women welcome the reassurance of regular review whether this is by a specialist or by a GP. A recent randomised controlled trial suggested that an improved quality of life occurred when patients had access to a breast CNS for one year following surgery (57, 58).

Supported directed access offers a more effective approach to after-care than traditional medical models of follow-up which has the potential to reduce costs and improve patient satisfaction. Evidence for this model is based on the work undertaken by the National Cancer Survivorship Initiative in 2011 which has been emulated in other parts of the country such as Bath Breast Service and Northern Ireland. The Northern Cancer Alliance model builds on this and can be seen below.

STRATIFIED FOLLOW UP PATHWAYS



Following clinical assessment of their needs, patients can be supported to manage their own follow-up, with back up from the clinical team as needed. This is designed for all patients who have had curative treatment for primary breast cancer. Under this system patients will no longer have routine follow up appointments; instead they are educated and encouraged to contact the breast care nurses when they have a new concern or problem regarding their breast cancer. Surveillance imaging will be arranged with automated appointments and a system to relay the results to the patient in a timely fashion.

The aim of this follow up is to allow patients to manage their own health and avoid unnecessary hospital visits and the anxiety that many women feel when attending routine follow up appointments. It will give patients access to the breast clinics when they need it.

The patients follow up plan will be discussed with the patient when they attend the consultant's clinic for their histology results and written information about the plan will be given to the patient by the BCNs.

ELIGIBILITY CRITERIA

All patients who have been treated with curative intent are eligible for this pathway.

Exceptions are:

- Patients on clinical trials where the protocol requires clinical review.
- Patients whose holistic needs assessment suggests that they are not yet ready to self-manage their aftercare.

PROCESS

Existing Patients

All existing patients who are over a year post surgery on the five year follow up pathway will be encouraged to transfer onto the new pathway. Existing patients who have been on the follow up pathway for **less than two years** will follow the process for new patients. Patients who have been on the follow up pathway for 3 years or more should have an HNA and transferred onto the stratified follow up pathway.

For patients in this group who need more support, a further appointment with the BCN can be arranged where the BCN can discuss the self-supported plan in more detail.

New patients

After surgery/chemotherapy/radiotherapy is completed patients will attend the clinic and be reviewed by the team. The clinician will discuss the follow up plan with the patient as per the eligibility criteria and any MDT discussion. At the point of review the patient will have an HNA and either put on the stratified follow up pathway or given a further review appointment based on their needs.

At the appointment with the BCN, which should take place within three months, following the end of treatment there will be:

- A review of the holistic needs assessment (HNA)
- A comprehensive information booklet be given to the patient which advises them of their planned follow up, access back into the service and support services available
- Completion of the treatment summary clearly stating the method of follow up and sent to the patient and their GP.
- Information supplied regarding the next available health and wellbeing event
- Confirmation of booking of annual mammograms for 5 years and how results will be received

CLINICAL RESPONSIBILITIES AND ROLES

Stratification

The breast team / consultant is responsible for identifying patients suitable for supported self-management. The decision should be made based on holistic needs assessment, clinical judgement and discussion with the patient, then recorded on the post-surgery MDT Proforma and filed in the patients notes.

Stratified Follow up Consultation

The Breast Care Nurse Specialists will manage the stratified follow up consultation. They will ensure that the patient is provided with written information, a treatment summary has been completed and a copy has been sent/given to the patient and sent to the GP. A holistic needs assessment will also be carried out and action taken as necessary. A copy will be placed in the patient's notes. All surveillance and scans should be in place and patients are aware of how results will be received.

Surveillance and Scans

Mammograms

When the patient is selected to go on to supported self-management, the clinician will arrange the booking of annual surveillance mammography. The patient will receive a yearly mammogram for 5 years. At this point patients will receive 3 yearly mammograms via the screening programme. For patients who are under the age for the national screening

programme surveillance mammograms will be booked for alternate years until they reach the screening age.

DEXA scans

Local interpretation will be implemented in relation to the process of organising and implementation of DEXA scans and blood tests.

Re- access to Breast Services

Patients will receive verbal and written information about how to re access the service if they have a problem or concern at the consultation appointment with the BCN. Patients should contact their breast care nurse via telephone who will give them verbal advice or arrange a clinic appointment for the BCN clinic /follow up clinic/symptomatic clinic. Patients can also re-access the service via their GP.

Discharge from service

All patients on this pathway will be discharged back to the GPs care at 5 years and will have to re-access the service via their GP. Written information will be given to the patient/GP on the patient's treatment summary to advise them regarding this date.

ADVICE

Endocrine therapy

Patients, who are having problems/side effects from endocrine therapy, will be advised to contact their breast care nurse who will give verbal advice or refer to the appropriate consultant's clinic.

Prosthesis service

Patients will have direct access to the prosthetic service and will be given information on how to access the service by their BCN at their final appointment.

Lymphoedema

Patients can access the lymphoedema service directly via their Breast Care Nurse. Clinicians can refer to the lymphoedema clinic by sending a written referral to the Breast Care Nurse Specialists.

Patient who would like to consider reconstruction

If a patient would like to consider breast reconstruction they can contact their breast care nurse who will arrange for them to attend for a discussion on their options of breast reconstruction. The patient will then be added to the consultant's clinic if they wish to discuss further or proceed with reconstruction.

Psychological support

Patients can continue to contact their breast care nurse if they need psychological support/ advice. All BCNs should have access to the psychology service.

Support services

All patients will receive an information package from their BCN which will give them contact details of local support services and signpost them to available services.

National data collection

National data collection will be required to demonstrate patients are stratified to follow up [66%], this will be via COSD [April 2020]. As an interim measure Trusts will be asked to collect this information manually until a national solution is rolled out. It will be Trusts responsibility and determined locally who is best placed to collect the data. Trusts will be asked to submit

manual data on a quarterly basis to the Northern Cancer Alliance for monitoring and assurance purposes which will be uploaded to the National Team.

This is an example of an Information booklet Breast Care Nursing Department at the Queen Elizabeth Hospital, Gateshead which can be adopted and amended for local interpretation

Information booklet for care after treatment for breast cancer

Your Breast Care Nurse is: _____
Contact tel no: _____

After Care plan

This booklet will inform you of your planned after care following treatment for breast cancer. Once you have completed treatment you will not need to attend the clinic regularly but you will remain under our care for the next five years. This means that you will not have to attend regular hospital appointments; instead you can quickly gain access to the breast care team and hospital when you need to. After five years unless you are too young to access the national breast screening programme your care will be transferred to your GP.

Treatment summary

When you visit the clinic for the final time you will receive a treatment summary. This gives information about your diagnosis and treatment as well as how your after care will be organised. This includes:

- the dates of your future mammograms, if needed
- the dates you started and should complete any ongoing anti-cancer medication
- the dates of bone density (DEXA) scans if applicable to you
- further help and support
- How to contact the breast care team

What about mammograms in the future?

After breast cancer you have a small increased risk of developing a further cancer in the same breast or a new cancer in the other breast. Mammograms (breast x rays) can detect breast cancer before it is able to 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 if at that time you are below the age at which the National Breast Screening Programme starts further mammograms will be performed every 2 years until you are called by the national breast screening programme. These mammograms will be organised by the breast care team. For a small number of women mammography may not be appropriate and if this is the case, we will discuss the other options with you.

Results of mammograms

After your mammogram, you will receive your results letter within two weeks. If you do not receive your results within one month of having your mammogram, please contact us on:

Sometimes, after having treatment for breast cancer, mammograms are not as easy to read; therefore, we may call you so we can carry out further assessment or investigations. We will contact you by 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 years. If you have recently undergone treatment for breast cancer and receive an invitation to attend for a screening mammogram during the 5 years when you are under our care, please cancel the appointment with the NHS Breast Screening Unit, telling them that you are receiving regular mammograms at the hospital after treatment for breast cancer.

After your annual mammograms

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

If you are aged under 50 years: we will recommend that you continue with mammograms every 2 years until you are invited for routine screening. You will then be offered mammograms every three years through your local NHS Breast Screening service.

If you are aged 70 years or over: you may not be automatically called for routine screening. However, you can continue to receive three yearly mammograms under the NHS Breast Screening Programme by requesting an appointment and it is recommended that you do this. Please contact your local NHS Breast Screening Unit on 0191 4452554 or your GP to arrange this.

Your cancer medication - endocrine therapy

Patients with hormone sensitive cancers are usually prescribed anti-hormone tablets, also known as endocrine therapy. Anti-hormone therapy will be one of the following: Tamoxifen, Letrozole, Anastrozole or Exemestane. You will usually be on these tablets for five to ten years, although some patients may be advised to continue with their tablets for a longer period of time. Your treatment summary will confirm the date you started your hormone medication and the date you will complete 5 – 10 years of hormone therapy.

You will not have to pay for tablets as you are entitled to free prescriptions for 5 years. A medical exemption certificate is available from your GP surgery, hospital pharmacy or local chemist.

Possible side effects of hormone medication

You may experience side effects. These will have been explained to you when the treatment was started.

The most common is hot flushes. There are a number of treatments that can help.

Aromatase inhibitors such as Letrozole can sometimes cause joint stiffness and pain, as well as vaginal dryness which some women find uncomfortable.

Tamoxifen may cause the lining of your womb to become thicker which can then cause vaginal discharge/bleeding. This is not usually serious. However, if your periods have stopped and you experience unexpected vaginal bleeding please contact your GP. You may need to be referred to a gynaecologist. Contact your breast care nurse if you need advice.

There is some research that suggests some drugs – including the antidepressants paroxetine (Seroxat®) and fluoxetine (Prozac®) – may cause tamoxifen to be less effective, but this isn't certain. If you are prescribed these whilst you are taking tamoxifen please contact your GP as you may need to change your antidepressant medication. If you are experiencing side effects of medication please contact your breast care nurse who will be able to offer further support and advice.

What can I do about hot flushes?

Some patients experience hot flushes as a result of treatment for breast cancer. 'Coping with Cancer' provide a service to help relieve these symptoms with the use of acupuncture. If you are interested in finding out more about this, your breast care nurse can provide you with written information. 'Coping with Cancer' can be contacted on 0191 280 5610.

DEXA scans and bone health

When you are taking an aromatase inhibitor such as Letrozole, Anastrozole or Exemestane, we will recommend you have DEXA scans (a scan to check your bone mineral density) as these drugs can cause a reduction in the strength of your bones. These scans can tell us if you are developing bone thinning which could lead to a condition called osteoporosis. These scans will be organised by the team. You may also need to attend an osteoporosis clinic. Regular exercise such as walking as well as a diet high in calcium will help to maintain bone health. Excess alcohol and smoking increase the rate at which bone strength is lost.

Possible side effects of treatment

All treatments (surgery, chemotherapy, and radiotherapy and hormone therapy) may leave you with 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
- Fatigue (tiredness) – this is very common after treatment for breast cancer but will usually improve over time.

- Lymphoedema – swelling of your breast, chest wall or arm on the side of your surgery, which is caused by a build-up of lymph fluid in the tissues. This occurs as a result of damage to the lymph drainage system by surgery or radiotherapy to the lymph nodes.

If you have concerns about any of these side effects please contact your breast care nurse or GP.

What symptoms do I need to look for?

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. There is no maximum time span as to when breast cancer can return but 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 (distant recurrence also known as metastatic breast cancer or secondary breast cancer)

Everyone has aches and pain, but when you have had breast cancer, you may be more aware of them and may be concerned that any pain is related to cancer. Included below is a summary of symptoms that you may want to report to either your breast care nurse or your GP. 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.

Getting a recurrence or a new cancer can be frightening, but it is important to remember that if breast cancer returns, it can usually be treated.

Summary of symptoms you should report

Please contact us if you experience:

- a lump or a swelling in your breast, in the skin after a mastectomy, above your collarbone, 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 (arm swelling on the side you have had surgery)

Or if you experience:

- any new persistent shortness of breath or a cough
- any new persistent aches or pains in any part of your body
- persistent headaches/dizziness

Symptoms that improve and go away over a few weeks are not likely to be related to 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 not normal for you, please contact your breast care nurse.

There is no right or wrong way to get to know your breasts. Try to get used to the way your breasts look and feel. You can do this around once a month, in the bath or shower, when using soap or body lotion. There is really no need to change your everyday routine. You can find leaflets and websites which may be helpful. Your breast care nurse can recommend you to some if you wish. You know better than anyone how your breasts look and feel normally, so if you notice a change, contact your breasts care nurse.

Younger women

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

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

Your Breast care nurse may be able to advise you on this. You can also discuss your fertility needs with your oncologist.

There are various support groups available locally and on social media specifically for younger women. Breast Cancer Care provides services specifically for younger women with breast cancer, these include:

Volunteer peer supporters – younger women with personal experience of breast cancer trained in one to one support

- Telephone support groups
- A help line – Tel 0808 800 6000
- Younger women's forum- breastcancer.org.uk
- Internet chat rooms
- Accurate up to date written information

Contraception

Even though you may not be having regular periods, you may still be able to get pregnant. Effective contraception is important. You may be advised to avoid hormone based contraception such as the pill.

Breast Reconstruction

If you have had a mastectomy and decided or were advised against immediate breast reconstruction but change your mind at a later date, please contact us via your breast care nurse to discuss delayed reconstruction. In some cases surgery can be offered to correct unequal breast sizes and your breast care nurse 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.

How do I arrange to get new breast prosthesis?

If you need a new prosthesis, please contact the breast care nurse secretary on ----- and she will arrange an appointment with our prosthetic fitter. If you just want a replacement and not a fitting please inform the secretary of the name and code of your prosthesis and she will arrange for this to be ordered for you and can be collected from the breast screening unit reception at your convenience.

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. Most people worry about the cancer coming back at times. 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 your Breast Care Nurse/GP may be able to arrange an appointment for counselling. 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.

Who do I contact if I have a concern?

Once you have been discharged from the clinic you should contact your breast care nurse by telephone 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. When you reach 5 years following treatment your care will be transferred back to your GP and you would need to be re-referred into the breast service.

If your breast care nurse advises you that you need to be seen back in one of our clinics because of any symptoms you are experiencing, we will ensure that you are contacted with an offer of an appointment. This Appointment will be within 14 days of contacting us. However if you decline this appointment then you will be offered the next available appointment. If necessary, further investigations may be organised and an out-patient appointment arranged to receive the results. Sometimes, verbal advice may replace the need for an outpatient appointment and may be supported by a written letter to you and your GP. We hope that this 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 /Health and well being

Diet/exercise

There is a lot of research being done to find out how diet may affect the risk of cancer developing. Some research has shown that being overweight and not eating enough fruit and vegetables could increase your risk of cancer.

Eating a balanced diet is one of the best choices you can make for your overall health. Keeping to a healthy weight will help you maintain or regain your strength and have more energy. Regular exercise is also important. More and more research is showing that exercise can reduce the risk of breast cancer coming back (recurrence) if you've been diagnosed, as well as reducing the risk of developing breast cancer if you've never been diagnosed. Exercise can also help you maintain a healthy weight, ease treatment side effects and boost your energy. All these steps can also reduce the risk of new cancer, heart disease, stroke and diabetes.

Making changes to your diet is not always easy. It may be more difficult if you are coping with a cancer diagnosis and having treatment. You could make changes gradually so that it is easier to eat differently. Many people find making this positive choice helps give them back a sense of control. It can also help you feel that you're doing the best for your health. Thinking about what and how much alcohol you drink is part of this too. Eating well and keeping to a healthy weight will help you maintain or regain your strength, have more energy, and have an increased sense of well-being.

Local Support services

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 care nurse. 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.

Cancer information centre

If you are experiencing housing, employment, immigration, financial or welfare benefits issues, you can get help by contacting cancer information centre at the Queen Elizabeth Hospital on 0191 445 2979 or the cancer information centre in Sunderland Royal Hospital, Deborah Spraggon, Macmillan cancer support manager on 0191 05410122.

If there are other issues which concern you, that are not offered here, please discuss them with your breast care nurse, who may be able to advise you on where to get help and support and information if you need it.

Macmillan nurses

Macmillan nurses give supportive care and advice to patients with cancer. This includes emotional, financial and practical support. A Macmillan nurse can be contacted via your GP, District nurse, Breast care nurse or Oncologist.

You can contact the Macmillan support line direct on 0808 808 0000 (Monday to Friday 9am-8pm). Or visit be.macmillan.org.uk

Marie Curie Centre

Offers specialist nursing and medical care.
Tel 0191 2737931.

Breast Cancer Care

Breast cancer care is an organisation that offers practical advice and information. They also provide discussion forums, a confidential helpline chat and one to one support.
Tel 0808 8006000 *Info@breastcancercare.org.uk*

Free booklet available on moving forward for people living with and beyond breast cancer (contact Breast Cancer Care).

Cancer connections (South Tyneside)

Offers emotional, financial and practical support including counselling and complementary therapies. Tel 0191 4565081.

FACT (Fighting All Cancers Together)

FACT is a local charity based in Gateshead that offers support, advice and practical help to cancer patients and their families. Tel 0191 4420833. www.fact-cancersupport.co.uk

Maggie's (Freeman Hospital)

Offers practical, emotional and social support to people with any form of cancer and their families. You can drop in to the centre Monday – Friday 9am-5pm. Maggie's have a rolling programme of support events or tel 01912336600. newcastle@maggiescentres.org

Coping with Cancer

Offers help and support as well complimentary therapies. Tel 0191 2805610.

CANCERBACUP

London. Tel 0800 181 199.
www.londonline.co.uk

CANCERLINK

London Tel 0808 808 0000.
www.cancerlinkfoundation.org.uk

Breakthrough Breast Cancer

London 0207 557 6600.
www.breakthrough.org.uk

Data Protection

Any personal information is kept confidential. There may be occasions where your information needs to be shared with other care professionals to ensure you receive the best care possible.

In order to assist us to improve the services available your information may be used for clinical audit, research, teaching and anonymised for National NHS Reviews. Further information is available in the leaflet Disclosure of Confidential Information IL137, via Gateshead Health NHS Foundation Trust website or the PALS Service.