

Information booklet for follow-up care after treatment for breast cancer

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Your Breast Care Nurse is: _____

Contact tel no: _____

Follow up plan

This booklet will inform you of your planned follow up care after treatment for breast cancer. Once you have completed treatment you will not need to attend the follow up 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 or when you reach screening age 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. The Treatment Summary gives information about your diagnosis and treatment as well as how your follow up care will be organised. This includes:

- the dates of your future mammograms, if needed
- the dates you started and should complete your 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 (recurrence) 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 until you reach the age at which the National Breast Screening Programme starts. These mammograms will be organised by the surgical team. For a small number of women mammography may not be appropriate and if this is the case, we will discuss the other options available to 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 0191 4452554.

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 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 five 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 annual mammograms 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 include Tamoxifen, Letrozole, Arimidex and 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 to 10 years of hormone therapy.

You will not have to pay for tablets as you are entitled to free prescriptions for five 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 that are particular 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 vaginal discharge/bleeding. This is common and 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. Aromatase inhibitors such as Letrozole can sometimes cause joint stiffness and pain, as well as vaginal dryness which some women find uncomfortable. If you are experiencing side effects of medication please contact your breast care nurse who will be able to offer further support and advice.

DEXA scans and bone health

When you are taking an aromatase inhibitor such as Letrozole, Arimidex 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 density of your bone mineral) 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 osteoporosis team. You will also need to attend the osteoporosis clinic. Regular exercise such as walking as well as a diet high in calcium will help to maintain bone health.

Possible side effects of treatment

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

- breast discomfort or tenderness
- menopausal related side effects
- fatigue (tiredness) – this is very common after treatment for breast cancer but will usually improve over time.
- lymphoedema – swelling to the side of your surgery, breast, arm, chest wall which is caused by a build-up of lymph fluid in the tissues. This builds up as a result of damage to the lymph system because of surgery or radiotherapy to the lymph nodes.

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

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 room
- Accurate up to date written information

Contraception

Even if 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/ marina coil.

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 based at the Queen Elizabeth Hospital and at South Tyneside Hospital 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.

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 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 or
- 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 may want 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, 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

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 breast care nurse.

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 a new breast prosthesis ?

If you need a new prosthesis, please contact the breast care nurse secretary on (0191 4453746) 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 they 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 five years 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 offered an appointment within one week 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 outpatient 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 City Hospitals Sunderland telephone, Deborah Spraggon, Macmillan cancer support manager on 0191 5410122.

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). 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. Tel 0191 2336600.

newcastle@maggiescentres.org

Maggie's have a rolling programme of support events.

Coping with Cancer

Offers help and support. Offers complementary 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.

This leaflet can be made available in other languages and formats upon request