Discharge from routine follow up for patients who have been treated for breast cancer

Breast Care

Patient Information Leaflet
This leaflet has been designed to explain why you have been discharged from clinical follow-up and advises you how you can be referred back to the breast care team should you have any concerns.

**Discharge from routine follow up from the hospital**

It has been at least five years since you were treated for breast cancer. Since then you have been reviewed yearly by the breast care surgical team. You have now completed the follow up period and will now only be seen by the breast team at the hospital if you or your G.P requests it. However you will still receive support from us during this period and your GP will have easy access to refer you back to the hospital breast care team if it is required. Your G.P will be informed of your discharge from routine follow-up.

**Why have I been discharged from follow-up?**

Over the years patients have been followed up indefinitely following breast cancer surgery but research has indicated that this may not be the best way of delivering care. (NICE guidance on follow up). Most patients will be discharged after five years however patients who still remain under the age to receive NHS breast screening will remain in follow up until they reach an age whereby they can access this service. Patients who are involved with clinical trials may also find that their length of hospital follow up may differ.
Exercise and healthy living

There is good quality evidence that regular exercise may reduce the risk of cancer coming back in some women and moderate exercise improves quality of life in a vast majority of women. It is recommended that women should walk for half an hour a day for 5 days a week at a medium pace that is you may be mildly out of breath but can still hold a conversation. However, other forms of exercise are also beneficial. More information regarding exercise and healthy living is available on the Breast Cancer Care website or ask your breast care nurse.

Acknowledgements
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Guidelines on what signs and symptoms to look out for and how to access services are discussed further in this booklet.

Follow up breast imaging

Breast imaging which can include mammogram, ultrasound and MRI is an important part of your follow up as it can help detect possible early new changes.

Most of you will have received yearly imaging for the last five years from diagnosis. This will now stop and individual programmes of imaging will recommended tailored to the type of problem you had and age in relation to the NHS breast screening programme. You should be informed of these arrangements at the time of your discharge.

If you have any queries re your breast imaging appointments please contact the main x-ray department as Russells Hall Hospital on 01384 456111 ext 2327.

If our appointment is with the National Health Breast Screening Programme please contact. The Breast Screening Department on 01384 244177

Will I need any other tests?

Current research does not support the use of doing any other routine investigation other than breast imaging. Research suggests that performing unnecessary tests can increase levels of anxiety.
It is recommended that the most appropriate way forward is to investigate any suspicious physical symptom and/or any suspicious findings on imaging.

**Medication**

You will be advised at the time of discharge whether you need to continue or stop any current medication.

**Clinical Trials**

If you have agreed to participate in a clinical trial you may be asked to attend for review more frequently or for a longer period of time. This is in order to answer the questions that the trial was set up to answer. This does not mean that we are more concerned about your wellbeing than anyone who is not in a clinical trial.

**Are there any late side effects of treatment that I need to know about?**

Yes, there are always late side effects that you may develop many months and years after treatment has finished. We have listed below the two main ones and what you need to know about them.

**Lymphoedema**

If you had some of the lymph glands removed at the time of your breast surgery you may be at risk of developing lymphoedema.

- A swelling under your armpit or above your collar bone. (Where the lymph nodes are)
- A lump or a thickening in your breast that feels different from the rest of your breast
- Irritation, puckering or dimpling of the skin
- Discharge other than breast milk coming from one or both breasts
- Nipple abnormalities (such as pain, rash, redness, scaling or inversion)
- Constant pain in one part of the breast or armpit

Your breast care nurse will be happy to demonstrate techniques of breast examination if you wish.

**What do you do if you find a change?**

Women who are breast aware are in a much better position to know how their breasts look and feel, so as the 5 point code recommends reports it to your GP without delay.

Most breast symptoms will turn out to be nothing worrying and your GP may be able to reassure you, however you GP may wish to refer you to a breast clinic for further assessment.
Breast awareness

Breast awareness is an important part of caring for yourself. Being breast aware is about becoming familiar with your breasts and the way they change throughout your life. By being familiar with how your breasts look and feel it will give you the confidence to report anything that is different, new or unusual.

Breast Cancer Care has a comprehensive guide to breast awareness, entitled "Your breasts your health-Throughout your life" a copy of this can be obtained from your breast care nurses and or you can order it directly from Breast Cancer Care. They provide this information also in a DVD and in other languages.

Breast Cancer Care promote the five point breast awareness code
This is:
1. Know what is normal for you
2. Know what changes to look and feel for.
3. Look and feel
4. Report any changes without delay
5. Attend for routine breast screening if you are aged 50yrs or over.

Changes to be aware of:

- A change in size - It may be that one of your breasts has become noticeably larger or lower
- Swelling of the breast

Over time lymph fluid can collect and cause your breast and/or arm to swell. If you think this happening please contact your GP or Breast Care Nurse.

Care in the sun
If you have received radiotherapy as part of your treatment you should take care to protect the treated area from the sun. Particularly in the first year, but even after this time you may find that your skin is more sensitive.

We recommend that you use a high factor protection in the sun and keep covered where possible. It is important to remember that you can burn through clothing if the temperature is hot and you are exposed for a long time.

Will the cancer come back?
Many women will have no recurrence from their breast cancer following treatment and will lead a normal life without any cancer related problems.

However cancer can be complicated and it is different in everyone. You will experience coughs and colds and aches and pains like anyone, this does not mean the cancer has returned.

If problems do occur they are usually noted by the person themselves. We would recommend that you examine your breast(s) armpits once a month.
Following surgery it is important when you examine yourself that you pay particular attention to your breast(s), armpits, and along the scar line and above your collar bone. If you require more information on how to examine yourself please ask your breast care nurse who will be happy to show you.

Listed below are some signs and symptoms to look out for and you should report these to your GP or your breast care nurse who may be able to advise you.

Contact your GP if you notice any of the following:

- Any new lump in your breast or arm pit
- Any new changes in your skin, puckering, change in breast shape, rash
- Any changes in your scar line, rashes or new spots
- Lumps above the collar bone
- Unexplained vaginal bleeding
- Menopausal symptoms
- Persistent back or bone pain
- Unexplained weight loss, sickness, or poor appetite
- Unexplained Tingling in the either or both legs, feet and hands
- Unexplained shortness of breath or persistent cough
- New headache
- Any unexplained new pain in your body

British Lymphology Society: 9-11 Oldbury Road
Cheltenham
Gloucestershire GL51 0HH.
Telephone: 01242 695077
Email: info@thebls.com
Website: www.thebls.com

Lymphoedema Support Network: St Luke’s Crypt,
Sydney Street,
London SW3 6NH.
Telephone: 020 7351 0990
Email: adminlsn@lymphoedema.freeserve.co.uk
Website: www.lymphoedema.org/lsn

Cancer Research UK
Website: www.cancerhelp.org.uk

NHS Direct
Website www.nhsdirect.nhs.uk
Telephone: 0845 4647

Look Good...Feel Better: West Hill House,
32 West Hill Epsom Surrey KT19 8JD
Telephone: 01372 747 500
Fax: 01372 747 502
Email: info@lgfb.co.uk
You can contact your breast care nurse if you notice any of the following:

- Swelling of the arm or breast (lymphoedema)
- Menopausal symptoms
- If you require a new prosthesis

**How to contact the breast care nurses**

Either you or your GP can contact the breast care nurses between the hours of 8.30am and 5.00pm Monday to Friday. Please note the breast care nurses do not work at the weekend but they do have an answer machine which is on 24hrs per day. If you leave a message on 01384 244065 (answer machine) and we will contact you as soon as possible.

The breast care nurses can also be paged if you contact the main switchboard on 01384 456111 (Ask the operator to page one of the breast care nurses)

Please note if the nurse is with another patient she may not answer the phone in which case it is better to leave a message on the main number as shown above.

When you speak to the breast care nurse she will establish more details and she may wish to see you in order to assist more.

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**Rainbow breast reconstruction Group:** meets the third Thursday in the month 10am-12am. Meetings held at The White House 10 Ednam Road Dudley DY11JX.

**Dudley Breast cancer support group:** meets the second Monday in the month 6.45-8.30pm. Unit 44, Waterfront, Brierley Hill, West Midlands, DY1UA.

**Breast Cancer Haven:** A charity offering a free programme of care to help breast cancer patients. Most local centre is in Hereford. Telephone: 01432 361 081. Website: www.breastcancerhaven.org

**Where can I get more information?**

Breast Cancer Care : 5-13 Great Suffolk street London Se1 0NS
Telephone: 0845 092 0800
Fax: 0845 092 0820
Email: info@breastcancercare.org.uk

Macmillan Cancer Support: 89 Albert Embankment
London SE1 7UQ
Telephone: general enquiries: 020 7840 7840
Helpline: 0808 808 0000
Textphone: 0808 808 0121
Website: www.macmillan.org.uk
She may however feel it appropriate to refer you to another health care professional, which could include your GP, an oncologist, a surgeon or a lymphoedema specialist.

If you are or your GP are concerned about a symptom your GP can refer you to a breast clinic very quickly and we would hope to see you in two weeks or less.

What other advice should I follow?

If you need to see another health care professional, for example a physiotherapist, osteopath, specialist or dentist it is advisable to inform them that you have been treated from breast cancer and if you are continuing with any medication.

What follow up services are available to me?

Breast screening
When you are 50 up until the age of 70yrs you will be invited to attend the NHS Breast screening programme which provides mammography every three years. Your name is taken from your GP and an invitation is sent. The programme invites women until the age of 70yrs currently but this may change in the near future to 73yrs. You are however still at risk of developing breast cancer after the age of 70yrs and we therefore recommend that you ring the breast screening office every three years to arrange one. Breast Screening Office: 01384 244117.

Breast Prosthesis
If you have any queries with regard to your breast prosthesis or need a replacement please contact the breast care nurses. Replacement prosthesis is available every two to three years depending on the manufacturers guarantee or if there has been a significant weight gain or loss within that time. Breast care nurses: 01384 244065

What services are available to me in my area?

Cancer Support: The White House 10 Ednam Road Dudley DY1 1JX. Email Info@support$cancer.org.uk. Telephone 01384 231232. Website: www.support4cancer.or.uk. Cancer support is a registered charity which provides practical help and emotional support to people with cancer, their families, friends and carers. They offer:- Transport, one to one counselling, cancer care helpline, cancer information centre, complementary therapies, home and hospital visits, social activities and support a range of support groups for specific cancers.

St Agatha’s breast support Group: Meets the first Thursday in the month 10am-12pm. Dudley MBC, Priory Road Dudley Dy1 1HF. Please ring the breast care nurses if you need any more information.