

Follow up schedule - following treatment for breast cancer

Introduction

Once your breast cancer treatment has finished, it is not unusual to feel insecure as there is not as much contact with the breast surgeons or oncologists.

Research has shown that when you have had such intensive treatment it may be difficult to adjust to having fewer outpatient visits. This information sheet has been written to provide a link between you and the hospital.

The treatment you have had aims to cure you. However, there is still a small risk of developing breast cancer in the other breast, the cancer returning in the treated breast or elsewhere in the body.

What follow up appointments will I have?

As you have now finished your treatment you will go on to one of the following schedules, depending on the treatment you have had:

1. Six monthly clinic appointments for one year in the surgical clinic followed by annual appointments to year five.

Annual mammograms for five years

OR

2. Six monthly clinic appointments for years one to three (alternating between surgical clinic and Oncology clinic) followed by annual clinic appointment for years three to five in the surgical clinic only.

Annual mammograms for five years

Important: please note this is a general guide and there may be some variation due to individual circumstances. If you are concerned about anything in between your appointments then please speak to a member of the team who can make an earlier appointment for you.

What changes should I look for in the breasts?

Breast awareness is about knowing what is normal for you and recognising any change. Following your treatment the breast that has been treated will look and feel different than before. It is important to get familiar with the new feel and appearance so changes can be reported. You need to be aware of any changes that are new or different to you, such as:

- **A change in size** – has one breast become noticeably larger or lower? Breast surgery and radiotherapy may make your breast a different shape and size from before and you should get used to this new shape and size.

- **A change in nipple appearance** – are either of the nipples inverted (pulled in) or pointing in a different direction? Again surgery to the breast can cause the nipple to point in a different direction and radiotherapy can make the nipple thicker. Is there a rash on the nipple or any nipple discharge?
- **A change in skin texture** – radiotherapy can change the texture and colour of the breast that has been treated. Is there any new puckering or dimpling of the breast? Is there a rash?
- **A new lump or swelling** – is there a new lump or thickening in your breast, armpit or around your collar bone?

What other symptoms should I report?

It is important to remember that everyone can get coughs, colds, aches and pains and stomach upsets from time to time and it does not necessarily mean that the cancer has come back.

If you experience any of the following symptoms, listed below, for a persistent period or if the symptoms are getting worse please report them:

- Unexplained persistent or irritating cough
- Breathlessness
- Persistent new back, limb or neck pain
- Persistent unexplained pain anywhere in the body
- Persistent headaches
- Nausea, abdominal discomfort or loss of appetite
- Arm swelling (lymphoedema)
- Any abnormal vaginal bleeding or spotting

This list cannot include everything, but we hope is a useful guide. If you experience any of these symptoms, it does not mean that your cancer has returned, but it does mean you should have a medical assessment.

Who should I report any symptoms to?

If you are worried between appointments about any symptoms please contact your Breast Care Nurse or General Practitioner for advice. Once you have explained your concerns a suitable clinic appointment can be made for you, if required.

Do I still need to think about the risk of lymphoedema (arm swelling)?

If you have had surgery or radiotherapy to your axilla (armpit) as part of your breast cancer treatment, you will have been given advice about arm care and how to reduce your risks of lymphoedema. You need to follow this advice for life. If you have mislaid this information please ask the Macmillan Breast Care Nurse Specialist for another copy of alternatively you can download it from the Breast Cancer Care website (www.breastcancercare.org.uk) or call them on: free phone: 0800 800 600.

How long do I take hormonal treatment for?

Hormone treatment includes the drugs Tamoxifen®, arimidex®, letrozole® or exemestane®. The normal length of time for taking hormonal treatment is five years but in some cases we suggest taking it for longer but this will be discussed with you at your 5 year outpatient appointment.

If you are taking an aromatase inhibitor (arimidex®, letrozole® or exemestane®) it is advised that you take a calcium and vitamin D supplement which can be prescribed by your GP. This will help to protect your bones. Your GP should have also arranged a bone density scan for you (DEXA scan).

Breast Cancer care produces a leaflet on Bone Health which you can download it from the Breast Cancer Care website (www.breastcancercare.org.uk). Alternatively you can call them on: free phone 0800 800 600.

How do I get a new breast prosthesis?

At Conquest Hospital

The Surgical Appliances Department have trained staff who will provide breast prosthesis and give advice on suitable bras. They also stock a small number of bras. A fortnightly clinic is held on a Friday Morning, appointments can be arranged with Ros Kennard in Surgical Appliances. Tel: (01424) 755255 ext. 8547.

At Eastbourne District General Hospital

A prosthetics fitting clinic is held once a month on a Friday in a private room in Paget House where trained staff 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.

Appointments can be made by leaving a message on the answer machine of the Macmillan Breast Care Nurse Specialists – Tel: 0300 131 4500 Ext: 4334.

Where can I find emotional support?

There are local support groups available to help provide support and the opportunity to meet other women who have had breast cancer. Your Macmillan Breast Care Nurse Specialist is also available for advice, support and financial advice.

Useful Contacts

Bossom Buddies: “for ladies who need to talk”. This is patient led support group. Meetings are held on the 1st Tuesday of each month at various venues in Eastbourne between 19.00 and 20.30. For further details please contact Judy 01323 639057 (daytime), Janet 01323 743524 (evenings) or Debbie 01323 648469 (evenings)

Hastings and Bexhill Breast Cancer Support Group

This local group was set up in 1981 by breast cancer patients who formed an informal social group. Meetings aim to provide support in a social setting and often have guest speakers attending. They cover a wide range of topics including local and national issues around breast cancer.

Meetings are held once a month alternating between Hastings and Bexhill. Please visit the website www.1066pinkladies.org.uk or for further information please contact:

Pat: 01424 220665

Pam: 01424 753152

Breast Cancer Now

Is a national organisation offering support to those affected by breast cancer. Free confidential services provided by health care professionals and trained volunteers including a helpline, publications and practical and emotional support on a one to one or group basis.

Helpline: 0808 800 6000
Website: www.breastcancernow.org

Macmillan Cancer Support – provides practical, medical, emotional and financial support.

Helpline: 0808 808 00 00
Website: macmillan.org.uk

How to contact the Macmillan Breast Clinical Nurse Specialists

Macmillan Breast Clinical Nurse Specialists (Available Monday-Friday 09:00-17:00):

Louise Hunter: 03001314834
Juliette Twyman: 03001314833
Debbie Turnbull: 03001314833

Eastbourne District General Hospital

Monday to Friday (not Bank holidays) – 09.00 to 17.00
Heather Driver, Emma Robb and Katy Hollobon 0300 131 734604

The Macmillan Breast Clinical Nurse Specialists are not in the office all the time so please leave a message on the answer phone and you will be contacted as soon as possible. The Macmillan Breast Care Nurse Specialists are part of the Breast Team at East Sussex Healthcare NHS Trust.

Important information

The information in this leaflet 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 or by email at: 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 4500 Email: 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.

Reference

The Conquest and Eastbourne Multidisciplinary Breast Teams and the patient support groups have been consulted and agreed this patient information.

Next review date: November 2023

Responsible clinician/author: Lis Grimsey, Macmillan Consultant Nurse

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