
Oncology Directorate and **Cambridge Breast Unit**

Information Following Treatment – Breast Patients

This leaflet contains information on Patient Led Follow Up and many other aspects of post-treatment care for breast patients.

Patient Led Follow Up

You have now come to the end of the main part of your treatment. You have had surgery and/or radiotherapy and may now be receiving hormone tablet treatment. The breast care team would like to explain to you about your follow up.

We will now be offering you **patient led follow up**. This is a new and innovative form of follow up where you, the patient, take the initiative and are in control.

Up until now....

....patients have had regular follow up clinic visits organised by us. Research has shown that many patients have no problems at the follow up visit and do not find the clinic visit to be useful. Many patients find the follow up visit to the hospital causes a lot of anxiety.

Research has shown that having a regular outpatient follow up does not help prevent cancer returning and does not increase your life expectancy. Most problems occur in between clinic visits and an early clinic appointment usually has to be made.

After discussion

....with patient groups it was felt that it would be better for **you** to make appointments to see us when you have any worries or concerns about your health, rather than having a regular clinic visit. We propose to run our follow up clinic by asking you to contact us if you have problems.

TELEPHONE NO: 01223 596093

This telephone number has a 24 hour answer phone where you can leave a message. We will then get back to you within one working day to discuss the exact nature of the problem. Our two Nurse Practitioners will return your call and, after talking to you and if necessary, they will make an appointment at the appropriate clinic, where your problem will be reviewed.

Your GP may also use this telephone number to refer you for a clinic appointment if he or she is concerned about you. We would aim to see you within two weeks of telephoning.

We hope that this system will make the outpatient visit more satisfactory and a less anxious experience for you.

Further Information

We hope that this information will be useful to you following the main part of your treatment. It contains advice about what to look out for together with information about where to go for help. It also includes information about hormone treatment and mammograms. We hope this information will help to answer some of your questions about "what happens next?"

If you have concerns or questions that are not covered in this booklet, please talk to your doctor, breast care nurse or Oncology breast nurse practitioner. The numbers for these are given at the back of the booklet.

Reasons to contact us

Many patients ask us what sort of symptoms that they should be looking out for, or problems that we feel you should report to us.

1. Symptoms

Many women are cured of their cancer by the treatment they have received and live to an old age without any cancer related problems.

You will get normal coughs and colds, aches and pains. You may have symptoms that cause you anxiety and concern. You may worry that the cancer has come back.

The following symptom guide may help you to know which symptoms to seek further advice about. If you have any of the following symptoms, for more than two weeks, which are getting worse rather than better, then please contact us on the 24 hour answer phone line.

- New changes in your breast / breasts
- Swelling of the arm (lymphoedema).
- Unexpected vaginal bleeding.
- Lumps around the collar bone (clavicle)
- Persistent back pain or pains in your bones which wake you at night.

Telephone no: 01223 596093

2. Side effects of medication

You may experience symptoms and side effects from the tablets that we are giving you. You will have been given a leaflet about the specific side effects of the tablets.

However, you may have symptoms that you wish to discuss. These are often menopausal symptoms that the tablets cause by removing the effects of oestrogen from the body. You will also have been given a leaflet about menopausal symptoms and how to cope with them. The main symptoms are hot flushes and night sweats. If you have not been given a leaflet about how to cope with these symptoms and wish to have further advice about them please contact us on the 24 hour telephone line.

Telephone no: 01223 596093

3. Getting back on track

The end of treatment can be a strange time. Although you will be glad it is all over it may seem like an anticlimax. Once treatment has finished you and the people close to

you may be expecting things to get back to normal, but this can be easier said than done after what you have been through.

To help you get back on track the specialist nurses host a focus group on alternate months entitled 'Recoup your equilibrium'. They will invite you to come along once your treatment has finished and will discuss topics such as the after effects of treatment, medication and its effects plus sexuality and body image. As well as specialist nurses there will be a Dietitian and a physiotherapist to talk to you about diet and exercise. There will also be a chance to discuss privately, with a nurse, anything you want to talk through.

For information on the Focus group please contact the Breast Care Nurse on 01223 596291 or Breast Care Practitioner on 01223 596093

4. Psychological Support

We recognise that there will be times when you feel uncertain about the future. Reactions to breast cancer treatment are individual and varied and there is no right or wrong way to feel. It may take some time to feel that you are in control of your life. If you need additional support after treatment this too can be discussed with you at a clinic appointment with a breast care specialist nurse, or with your GP. The time it takes to recover from treatment can vary and again, this is an individual experience. We can refer you to a counsellor who is trained to work with patients who have had a diagnosis of breast cancer.

5. Self help groups

Every day, there are articles in newspapers and women's magazines, as well as radio and television discussions about breast cancer. Often myths and worrying facts make breast cancer seem something to be feared. Despite this, encouraging advances in the development of breast cancer treatment over the last decade have led to improved response rates and survival for women.

If you are uncertain or worried about anything you have heard, or read, Cancerbackup or Breast Cancer Care are useful organisations to contact.

- Cancerbackup: 0808 800 1234 www.cancerbackup.org.uk
(Mon – Fri 09.00 to 17.00)
- Breast Cancer Care: 0808 800 6000 www.breastcancercare.org.uk

It is helpful to come prepared for your follow up clinic appointment by writing down any questions you may have before coming to the clinic. It is important to us that when you leave you feel satisfied your questions have been answered.

Telephone no: 01223 596093

Advice and help

1. Breast care nurses

If you need advice on breast prosthesis/bras, support groups or just want to talk things through you can telephone the breast care nurses. They work Monday – Friday, 09:00 to 17:00 and regularly check their answerphones.

01223 586756 Answerphone
01223 586573
01223 596291

2. Oncology Breast Nurse Practitioner

If you have had treatment in the oncology department and need further support or advice, then please telephone our Oncology Breast Nurse Practitioner, who works:

Monday 07:30 to 15:30

Tuesday 08:00 to 16:00

Wednesday 08:30 to 16:30

Thursday 07:30 to 17:30

Friday 08:00 to 13:30

Telephone no: 01223 217541 Answerphone

3. Breast awareness

It is important to be Breast Aware for life and to be familiar with what is normal for you. Changes in the breast or scar areas that you have not noticed before should be reported. Examine your breasts regularly:

- If your periods have returned after treatment, then the week after your period is a good time each month to examine your breasts.
- If you are no longer having periods then try and examine your breasts the same time each month, for example the first day of the month is a useful time to remember.

It is important to feel confident and be able to examine your own breasts. If you are unsure of how to do this, please discuss this with the breast care nurse or nurse practitioner in the clinic who can help you examine your own breasts and advise you on what to look for. Information leaflets are available for breast self examination and breast awareness.

4. Diet and weight

We advise that you eat a balanced diet of fruit and vegetables, meat and dairy products. Recently a low fat diet has been shown possibly to be helpful. Breast cancer has not been proven to be linked with any particular food. It is also safe to drink alcohol in moderation.

Patients often find that they put a considerable amount of weight on following their treatment. This is an effect of the lack of oestrogen hormones and changed eating patterns. This weight gain may be minimised by taking exercise and watching the number of calories you eat. Weight gain has not been shown to be related to taking Tamoxifen.

What happens next?

1. Blood tests and scans

Blood tests are not routinely taken after treatment. This may cause you some concern, as you will have become used to having a blood test during your treatment. It is not necessary to take a blood test once treatment has finished, unless any unexpected symptoms you describe are causes for concern.

Scans are not done on a regular basis either, as they can cause unnecessary anxiety and do not provide any useful information. If any new symptoms develop, the appropriate scan will be organised after you have been reviewed in the clinic.

2. Hormone treatment

Hormone treatment benefits patients whose tumours are oestrogen sensitive.

- **Tamoxifen** 20 mg one daily
At present this tablet is taken for five years and then stopped. If you are on Tamoxifen, you may stop your Tamoxifen at the end of your five years with no need to tail it off slowly.
- **Anastrozole (Arimidex)** 1mg one daily
At present this tablet is taken for five years and then stopped. If you are on Anastrozole you may stop it at the end of five years.

You will need to have regular bone density scans whilst on Arimidex and you will receive these appointments by post.

From time to time our advice about hormone treatment changes as we gain further knowledge about these treatments. If this is the case then we would contact you and your GP with the further advice.

3. Mammograms

You will be invited to have further mammograms on a regular basis and you will receive mammogram appointments in the post.

1. Mastectomy

If you have had a mastectomy or a mastectomy and reconstruction then you will require a mammogram of the other breast every other year for the first five years.

2. Lumpectomy

If you have had the lump removed then we would advise you to have mammograms on both breasts every year for the first five years.

After the first five years:

- if you are **under the age of 47** we would recommend two yearly mammograms to the age of 47 then three yearly mammograms within the screening programme from 47–73.
- If you are **over 47** we advise you to have mammograms every three years, either, if you are between the ages of 47–73, within the screening programme, or, when you are over the age of 73, attending the breast unit.
- If you are over 73 we advise you to have mammograms every 3 years. Please telephone the breast unit to make an appointment.

Telephone no: 01223 217626

Results of the mammograms will be sent to you and your GP in the post.

4. Bone health

- Tamoxifen tablets will protect your bones from developing osteoporosis (thinning of the bones).
- Enclosed in the pack is a leaflet about how to generally look after your bone health after the diagnosis of breast cancer.
- If you are on Arimidex or Letrozole tablets then your bones are at greater risk of developing osteoporosis.
- You will have had a bone density scan organised at this clinic visit and we will write to you with the results of that test.

- Depending on the results of that test we may need to do further follow up bone density scans or advise treatment to prevent further bone loss.

5. At the end of 5 years

You will be discharged from patient led follow up.

We hope this information has been useful to you.

How to contact us:

- **24 hour answer phone number**

Breast Care Practitioner 01223 596093

You will be phoned back the next working day, Monday–Friday between 08.00 & 17.00

- **Breast Care Nurses** 01223 586756
01223 586573
01223 596291
- **Oncology Breast Nurse Practitioner** 01223 217541
- **Prosthetic Nurse** 01223 348272
- **Cambridge Breast Unit main reception** 01223 217627
- **Oncology Centre** 01223 216551

Other useful contacts

Cancerbackup www.cancerbackup.org.uk 0808 800 1234
Monday–Friday 09.00 to 17.00

www.addenbrookes.org.uk

www.breastcancercare.org.uk 0808 800 6000

www.cancerhelp.org.uk

Macmillan Cancer Line www.macmillan.org.uk 0808 808 2020

Wallace Cancer Support Centre 01223 596397
www.marywallacecentre.org.uk

Please ask if you require this information in other languages, large print or audio format: 01223 216032 or patient.information@addenbrookes.nhs.uk

Informacje te można otrzymać w innych językach, w wersji dużym drukiem lub audio. Zamówienia prosimy składać pod numerem: 01223 216032 lub wysyłając e-mail: patient.information@addenbrookes.nhs.uk

Polish

Se precisar desta informação num outro idioma, em impressão de letras grandes ou formato áudio por favor telefone para o 01223 216032 ou envie uma mensagem para: patient.information@addenbrookes.nhs.uk

Portuguese

Если вам требуется эта информация на другом языке, крупным шрифтом или в аудиоформате, пожалуйста, обращайтесь по телефону 01223 216032 или на вебсайт patient.information@addenbrookes.nhs.uk

Russian

若你需要此信息的其他語言版本、大字體版或音頻格式，請致電 01223 216032 或發郵件到：patient.information@addenbrookes.nhs.uk

Cantonese

Bu bilgiyi diger dillerde veya büyük baskılı ya da sesli formatta isterseniz lütfen su numaradan kontak kurun: 01223 216032 veya asagıdaki adrese e-posta gönderin: patient.information@addenbrookes.nhs.uk

Turkish

এই তথ্য বাংলায়, বড় অক্ষরে বা অডিও টেপে পেতে চাইলে দয়া করে 01223 216032 নম্বরে ফোন করুন বা patient.information@addenbrookes.nhs.uk ঠিকানায় ই-মেইল করুন।

Bengali



Addenbrooke's is smoke-free. Please do not smoke anywhere on the site. For advice on quitting, contact your GP or the NHS smoking helpline free, 0800 169 0 169

Document history			
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