

Please keep this booklet in an accessible place for reference. Inform the Hospital if you have any change of address of contact details.

Contact Details:

Key Worker – Clinical Nurse Specialist

As your key worker the Clinical Nurse Specialist will always make time for you.

Hours of work: Mon to Fri 9.00am – 5.00pm and can be contacted on:-

Telford: 01952 641222 ext 4164 or 4431

Shrewsbury :01743 261290

Acknowledgements;

Permission to use information based on a booklet produced by the Breast Care Nursing Team at The University Hospital of North Staffordshire and The Breast Cancer Action Group Wolverhampton & District

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Breast Awareness information kindly reproduced from Breast Cancer Care fact sheets

Introduction

This information leaflet has been written to help you understand why you are being discharged from routine follow-up and how you can easily access the breast care team if you should need to.

Why Ongoing Care following routine follow up at the hospital?

It has been several years since you were first diagnosed with breast cancer and received treatment. You have been followed up in outpatient clinics since then at intervals. You are now about to move into a new phase where you will only be seen by the Breast Care Team at the hospital if you or your GP request it. We will continue to offer support and care during this time and quick access back into the hospital system if necessary. Your GP will be informed of your care needs following discharge from routine follow-up at the hospital.

Why will I not be seen for follow up in the future?

For many years we have followed patients up indefinitely as part of their continuing care after breast cancer treatment. However evidence has now shown that this is not the best care that we can provide. Our change in practice has come from extensive research and has involved patient groups and national expert opinion. By changing our programme of follow up we aim to provide you with individual information and help as needs arise. This will mean that most patients will be discharged five years after their initial treatment was completed. If you have taken part in a trial this may be extended.

We expect that these changes will provide: a more patient led service, prompt access to an appointment when you need it and the opportunity to discuss other aspects of your well being with the appropriate health care professional.

Guidelines on the sorts of signs and symptoms you need to look out for and how you can access an appointment promptly if needed are provided in this booklet.

What will happen about my future screening?

We strongly recommend that you attend your Breast Screening appointments after you have been discharged from hospital.

An appointment will be sent directly to you every 3 years, currently until you reach the age of 73. You can still continue to attend for Breast Screening at 3 yearly intervals after this time but you will need to make your own appointment.

The telephone number for breast screening service queries in Shropshire is **(01743) 261000, ext 3674**. Breast screening in Powys is organised through Breast Test Wales, and the North Wales Breast Screening Centre can be contacted on **(01492) 860888** with any queries.

Will I need any other tests?

There is no clinical evidence that supports the routine use of follow-up blood tests, scans and x-rays (other than breast imaging), following treatment for breast cancer. Research has shown that carrying out such unnecessary tests can lead to intense anxiety. A sensible course to pursue is to reserve investigations for any suspicious physical or imaging findings.

What about my current medication?

If you are currently under the care of an Oncologist you will continue to be seen by the Oncology service until they discharge you.

What about Clinical trials?

If you have agreed to take part in one of the clinical trials you may be asked to come for review more frequently for a period of time in order to help answer the question that the trial was set up to answer. This does not mean that we are more concerned about your clinical well-being than that of women/men who are not part of a clinical trial.

Are there any late side effects of treatment that I should know about?

Yes, there are nearly always some side effects of treatment that you may be at risk of developing many months or years after your treatment has finished. We have listed the two main ones below that you should be aware of and what you need to know about them;

1.Lymphoedema

If you had some of the lymph glands in your armpit removed during breast surgery, you may be at risk of developing lymphoedema. Over time lymph fluid could start to build up causing your breast and arm to swell. If you think this is

happening to you, you should contact your Breast Care Nurses. Always remember not to offer your affected arm for blood tests, blood pressure etc.,

2.Care in the sun

If you have had radiotherapy as part of your treatment, you should take care to keep the treated area covered from the sun. Your skin will be more delicate, so extra care should be taken.

We would suggest using a sun screen of at least factor 30+ and wear a hat and a long-sleeved shirt. It is important to remember that you can burn even through clothing if you are out in hot sun for a long time.

What other advice should I follow?

Visits to other health professionals – Whenever you visit a health care professional such as your doctor, dentist, physiotherapist or osteopath to name just a few, it is important that you tell them that you have had cancer and about any medication that you are taking.

What about diet and exercise?

A normal healthy diet is encouraged and ‘fad’ diets are strongly discouraged. Moderate exercise is recommended. For more information on diet and exercise check out-

www.breastcancercare.org.uk/breast-cancer-breast-health/moving-forward/looking-after-yourself/diet-and-exercise/

What follow up services are available to me?

Breast Form / Prosthesis – If you have any queries about your breast prosthesis please contact the Breast Care Nurses. The normal life of prosthesis is approximately 2/3 years; however body changes may require you to change earlier than this.

A bra and swimming costume pocketing service is available via Pink Ribbons Breast Care Support Group. Tel: 01952 586898

How long does a silicone implant last?

Modern implants do not need to be changed or replaced as a matter of routine. It may need changing for cosmetic reasons (for instance you gain or lose weight, have capsular contraction (formation of tough, fibrous tissue around the implant), have an infection (when it must be removed and replaced at a later date).

It is very difficult to damage implants normally only a severe chest injury for instance a car crash would do this. So you can carry on with all your normal activities, including things like sports and air travel, without worrying that it will affect your implant.

Will the cancer come back?

The majority of women/men have no recurrence of their cancer after they have received treatment and live to old age without any cancer related problems. However breast cancer can be complicated and every woman is different.

You will get normal coughs and colds, and the aches and pains that most people get from time to time. This does not mean that the cancer has come back.

If problems do occur they are usually noticed by patients themselves. We would encourage you to regularly examine your breast/s and armpits, but no more than once a month. Following breast surgery it is important to pay particular attention during self examination to your scar line, both armpits and above your collar bone where a chain of lymph nodes extend from your armpit (see guide at the back of this booklet).

What should I be looking for and who do I contact?

The following information is a guideline to suggest what you should do if you have symptoms which last for more than 2 weeks and are getting worse.

	Call the Breast Care Nurses	Contact your GP
Any new lump in your breast or armpit	✓	
Any new changes in your breast eg skin puckering, nipple inversion, blood stained nipple discharge, change in shape.	✓	
Any changes to your scar line – particularly any new spots or rashes	✓	
Lumps above the collar bone	✓	
Swelling of the arm or breast (lymphoedema)	✓	
Unexplained vaginal bleeding or spotting	✓	
Persistent menopausal symptoms		✓
Persistent back pain or pain in your bones which wake you at night	✓	
Unexplained weight loss and sickness/loss of appetite	✓	
Unexplained tingling in hands and/or feet/legs		✓
Unexplained cough or breathlessness	✓	
New headache	✓	
Any new unexplained pain anywhere in your body	✓	

How can I contact a Breast Care Nurse?

Either you or your GP may contact the Breast Care Nurses. They are available Monday to Friday between 9.00am and 5.00 pm. Please leave a message on the helpline answer phone on **01952 641222 extn 4164/4431 for Princess Royal Telford** or **01743 261290 for Royal Shrewsbury** and your call will be returned.

When you speak to the Breast Care Nurse she will be able to discuss your concerns in more detail. She may need to see you herself in order to provide you with more support and information or to make an appropriate referral to any of the following: your own GP, your Consultant Breast Surgeon, your Consultant Oncologist, an Oncology registrar or a Lymphoedema Nurse Specialist. A prompt appointment will be made to see the appropriate health care professional if needed.

If you or your GP are worried about a symptom you are experiencing, we will aim to give you an appointment in one of the breast clinics within two weeks. Remember you are still “on our books” and we want to see you as soon as we can.

What services are available in my area?

- **Pink Ribbon Pals South Shropshire Breast Care Support Group**
The meetings are at 7.30pm at Lambeth House, Lambeth Close, Craven Arms on the second Thursday in the month.
www.pinkribbonpals.worldpress.com
The “Pink Ribbon “ ladies Alison 07966 169733
Sue 01584 841636 or 01588 630200
- **Pink Ribbons PRH Breast Care Support Group**
The meetings are at 7:30pm at Education Centre in The Princess Royal Hospital on the 3rd Wednesday in the month.
Betty Jenkinson (01952) 586898
- **Bosom Buddies – Breast Cancer Support Group**
The meetings are at 7.30pm at The Hamar Centre, Shrewsbury on the first Monday of the month (unless it’s a bank holiday, in which case the Monday after the bank holiday) Eileen Evans (01743) 873105
- **The Hamar Support and Information Centre**
www.sath.nhs.uk/cancer Tel: 01743 261035
Provides support and counseling, alternative therapies and general information to people with cancer and other serious illnesses. Monday to Thursday 9.00am – 5.00pm and Friday 9.00am – 4.30pm

- **Having Cancer Can be Expensive**

To find out about local services for advice on benefits:

Telford: PALS 01952 641222 ext 4741

Shrewsbury: BIAS 01743 261083

Where can I get more information?

- **Breast Cancer Care**

Breast Cancer Care is a national charity providing telephone advice and free leaflets on breast cancer.

Telephone 0808 800 6000

www.breastcancercare.org.uk

- **Breast Cancer Haven**

Aims to support the physical and emotional needs of those affected by this disease in the UK. Offers information, counseling and complementary therapies.

37 Owen Street, Hereford HR1 2JB

Tel: 01432 361061

www.breastcancerhaven.org.uk

- **British Association of Sexual and Relationship Therapy**

This is a national charity for sexual and relationship therapy.

It contains information on therapists available in your area.

Telephone 0208 543 2707

www.basrt.org.uk

- **The Cancer Survivors Handbook and Coping with Breast Cancer.**

Both books are by Dr Terry Priestman and are published by Sheldon Press.

- **Look Good Feel Better**

Free support service for women living with cancer, offering workshops on making the most of your appearance, at 29 leading hospitals around the country

Tel: 01372 470900, Fax: 01372 470959

E-mail: info@lookgoodfeelbetter.co.uk

- **Lymphoedema Support Network**

The LSN is a national charity that provides information and support to people with lymphoedema. It runs a telephone helpline, produces a quarterly newsletter and a wide range of fact sheets, and maintains an up-to-date website. Tel (Information & Support): 020 7351 4480

www.lymphoedema.org/lsn

- Macmillan**
 Macmillan develops publications specifically for people with cancer, their family and friends. To see the full range of publications and order them free of charge, please visit Be.Macmillan (you will need to register to browse and order from the website) or call 0800 500 800.
 If you and your family need information or emotional support you can contact the Macmillan CancerLine:
 Freephone 0808 808 2020, 9am to 10pm Monday to Friday
- National Hereditary Breast Cancer Helpline**
 A 24 hour helpline if you are concerned about your family history of breast cancer.
 Telephone 01629 813000
www.breastcancergenetics.co.uk
- NHS Direct**
 A Nurse-led advice service run by the NHS for patients with questions about diagnosis and treatment.
 Telephone 0845 4647
www.nhsdirect.nhs.uk
- United Kingdom Association of Cancer Registries**
 Collects patient identifiable information from hospitals following a cancer diagnosis. This information is invaluable and can be used in a number of ways, for example to determine the incidence of cancer in the UK to see if this is increasing or decreasing.
WWW.ukacr.org

Breast Changes in Women

Throughout pregnancy the breasts change in preparation for breastfeeding. First they become tender and more sensitive. The breasts and areola get much larger (as the number of milk-producing cells increases) and blood vessels on the skin become more noticeable. The nipples become darker and may remain that way following pregnancy. During breast-feeding large amounts of milk are being produced and the breasts change size many times a day. When breast-feeding stops the breasts gradually go back to how they were before pregnancy, although they may be a different size or less firm.

Around the menopause lumps are common, and these often turn out to be breast cysts (benign fluid-filled sacs). Breast tissue changes with age. It begins to lose its firmness and the milk-producing tissue is replaced by fat, making the breasts sag. This is more noticeable after the menopause when oestrogen levels fall and periods have stopped. As you grow older your breasts may change size. If you take HRT (hormone replacement therapy) your breasts may feel firmer and sometimes quite tender.

Normal changes and benign breast conditions

When women go to their GP with a breast problem, it is most likely to be a normal change to do with the developing or ageing breast. These changes can include tenderness/ pain, lumps/lumpiness and nipple problems. All these changes are linked to variations in the levels of the female hormones estrogen and progesterone. Sometimes such changes go beyond what is seen as normal and can be diagnosed as benign breast conditions. For example, breast pain linked to the menstrual cycle is common and usually seen as normal. However, when it is severe and long lasting it is seen as abnormal and something that needs treatment.

Breast Awareness

Breast awareness is an important part of caring for your body. Being breast aware is about becoming familiar with your breasts and the way they change throughout your life. It means knowing how your breasts look and feel normally so you can feel confident about noticing any change that might be unusual for you.

Get into the habit of looking at and feeling your breasts from time to time. There is no set way to do this, and you don't have to look at the same time. Some women/men do it when they are dressing or undressing, bathing or showering, or applying body lotion. Some women/men use a mirror, some don't. You can decide what you are comfortable with and when is convenient for you. One thing that is important is to feel all parts of the breast, from high up on the front of your chest, down and around into your armpit.

Changes to be aware of:

You need to be aware of any changes that are new or different for you such as:

- A change in size – it may be that one breast has become noticeably larger or lower.
- Swelling of the breast
- A swelling under your armpit or around your collarbone (where the lymph nodes are).
- A lump or thickening in your breast that feels different from the rest of your breast.
- Irritation, puckering or dimpling of the skin.
- A discharge other than breast milk from one or both nipples.
- Nipple abnormalities (such as pain, redness, rash, scaliness, turning inward).
- Constant pain in one part of your breast or armpit.

How to look at and feel your breasts

1. Stand in front of a mirror that is large enough for you to see your breasts clearly. Check each breast for anything unusual. Check the skin for puckering, dimpling, rash or scaliness. Look for a discharge from the nipples.
2. Watching closely in the mirror, clasp your hands behind your head and press your hands forward.
3. Next, press your hands firmly on your hips and bend slightly toward the mirror as you pull your shoulders and elbows forward.

Do steps 2 and 3 to check for any change in the shape or contour of your breasts. As you do these steps, you should feel your chest muscles tighten.

4. Gently squeeze each nipple and look for a discharge.
5. The breasts are best examined while lying down because it spreads the breast tissue evenly over the chest. Lie flat on your back, with one arm over your head and a pillow or folded towel under the shoulder. This position flattens the breast and makes it easier to check.

Use the pads of the fingers of your other hand to check the breast and the surrounding area firmly, carefully, and thoroughly. Some women like to use lotion or powder to help their fingers glide easily over the skin. Feel for any unusual lump or mass under the skin. Feel the tissue by pressing your fingers in small, overlapping areas about the size of a 5 pence. To be sure you cover your whole breast, take your time and follow a definite pattern: lines, circles, or wedges.

Some research suggests that many women examine their breasts more thoroughly when they use a pattern of up-and-down lines or strips. Other women feel more comfortable with another pattern. The important thing is to cover the whole breast and to pay special attention to the area between the breast and the underarm, including the underarm itself. Check the area above the breast, up to the collarbone and all the way over to your shoulder.

Lines: Start in the underarm area and move your fingers downward little by little until they are below the breast. Then move your fingers slightly toward the middle and slowly move back up. Go up and down until you cover the whole area.

Circles: Beginning at the outer edge of your breast, move your fingers slowly around the whole breast in a circle. Move around the breast in smaller and smaller circles, gradually working toward the nipple. Do not forget to check the underarm and upper chest areas, too.

Wedges: Starting at the outer edge of the breast, move your fingers toward the nipple and back to the edge. Check your whole breast, covering one small wedge-shaped section at a time. Be sure to check the underarm area and the upper chest.

You can use three different levels of pressure to examine your breasts:

- light pressure - to examine the tissue closest to the skin
- medium pressure - to feel a little deeper
- firm pressure - to feel deeper tissue closer to the chest wall

6. Some women repeat step 5 in the shower. Your fingers will glide easily over soapy skin, so you can concentrate on feeling for changes underneath.

The Breast Awareness 5 Point Code

- 1. Know what is normal for you.**
- 2. Know what changes to look and feel for.**
- 3. Look and feel.**
- 4. Report any changes to your Breast Cancer Nurse without delay.**
- 5. Attend for routine breast screening if you are aged 47 or over.**

**NOTE – If you ever find a change
contact your Breast Cancer Nurse
Specialist**

**Hours of work: Mon to Fri
9.00am – 5.00pm
and can be contacted on:-**

**Telford: 01952 641222 ext 4164 or 4431
Shrewsbury :01743 261290**



Shropshire and Mid Wales
Cancer Forum

The Shropshire & Mid Wales Cancer Forum is a partnership between service users and service providers established with the objective of

"improving cancer services in Shropshire & Mid Wales"

The Cancer Forum meets regularly to review its work and discuss information about developments in cancer service provision. The work programme focuses on:

- promoting best practice
- identifying issues of concern to cancer service users
- encouraging users to take an active role in development of cancer services
- raising issues in partnership with Health Professionals on behalf of patients

Membership of the Forum is open to cancer patients, their relatives and carers, Health Professionals living or working in Shropshire and Mid Wales.

The group meets informally at 2.00pm with the meeting starting at 2:30pm on the Second Tuesday of the month, either at Princess Royal, Telford or the Hamar Centre, Shrewsbury.

YOUR experience could influence local cancer Services.

www.cancerforum.org.uk

cancerforum@hotmail.co.uk

Interested?

Call: 07504 120315