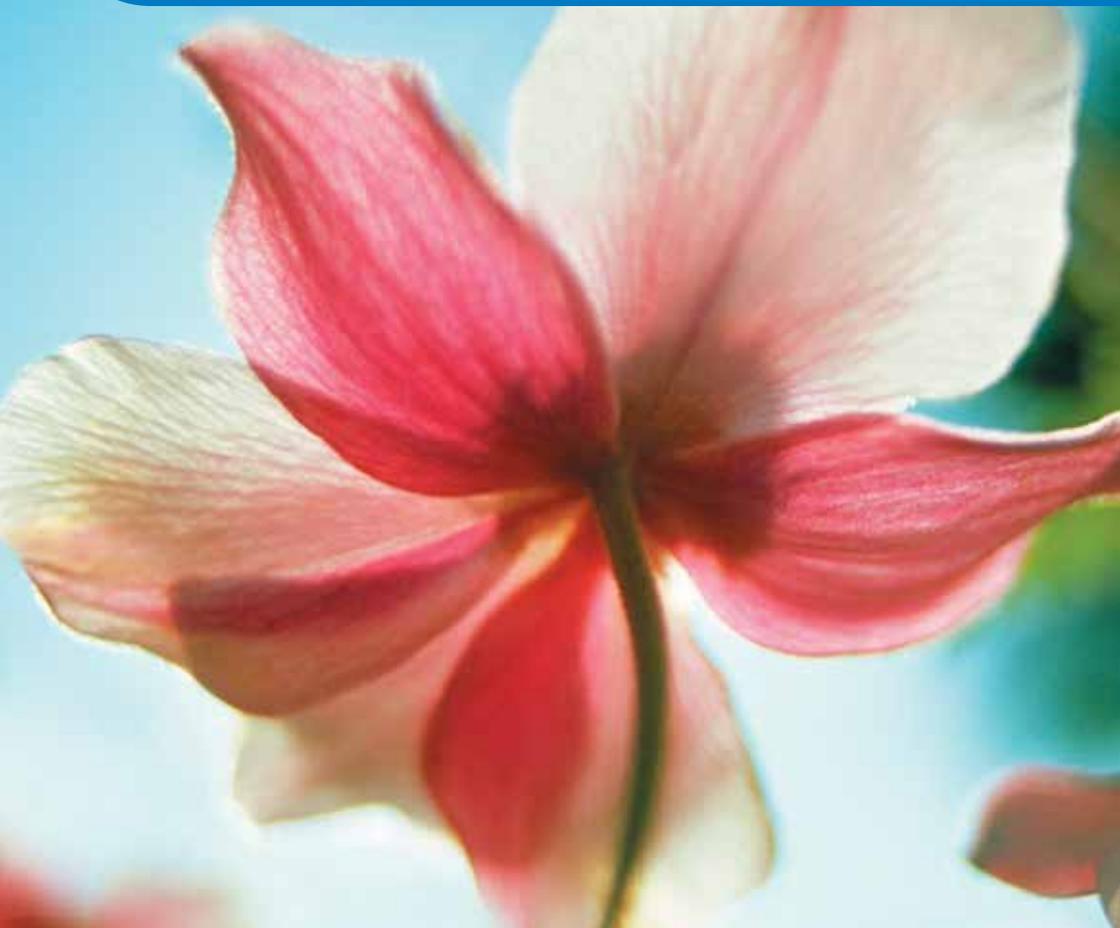




University Hospital
Southampton
NHS Foundation Trust

Southampton breast care support

Your guide to life after breast cancer
Information for patients



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Breast care team/breast unit

Telephone: 023 8120 3753

Important notice

If there is any change of your address or GP, please inform University Hospital Southampton NHS Foundation Trust on: **023 8120 8466**

Your personal details

Name:

Hospital number:

Date of diagnosis:

Pathological diagnosis:

Surgical treatment and dates:

Medical treatment and dates:

Radiotherapy treatment and dates:

Surgical consultant:

Oncology consultant:

Named breast care clinical nurse specialists:

Your treatment plan

Hormonal therapy prescription:

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Breast imaging prescription:

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Bone health prescription:

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Introducing self-supported management

In the past patients who had completed their treatment for early breast cancer were seen at regular intervals by their oncologist or surgeon for follow-up purposes. Although some patients found these pre-arranged visits useful and reassuring, many people found these hospital visits a source of great anxiety and not particularly helpful, unless they had a particular concern that they wished to discuss. There is now very good evidence to show that following-up patients in this way does not prevent cancer returning and does not increase life expectancy.

Like many other breast units in other parts of the UK, Southampton breast unit allows you to arrange follow-up appointments as and when you need them, for five years after the end of your treatment.

This booklet aims to explain what self-supported management is and how it works. It contains all the information you need to contact the breast unit and arrange follow-up appointments for yourself. It also contains details about your personal type of breast cancer, the treatments you have received so far and any medication and investigations that you will need in the future – your treatment plan. This booklet also contains information that we think you may find useful as you recover from your treatment for early breast cancer.

What is self-supported management?

Self-supported management puts you in control of your hospital follow-up. Once you have received this booklet, you will no longer be given routine follow-up clinic appointments at regular pre-set intervals. Instead, you will simply be able to contact the breast unit directly to arrange a follow-up appointment with the breast team as and when you feel concerned that you might need to be seen in clinic. After five years you will still continue to have your regular mammograms but will need to go back to see your GP if you have any concerns or notice anything unusual.

When should I be seen by the breast unit?

You should arrange a review by a member of the breast unit if you have concerns about any of the following issues:

- your ongoing hormonal treatment
- possible side effects from your chemotherapy or radiotherapy treatment
- problems related to your original breast surgery or questions about breast reconstruction
- new changes in your breasts, chest wall region, neck or under your arm
- new medical symptoms that you are worried could represent a spread of your breast cancer (see also page 19)

Who do I call to arrange a review?

You can contact the breast care team/breast unit on: **023 8120 3753**

Please leave a brief message and a contact telephone number on our answer phone. You will be contacted by one of our breast care clinical nurse specialists within two working days. They will briefly discuss the nature of your concern with you and if necessary arrange a clinic appointment with either your surgeon or your oncologist. We will aim to see you within two weeks of your telephone call. Your GP can also use this number to contact us if he or she feels that you need to be seen by the breast unit.

Recovering from your surgery

Is it normal to still get aches and pains in my breast or chest several months after my surgery?

Many women continue to get aches and pains in their breast or underarm area for many months after their surgery. These can be made worse by radiotherapy and can continue for a year or more. If, however, you develop a new pain that gets worse over two to three weeks then contact us to arrange a review.

Why do I have a strange sensation on the inside of my arm?

This is usually due to surgery interfering with the nerves in the under arm area, resulting in a changed sensation (often numbness) affecting the underside of the upper arm. This altered sensation can be either temporary or permanent.

My scar feels hard and lumpy. Is this normal?

After an operation this may be due to the healing process and formation of scar tissue. Gently massaging the scar with a moisturising cream can help to break down the hardened area and even out the scar line (using whichever moisturising cream you usually use). Any new lump in or around the scar should be checked by your surgeon.

What is this tight 'pulling' sensation stretching down my arm?

This is known as 'cording' and it is a common problem after an operation. It is thought to be caused when the lymph vessels harden and tighten due to the surgical procedure (particularly axillary surgery). This side effect can either settle by itself or be encouraged to 'ease' by massaging and stretching the affected area.

Can I wear deodorant?

Yes, there are no proven studies to suggest otherwise.

My arm is swollen. Is this normal?

Some women who have had surgery to remove lymph nodes from their armpit, (axillary node clearance) develop swelling of this arm in the weeks or months following their surgery. This is known as lymphoedema and is due to disruption of the normal channels that the lymph fluid flows through away from the arm. If your arm is swollen, please contact the breast care clinical nurse specialists who will be able to refer you on for a clinical review.

If your arm swells up many months or even years after your original surgery, you should contact the breast care unit to arrange a review by your consultant.

What about breast reconstruction?

There are various options for breast reconstruction. Your breast care clinical nurse specialist will be happy to discuss these and provide further information. Regular clinics are also held jointly with the breast and plastic surgeons in Southampton and any member of the clinical team can refer you to these clinics.

Staying breast aware

What is my chance of developing a cancer in my other breast?

We will arrange for you to have mammograms more regularly (either every year or every other year) because your risk of developing cancer in your other breast is slightly higher than it would be if you hadn't had breast cancer. Unless you have an inherited genetic predisposition (such as BRCA1 or BRCA2 alteration) or strong family history, your risk will not be much higher than most people your age. There is no evidence that removing your other breast (contralateral mastectomy) will enable you to live longer, unless you have an inherited genetic disposition or your risk has been assessed as very high by the genetics team.

Should I still examine my breasts and what should I do if I find a lump or notice a new change in my breast?

We recommend that you examine your breasts once a month, so that you are familiar with the way that they look and feel. If you find a new lump or notice any other abnormality within your breast, or near your mastectomy scar then contact the breast care clinical nurse specialists on **023 8120 3753**.

We will arrange for you to be reviewed by your medical team and then to have any further investigations that are required.

Will I have regular mammograms?

All women who have had breast cancer have regular follow-up mammograms. If you were aged 50 or over at your diagnosis and had a mastectomy, you will have a mammogram of the other breast every other year for 10 years. If you were aged 50 or over and had a lumpectomy you will have a mammogram of both breasts every year for five years and then every other year for a further five years. After ten years you will have mammograms every three years. If you were aged under 50 years at your diagnosis then you will have annual mammograms until you are 50 and then further follow-up as above. However, these arrangements may change in the future with developments in national policies.

My breast cancer wasn't seen on a mammogram. What should I do?

We can arrange for you to have extra investigations such as a breast MRI or an ultrasound examination of the breast as well as your regular mammogram.

How will I get my results?

We will write to you and your GP with your mammogram results within two weeks.

Recovering from your chemotherapy

How long will I feel tired for?

Almost all women feel very tired by the end of their chemotherapy. This can get worse if they are receiving radiotherapy. Your tiredness should start to improve one to two months after your last cycle of chemotherapy and then steadily improve. However it can take at least six months before your energy levels return to normal and some women still feel tired 12 to 18 months after the end of their treatment.

When will my hair grow back and when can I dye it?

Most women find that their hair starts to grow back three to four weeks after their last chemotherapy session. The hair grows slowly to begin with and can be quite thin and 'fluffy', but over time the hair thickens up and after six months most women will have a good head of hair again.

As your new hair will be rather delicate, we recommend that you wait for six months before using chemical, permanent or semi-permanent dyes on your hair. However, it is safe for you to use herbal or non-permanent dyes while you are waiting.

Why have I put on weight?

It is quite common for women who have had chemotherapy for breast cancer to gain some weight during their treatment. The chemotherapy drugs themselves do not cause weight gain but the steroid tablets that we use as anti-sickness tablets can increase appetite. Many women also find that their diet changes whilst they are on chemotherapy and that they do less exercise than usual because of the tiredness that it can cause.

When will I recover feeling in my fingers or toes?

If you have developed pins and needles or numbness of your fingers or toes during your chemotherapy treatment, this should gradually improve in the weeks and months after the end of your treatment. However, you may find

that it initially gets worse after your last treatment before it starts to get better. A small number of patients may find that sensation in their fingers or toes remains altered permanently.

Are there any long-term side effects of chemotherapy?

There is a very low risk that one of the chemotherapy drugs that we commonly use can affect the heart muscle. Please discuss this with your oncology consultant if you have any concerns. There is also a very low risk that patients treated with chemotherapy for early breast cancer can develop different, unrelated cancer years later.

Can chemotherapy treatment affect my fertility?

Chemotherapy for breast cancer can bring on the menopause earlier than it would have naturally occurred. This is more common if you are close to menopausal age when you start your treatment. Some women therefore find that their periods stop whilst they are having chemotherapy and never come back.

If you do have a premature menopause as a result of chemotherapy, this will affect your ability to have children (fertility).

Free resources

Understanding chemotherapy (July 2015) – Macmillan Cancer Support
Available online at publications.macmillan.org.uk

Recovering from your radiotherapy

How long will radiotherapy side effects last for?

Radiotherapy causes acute side effects which occur during treatment, and tend to peak at the end or up to two weeks after finishing treatment. Most skin reactions resolve and completely heal by four to six weeks after radiotherapy.

Up to half of patients treated may experience rib tenderness or shooting pains in the breast. These generally settle within a few months of radiotherapy treatment but they can persist intermittently in the long term.

Many patients feel tired both during and after radiotherapy. This is usually worse if you also had chemotherapy. Tiredness tends to improve about six weeks after completing radiotherapy but it can often take several months to recover.

When can I go out in the sun?

Take sensible precautions in the sun and avoid getting sunburnt. The treated area may be more sensitive and should be covered. High factor sun cream should be used (at least factor 20).

Will I get any long-term side effects from my radiotherapy?

Long-term effects are rare but can occur in a small percentage of people. There may be a change in the appearance of the skin, with the skin within the treatment area being darker and firmer to the touch, and the breast may be smaller in size.

After a mastectomy the chest wall can feel tight and there may be permanent skin changes if there was a severe skin reaction.

People who have had breast reconstruction with implants may experience contraction of the capsule around the implant. Occasionally it is necessary to remove or exchange the implant.

There is a slightly increased risk of rib fracture in the treated area and a small risk of heart damage after treatment to the left side. Occasionally, radiotherapy can cause inflammation of a small area of lung tissue. There is a very small risk of a second cancer developing in the treated area as a result of radiotherapy

Lymphoedema

Lymphoedema often presents as swelling of the arm, breast or chest wall on the treated side. This can sometimes be made worse by radiotherapy treatment. If you notice any swelling, contact the breast unit for further advice and possible assessment in our lymphoedema clinic.

Free resources

Understanding radiotherapy (December 2015) – Macmillan Cancer Support
Available online at publications.macmillan.org.uk

Hormonal therapy

Why do I have to take hormone tablets?

If your breast cancer was sensitive to the hormones oestrogen and /or progesterone we will generally recommend that you have a course of anti-hormonal treatment for your breast cancer. Taking anti-hormone therapy, usually for five to ten years, will significantly reduce the risk of your cancer recurring, in addition to the other treatments you have already had.

Are there different types of hormonal therapy?

There are two main types of hormone therapy:

- 1) Tamoxifen is an anti-oestrogen and it acts by blocking oestrogen receptors on tumour cells. Tamoxifen is prescribed for pre-menopausal women and some post-menopausal women.
- 2) Arimidex (Anastrozole), Femara (Letrozole) and Aromasin (Exemestane) are all aromatase inhibitor drugs and work by switching off the enzyme that makes oestrogen in the body. These drugs are only suitable for post-menopausal women.

What side effects may I experience?

All of these tablets can cause menopausal type symptoms such as hot flushes and night sweats. Tamoxifen is associated with a small risk of blood clots and can also rarely cause abnormal thickening of the lining of the womb, which can show itself as post-menopausal vaginal bleeding. You must inform your doctor if you experience any post-menopausal vaginal bleeding whilst on Tamoxifen.

Arimidex, Femara and Aromasin can cause aching and stiffness of the joints and are also associated with thinning of the bones (osteoporosis). Your bones will be monitored for signs of this with regular bone density scans.

If you are getting troublesome side effects from your hormone tablets, please contact the breast care clinical nurse specialists to discuss these with your consultant.

Managing menopausal symptoms

Many women who receive treatment for breast cancer develop menopausal symptoms. These can be due to the effect of chemotherapy or hormone therapies on your own hormone levels, or simply due to stopping your usual hormone replacement therapy. Hot flushes and night sweats are the most common menopausal symptoms, but many women also notice weight changes, vaginal dryness, changes in libido and mood swings.

Can I use hormone replacement therapy?

Hormone replacement therapy (HRT) is not recommended for women who have been treated for breast cancer as it may increase your risk of disease recurrence (particularly if your breast tumour was sensitive to oestrogen), or increase your risk of developing a second breast cancer. However, very occasionally women who are at very low risk of cancer recurring and are experiencing severe menopausal symptoms that are affecting their quality of life may decide that the benefits of HRT outweigh the risks. This is a decision that should always be made after a discussion with your oncologist or surgeon.

If you are suffering from vaginal dryness, vaginal lubricants such as Replens MD or KY-Jelly can be helpful. If these do not solve this problem then a topical oestrogen cream may help. However, this should be discussed with your consultant, GP or breast care clinical nurse specialist.

Can I take herbal therapies to help?

Some 'natural' remedies, such as Black Cohosh and Red Clover are often advertised for the relief of menopausal type symptoms. However these contain plant oestrogens (phyto-oestrogens) and are **not** recommended for use by women who have had breast cancer. Evening primrose oil is safe to use and some women do report that it is helpful for menopausal symptoms. However, there is no scientific evidence to prove this. There is no good evidence for the use of vitamin E for hot flushes and vitamin E supplements may even be harmful, especially for people with heart disease.

What else can I do?

Do tell your breast care clinical nurse specialist if your menopausal symptoms are troubling you. Several prescription drugs can be effective in reducing hot flushes and your doctor will be able to discuss the potential benefits and side effects of these medications with you.

Alternatively, some women find relaxation-based complementary therapies such as acupuncture, hypnotherapy, massage or aromatherapy helpful for their symptoms.

Free resources

Fertility issues and breast cancer treatment – Breast Cancer Care

Menopausal symptoms and breast cancer – Breast Cancer Care

Osteoporosis and breast cancer treatment – Breast Cancer Care

Tamoxifen – Breast Cancer Care

Anastrozole (Arimidex) – Breast Cancer Care

Goserelin (Zoladex) – Breast Cancer Care

All available online at www.breastcancercare.org.uk/information-support/download-order-publications

Ovarian ablation and breast cancer - Macmillan Cancer Support

Available online at www.macmillan.org.uk/cancerinformation/cancertypes/breast/treatingbreastcancer/hormonaltherapies/ovarianablation.aspx

Getting back to normal

Reaching the end of your treatment can be a difficult time for many patients. Although you will feel relieved that your treatment is finally over, you may also find that you miss the security of being seen at the hospital on a regular basis. Most patients will also find that it takes rather longer than they expect to recover fully from their treatment (see pages 7 to 12).

Where can I find support?

You may already have found that people find different ways of living with breast cancer after having treatment. There is no right or wrong way, just what works for you. Some people prefer not to talk, while others like to get support from talking about their experience. Ask the breast care clinical nurse specialist about details of local support groups if you think they might be helpful.

Free resources

Life after cancer treatment (September 2014) – Macmillan Cancer Support
How are you feeling? The emotional effects of cancer (September 2014) – Macmillan Cancer Support

Talking about your cancer (February 2015) – Macmillan Cancer Support
All available online at publications.macmillan.org.uk

When can I return to work?

You can return to work whenever you feel ready to do so. Whenever you return, remember that it will be a big shock to the system to begin with. It can be very useful to return in a 'phased' manner, increasing your working hours over a few weeks.

Free resources

Work and cancer (November 2016) – Macmillan Cancer Support
Available online at publications.macmillan.org.uk

Can I travel abroad?

Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients can have difficulties getting travel insurance if they have been treated for cancer. Both the Southampton Macmillan Support and Information Centre and the Macmillan website have a list of insurers who specialise in the cover of patients who have had cancer and will be able to offer advice.

Free resources

Travel and cancer (April 2017) – Macmillan Cancer Support
Available online at publications.macmillan.org.uk
British Insurance Brokers Association (BIBA) - www.biba.org.uk

Should I exercise?

Most women feel tired for a number of weeks or months after they have had treatment for breast cancer. We recommend that once you have completed your treatment, you try to gradually increase your daily activity with the aim of trying to build up to three or more twenty minute sessions of moderate activity each week.

What diet should I follow?

Enjoying a healthy diet, avoiding excessive weight gain and maintaining a moderate level of physical activity is important if you have had breast cancer. There are conflicting theories about diet and cancer, which can be confusing. Most experts would agree that healthy eating means eating a balanced, varied diet that provides all the nutrients you need.

Evidence suggests that maintaining a healthy weight and avoiding excessive weight gain can improve breast cancer survival and overall survival. There is also evidence that keeping up a moderate level of physical activity, such as taking a daily half hour walk, is beneficial too.

For a healthy diet:

- eat the right amount to maintain a healthy weight
- eat plenty of fresh fruit and vegetables
- eat plenty of foods rich in fibre and starch
- avoid eating too much fatty food
- avoid sugary food and drinks
- avoid alcohol or drink in moderation.

These guidelines are also suitable for people who don't have cancer and can be followed by members of your family. They may reduce the chances of getting heart disease and diabetes as well as certain types of cancer including breast cancer. A summary of the evidence regarding diet, lifestyle and cancer prevention was produced in February 2009 by the World Cancer Research Fund. There is a lot of information available on healthy eating from organisations such as the Food Standards Agency and NHS Direct.

Free resources

Diet and breast cancer – Breast cancer care

Available online at www.breastcancercare.org.uk/information-support/download-order-publications

Healthy eating and cancer (September 2014) – Macmillan Cancer Support

Available online at publications.macmillan.org.uk

Can I drink alcohol?

There is no need to avoid alcohol entirely. However, a number of research studies have indicated that increased alcohol intake may be associated with a slight increase in risk of breast cancer. We would always advise that you should not drink in excess of the Department of Health's recommendations (no more than two to three units of alcohol per day, where a unit of alcohol equals a small glass of wine).

What about sex?

Cancer has many effects and your treatment may have affected your physical ability to give and receive sexual pleasure. It may have changed how you feel about your body, and you might find it difficult to talk to your partner about this. Your partner may also have concerns but talking to each other may help with this. Making love might not be the same as it was before your diagnosis and you may have to find ways of adapting to the changes. It can help to take things slowly at first. Some practical ways to help include trying different positions, and using vaginal lubricants if dryness is a problem. Your breast care clinical nurse specialist will be happy to discuss any of these issues with you.

Support with sex and relationships

Breast Cancer Care – www.breastcancercare.org.uk

College of Sexual and Relationship Therapists – www.cosrt.org.uk

Relate – www.relate.org.uk

What should I do about contraception?

We recommend that you should avoid pregnancy for at least two years after chemotherapy and for the duration of treatment with hormonal therapies. Women who have been treated for breast cancer should not use oral contraceptive pills (the combined pill or mini pill) or hormonal implants. Your GP will be able to advise you about suitable contraceptive methods which include barrier contraceptives (such as condoms and the cap) and intra-uterine devices (the coil).

Dealing with worries about breast cancer returning

Am I cured?

You will find that most doctors do not use the term cured, as this implies that they can give you a 100% guarantee that your breast cancer will never return. Unfortunately, we can never make this promise to any patient.

What is the chance of my breast cancer returning?

The risk that your breast cancer will come back is different for every patient. However, by having the treatment recommended by your surgeon and oncologist you have minimised your personal risk of having any further problems from breast cancer as much as possible.

Will I have any tests to check that the cancer hasn't returned?

You will continue to have regular follow-up mammograms. Research studies have shown us that doing regular blood tests, x-rays or CT scans on women who have no symptoms are not helpful in diagnosing recurrent breast cancer and cause unnecessary anxiety. However, if you develop any new symptoms, the appropriate test or scan will be organised for you once you have been reviewed in the clinic.

I am constantly anxious that my breast cancer will return. What can I do?

It is entirely natural to feel anxious that your breast cancer will return and we recognise that this can make you feel very uncertain about the future and lead to difficulties in getting on with life. Some people find it useful to have some additional support in dealing with these feelings and benefit from counselling. This may be available from your GP, or alternatively let us know and we can refer you to the Wessex Cancer Trust for individual or family counselling.

What sort of symptoms will I get if my cancer returns?

Breast cancer can return almost anywhere in the body. If you experience any of the following symptoms for more than one to two weeks, please contact us to arrange a medical review:

- new lump in or near breast, mastectomy scar, armpit or neck.
- new swelling of the arm
- unexpected weight loss or loss of appetite
- shortness of breath or a persistent cough
- nausea or abdominal pain
- headaches or visual disturbances
- loss of balance
- unexplained bone pain in one or more places

Do remember, however, that all of these symptoms can also be caused by other conditions that are completely unrelated to breast cancer, so please do not become unduly anxious while you're waiting for your review.

Further information and useful contacts

Breast Cancer Now

UK charity committed to fighting breast cancer through research, campaigning and education.

www.breastcancer.org

Breast Cancer Care

Support and information for anyone affected by breast cancer.

Helpline: 0808 800 6000

www.breastcancercare.org.uk

Cancer Research UK

Information, research and details of clinical trials .

Helpline: 0808 800 4040

www.cancerresearchuk.org

Hereditary Breast Cancer Helpline

Support and information for anyone concerned about hereditary breast cancer.

01629 813000

www.breastcancergenetics.co.uk

Look Good...Feel Better

Make up workshops with the aim of enhancing self-esteem and confidence during or after breast cancer treatment.

01372 747500

www.lookgoodfeelbetter.co.uk

Macmillan Cancer Support

Emotional and practical support for people with cancer
Information about cancer types and treatments.

Helpline: 0808 808 0000

www.macmillan.org.uk

NHS Choices

Includes all NHS online service and information, to help you make choices about your health.

www.nhs.uk

Turn2us

UK charity helping people access money that may be available to them – through welfare benefits, grants and other help.

0808 802 2000

www.turn2us.org.uk

Cancerwise

Chichester based drop in support and information centre for people affected by cancer.

01243 778516

www.cancerwise.org.uk

Local contacts

Quitters stop smoking services

Support for people who want to stop smoking.

Hampshire: 0845 602 4663

www.quit4life.nhs.uk

Southampton 0300 123 3791

www.southamptonhealthyliving.org.uk

Southampton Macmillan Cancer Information and Support Centre

B level, Southampton General Hospital:

023 8120 6037

www.uhs.nhs.uk/macmillan

Email: mary.weavers@uhs.nhs.uk

Portsmouth Macmillan Centre

Queen Alexandra Hospital, Portsmouth

023 9228 3323

www.porthosp.nhs.uk/departments/maxtac/Macmillan-Centre/Macmillan-Information-and-Support-Centre.htm

Email: macmillancentre@porthosp.nhs.uk

Health trainers

A free confidential one to one service providing support and encouragement with lifestyle changes.

Southampton: 023 8051 5222

Rushmoor Healthy Living: 01252 362660

If you would like to make a donation to support our work please contact:

Southampton Hospital Charity Breast Fund

Mailpoint 135

Southampton General Hospital

Tremona Road

Southampton

SO16 6YD

Telephone: 023 8120 8881

Charity registration number: 1051543

Some of the sections in this leaflet have been adapted with permission from information by Macmillan Cancer Support.

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone 023 8120 4688 for help.

www.uhs.nhs.uk