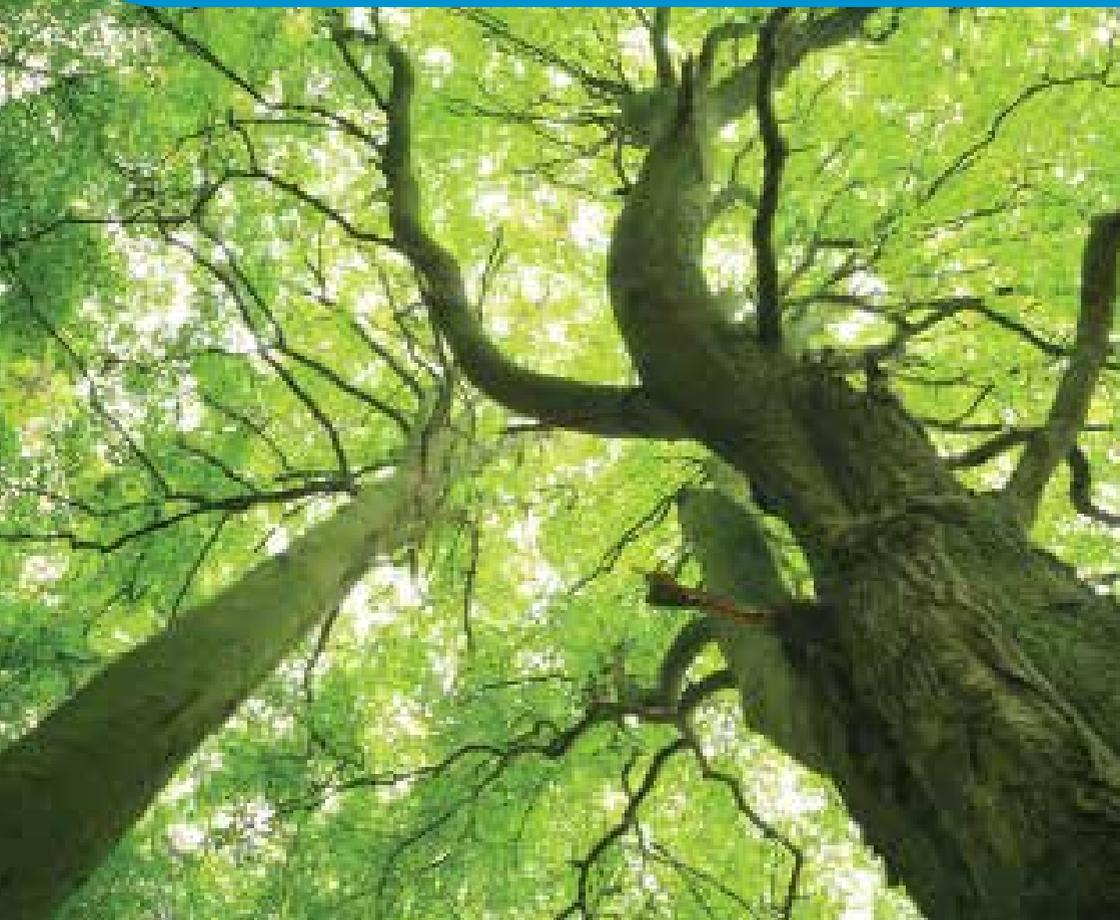




University Hospital
Southampton
NHS Foundation Trust

Southampton breast care support

Your guide to life after breast cancer in men
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 nurse:

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
- New changes in your breasts or chest wall region
- New medical symptoms that you are worried could represent a spread of your breast cancer (see also p.16).

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 (CNS) by the end of the next working day. 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/chest several months after my surgery?

Some men continue to get aches and pains in their breast/chest 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 worsens over a few 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?

This may be due to the healing process and formation of scar tissue after surgery. Gently massaging the scar with a moisturising cream can help to break down the hardened area and even out the scar line. 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 a common post-operative problem known as 'cording'. 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.

I've developed swelling of my arm. Is this normal?

Some men who have had surgery to remove lymph nodes from their armpit, (axillary node clearance or sentinel node biopsy) develop swelling of their 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 CNS who will be able to arrange any necessary review and refer you to a lymphoedema clinic for further advice. You may, for example, benefit from wearing a compression sleeve or from special massage.

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.

Breast reconstruction is generally not recommended for men. However, if you are unhappy with the appearance of your scar or your chest wall after your surgery, please do discuss this with your surgeon as techniques may be available to improve the appearance. Nipple reconstruction may be possible. Alternatively, some men choose to use plastic “stick-on” nipples. Your breast care nurse will be able to provide you with more information about these issues.

Remaining breast aware

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

We recommend that you examine your chest or breasts once a month, so that you are familiar with the way that they look and feel. If you find a new lump or other abnormality within your breast, or near your scar then contact the specialist breast care nurses on:

023 8120 3753

We will arrange for you to be reviewed by your surgeon and then, if required, for you to have an ultrasound of the area.

Recovering from your chemotherapy

How long will I feel tired for?

Most people feel very tired by the end of their chemotherapy. This can get worse if they are then 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 will return to normal and some men still feel tired 12 to 18 months after the end of their treatment. Having Herceptin treatment after your chemotherapy should not affect your recovery from the chemotherapy treatment.

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

Most people 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 after six months your hair should be the same as it was before your treatment. We recommend that you avoid dying your hair for the first six months whilst it is growing back.

Why have I put on weight?

It is quite common for men 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 medicine can increase appetite. Many men 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/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 following 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. Again, please ask your oncology consultant for further information about this. These issues will have been discussed with you before you began your chemotherapy treatment.

Can chemotherapy treatment affect my fertility?

Chemotherapy can reduce or even stop sperm production and therefore may reduce your ability to have children (fertility). Your oncologist will discuss this with you before you start chemotherapy treatment.

Further reading

[Understanding chemotherapy - available from Macmillan Cancer Support](#)

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 and two weeks after the end of 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/ chest. These generally settle within a few months of radiotherapy treatment although can persist intermittently longer term.

Many patients feel tired both during and following radiotherapy. This is generally worse if you also received 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?

Sensible precautions should be taken in the sun. Sunburn should be avoided. The treated area may be more sensitive and should be covered. High factor sun cream should be used, at least factor 20.

Once the skin reaction has settled it is possible to return to activities such as swimming. This is normally possible within a month of treatment finishing.

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, firmer to the touch and the breast may be smaller in size.

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

There is a slightly increased risk of rib fracture in the treated area and a small risk of heart damage following left-sided treatment. 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 or breast/chest wall. This can be made worse by radiotherapy treatment. If you notice any swelling you are advised to contact the breast unit for further advice and possible assessment in our lymphoedema clinic.

Further reading:

[Understanding radiotherapy - available from Macmillan Cancer Support](#)
[Treatment Options – Chemotherapy - available from Wessex Cancer Trust](#)

Hormonal therapy

Why do I have to take hormone tablets?

Tests will have been done on your cancer cells when you were first diagnosed to see if they have hormone receptors. If they do, the breast cancer is likely to respond to hormone therapy. Breast cancer cells can have oestrogen receptors or progesterone receptors. Most male breast cancer cells do have hormone receptors. This is known as being hormone receptor positive. Taking hormone therapy, usually for five years, will significantly further reduce your risk of disease recurrence in addition to the other treatments you have already had.

Are there different types of hormonal therapy?

The main type of hormone therapy used for men is Tamoxifen which is an anti-oestrogen. It acts by blocking oestrogen receptors on tumour cells. Other hormonal therapies for breast cancer are available, such as the aromatase inhibitors anastrozole (Arimidex) and letrozole (Femara). These drugs have been shown to reduce the risk of breast cancer recurrence in post-menopausal women, but more research is required to establish whether they are effective in the treatment of male breast cancer.

What side effects may I experience?

The side effects from Tamoxifen are similar for men and women. You might feel sick when you start taking it, but this usually stops quite quickly. You may also experience hot flushes, weight gain, difficulty sleeping, low mood and depression. Men on Tamoxifen may also experience a loss of sex drive and, sometimes, difficulty in having erections. This side effect generally improves as your body gets used to the drug and disappears once you have stopped taking it. Tamoxifen is associated with a small risk of blood clots. If you are getting troublesome side effects from your hormone tablets, please contact the breast unit to discuss these with your consultant.

Further reading:
Available from Breast Cancer Care
Bone health and Breast Cancer
"Tamoxifen"

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 experience a feeling of "what now?" and 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 7-13).

Where can I find support?

It is difficult for anyone diagnosed with breast cancer, but as male breast cancer is rare it can be particularly difficult to get support, so you might feel rather isolated. If the clinic has not been able to help, you can contact Breast Cancer Care who have male volunteers on their helpline.

Further reading:
Available from Macmillan Cancer Support:
Adjusting to life after cancer treatment
The emotional effects of cancer
Talking about your cancer

When can I return to work?

You can return to work whenever you feel ready to do so. Some men find that they can work throughout their chemotherapy and/or radiotherapy treatment, whilst other men find that they need a recovery period of several months after the end of their treatment before they are ready to return to their job. Whenever you return, remember that it will be a big shock to the system to begin with and it can be very useful to return in a "phased" manner, increasing your working hours over a few weeks.

Further reading:
Work and cancer - available from Macmillan Cancer Support

Can I travel abroad?

Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients can encounter difficulties in acquiring 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 specialising in the cover of patients who have had cancer and will be able to offer advice. www.macmillan.org.uk

Should I exercise?

Most men feel tired for a number of weeks if not months after completing their treatment. However, we recommend that you try to gradually build up your daily activity to at least three twenty minute sessions of moderate activity each week. UK physical activity guidance: www.gov.uk/government/publications/uk-physical-activity-guidelines

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 a healthy diet is balanced and varied and provides all the right nutrients needed.

There is evidence in women that following a diagnosis of breast cancer maintaining a healthy weight and avoiding excessive weight gain is associated with an improved breast cancer survival and overall survival. There is also evidence that maintenance of a moderate level of physical activity, for example taking a daily half hour walk is beneficial too.

The main things to consider in a healthy diet include:

- 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 suitable for people who don't have cancer and can be followed by members of your family too. 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 www.nhs.uk.

Further reading:

Diet and breast cancer - available from Breast Cancer Care
Diet and cancer - available from Macmillan Cancer Support

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?

We recommend that you should avoid having children for at least two years after completion of chemotherapy treatment and for the duration of treatment with hormonal therapies. If you are hoping to have children after treatment for breast cancer, please make an appointment to discuss this with your consultant as they will be able to advise you about the best time to start trying.

A very small number of men develop sexual problems once they have been diagnosed with cancer. This might be an emotional reaction to being diagnosed with cancer, and talking with your partner might help.

You might experience any of the following:

1. Loss of interest in sex
2. An inability to have an erection
3. An inability to keep an erection during sex or intimacy
4. Ejaculation without producing semen

You can be referred to a counsellor if necessary. To get a referral call the Breast CNS team or speak to your GP.

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?

Research studies have shown us that doing regular blood tests, x-rays or CT scans on men 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 two to three 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 whilst awaiting your review.

Further information and useful contacts

Breakthrough Breast Cancer

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

www.breakthrough.org.uk

Breast Cancer Care

Support and information for anyone affected by breast cancer.

Helpline: 0808 800 6000

www.breastcancercare.org.uk

Breast Cancer Haven

Support, information and free complementary therapies for anyone affected by breast cancer.

0207 384 0099

www.breastcancerhaven.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.breastcancer genetics.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 UK

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

Health trainers

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

Southampton: 023 8051 5222

Havant Council of Community Services: 023 9241 5563

Gosport Voluntary Action: 023 9241 5563

Rushmoor Healthy Living: 01252 362660

Quitters stop smoking services

Support for people who want to stop smoking.

Hampshire: 0845 602 4663 www.quit4life.nhs.uk

Southampton Macmillan Cancer Information and Support Centre

B level, Southampton General Hospital:

023 8120 6037

www.uhs.nhs.uk/macmillan

Email: macmillancentre@uhs.nhs.uk

Portsmouth Macmillan Centre

Queen Alexandra Hospital, Portsmouth

023 9228 3323

www.porthosp.nhs.uk/macmillan

Email: macmillancentre@porthosp.nhs.uk

Wessex Cancer Trust

Local charity providing information, counselling, complementary therapies

023 8067 2200

www.wessexcancer.org

Breast care team/breast unit

Telephone: **023 8120 3753**

University Hospital Southampton NHS Foundation Trust

Tremona Road
Southampton
SO16 6YD

Southampton Hospital Charity breast fund enhances the support, care and treatment of patients at University Hospital Southampton. If you would like to support us please call **023 8120 8881** or visit **www.southamptonhospitalcharity.org**

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