



Cancer survivorship information for survivors and carers



Follow-up of survivors of breast cancer

This fact sheet is for people who have completed treatment for early stage breast cancer. It explains why follow-up appointments are important and possible effects from treatment. You may know that when breast cancer is found and treated early, the outcome is often very good.

In Australia:

- 5-year survival for women with breast cancer is about 87.7%. This means that for a women treated for breast cancer, nearly 88 will still be cancer free 5 years later.
- 10-year survival is about 79.4%. This means that for every 100 women treated for breast cancer, nearly 80 will still be cancer free 10 years later.

For some women treated for early stage breast cancer, there is a small chance the cancer could come back (recur).

Your doctor will schedule regular follow-up appointments to check on your health and look for any signs of breast cancer recurrence.

Your doctor will also talk to you about possible effects from your breast cancer or treatment.

Potential issues

As a breast cancer survivor, you may have physical, emotional, social and practical concerns after completing treatment. Care from your health care team should address all of these issues.

Your medical care should include:

- good communication between your cancer specialist and GP about your health needs
- looking for any signs of cancer spread, recurrence or second primary cancers
- treating any side effects or late effects from your cancer and treatment

- advice about preventing new cancers and reducing your risk of your cancer recurring.

If cancer does come back, it tends to happen within 5 years after diagnosis. Sometimes, this can happen more than 20 years after the first diagnosis.

Follow-up frequency

Everyone who has been treated for breast cancer should be followed up.

Your doctor will use breast checks, mammography and possibly other scans to look for signs of recurrence.





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Example follow-up schedule for women treated for early breast cancer

Type of follow-up	Years 1 and 2	Years 3–5	After 5 years
History (talking about your health) and physical examination	Every 3–6 months	Every 6–12 months	Every 12 months
Mammography (if you had breast conserving therapy)	Every 12 months	Every 12 months	Every 12 months
Chest X-ray, bone scan, CT, PET or MRI scans, blood count, biochemistry and tumour markers	These tests may be ordered if your doctor suspects recurrence but are not recommended routinely		

Note: this schedule may vary, for example if your doctor suspects recurrence or if you have another illness.

When to contact your doctor

Contact your doctor if you notice a breast change or any other symptom that concerns you. You don't have to wait for your follow-up appointment.

Contact your doctor if you notice:

- unexplained persistent changes in your general condition (such as loss of weight, loss of appetite, loss of energy)
- unexplained persistent pain or discomfort
- any symptom that concerns you.

Coordinating follow-up

It is very important that your follow-up is properly coordinated and you do not attend excessive appointments.

Your specialist and GP should consult and decide on who will coordinate your follow-up.

Ideally, this will be documented on a survivorship care plan. If you don't have a survivorship care plan, please ask your GP, specialist or cancer nurse who should be able to provide this for you.

Possible long-term effects and late effects of treatment

Not everyone will have long-term or late effects. If you have had treatment for breast cancer, this does not mean you will get all or even any of the effects described here. Long-term and late effects will vary depending on the stage of your breast cancer as well as the treatment you had. Some effects from treatment for breast cancer are more common than others. Some are rare. Some will become less severe over time and disappear completely whilst others may be permanent. Please speak to your doctor if you have any concerns about effects from your cancer treatment.





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Possible long-term effects and late effects of treatment

All common cancer treatments (surgery, chemotherapy, hormone therapy, Trastuzumab (Herceptin®) or radiotherapy) can cause both long-term and late effects. Possible long-term and late effects following treatment for breast cancer and their causes include:

Long-term and late effects	Cause
Fatigue (extreme tiredness that isn't helped by sleep or rest)	Sometimes occurs following treatment, however the reasons are not clear May be associated with anxiety or depression
Heart problems	Can be caused by some chemotherapy drugs and Trastuzumab (Herceptin®)
Lymphoedema (persistent swelling in the limb)	Can occur when underarm lymph nodes are surgically removed or treated with radiotherapy
Premature menopause	Due to chemotherapy, radiotherapy to ovaries or surgical removal of ovaries, tamoxifen or aromatase inhibitor drugs
Endometrial cancer, stroke or blood clots	Rare complications of tamoxifen
Pain	Surgery or radiotherapy
Sexual problems	Premature menopause or vaginal dryness from treatment Cancer treatment can affect a person's libido, self-image and sexual confidence
Fertility problems	Due to chemotherapy, radiotherapy to ovaries or surgical removal of ovaries, tamoxifen or aromatase inhibitor drugs
Bone density problems, increased risk of fractures	Due to chemotherapy, high dose steroids, radiotherapy to ovaries or surgical removal of ovaries, tamoxifen or aromatase inhibitor drugs
'Chemo brain' or 'Chemo fog', which may include poor concentration and forgetfulness	It is common in people who have had chemotherapy but is not well understood
Unhappiness with changes in appearance	Mastectomy (with or without reconstruction) or other breast surgery
A second primary cancer	May occur rarely due to radiotherapy or chemotherapy

Further information related to effects of treatment for breast cancer

- Your doctor will tell you if there is a risk of heart problems due to chemotherapy. Your doctor will recommend regular long-term checks of your heart and advise you about smoking, alcohol, exercise and diet.
- Lymphoedema may occur years after treatment. If your underarm lymph nodes were removed during surgery or affected by radiotherapy, you need to take special care to avoid injury to your hand and arm. Be alert for any arm changes and report these.
- A small number of women have a genetic change called a 'BRCA mutation'. If this affects you and your family, your doctor will discuss referral to a family cancer clinic for advice about prevention and screening.
- You may have particular needs if your fertility has been affected, if you require contraception or find it difficult in dealing with changes in sexuality. Your doctor may suggest that you see a fertility or menopause specialist or sexual counsellor.
- Depression, anaemia, pain and an underactive thyroid can all contribute to fatigue and can be treated.
- If you are at risk of low bone density your doctor may suggest having regular bone scans. Your doctor may also discuss prevention strategies such as weight-bearing exercise, giving up smoking, and treatment with calcium and vitamin D supplements. Some people may be prescribed bisphosphonate drugs (medications that prevent loss of bone density).
- You may begin or continue to have fears about the future. You may be feeling worried, sad or unable to get through the day. Many of these feelings are normal when adjusting to life after a cancer diagnosis and usually lessen with time. You may find it helpful to attend a support group and/or speak with a fellow survivor. Contact via the Cancer Council Helpline (13 11 20). If you feel low in mood or depressed for long periods, it is important that you speak to your doctor and get treatment.



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Getting help and support

Any change in how your body looks, feels or functions can be very hard to deal with. Certain late or long-term effects may be annoying but manageable. However others can be more severe and have a big effect on your quality of life.

There are things that can be done to help control or treat many long-term and late effects from treatment for breast cancer. It is important you find the right support to help you manage and cope with any side-effects you have or may develop.

For you and your partner, there may be relationship effects, including issues about changed roles, fear of recurrence of breast cancer and fear of 'being a burden'.

Survivors who go through and beyond cancer treatment without partners or close family and friends may experience great loneliness.

Speak with your doctor or specialist nurse about how you are feeling. Support groups and/or contact with a fellow survivor through a service such as Cancer Connect may be helpful. Contact via the Cancer Council Helpline (13 11 20).

Staying well

Having cancer and treatment often makes people think about their health in different ways. Some people decide they want to live a healthier lifestyle than they did before getting cancer. Some people look for ways to reduce the chance of their cancer coming back and preventing a new cancer developing. It's a great time to make some changes and commit to staying healthy.

This includes:

- having a healthy diet
- maintaining a healthy weight
- stopping smoking
- increasing physical activity (most people need to do at least 30 minutes of moderate-intensity physical activity on most, preferably all, days).

These simple measures may help to prevent secondary, recurrent or a new primary breast cancer. They may also reduce many of the physical and emotional effects of cancer treatment.

Further information

Lymphoedema Association of Victoria

 The Lymphoedema Association of Victoria is a non-profit organisation working towards increased awareness, education, research and support for those with lymphoedema. Phone: 1300 852 850
www.lav.org.au

Cancer Australia

 In July 2011, National Breast and Ovarian Cancer Centre (NBOCC) and Cancer Australia amalgamated to form a single national agency to provide leadership in cancer control and improve outcomes for Australians affected by cancer. They provide comprehensive, easy to read information to help women with breast or ovarian cancers understand their diagnosis, treatment and support options. Freecall: 1800 624 973
www.canceraustralia.gov.au

The Australian Cancer Survivorship Centre – A Richard Pratt Legacy

 The Australian Cancer Survivorship Centre – A Richard Pratt Legacy is a web-based centre. It is funded by Peter MacCallum Cancer Centre, The Pratt Foundation and the Victorian Department of Health. The Australian Cancer Survivorship Centre aims to help improve services and care for cancer survivors in Australia as well as focusing on increased awareness, especially about issues that affect survivors after their treatment ends.

Screening

It's important to have screening for other cancers.

- Have regular Pap tests.
- If you are over 50 years, talk to your doctor about screening for bowel cancer.
- If you are at increased risk of ovarian cancer, your doctor may refer you to a family cancer clinic.

You will have mammography as part of your follow-up. You do not need to respond to invitations from BreastScreen.

In addition:

- Have your usual cholesterol, blood pressure and blood glucose checks.
- Have regular dental examinations.
- Take care to protect your skin from the sun.

The information on this site is divided into four sections: Health Professionals, Survivors, Family & Friends and Research. There are links to useful information and reliable websites.

www.petermac.org/cancersurvivorship

Breast Cancer Network Australia

 The role of this website is to 'empower, inform, represent and link together' Australians personally affected by breast cancer. BCNA work to ensure that Australians diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible, no matter who they are or where they live. Freecall: 1800 500 258
www.bcna.org.au

Cancer Council

 Contact the Cancer Council Helpline on 13 11 20 for information about side effects from treatment, or any other questions you have about cancer and surviving cancer. Cancer Council booklets include 'Living well after cancer: a guide for cancer survivors, their families and friends'. Call the Cancer Council to find out about Life after Cancer forums. Through the Cancer Council Helpline you can speak with a cancer nurse: ask about Family Cancer Connect and support groups and other support services that may help you. Cancer Connect is a free phone peer support service that puts people in touch with others who've had a similar cancer experience.

www.cancer.org.au

All of these services may be accessed through their websites

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



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