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# Surgery

## Summary

- Surgery is uncommon for secondary breast cancer.
- Surgery may be used to treat breast cancer that has spread to the bones, lungs or brain, or more rarely the liver.

## When is surgery recommended?

The aim of treatment for secondary breast cancer is to destroy cancer cells that are circulating in the body or that have spread to areas of the body outside the breast. Surgery is not routinely used in the treatment of secondary breast cancer but may have an important role for some women as a way of controlling the disease or reducing symptoms in particular parts of the body.

Some of the situations in which surgery may be recommended are listed below.

## If cancer is in the breast

If secondary breast cancer is your first diagnosis of breast cancer, you will usually have a biopsy of the cancer in your breast to confirm the diagnosis and find out what receptors are on the breast cancer cells. This biopsy can usually be done under local anaesthetic. It is often not necessary to remove all of the cancer from the breast. **If you feel uncomfortable about leaving the breast cancer in your breast, talk to your doctor about surgery to remove the cancer.**

In some situations, your doctor may recommend removing all of the cancer from the breast. This will be done under a general anaesthetic.



**Biopsy:** removal of cells or tissue from the body for examination under a microscope.

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Radiotherapy to the breast after surgery and removal of lymph nodes from the armpit are not usually recommended for women with secondary breast cancer.



### **If cancer is in the bone**

If secondary breast cancer has spread to the bone, surgery can be used to:

- prevent or treat a fracture
- replace a joint that has been damaged by cancer
- remove cancer in or around the spine that is putting pressure on the spinal cord.

Surgery to the bone is often followed by radiotherapy.

### **If cancer is in the lungs**

If secondary breast cancer has spread to the lungs, surgery can be used to:

- remove fluid from the pleural cavity
- treat cancer in the pleura that is not being controlled by other cancer therapies.



**Pleura:** the membrane that lines the rib cage and covers the lungs.

**Pleural cavity:** the space between the membrane that lines the rib cage and covers the lungs.

There are different types of surgery to manage cancer in the pleura. These are listed below. Some techniques can be carried out under local anaesthetic while others will require a general anaesthetic. Ask your surgeon to explain whether any of these types of surgery are recommended for you and what will be involved.

- **Pleural drainage** — involves using a needle to drain fluid from around the lungs. This will relieve breathlessness but usually symptoms will come back if the fluid returns. This procedure can be repeated as needed.

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- **Tube thoracotomy** — involves inserting a tube into the pleural cavity and leaving it there to drain the fluid. Once the fluid has drained, drugs can be used to harden the pleura and stop fluid from leaking into the pleural cavity.
  - **Thoracoscopy and talc insufflations** — involve inserting an instrument called a thoroscope into the pleural cavity, which allows the surgeon to look into the cavity. The fluid is drained and talc is sprayed into the pleural cavity, which makes the pleura harder and stops fluid leaking into the pleural cavity.

### **If cancer is in the brain**

If secondary breast cancer has spread to the brain, surgery may be used to remove the cancer. This is usually only appropriate if the cancer is small and in one area of the brain. Surgery to remove cancer from one area of the brain is usually followed by radiotherapy.

Surgery may also be used to drain fluid from the brain.

### **If cancer is in the liver**

If secondary breast cancer has spread to the liver surgery is rarely performed. This is usually only appropriate if one isolated area of the liver is affected.

### **Other reasons for surgery**

Surgery may be used to treat other symptoms of secondary breast cancer. These include:

- cancer that has grown through the skin
- cancer that has blocked the bowel
- cancer that is pressing on nerves in the body causing nerve pain.

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## What does surgery involve?

The length of your operation and your stay in hospital will depend on the type of surgery you have. If you live in a rural or regional area, you may have to travel for surgery. If you need to travel long distances for surgery, you may be able to get some help with the costs of your travel and accommodation.



For information about financial support for breast cancer treatment, see the 'Finding support' section.



## Questions to ask about surgery

Listed below are some questions you might want to ask a member of your healthcare team about surgery.

- Do I need to have surgery?
- What will surgery involve?
- What are the benefits to me of having surgery?
- Will I have scars after surgery? Where will they be and what will they look like?
- How long will I be in hospital?
- How long will I take to recover from surgery?
- What side effects can I expect?
- Whom should I contact if side effects happen?
- How much will the surgery cost?
- What difference will surgery make to the quality of my life?

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## Frequently asked questions

### **If secondary breast cancer is my first diagnosis of breast cancer, why is surgery to the breast usually not recommended?**

When cancer is confined to the breast, the priority for treatment is to remove the cancer and stop cancer cells from spreading to other parts of the body. Once cancer has spread outside the breast, the priority becomes controlling the cancer in the different parts of the body that are affected and slowing the further spread of the cancer. For many women with secondary breast cancer, the cancer in the breast does not cause major symptoms or health problems. Surgery to the breast will not usually help to treat the cancer overall and may actually delay the other more useful treatments such as chemotherapy. However, in certain specific circumstances, surgery to remove the cancer in the breast may be recommended.

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# Palliative care

## Summary

- Palliative care improves quality of life for people who have a disease that cannot be cured.
- Palliative care is not just for people who are dying, but can begin soon after a diagnosis of secondary breast cancer.
- Palliative care provides pain control and treatment of other symptoms.
- Palliative care also provides emotional, spiritual and social support to patients and their families.

## What is palliative care?

Palliative care is specialised care for people who have a disease that cannot be cured. It focuses not only on helping to control physical symptoms such as pain, but also on emotional wellbeing, relationships with others and spiritual needs. In later stages, palliative care can also help people to prepare for death.

Palliative care includes more than care for people who are dying. Any treatment you have for secondary breast cancer that helps to relieve your symptoms and improve your day-to-day life can be called palliative care.

You can continue to have treatment from the rest of your healthcare team while you are receiving palliative care.

***“I didn’t like the idea about being referred to palliative care when I had only just been diagnosed with secondary disease but I found it really helped. They told me how to apply for financial assistance and they gave me helpful suggestions about how to control the pain under my shoulder.”***

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## Who provides palliative care?

Palliative care includes care at home or in hospitals, hospices or specialist palliative care units. The palliative care team works with the other health professionals involved in your care.

Palliative care might involve:

- a palliative care specialist
- a local general practitioner with skills in palliative care
- a palliative care nurse
- palliative care volunteers
- allied health professionals, such as a dietitian or occupational therapist
- social workers
- counsellors.

***“The palliative care team were very friendly and very helpful. They explained to me it wasn’t just for people who were dying. It was more pain relief.”***

## What does palliative care involve?

Palliative care is available for anyone who has a progressive life-limiting disease. The care required is determined by an individual patient’s needs. Services are available that are age and culturally appropriate. Your palliative care team will work with you to help to provide care that is most helpful for you and those close to you.

A specialist palliative care service can provide:

- pain and symptom relief by providing medication and information about drugs
- practical advice and support for you and your family/carers
- temporary respite care to give your carers some ‘time out’



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- counselling and support groups for you and those close to you
  - support with spiritual issues through referral to appropriate resources
  - support in helping you and those close to you prepare for the later stages of your disease, including understanding your preference for where you would like to die
  - bereavement support for families and carers.

### **When can I access palliative care?**

You can ask your doctor to refer you to a specialist palliative care service at any point after your diagnosis of secondary breast cancer. Palliative care may be particularly helpful if you decide you no longer wish to have active treatment to control your cancer. However, there are benefits in making contact with a specialist palliative care service, even when you are relatively well. **Making contact with a palliative care service does not mean you cannot continue to have treatments recommended by your doctor.**

Your doctor may decide to consult a palliative care specialist to get advice about how to manage your symptoms even while you are having active treatment. This should occur if you have any symptoms that are difficult to control. **Ask your specialist or general practitioner to refer you to a specialist palliative care service if you feel you would benefit from the extra support and information.**

You may be able to consult a palliative care specialist at a hospital clinic. If you are not well enough, a member of the palliative care team may visit you at home. If you are in hospital or in a hospice, they may visit you there.

***“I thought that once you had palliative care you were going to die. I didn’t realise that they could come in when you were in a crisis situation and then as you got better they went out.”***



Palliative Care Australia has a directory of palliative care services in Australia as well as a list of organisations in each State and Territory who can provide more information about palliative care. For more information, visit the Palliative Care Australia website at [www.palliativecare.org.au](http://www.palliativecare.org.au).



### Questions to ask about palliative care

Listed below are some questions you might want to ask a member of your healthcare team about palliative care.

- Would palliative care be helpful for me and/or my family?
- Can you refer me to a palliative care service?
- What support can palliative care provide?

You may like to write your own questions here:

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## **Frequently asked questions**

### **Do I have to be in a hospice or hospital to have palliative care?**

No. Palliative care can be provided for you as an outpatient through a clinic, at home or in a hospital or hospice.

### **Does palliative care mean I am dying?**

No. Palliative care can be provided to anyone who has an illness that cannot be cured.

### **If I have palliative care, does that mean that my other treatments will stop?**

No. Palliative care can be provided at the same time as active treatment.

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# Clinical trials



## Summary

- Clinical trials are studies used to find new ways to prevent, diagnose or treat diseases.
- You may or may not be eligible to take part in a clinical trial.
- If you are invited to join a clinical trial, you should weigh up the benefits and risks of taking part.

## What are clinical trials?

Clinical trials are studies carried out to help to find new ways to prevent, diagnose or treat diseases.

Clinical trials with cancer patients try to find out whether new approaches to cancer prevention, diagnosis and treatment are safe and effective.

Many clinical trials about breast cancer involve people in Australia and overseas. Major improvements in breast cancer treatments are always first tested in carefully conducted clinical trials.

Every clinical trial must be approved by an **ethics committee**.



**Ethics committee:** a group of experts who review clinical trial protocols to make sure that the rights of the patients involved are protected.

In a clinical trial, there are usually two groups of patients:

- those who receive the newer treatment (**the intervention group**)
- those who receive the standard treatment (**the control group**).

Standard treatment is the currently recommended treatment. Two groups of patients are needed, to see whether the newer treatment is better than the standard treatment.

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If you take part in a clinical trial, you will not be able to choose whether you have the newer treatment or the standard treatment.

### **How do I decide whether to take part in a clinical trial?**

To join a clinical trial, you must meet certain criteria. For example, a trial may be for women in a particular age group, or for women who have had certain treatments. If you meet the criteria, your doctors may invite you to join the trial.

**If you are invited to join a clinical trial, you need to weigh up the risks and benefits of this decision.**

You will not have to pay any additional costs to be in a clinical trial. Your treatment and care will not be affected should you decide not to take part.

Advantages of joining a clinical trial include:

- you may receive a newer treatment that is not yet available to the general public
- the newer treatment may be more effective than standard treatments
- the progress of your treatment will be monitored closely
- you will also be helping other women who are diagnosed with secondary breast cancer in the future.

Disadvantages of joining a clinical trial include:

- you cannot choose which treatment you have
- if you are in the control group, you will not receive the newer treatment
- the newer treatment might not be more effective than standard treatments
- the newer treatment might have more or different side effects to standard treatments
- you may need to have more tests during and after treatment than with standard treatments
- you may be asked to fill in more forms and surveys than with standard treatments.

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It is up to you whether you choose to join a clinical trial. If you decide to join a clinical trial, you will be asked to sign a consent form. You can withdraw from the trial at any time. If you decide not to join a clinical trial, or if you withdraw from one, you will receive the standard treatment and care available. **The quality of your care and treatment will not be affected should you decide not to take part in, or withdraw from a clinical trial.**

**If you are interested, ask your doctors about any clinical trials that are suitable for you.**



Several different organisations have information available on their websites about clinical trials for breast cancer in Australia. These include:

Cancer Australia  
[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)

The Australian and New Zealand Clinical Trials Register  
[www.anzctr.org.au](http://www.anzctr.org.au)

The Australian and New Zealand Breast Cancer Trials Group  
[www.anzbctg.org](http://www.anzbctg.org)

The Trans-Tasman Radiation Oncology Group  
[www.trog.com.au](http://www.trog.com.au)



### **Questions to ask about clinical trials**

Listed below are some questions you might like to ask a member of your healthcare team about clinical trials.

- What is the purpose of the trial?
- What treatments or tests does the trial involve?
- What treatments or tests will I have if I do not join the trial?
- What are the advantages and disadvantages of joining the trial?
- What are the possible side effects of the treatment or tests being studied in the trial?

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- What are the possible side effects of the treatments or tests I will have if I *do not* join the trial?
  - What follow-up tests will I have if I join the trial?
  - Have the treatments being tested been used before to treat other types of breast cancer?
  - Have the treatments been used before to treat other cancers?
  - Can I leave the trial at any time?
  - Are there any costs involved if I join the trial?

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## Frequently asked questions

### How do I know what the clinical trial involves?

Your doctor will give you information about the trial. If the trial involves a new drug, it will have undergone some tests and checks before the trial started. Ask your doctor about what tests have already been done and how many other people are involved in the trial.

### Will I need extra tests if I agree to join a clinical trial?

If you agree to join a trial, you may need to have some extra tests during and after your treatment. This may involve blood tests or other checks so that your doctor can record what effect the treatment is having. Your doctor will explain what tests are involved before you decide whether to join the trial. You will not be charged for additional tests used as part of a clinical trial.

### If I agree to take part in a clinical trial, can I change my mind later?

Yes. You can change your mind at any time.

### Whom do I contact if I have a complaint about a clinical trial?

If you have a complaint about a clinical trial you have joined, you can contact your local ethics committee. Ask your doctor or nurse for more information. The details about whom you can contact should also be included in the information provided to you when you joined the clinical trial.

### Can I ask to see the results of the trial?

If you join a clinical trial, you have a right to access the results when they are published, although depending on the length of time that the trial runs for, it may be a number of years before the results are available. Ask your doctor or nurse for more information.

### What are the phases of clinical trials?

The 'phase' of a clinical trial refers to how much is known about the new treatment/test.



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- A phase I trial is the first time a treatment is tested in humans. Phase I trials usually involve a small number of healthy volunteers or patients and a range of doses to test how the body responds to the treatment and to look for side effects.
  - A phase II trial tests the effects of a drug in people with a particular disease. These trials usually involve small numbers of patients and are used to work out the correct dose of the treatment and how effective it is in the short term.
  - A phase III trial compares the effect of a new treatment with the current standard treatment and usually involves a large number of patients in several different countries.
  - A phase IV trial is a trial or study of a drug that is already approved. Phase IV studies check how well a treatment works over a longer period of time and monitor long-term side effects.

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# Complementary and alternative therapies



## Summary

- Complementary therapies are a range of approaches to care aimed at enhancing your quality of life and improving your wellbeing. Complementary therapies may be used alongside conventional treatments for cancer.
- Alternative therapies are approaches to care that are used instead of conventional treatments for cancer. There is no evidence to support the use of alternative therapies in the treatment of breast cancer.
- There is no evidence that complementary therapies can remove breast cancer, or stop it from growing or spreading.
- It is important to tell your doctor about any complementary therapies you are taking or are planning to take.

## What are complementary and alternative therapies?

Complementary therapies are a range of approaches to care aimed at enhancing quality of life and improving wellbeing. They may be used alongside conventional treatments such as hormonal therapies, chemotherapy or radiotherapy.

Complementary therapies may include acupuncture, relaxation therapy, meditation, gentle exercise, guided imagery, music or art therapy, massage, aromatherapy, vitamins, dietary therapies and some support group programs.

You may also hear people talk about alternative therapies. These are therapies that are taken instead of conventional approaches to treatment. When cancer has spread and you have been told that a cure is unlikely, you may feel that conventional medicine has failed you. However there is no evidence that the use of alternative therapies results in better outcomes than standard treatments.

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***“In moments of stillness I have come to realise that I am already whole, already complete in my being, even if I have cancer or pain, even if I do not know how long I will live or what will happen to me.”***

### **What is the evidence about complementary therapies?**

There is evidence that some complementary therapies can improve the wellbeing of people with cancer. For example:

- relaxation techniques and guided imagery can reduce feelings of anxiety, stress or depression
- exercise can improve feelings of fatigue and distress
- relaxation techniques, guided imagery, massage and reflexology can relieve pain and some side effects caused by cancer and its treatments.

These therapies are encouraged by health professionals and are part of clinical practice guidelines.

Healthy living, including a good diet, exercise within limits, enough sleep and relaxation and effective management of stress is important for everybody.

***“I’ve changed my eating habits but you also have to be happy. If you’re eating this really stringent diet that’s so good for you and you feel miserable about it, it is no good for you overall. So I’ll go out and have my cappuccino and a nice piece of cake and enjoy it...but not often.”***

However, it is important to note that a number of complementary therapies have not been tested in clinical trials so we do not know how effective they are or what their long-term side effects might be. Some therapies can interact with conventional treatments and make them less effective. Others may actually be harmful if taken with conventional treatments. **It is important that you talk to your doctor before starting any complementary therapies to check that they will not interact with your treatments.**

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There is no evidence that complementary therapies can remove breast cancer, prevent it from growing or from spreading to other parts of the body.

***“I have realised that I am not my cancer and I have made a commitment to living each moment of my life as fully as possible, and to use my cancer to help me rather than shower blame on myself for having it.”***



Cancer Council NSW has produced a booklet about complementary therapies and cancer. To download a copy of *Understanding Complementary Therapies*, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

Memorial Sloan Kettering Hospital in the USA has developed a website with information about complementary therapies. The website describes what is currently known about a range of herbal products and supplements. To access this information, go to [www.mskcc.org](http://www.mskcc.org). Please note that this is a USA website and not all of the products listed may be available in Australia.



### **Questions to ask a complementary health practitioner**

Before you decide on any course of treatment or activity, it is important to be well informed. You should also feel confident about the training of any complementary health practitioner. Questions you may want to ask include:

- What is your training?
- Exactly what is the therapy you are proposing?
- What do you hope it will do?
- What is the evidence for the success of this therapy?
- What side effects could there be?
- How common are the side effects?

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- Will this therapy affect other treatments I am receiving?
  - How much will this therapy cost?

It is also important to ask the doctor(s) who are providing your conventional treatment whether the complementary therapies you are considering could interact with the conventional treatments you are receiving.

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## Frequently asked questions

### **Can I take complementary therapies at the same time as my conventional treatments?**

Some complementary therapies are encouraged by health professionals. These include relaxation therapy, guided imagery, meditation and gentle exercise. Some complementary therapies may be harmful if taken at the same time as conventional treatments, such as some vitamins. It is important that you tell the health professionals managing your care about any treatments you are taking or involved in.

### **What is the difference between complementary and alternative therapies?**

Complementary therapies are therapies or treatments that are used alongside conventional medicine. Alternative therapies are therapies or treatments that are used instead of conventional medicine.

### **Can complementary or alternative therapies be used to treat or prevent breast cancer?**

There is no evidence that complementary or alternative therapies can remove breast cancer, stop it from coming back or stop it from spreading to other parts of the body.

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**Notes:**

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# Symptoms and side effects



This section explains what you can do to help to control pain and other symptoms of secondary breast cancer. It also includes some information about side effects of treatment, including effects on fertility and menopause.

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# Managing pain

## Summary

- Not everyone with secondary breast cancer experiences pain, and pain does not always get worse with time.
- Cancer pain can usually be controlled using medical and non-medical treatments.
- The treatments recommended to manage your pain will depend on the type of pain, how severe it is and what other symptoms you have.
- If one type of pain relief stops working, there are others you can try.
- It is important to tell the people managing your care about any new pain or if pain gets worse.
- You may find it helpful to keep a diary to help you to describe your pain to your healthcare team.

## Will my secondary breast cancer be painful?

Secondary breast cancer affects different women in different ways. Some women have no pain, others find that pain affects them at certain times of the day or night or while doing different activities. Pain caused by secondary breast cancer does not always get worse with time.

The type and level of pain experienced by one woman may not be the same as that for another woman with cancer in the same parts of the body. Not everyone with secondary breast cancer finds it painful.

**Cancer pain can usually be controlled. It is rare to have cancer pain that cannot be lessened or changed.**

***“That’s the way I think now — quality of life is number one.”***

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## What causes pain?

Understanding the reasons for cancer pain can help your healthcare team to work out the best way to manage the pain. There are a number of different reasons for cancer pain, including:

- cancer pressing on nerves or soft tissue in the body
- side effects of treatment, such as radiotherapy or surgery
- a bone fracture
- cancer in the bone
- infection
- a blood clot caused by cancer or its treatment
- a blockage in the bowel.

You might also have pain due to other medical conditions that have nothing to do with the cancer.

**If you have pain, it does not mean that the cancer is more serious than if you did not have pain.**

Any pain can be difficult to cope with. However, it can be harder to cope with pain if you are anxious or depressed. If you are feeling anxious, depressed or down on a regular basis, talk to a member of your healthcare team. Managing your emotional health can help you to manage your physical symptoms.



For more information about your feelings, see the 'Finding support' section.

***"The human spirit is a remarkable thing I've realised."***

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## How to report pain

Many people do not like to complain about pain. However, it is important that you tell the people managing your care about any pain you are experiencing — even if it is minor. Reporting your pain means that your doctor can find out what is causing it and recommend the best way of managing the pain.

**Always tell a member of your healthcare team about any new pain or if your pain gets worse. Cancer pain can usually be controlled.**

When you describe your pain, try to give as much information as possible. The table below lists some questions that will help you to describe your pain. You may find it helpful to keep a diary, noting the times of the day when your pain gets better or worse. This can help you to describe your pain to your healthcare team.

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## Questions to help you to describe pain

Question	What to think about
Where is the pain?	Is it in one part of your body or more? Does it start in one place and spread during the day?
What is the pain like?	What words best describe the pain? Is it a dull ache or throb? Is it a sharp, stabbing pain? Is it more like a burning feeling or pins and needles?
How bad is the pain?	How does the pain compare with pain you have had before — for example, period pain, headache, a sports injury or childbirth?  How would you rate the pain on a scale of 1–10 (where 10 is the worst pain you can imagine)?  Does the pain keep you awake or wake you up at night?
Does anything make the pain better?	Do you feel more comfortable if you sit or lie in a particular position?  Does a hot water bottle or ice pack help?  Does the pain get better if you take a painkiller like paracetamol?  Can you distract yourself with music or a good book?
Does anything make the pain worse?	Does it hurt more if you are moving around or sitting in a particular position?
Is the pain there all the time?	Does the pain come and go? Is the pain worse at night?

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## Treatments for pain

### Drug treatments

There are many drugs available to manage different types of pain. Everyone is different in how they respond to pain relief. It may take a while for your doctors to find the treatment or combination of treatments that are right for you.

If your pain comes and goes, you might only need to take painkillers from time to time. If you have pain all the time, you should take painkillers at regular intervals. Do not wait until the pain comes back before taking the next painkiller. The important thing to remember with pain relief is that it is best to take it when you first start to feel uncomfortable and to keep taking it at regular intervals. It is better to prevent pain rather than waiting until it comes back.

Listed below are some of the most common drugs used to control pain. More information about some of these drugs is provided later in this section. It is not possible to list all of the drugs used to control pain or to list all of the possible side effects. Talk to your doctor about the drugs most suitable for you and their side effects.

**Do not start or change any pain relief medication without consulting your doctor.**

Addiction to painkillers is very unlikely in women with secondary breast cancer. The dose of the drugs you take can be increased or decreased according to your needs.

Type of drug	Examples	Can be useful for:	Things to note
Paracetamol	Panadol®, Panamax®	Mild-to-moderate pain  For example: mouth ulcers, ulcers in the skin, cancer in the bone	Take no more than eight painkillers containing paracetamol per day unless told to do so by your doctor  Can be used with stronger pain drugs for moderate or severe pain
Non-steroidal anti-inflammatory drugs (NSAIDs)	Aspirin	Mild-to-moderate pain  For example: cancer in the bone	Can cause indigestion and can irritate the stomach lining and make it bleed  Do not take on an empty stomach  Can interact with other medications: always check with your doctor before using  Can be used with stronger pain drugs for moderate or severe pain



Type of drug	Examples	Can be useful for:	Things to note
Non-steroidal anti-inflammatory drugs (NSAIDs) (cont)	Ibuprofen e.g. Nurofen®, Brufen®  Naproxen e.g. Naprosyn®	Mild-to-moderate pain  For example: bone pain, pain caused by swelling or inflammation	Can cause indigestion and can irritate the stomach lining and make it bleed  Only use after advice from a doctor  Do not use in combination with aspirin
	COX-2 inhibitors e.g. Celebrex®	Mild-to-moderate pain  For example: bone pain, pain caused by swelling or inflammation	Can cause nausea and indigestion  Can cause abdominal pain, back pain or headache  Only use after advice from a doctor
Codeine-based drugs	Panadeine®, Panadeine Forte®	Moderate pain	May cause drowsiness for the first few days of treatment  May cause constipation (can be avoided by taking laxatives)  May cause a dry mouth and nausea initially

Type of drug	Examples	Can be useful for:	Things to note
Opioid drugs	Morphine e.g. Kapanol®, MS Contin®, Ordine®  Fentanyl e.g. Durogesic®, Actiq®  Oxycodone e.g. OxyContin®, OxyNorm®, Endone®  Hydromorphone e.g. Dilaudid®  Methadone e.g. Biodone forte®	Moderate-to-severe pain	Dose can be increased or reduced depending on how severe the pain is  See below for side effects and how to manage them
Bisphosphonates	Clodronate e.g. Bonefos®  Zoledronic acid e.g. Zometa®	Bone pain	Used to control cancer in the bone and reduce bone pain  Can cause dental problems with long-term use
Steroids	Dexamethasone Prednisolone	Pain caused by cancer pressing on a nerve, cancer in the brain, cancer in the liver, cancer in the bone	Can cause side effects if used at high doses and for a long time  Do not use with aspirin and NSAIDs



Type of drug	Examples	Can be useful for:	Things to note
Benzodiazepines	Diazepam e.g. Valium®	Muscle spasm pain	Can cause drowsiness
Antidepressants	Amitriptyline e.g. Endep®	Pain that involves the nerves	Can be used in combination with morphine or opioid drugs
Anticonvulsants	Carbamazepine e.g. Tegretol®  Gabapentin e.g. Gabatin®	Pain that involves the nerves	Can be used in combination with morphine or opioid drugs
Antibiotics	Choice of antibiotics depends on the cause of infection	Pain caused by an infection	May be used in combination with other medications

***“The doctor talked a lot about pain medication, its effects and that you should take the next dose before the first dose wears off.”***

### **Ways of taking drugs to manage cancer pain**

There are different ways of taking or giving drugs to manage cancer pain. Importantly, taking pain medication in tablet or liquid form is as effective as other forms. This can make it easier to manage your medication at home. The method used will vary according to the drug, the level of pain and whether you have other symptoms, such as feeling sick.

**Tablets or liquids** — thought to be the best way to take painkillers and allows the dose to be adjusted to meet your needs.

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**Suppositories** — if you are feeling sick or vomiting, drugs can be given as a suppository, which is inserted into your rectum (back passage).

**Patches** — some pain relief drugs are available as skin patches.

**Injections** — some painkillers and other drugs used to manage cancer pain in the short term are given as an injection into the skin or muscle. This can be helpful if you are feeling sick or vomiting.

**Pumps** — if you are experiencing severe cancer pain or pain after surgery, you may have a small pump attached to a needle under your skin or to a tube inserted into a vein. The pump can be set to deliver drugs continuously or at intervals to keep your pain under control. Some pumps allow you to control the drugs by pressing a button — so you can increase the dose when you feel uncomfortable. This is called patient-controlled analgesia.

**Injections into the spine or brain** — morphine or other drugs can be injected into the spine or brain if pain cannot be controlled with other treatments.

### **Remembering to take painkillers**

Some people find it difficult to remember to take regular medications. However, it is best not to leave painkillers lying around as a reminder to take them. It is important that you store painkillers carefully. Keep them away from children and make sure you label them properly. You might find it helpful to set an alarm on your clock, mobile phone or computer to remind you to take your drugs. Some people like to keep a record in a pain diary of when they have taken their medication.

### **More information about morphine and opioid drugs**

**Opioids can be useful drugs at all stages of cancer treatment.**

It can take a while to get used to taking strong painkillers such as morphine and opioid drugs. Possible side effects are listed below. **If you experience side effects, it is important not to stop taking your painkillers.** Talk to your doctor about any side effects that are concerning you.

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**Drowsiness** — you may feel drowsy when starting or increasing your dose. This usually wears off once you get used to the drug. If you continue to feel drowsy, contact your doctor. Talk to your doctor about what effect the painkillers will have on your ability to drive or do other activities. More information about driving while taking painkillers may also be available from the road and transport authority in your State/Territory.

**Constipation** — morphine and fentanyl cause constipation. Your doctor will probably give you a laxative to take at the same time to help with this.

**Dry mouth** — this is a common side effect of morphine and other opioid drugs. Drinking liquids and chewing gum can help.

**Nausea and vomiting** — some people feel sick when they start taking morphine or other opioid drugs. Your doctor can give you an anti-emetic for the first week or so of treatment.

**Itchiness** — this is a less common side effect of treatment. See your doctor if itchiness occurs.

**Vivid dreams** — some people describe very vivid and 'loud' dreams with some painkillers.



**Anti-emetics:** drugs used to control nausea and vomiting.

It is more common to experience side effects such as drowsiness or muscle twitches while the body is getting used to the required dose of painkiller. Talk to your doctor if these symptoms are troubling you.

### Other medical treatments for pain

There are other medical treatments that can help to control pain caused by secondary breast cancer.

- **Radiotherapy** is the most effective way of controlling pain in the bones and can be useful for pain in other parts of the body.
- **Surgery** can be helpful to manage certain types of cancer pain.



For more information about radiotherapy and surgery, see the 'Treatment' section.



### Non-medical pain relief methods

There are a number of other ways to control pain that do not involve using drugs. These can be helpful on their own or in combination with medical treatments.

- **Relaxation** — relaxation methods such as abdominal breathing, progressive muscle relaxation and yoga, can ease cancer pain.
- **Acupuncture** — involves placing small needles in key areas of the body and can ease pain. Ask a member of your healthcare team about how to find a qualified acupuncture practitioner.
- **Massage** — some women find that massage and aromatherapy can help with relaxation and coping with pain. Massage should not be used on swollen or inflamed parts of the body. Massage should not be used if you are having radiotherapy. Vigorous massage should not be used on parts of the body where there is known to be a cancer.
- **Cold and hot packs** — some women and health professionals suggest that cold packs can help to relieve pain where there is swelling or inflammation, and that hot packs can help to relieve back or joint pain.
- **Support** — support from friends, family, trained counsellors, other health professionals or other sources may help you to cope with your pain.
- **Transcutaneous electrical nerve stimulation (TENS)** — this is a way of stimulating the body's own natural painkillers and can be helpful for relieving pain in particular parts of the body.

*“When I’m feeling bad I do a bit more meditation to try and relax, dream of attacking the area where the pain is and sort of say ‘go away’. It seems to help.”*

*“The massage therapy is just wonderful. You come away floating.”*



## Questions to ask about managing pain

Listed below are some questions you might want to ask a member of your healthcare team about managing pain.

- What pain relief drugs do you recommend for me and why?
- How often should I take the drugs you are recommending?
- What are the side effects of the drugs you are recommending?
- Whom should I contact if I develop side effects?
- Are there ways I can manage the side effects?
- Are there other ways I can help to relieve my pain?
- Can the pain relief drugs interact with other medicines I am taking?
- If I am taking pain relief drugs, can I drink alcohol?
- Can I still drive while I am taking pain relief drugs?
- Whom should I contact if my pain changes/gets worse?

You may like to write your own questions here:

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## Frequently asked questions

### What happens if my painkiller becomes less effective?

There are many different drugs that can be used to manage pain. If the painkiller you are taking stops working, or if your pain gets worse, your doctor can recommend whether to increase the dose or try another drug. Do not stop taking your painkillers without first talking to your doctor.



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# Managing other symptoms

## Summary

- The symptoms of secondary breast cancer and side effects of treatment will depend on where your cancer is and what treatments you are having.
- Your symptoms might change with time.
- Treatments are available to control and relieve symptoms of secondary breast cancer and side effects of treatment.
- It is important to tell the people managing your care about any new symptoms or side effects or if a symptom or side effect gets worse.

## Symptoms of secondary breast cancer

Not all the symptoms you experience will be due to the secondary breast cancer. Some may be the result of treatment and others may be caused by other illnesses or medical conditions. Your doctor should tell you about possible side effects of treatments you are receiving and how to manage them.

**It is important that you tell the people managing your care about any new symptoms or if a symptom gets worse.**

When you describe a symptom, try to provide as much information as possible. You may find it helpful to keep a diary of how frequent or severe your symptoms are. You can also keep a record of how well your symptoms are being controlled to take with you when you meet with your doctor.

***“Live for today and make the most of it. I don’t think there are magic solutions.”***

***“When I catch up with people I haven’t seen for a while they’ll say ‘Wow you look so great, is everything fine?’ and I say ‘Well no I’m not OK, metastatic breast cancer is a chronic disease!’”***

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## Managing symptoms and side effects

This section lists the possible symptoms of secondary breast cancer or side effects of treatment and how to control or manage them. **It is extremely unlikely that you will have all of these symptoms.** The treatment recommended for some symptoms and side effects may depend on what is causing the symptom.

### Hypercalcaemia

**What is it?** High level of calcium in the blood

**What causes it?** Cancer in the bone:

- increase in the amount of calcium absorbed into the blood from the bones
- inability of the kidneys to get rid of the excess calcium

**What are the symptoms?** Increased urination, excessive thirst, dehydration, vomiting, constipation, muscle weakness, drowsiness, confusion

**How to treat it** Fluids to treat the dehydration  
Treatment with drugs called bisphosphonates to stop damage to the bone  
A change in the hormonal therapy or chemotherapy used

***“Be prepared. For example, make sure you have the necessary medications/creams before side effects take hold; it is invariably a holiday period when they strike and it’s more difficult to obtain them then.”***

### Tiredness (fatigue)

Over half of women with secondary breast cancer feel tired.

**What causes it?** The cancer itself  
Low levels of red blood cells in the blood (anaemia)  
Changes in the body’s metabolism  
Side effects of treatment



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Travelling for treatment  
Coping with pain or other symptoms  
Being worried or anxious about living with cancer  
Depression  
Sleeping difficulties

**How to  
manage it**

Finding out what is causing the tiredness can help to find ways to manage it  
Gentle exercise  
Red blood cell transfusion (for women with significant anaemia)



**Anaemia:** a condition in which there are fewer red blood cells in the blood than normal.

**Tips to help you to conserve your energy**

The following tips are based on the experience of health professionals and women themselves:

- make sure symptoms such as pain are controlled properly
- save your energy for things you enjoy doing
- take things easy and break tasks down into manageable steps
- try to get enough sleep
- build in rest periods during your day
- work out the best time of day for you to do things
- organise some practical help before you start chemotherapy — help with childcare or preparing meals can give you more time to recover
- encourage friends and family to have short, frequent visits rather than longer ones
- eat a well-balanced diet
- pace yourself and think about using aids or devices that will help you to conserve your energy and help you to get around more easily.



For more information about practical support during treatment for breast cancer, see the 'Finding support' section.

***"If my husband and I go to the park I usually sit on a seat while he pushes the grandchildren on the slide because I get tired standing up. But at least I'm there aren't I? At least I'm still around."***

### **Exercise**

A normal reaction to feeling tired is to rest. However, research shows that exercise can help to reduce fatigue caused by chemotherapy and other treatments. Although it may not be what you would expect, exercise during and after treatment can help you to feel less tired. Exercise can also reduce your chances of weight gain and has been shown to help to improve sleep, body image and mood. Gentle exercise like walking is ideal. Try to go for a walk on days when you feel well enough. Some women find that more strenuous exercise is also helpful. Talk to a physiotherapist or another member of your healthcare team about a suitable exercise program for you.

***"Exercise does help sometimes. The best exercise I found is dragon boat paddling. It also helps you relax as the main thing you have to think about is keeping in time with everyone else; all worries are forgotten."***

***"I walk three kilometres every day if possible. It helps with fatigue and gives me time for mental quietness."***

### **Nausea and vomiting**

Over half of women who have chemotherapy feel sick. You might feel sick or vomit even if you are not having chemotherapy.

**What causes it?** Treatments for secondary breast cancer such as chemotherapy and radiotherapy (less common with taxane chemotherapy)  
Nervousness before the next cycle of chemotherapy (this is called **anticipatory vomiting**)

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Drugs for pain or symptom relief  
Hypercalcaemia  
Cancer in the brain or liver  
A blocked bowel (bowel obstruction)

**How to treat it** Depends on the cause of the nausea  
Treatment with drugs called **anti-emetics**  
Treatment with drugs called **steroids**  
Diet modification  
Relaxation



**Anti-emetics:** drugs used to control nausea and vomiting. They are usually given at the same time as chemotherapy.

**Steroids:** drugs used to relieve swelling and inflammation.

***“I have a remedial massage once a month. It helps to alleviate the pain and discomfort from the metastases.”***

### **Tips to help to prevent nausea and vomiting**

The following tips are based on the experience of health professionals and women themselves:

- have frequent small meals instead of bigger main meals
- avoid fatty or fried foods
- rest before and after eating
- do not lie down during or after eating
- make sure you drink enough fluids
- see a dietitian for advice about what you should eat
- do some relaxation training — this can be particularly helpful if your nausea is caused by nervousness.

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***“I found that having hypnotherapy and being able to relax deeply whilst receiving chemotherapy reduced the anxiety and the pain and the after effects.”***



### **Loss of appetite**

About a quarter of women with secondary breast cancer lose their appetite.

**What causes it?** The cancer itself  
Treatments for secondary breast cancer  
Drugs for pain or symptom relief  
Being less active

**How to treat it** Seek advice from a dietitian  
Eat smaller, more frequent meals  
Treatment with drugs such as **medroxyprogesterone** or **steroids**

### **Tips to help you to eat more**

The following tips are based on the experience of health professionals and women themselves:

- eat small meals and snacks as often as you can during the day
- eat a variety of foods and try to include foods that are high in fibre
- choose foods you think you will enjoy and treat yourself when you feel like it
- use ready-made foods if you are too tired to cook
- drink protein and carbohydrate drinks if you find it difficult to eat solid food
- do not force yourself to eat if you cannot face it but take advantage of those times when you do feel able to eat.

***“Certainly I did find regular, gentle exercise to be most beneficial.”***

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## Difficulty sleeping

**What causes it?** Side effects of some drugs

Anxiety or depression

Pain

**How to manage it** Finding out what is causing sleeping difficulties can help to find ways to manage it

Treatment with drugs to help you to sleep

### Tips to help you to sleep better

The following tips are based on the experience of health professionals and women themselves:

- tell your healthcare team about any pain or other symptoms you have
- do some gentle exercise each day — ask your doctor, nurse or physiotherapist about exercises you can do even if you are in bed or sitting down for much of the day
- try and get into a routine during the day with visits from friends to keep you busy and stop you from dozing during the day
- avoid coffee, tea and other drinks with caffeine in them in the afternoon and evening
- have a warm drink such as herbal tea or warm milk before you go to bed
- try deep breathing and relaxation
- have a massage from a qualified massage therapist or a friend or partner
- have a warm bath before you go to bed
- try putting essential oils, such as lavender oil, on your pillow
- if you have problems sleeping, use the time to read or listen to music.

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If you are having problems sleeping because you are anxious or worried, talk to a member of your healthcare team. You might find it helpful to talk to a counsellor or psychologist.

*“This time I’ve needed antidepressants because I wasn’t sleeping. I was just lying awake in bed feeling afraid about what’s going to happen to me, what’s going to happen to my daughter, that sort of thing.”*

*“I still continue with yoga each week. Meditation, while it can take time to master, is invaluable for pain control or to help with sleeping.”*

### **Constipation**

Constipation is common in women with secondary breast cancer, particularly if you are taking painkillers.

**What causes it?** Side effects of drugs, especially painkillers

- A low-fibre diet
- Not drinking enough fluids
- Not eating enough
- Being less active

**How to treat it** Drink more fluids

- Increase the amount of fibre in the diet
- Treatment with oral laxatives
- Suppositories or enemas (if required)
- Gentle exercise

### **Tips to help to prevent and relieve constipation**

The following tips are based on the experience of health professionals and women themselves:

- do gentle exercise — ask your doctor, nurse or physiotherapist about exercises you can do even if you are in bed or sitting down for much of the day

- 
- eat fresh fruits, vegetables, cereals and grains
  - abdominal massage can be helpful
  - drink more water or other fluids.

Talk to your doctor before using any laxatives or medication for constipation.

***“I’m amazed that anybody can get something so destructive and yet be well, be coping with life and doing everything you do without any symptoms.”***

### **Hair loss**

Hair loss is a side effect of chemotherapy. Not all chemotherapy drugs cause hair loss.

**What causes it?** Side effects of chemotherapy drugs, especially anthracyclines and taxanes

### **Tips to help you to cope with hair loss**

The following tips are based on the experience of health professionals and women themselves:

- to help to slow down hair loss, use gentle hair products and avoid blow drying your hair, having it permed or using curlers, straighteners or tongs
- use a soft hair brush
- think about cutting your hair short so that it is less upsetting if your hair falls out
- wear a scarf, hat or wig to cover your head while your hair grows back
- depending on where you live you might be able to go to a free *Look Good... Feel Better* workshop; workshops are available in capital cities and other major centres and provide tips and advice about dealing with changes to the way that you look while having treatment.



For more information about *Look Good... Feel Better* workshops in your area, call the Cancer Council Helpline on 13 11 20.

***“My friends and I have found that being able to talk to someone who understands helps reduce the anxiety of managing the symptoms and therefore also reduces the tension and the fear and consequently the pain.”***

### **Mouth ulcers**

Mouth ulcers can be painful and can affect what and how much you eat.

<b>What causes them?</b>	Chemotherapy Other unknown reasons
<b>How to treat them</b>	Treatment with painkillers such as soluble paracetamol Treatment with a pain-relieving (analgesic) gel Treatment of thrush or other mouth or throat infections

### **Tips to help to relieve mouth ulcers**

The following tips are based on the experience of health professionals and women themselves:

- brush your teeth and gums with a very soft brush after every meal to prevent infection
- use an analgesic gel from the chemist or sodium bicarbonate (baking soda) mouthwash to help to relieve discomfort
- you might need to take pain relief such as paracetamol.

**Talk to your doctor before using a mouthwash, as some mouthwashes (especially those that contain alcohol) can make ulcers worse.**



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## **Lymphoedema**

<b>What is it?</b>	Swelling of the arm, breast, hand or other area of the body due to a build-up of fluid
<b>What causes it?</b>	Removal of, or damage to lymph nodes by surgery or radiotherapy
<b>What are the symptoms?</b>	<p>A feeling of heaviness, tightness or fullness in the affected part of the body</p> <p>Swelling of the affected part of the body (you may notice indentations in the skin from tight clothing, jewellery or shoes)</p> <p>Aching, pain or tension in the affected part of the body</p>
<b>How to treat it</b>	<p>Good skin care</p> <p>Exercise</p> <p>Raising the affected part of the body</p> <p>Wearing a compression garment (an elastic bandage or sleeve)</p> <p>Massage of the affected area by a trained lymphoedema therapist</p>

### **Tips to prevent and relieve symptoms of lymphoedema**

The following tips are based on the experience of health professionals and women themselves:

- reduce the risk of infection by keeping the skin healthy and avoiding damage by cuts, insect bites, scratches or burns
- avoid sunburn or overheating the affected area (for example, through hot baths or saunas)
- try to keep to a healthy weight
- avoid tight or poorly fitting clothing
- see a qualified lymphoedema therapist for more advice.



Cancer Australia's booklet, *Lymphoedema – what you need to know*, provides information about lymphoedema for people who have been treated for cancer. To order a copy go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973. The booklet is also available in Chinese, Vietnamese, Greek, Italian and Arabic. A brochure for Indigenous women is also available.



## Skin changes

**What are they?** Skin redness, cracking, itching, peeling, dryness or acne

Nail changes

Increased sensitivity to the sun

**What causes them?** Treatment with chemotherapy containing capecitabine (Xeloda®)

Radiotherapy (although this is uncommon with the doses used for secondary breast cancer)

**How to treat it** Moisturising creams (ask a health professional for advice about what type to use)

Vitamin B6 (pyridoxine)

Steroids (for severe cases)

Referral to an occupational therapist may be helpful

## Tips to prevent and relieve symptoms of skin changes

The following tips are based on the experience of health professionals and women themselves:

- wear sun protective clothes or use sun screen when you are in the sun
- avoid irritants — protect the skin from chemicals (for example, perfumes, deodorants, hair dyes or hair spray)
- keep skin folds dry

- 
- keep hydrated — drink plenty of fluids, as dehydration is a common cause of skin dryness
  - avoid extreme weather conditions like severe cold and hot weather — these conditions can aggravate dry skin
  - wash clothes in a mild detergent — look for detergents labelled 'allergen free' or 'unscented'.

### **Movement problems**

**What causes it?** Muscle weakness

Muscle wasting

Pain (especially bone pain)

Nerve problems

Pressure on the spinal cord

**How to treat it help** Finding out what is causing movement problems can to find ways to improve movement

Physiotherapy

Care to prevent pressure sores

Pain relief before any tests or activities that make the pain worse.

***"I'm not my cancer. I'm me first and the cancer just happens to be one of the things around me, like all the other things that are around me."***

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## Headaches

See your doctor if you have a headache that does not go away or is getting worse.

**What causes them?** Muscular tension  
Tiredness/exhaustion  
Hypercalcaemia  
Cancer in the brain

**How to treat them** Identifying and treating the cause of headaches, if possible, can help to prevent or manage them  
Treatment with pain relief

### Tips to help to prevent headaches

The following tips are based on the experience of health professionals and women themselves:

- avoid bright lights and loud noises
- lying with your head slightly elevated can help when the problem is due to cancer in the brain.

***“I found it important to be honest about my pain — not allowing the pain to take hold.”***

## Pressure sores

**What are that they?** Sores or broken skin on a pressure point on the body develop due to the pressure of lying or sitting

**What causes them?** Lying or sitting in one position for long periods of time

**How to treat them** Try and move or change position as much as possible avoid them If you are confined to bed, palliative care or community nurses can show your carers how to move you properly

Special mattresses are available and may be useful (see our community nurse or palliative care team for more information).

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## More severe symptoms

The following symptoms are less common but may be a sign of an underlying problem that requires medical care. It is important to let a health professional know if you experience the following problems.

### Enlarged abdomen

**What causes it?** Constipation  
Cancer in the liver  
Fluid in the abdomen  
Blockage in the bowel  
Inflammation (swelling) of the bowel due to treatment with chemotherapy or radiotherapy  
Steroids

**How to treat it** Treatment depends on the underlying cause  
The most important step is to work out why the abdomen is enlarged.

### Breathing problems

It is important to see your doctor immediately if you suddenly have difficulty breathing or if your symptoms become worse.

**What causes it?** Infection  
Low level of red blood cells in the blood (anaemia)  
Cancer in the lungs  
Fluid around the lungs  
Fluid around the heart  
Rare side effect of chemotherapy with taxanes or radiotherapy  
Blood clots in the lungs

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**How to treat it** Treating the underlying cause of the breathing problems  
Removing fluid from around the lungs  
Counselling or relaxation therapy  
Find a position that makes breathing easier, such as sitting upright  
Pacing activities (alternating periods of activity with periods of rest)  
Treatment with antidepressants or anti-anxiety drugs  
Treatment with morphine or other opioid drugs.



### **Confusion or other changes in thinking**

See your doctor if you or your family notice a change in your memory or thinking ability.

**What is it?** Range of symptoms can include confusion, agitation, disorientation, problems with concentration, change in behaviour, problems remembering things

**What causes it?** Anxiety and depression  
Infection  
Drugs used to treat secondary breast cancer and symptoms  
Cancer in the brain  
Hypercalcaemia  
Hypoglycaemia (low blood sugar)  
Liver or kidney failure  
Low oxygen levels due to cancer in the lungs

**How to treat it** Treatment depends on the symptoms and the cause  
The most important step is to work out the most likely cause of the problem.

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### **Tips if you experience confusion or changes in thinking**

The following tips are based on the experience of health professionals and women themselves:

- while doctors are working out why the problem has arisen, it is important that you have a family member or friend with you
- surround yourself with familiar things and things that keep you motivated
- keep a night light on when you go to bed as it is easy to become disoriented in the dark
- do not drive your car while the problem is being investigated
- try to maintain a quiet and calm environment; some people find meditation helpful.

### **Incontinence**

Incontinence is a rare symptom of secondary breast cancer. If you lose control over your bladder or bowel, talk to your doctor or community nurse about how to control it and make yourself more comfortable.

**See your doctor as soon as possible if you suddenly lose control over your bowel and bladder as this may be due to pressure on your spinal cord.**

### **Questions to ask about managing symptoms**

Listed below are some questions you might want to ask a member of your treatment team about managing symptoms.

- What is causing my symptoms?
- What can be done to manage my symptoms?
- Are there things I can do to help to relieve/prevent symptoms?
- Whom should I contact if my symptoms get worse?
- How will these symptoms affect my quality of life?





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## Frequently asked questions

### **Should I worry about taking strong painkillers?**

No. Pain is a warning system to alert health professionals to a problem. Once the problem has been identified, it is most important to relieve the pain. This is why stronger painkillers might be given to you. If pain is not relieved it can interfere with your ability to move freely and interact with others. This can often be worse than the possible side effects of the painkillers.

### **Should I expect to have many unrelieved symptoms as part of having secondary cancer?**

Like pain, it is possible to manage or relieve other symptoms of secondary breast cancer. In many cases, adequate symptom relief can easily be achieved.

### **Will I be distracting my doctors and nurses from their job of treating my cancer by telling them about my symptoms?**

No. Uncontrolled symptoms are a burden and may interfere with your ability to tolerate cancer treatments. It is important that you tell the people looking after you about any symptoms or side effects you experience so that solutions can be sought to ensure you feel as comfortable as possible, regardless of where you are in your cancer journey.

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# Breast cancer, menopause and fertility



## Summary

- Treatment for breast cancer may cause younger women to become menopausal. The menopause may be temporary or permanent.
- If menopause is permanent, this means you will no longer be able to have children naturally.

## Breast cancer and menopause

About two-thirds of women who are younger than 50 years of age when their breast cancer is diagnosed, will go through menopause because of treatment. Menopausal symptoms are a common side effect of hormonal therapies and some chemotherapy drugs. Sometimes the menopause is temporary and sometimes it is permanent. The closer you are to the age of natural menopause, the more likely it is that the menopause will be permanent.

Regardless of whether menopause is temporary or permanent, you may experience menopausal symptoms during treatment. Some women who have already gone through menopause also experience menopausal symptoms with certain treatments. For example, drugs such as tamoxifen, and aromatase inhibitors — anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®) — can cause symptoms such as hot flushes.



Cancer Australia has information for younger women with breast cancer who may be at risk of early menopause. To order a copy of the booklet *Breast cancer and early menopause: a guide for younger women*, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

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## Symptoms of menopause

Whether your menopause is temporary or permanent, you may experience some or all of the following symptoms:

- hot flushes
- mood changes
- sleep disturbance
- vaginal dryness and/or discharge
- a decrease in libido (sex drive)
- no menstrual periods, or irregular menstrual periods.

Some women have menopausal symptoms for only a few months, while other women have them for much longer. You are also at risk of developing **osteoporosis**. Ask your doctor for advice about preventing osteoporosis. Your doctor can also monitor you for osteoporosis, and recommend treatment if it develops.

A range of medical treatments, lifestyle changes and complementary therapies are used by women to manage their menopausal symptoms.

**Talk to your doctor about the options for managing menopausal symptoms and weigh up the benefits and risks of the different options for you.**



**Osteoporosis:** thinning of the bones that can lead to bone pain and fractures.

## Will treatment affect my ability to become pregnant?

The issue of pregnancy for women with secondary breast cancer is quite complex. There are a number of things to consider. Some treatments for breast cancer can affect a woman's ability to become pregnant (her fertility). Some treatments have this effect during the treatment period only, while others have a permanent effect. If your periods stop for a year or more, it is likely that your menopause will be permanent. If your menopause is permanent, you will be unable to have children naturally.

**Talk to your doctor if you are concerned about the effect of treatment on your fertility.**

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## Contraception during and after breast cancer treatment

Treatments for breast cancer may reduce fertility temporarily or permanently. However, this does not mean it is impossible to become pregnant during or after treatment.

There is no evidence about whether or not it is safe to take the oral contraceptive pill ('the pill') or use implants (Implanon®) during or after treatment for breast cancer. Therefore, it is recommended that you use non-hormonal forms of contraception, such as condoms, diaphragms, intrauterine contraceptive devices (IUDs) or male or female sterilisation. It is still possible to catch sexually transmitted infections (STIs) after menopause. Condoms are the most effective way of protecting against STIs.

**If you were pre-menopausal before breast cancer and you are sexually active, talk to a member of your healthcare team about suitable methods of contraception for you.**

### Coping with infertility

Infertility can be very hard to come to terms with, and not only for women who were planning to have children in the future. Even if you were not planning to have children before your diagnosis, or if you already have children, it can be upsetting to know that the choice is taken away because of infertility.

Talk to a member of your healthcare team about your feelings and concerns. You may also find it helpful to talk with other women in a similar situation or a counsellor, psychologist or psychiatrist. Ask your doctor for a referral, or call the **Cancer Council Helpline** on **13 11 20**.



## Questions to ask about the effect of breast cancer treatment on fertility and menopause

Listed below are some questions you might want to ask a member of your healthcare team about the effect of breast cancer treatment on fertility and menopause.

- Will my diagnosis and treatment for secondary breast cancer affect my ability to have children in the future?
- What contraception should I use while I am having treatment?
- How can I manage my menopausal symptoms?
- Will this treatment affect my risk of developing osteoporosis? Can this be monitored?

You may like to write your own questions here:

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## Frequently asked questions

### **Is it safe to use hormone replacement therapy (HRT) after a diagnosis of secondary breast cancer?**

Hormone replacement therapy (HRT) is a very effective treatment for menopausal symptoms. However, it is generally not recommended for women with breast cancer.

Studies of HRT after breast cancer have shown mixed results. We do not know whether HRT is definitely safe in women with breast cancer. The most common forms of HRT are 'combined HRT' which contain the hormones oestrogen and progestogen. Some treatments only use progestogen. These treatments are not as effective as those containing oestrogen. We do not yet know whether it is safe for women with breast cancer to take progestogen.

Some women's menopausal symptoms are severe and cannot be controlled with other treatments. HRT may be recommended for these women to relieve severe symptoms and lower the risk of fractures from osteoporosis. If you have questions, discuss these with your doctor.

### **Can I use a topical vaginal oestrogen?**

Many women experience vaginal dryness, either as a side effect of early menopause caused by treatment or as a side effect of hormonal therapies. Topical oestrogens can increase the level of oestrogen in the body. If you are taking an aromatase inhibitor (which works by blocking the production of oestrogen), it is best to avoid topical oestrogens. If you need to use a topical oestrogen, it may be better to take a hormonal therapy such as tamoxifen, which works by blocking oestrogen receptors, as the increase in oestrogen levels will be less important.

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**Notes:**

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# Finding support



This section provides information about how you, your partner and your children might feel after a diagnosis of breast cancer and where to find emotional and practical support.

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# Finding support

## Summary

- You may face a range of emotional, psychological, physical and practical challenges during your cancer journey.
- Your emotional wellbeing is as important as your physical wellbeing during your treatment for cancer.
- There are many sources of help and support, including your treatment team, partner, family, friends and support groups.
- It is important to be open and honest with your partner and children about your diagnosis and how you are feeling. They may also need support to help them to manage their feelings.
- You may be eligible for financial and practical assistance during treatment.

## Your feelings

The experience of being diagnosed with secondary breast cancer is very personal. Many people find the news that cancer has come back more devastating than their original diagnosis. It is likely that you will experience a range of emotions and feelings. These feelings are common. Everyone has their own coping strategies, beliefs and strengths. You and those close to you will find your own way to cope with your diagnosis. However, it can be reassuring to know that other women with secondary breast cancer have felt what you are feeling.

***“Most of the time I feel really positive and happy, but I’ll go through big downers too.”***

***“Although I have many friends and supporters, I am still the only one going through this and having the fears and the pain. I am the one who has to face each day with the knowledge that my days are numbered and keep on going.”***

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## Sharing your thoughts and feelings with others can help you to adjust to your diagnosis of secondary breast cancer.

The road ahead will be a bumpy one. There will be difficult times but there are still opportunities ahead. Many women find that their diagnosis gives them a new perspective on life and makes them rethink what is important to them. For some women, the experience of being diagnosed and treated for secondary breast cancer provides opportunities they would not have considered before their diagnosis. You may discover your strengths and weaknesses. You may deepen your relationships with others or form new friendships. You may explore your spirituality. It is not always easy, but many women find that with time they are able to adjust to their diagnosis and get pleasure from the things that are important to them.

***“In the support group I could tell people what a bloody awful week it has been because for other people I have to be so positive.”***

***“It’s interesting to be with other people in the same situation (in the support group). As we say to each other, we’re really the only ones who can understand what we’re going through.”***



Breast Cancer Network Australia’s *Hope & Hurdles* pack is a free resource for women diagnosed with secondary breast cancer. The pack, which has been developed by women with breast cancer, contains booklets, brochures, magazines and CDs that offer information, support and hope for women and their families. BCNA’s *Hope & Hurdles* pack can be ordered online at [www.bcna.org.au](http://www.bcna.org.au) or by calling 1800 500 258.

### How you might be feeling

Women describe a number of feelings after a diagnosis of secondary breast cancer. If you have gone through diagnosis and treatment for breast cancer before, you may feel angry or frustrated that the breast cancer has come back. Some women blame themselves or feel they are being punished for something they have done. It is important to

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remember that we do not know why breast cancer comes back for some women and not for others. There is nothing you have done to cause your breast cancer to come back. You should be reassured that you and your doctors made the best possible decisions about your original treatment at the time.

***“I was fairly shocked, but then my belief is that you are not dying until the last minute. That you have to focus on living and getting the most out of life while you are here.”***

It can be very difficult to face an uncertain future and it is natural to feel a sense that you are no longer in control. Talk to the people managing your care and those close to you and ask for as much information as you feel you need. You and those close to you may find it helpful to set short-term goals to work towards.

It is likely that your feelings will change or become more intense at different times. You may feel shocked, angry, scared, anxious, sad or depressed. You may feel a sense of loneliness or isolation or that you have lost your identity. Some people find themselves asking questions about the meaning of life, or may find their beliefs are shaken by their diagnosis.

**If any of your feelings are overwhelming you or preventing you from sleeping or doing everyday activities, talk to your doctor, nurse or another health professional. Treatments and therapies are available and can help.**

Listed below are some quotes from other women with secondary breast cancer. You may find these quotes helpful as you think about how you feel about your diagnosis.

***“I think I felt for the whole of this year that I was living as though I was expecting to die. I wasn’t doing a lot of things. And I realised that’s ridiculous.”***

***“Everyone is their worst critic. Be kinder to yourself in every way. Nobody’s perfect.”***

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## Seeking help and support

It is very important that you are supported through your diagnosis and treatment for secondary breast cancer. There are many different sources of support. Your healthcare team can provide you with support and advice. You might find it helpful to share your feelings with your partner or another family member or friend. Some women also find it helpful to talk to other women with secondary breast cancer. If you feel you would benefit from talking to a specialist or having some additional therapy, talk to a member of your treatment team.

***“I think in many ways it has been a kind disease. I have gained so much from it. I have met so many friends.”***



Breast Cancer Network Australia (BCNA) produces a free national magazine called *The Beacon*. *The Beacon* is written by women with breast cancer, for women with breast cancer, their families and friends. A special supplement to *The Beacon*, *The Inside Story* is specifically for women with secondary breast cancer. To find out more about the magazine and supplement, or to subscribe, visit [www.bcna.org.au](http://www.bcna.org.au) or contact BCNA on 1800 500 258.

Some of the things that might help are listed below:

- **Relaxation** — can help to control pain and reduce feelings of anxiety.
- **Muscle relaxation and imagery** — can help with anxiety and can help to reduce symptoms.
- **Support groups** — some women find it helpful to meet with other people in the same situation to share their experiences, concerns and fears; meetings can be face-to-face or held over the telephone or internet.
- **Counselling** — counselling with a trained health professional can help you to think more clearly about your feelings and help you to deal with issues that may have been brought up by your diagnosis and treatment.

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- **Anti-depressants or anti-anxiety medication** — medication can be valuable to get you through difficult times. You will usually only need to take medication for a short period of time. Taking medication does not mean that you are ‘weak’ or ‘crazy’. Talk to your doctor about the benefits and side effects of medications that might be helpful for you.



In some States/Territories, the Cancer Council can put you in touch with other women who have had breast cancer. To find out more about the Cancer Connect program, call the **Cancer Council Helpline** on **13 11 20**.

*“In our community, cancer is taboo — no-one talks about cancer at all.”*

### **Deciding about work**

If you were working when you were diagnosed, you may find yourself wondering whether you should continue. Some women who feel well enough find that continuing to work helps them to feel valued, and they feel comforted by being around familiar people and situations. Other women find that their diagnosis makes them want to make changes in their work life. You may decide you want to stop work so that you have more time to do the things that are important to do. Or you may decide to change jobs, work part time, or do some volunteer work.

Your decision about whether to continue working will depend on your health, your finances and your priorities. Talk to those close to you about your decision. If you would like some additional help in making decisions, ask your doctor to refer you to a counsellor or social worker.

If you do continue to work, you may find it difficult to talk with your colleagues or friends about your experience of being diagnosed with secondary breast cancer. If you want to, you can share your experience with just a few close friends or colleagues. Sharing your feelings could lead to valuable support.



Cancer Council NSW has produced a booklet about returning to work after a diagnosis of cancer. To download a copy of *Cancer, work and you*, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

Breast Cancer Network Australia (BCNA) has produced a brochure called *Helping a friend or colleague with breast cancer*. To download a copy of the brochure, go to [www.bcna.org.au](http://www.bcna.org.au) or to obtain a printed copy, call BCNA on 1800 500 258.



***“People come up to me and say ‘You’re so brave! I don’t see myself as being brave. I’m just doing whatever I have to do to get through this.’”***

### **Your family and friends**

Secondary breast cancer can have a significant impact on those close to you — your partner, children, family and friends. They will probably find the journey difficult and need support. They might also need advice about how they can help you.

***“I don’t always want people to be here all day anyway. I’d rather be left alone some of the time.”***

A diagnosis of cancer can show up strengths and weaknesses in your relationships. Talk to your doctor, nurse or other health professional if you are having difficulties in your relationships or if you feel that a family member is not coping.

If you live alone or if you do not have supportive family or friends close by, you can try seeking support from other places. You might find that a local community group is supportive or that neighbours can provide help. You may also find support from your healthcare team, a support group or a religious organisation.

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***“My husband’s not the easiest person to talk to. He doesn’t show his emotions. I know he’s upset.”***

***(From partner) “Some friends cope well and others, they don’t know what to say.”***

### **Your partner**

If you have a partner, he or she may feel many of the same emotions as you following your diagnosis. Partners can experience higher levels of stress than the person diagnosed with cancer. They also have different information needs. Everyone is different and will have his or her own way of coping.

**It is important that you and your partner are open with each other about how you are feeling.** Going to appointments together can provide you with support and can give your partner the opportunity to ask questions. Your partner may want to make a separate appointment with your doctor or another member of the team to discuss how they are feeling. Or you may like to see a counsellor or other trained professional together.

***“Lacking a partner never worried me up until this point, but I suppose it would be nice to have someone to really share with.”***



Cancer Australia provides resources for the partners of women with breast cancer. For web-based information, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources).

To order an audio CD called *When the woman you love has advanced breast cancer*, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

Mensline offers telephone counselling and support for men, call 1300 789 978 or visit [www.menslineaus.org.au](http://www.menslineaus.org.au).

### **Your carers**

Whether or not you have a partner, you may have other close friends or family members who support you through your cancer journey.

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It is important that your carers also feel supported and know where to find help if needed. Some palliative care services offer 'carer training' to provide carers with practical skills and emotional support. Respite care is also available to give your carer 'time out' when needed.



To find out more about services available to help to support carers, ask your GP or another member of your healthcare team or call the **Cancer Council Helpline** on **13 11 20**.

### Tips to help you and your partner and others close to you to cope with your diagnosis

The following tips are based on the experience of health professionals and women themselves:

- think of your partner, family and friends as a support team — try not to rely on just one or two people
- talk to those close to you about how you are feeling and encourage them to do the same
- tell people what you need — sometimes they might want to help but might not know what to do
- recognise that you do not always have to stay positive — tell each other if you feel tired or irritable
- encourage those close to you to have time away from you — this will help to give them the energy to support you when you need it
- find time to do enjoyable things together and choose activities that suit how much energy you have
- talk to a member of your healthcare team if you are concerned about any of your relationships or about the impact of your diagnosis on those close to you.

### Your children

If you have children, they are likely to be affected by your diagnosis. Depending on their age, children may know something is wrong without you even telling them.



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The following information is aimed particularly towards dependent children. However, even if your children are adults with children of their own, your diagnosis can be upsetting. Having open and honest communication is generally helpful. Your adult children might find it helpful to access further information about supports through the **Cancer Council Helpline on 13 11 20.**

Change can be frightening for children. It can be difficult for them to adjust, especially if you look different or are in hospital. You may want to talk to your children about what is happening to you so they understand what is going on. Answer their questions as honestly as possible in words they can understand. What they imagine to be happening is possibly more upsetting to them than the reality will be, once it is explained.


***“It is very difficult to know with teenagers how much they want to talk about things and how much they don’t. And boys particularly tend not to be great talkers.”***

The effect of your diagnosis on your children may be reflected in their behaviour. They may behave differently to gain attention, or become insecure and refuse to leave your side or your partner’s side. If you are concerned about your children’s behaviour at school, you may decide to tell the teacher about your breast cancer so that he or she understands the reason for the change in behaviour.

Children may worry about what your diagnosis means for them — whether they will be left alone and whether they might also develop cancer. Teenagers may be particularly vulnerable. They may be worried about how you are coping, as well as dealing with their own feelings, and may take on the role of helping to run the house. Adolescence is a time of great change, and fear about a parent’s illness adds to the teenager’s burden.

It is important for you and your partner to ask your children how they are feeling and to recognise their distress. Some suggestions about how to talk to your children about your cancer are listed below.

- Try to understand what it is that they fear will happen. This will help you to decide what information they can handle and how it should be given.

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- Talk to them about feelings as well as facts.
  - Give simple, honest answers to their questions and correct any misunderstandings. Children respond well when they feel they are being given time especially for them.
  - Try to explain what will happen next.
  - Do not make promises you may be unable to keep.
  - Maintain a sense of routine and encourage them to play with their friends and participate in their usual activities.
  - Build in special times with your children — depending on your level of energy — such as reading a book together, singing, watching TV together or playing cards.
  - Reassure them that the breast cancer is not their fault — this is especially important for younger children.
  - Teenagers may have mixed emotions, loyalties and coping abilities because of their own stage of development. In some respects, they thrive on being regarded as an adult, but during times of illness in the family, it can be really hard going. Be aware of this and look for signs that an adolescent needs a little extra support and encouragement. It is important that they are allowed to talk about death and how this makes them feel. If they find it hard to talk to you, there may be a relative or friend with whom they can share their feelings.

If you are worried about your children, you can ask your doctor to refer them to a counsellor, social worker, psychologist or psychiatrist; or some or all of the family can see a family therapist.



Cancer Australia has information for children who have a parent with cancer at [www.canceraustralia.gov.au/myparentscancer](http://www.canceraustralia.gov.au/myparentscancer).

Cancer Council NSW has developed a booklet about talking to children about cancer. To download a copy of *When a parent has cancer: how to talk to your kids*, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au).



CanTeen has developed a website [www.nowwhat.org.au](http://www.nowwhat.org.au) for young people who have a parent or family member with cancer.

***“You just feel it’s not fair. You feel cheated out of a few years of watching your grandchildren.”***

### **Secondary breast cancer and body image**

Secondary breast cancer and its treatment can affect how you feel about your body. This is not unusual and can happen regardless of your age or stage of life. Some treatments can cause you to gain or lose weight. You might find that you lose weight because you feel sick or lose your appetite. Or you might find that you put on weight because you are not as active as you used to be. Some treatments can also cause hair loss or skin changes. **Talking to others about your concerns or feelings about your body image can help.**

Depending on where you live, you might be able to go to a Look Good... Feel Better workshop. These are free of charge and provide tips and advice about dealing with changes to the way that you look while having treatment. Workshops are available in capital cities and other major centres.



For more information about *Look Good... Feel Better* workshops in your area, call the **Cancer Council Helpline** on **13 11 20**.

***“I dropped so much weight when I first got the cancer secondaries but now I’ve put it all back on again.”***

### **Secondary breast cancer and sexuality**

A diagnosis of secondary breast cancer can affect your relationship with your partner, including your sexual relationship. The different treatments often have a significant effect on how women feel about themselves and their attractiveness. This can happen to any woman, whether or not she has a partner. Your partner may also feel less able to be sexual with you because he or she is worried about hurting you.

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Some of the sexual difficulties that may arise as a result of treatment include:

- feeling less attractive because of treatment
- lower libido because of feeling unwell, tired or worried
- vaginal dryness caused by different drugs
- difficulty being physically active because of pain or disability.

Even if it is difficult, try to talk with your partner about how you are feeling and share your fears and concerns. Ways can be found to adapt to your situation and help you to feel closer to each other. If sexual intercourse is difficult or not what you want to do, explore being sexual in other ways. Or increase the affection in your relationship by holding hands, back rubs and cuddles. There are some practical things that can help to overcome some of the physical changes due to treatment. Water-based lubricants, vaginal moisturisers and creams can help with vaginal dryness. Talk to someone you feel comfortable with in your healthcare team to find out more.

You and your partner may find it helpful to talk to a health professional about your concerns — you can do this together or separately. You may want to ask for advice from a trained specialist such as a relationship counsellor or sex therapist.

***(From partner) “Things change and you can’t really go back to the way you were before. It is a little like a rollercoaster, it stops and you get off, you go for a walk in the woods and then you have to get back on again.”***

### **Same-sex couples**

You may feel that a lot of attention is placed on heterosexual couples and that lesbian sexuality is not mentioned when the impact of breast cancer on sexuality is discussed. It is up to you whether you let your treatment team know about your sexuality. However, if you feel comfortable with your treatment team, telling them may help you to feel more supported.



To find out about support services specifically for lesbian women, contact your local women’s health centre or call the **Cancer Council Helpline** on **13 11 20**.

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## Practical support

As you go through treatment, or when the cancer progresses, you may no longer be able to do all the things you would normally do at home. It can be difficult to come to terms with losing your independence. **However, accepting help and support can help you to save your energy for the things that are important to you.**

Concern about practical issues can affect how you are feeling, especially if it interrupts your daily activities. You may be worried about who will look after the children or another family member while you are in hospital, or how you will cope financially if you are unable to work. Sometimes women feel guilty about the impact of their cancer and its treatment on the family. **It is important to remember that you do not have to go through this alone. Support and assistance is available through your healthcare team.**

***“It’s important to do the things that you really want to do, and leave the other things to take care of themselves.”***

## Costs of treatment

Talk to your doctors about the likely costs of medical tests and treatments. These may include the cost of treatment and support, travel and accommodation costs, childcare or the cost of wigs or medical equipment.

The costs may depend on whether you:

- are treated in the public or private system
- decide to continue working or not
- live in a rural area and need to travel for treatment
- have private health insurance
- have a healthcare card.

You may find it useful to talk to a social worker or welfare worker about what financial and practical support services are available. It may also be helpful to talk to your local Medicare office about the ‘safety net’ on costs of medications and medical bills. You can also contact your private health insurer to discuss your likely rebates and benefits.



The External breast prostheses reimbursement program is an Australian Government initiative that provides reimbursement for both new and replacement external breast prostheses to all eligible women who have had a mastectomy as a result of breast cancer. Cost limits apply. For more information about the program and eligibility criteria, visit Australian Government Department of Human Services website at [www.humanservices.gov.au](http://www.humanservices.gov.au). You can also call Medicare on 13 20 11 or visit a Medicare office.

For further information about where to find a breast prosthesis in your area, ask your health professional or call the **Cancer Council Helpline** on **13 11 20**.



### **Financial assistance during treatment**

If you need to have treatment in a hospital far away from your home, you may be able to get help with the cost of accommodation and travel. Depending on your situation and where you live, you may also be able to get assistance with childcare, meals and general home help. You might also be eligible for a sickness allowance while you are having treatment.

### **Government-assisted travel schemes**

Each State and Territory has a government-funded scheme to help patients who have to travel long distances to obtain specialist treatment that is not available locally. The names for these schemes vary but may include:

- Patient-Assisted Transport Scheme (PATS)
- Transport for Health
- Isolated Patient Transport and Accommodation Assistance Scheme (IPTAAS)
- Interstate Patients Transport and Accommodation Service (IPTAS).



To find out about what financial and practical help may be available for you, talk to the nurse or social worker at your hospital, your community nurse, or call the **Cancer Council Helpline** on **13 11 20**. Your local council, Centrelink and the Department of Veterans Affairs can also provide information.

### Superannuation for people with a terminal illness

Current legislation allows individuals with a terminal illness to access their superannuation as a tax-free lump sum. In order to do this you need certificates from two medical practitioners (one of whom is a specialist) stating that you have a terminal illness with a life expectancy of 12 months or less.



To find out about superannuation for people with a terminal illness, visit the Australian Taxation Office website at [www.ato.gov.au](http://www.ato.gov.au) or call 13 28 61.


Breast Cancer Network Australia has developed a fact sheet about accessing superannuation for women with secondary breast cancer. To download a copy, visit [www.bcna.org.au](http://www.bcna.org.au) or to obtain a printed copy call BCNA on 1800 500 258.

### Support in your home

If you find you are less able to manage at home, help may be available for you and your family. Listed below are some of the people and organisations who may be able to provide help and care at home. The services available to you will depend on where you live and your circumstances.



Ask your general practitioner or nurse for more information about the services available in your area or call the **Cancer Council Helpline** on **13 11 20**.

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- **General practitioner** — may be responsible for your ongoing care and can help to arrange other support services for you at home.
  - **Social worker** — can help to find the right people to help you at home.
  - **Community/district nurse** — can visit you at home at regular intervals according to your needs and can help with things like bathing, changing dressings, giving medications and providing support to you and your carers.
  - **Breast care nurse/care coordinator** — may be able to continue to provide you with support and care while you are at home.
  - **Occupational therapist** — can provide you with practical advice and aids to help you at home, such as walking frames, wheelchairs, shower chairs or can recommend minor changes to your home that will make it easier for you to get around.
  - **Physiotherapist** — can help to keep you mobile and provide pain relief and massage. Some physiotherapists specialise in exercises for people with cancer or lymphoedema.



To find a physiotherapist in your area, visit the Australian Physiotherapy Association website at [www.physiotherapy.asn.au](http://www.physiotherapy.asn.au)

- **Palliative care team** — can help to control your pain and other symptoms and provide support for you and those close to you.
- **Home care** — a range of public and private services are available for eligible women to help with things like cleaning, shopping, cooking, personal care and respite care for those who are looking after you.
- **Private nursing agencies** — provide a 24-hour service in some areas to cover nursing care and practical support.
- **Meals-on-wheels** — deliver meals to people who cannot leave their homes (requires a referral from a health professional).



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- **Volunteer carers** — volunteer carers can come and visit you for a set time each week or fortnight to chat or help with telephone calls or letter writing, or just to be there.
  - **Church/religious groups** — some church or religious groups provide support for their members with things like shopping.

### Support outside your home

If your illness progresses, you may feel you need to be looked after in a hospital, hospice or palliative care unit. Or you may decide you need some additional support for a short time to give your carers a break. This is called **respite care**.

Listed below are some of the services that can provide care outside your home. The services available for you will depend on where you live.



Ask your general practitioner, social worker, community nurse or breast care nurse for more information about the services available in your area.

- **Day centres** — are often attached to hospitals, hospices or nursing homes and are available to give your carers some 'time out'. These centres are open during the day and often provide transport to and from your home.
- **Hospitals** — public and private hospitals can provide short- or long-term care. Access to a public hospital will depend on your level of need and whether there are beds available.
- **Hospices/palliative care units** — specialise in the care of people who are living with and dying from cancer. They focus on controlling pain and other symptoms. Some people go to hospices for a short period to help to control symptoms or to give their carers a rest. Some hospices also have accommodation available for carers. Some are public, some are funded by a charity and some are attached to private hospitals. Palliative care units may be wards in local hospitals.
- **Nursing homes** — some nursing homes offer short- or long-term stays to give your carers a break. They will charge a fee for the care provided.

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***“I’m learning to accept help a bit. I was terribly proud. And I think part of that is learning to know that you deserve help.”***



### **Questions to ask your healthcare team about practical support**

Listed below are some questions you might want to ask your GP, specialist or nurse about practical support.

- What will the treatment you are recommending cost?
- Will I need to have time off work?
- Am I eligible for help with travel and accommodation costs?
- Can I get help with other costs of treatment and care?
- How can I find out about help and support at home?
- How can I find out about help with childcare?
- What support is available to give my carer a rest?
- Where is my nearest hospice/palliative care unit?
- Can you give me a list of people/organisations that provide local supportive care?



### **Questions to ask your health fund about treatment costs**

Listed below are some questions you might want to ask your health fund about treatment costs during treatment for breast cancer.

- Which treatments are covered by my policy?
- Which treatments are not covered by my policy?
- Does my policy cover other services, such as the cost of wigs?
- Does my policy cover palliative care services such as respite care?
- Does my policy cover convalescent stays, for example after a particular procedure or treatment?

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- What ambulance services are covered by my policy? Does it include transfers between hospitals?
  - Does my policy cover emergency department admissions?
  - If I claim for a particular treatment now, does that affect what treatments I can claim for later?
  - What is the gap between the cost of treatment and the private medical insurance rebate?

You may like to write your own questions here:

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## **Frequently asked questions**

### **How do I know if I am anxious?**

Some of the warning signs of anxiety include constantly feeling agitated or angry. You may have difficulty sleeping or you may have trouble concentrating or making decisions. You may find yourself avoiding distressing situations or you may get sudden feelings of panic or fear.

### **How do I know if I am depressed?**

Some of the warning signs of depression include feeling low or flat and losing interest in things you used to enjoy. You may feel tearful or find it hard to see the funny side of things. You may have difficulty sleeping or lose your appetite (although bear in mind this can also be a side effect of some treatments).

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**Notes:**

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# Putting your affairs in order



This section explains some of the things you may want to consider when facing the possibility of dying. It may be difficult for you to read this chapter. Read it when you feel you are able to do so. You may want to read it on your own or with your partner or someone else close to you.

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# Putting your affairs in order

You and those close to you may find it difficult to read this chapter. Read it when you feel you are able to.

## Summary

- Planning for what will happen when you die can bring a sense of relief and help you to focus on living.
- Stopping active treatment does not mean that steps cannot be taken to help to maintain your quality of life.
- Think ahead and make plans when you feel able to.
- Talk to your doctors and those close to you about your decisions about when to stop treatment.
- Think about practical aspects such as making a Will and letting others know about your preferences for your care while you are still feeling well.

## Facing the possibility of dying

No-one likes to think about dying. Thinking about dying can be upsetting and may make you feel anxious, depressed, scared or experience a sense of loss. These are all normal feelings. However, planning for what will happen when you die can bring a sense of relief and leave you free to focus on living and the things that are important to you.

Thinking about and planning for your death can be overwhelming. It is important for you and those close to you to do this when you feel the time is right for you.

***“I don’t know too much about the whole process of dying — how sick you’ve got to get before you die. Do you fade away to a shadow or are you almost healthy one day and dead the next week?”***

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## Unfinished business

Many women with secondary breast cancer find that facing an uncertain future makes them think about the relationships and friendships that are important to them. You may not have been in touch with friends or family for a while or you may have had a disagreement with someone and feel you would like to make amends. You may decide the time is right to say something to a friend you have always wanted to say. You should not feel you have to resolve all the problems in your past or present relationships. However, this can be a time for healing and strengthening the relationships and friendships that are important to you.

Some women find themselves thinking about the past. You may decide you want to visit the place where you were born, or look through old photographs. This can give you a chance to think about your life and the experiences you have had.

Some women decide to write letters or cards to people they are close to, or put together a journal, tape or CD to be given to children or grandchildren in the future.

**Whatever you do is a personal experience. You need to do what is right for you at the time.**

## Spiritual or religious comfort

Some women with secondary breast cancer find that religious beliefs and spirituality become more important to them as they think about dying. You may find your diagnosis has deepened your faith or has made you question it. You may find it useful to talk to a religious representative about questions you have, even if you have not attended a service for a while. Other women find that sitting quietly and thinking or meditating can help with their thoughts and spirituality.

***"I feel a bit cross with God I must admit because I've been in Church all my life. But I feel God's let me down a bit."***



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***“I’m not concerned about dying. I have firm beliefs about dying and spirituality — not religion but spirituality. I know that when the time comes it will be my time, this body will be worn out and my time will come and I’ll go on to something else.”***

### **Making the decision to stop treatment**

Living with secondary breast cancer involves having different treatments, often over a number of years. In later stages, the cancer may spread more widely and treatments may become less effective. **Even when treatments stop working, pain and symptom control and support will be available to make you as comfortable as possible.**

Making the decision about when to stop treatment is difficult. Ask for as much information as you need from your healthcare team and talk with your doctors, nurses, your family and friends about the benefits and side effects of treatments. Remember, there is no cure for secondary breast cancer. Many women say that what is important to them is the quality of the life they have left and what they do with the time they have.

The decision about whether and when to stop treatment is yours to make. If you feel differently to your partner or those close to you, it may be helpful to talk to a counsellor or psychologist to work through your thoughts and concerns.

Deciding to stop treatment does not mean giving up hope. Everyone will find hope in their own way — whether it is about finishing something that is important to you, spending time with family and friends or thoughts about an afterlife, if that is what you believe.

***“I know that the cancer’s there and spreading. I hope that when it spreads it makes up its mind to spread, it spreads quickly and gets it over with.”***

### **Thinking about dying**

Many people are scared of dying. This is only natural. However, dying can be a very peaceful process. Those who work with people who are dying often say there is a sense of calm around the person who is dying.

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The process of dying for women with secondary breast cancer does not happen in an instant. The body usually gets weaker over time and this can help women to let go.

You can be reassured that everything will be done to keep you as free of pain and as comfortable as possible. You will be able to have loved ones around you. Some women say they would like to die at home and this is often possible.

It can be difficult to talk to others about your fears and thoughts about dying. And it can be difficult for your loved ones to talk to you about their fears and grief with you. Sharing your feelings can help you to come to terms with dying and can bring you closer together. You and those close to you may also find it helpful to talk about your questions or concerns with a member of your healthcare team.

***“I hope my family will accept it even if I die. You see I don’t believe that death is everything and that’s been a great help.”***

### **Practical aspects**

Although difficult, it is important to think about the practical aspects of preparing for death. Planning in advance can make sure that your wishes are carried out. It can also help to avoid any painful decisions that your family or partner may need to make if you do not tell them your wishes.

Legal requirements will vary depending on where you live. Some things to think about are listed below.

- **Preparing a living will** — talk to your family and friends about whether you wish to be kept alive or resuscitated if you stop breathing. You can also write a **living will** or an **advanced healthcare directive** stating your wishes. Talk to your doctor about what you want and how to make sure your wishes are carried out.
- **Naming a power of attorney** — there are four types of power of attorney:
  - **Power of attorney** — someone you trust who can make decisions about your care at a given point in time if you are not

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able to decide for yourself; if you wish, a power of attorney can also manage your financial arrangements if you are unable to do this for yourself

**Enduring power of attorney (financial)** — someone you appoint who can make financial or legal decisions for you if at some time in the future you are unable to make those decisions for yourself

**Enduring power of attorney (medical treatment)** — someone you appoint who can make medical treatment decisions for you if at some time in the future you are unable to make those decisions for yourself

**Enduring power of guardianship** — someone you appoint who can make decisions related to your lifestyle, such as where you will live, if at some time in the future you are unable to make those decisions for yourself.

These names may vary slightly by State and Territory — talk to your healthcare team or a solicitor for more information.

**Before you appoint someone, it is important to discuss with them the kinds of decisions they might be asked to make. They need a clear understanding of your views and wishes.**

- **Making a will** — a will outlines who should receive your possessions and property after you die. It can also contain instructions for your funeral arrangements. If you do not make a will, a government body will decide for you. This may not be in line with your wishes and can be expensive. Talk to a solicitor about drawing up a Will. It is better to do this while you are feeling well.

**Remember to tell a family member or close friend about where you keep any legal documents and how to contact your solicitor.**

Other things to think about and discuss with those close to you include:

- how any children younger than 18 will be cared for
- your wishes for your funeral arrangements

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- whether you would prefer to die at home or in a hospice, palliative care unit or hospital.

Your thoughts might change over time and it is important to let others know if you change your mind.



***“My husband said ‘I’ve got no idea what sort of funeral you’d like or even whether you want to be buried or cremated, and we should update our wills’. So we discussed what sort of funeral I wanted and we talked about those sorts of things.”***

***(From partner) “I felt very privileged and pleased to be able to fulfil her last wish of looking after her at home and letting her die peacefully in our bed.”***



### **Questions to ask your doctor or a solicitor about your affairs**

Listed below are some questions you might want to ask your doctor or a solicitor about your affairs.

- How do I make a will?
- How do I make a living will/advanced healthcare directive?
- How do I appoint a power of attorney?
- What will happen at the end? Can I have my family with me?

You may like to write your own questions here:

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## Frequently asked questions

### How do I make a living will/advanced healthcare directive?

Some people find it reassuring to know that their close family or friends know what is best for them if they are not able to communicate their wishes themselves. An advanced care directive or living will can be designed in different ways. It would usually include your instructions about what medical treatment you would like to consent to or refuse if you were not able to communicate this yourself. You may find it helpful to talk with health professionals about specific scenarios that may arise in your situation and what the benefits or burdens of different treatments may be in these situations. You should also talk with your family about your wishes.

### How do I decide when I should stop treatment?

There may come a time when your quality of life could be better without further treatment. Health professionals will work with you to monitor the benefits and side effects of your treatment. It is important to talk with them about options if the treatment is not helping you. If you do decide to stop your treatment, health professionals will continue to provide any treatments that are needed to ensure you are comfortable.

### What will it be like at the end?

Health professionals who work with people who have a terminal illness say that often people who are dying become drowsier in their final days of life and less aware of what is going on around them. As far as we know, this is not distressing or frightening. Other symptoms (like pain or shortness of breath), if they occur, can be controlled with medications. Your healthcare team will do their best to make sure you are as comfortable as possible. Assistance from a palliative care team may be helpful to enable you to die in the place of your choosing, where feasible. Your healthcare team, with assistance from a palliative care team as needed, can also provide support to your family and those close to you.

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**Notes:**



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SBC 06/13