



Understanding Cancer of Unknown Primary

A guide for people with cancer,
their families and friends

Cancer
information

Cancer Council Helpline

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professionals' advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Cancer Council Australia

Cancer Council Australia is the nation's peak non-government cancer control organisation. Together with the eight state and territory Cancer Councils, it coordinates a network of cancer support groups, services and programs to help improve the quality of life of people living with cancer, their families and carers. This booklet is funded through the generosity of the people of Australia. To make a donation and help us beat cancer, visit Cancer Council's website at www.cancer.org.au or call your local Cancer Council.



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Introduction

This booklet has been prepared to help you understand more about cancer of unknown primary. Health professionals use several terms to describe this cancer, including occult primary cancer, tumour of unknown origin or metastatic malignancy of unknown primary. In this booklet we use the term cancer of unknown primary or CUP.

Many people feel shocked and upset when told they have cancer. It can be even more distressing if the cancer has spread and the primary site cannot be found. You may find it hard to believe that in this scientific age the primary cancer can't be located.

We hope this booklet will help you understand how CUP is diagnosed and treated. We cannot advise you about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer your questions and help you think about other questions to ask your doctors.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may like to pass this booklet to your family and friends for their information.

How this booklet was developed

The information in this booklet was developed with help from medical experts and people who have been diagnosed with CUP. Sections of this booklet were developed by Cancer Council South Australia, and publications from the Cancer Institute NSW and Cancer Council Victoria were used as source material.

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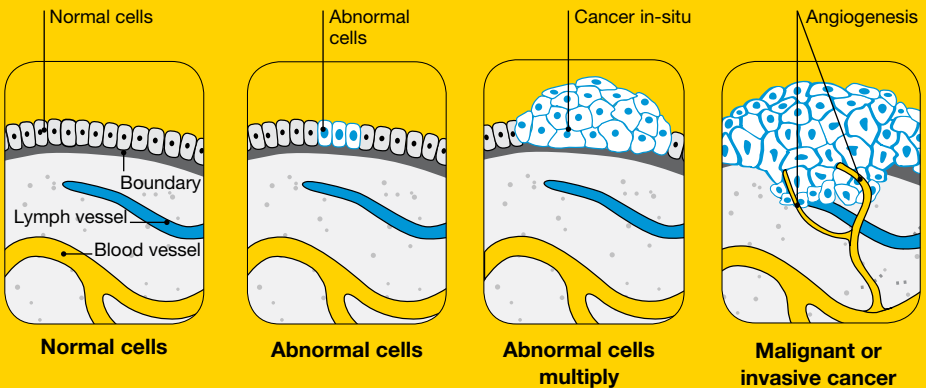
What is cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury.

Normally cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in a lump called a tumour or may develop into abnormal blood cells.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread to other parts of the body. A malignant tumour is made up of cancer cells. The original organ or tissue where a cancer began is called the primary site.

How cancer starts

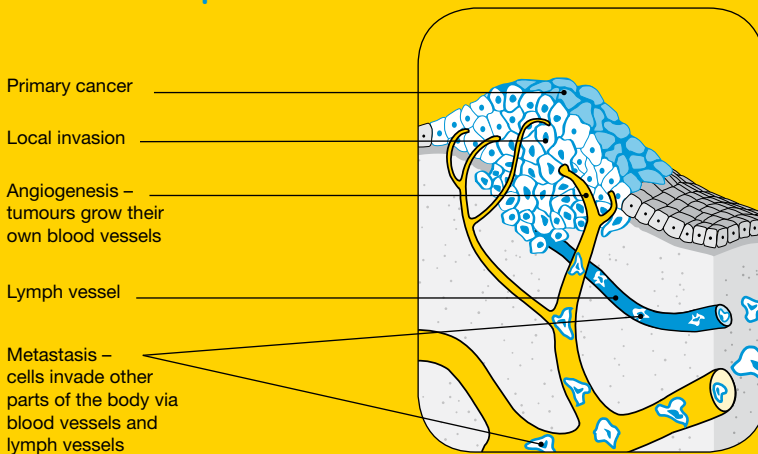


When it first develops, a malignant tumour may not have invaded nearby tissue. This is known as a localised cancer.

As the tumour grows, cancer cells can spread to other parts of the body by travelling through the bloodstream or lymphatic system. They may continue to grow into another tumour at this new site. This is called a secondary cancer or metastasis.

A metastasis keeps the name of the original cancer. For example, lung cancer that has spread to the bones is still called lung cancer, even though the person may be experiencing symptoms caused by problems in the bones.

How cancer spreads





Key questions

Q: What is cancer of unknown primary?

A: This is a cancer that has spread from somewhere else in the body, but it's not clear where in the body it started.

For most people who have cancer, the primary cancer is easy to identify. Doctors conduct tests to find where in the body the cancer started to grow. They may also do other tests to see if the cancer has spread.

When cancer is found in one or more secondary sites but the doctor can't tell from the test results where the cancer began, the cancer may be called cancer of unknown primary or CUP.

Q: Why can't the primary cancer be found?

A: This may be for several reasons.

- Your immune system may have destroyed the primary tumour, but not the secondary tumours (metastases).
- The secondary tumours may have grown and spread quickly, but the primary tumour is still too small to be seen on scans.
- The primary tumour may not be seen on x-rays or scans as it is hidden by secondaries that have grown close to it.
- The primary cancer may have spread throughout the body then disappeared. It is thought that primary tumours of the lining of the digestive system (from the mouth to the anus) may occasionally be passed out of the body through the bowel.

Q: Does it matter that the primary cancer can't be found?

A: Finding the primary cancer helps doctors decide what treatment to recommend. If it can't be found, the treatment path is less clear. However, doctors try to learn as much as they can about the spread of the cancer, the cells involved, your symptoms and medical history to help plan treatment.

Q: Will I need lots of tests?

A: Many people find they need several tests to try to find where the cancer started. The tests may take time and be tiring, particularly if you are feeling unwell. You may also feel frustrated if the tests don't find the site of the primary cancer.

You may want to talk to your doctor about how many tests you need. They will only suggest tests they feel are necessary. Ask your doctor or nurse to explain the tests you are having, as knowing more about the tests may help you make an informed decision.

At some point your doctors may decide that having more tests won't help find the primary site. It may be of more benefit to you to focus on controlling the symptoms.

Even if you decide against having further tests, you may find your family and friends encourage you to continue. This can be a challenging situation and it may help to explain your decision to your loved ones.

Q: What are the different cell types?

A: Even if tests can't find where the cancer started, your doctor will try to discover the type of cell the cancer developed from. Knowing the type of cell may give doctors a clue as to where the cancer started.

- **Adenocarcinoma** – Most people with CUP have cancers that develop from glandular cells, which are found in many organs of the body. Common primary sites for adenocarcinomas include breast, colon, prostate, stomach, pancreas, liver and lung.
- **Poorly differentiated carcinoma** – There is enough detail to tell that the cells are cancerous but they may look too abnormal to classify further under the microscope.
- **Squamous cell carcinoma** – These cancers look like the flat cells that are normally found on the surface of the skin or the lining of certain organs. About 5% of people with CUP have squamous cell cancers. Common sites include the head and neck area, skin, oesophagus, lungs and cervix.

Q: What are the causes?

A: Cancer is a group of more than 200 different diseases. Each type of cancer has different risk factors, such as getting older, poor diet, smoking, excessive alcohol consumption and being obese. These may play a role in CUP.

Q: What are the symptoms?

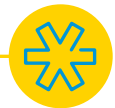
- A:** Symptoms are different for everyone and are related to the area where the secondary cancer is found. Some people with CUP have few or no symptoms; others have a range of symptoms that may include:
- shortness of breath
 - bone pain and/or back pain
 - swelling and discomfort in the abdomen, feeling sick (nausea), fluid collecting in the abdomen (ascites)
 - yellowing of the skin and eyes (jaundice)
 - swollen lymph nodes in the neck, underarm, chest or groin
 - looking pale, feeling tired and breathlessness due to a lack of red blood cells (anaemia).

You may also have general symptoms such as unexplained weight loss, no appetite or feeling extremely tired.

Q: How common is CUP?

- A:** CUP is the eighth most common cancer in Australia. It is the seventh most common cancer in women and the ninth most common in men. There are nearly 3,000 new cases of CUP diagnosed each year in Australia. It is more common in men than women and the risk increases with age.

Although CUP is a relatively common cancer, some people with CUP feel there is less support and information available for them.





Diagnosis

Usually you begin by seeing your general practitioner (GP). They will examine you and refer you to a specialist. The specialist will ask about your general health and any previous medical problems.

There are no standard tests for CUP. The information in this chapter describes the possible tests you may have. Each person's situation will probably be different. Often several different tests are needed to look for the primary cancer.

Blood tests – These will examine the number and type of blood cells and will measure the levels of certain blood chemicals.

Biopsy – Samples of tissue from a tumour or an enlarged lymph gland are removed for examination under a microscope.

Endoscopy – A procedure that uses an instrument called an endoscope to look inside the body and remove small tissue samples.

Imaging tests – Scans such as x-rays, ultrasounds, CT, MRI and PET scans create pictures of the inside of the body.

If these tests find where the cancer started, the cancer is no longer an unknown primary and is treated according to the tissue of origin.

“ I found it complex to talk to people about my cancer. I can explain it but they find it hard to understand. It does seem incomprehensible to have a cancer that has spread but no named starting point. ” Jane

Blood tests

Complete blood count – Blood is checked for levels of red blood cells, white blood cells and platelets.

Tumour markers – These are chemicals made by some cancer cells that can be measured in the blood. Your symptoms and gender help the doctor decide which markers to check. These may include:

- prostate specific antigen (PSA) – a high PSA level may indicate prostate cancer
- alpha-fetoprotein (AFP) – high levels may be a sign of testicular or liver cancer
- human chorionic gonadotrophin (HCG) – high levels of HCG can suggest cancer of the placenta or a rare type of ovarian cancer
- carcinoembryonic antigen (CEA) – may be raised in people who have bowel cancer. Other cancers that may have a high CEA level include lung, pancreas, stomach, ovarian, breast and thyroid
- cancer antigen 125 (CA 125) – may be high in women with ovarian cancer
- cancer antigen 19-9 (CA 19-9) – may be raised in people with stomach or pancreatic cancer.

Urine tests

Urine can be tested for any abnormal cells or substances and to see if there are any problems with organs such as the kidneys or bladder.

Biopsy

This is the most important test for diagnosing CUP. A biopsy is usually an outpatient procedure. It may be done with a general anaesthetic but it is often done under local anaesthetic. You may have one of the following types of biopsies:

- **Fine-needle aspiration** – The removal of cells from tissue using a thin needle.
- **Core** – The removal of tissue using a wide needle.
- **Excisional** – The surgical removal of an entire piece of tissue.

Lab tests of biopsy samples

Immunohistochemistry – Uses dyes to find particular proteins called antigens in cells of a tissue section. It uses antibodies that bind to these antigens.

Histology study – A stain is added to a sample of cancer cells and viewed under a microscope to look for specific changes in cells that are linked to certain types of cancer.

Endoscopy

This is a medical procedure used to look inside the body for any abnormal areas. A thin flexible tube with a camera on the end, called an endoscope, is inserted through one of the body's natural openings, such as the mouth, anus or vagina. The endoscope has a small cutting instrument on the end so a biopsy can be taken at the same time if something suspicious is seen.

Imaging tests

- **Bone scan** – This shows any abnormal areas of bones. A small amount of a radioactive dye is injected into a vein, usually in the arm. You will wait 2–3 hours to allow the dye to circulate and be absorbed by your body. A scan of your whole body is then taken and any abnormal areas show up as highlighted areas known as hot spots.
- **X-rays** – These create pictures of the inside of the body. X-rays of the chest and other parts of the body may be taken.
- **Mammogram** – An x-ray of the breast. The breast is positioned against an x-ray machine and gently but firmly compressed with a flat, clear, plastic plate. This test can be uncomfortable and may be painful for a short time.
- **CT (computerised tomography) scan** – This scan uses a series of x-rays to produce detailed pictures of the inside of the body. It can take up to 30 minutes. You may be given a drink or an injection of a dye to make particular areas easier to see.
- **MRI (magnetic resonance imaging) scan** – Uses a magnet and radio waves to take detailed pictures of an area of the body.
- **PET (positron emission tomography) scan** – Uses low-dose radioactive glucose injected into a vein to measure cell activity in different parts of the body. A scan is taken a couple of hours after the injection. Areas of cancer usually absorb more sugar than surrounding tissue and show up on the scan.

Which health professionals will I see?

The specialist you see will depend on the symptoms you have and the presumed location of the primary cancer as there are no formally recognised CUP specialists.

Specialist health professionals

gastroenterologist	digestive tract, bowel or stomach symptoms
gynaecologist	symptoms of the vagina, cervix, womb or ovaries (female reproductive system). Women who have fluid collecting in the abdomen (ascites) are usually seen by a gynaecologist
respiratory physician or thoracic surgeon	chest/lung symptoms

Multidisciplinary team

medical oncologist	prescribes and coordinates chemotherapy
radiation oncologist	prescribes and coordinates radiotherapy
radiation therapist	health professional who administers radiotherapy
surgeon	surgically removes tumours
nurses	administer drugs and support you through all stages of your treatment

It is common for people diagnosed with cancer to be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team.

urologist	urinary or kidney symptoms; disorders of the male reproductive system
haematologist	symptoms to do with your blood cells

cancer care coordinator	supports patients and families throughout treatment and liaises with other staff
palliative care doctors and nurses	work closely with the GP and oncologist to provide palliative care
dietitian	recommends the best eating plan to follow while you're in treatment and recovery
occupational therapist, physiotherapist	rehabilitate patients with physical problems
social worker, psychologist	link you to support services and help with emotional, physical or practical issues

Staging CUP

Staging means determining how far the cancer has spread. This information helps doctors plan the best treatment for you. Staging systems are different for every type of cancer. For most cancers there are four stages. The stage is worked out according to the size of the cancer, growth into nearby organs, and spread to lymph nodes or other organs in the body. Stage 1 is an early cancer and stage 4 is an advanced cancer.

With CUP, the cancer has spread beyond the primary site and must be at least stage 2 or higher.

Prognosis

Prognosis means the expected outcome of a disease. The doctor most familiar with your situation is the best person to discuss your prognosis with, but it is not possible for any doctor to predict the exact course of the disease.

Although most cancers of unknown primary can't be cured, treatment can keep some cancers of unknown primary under control for months or years. In other cases, treatment can relieve symptoms such as pain and help to improve quality of life. See page 24 for more information about palliative care.



Asking questions about prognosis is a personal decision. It is up to you to decide how much information you want.



Key points

- Cancer of unknown primary, or CUP, is the term used when cancer cells are found in the body but the place where the cancer started (the primary site) cannot be located.
- In most cases the primary cancer is never found.
- The symptoms of CUP are different for each person and will depend on where the cancer is found in the body.
- Many different tests are used to diagnose CUP. Taking a tissue sample (biopsy) is the most important test.
- Scans and tests can help your medical team decide on the best treatment plan.
- The doctors will assign a stage to your cancer based on diagnostic tests. The stage describes the size of the cancer and how far it has spread.
- Your doctor may talk to you about your prognosis. This is a general prediction about what may happen to you. No one can predict the exact course of your illness.
- You may see many health professionals who will work together as a multidisciplinary team to diagnose and treat you.



Treatment

When tests have been unable to find the primary cancer, CUP is confirmed. This is often a difficult time and it can be hard to accept that the primary will never be found. Some people may feel relieved that the tests are over and that treatment can start.

To work out what treatment to suggest your doctors will use the information they have about the cancer, including the location of the secondary cancer, test results and how likely it is to be a certain type of cancer.

CUP can be treated using chemotherapy, radiotherapy, surgery and hormone treatment or a combination of these. Treatment will depend on factors that are unique to your situation.

For many people, CUP is diagnosed at an advanced stage and treatment is unlikely to cure it. However, treatment may be able to control the cancer and improve your symptoms. It is possible that treatment may make you feel better and help you live longer. This is called palliative treatment (see page 24).

“ I was told I had metastatic neck cancer – unknown primary – by the first consultant I saw and he explained the risks of surgery. I did not want any treatment. All options seemed terrible. A second opinion changed that. This specialist had a more moderate approach. He also had the ability to help me see that I could face treatment. It was a huge turnaround. ” *Jane*

Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. The aim of chemotherapy is to kill cancer cells while doing the least possible damage to healthy cells.

Chemotherapy is one of the treatments for CUP. The drugs circulate through the bloodstream and can kill cancer cells throughout the body (called a systemic treatment). Chemotherapy is used to shrink tumours, and to relieve symptoms caused by the cancer. It can also be used in combination with radiotherapy or surgery to try and kill any local collections of cancer cells in the body.

Generally, chemotherapy is given intravenously through a drip or plastic tube (catheter) inserted into a vein in your arm, hand or chest. Some types of chemotherapy are taken orally (tablet form). Different cancer cells respond to different chemotherapy drugs. People with CUP may have a combination of drugs.

Chemotherapy is given in cycles, which consists of a treatment period followed by a recovery period. The number of treatment cycles you have may vary. You may be able to have treatment as an outpatient but sometimes a short stay in hospital is required.

Let your doctor know if you are taking nutritional or herbal supplements as these can interact with chemotherapy drugs and may be harmful.



Side effects

Most chemotherapy drugs cause side effects. Different drugs have different side effects and your medical oncologist or nurse will discuss them with you.

The most common side effects include feeling sick (nausea), vomiting, mouth sores, tiredness, loss of appetite, diarrhoea and some thinning or loss of hair from your body and head. These side effects are usually temporary, and can be prevented or reduced. Many go away once treatment is finished.

Chemotherapy temporarily weakens your immune system so your body may have trouble fighting infections. You will have regular blood tests to check your immune system. If you have a high temperature (38°C or above) while receiving chemotherapy, contact your medical oncology team or hospital immediately.

For more information, call Cancer Council Helpline **13 11 20** for a free booklet on chemotherapy.

Radiotherapy

Radiotherapy treats cancer by using x-ray beams to kill cancer cells. For CUP, radiotherapy can be used to relieve symptoms such as pain, bleeding, difficulty swallowing, breathlessness, blocking of the intestines, compression of blood vessels or nerves by tumours, and problems caused by the cancer spreading to the bones.

To plan radiotherapy treatment, your doctor will take an x-ray of the treatment area. To ensure that the same area is treated each time, the radiation therapist will make a few small marks

on your skin. Sometimes these are permanent tattoo marks. You may have treatment as external or internal radiotherapy. External radiotherapy is given from a machine outside the body, while internal radiotherapy is given using implants.

During external radiotherapy you will lie on a treatment table. A machine that delivers the radiation will be positioned around you. The treatment session will take about 10–15 minutes but it will take longer to set up the machine. Radiotherapy treatment is painless.

The total number of radiotherapy treatments and their duration will depend on your situation. Sometimes only a couple of treatments are necessary, or you may need radiotherapy every weekday for several weeks.

Side effects

The side effects of radiotherapy depend on the area of the body being treated and the dose of radiation.

Common side effects include nausea, loss of appetite, diarrhoea, tiredness and shortness of breath. It can also make your skin dry and itchy in the treatment area. Your skin may look red or sunburnt.

Side effects tend to develop as you go through treatment and most improve after treatment is finished.

Talk to your doctor or nurse about ways to manage the side effects of radiotherapy. Cancer Council's booklet on radiotherapy has a lot of useful information. Call the Helpline for a free copy.

Surgery

Surgery is a common treatment for many types of cancer if they are found at an early stage. With CUP, the cancer has already spread beyond the site where it started, so surgery may not be used as a treatment.

If the cancer is found in only one area (e.g. in the lymph nodes in the neck, underarm or groin) it may be possible to remove it with an operation. Small secondary cancers in the brain are sometimes removed in people who are well enough to have surgery and who don't have any other secondary cancers. If the cancer has spread extensively, it may not be possible to remove it all surgically.

Surgery may be followed by radiotherapy or chemotherapy to kill any cancer cells left in the body. Sometimes surgery is recommended to help with symptoms. For example, surgery may help relieve the discomfort or pain caused by a cancer pressing on a nerve or organ.

Side effects

Some people experience pain after surgery but this is often temporary. You can ask your doctor or nurse for pain-killers.

If you've had lymph nodes removed, you may develop lymphoedema. This is swelling

caused by a build up of fluid in part of the body, usually in an arm or leg. For more information see the Lymphoedema Association of Australia website at www.lymphoedema.org.au.

Hormone treatment

Hormones are substances that occur naturally in the body but they can also be synthetically made. Synthetic hormones are used to block the effect of the hormones in the body that help cancer cells grow. Hormone treatments may be taken as tablets by mouth or as injections.

Hormones may be used to treat hormone-dependent cancers such as breast, prostate or uterus where the cancer cells are stimulated to grow by oestrogen (breast cancer) or testosterone (prostate cancer). Hormone treatments are also sometimes used for kidney cancer and for melanoma. If CUP is thought to have originated in one of these organs, hormone therapy may be recommended to slow the growth of the cancer or shrink it.

Hormone treatment may be used in combination with other treatments, e.g. to shrink a tumour before radiotherapy or surgery.

Side effects

General side effects of hormone treatment include tiredness, nausea, diarrhoea, constipation, appetite changes, mood changes, pains in your joints and thinning of your bones. The side effects vary depending on the hormones you are given.

Women may experience menopause, which may be temporary or permanent. Men may have problems getting an erection.

For more information call Cancer Council Helpline.

Palliative care

Palliative care helps to improve people's quality of life by alleviating symptoms of cancer without trying to cure the disease. It brings together different services that work together as a team. It can include medical treatment, nursing care, social work, occupational therapy, physiotherapy, counselling and dietary assistance. You may have chemotherapy, radiotherapy or hormone therapy as palliative treatments.

Often palliative care is concerned with pain relief but it can also help manage other physical and emotional symptoms, such as depression. Palliative care:

- can be provided at home, a hospital or a palliative care unit
- is available at different stages of cancer
- regards dying as a natural event and does not prolong cancer treatment when it is no longer beneficial
- does not include deliberate ending of life (euthanasia)
- offers support for families and friends during a person's illness and in bereavement.

It is best to make contact with a palliative care team as early as possible. You can find out what the different team members do to work out which services might be useful now or in the future. This will vary according to how you feel, what problems you have and how your carers are managing. Talk to the team about any needs you have and how they can help you achieve your goals.

Call Cancer Council Helpline 13 11 20 to request free information about palliative care and advanced cancer.



Linda's story

My husband, Steve, was diagnosed with cancer of unknown primary. It started off with a sore back. Then he had trouble walking and the pain was unbearable.

Steve had some scans, which showed a mass. He was then referred to the hospital for further tests and an MRI.

They never found the primary site; they only found the secondary sites on my husband's spine, in his lungs and in his liver. The doctors said

the cancer was inoperable and untreatable.

He had chemotherapy and radiation to relieve his pain and to reduce the size of the secondary tumour on his spine.

I nursed Steve at home but took him to hospital for chemo. I gave him injections to help control his pain. We also had an excellent palliative care nurse visit every day.



Key points

- Treatment can help control the symptoms of CUP but it may not cure the disease.
- There are many types of treatment for CUP including chemotherapy, radiotherapy, surgery and hormone treatment. Your treatment will depend on the type of cancer cell, the suspected primary site and the location of the secondary cancer(s). It will also depend on your general fitness.
- Chemotherapy treats cancer with drugs.
- Most chemotherapy drugs cause side effects, such as nausea, vomiting, fatigue, hair loss, mouth sores, loss of appetite, diarrhoea, and increased risk of infections. Side effects depend on what kinds of drugs you are given.
- Radiotherapy treats cancer by using x-ray beams to kill cancer cells. It is painless but radiotherapy may cause burning on the skin, scarring or shortness of breath. Other side effects include tiredness and nausea.
- Surgery may be used to remove lymph nodes in the neck, underarm or groin.
- Hormone treatments are sometimes used to treat CUP, by slowing the growth of the cancer or shrinking it.
- Palliative care is treatment that helps improve quality of life.



Managing symptoms

Symptoms caused by CUP vary from person to person – you may have none or only a few. What you experience will depend on the size and location of the cancer and the type of treatment you receive. Symptoms can be treated. There are often things that you or your treatment team can do to prevent or manage them.

Pain

Many people with CUP worry that they will be in pain. Not everyone will experience pain and those who do may find their pain comes and goes. Pain depends on the location of the cancer and its size. If you do experience pain, it can usually be controlled.

Pain management is now recognised as a specialised field of medicine. Palliative care services specialise in pain management.

There are many ways to relieve pain, including:

- pain medications such as paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs), codeine and opioids
- a pain-relieving nerve block procedure
- epidural or spinal medication
- non-medication methods, such as massage, meditation, yoga or hypnotherapy
- treating the cause of the pain with chemotherapy, radiotherapy or surgery.

“ When you get pain relief right, there is really nothing better – even winning the lottery wouldn't be better. ”

Patient

You may need to use more than one of these pain-relieving methods. It may take time to find the right pain-control measure for you. If one method doesn't work, you can try something else.

How and where the pain is felt, and how it affects your life, can change. Regular reviews by pain management experts will help keep the pain under control. It's better to take medication regularly, rather than waiting for the pain to occur.

Treatments used to relieve pain

Chemotherapy, radiotherapy and surgery may be used to reduce pain, even though they may not be able to treat CUP.

Chemotherapy – This treatment can shrink the size of a cancer that is pressing on nerves or organs and causing pain.

many places in the bone – the radioactive drug settles in the bones near the cancer and helps to stop its growth and relieve pain.

Radiotherapy – This can relieve some types of pain. The number of treatments varies, but they may be fewer than when radiotherapy is used in early-stage cancer. Different types of radiotherapy may be used. Radioactive injections are sometimes used when the cancer has spread to

Surgery – Surgery may be done to remove an isolated tumour; treat a serious condition like a bowel obstruction that is causing pain; or improve outcomes from chemotherapy and radiotherapy by reducing the size of the cancer.

Nausea

Feeling sick in the stomach (nausea) is an unpleasant symptom that can be caused by:

- treatment with chemotherapy or radiotherapy
- the location of the cancer
- stress or anxiety
- an imbalance of minerals in the blood, e.g. calcium
- drugs that control other symptoms, e.g. morphine for pain
- a bowel obstruction or blockage
- increased pressure around the brain as a result of cancer in the brain or cancer affecting the fluid around the spinal cord.

You don't have to put up with nausea. Tell your doctor or nurse so they can treat you. They may prescribe anti-nausea medication or drugs that lower blood calcium levels, or suggest dietary changes.

tips

- Eat small meals as often as you can.
- Eat cold foods, such as sandwiches, salads, stewed fruit or jelly.
- Have food or drink with ginger, e.g. ginger ale, ginger tea or ginger cake.
- Avoid strong odours and cooking smells.
- Take anti-nausea medication regularly and before pain medication.
- Use stress reduction techniques such as meditation or relaxation.
- Call Cancer Council Helpline **13 11 20** for information on dealing with nausea and lack of appetite.

Breathlessness

Some people with CUP experience breathlessness. You may find the feeling of being breathless frightening. Feeling anxious can make breathlessness worse. Some of the causes of shortness of breath include:

- fluid surrounding the lungs (pleural effusion)
- having an infection in the lung
- the cancer itself
- anaemia
- pressure from a swollen abdomen
- chronic breathing disorders, such as asthma or emphysema.

Treatment will depend on what is causing the breathlessness. You may need fluid drained from the pleural cavity or medication prescribed for an infection or other lung problem. Opioid medication (often used for strong pain) is sometimes used to ease the distress of breathlessness, even when you have no pain.

tips

- Sit up to ease your breathing or lean forward resting on a table. You might want to try sleeping in a more upright position.
- Use a fan or open a window to get a draught of air moving near your face.
- Try to relax or practise breathing techniques. A physiotherapist can help you with different techniques, or listening to a meditation or relaxation CD might be useful.
- Try breathing in time with someone else, especially slowing your breath. This can be done during a breathless episode, or you can do it at other times, as practice for when you need it.

Lack of appetite

Lack of appetite is a common problem faced by people with CUP. Some people don't feel like eating because of stress from the diagnosis and treatment. The treatment may also change the way food tastes or smells. If you are feeling sick (nauseous) or have a sore mouth, this may also make you not want to eat.

You may go through periods of not wanting to eat. This may last a few days or weeks or it could be ongoing. You may be unable to eat the way you used to.

tips

- Eat small meals and snacks frequently.
- Use small dishes so food isn't 'lost' on the plate, such as soup in a cup or dessert in a wineglass.
- Avoid fatty, sugary and heavy food.
- Eat moist food, e.g. scrambled eggs or stewed fruit, which is less irritating to a sore mouth.
- Eat more of your favourite foods – follow your cravings.
- Add an egg, ice-cream or fruit to a drink to increase calories and nutrients.
- Use lemon juice and salt to add flavour to bland food.
- Try sipping clear liquids followed by something light such as biscuits.
- Let your doctor or nurse know if you're not eating properly due to a sore mouth, as this can be treated.
- Ask your dietitian if you can use nutrition supplements to help slow weight loss and maintain muscle strength. A dietitian can also advise you about other useful supplements.

Fatigue

For many people, extreme and constant tiredness (fatigue) can be a major problem. It can be very distressing for the person experiencing it and for those around them. Some people say their tiredness is worse than any pain or nausea they experience.

Tiredness can be caused by a range of things such as:

- progression of the cancer
- cancer treatment such as chemotherapy and radiotherapy
- inadequate nutrition causing loss of weight and muscle tone
- anxiety
- poor sleep
- drugs such as analgesics, antidepressants and sedatives
- anaemia (low red blood cell levels)
- infection.

tips

- Talk about the fatigue with your friends, relatives and supporters so it helps them understand how you feel.
- Plan to do things at the time of day when your tiredness is least severe.
- Research shows that gentle exercise reduces tiredness, helps preserve muscle strength and gives a sense of normality. Even activities such as walking to the letterbox, doing stretches or sitting out of bed for meals can help.
- Have a short rest during the day. Naps can refresh you without making it hard for you to sleep at night.
- Call Cancer Council Helpline for information about managing your fatigue.



Key points

- Treatment can affect the body in different ways and cause various symptoms.
- Not everyone experiences all the same symptoms and there are ways to treat them.
- Depending on the cancer and treatment(s) given, patients may experience other symptoms not listed in this chapter.
- Pain is a common symptom for people diagnosed with CUP. It can usually be controlled.
- Nausea can be caused by many things. Eating small meals may help.
- Treatment of breathlessness will depend on the cause. Relaxation and breathing techniques may help.
- Lack of appetite is a common problem faced by people with CUP. This may last a few days or weeks or be it could be ongoing.
- Fatigue can be a major issue for many people, and may be caused by anaemia.
- Talk to your health care team about any of the symptoms that you experience as they may be able to suggest ways to manage them.



Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast that you don't have time to think things through, but there is usually time to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your illness, the treatment and its side effects will help you make your own decisions.

- If you are offered a choice of treatments, you will need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, particularly those that affect your lifestyle.
- If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.
- If you have a partner, you may want to talk about treatment options with them. You can also talk to friends and family.

When treatment seems too much

For many people, deciding to have treatment when there is a possibility of cure seems worthwhile. However, when a cure seems unlikely, some people may wonder if cancer treatment is worth it. It may

seem less reasonable to have treatment that leaves you feeling exhausted or sick, even if it will help you to live longer.

Give yourself time to consider the possible benefits of

You have the right to accept or refuse any treatment. You can choose to stop treatment at any time.

Some people with CUP will choose cancer treatment, even if it only offers a small benefit. Others want to make sure the benefits of treatment outweigh any side effects, while others want to choose the treatment they consider offers them the best quality of life. Some people decide not to have treatment for the cancer, but to have symptoms managed to reduce pain and discomfort, and to make them feel as well as possible. Everyone has their own way of looking at this. No matter what you decide, you should discuss this with your family and friends.

Talking with doctors

When your doctor first tells you that you have cancer it is very stressful and you may not remember many details about what you are told. You may want to see the doctor a few times before deciding on treatment.

treatment against the possible side effects. If you are finding the side effects difficult to deal with, these can often be managed. It may be possible to stop treatment for a break or to reduce the dose.

Talk with your doctor, and family and friends. Their input may help clarify your thoughts. You can also speak to a counsellor or Cancer Council Helpline to help you weigh up what is best for you.

If your doctor uses medical terms you don't understand, it's okay to ask for a simpler explanation. You can also check the meaning of a word in the glossary (see page 49). You may be interested in looking for information on the Internet; some recommended sites are listed on page 47.

Before you see the doctor it may help to write down your questions – see the list of suggested questions on page 48. Taking notes or recording the discussion can also help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

tip

If you have a lot of questions for your doctor, you may want to book a longer appointment.

A second opinion

You may want to ask for a second opinion from another specialist. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.

Your specialist or general practitioner can refer you to another specialist and send them your test results. You can still ask for a second opinion even if you have started treatment or still want to be treated by your first doctor.

Taking part in a clinical trial

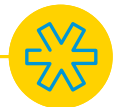
Your doctor may suggest you consider taking part in a clinical trial. These are carefully controlled research studies to test new or modified treatments to see if they are better than current treatments. There are trials for all sorts of treatments, including chemotherapy, radiotherapy, counselling, and medication for symptoms. Over the years, clinical trials have improved cancer treatment standards and led to better outcomes for patients.

If you decide to join a randomised controlled trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment for cancer.

For more information about clinical trials – such as questions to ask your doctor and how to find a trial that is suitable for you – call Cancer Council Helpline 13 11 20.

It may be difficult to find a suitable trial for CUP as it covers many different types of cancer.





Looking after yourself

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and anxiety, and improve well-being. Dealing with changes in your emotions and relationships early on is also very important.

Healthy eating

Eating nutritious food will help you to keep as well as possible and cope with cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help you to plan the best foods for your situation.

Cancer Council Helpline can send you free information about nutrition and cancer.

Being active

You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity, even if gentle or for a short duration, helps to improve circulation, reduces tiredness and elevates mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

If you aren't used to exercise or haven't exercised for awhile, make small changes to your daily activities. You could walk to the shops, take the stairs or do some gardening. To do more vigorous exercise or weight-bearing exercise, ask your medical team what is best for you.

Complementary therapies

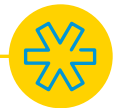
Complementary therapies are sometimes called natural therapies. They are used in conjunction with conventional medicine, such as chemotherapy or radiotherapy. Therapies include acupuncture, massage, hypnotherapy, herbal medicine, nutrition and relaxation. These may help you cope better with side effects and help you feel as well as possible. They may also increase your sense of control over what is happening to you, reduce your feelings of helplessness, decrease stress and anxiety, and improve your mood.

Some complementary therapies may reduce the amount of medication needed for pain control. Massage can also be a good release, but check with your medical team if there are areas of your body that are too tender or fragile to touch.

While some cancer treatment centres and palliative care units offer complementary therapies such as massage or meditation as part of their services, you may have to see a private practitioner.

Let your doctor know if you plan to use complementary therapies. This is important, as some therapies may not be appropriate, depending on your conventional treatment or what is happening in your body. For example, some herbs and nutritional supplements may interact with your medication, resulting in harmful side effects.

Call Cancer Council Helpline **13 11 20** for more information about complementary therapies.



Relationships with others

The strong emotions you experience as a result of a cancer diagnosis may affect your relationships. Your experiences may cause you to make some changes in your life or develop a new outlook on your values, priorities and life in general.

Sharing those thoughts and feelings with your family, friends and work colleagues may strengthen your relationships.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment. Calling Cancer Council Helpline may help build your confidence and help you discuss your feelings with others.

While you are giving yourself time to adjust to cancer, do the same for your friends and family. Everyone will react in a different way, by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting in their own way to changes. If someone's behaviour upsets you, it may help to discuss how you both feel about the situation.

“ The whole time I was on chemotherapy and radiotherapy, my friend called me everyday between 8–9am. She could hear if I was well by my voice. There aren't many friends like that around. ” *Patient*

Sexuality, intimacy and cancer

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, and your self-confidence. Knowing the potential challenges and addressing them will help you adjust to these changes.

Some people with cancer have the support of a partner, while others do not. If you meet a new partner during or after cancer treatment, it can be difficult to talk about cancer with them, particularly if it has had an impact on your sexuality.

Sexual intercourse may not always be possible during and immediately after treatment, but closeness and sharing are vital to a healthy relationship. Call Cancer Council Helpline 13 11 20 for more information on sexuality and cancer.

Some treatments may also affect your fertility permanently or temporarily. If having children or completing your family is important to you, then talk to your doctor before you start treatment.

Contraception

If you have certain types of treatment, such as chemotherapy, you may be advised to use contraception for 48 hours after treatment. This is to protect your partner from chemicals that may be in your body fluids. Talk to your medical oncologist or nurse about how these issues affect you and for advice on contraception.

Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about hair loss, weight changes and other physical changes, call Cancer Council Helpline.



Seeking support

Living with a CUP diagnosis

When you are first diagnosed with metastatic cancer, and throughout the different stage of treatment, you may experience a range of emotions, such as fear, sadness, anxiety, depression, anger and frustration.

You may find it hard to believe that the primary cancer can't be located. The 'unknown' aspect of the disease can make people feel scared and lonely, and frustrated when looking for information and support.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 45
- Cancer Council Helpline.

If you need assistance, such as help around the house, it may be hard to tell people what would be useful. Some people prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people are supportive, others may not know what to say to you. This can be difficult and may make you feel confused and upset. Cancer Council has information about coping with your emotions – call 13 11 20 for a free copy.

Practical and financial help

A serious illness may cause practical and financial problems. This can add to the stress and anxiety you may already be feeling about having cancer and going through treatment.

Many services are available to help so you don't have to face these difficulties alone:

- Financial assistance, through benefits and pensions, can help pay for prescription medicines, transport costs to medical appointments or general utility bills.
- Home nursing care may be available through community nursing services or local palliative care services.
- Meals on Wheels, home care services, aids and appliances can be arranged to help make life easier at home.

Check with the hospital social worker, occupational therapist or physiotherapist if these services are available in your state, or call Cancer Council Helpline.

Cancer Council library*

Following a cancer diagnosis many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Your local library may also have some relevant resources.

*This service is not available in Victoria and Queensland

Talk to someone who's been there

Getting in touch with other people who have been through a similar experience can be beneficial. In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Although there are no face-to-face specific CUP support groups, some people say they have found support online from others diagnosed with CUP. The UK site www.cupfoundjo.org has an online forum where you can chat with others.

Support services available in your community

- **Face-to-face support groups** – held in community centres, hospitals or over the phone
- **Online discussion forums** – where people can connect with each other any time – see www.cancerconnections.com.au
- **Telephone support groups and forums** – for certain situations or types of cancer, which trained counsellors facilitate.



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be very stressful. Try to look after yourself, give yourself some time out and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

Many cancer support groups are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many organisations and groups that can provide you with information and support, such as Carers Australia, the national peak body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information.

Call Cancer Council Helpline to find out more about different services or to request free information for carers.



Useful websites

The Internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

Australian

Your local Cancer Council

Australian Capital Territory	www.actcancer.org
New South Wales	www.cancercouncil.com.au
Northern Territory	www.cancercouncilnt.com.au
Queensland	www.cancerqld.org.au
South Australia	www.cancersa.org.au
Tasmania	www.cancertas.org.au
Victoria	www.cancervic.org.au
Western Australia	www.cancerwa.asn.au

National websites

Cancer Council Australia	www.cancer.org.au
Cancer Trials Online	www.australiancancertrials.gov.au
Cancer Voices Australia	www.cancervoicesaustralia.org.au

International

American Cancer Society	www.cancer.org
National Cancer Institute (US)	www.cancer.gov
Macmillan Cancer Support	www.macmillan.org.uk
Jo's Friends (UK)	www.cupfoundjo.org



Question checklist

You might find this checklist helpful when thinking about the questions you want to ask your doctor about your diagnosis and treatment. If your doctor gives you answers you don't understand, it is okay to ask for clarification.

- What kind of CUP do I have? Where are the secondaries?
- What tests do you recommend and why? How invasive will they be? What difference will these tests make?
- What happens if you can't find out where the cancer started? How will this affect your treatment?
- What treatment do you recommend and why?
- What will treatment involve?
- How much will treatment cost?
- What are the likely side effects of treatment?
- What can I do to help reduce the side effects I may have from treatment?
- If you find out where the primary cancer is, will my treatment change?
- What will happen if I don't have treatment?
- Are there any clinical trials I should think about taking part in?
- What are the chances that the cancer will come back if initial treatment seems to be successful? What will happen then?



Glossary

advanced cancer

Cancer that has spread from where it started (the primary site) to other parts of the body. If it has spread to distant parts of the body it is called metastatic advanced cancer.

alpha-fetoprotein (AFP)

A chemical that is used to determine if certain cancers are present, such as testicular or liver cancer.

anaemia

A reduction in the number or quality of red blood cells in the body.

antibody

Part of the body's immune system. Antibodies are proteins made by the blood in response to an invader (antigen) in the body. They help protect against viruses, bacteria and other foreign substances.

antigen

Any substance that causes the body's immune system to respond. This response often involves making antibodies.

benign

Not cancerous or malignant.

biopsy

The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease.

blood test

A test to look for abnormalities in a person's blood.

bone scan

A technique to create images of bones on a computer screen.

A small amount of radioactive dye is injected into a vein. It collects in the bones and is detected by a scanning machine.

CA125

A protein found in the blood. This protein is often higher than normal in women with ovarian cancer.

CA19-9

A chemical marker produced by some types of cancer, which can be found in the blood. It is sometimes raised in people with pancreatic or stomach cancer.

cancer of unknown primary

Cancer is found in the body but the place where the cancer first started growing (the primary site) cannot be determined.

carcinoembryonic antigen (CEA)

A chemical in the blood which, in part, can reflect the amount of cancer cells in the body.

cells

The basic building blocks of the body. A human is made of billions of cells, which are adapted for different functions.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth. Chemotherapy can also be used to reduce the size of the cancer and help lessen pain.

clinical trial

A research study that tests new and different ways of improving people's health.

complementary therapies

Supportive treatments that are used in conjunction with

conventional treatment. They may improve well-being and quality of life, and help people cope with side effects of cancer.

complete blood count

A test to check the number of red blood cells, white blood cells and platelets in a sample of blood.

core biopsy

A type of biopsy where a tissue sample is removed with a wide needle for examination under a microscope. Also called core needle aspiration.

CT scan

Computerised tomography scan. This scan uses x-rays to create a picture of the body.

endoscopy

A type of internal examination or diagnostic test. A thin, flexible tube called an endoscope is used to examine the body.

excisional biopsy

A type of biopsy where a lump is surgically removed (excised) so it can be looked at under a microscope.

fine needle aspiration

A type of biopsy where a thin needle is inserted into a lump to extract cells. Also called fine needle biopsy.

histology

The study of body tissues and cells under a microscope.

hormone

A chemical messenger in the body that transfers information between cells.

hormone treatment

A treatment that blocks the body's natural hormones that help cancer grow. Also called hormone therapy.

human chorionic gonadotrophin (HCG)

A hormone made by the body in early pregnancy. This hormone may also be produced by some types of cancer.

immune system

A network of cells and organs that defends the body against attacks by foreign invaders, such

as bacteria and viruses.

immunohistochemistry

A technique that uses antibodies to identify specific proteins called antigens in cells of a tissue sample.

lymph nodes

Small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells.

malignant

Cancer. Malignant cells spread (metastasise) and can eventually cause death if they cannot be treated.

mammogram

An x-ray of the breast.

metastasis

A cancer that has spread from where it started in the body to

another part of the body. Also called secondary cancer.

MRI scan

Magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

oncologist

A doctor who specialises in the study and treatment of cancer.

palliative care

The holistic care of people with a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual, social and practical needs. It is not just for people who are about to die, although end-of-life care is a part of palliative care.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer.

pathologist

A specialist who interprets the results of tests (e.g. biopsy or blood count) to diagnose diseases.

PET scan

Positron emission tomography scan. A specialised imaging test that uses low-dose radioactive glucose solution to identify cancer cells in the body.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

primary site

The part of the body where the cancer first developed.

prognosis

The expected outcome of a person's disease.

prostate specific antigen (PSA)

A protein produced by prostate cells and found in the blood.

High levels may indicate prostate cancer.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so that they cannot grow and multiply. Sometimes radiotherapy is used to control pain.

secondary cancer

See metastasis.

side effect

Unintended effect of a drug or treatment.

staging

Tests to find out how far the cancer has spread from an original site to other parts of the body.

tumour

A new or abnormal growth of tissue in the body. A tumour may be benign (not cancer) or malignant (cancer).

tumour markers

Chemicals produced by cancer cells and released into the blood. These may suggest the presence of a tumour in the body. The markers can be found by

blood tests or by testing tumour samples.

x-ray

A type of high energy radiation. X-rays are used to diagnose diseases by making pictures of the inside of the body.



How you can help

At Cancer Council we're dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events like Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any donation, whether large or small, will make a meaningful contribution to our fight to defeat cancer.

Buy sun protection products from our website or retail stores: Every purchase helps you prevent cancer and contributes financially to our work.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types.

To find out more about how you or your family and friends can help, please call your local Cancer Council.



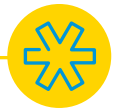
Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided throughout Australia for people affected by cancer.

For the cost of a local call (except from mobiles), you, your family, carers or friends can talk confidentially with oncology health professionals about any concerns you may have. Helpline consultants can send you information and put you in touch with services in your area. They can also assist with practical and emotional support.

You can call Cancer Council Helpline on 13 11 20 from anywhere in Australia, Monday to Friday, 9am to 5pm (or in South Australia or the Northern Territory 8.30am to 8pm).

If calling outside business hours, you can leave a message and your call will be returned the next business day.



For support and information on cancer and cancer-related issues, call the Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancer.org.au



Cancer Council
Helpline

13 11 20