



# Understanding Cancer of Unknown Primary

A guide for people with cancer,  
their families and friends

Cancer  
information

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**13 11 20**



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*Understanding Cancer of Unknown Primary* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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This booklet is funded through the generosity of the people of Australia.

### 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 medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

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Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# About this booklet

This booklet has been prepared to help you understand more about cancer of unknown primary (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 original (primary) site cannot be found. You may find it hard to believe that modern medicine cannot find where the cancer started.

We hope this booklet helps you, your family and friends understand how CUP is diagnosed and treated. We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may help you think about what to ask your treatment team (see page 48 for a question checklist).

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 (see page 49). You may also like to pass this booklet to family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by cancer. It is based on clinical practice guidelines for the diagnosis and treatment of CUP.<sup>1</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council**  
**13 11 20**

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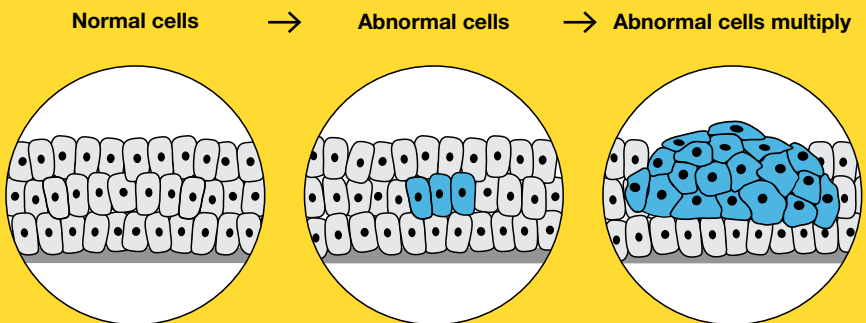
# What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as bowel cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours,

## How cancer starts

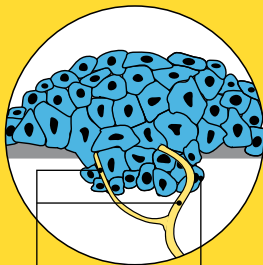


have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis.

A metastasis keeps the name of the original cancer, unless the primary cancer is unknown. For example, bowel cancer that has spread to the liver is called metastatic bowel cancer, even though the person may be experiencing symptoms caused by problems in the liver.

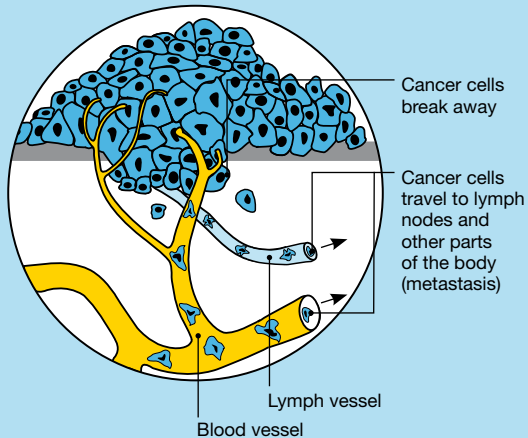
→ **Malignant cancer**



Grows own  
blood vessels  
(angiogenesis)

Invades  
surrounding  
tissue

**How cancer spreads**



Cancer cells  
break away

Cancer cells  
travel to lymph  
nodes and  
other parts  
of the body  
(metastasis)

Lymph vessel

Blood vessel



## Key questions

### Q: What is cancer of unknown primary?

**A:** Cancer of unknown primary (CUP) is when cancer cells are found in the body but the place the cancer began is not known. This means it is a secondary cancer that has spread to a new place from an unknown primary cancer somewhere else in the body.

For most people diagnosed with cancer, the primary cancer is easy to identify. Doctors conduct tests to find out where the cancer started to grow and to see if it has spread. When cancer is found in one or more secondary sites but it is not clear from the test results where the cancer began, the cancer is usually called cancer of unknown primary, or CUP. In some cases, health professionals may also call it metastasis of unknown origin (MUO), metastatic malignancy of unknown primary, or occult primary cancer.

CUP is considered advanced cancer. This means that your treatment may focus on controlling symptoms and helping you plan the best possible future care for yourself. In certain cases, doctors may actively treat the cancer while still making sure that symptoms are well managed and you have planned your future care. Your doctor will discuss the best approaches for you.



It is a shock to be told you have any type of advanced cancer. For information on coping with the diagnosis, read Cancer Council's *Living with Advanced Cancer* booklet. You can also listen to our podcast series *The Thing About Advanced Cancer*.



## Q: How can doctors tell it is a secondary cancer?

**A:** To diagnose secondary cancer, a specialist doctor called a pathologist looks at the cancer cells under a microscope.

The pathologist can see that the cancer cells do not belong to the surrounding tissue, and this can be confirmed by further tests on the cells. With CUP, the cancer cells might have come from a number of places.

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

**A:** There could be several reasons why your doctors cannot find the primary cancer. If you are diagnosed with CUP, it may be that:

- the secondary cancer has grown and spread quickly, but the primary cancer is still too small to be seen on scans
- your immune system has destroyed the primary cancer, but not the secondary cancer
- the primary cancer cannot be seen on x-rays, scans or endoscopies (see page 19) because it is hidden by a secondary cancer that has grown close to it
- the primary cancer was removed during surgery for another condition without realising the cancer was there, so some cancer cells remained behind and have since spread
- the primary cancer may have been too small to be found in tests – a single cell may have changed into cancerous cells and then spread through the body.

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

**A:** Finding the primary cancer helps doctors decide what treatment to recommend and gives them a better idea of how the cancer is likely to respond to treatment. If the primary cancer can't be found, tests on cells from the secondary cancer can often suggest what the primary cancer is most likely to be. This helps your doctor plan the treatment. They will also try to learn as much as possible about the spread of the cancer, your symptoms and your medical history.

## **Q: Will I need lots of tests?**

**A:** Most people with a new diagnosis of cancer need several tests. People with CUP may need extra 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 primary cancer.

Your doctors will only suggest tests that they think are needed. It is okay to ask your doctors to explain the tests and the difference the results will make to your care. You may also want to ask if there are any specialised tests available at another hospital or treatment centre that may help find the primary cancer.

At some point, your doctors may decide that having more tests won't help find the primary cancer and it would be better to focus on starting your treatment. If you do decide not to have further tests, you may find your family and friends encourage

you to continue having tests. This can be challenging, and it may help to explain your reasoning and share this booklet with them. Your medical team can provide support with these discussions.

## **Q: How common is CUP?**

**A:** CUP is a rare diagnosis. There are about 2600 new cases of CUP diagnosed each year in Australia. CUP is more likely to occur in people over the age of 60.<sup>2</sup>

## **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:

- feeling very tired (fatigue)
- poor appetite and/or feeling sick (nausea)
- unexplained weight loss
- shortness of breath or discomfort in the chest
- cough
- pain in the bones, back, head, abdomen or elsewhere
- swelling of the abdomen
- change in bowel habits, such as constipation or diarrhoea
- yellowing of the skin and eyes (jaundice)
- swollen lymph nodes in the neck, underarm, chest or groin.

Not everyone with the symptoms listed above will have cancer, but see your general practitioner (GP) if you are concerned.



## Gary's story

At the time of my diagnosis, I was working as a senior lawyer. One morning, I was on the phone to a client and looking out the window. I was running a hand over my chin when I felt a lump. I actually said to the client, "I've just felt this lump, so I'm going to see my GP. Goodbye."

I had to have a needle biopsy the next day and the results of that were significant. It was squamous cell carcinoma and it was metastatic.

The doctors did another couple of biopsies to look for the primary, but they couldn't find it. They guessed the cancer had started in my mouth, but I have a fair complexion and red hair, so it might also have started somewhere on my skin.

I had surgery to take out most of my molars, then more surgery to remove all the lymph nodes down one side of my neck.

Even though we hadn't found the primary cancer, I talked about the treatment options

with my doctors and we agreed to forge ahead. I was 51 and fit, so we decided on a broad approach with a combination of strong chemotherapy and radiation therapy.

The cancer diagnosis knocked me for six. I went into a deep black hole. The fact that it was CUP didn't affect me at the time – I actually didn't grasp what metastatic meant.

I like to think that I'm a fairly optimistic and together person, but after the treatment was over, I struggled with anxiety about the cancer recurring. The fact that the primary cancer wasn't found added to that anxiety – it was an extra element.

I ended up seeing a psychiatrist about a year after my treatment, but it would have been better to get that sort of help earlier.



For an overview of what to expect during all stages of your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/cancer-of-unknown-primary](https://cancerpathways.org.au/optimal-care-pathways/cancer-of-unknown-primary). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Q: What are the risk factors?

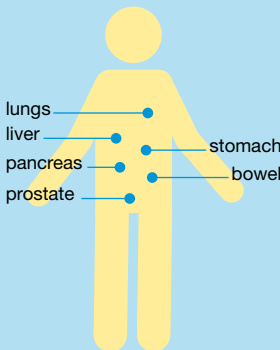
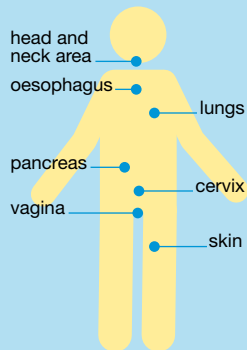
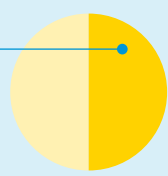
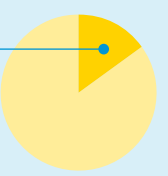
**A:** Different cases of CUP will have different causes, but without knowing where the cancer started, it's difficult to be specific. Cancer is a group of more than 200 different diseases. Each type of cancer has different risk factors, such as getting older, eating an unhealthy diet, smoking, drinking too much alcohol, your family history, being overweight or having certain infections. These risk factors may play a role in some cases of CUP.

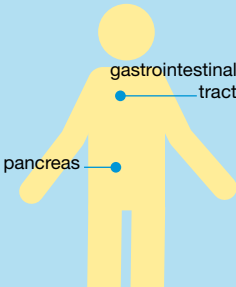
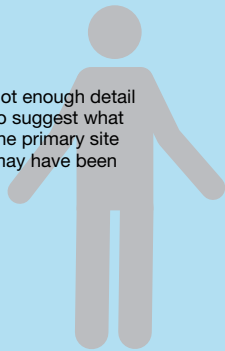
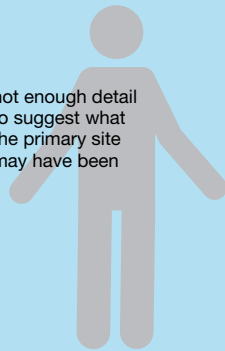
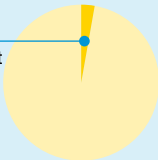
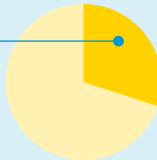
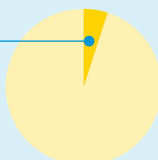
## Q: Are there different types of CUP?

**A:** Even if tests can't find where the cancer started, your doctor will try to work out what type of cell the cancer developed from. Knowing the type of cell helps doctors work out what sort of treatment is most likely to be helpful.

Most cancers are cancers of the epithelial cells, which are found in the lining of the skin and internal organs. These cancers are known as carcinomas. In most people with CUP, doctors can tell that they have some sort of carcinoma. There are different types of carcinoma depending on which type of epithelial cell is affected (see table on pages 12–13 for more information).

## Types of CUP

	adenocarcinoma	squamous cell carcinoma (SCC)
Which cells are affected?	develops from mucus-producing (glandular) cells, which form part of the lining of many organs	develops from squamous cells, which are thin, flat cells normally found on the surface of the skin or in the lining of some organs
Where might it have started?	 <p>lungs liver pancreas prostate stomach bowel</p>	 <p>head and neck area oesophagus lungs pancreas cervix vagina skin</p>
How common is it?	<p>makes up about <b>50%</b> of CUP cases</p> 	<p>makes up about <b>10–15%</b> of CUP cases</p> 

neuroendocrine carcinoma	poorly differentiated carcinoma	undifferentiated neoplasm
<p>develops from specialised nerve cells that sometimes produce hormones</p>	<p>there is enough detail to tell that the cells are a carcinoma, but not enough detail to work out the type of cancer</p>	<p>the cells can be identified as cancerous, but it is not possible to work out whether they are a carcinoma or another form of cancer such as a sarcoma or melanoma (neoplasm is another word for tumour)</p>
 <p>* less commonly may start elsewhere, such as in the lungs or gynaecological or urinary system</p>	 <p>not enough detail to suggest what the primary site may have been</p>	 <p>not enough detail to suggest what the primary site may have been</p>
<p>makes up about <b>3%</b> of CUP cases</p> 	<p>makes up about <b>30%</b> of CUP cases</p> 	<p>makes up about <b>5%</b> of CUP cases</p> 

## Q: Which health professionals will I see?

**A:** Your general practitioner (GP) will arrange the first tests. If these tests do not rule out cancer, you will usually be referred to a specialist for further tests. The specialist you see will often depend on the symptoms and the possible location of the cancer. For example, you may see a gastroenterologist (digestive tract, bowel or stomach), a gynaecologist (female reproductive system), a urologist (urinary tract or kidneys; male reproductive system), a respiratory physician or thoracic surgeon (chest and

### Health professionals you may see

<b>GP</b>	assists you with treatment decisions and works with your specialists in providing ongoing care
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>surgeon*</b>	surgically removes tumours and performs some biopsies
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>radiologist*</b>	analyses x-rays and scans; an interventional radiologist also does some biopsies and treatments
<b>pathologist*</b>	examines cells and tissue samples to determine the type and extent of the cancer
<b>tumour-specific specialists*</b>	specialise in particular areas of the body



lung), a neurologist/neurosurgeon (brain and spinal cord) or a haematologist (blood cells). Sometimes your main specialist will be a medical oncologist who treats all types of cancer.

If cancer is diagnosed, the specialist will consider the treatment options. Often these options will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see various health professionals who specialise in different aspects of your care.

<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>cancer care coordinator</b>	coordinates care and supports you and your family throughout treatment; may also be a clinical nurse consultant or clinical nurse specialist
<b>palliative care team</b>	works closely with the GP and cancer team to help control symptoms and maintain quality of life
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring movement and mobility
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues
<b>psychiatrist*, psychologist</b>	help you manage your emotional response to diagnosis and treatment

*\* Specialist doctor*



# Diagnosis

Before CUP is diagnosed, you will usually see your GP, who will ask about your symptoms, examine you, send you for tests and refer you to a specialist doctor (see pages 14–15). The specialist will ask you about any previous medical problems and arrange extra tests.

At first, the aim of the tests is to work out whether you have primary or secondary cancer. If the tests show that the cancer is secondary, more tests will be done to try to find the primary cancer. The tests you have will depend on your health and symptoms, the location of the secondary cancer and the suspected location of the primary cancer.

If the tests find where the cancer started, the cancer is no longer an unknown primary. It will then be treated like the primary cancer type. For example, bowel cancer that has spread to the liver will be given the treatment for advanced bowel cancer.

## Tests used to find where the cancer started

### blood and urine tests

samples of your blood and urine are sent to a laboratory to be checked for abnormal cells and chemicals called tumour markers – see opposite

### biopsy

a tissue sample is taken from a secondary tumour, an enlarged lymph node or bone marrow and sent to a laboratory for examination – see pages 17–18

### endoscopy/ colonoscopy

this procedure uses an instrument to look inside the body and take small tissue samples – see page 19

### imaging tests

X-rays; ultrasounds; and CT, PET-CT, MRI and bone scans create images of the inside of the body – see pages 20–21

## Blood and urine tests

A complete blood count is a test that checks the levels of red blood cells, white blood cells and platelets. Blood may also be tested to see how well the kidneys or liver are working. Urine may be tested to look for any abnormal cells or bleeding that may be coming from the bladder or kidneys. In some cases, blood and urine may also be tested for a protein that might help diagnose a blood cancer called myeloma.

Tumour markers are chemicals made by some cancer cells, and high levels are found in the blood, urine or other body fluids of some people with cancer. Markers that may suggest certain types of cancer include:

- **prostate specific antigen (PSA)** – prostate cancer
- **alpha-fetoprotein (AFP)** – testicular and liver cancers
- **human chorionic gonadotropin (HCG)** – testicular cancer and a rare type of ovarian cancer
- **carcinoembryonic antigen (CEA)** – bowel, lung, pancreatic, stomach, ovarian, breast, thyroid and liver cancers
- **cancer antigen 125 (CA125)** – ovarian, endometrial, fallopian tube and peritoneal cancers
- **cancer antigen 19-9 (CA 19-9)** – pancreatic, stomach, bile duct, gall bladder and ovarian cancers
- **cancer antigen 15-3 (CA15-3)** – breast cancer.

## Biopsy

A biopsy is the removal of a tissue sample for examination in a laboratory. It is usually the most important test in the diagnosis of CUP because it can show what type of cell has changed. This can point to where in the body the cancer may have started.

For a biopsy, you will usually have a local anaesthetic to numb the area, but in some cases, you may need a general anaesthetic, which makes you unconscious.

There are different ways to remove a biopsy sample. You may have one of the following procedures:

- **fine needle aspiration** – removes cells using a thin needle
- **core biopsy** – removes tissue using a wide needle
- **incisional biopsy** – cuts out only part of a tumour
- **excisional biopsy** – cuts out the whole tumour.

You might not have a biopsy if the cancer is too hard to reach or if you are too unwell for the procedure.

## Tests on the biopsy

If you have a biopsy, the sample will be sent to a laboratory, where a pathologist uses a series of stains on the sample. These stains may show changes in the cells or highlight proteins that are linked to various types of cancer.

In some cases, more specialised tests are done on the biopsy sample. These may include a genomic panel, a series of tests that looks for patterns of abnormalities within the cancer cells. The results may suggest what the primary cancer is most likely to be and which targeted therapy or immunotherapy drugs (see pages 29 and 30) may be helpful. This more extensive testing is usually part of research projects and it is not yet clear how useful it is for people with CUP. You can ask your cancer specialists for more information about these specialised tests.

## Endoscopy

This procedure is used to look inside the body for any abnormal areas. A thin, flexible tube with a light and camera on the end, called an endoscope, is inserted through a natural opening (such as the mouth) or through a small cut made by the surgeon. Your doctor can also use the endoscope to take a biopsy at the same time if they see something suspicious. The most common types of endoscopies are listed below.

Type of endoscopy	What may be checked	Where the tube is inserted
bronchoscopy or endobronchial ultrasound (EBUS)	lungs or respiratory tract (airways)	mouth or nose
colonoscopy	colon (large bowel)	anus
colposcopy	vagina and cervix	vagina held open by an instrument called a speculum so the doctor can look inside
cystoscopy	bladder	urethra
gastroscopy	stomach and first part of the small bowel	mouth
hysteroscopy	uterus (womb)	vagina
laparoscopy	stomach, liver, uterus	small cuts in abdomen
laryngoscopy	larynx (voice box)	mouth
sigmoidoscopy	lower part of the colon (large bowel)	anus
thoracoscopy	lungs	small cut in the chest

## Imaging tests

These scans create images of the inside of your body and provide different types of information. Your doctors will recommend the most useful scans for your situation.

Test	How it works	Duration
<b>x-ray</b>	uses low-level radiation to create images of parts of the body, such as bones and chest	10–30 mins
<b>mammogram</b>	uses a low-dose x-ray to create an image of the inside of the breast	10–30 mins
<b>ultrasound</b>	uses soundwaves to build up a picture of your body	10–20 mins
<b>CT scan (computerised tomography scan)</b>	uses multiple x-ray beams to produce detailed pictures of the inside of the body, showing blood vessels, soft tissue and bone all at once	up to 30 mins
<b>PET-CT scan (positron emission tomography scan with CT scan)</b>	a PET scan uses a low-dose radioactive glucose solution to measure cell activity in different parts of the body; combined with a CT scan	several hours
<b>bone scan</b>	uses radioactive dye to show any abnormal areas of the bones	several hours
<b>MRI scan (magnetic resonance imaging scan)</b>	uses a magnet and radio waves to take detailed pictures of an area of the body	30–90 mins

What happens	Special notes
<p>you hold still in front of or on a machine while the images are taken; you might be injected with a dye (contrast) to improve the image</p>	<p>painless; the small dose of radiation will not make you give off radiation</p>
<p>the breast is positioned against an x-ray plate and gently but firmly compressed with a clear plastic plate</p>	<p>can be uncomfortable</p>
<p>a device called a transducer is placed on or in your body, and sends out soundwaves that echo when they meet something dense, like a tumour; images are sent to a computer screen</p>	<p>usually painless, but can be uncomfortable</p>
<p>before the scan, you may be given a drink or an injection of a dye (contrast) to make the pictures clearer; you lie on a table that moves in and out of the scanner, which is large and round like a doughnut</p>	<p>for a few minutes, the dye may make you feel hot and cause a strange taste; tell your medical team if you've had a reaction to dyes during a previous scan</p>
<p>you will have an injection of the radioactive glucose, wait 30–90 minutes for it to circulate through your body, and then have a CT scan; cancer cells take up more glucose than normal cells do and light up on the scan</p>	<p>radioactive glucose leaves your body in urine after a few hours; you may be advised to avoid children and pregnant women for a number of hours</p>
<p>you are injected with a small amount of a radioactive dye, then wait 2–3 hours for it to circulate; your whole body is scanned; abnormal areas show up as brighter areas</p>	<p>radioactive dye leaves your body in urine after a few hours; you may be advised to avoid children and pregnant women for a number of hours</p>
<p>dye (contrast) may be injected into a vein to make the images clearer; you lie on a table that slides into a narrow metal cylinder that is open at both ends; the scan is noisy, so you will often be given earplugs or headphones</p>	<p>if you feel anxious about the cylinder, ask for a mild sedative beforehand; people with some pacemakers or other metallic objects cannot have an MRI</p>



Staging is a way to describe the spread of cancer. CUP cannot be given a stage because the primary cancer is not known and the cancer has already spread to other parts of the body when it is found.

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. To work out your prognosis, your doctor will consider test results; the type of CUP you have; the location, rate and depth of tumour growth; how well you respond to treatment; the impact the cancer has had on your health; and factors such as your age, fitness and medical history.

Although most cases of CUP can't be cured, treatment can keep some cancers under control for months or years. For example, some people who have CUP in just one small area (e.g. in a lymph node in the neck) are able to achieve long-term control, or sometimes even a cure, with surgery or high-dose chemoradiation (a combination of chemotherapy and radiation therapy). Whatever the prognosis, palliative treatment can relieve symptoms such as pain to improve quality of life. It can be used at any stage of advanced cancer. See page 32 for more information.

Discussing your prognosis and thinking about the future can be challenging and stressful. It is important to know that although the statistics for CUP can be frightening, they are an average and may not apply to your situation. Talk to your doctor about how to interpret any statistics that you come across.





## Key points about diagnosing CUP

### Diagnosis and prognosis

- Several different tests are used to try to identify the primary cancer.
- If any test finds where the cancer started, the cancer is no longer an unknown primary and is treated as the primary cancer type.
- Your doctor may talk to you about prognosis. This is a general prediction – no-one can predict the exact course of the illness.

### General tests

- Blood tests can check your general health, examine the number and type of blood cells, and measure the levels of tumour markers.
- Urine may also be tested for abnormal cells.

### Main tests

- Taking a tissue sample (biopsy) is the main test for CUP. The doctor may use a needle to take out the tissue (fine needle aspiration or core biopsy) or surgically remove the sample (incisional or excisional biopsy).
- An endoscopy is another way to look inside the body and remove small tissue samples. It uses a thin, flexible tube known as an endoscope. Different types of endoscopies are known by different names; for example, a colonoscopy checks the colon (large bowel).

### Imaging scans

- X-rays, ultrasounds, MRI, CT, PET-CT and bone scans may be used to create pictures of the inside of the body.
- Your doctor will recommend the most useful scans for your situation.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a short time. Ask them to explain the options, and take what time you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see pages 14–15) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help, or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 48 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

**Consider a second opinion** – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet.

### Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

➤ See our *Understanding Clinical Trials and Research* booklet.

## Treatment

When tests have been unable to find the primary cancer, you will be given a diagnosis of CUP. This is often a difficult time and it can be hard to accept that the primary site cannot be found. Some people may feel relieved that the tests are over and that the focus can now be on treatment options.

Your doctors will recommend treatment based on:

- what will give you the best outcome
- the location of the secondary cancer
- test results
- where in the body they suspect the cancer started
- your general health
- your preferences.

The most common treatment for CUP is chemotherapy. You may also have hormone therapy, targeted therapy, radiation therapy or surgery. Different types of treatment may be combined.

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 also help you live longer. This is called palliative treatment (see page 32).

“ I have 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

## Chemotherapy

Chemotherapy is the use of drugs to kill or slow down the growth of cancer cells. Medical oncologists and some other specialists prescribe chemotherapy to relieve symptoms caused by the cancer. It can also be used together with radiation therapy or surgery to try to kill any local collections of cancer cells in the body. As different cancer cells respond to different chemotherapy drugs, you may be given a combination of drugs.

You will usually be given the chemotherapy drugs by drip into a vein (intravenously), but some types are taken by mouth as tablets. The drugs circulate through the bloodstream and can kill cancer cells throughout the body (systemic treatment).

Chemotherapy is given in courses known as cycles. Typically, you will have chemotherapy as an outpatient, but sometimes a short stay in hospital is needed. Each cycle is followed by a recovery period. The number of treatment cycles you have depends on your situation. With CUP, it is recommended that your doctors test how the cancer responds to the chemotherapy after two or three cycles. This will allow you to weigh up the benefits of continuing against the effects on your quality of life.

### Side effects of chemotherapy

Most chemotherapy drugs cause side effects. Side effects are usually temporary, and can be prevented or reduced. The most common side effects include feeling sick (nausea), vomiting, mouth sores, tiredness, loss of appetite, diarrhoea or constipation, and some thinning or loss of hair from your body and head.

Chemotherapy weakens the immune system, making it harder for your body to fight infections. You will have regular blood tests to check your immune system. If your temperature rises to 38°C or above, contact your medical team or hospital immediately.

The side effects of some chemotherapy drugs can be longer lasting or permanent (e.g. damage to the heart or nerves). Ask your doctor to explain the potential risks and benefits of the chemotherapy recommended for you.

## Hormone therapy

Hormones are substances that occur naturally in the body. Some hormones can stimulate certain cancers to grow – for example, oestrogen and breast cancer. Hormone therapy uses hormones made in a laboratory (synthetic hormones) to block the effect of these natural hormones that are helping the cancer to grow.

If tests show that the CUP may have started as a cancer that is hormone dependent, your doctor might suggest hormone therapy. The treatment may be given as tablets or injections. It is sometimes used with other treatments.

## Side effects of hormone therapy

The side effects of hormone therapy will vary depending on the hormones you are given. General side effects include tiredness, nausea, appetite changes, weight gain, mood changes, pain in the joints, thinning of the bones (osteoporosis), hot flushes and erection problems.



You can call Cancer Council **13 11 20** to ask for our free booklets on chemotherapy, radiation therapy or surgery. You can also find the booklets on your local Cancer Council website, along with information about hormone therapy, targeted therapy and immunotherapy.

## Targeted therapy

Targeted therapy is a type of drug treatment that attacks particular features of cancer cells, known as molecular targets, to stop the cancer growing and spreading. Many targeted therapy drugs are given by mouth as tablets, but some are given by injection.

To check whether targeted therapy is suitable for your situation, your doctors need to test the cancer to see if the cells contain a particular molecular target that is helping the cancer grow. Different people with the same cancer type may receive different treatments based on their test results. Only a small number of CUP tumours will be suitable for a particular targeted therapy.

Clinical trials (see page 25) are testing combinations of chemotherapy and targeted therapy drugs to see whether they work for CUP.

## Side effects of targeted therapy

Targeted therapy drugs minimise harm to healthy cells, but they can still have side effects. These side effects vary greatly depending on the drug used and how your body responds. Common side effects of targeted therapy include tiredness, mouth ulcers, changes in appetite, fevers, allergic reactions, skin rashes and diarrhoea.

## Immunotherapy

Immunotherapy uses the body's own immune system to fight cancer. Sometimes the results of specialised tests on a CUP tumour may suggest that immunotherapy could help to treat the cancer. However, immunotherapy drugs currently approved for other cancers are still being tested within clinical trials to work out how often they help people with CUP. You can ask your specialist for more information.

## Radiation therapy

Radiation therapy, also known as radiotherapy, uses targeted radiation to kill or damage cancer cells. The radiation is usually in the form of x-ray beams. Most people with CUP have radiation therapy to relieve symptoms, such as bleeding, difficulty swallowing, shortness of breath, blockages in the bowel, tumours pressing on blood vessels or nerves, and pain caused by cancer spreading to the bones.

People with CUP are most likely to have external beam radiation therapy (EBRT), which is given from a machine outside the body. To help plan treatment, you will have an x-ray or CT scan of the treatment area. To ensure that the same area is treated each time, the radiation therapist will make a few small dots (tattoos) on your skin that may be temporary or permanent. Radiation treatments are painless. The total number of treatments and when you have them will depend on your situation. You might need only a single treatment, or you may need them every weekday for several weeks.

Some people with localised squamous cell carcinoma (see page 12) in the lymph nodes of the neck may be offered a combination of



chemotherapy and radiation therapy. This treatment is known as chemoradiation. It may be given for up to seven weeks.

## Side effects of radiation therapy

The side effects will depend on the area of the body being treated and the dose of radiation. The most common side effect is fatigue. Radiation therapy can also make your skin dry and itchy in the area treated. Your skin may look red or sunburnt and feel sore – talk to your radiation therapy team about creams and other ways to manage this.

Side effects tend to develop as you go through treatment, and most improve or go away in the weeks after treatment is finished. Talk to your doctor or nurse about ways to manage them.

## Surgery

Surgery removes cancer from the body. It is mostly used if cancer is found at an early stage, and is often followed by radiation therapy or chemotherapy to kill or reduce any cancer cells left in the body.

For many people, CUP has already spread to a number of places in the body, so surgery may not be the best treatment. If surgery is used, it may remove only some of the cancer. If the cancer is found only in the lymph nodes in the neck, underarm or groin, it may be possible to remove all of it with an operation. This is called a neck dissection or lymphadenectomy.

Sometimes surgery can help with symptoms – for example, to relieve pain caused by the tumour pressing on a nerve or organ.

## Side effects of surgery

Some people experience pain after surgery, but this is often temporary. Talk to your doctor or nurse about painkillers.

If lymph nodes have been removed, you may develop lymphoedema. This is swelling caused by a build-up of lymph fluid in part of the body, usually in an arm or leg. For more details, speak to your nurse, visit [lymphoedema.org.au](http://lymphoedema.org.au) or call Cancer Council 13 11 20.

➤ See our *Understanding Lymphoedema* fact sheet.

## Palliative treatment

Many people with CUP receive palliative treatment. This is treatment that aims to slow the spread of cancer and manage symptoms (see pages 34–40) without trying to cure the disease. It can be used at any stage of advanced cancer to improve quality of life and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can. Some people receive palliative treatment as well as active treatment of the cancer.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, social and spiritual needs. The team also provides support to families and carers. Specialist palliative care services see people with complex needs and can also advise other health professionals. Contacting a specialist palliative care service soon after diagnosis gives them the chance to get to know you. You can ask your doctor for a referral.

➤ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets and listen to our podcast about advanced cancer.



## Key points about treating CUP

### Overview

- Treatment can help control the symptoms of CUP, but it may not cure the disease.
- The best treatment for you will depend on the type of cancer cell, the suspected primary site, the location of the secondary cancer(s), and your general health.
- The aim of palliative treatment is to manage symptoms to improve quality of life. Try to get in touch with the palliative care team early.

### Types of treatments

- Chemotherapy treats cancer with drugs. Side effects depend on what kind of drugs you are given, but may include nausea, vomiting, mouth sores, tiredness, loss of appetite, diarrhoea or constipation, and hair loss. You may be at higher risk of infections.
- Hormone therapy is sometimes used to treat CUP that is growing in response to hormones.
- Targeted therapy and immunotherapy are newer types of cancer drugs. Clinical trials are testing their usefulness for CUP.
- Radiation therapy uses radiation such as x-ray beams to kill or damage cancer cells. Common side effects include tiredness and skin irritation.
- Surgery may be used to remove tumours or lymph nodes in the neck, underarm or groin. It is not always a treatment option for CUP.
- Many people with CUP need specialist palliative care to help with managing symptoms and planning care.



# Managing symptoms and side effects

Symptoms and side effects vary from person to person – you may have none or only a few. This chapter describes the most common symptoms and side effects experienced during treatment for CUP. You may experience others not mentioned here. Most symptoms and side effects can be relieved and some can even be prevented.

## Pain

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

There are many options for relieving pain. These include:

- pain medicines, such as paracetamol; ibuprofen and other non-steroidal anti-inflammatory drugs; and opioids
- an injection of pain-relieving drugs into the spinal column (epidural or spinal block)
- relaxation therapies, such as massage, meditation, mindfulness meditation or hypnotherapy
- treating the cause of the pain with chemotherapy, radiation therapy and surgery.

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

## Treatments used to relieve pain

Chemotherapy, radiation therapy and surgery are common cancer treatments. They may also be used as palliative treatment for pain.

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

**Radiation therapy** – This treatment can be used to relieve most types of pain. The most common form of radiation therapy for pain is external beam radiation therapy (see pages 30–31). If cancer has spread to many places in the bone and is causing pain, another form of radiation therapy may be used. In this case, the doctor gives you an injection of a radioactive form of the metal strontium, which then settles in the bones near the cancer.

**Surgery** – Surgery can sometimes remove an isolated tumour. It can also be used to treat a serious condition such as a bowel blockage (obstruction) that is causing pain, or to reduce the size of the cancer and improve the effectiveness of chemotherapy and radiation therapy.

## **Pain management experts**

Your GP or oncologist may be able to suggest effective medicine for your pain, but if you are still uncomfortable, you can ask to see a palliative care specialist. Good pain control is one of the major ways a specialist palliative care team can help someone whose pain is difficult to manage.

How and where the pain is felt, and how it affects your life, may change. Regular check-ups with pain management experts can help keep the pain under control. It's better to take your pain medicine regularly, rather than waiting for the pain to occur.

- See our *Overcoming Cancer Pain* booklet and listen to our podcast episode “Managing Pain when Cancer Is Advanced”.

## Fatigue

For many people, extreme and constant tiredness (fatigue) can be the most difficult symptom to manage. It can be very distressing both for the person experiencing it and for those around them. Tiredness can be caused by a range of things, such as:

- the cancer itself or cancer treatments
- low levels of red blood cells (anaemia) or high levels of calcium in the blood (hypercalcaemia)
- drugs such as pain medicines, antidepressants and sedatives
- infection
- poor nutrition causing loss of weight and muscle tone
- anxiety or low mood
- lack of sleep
- poorly managed pain.



### Tips for managing fatigue

- Pace yourself. Spread your activities throughout the day with rest periods in between.
  - Try to do gentle exercise. Research shows this reduces tiredness and preserves muscle strength. Even walking to the letterbox or getting up for meals can help.
  - Have a short nap of no more than 30 minutes during the day. This can refresh you without making it hard to sleep well at night.
  - Speak to an occupational therapist about ways to conserve energy.
  - Talk to your doctor if you often feel anxious or sad or if you are having trouble sleeping at night.
- See our *Fatigue and Cancer* fact sheet and listen to our podcast episode on fatigue.

## 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. You might also not want to eat much if you are feeling sick (nauseated) or have a sore mouth. These problems can often be treated, so let your treatment team know.

You may go through periods of having no appetite. These may last a few days or weeks, or be ongoing. During these periods, it may help to have liquid meal substitutes. These are high-kilojoule drinks containing some of the major nutrients needed by your body. Drinking these may help keep your energy levels up during periods when your appetite is poor.



### Tips for when you don't feel like eating

- Have small meals and snacks frequently throughout the day.
- Use small dishes so food isn't "lost" on the plate, e.g. serve soup in a cup.
- Choose full-fat foods over low-fat, light or diet versions.
- Use lemon juice, fresh herbs, ginger, garlic or honey to add more interesting flavours to bland food.
- Sip fluids throughout the day. Add ice-cream, yoghurt or fruit to drinks to increase kilojoules.
- If you have a sore mouth, eat soft food, such as scrambled eggs or stewed fruit.
- Ask your dietitian if you can use nutrition and protein supplements to help slow weight loss and maintain muscle strength.

## Nausea

Feeling sick in the stomach (nauseated) is an unpleasant symptom that may be caused by the cancer itself. Nausea can also be a side effect of some types of chemotherapy, but anti-nausea medicines can often prevent or manage this. Other causes of nausea include:

- treatment with radiation therapy
- stress or anxiety
- too much or too little of a mineral in the blood, e.g. calcium
- drugs used to control other symptoms, e.g. morphine for pain
- the kidneys not working properly
- an oral thrush infection, sometimes related to chemotherapy
- a bowel blockage (obstruction) or constipation
- increased pressure around the brain as a result of cancer in the brain or cancer affecting the fluid around the spinal cord.



### Tips for easing nausea

- Eat small meals as often as you can.
  - Eat cold foods, such as sandwiches, salads, stewed fruit or jelly.
  - Avoid strong odours and cooking smells.
  - Have food or drink that contains ginger, such as ginger ale, ginger tea or ginger cake.
  - Use stress-reduction techniques such as meditation or relaxation.
  - Talk to your doctor or nurse about anti-nausea drugs or treatments that can help relieve constipation.
- › See our *Nutrition and Cancer* booklet and listen to our podcast episode “Appetite Loss and Nausea”.



## Breathlessness

Some people with CUP experience shortness of breath. Causes of breathlessness include:

- fluid surrounding the lungs (pleural effusion)
- an infection in the lungs
- blood clot in the lung (pulmonary embolus)
- pressure from the cancer itself or from a swollen abdomen
- anaemia (low levels of red blood cells)
- chronic breathing disorders, such as asthma or emphysema.

Treatment will depend on what is causing the breathlessness. You may need fluid drained from the chest (pleural tap) or medicine for an infection or other lung problem. A low-dose opioid medicine (also used for strong pain) is sometimes prescribed.



### Tips to help your breathing

- Use a fan or open a window to get a draught of air moving near your face. A battery-operated handheld fan may be helpful.
- Sit up to ease your breathing or lean forward to rest on a table. Try sleeping in a more upright position.
- Ask someone else to breathe in time with you so you can focus on slowing your breath to their pace.
- Try relaxation or breathing techniques to see if they help. A physiotherapist can teach you these techniques, or you can listen to a meditation or relaxation recording.
- > Listen to our podcast episode “Managing Breathlessness when Cancer Is Advanced”.



## Key points about managing symptoms and side effects

### Overview

- Cancer and its treatment can affect the body in different ways and cause various symptoms and side effects.
- Talk to your treatment team about any symptoms or side effects that you experience. Your team can suggest ways to manage symptoms and side effects.

### Common symptoms and side effects

- Pain can usually be controlled with medicine, so tell your treatment team about any pain you have.
- Fatigue is a common problem for people with cancer. Ways to manage the tiredness include planning your day, doing gentle exercise and taking a short nap.
- Lack of appetite may last a few days or weeks or it could be ongoing. Try to increase your kilojoule intake by choosing full-fat products, adding extra ingredients to drinks, and following your cravings.
- Nausea can be caused by many things. Eating small meals may help. You can also talk to your treatment team about medicine or dietary changes to manage nausea.
- Shortness of breath may have various causes. If you become breathless, try to get a flow of air from a window or fan moving near your face. Relaxation and breathing techniques may also help.



# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

**Sexuality** – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

**Contraception and fertility** – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



# Seeking support


## Living with a CUP diagnosis

When you are first diagnosed with CUP, and throughout the different stages of treatment, you may experience a range of emotions, such as fear, sadness, uncertainty, anxiety, depression, anger and frustration. You may also find that some people are supportive, but others don't know what to say to you. This can be difficult and leave you feeling confused and upset.

Many people with CUP find it hard to believe that the primary cancer can't be located. The "unknown" aspect of the disease can make them feel scared and lonely, as well as frustrated when they are looking for information and support.

It may help to talk about your feelings. Your partner and your family members and friends can be good sources of support, or you might prefer to talk to members of your treatment or palliative care team; a counsellor, social worker or psychologist; or your religious or spiritual adviser.

You can also call Cancer Council 13 11 20 to talk about your concerns. Cancer Council 13 11 20 can help you connect with other people who are living with advanced cancer, and provide you with information about the emotional and practical aspects of living with CUP.

“It is really important to ask for help when you need it – whether it be for practical, financial or spiritual needs. Volunteers, in particular, can offer lots of practical support, as well as friendship.”  Leon

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline **13 11 14** or visit [lifeline.org.au](http://lifeline.org.au).

## Practical support

A cancer diagnosis can affect every aspect of your life and often creates practical and financial issues. There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including information about cancer and its treatment; access to benefits and programs to ease the financial impact of cancer treatment; home care services, such as Meals on Wheels, visiting nurses and home help; aids and appliances; support groups and programs; and counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost. To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

### Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



### Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

### Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



### Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

### Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).



## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Carers Australia	<a href="http://carersaustralia.com.au">carersaustralia.com.au</a>
Department of Health	<a href="http://health.gov.au">health.gov.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Optimal Care Pathways	<a href="http://cancerpathways.org.au">cancerpathways.org.au</a>
Palliative Care Australia	<a href="http://palliativecare.org.au">palliativecare.org.au</a>
Rare Cancers Australia	<a href="http://rarecancers.org.au">rarecancers.org.au</a>
Services Australia (including Medicare and Centrelink)	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
CUP Foundation – Jo’s friends (UK)	<a href="http://cupfoundjo.org">cupfoundjo.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>





# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides advocacy and information for carers, and is the national peak body representing them to the Australian Government. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



# Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

## Diagnosis

- Is there any sign of where the cancer started or what type of cancer it is?
- What tests do you recommend and why? How invasive will they be?
- What type of genetic tests might be useful?
- Are the latest tests and treatments for CUP available in this hospital?
- Can you explain the results of the tests to me?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

## Treatment

- What happens if you can't find where the cancer started?
- What treatment do you recommend? What is the aim of the treatment?
- If you find out where the primary cancer is, will my treatment change?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- Are there any clinical trials or research studies I could join?
- Are there any new drugs that might be beneficial to me?
- Who can help me manage my symptoms, make treatment choices and plan for my future? Can you tell me about advance care planning?

## Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?



# Glossary

## **adenocarcinoma**

Cancer that starts in the mucus-producing (glandular) cells that form part of the lining of internal organs. Most cancers of the breast, pancreas, lung, prostate and colon are adenocarcinomas.

## **advanced cancer**

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and help manage symptoms.

## **anaemia**

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

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure.

## **antibody**

Part of the body's immune system. Antibodies are proteins made by the blood in response to an invader (antigen) in the body.

## **antigen**

Any substance that causes the immune system to respond, often prompting the blood to make 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.

## **cancer of unknown primary (CUP)**

A diagnosis given when doctors find a secondary cancer in the body, but tests

don't show where the cancer first started growing (the primary site). Also known as metastasis of unknown origin (MUO), metastatic malignancy of unknown primary, or occult primary cancer.

## **carcinoma**

A cancer that starts in the cells lining the skin and internal organs of the body (epithelial cells).

## **cells**

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

## **chemotherapy**

A treatment that uses drugs to kill cancer cells or slow their growth. It can also be used as a palliative treatment to shrink the cancer and help lessen pain.

## **core biopsy**

A type of biopsy that uses a wide needle to remove a tissue sample.

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

## **endoscopy**

A procedure that uses a thin, flexible tube with a light and camera (endoscope) to examine inside the body.

## **fine needle aspiration**

A type of biopsy where a sample of cells is removed with a thin needle. Also called fine needle biopsy.

## **genomic panel**

A series of tests that looks for patterns of abnormalities within cancer cells.

### **hormones**

Chemicals in the body that send information between cells to control growth and reproduction.

### **hormone therapy**

A treatment that blocks the body's natural hormones. It is used when the cancer is growing in response to hormones. Also called endocrine therapy.

### **lymph nodes**

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

### **malignant**

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

### **mammogram**

A low-dose x-ray of the breast.

### **medical oncologist**

A doctor who specialises in treating cancer with drug therapies such as chemotherapy, hormone therapy, targeted therapy and immunotherapy.

### **metastasis (plural: metastases)**

See secondary cancer.

### **MRI scan**

Magnetic resonance imaging scan. It uses magnetic fields and radio waves to take cross-sectional pictures of the body.

### **myeloma**

Cancer of the white blood cells known as plasma cells.

### **neoplasm**

See tumour.

### **neuroendocrine carcinoma**

A cancer that starts in specialised nerve cells that sometimes produce hormones.

### **opioids**

The strongest pain medicines available. Opioids include morphine, fentanyl, codeine, oxycodone, hydromorphone and methadone.

### **palliative care**

The holistic care of people who have a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, cultural, spiritual and social needs. Also known as supportive care.

### **palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other symptoms of cancer. Treatment may include radiation therapy, chemotherapy or other therapies. It is an important part of palliative care.

### **pathologist**

A specialist doctor who interprets the results of tests (such as blood tests and biopsies).

### **PET-CT scan**

Positron emission tomography scan combined with CT scan. In the PET scan, a person is injected with a radioactive glucose solution that makes cancerous areas brighter on the scan.

### **platelets**

One of the three main types of cells found in the blood. Platelets help the blood to clot and stop bleeding. Also called thrombocytes.

### 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.

### prognosis

The expected outcome of a particular person's disease.

### radiation oncologist

A doctor who specialises in treating cancer with radiation therapy.

### radiation therapy

The use of targeted radiation, usually x-ray beams, to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

### red blood cells

One of the three main types of cells found in the blood. They carry oxygen around the body. Also called erythrocytes.

### secondary cancer

A cancer that has spread from a primary cancer in another part of the body. Also known as metastatic or advanced cancer.

### squamous cell carcinoma (SCC)

Cancer that starts in the squamous cells, which are flat cells found on the surface of the skin or the lining of some organs.

### tumour

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

### tumour marker

Chemical produced by cancer cells and released into the blood. It may suggest the presence of a tumour in the body.

### ultrasound

A scan that uses soundwaves to create a picture of part of the body.

### white blood cells

One of the three main types of cells found in the blood. They help fight infection.

### x-ray

A test that uses a low dose of radiation to create images of areas inside the body. Also, the type of radiation used in this test, in CT scans and in most radiation therapy.

### Can't find a word here?

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## References

1. K Fizazi et al. on behalf of the ESMO Guidelines Committee, "Cancers of unknown primary site: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 26, suppl. 5, 2015, pp. v133–v138.
2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia, Australian Cancer Incidence and Mortality (ACIM) books: cancer of unknown primary site*, AIHW, Canberra, 2018.



## How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

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

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**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 important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

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



# Cancer Council

## 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

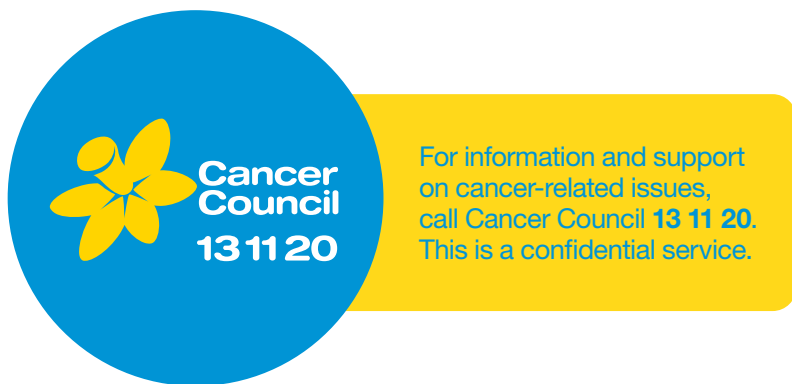
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*