

Understanding Cancer of Unknown Primary

A guide for people with cancer, their families and friends



For information & support, call **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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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.

Cancer Council

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 or call your local Cancer Council.



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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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 your doctors and modern medicine cannot find where the cancer started.

We hope this booklet will help 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.¹



If you or your family have any questions or concerns, 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).

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Key to icons

Icons are used throughout this booklet to indicate:



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Alert



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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. These abnormal cells may turn into cancer.

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.

How cancer starts

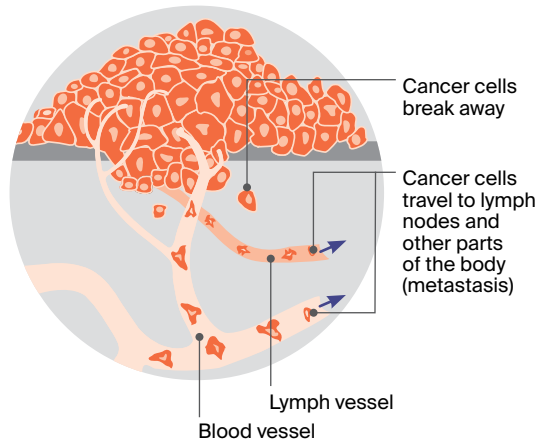


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break 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 this is unknown. For example, bowel cancer that has spread to the liver is called metastatic bowel cancer, even though the main symptoms may be coming from the liver.

How cancer spreads

.....▶ Malignant cancer



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.

With CUP, secondary cancers are commonly found in the liver, lung, abdomen, bones and lymph nodes, although they can grow in any part of the body.

Health professionals may also call CUP metastatic malignancy of unknown primary or occult primary cancer.

Q: How do doctors know that it is a secondary cancer?

A: To diagnose secondary cancer, a specialist doctor called a pathologist looks at the cancer cells under a microscope. They can see that the cancer cells do not belong to the surrounding tissue, and this can be confirmed by further tests on the cells (see *Tumour markers*, page 17). With CUP, there are many different places in the body the cancer cells might have started.

Q: How common is CUP?

A: CUP is not very common. 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 60.²

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

A: 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. Sometimes, however, cancer is found in one or more secondary sites and test results can't show where the cancer began.

Reasons why your doctors cannot find the primary cancer include:

- the secondary cancer has grown quickly, but the primary cancer is still too small to be seen on scans or found on tests
- your immune system has destroyed the primary cancer, but not the secondary cancer
- the primary cancer can't be seen on x-rays, imaging scans or endoscopies (see page 19) because it's hidden by a secondary cancer that has grown close to or over it
- the cancer may be found in many parts of the body, but it isn't clear from the scans or pathology tests which is the primary cancer.

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

A: Finding the primary cancer can help doctors decide what treatment to recommend and give 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 to plan treatment.

“I have found it complex to talk to people about my cancer... It seems incomprehensible to have a cancer that has spread but has no named starting point.” JANE

Q: Can CUP be treated?

A: It can be frightening to be diagnosed with CUP, but there are treatments available. Your doctor will discuss the best options for you. The aim of treatment may be to:

- **Slow the cancer's growth or spread and prolong overall survival** – In many cases, doctors may actively treat the cancer but not be able to cure it. In some cases, CUP presents in a pattern that is very like cancers from a known primary and can respond well to the same kind of treatment, even though the primary can't be found.
- **Relieve symptoms and maintain quality of life** – CUP usually presents as advanced cancer, so treatment may focus on controlling symptoms and helping you plan the best possible future care for yourself. This is known as palliative treatment.
- **Remove as much of the cancer as possible** – In a small number of cases, CUP is found as a small area of cancer that may be able to be removed with surgery or high-dose radiation.

Q: Will I need lots of tests?

A: Most people with a new diagnosis of cancer need several tests to find out how far the cancer has spread throughout the body.

People with CUP may need extra tests to try to find where the cancer started (for more information on tests, see pages 16–21). The tests may take time and be tiring, particularly if you are feeling unwell. Waiting for the results can be a stressful time. 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 treatment. Even if you decide not to have more tests, your family and friends may encourage you to continue having tests. This can be challenging. It may help to explain why you want to stop testing and share this booklet with them. Your medical team can provide support with these discussions.

Q: What are the symptoms?

A: Symptoms of CUP are different for everyone and are related to the area where the secondary cancer is found. Some people have few or no symptoms; others have a range of symptoms that may include:

- swollen lymph nodes in the neck, underarm, chest or groin
- 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).

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.

Q: What are the risk factors?

A: A risk factor is anything that increases your chance of developing cancer. CUP can have many different risk factors but without knowing where the cancer started, it's difficult to be specific.

Examples of things that can increase a person's risk of developing cancer are getting older, eating an unhealthy diet, smoking, not being physically active, drinking too much alcohol, spending too much time in the sun, a family history of cancer, and being overweight. Some of these things you can change and others you can't. These risk factors may play a role in some but not all 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.

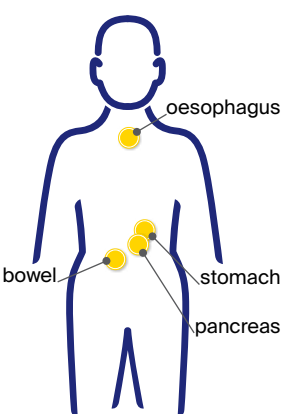
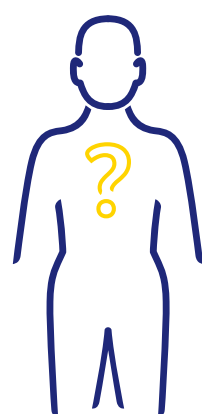
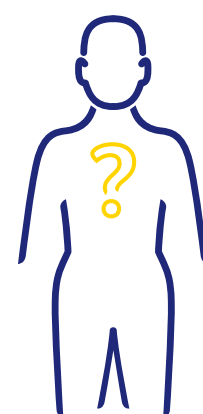
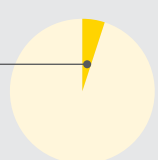
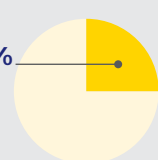
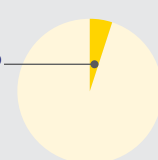
Most cancers are cancers of the epithelial cells, which are found in the lining of the skin and internal organs. These cancers are known as carcinomas. In most people with CUP, doctors can tell that they have some sort of carcinoma. There are different types of carcinoma depending on which type of epithelial cell is affected (see table on next 2 pages for more information). Your doctor will explain the type of CUP you have.



For an overview of what to expect during all stages of your cancer care for CUP, visit cancer.org.au/cancercareguides/cancer-of-unknown-primary. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Types of cancer of unknown primary (CUP)

	adenocarcinoma	squamous cell carcinoma (SCC)
Which cells are affected?	mucus-producing (glandular) cells, which form part of the lining of many organs	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>oesophagus lung liver breast bowel stomach ovary uterus pancreas prostate</p>	<p>head and neck area oesophagus lung cervix vagina anus skin</p>
How common is it?	<p>about 60% of CUP cases</p>	<p>about 5% of CUP cases</p>

neuroendocrine carcinoma	poorly differentiated carcinoma	undifferentiated neoplasm (tumour)
<p>specialised neuroendocrine cells found throughout the body that sometimes produce hormones</p>	<p>tests show that the cancer cells are a carcinoma, but don't show the specific type of epithelial cell affected</p>	<p>unknown – tests show that the cells are cancerous, but not whether they are a carcinoma or another form of cancer (such as a sarcoma or melanoma)</p>
 <p>oesophagus</p> <p>bowel</p> <p>stomach</p> <p>pancreas</p> <p>less commonly may start elsewhere such as in the lungs or gynaecological or urinary systems</p>	 <p>not enough detail to suggest where the primary site may have been</p>	 <p>not enough detail to suggest where the primary site may have been</p>
<p>about 5% of CUP cases</p> 	<p>about 25% of CUP cases</p> 	<p>about 5% of CUP cases</p> 

Q: Which health professionals will I see?

A: Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist for further tests.

The type of specialist you see will depend on your symptoms, the suspected location of the cancer and the types of tests you need. For example, you may see a gastroenterologist (digestive tract, bowel or stomach), gynaecologist (female reproductive system),

Health professionals you may see

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
surgeon*	surgically removes tumours and performs some biopsies; specialist cancer surgeons are called surgical oncologists
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
radiologist*	analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments
pathologist*	examines cells and tissue samples to determine the type and extent of the cancer
nurse or nurse practitioner	administers drugs and provides care, information and support throughout treatment; a nurse practitioner works in an advanced nursing role and may prescribe some medicines and tests

urologist (urinary tract or kidneys; male reproductive system), respiratory physician or thoracic surgeon (chest and lung), neurosurgeon (brain and spinal cord), ear nose and throat surgeon, or 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 treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting.

palliative care specialists* and nurses	work closely with the GP and cancer team to help control symptoms and maintain quality of life
pharmacist	dispenses medicines and gives advice about dosage and side effects
dietitian	helps with nutrition concerns and recommends changes to diet during treatment and recovery
physiotherapist, exercise physiologist	help restore movement and mobility, and improve fitness and wellbeing
social worker	links you to support services and helps you with emotional, practical and financial issues
psychologist, psychiatrist*	help you manage your emotional response to diagnosis and treatment
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; may be a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)

** Specialist doctor*

Diagnosis

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

The specialist will arrange extra tests 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 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 page)
biopsy	a tissue sample is taken from a tumour, enlarged lymph node or bone marrow and sent to a laboratory for examination; tests on the sample can suggest the primary site (see pages 17–18)
endoscopy	uses an instrument to look inside the body and take small tissue samples (see page 19)
imaging tests	x-rays, ultrasounds and other scans create images of the inside of the body (see pages 20–21); PET-CT scans have been shown to help find the primary site in new cases of CUP



The diagnosis and treatment of CUP can be complex and you might need to travel to a specialist centre. Call Cancer Council 13 11 20 to ask about patient travel assistance that may be available to you.

Blood and urine tests

A full blood count is a test that checks the levels of red blood cells, white blood cells and platelets. Blood tests can also show how well the kidneys and liver are working. Urine may be tested to look for any abnormal cells or bleeding that may be coming from the bladder or kidneys.

Tumour markers

In some cases, blood, urine or tissue samples may be tested for tumour markers. These are proteins made by some cancer cells. High levels of tumour markers may suggest cancer. However, other conditions can also raise the levels of tumour markers, and some people with cancer have normal levels. Tumour marker levels can't be used on their own to diagnose the primary cancer, but they may suggest certain types of cancer for your doctors to look for.

Biopsy

A biopsy is when doctors remove a sample of cells or tissue from an area of the body. A specialist doctor called a pathologist examines the sample under a microscope to look for signs of cancer and work out what type of cell is affected. 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. In some cases, you may need a general anaesthetic, which puts you to sleep.

Ways of taking biopsies

There are different ways of taking a biopsy and you may need more than one type. A biopsy is often done using an ultrasound or CT scan to guide the needle to the correct place. You might not have a biopsy if the cancer is too hard to reach or if you are too unwell for the procedure.

Common types of biopsies used to diagnose cancer include:

- **fine needle aspiration** – removes cells using a thin needle
- **core biopsy** – removes tissue using a hollow needle
- **incision biopsy** – cuts out part of a tumour
- **excision biopsy** – cuts out the whole tumour.

Tests on the biopsy sample

Using special stains (immunohistochemistry) – After the biopsy procedure, 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 markers (e.g. specific proteins) that are linked to certain types of cancer.

Looking at the molecular level – In some cases, you may be offered extra tests on the biopsy sample. These are called molecular or genomic tests, and they look for gene changes and other features in the cancer cells that may be causing them to multiply and grow. The results may suggest what the primary cancer is most likely to be and which targeted therapy drugs (see page 29) may work best to treat it.

Molecular testing for CUP is not covered by Medicare, which can make it expensive. Check what costs are involved and how helpful it would be. If you are having molecular testing as part of a clinical trial (see page 25), the costs may be covered. 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. It is done with an endoscope – a thin, flexible tube with a light and camera on the end. The endoscope is put into the body through a natural opening (such as the mouth) or a small cut made by the surgeon. The camera projects images onto a monitor so the doctor can see inside the body. If they see something suspicious, they can also take a tissue sample (biopsy) using the endoscope.

Common types of endoscopy

Type	What is checked	Where inserted
bronchoscopy or endobronchial ultrasound (EBUS)	lungs or respiratory tract (airways)	mouth or nose
colonoscopy	colon (large bowel)	anus
colposcopy	vagina and cervix	placed outside the vulva and vagina, held open by a speculum
cystoscopy	bladder	urethra
gastroscopy	oesophagus, stomach and first part of the small bowel	mouth
hysteroscopy	uterus (womb)	vagina
laparoscopy	abdominal cavity, liver, bowel, uterus and ovaries	small cuts in abdomen
laryngoscopy	larynx (voice box)	mouth
sigmoidoscopy	lower part of the colon (large bowel)	anus
thoracoscopy	lungs	small cut in 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. Ask your doctor or imaging centre what you will have to pay and whether Medicare covers the cost.

Test	How it works	How long
x-ray	uses low-energy beams of radiation to create images of parts of the body, such as bones and the chest	10–30 mins
mammogram	uses a low-dose x-ray to create an image of the inside of the breast	10–30 mins
ultrasound	uses soundwaves that echo when they meet something solid, such as an organ or tumour; a computer turns the soundwaves into a picture of the inside of the body	10–20 mins
CT scan (computerised tomography scan)	uses x-ray beams and a computer to create detailed pictures of the inside of the body; the scanner is large and round like a doughnut	up to 30 mins
PET-CT scan (positron emission tomography scan with CT scan)	uses a low-dose radioactive solution to measure cell activity in different parts of the body; when combined with a CT scan it provides more detailed information about the cancer	about 2 hours
bone scan	uses radioactive dye to show any abnormal bone growth	several hours
MRI scan (magnetic resonance imaging scan)	uses a magnet and radio waves to build up detailed pictures of an area of the body	30–90 mins

Before having scans, tell the doctor if you have any allergies or have had a reaction to dyes during previous scans. You should also let them know if you have diabetes or kidney disease, or are pregnant or breastfeeding.

What happens	Special notes
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	painless; the small dose of radiation will not make you give off radiation
your breast is placed between 2 x-ray plates, which press together firmly to spread the breast tissue	can be uncomfortable
a cool gel is spread on your skin and a handheld device called a transducer sends out the soundwaves as it is moved across the area; some transducers are wands that can be inserted in a body cavity	usually painless, but can be uncomfortable
before the scan, you may be given a drink or injected with a dye (contrast) to make the pictures clearer; you lie still on a table that moves in and out of the scanner	painless; the dye may make you feel hot all over and leave a bitter taste in your mouth
you are injected in the arm with a small amount of radioactive solution, wait 30–90 minutes for it to move through your body, and then have the scan; cancer cells take up more of the solution than normal cells do and light up on the scan	the solution leaves your body in urine after a few hours; you may be told to avoid children and pregnant women for a number of hours
you are injected in the arm with a small amount of radioactive dye, wait 2–3 hours for it to move through your bloodstream to the bones, then your body is scanned; a larger amount of dye will usually show up in any areas of bone with cancer cells	the dye leaves your body in urine after a few hours; you may be told to avoid children and pregnant women for a number of hours
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	let the medical team know if you feel anxious, you may be given medicine to help you relax; people with some pacemakers or other metallic objects cannot have an MRI



Staging is a way to describe how far a cancer has spread. 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. This is considered advanced cancer. For more information, read our *Living with Advanced Cancer* booklet and listen to our podcast series, *The Thing About Advanced Cancer*.

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; where the cancer is located and how far it has spread through the body; how fast the cancer is growing; 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. 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 as no-one can predict the exact outcome of a disease.

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 tumour (incision or excision biopsy).
- An endoscopy is a way to look inside the body and remove small tissue samples. It uses a thin, flexible tube known as an endoscope.
- There are different types of endoscopy – e.g. a colonoscopy checks the colon (large bowel).
- Tests can be performed on the tissue sample that may suggest, and sometimes confirm, the primary site.

Imaging tests

- A range of imaging 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 page 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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 designed for people with CUP.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods.

Clinical trials also provide a way for people with CUP to have extra tests that may help show where the

primary cancer is and other tests not covered by Medicare.

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.

► 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. On the other hand, you may feel relieved that the tests are over and that the focus can now be on treating the cancer.

Your treatment plan

The treatment recommended by your doctors will depend on:

- where the secondary cancer is in the body and how far it has spread
- where they think the cancer started
- how quickly the cancer seems to be growing
- how you are feeling (your symptoms)
- your general health, age and treatment preferences
- what treatments are currently available and whether there are any newer treatments available on clinical trials (see previous page)
- the aim of treatment (whether to remove as much of the cancer as possible, slow the cancer's growth or relieve symptoms).

The most common treatment for CUP is chemotherapy, and many people also have radiation therapy and surgery. Some cancers may respond to hormone therapy, targeted therapy or immunotherapy. Your doctor may suggest a combination of treatments.



Call Cancer Council 13 11 20 and ask for our free booklets on chemotherapy, radiation therapy or surgery. Or visit your local Cancer Council website for copies, along with information on hormone therapy, targeted therapy and immunotherapy.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells or slow their growth. Medical oncologists and some other specialists prescribe chemotherapy to shrink a cancer and relieve symptoms. It can also be used together with radiation therapy or surgery to try to kill a collection of cancer cells in the body.

How chemotherapy is given – Generally, chemotherapy is given through a drip inserted into a vein (intravenously), but some types are taken by mouth as tablets. As different cancer cells respond to different chemotherapy drugs, you may have a combination of drugs.

Chemotherapy is commonly given as a period of treatment followed by a break. This is called a cycle. The length of the cycle depends on the drugs used. Usually, you will have chemotherapy during day visits to a hospital or treatment centre. Sometimes a short stay in hospital is needed.

Number of sessions – The total number of treatment cycles you have depends on your situation. With CUP, after 2 or 3 cycles you will usually have imaging scans to test how the cancer is responding to the drugs. The results will let you weigh up the benefits of continuing the treatment against the effects on your quality of life. It may also mean a change in treatment if the chemotherapy is not shrinking the cancer.

Side effects of chemotherapy

Most chemotherapy drugs cause side effects. These 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 body's immune system, making it harder 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 go to the nearest hospital emergency department 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 cancers depend on hormones to grow (e.g. oestrogen may help breast cancer grow). Hormone therapy aims to lower the amount of hormones in the body in order to slow or stop the cancer's growth. The treatment may be given as tablets you swallow or injections. If tests show that the CUP may have started as a cancer that is hormone dependent, your doctor might suggest hormone therapy. 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. Common 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.



It is important to tell your treatment team about any side effects you have from drug therapies. Side effects can be better managed when reported early. You may be given medicine to prevent or reduce side effects. Sometimes, your doctor may delay treatment or reduce the dose to lessen side effects.



You may be able to get other drugs to treat CUP through clinical trials (see page 25). Ask your doctor about recent developments and whether a clinical trial may be an option for you.

Targeted therapy

This is a type of drug therapy that attacks specific features of cancer cells to stop the cancer growing and spreading. Many targeted therapy drugs are given by mouth as tablets, but some are given by injection.

Only a small number of CUP tumours will be suitable for targeted therapy. Your doctors will need to test the cancer to see if the cells have a particular cell change that is helping the cancer grow (see page 18).

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 skin rashes, fever, tiredness, joint aches, nausea, diarrhoea, bleeding and bruising, and high blood pressure.

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.

The usefulness of immunotherapy for CUP is still being tested, so it is not funded on the Pharmaceutical Benefits Scheme (PBS) for CUP. However, it may be accessed on the PBS if test results strongly suggest that you have one of the cancer types for which it is funded (e.g. lung, kidney or bladder cancer). Ask your specialist for more information.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of 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 pain, bleeding, difficulty swallowing, bowel blockages, shortness of breath, and tumours pressing on blood vessels or nerves or within bones.

Having radiation therapy – 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 usually have a 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, although it can be uncomfortable lying on a hard treatment table.

Number of sessions – 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.

Chemoradiation – If squamous cell carcinoma (see page 12) spreads to the lymph nodes (e.g. in the neck or groin area), you may be offered a combination of chemotherapy and radiation therapy. This treatment is known as chemoradiation. It may be given for up to 7 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. Nausea or altered sense of taste can sometimes occur. Your skin may become dry and itchy in the area treated, look red or sunburnt and feel sore.

Side effects tend to develop as you go through radiation therapy, and most improve or go away in the weeks after you finish treatment. Talk to your doctor or nurse about ways to manage any side effects you have.

Surgery

Surgery removes cancer from the body. It is mostly used if cancer is found at an early stage. If CUP has already spread to a number of places in the body, surgery may not be the best treatment. If surgery is used, it may remove only some of the cancer. Surgery is often followed by radiation therapy or chemotherapy to kill or shrink any cancer cells left in the body.

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 lymph node 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

After surgery, you may have some side effects. These will depend on the type of operation you have. Your surgeon will talk to you about the risks and complications of your procedure. These may include infection, bleeding and blood clots. You may experience pain after surgery, but this is often temporary. Talk to your doctor or nurse about pain relief.

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 or call Cancer Council 13 11 20.

► See our *Understanding Lymphoedema* fact sheet.

“There is still a life to be lived and pleasures to be found and disappointments to be had. Living with advanced cancer is a different life, not just a journey towards death.” JULIE

Palliative treatment

Most people with CUP receive palliative treatment. This is treatment that aims to slow the spread of cancer and relieve symptoms without trying to cure the disease.

Cancer treatments such as surgery, radiation therapy, chemotherapy or other medicines are often given palliatively. It is possible that palliative treatment may make you feel better and also help you live longer.

You might think that palliative treatment is only for people at the end of their life, but it may help at any stage of advanced cancer. It is about living for as long as possible in the most satisfying way you can.

What is palliative care?

Palliative care supports the needs of people with a life-limiting illness in a holistic way.

The main goal is to help you maintain your quality of life by dealing with your physical, emotional, cultural, spiritual and social needs. Palliative care also provides support to families and carers.

Specialist palliative care services don't prescribe cancer treatments, but help people with CUP manage symptoms related to the cancer. They can also help you work out how to live in the most fulfilling way you can. You can ask your doctor for a referral.

► See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Key points about treating CUP

Overview

- 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 treatment may be to remove as much of the cancer as possible, slow the cancer's growth or relieve symptoms.

Types of treatment

- Chemotherapy treats cancer with drugs. Side effects depend on the drugs you are given, but may include nausea, vomiting, mouth sores, tiredness, loss of appetite, diarrhoea or constipation, and hair loss. You may also 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 drug therapies that may be suitable for some CUP cases.
- Radiation therapy uses a controlled dose of radiation 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.
- Cancer treatments such as chemotherapy and radiation therapy can be given palliatively to slow the spread of the cancer and make you feel better.
- Many people with CUP need specialist palliative care to help with managing symptoms and maintaining quality of life.

Managing symptoms and side effects

Symptoms and side effects vary from person to person – you may have none, a few or many. This chapter describes the most common symptoms and side effects experienced during treatment for CUP. You may have others not mentioned here. Talk to your treatment team about ways to manage any symptoms and side effects you have.

Pain

Many people with cancer worry that they will be in pain. Not everyone will have pain, and those who do may find the pain comes and goes. Pain is affected by the location of the cancer and its size. Ways to relieve pain include:

- pain medicines, such as paracetamol, ibuprofen and other non-steroidal anti-inflammatory drugs, and opioids (e.g. oxycodone, morphine)
- medicines that are normally used for other conditions, such as antidepressants and anticonvulsants (known as adjuvant analgesics)
- procedures to block pain signals (e.g. nerve blocks or spinal injections)
- therapies, such as massage, meditation, relaxation, hypnotherapy, exercise and physical therapy
- psychological therapies that can change the way you think about and respond to pain
- cancer treatments used palliatively (see opposite page).

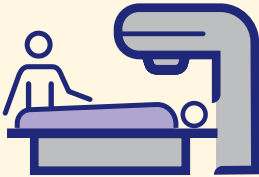
Often a combination of methods is needed and it may take time to find the right pain relief for you. If one method doesn't work, you can try something else.

▶ See our *Understanding Cancer Pain* booklet.

Using cancer treatments to control pain

Chemotherapy, radiation therapy and surgery are common cancer treatments. They can sometimes be used palliatively to reduce pain by helping to remove its cause.

Radiation therapy



This treatment can be used to relieve many types of pain. The most common form of radiation therapy for pain is external beam radiation therapy (see page 30). If cancer has spread to many places in the bone and is causing pain, you may have another form of radiation therapy.

Cancer drug therapies



In some cases, chemotherapy, hormone therapy, targeted therapy and immunotherapy can shrink a tumour that is pressing on nerves or organs and causing pain.

Surgery



Some people have an operation to remove part or all of a tumour. Surgery 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 a cancer and improve how well chemotherapy and radiation therapy work.

Pain management experts



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

Fatigue

For many people, feeling tired and lacking energy (fatigue) can be the most difficult symptom to manage. It can be very frustrating if other people don't understand how you're feeling.

Fatigue 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
- loss of weight and muscle tone
- anxiety or depression
- 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.
- Speak to an occupational therapist about ways to conserve energy.
- 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.
- 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 episodes on fatigue and sleep.

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
- a bowel blockage (obstruction) or constipation
- increased pressure around the brain as a result of cancer in the brain or cancer affecting the flow of fluid around the brain and spinal cord.



Tips for easing nausea

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

Loss of appetite

Not feeling like eating is a common problem faced by people with CUP. This may be caused by the cancer itself or side effects of treatment. You may not enjoy the way food tastes or smells, or you may be worried about the diagnosis and treatment. You might also not want to eat much if you are feeling sick (nauseated) or have a sore mouth or oral thrush infection. These problems can often be managed, 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).
- Use lemon juice, fresh herbs, ginger, garlic or honey to add more interesting flavours to food.
- Sip fluids throughout the day. Add ice-cream, yoghurt or fruit to drinks to increase the kilojoules.
- Choose full-fat foods over low-fat, light or diet versions.
- If you have a sore mouth, eat soft food, such as scrambled eggs or stewed fruit.
- Ask your dietitian or doctor to recommend the right nutritional supplement for you to help slow weight loss and maintain your muscle strength.

Breathlessness

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

- fluid surrounding the lungs (pleural effusion)
- an infection in the lungs
- a blood clot in the lungs (pulmonary embolism)
- pressure from the cancer itself or from a swollen abdomen
- anaemia (low levels of red blood cells).

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

Feeling short of breath may make you feel anxious, which can make the breathlessness worse. Your doctor or a psychologist can help you find ways to manage any anxiety.



Tips to help your breathing

- Use a battery-operated handheld fan or open a window to increase airflow near your face.
- Sit up straight to ease your breathing or lean forward on a table with an arm crossed over a pillow. Try sleeping in a more upright position.
- Try relaxation or breathing techniques to see if they help. A physiotherapist or psychologist can teach you these techniques. You can also try listening to recorded meditation or relaxation exercises.
- Ask someone else to breathe in time with you so you can focus on slowing your breath to their pace.
- ▶ Listen to our podcast episode “Managing Breathlessness when Cancer Is Advanced” or our *Finding Calm During Cancer* podcast.

Key points about managing 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. They can suggest ways to manage or lessen them.

Common symptoms and side effects

- Pain can usually be controlled with medicine, cancer treatments used palliatively, and other therapies.
- 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.
- Nausea can be caused by many things. Eating small meals may help. You can also talk to your treatment team about medicine or ways to change what you eat to manage nausea.
- Loss of appetite may last a few days or weeks, or it could be ongoing. Try to have more kilojoules by adding extra ingredients to drinks, choosing full-fat foods, and following your cravings.
- Breathlessness may have various causes. Treatment will depend on what is making you feel short of breath. Your doctor can suggest ways to manage your breathing. You can also try sleeping upright, using a handheld fan and relaxation techniques.

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 for People Living with 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ 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. The experience of cancer 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 (see next page). 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.

For many people with CUP, the cancer cannot be cured. Talking to your health care team can help you understand your situation and plan for your future care. Palliative treatments (see page 32) may stop the cancer growing and allow you to continue doing the things you enjoy for months or even several years.

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 social worker, psychologist or counsellor; or your spiritual adviser.

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.

- ▶ See our *Living with Advanced Cancer* booklet and listen to *The Thing About Advanced Cancer* podcast.

How you might feel

Being diagnosed with CUP can be stressful. It is natural to have a wide variety of emotions, including anxiety, anger, fear, sadness and resentment. These feelings may become stronger over time as you adjust to the side effects of treatment.

Everyone has their own ways of coping. There is no right or wrong way. It is important to give yourself time to deal with the emotions that a cancer diagnosis can cause.

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 cancer.

If you think you may be depressed or feel that your emotions are affecting your day-to-day life, talk to your GP. Counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. 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. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Practical support

A cancer diagnosis can affect every aspect of your life and may create practical and financial issues. There are many sources of support to help you, your family and carers navigate the cancer experience. These include benefits and programs to ease the financial impact; home care services; aids and appliances; support groups; and counselling services.

Availability of services may vary depending on where you live, and some services will be free but others might have a cost. For more information, 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 by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 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.

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.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

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.

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	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Guides to Best Cancer Care	cancer.org.au/cancercareguides
Australian Cancer Trials	australiancancertrials.gov.au
Cancer Australia	canceraustralia.gov.au
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Department of Health and Aged Care	health.gov.au
Healthdirect Australia	healthdirect.gov.au
Palliative Care Australia	palliativecare.org.au
Rare Cancers Australia	rarecancers.org.au
Services Australia (including Centrelink and Medicare)	servicesaustralia.gov.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
CUP Foundation – Jo's friends (UK)	cupfoundjo.org
Macmillan Cancer Support (UK)	macmillan.org.uk

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.

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. Visit 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? What will they cost?
 - What type of specialised 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?
-

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 of help to me?
 - Who will be my main point of contact during my treatment?
 - Who can help me manage my symptoms and make treatment choices?
 - Who can help me 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

abdomen

The part of the body between the chest and hips, which contains the stomach, liver, bowel, kidneys and uterus. Also known as the belly.

adenocarcinoma

Cancer that starts in the mucus-producing (glandular) cells that form part of the lining of internal organs. Includes most cancers of the breast, pancreas, lung, prostate and bowel.

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 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. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

antibody

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

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 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 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 perform different functions.

chemotherapy

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

core biopsy

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

CT scan

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

endoscopy

An examination of the inside of the body using a thin, flexible tube with a light and camera on the end (endoscope).

fine needle aspiration

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

genomic test

A test that checks a number of genes at once to look for patterns of changes.

hormones

Chemicals in the body that send information between cells. Hormones control many of the body's functions, including how people grow, develop and reproduce.

hormone therapy

A treatment that blocks the body's natural hormones. It may be used when the cancer is growing in response to hormones.

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. 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 (systemic treatment).

metastasis (plural: metastases)

See secondary cancer.

molecular test

A test that looks for changes in the genes involved in cancer.

MRI scan

Magnetic resonance imaging scan.

A scan that uses magnetic fields and radio waves to take cross-sectional pictures of the body.

neoplasm

See tumour.

neuroendocrine carcinoma

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

opioids

The strongest pain medicines available. They 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. Treatment may include radiation therapy, chemotherapy or other therapies.

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 a PET scan, a person is injected with a low-dose radioactive solution. This makes cancerous areas show up brighter on the scan.

platelets

One of the 3 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 to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

red blood cells

One of the 3 main types of cells found in the blood. They carry oxygen around the body.

secondary cancer

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

speculum

An instrument used to hold open the vagina during an internal examination to see the vagina and cervix more clearly.

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, such as the mouth, lungs, vagina and cervix.

surgery

A procedure performed by a surgeon to remove or repair a part of the body. Also known as an operation or surgical resection.

tumour

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

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 3 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
 - cancervic.org.au/glossary
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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 2022*, AIHW, Canberra, viewed 7 July 2022, available from aihw.gov.au/reports/cancer/cancer-data-in-australia/data.



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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council Queensland
cancerqld.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council NSW
cancercouncil.com.au

Cancer Council SA
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cancerwa.asn.au

Cancer Council NT
cancer.org.au/nt

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To support Cancer Council, call your local Cancer Council or visit your local website.*

