



Understanding Cancer of Unknown Primary

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



Understanding Cancer of Unknown Primary

A guide for people with cancer, their families and friends

First published July 2001. This edition May 2016.

© Cancer Council Australia 2016. ISBN 978 1 925136 87 6

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

Editor: Jenni Bruce. Designer: Paula Marchant. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: A/Prof Linda Mileshkin, Medical Oncologist, Peter MacCallum Cancer Centre, VIC; Dr Sarwan Bishnoi, Medical Oncologist, Adelaide Cancer Centre, SA; Dave Clark, Consumer; Dr Jan Maree Davis, Area Director, Palliative Care Service, Calvary Health Care and St George Hospital, NSW; Linda Tompsitt, Cancer Nurse 13 11 20, Cancer Council WA; Catherine Trevaskis, Gastrointestinal Cancer Specialist Nurse, The Canberra Hospital, ACT.

We would also like to thank the health professionals and consumers who have worked on previous editions of this title.

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.

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 Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

Introduction

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 primary site cannot be found. You may find it hard to believe that modern medicine cannot locate the primary cancer.

We hope this booklet helps you understand how CUP is diagnosed and treated, but we cannot give advice about the best treatment for you. You need to discuss this with your doctors. This information may help you think of questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your 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, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer
Council
13 11 20**

Contents

What is cancer?	4
Key questions	6
What is cancer of unknown primary?	6
How can doctors tell it is a secondary cancer?	7
Why can't the primary cancer be found?	7
Does it matter that the primary cancer can't be found?	8
Will I need lots of tests?	8
What are the causes?	9
What are the symptoms?	9
How common is CUP?	10
What are the different types of CUP?	10
Diagnosis	13
Blood and urine tests	14
Biopsy	15
Endoscopy	16
Imaging tests	18
Prognosis	20
Making treatment decisions	22
Talking with doctors	22
A second opinion	23
Taking part in a clinical trial	23
Which health professionals will I see?	24
Treatment	26
Chemotherapy	27
Radiotherapy	28

Hormone therapy 30
Surgery 31
Palliative treatment 31

Managing symptoms and side effects 34

Pain 34
Nausea 36
Lack of appetite..... 37
Breathlessness 38
Fatigue..... 39

Looking after yourself 41

Relationships with others 42

Seeking support 43

Living with a CUP diagnosis..... 43
Practical and financial help 44
Talk to someone who's been there..... 45

Caring for someone with cancer 46

Useful websites 47

Question checklist..... 48

Glossary 49

How you can help..... 52



What is cancer?

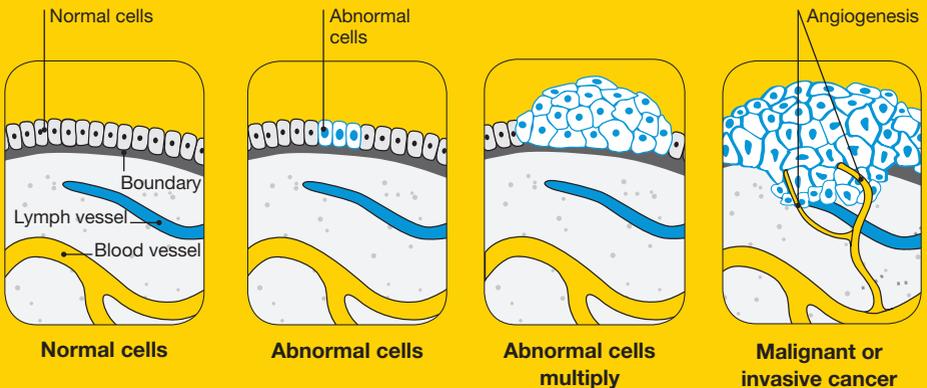
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process called angiogenesis.

If cancerous 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. 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.

How cancer spreads

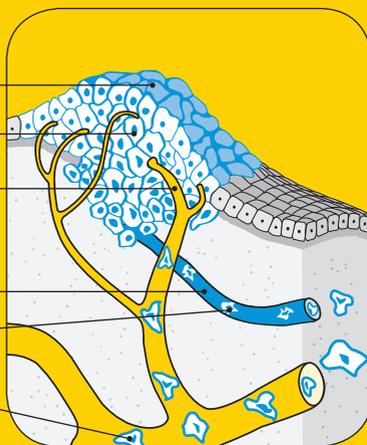
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





Key questions

Q: What is cancer of unknown primary?

A: This is a secondary cancer that has spread to a new location from somewhere else in the body. However, it's not clear where in the body it started, so the primary cancer is unknown.

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 the cancer 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 known as cancer of unknown primary, or CUP. Health professionals may also call it tumour of unknown origin (TUO), metastatic malignancy of unknown primary, or occult primary cancer.

Because it is a secondary cancer, CUP is considered advanced cancer. This means that in some cases, treatment focuses on controlling symptoms. In other cases, doctors actively treat the cancer while still making sure that symptoms are well managed. Your doctor will discuss the best approach 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. Call **13 11 20** for a free copy or download it from your local Cancer Council website.

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

A: To diagnose secondary cancer, a specialist doctor called a pathologist examines the cancer cells under a microscope. The pathologist can see that the cancer cells do not belong to or originate in the surrounding tissue, and this can be confirmed by further laboratory tests. With CUP, the cells could possibly have come from a number of places but no primary cancer can be found.

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

A: There could be several reasons why the primary cancer cannot be found. It may be that:

- the secondary cancers have 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 16) because it is hidden by a secondary cancer that has grown close to it
- the primary cancer has been removed during surgery for another condition without doctors realising the cancer was there, so some cancer cells remained behind and have since spread
- there may never have been a primary cancer mass – 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. If it can't be found, the treatment path can be less clear but treatment can still be given. To plan the treatment, your doctor will try to learn as much as possible about the spread of the cancer, the cells involved, and your symptoms and medical history.

Q: Will I need lots of tests?

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

Your doctors will only suggest tests they feel are necessary. It is okay to ask them to explain the tests and what difference the results will make to your care. With this information, you can weigh up the potential benefits of the tests and make an informed decision about having them. At some point, your doctors may decide that having more tests won't help find the primary site. It may be of more benefit to focus on your treatment even if the primary cancer can't be found.

If you do decide against having further tests, you may find your family and friends encourage you to continue. This can be a challenging situation, and it may help to explain your reasoning to them.

Q: What are the causes?

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 has different risk factors, such as getting older, poor diet, smoking, excessive alcohol consumption, being overweight and certain infections. These risk factors may play a role in some cases of CUP.

Q: What are the symptoms?

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

- shortness of breath
- cough
- bone pain and/or back pain
- swelling and discomfort in the abdomen, feeling sick (nausea), fluid collecting in the abdomen (ascites)
- yellowing of the skin and eyes (jaundice)
- swollen lymph nodes in the neck, underarm, chest or groin
- looking pale, feeling tired and becoming breathless due to a lack of red blood cells (anaemia).

You may also have general symptoms such as unexplained weight loss, poor appetite, night sweats or fatigue. Not everyone with the symptoms listed above will have CUP, but see your general practitioner (GP) if you are concerned.

Q: How common is CUP?

A: CUP is diagnosed more often than many people realise – it is the 11th most common cancer in Australian women and the 12th most common cancer in Australian men.²

There are nearly 3000 new cases of CUP diagnosed each year in Australia. For both men and women, CUP is more likely to occur over the age of 60.³

Q: What are the 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.

In about 95% of people with CUP, doctors can tell that they have some sort of carcinoma. Carcinoma means any cancer that begins in the cells lining the skin and internal organs (epithelial cells). There are different types of carcinoma depending on which type of epithelial cells are affected.

There are other forms of cancer that are not carcinomas. For example, lymphomas begin in the cells of the immune system, melanomas begin in the cells that give skin its pigment, and sarcomas begin in the cells of muscles, fat and other connective tissue.

Types of CUP

Adenocarcinomas	<ul style="list-style-type: none">• Adenocarcinomas develop from glandular cells, which form part of the lining of many organs.• Common primary sites include the breast, colon, prostate, stomach, pancreas, liver and lungs.• Most people with CUP have an adenocarcinoma.
Squamous cell carcinomas (SCC)	<ul style="list-style-type: none">• These carcinomas develop from squamous cells, which are thin, flat cells normally found on the surface of the skin or the lining of certain organs.• Common primary sites include the head and neck area, skin, oesophagus, lungs, vagina and cervix.• About 5% of people with CUP have squamous cell carcinomas.
Neuroendocrine carcinomas	<ul style="list-style-type: none">• These carcinomas develop from specialised nerve cells that sometimes produce hormones.• Common primary sites include the pancreas and gastrointestinal tract.• About 3% of people with CUP have neuroendocrine carcinomas.
Poorly differentiated carcinomas	<ul style="list-style-type: none">• There is enough detail to tell that the cells are carcinomas, but they look too abnormal to classify further.• About 30% of people with CUP have a poorly differentiated carcinoma.
Undifferentiated neoplasms	<ul style="list-style-type: none">• Neoplasm is another word for tumour. In an undifferentiated neoplasm, the cells can be identified as cancerous, but it is not possible to work out whether they are a carcinoma, sarcoma, melanoma or another form of cancer.• About 5% of people with CUP have undifferentiated neoplasms.



Key points

- CUP, or cancer of unknown primary, is a secondary cancer that has spread from somewhere else in the body, but it's not clear where in the body it started. The secondary cancer can be identified, but not the primary.
- It is also called tumour of unknown origin (TUO), metastatic malignancy of unknown primary, or occult primary cancer.
- There are a number of reasons why it may not be possible to find the primary cancer. For example, the primary tumour might be too small to be seen on scans, it might be hidden by secondary tumours that have grown nearby, or it may have been destroyed by the immune system.
- Doctors will try to find the primary cancer because it helps them decide what treatment to recommend.
- Your doctor may ask you to have several tests to try to find the primary cancer.
- If the tests cannot find where the cancer started, the doctor will try to identify the type of cell the cancer developed from. This gives the doctor a better idea of where the cancer may have started.
- Some people with CUP feel too unwell or simply prefer not to have lots of tests.
- Symptoms of CUP are often related to the area where the secondary cancer is found, and may include shortness of breath, bone pain and/or back pain, swelling and discomfort in the abdomen, and swollen lymph nodes in the neck, underarm, chest or groin.
- CUP is the 11th most common cancer in Australian women and 12th most common cancer in Australian men.



Diagnosis

Before CUP is diagnosed, you will usually see your GP, who will examine you, send you for tests and refer you to a specialist doctor (see pages 24–25). The specialist will ask you about your general health and any previous medical problems.

This chapter describes the various tests that your doctors may arrange. Initially, the purpose of the tests is to work out whether you have cancer, and whether it is primary or secondary. If the tests show that the cancer is secondary, you will have further tests to try to find the primary cancer.

The recommended tests for CUP vary depending on your general health, the location of the secondary cancer and the presumed location of the primary cancer. Often several different tests are needed to look for the primary cancer. You may have questions about the tests your doctor suggests – see the *Question Checklist* on page 48.

Blood and urine tests – These tests will look for abnormal cells and measure the levels of certain chemicals (tumour markers). See page 14.

Biopsy – In this procedure, samples of tissue are removed from a secondary tumour or an enlarged lymph gland and sent to a laboratory for examination under a microscope. See page 15.

Endoscopy – This procedure uses an instrument called an endoscope to look inside the body and remove small tissue samples. See page 16.

Imaging tests – X-rays, ultrasounds and CT, PET-CT, MRI and bone scans create images of the inside of the body. See pages 18–19.

If these tests find where the cancer started, the cancer is no longer an unknown primary and is treated like the primary cancer type.

Blood and urine tests

A complete blood count checks the levels of red blood cells, white blood cells and platelets. Urine may also be tested for any abnormal cells or substances and to see if there are any problems with organs such as the kidneys or bladder.

Tumour markers are chemicals made by some cancer cells. Some are found in the blood, but others are found in urine or other body fluids. Your symptoms and sex help the doctor decide if it would be helpful to check for any of these markers. Tumour markers include:

- **prostate specific antigen (PSA)** – high PSA levels may indicate prostate cancer
- **alpha-fetoprotein (AFP)** – high AFP levels may be a sign of testicular or liver cancer
- **human chorionic gonadotropin (HCG)** – high levels of HCG can suggest testicular cancer or a rare type of ovarian cancer
- **carcinoembryonic antigen (CEA)** – CEA levels may be raised in people who have bowel cancer. Other cancers that may have high CEA levels include lung, pancreatic, stomach, ovarian, breast, thyroid and liver cancers
- **cancer antigen 125 (CA125)** – CA125 levels may be raised in women with ovarian 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, and this indicates where in the body the cancer may have started.

The tissue sample is often removed under local anaesthetic, but it may sometimes be removed under general anaesthetic. You may have one of the following types of 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.

At the laboratory, a specialist doctor called a pathologist will run a series of stains on the sample to see if they can work out the type of cancer. These stains may show specific changes in the cells or highlight proteins (antigens) that are linked to various types of cancer. It may be a week or more before results are available.

Some labs can test a biopsy for genetic changes or patterns linked to specific types of cancer. These may be called cytogenetic tests or gene expression-based profiling (GeBP). As it is not yet clear how useful these tests are, their availability is still limited.

A biopsy may not be helpful if the cancer is too difficult to reach or if you're too unwell for the procedure. Talk to your doctor if you have any questions about this.



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, anus or vagina) or through a small cut made by the surgeon. The endoscope has a small cutting instrument on the end so a biopsy can be taken at the same time if something suspicious is seen. The most common types of endoscopies are listed in the table below.

Type of endoscopy	Part of body tested	Where the tube is inserted
bronchoscopy	lungs or respiratory tract	mouth or nose
colonoscopy	colon (large bowel)	anus
colposcopy	vagina and cervix	organs are viewed from outside the vagina
cystoscopy	bladder	urethra
gastroscopy	stomach and small bowel	mouth
hysteroscopy	uterus (womb)	vagina
laparoscopy	stomach, liver, female reproductive organs	small cuts in the abdomen
laryngoscopy	larynx (voice box)	mouth
sigmoidoscopy	colon (large bowel)	anus
thoracoscopy	lungs	small cut in the chest



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 had 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 radiotherapy.

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 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.

Imaging tests

X-ray	Ultrasound	CT scan
<ul style="list-style-type: none">• This test creates pictures of the inside of the body.• X-rays of the chest and other parts of the body may be taken.• For some types of x-rays, a dye (contrast) is used to improve the image.• This test is painless and the dose of radiation is small and will not make you radioactive.• A mammogram is a low-dose x-ray of the breast. The breast is positioned against an x-ray plate and gently but firmly compressed with a clear plastic plate. This test can be uncomfortable but usually only takes 10–30 minutes.	<ul style="list-style-type: none">• This test uses soundwaves to build up a picture of your body.• A device is placed on or in your body and sends out soundwaves that echo when they meet something dense, like a tumour. The images are projected onto a computer screen.• The device may be a small, handheld device (transducer) that is passed over part of your body, such as your abdomen, or a probe that is inserted into part of your body, such as the vagina or rectum.• This scan takes 10–20 minutes and should be painless.	<ul style="list-style-type: none">• Computerised tomography scan.• This test uses a series of x-rays to produce detailed pictures of the inside of the body.• Before the scan, you may be given a drink or an injection of a dye (called the contrast) to make particular areas easier to see. If the contrast is injected, you may feel hot all over for a few minutes and have a strange taste in your mouth.• The CT scanner is large and round like a doughnut. You lie on a table that moves in and out of the scanner.• The scan can take up to 30 minutes.

PET-CT scan	Bone scan	MRI scan
<ul style="list-style-type: none"> ● Positron emission tomography scan, combined with a CT scan. ● This uses low-dose radioactive glucose to measure cell activity in different parts of the body. ● A small amount of glucose is injected into a vein. You wait 30–90 minutes for the solution to circulate through your body. ● Your body is then scanned. Areas of cancer usually absorb more glucose than the surrounding tissue does, so they show up on the scan. 	<ul style="list-style-type: none"> ● This test shows any abnormal areas of the bones. ● A small amount of a radioactive dye is injected into a vein, usually in the arm. ● You wait 2–3 hours to allow the dye to circulate and be absorbed by your body. ● A scan of your whole body is then taken and any abnormal areas show up as highlighted areas, which are known as hot spots. ● This scan is painless and will not make you radioactive. 	<ul style="list-style-type: none"> ● Magnetic resonance imaging scan. ● This uses a magnet and radio waves to take detailed pictures of an area of the body. ● Dye (contrast) may be injected into a vein before the scan to make the images clearer. ● You lie on a table that slides into a narrow metal cylinder that is open at both ends. The cylinder makes some people anxious, but you can ask for a mild sedative beforehand to help you relax. The scan is also very noisy, so you will probably be given earplugs or headphones to help block the sound. ● People with some types of pacemakers or other metallic objects cannot have an MRI.

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 any doctor to predict the exact course of your disease.

To come up with your prognosis, your doctor will consider test results, the type of CUP you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as your age, fitness and medical history.

Although most cancers of unknown primary can't be cured, treatment can keep some cancers under control for months or years. For example, some people with a localised deposit of CUP (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 radiotherapy).

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 pages 31–32 for more information.

“ I've been having palliative treatment for five years. I'm not trying to get rid of the disease, just keeping it under control. My quality of life is excellent. ” *Kate*



Key points

- Several different tests are used to try to identify the primary cancer.
- The type of tests you have will depend on your general health, the location of the secondary cancer, and the presumed location of the primary cancer.
- Blood tests will examine the number and type of blood cells and will measure the levels of various blood chemicals (tumour markers). Urine may also be tested to check for abnormal cells.
- Taking a tissue sample (biopsy) is the main test for CUP. There are a few ways of doing a biopsy. The doctor may use a needle to take out the tissue (fine needle aspiration or core biopsy). Other options involve surgically removing the sample (incisional or excisional biopsy).
- An endoscopy is another way to look inside the body and remove small tissue samples. This procedure uses a thin, flexible tube called an endoscope. Different types of endoscopies are known by different names, e.g. a colonoscopy checks the colon (large bowel).
- Imaging scans such as x-rays, ultrasounds, MRI, CT, PET-CT and bone scans may be used to create pictures of the inside of the body.
- If any of these tests find where the cancer started, the cancer is no longer an unknown primary and is treated according to the primary cancer type.
- Your doctor may talk to you about your prognosis. This is a general prediction about what may happen to you, but no-one can predict the exact course of your illness.



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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the expected benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask for further explanation – see page 48 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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.

Taking part in 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. For some people with CUP, participation in a clinical trial may be a way to access new therapies.

It may be helpful to talk to your specialist or a clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit australiancancertrials.gov.au.

Which health professionals will I see?

Once CUP has been diagnosed, you will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT) and it may include some or all of the health professionals listed below. Note that only some patients see a cancer care coordinator.

MDT health professionals

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
medical oncologist*	prescribes and coordinates chemotherapy and other medical treatments for cancer
surgeon*	surgically removes tumours and performs some biopsies
radiation oncologist*	prescribes and coordinates radiotherapy
radiation therapist	plans and delivers radiotherapy
radiologist*	analyses x-rays and scans
pathologist*	examines cells and tissue samples to try to determine the type and extent of the cancer
other specialists*	specialise in particular areas of the body

The type of specialists in your MDT will depend on your symptoms and the presumed location of the primary 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/lung), or a haematologist (blood cells).

cancer care coordinator or clinical nurse consultant (CNC)	coordinates your care, liaises with other members of the MDT, and supports you and your family throughout treatment
nurses	administer drugs, including chemotherapy, and provide care, information and support
palliative care specialists* and nurses	work closely with the GP and oncologist to help control symptoms and maintain quality of life
dietitian	recommends an eating plan to follow
occupational therapist, physiotherapist	assist with physical and practical problems
social worker	links you to support services and helps with emotional, physical or practical issues
psychiatrist*, counsellor, psychologist	provide emotional support and help manage anxiety and depression
pastoral care worker	helps you work through spiritual matters

**Specialist doctor*



Treatment

When tests have been unable to find the primary cancer, a diagnosis of CUP is given. This is often a difficult time and it can be hard to accept that the primary 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
- how likely it is to be a certain type of cancer
- your general health
- your preferences.

The most common treatment for CUP is chemotherapy. You may also have radiotherapy, hormone therapy, surgery or targeted therapies. 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 pages 31–32).

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

Chemotherapy

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

Medical oncologists and sometimes other specialists prescribe chemotherapy to shrink tumours, and to relieve symptoms caused by the cancer. It can also be used in combination with radiotherapy or surgery to try to kill any local collections of cancer cells in the body. Different cancer cells respond to different chemotherapy drugs. People with CUP may have a combination of drugs.

Generally, chemotherapy is given by injecting the drugs into a vein (intravenously), often through a drip. The drugs circulate through the bloodstream and can kill cancer cells throughout the body (systemic treatment). Some types of chemotherapy are taken by mouth as tablets.

Chemotherapy cycles

Chemotherapy is given in courses known as cycles. Each cycle consists of a treatment period followed by a recovery period. You may be able to have treatment as an outpatient, but sometimes a short stay in hospital is required.

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 effect on quality of life.

Side effects of chemotherapy

- Most chemotherapy drugs cause side effects. Different drugs have different side effects. Your medical oncologist or nurse will discuss them with you.
- The most common side effects include feeling sick (nausea), vomiting, mouth sores, tiredness, loss of appetite, diarrhoea, and some thinning or loss of hair from your body and head. Most side effects are temporary, and can be prevented or reduced.
- 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 while receiving chemotherapy, contact your medical team or hospital immediately.

Radiotherapy

Radiotherapy uses x-ray beams to kill cancer cells. For most people with CUP, the purpose of radiotherapy is to relieve symptoms, such as bleeding, difficulty swallowing, breathlessness, blocking of the intestines, compression of blood vessels or nerves by tumours, and pain caused by cancer spreading to the bones.

You will have an x-ray of the treatment area to help with planning your treatment. 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, in some cases, permanent. Talk to your radiation oncologist if you are concerned about the tattoos.

You may have external or internal radiotherapy. External radiotherapy is given from a machine outside the body. For internal radiotherapy, a radiation source is put inside the body on or near the cancer. Radiotherapy treatments are painless. The total number of treatments and their duration will depend on your situation. You might need only a couple of treatments, or you may need them every weekday for several weeks.

Some people with localised squamous cell carcinoma (see page 11) in the lymph nodes of the neck may have a combination of chemotherapy and radiotherapy (chemoradiation) to try to treat the disease.

Side effects of radiotherapy

- The side effects of radiotherapy depend on the area of the body being treated and the dose of radiation.
- Common side effects include nausea, loss of appetite, diarrhoea, tiredness and shortness of breath. It can also make your skin dry and itchy in the area treated. Your skin may look red or sunburnt.
- Side effects tend to develop as you go through treatment, and most improve or go away after treatment is finished. Talk to your doctor or nurse about ways to manage them.

For more information, call Cancer Council **13 11 20** and ask for our free booklets on chemotherapy or radiotherapy, or download digital versions from your local Cancer Council website.



Hormone therapy

Hormones are substances that occur naturally in the body, but some cancers are stimulated by particular hormones – for example, breast cancer by oestrogen. Hormone therapy uses hormones made in a laboratory (synthetic) to block the effect of the 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, e.g. to shrink a tumour before surgery.

Side effects of hormone therapy

- The side effects vary depending on the hormones you are given.
- General side effects include tiredness, nausea, diarrhoea, constipation, appetite changes, weight gain, mood changes, hot flushes, pain in the joints, thinning of the bones, hot flushes (for women) and erection problems (for men).

Targeted therapies

Targeted therapies are a new group of drugs that destroy or stop the growth of cancer cells while minimising harm to healthy cells. It is not yet clear how useful targeted therapies are for CUP, but clinical trials

(see page 23) are testing combinations of chemotherapy and targeted therapies.

Most targeted therapies are injected into a vein, but some are given by mouth as tablets.

Surgery

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

If the cancer is found in only one area (e.g. in the lymph nodes in the neck, underarm or groin), it may be possible to remove it with an operation. Surgery may be followed by radiotherapy or chemotherapy to kill any cancer cells left in the body. Sometimes surgery can help with symptoms – for example, to relieve pain caused by the cancer 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 you've had lymph nodes removed, you may develop lymphoedema. This is swelling caused by a build-up of fluid in part of the body, usually in an arm or leg. For more information, speak to your nurse or visit lymphoedema.org.au.

Palliative treatment

Many people with CUP receive palliative treatment, which can be used at any stage of advanced cancer to improve quality of life. Palliative treatment aims to slow the spread of cancer and manage symptoms (see pages 34–40) without trying to cure the disease. It is one aspect of palliative care, in which a team of health

professionals aim to meet your physical, emotional, practical and spiritual needs. Palliative care is not just end-of-life care and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can. It also provides support to families and carers.

It is best to make contact with the palliative care team as early as possible. You can find out what the different team members do and work out which services might be useful now or in the future. Call Cancer Council 13 11 20 for free booklets about palliative care and living with advanced cancer, or download digital versions from your local Cancer Council website.



Linda's story

My husband, Steve, was diagnosed with cancer of unknown primary. It started off with a sore back. Then he had trouble walking and the pain became unbearable. Steve had some scans, which showed a mass. He was referred to the hospital for further tests.

They never found the location of the primary cancer; they only found the secondary tumours on Steve's spine and in his

lungs and liver. The doctors said the cancer was inoperable and untreatable. He had chemotherapy and radiotherapy to relieve his pain and to reduce the size of the secondary tumour on his spine.

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



Key points

- Treatment can help control the symptoms of CUP, but it may not cure the disease.
- CUP treatment may include chemotherapy, radiotherapy, hormone therapy, surgery and targeted therapies. 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.
- Chemotherapy treats cancer with drugs. Most of the drugs used for chemotherapy cause side effects, such as nausea, vomiting, mouth sores, tiredness, loss of appetite, diarrhoea and hair loss. There may also be an increased risk of infections. Side effects depend on what kinds of drugs you are given.
- Radiotherapy treats cancer by using x-ray beams to kill cancer cells. It is painless but radiotherapy may cause side effects such as skin irritation or shortness of breath. Other side effects include nausea and tiredness.
- Hormone therapy is sometimes used to treat CUP by slowing the growth of the cancer or shrinking it.
- Surgery may be used to remove lymph nodes in the neck, underarm or groin. It's not always a treatment option for CUP, and sometimes only part of the cancer can be removed.
- Targeted therapies are a new group of cancer drugs. Clinical trials are testing their usefulness for CUP.
- The goal of palliative treatment is to manage symptoms to improve quality of life. If possible, get in touch with the palliative care team early.



Managing symptoms and side effects

This chapter discusses the most common symptoms and side effects experienced during treatment for CUP. However, these will vary from person to person – you may have none or only a few, or 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. If you do experience pain, it can usually be controlled. There are many ways to relieve pain, including:

- pain medicines such as non-steroidal anti-inflammatory drugs (NSAIDs), paracetamol and opioids
- an injection of pain-relieving drugs into the spinal canal (epidural or spinal block)
- relaxation therapies, such as massage, meditation or hypnotherapy
- treating the cause of the pain with chemotherapy, radiotherapy or surgery.

You may need to use more than one pain-relieving method. 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, radiotherapy and surgery are common cancer treatments. They may also be used as palliative treatment to reduce pain, even though they may not be able to treat the CUP itself.

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

Radiotherapy – This can relieve some types of pain. Different types of radiotherapy may be used. The radioactive form of the metal strontium is sometimes used when the cancer has spread to many places in the bone – the drug is injected and settles in the bones near the cancer. It helps to stop the cancer's growth and relieves pain.

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

Pain management experts

Your GP or oncologist may be able to prescribe effective treatment for your pain, but if you are still uncomfortable, ask about seeing a palliative care specialist. Good pain control is one of the major contributions that a specialist palliative care team can make for 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.

For more information, call 13 11 20 and request a free copy of the *Overcoming Cancer Pain* booklet, or download a digital version from your local Cancer Council website.

Nausea

Feeling sick in the stomach (nauseated) is an unpleasant symptom that may be caused by the cancer itself. Other causes include:

- treatment with chemotherapy or radiotherapy
- stress or anxiety
- an imbalance of minerals in the blood, e.g. calcium
- drugs that control other symptoms, e.g. morphine given for pain
- the kidneys not working properly
- oral thrush infection, sometimes related to chemotherapy
- a bowel blockage (obstruction)
- increased pressure around the brain as a result of cancer in the brain or cancer affecting the fluid around the spinal cord.

You don't have to put up with nausea. Your doctor or nurse can suggest treatments such as anti-nausea drugs and dietary changes.



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 with ginger, e.g. ginger ale, ginger tea or ginger cake.
- Take anti-nausea medicine regularly and before taking pain medicine.
- Use stress-reduction techniques such as meditation or relaxation.
- Call Cancer Council **13 11 20** for more information on dealing with nausea and lack of appetite.

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, but 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 the lack of appetite could be ongoing. You may be unable to eat the way you used to. If you are trying to overcome a lack of appetite, eat when you feel like it and what you feel like. For example, you may find it easier to have your main meal at lunch. Follow your cravings and eat more of your favourite foods.



Tips for when you don't feel like eating

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

Breathlessness

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

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

Treatment will depend on what is causing the breathlessness. You may need fluid drained from the 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.
- Sit up to ease your breathing or lean forward to rest on a table. Also try sleeping in a more upright position.
- Try breathing in time with someone else and focus on slowing your breath.
- Relaxation or breathing techniques may help. A physiotherapist can teach you these, or you could listen to a meditation or relaxation CD.
- Watch the *Managing Your Breathlessness* video at lungfoundation.com.au/patient-support/living-with-a-lung-condition/self-management.

Fatigue

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

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

- the cancer itself
- cancer treatment such as chemotherapy or radiotherapy
- poor nutrition causing loss of weight and muscle tone
- anxiety
- lack of sleep
- drugs such as pain medicines, antidepressants and sedatives
- anaemia (low levels of red blood cells)
- infection.

Tips for managing fatigue

- Talk about the fatigue with your friends, relatives and carers to help them understand how you feel. a sense of normality. Even activities such as walking to the letterbox or getting up for meals can help.
- Plan to do things at the time of day when your tiredness is least severe.
- Try to do gentle exercises. Research shows this reduces tiredness, helps preserve muscle strength and gives
- A short nap of no more than 30 minutes during the day can refresh you without making it hard for you to sleep at night.
- Call Cancer Council **13 11 20** for more information about coping with fatigue.





Key points

- Cancer and its treatment can affect the body in different ways and cause various symptoms and side effects.
- Depending on the cancer and the treatment(s) that you are having, you may experience other symptoms and side effects not listed in this chapter. Ask your treatment team for more information.
- If you are experiencing symptoms or side effects, there are a number of ways to manage them.
- Pain is a common symptom for people diagnosed with CUP. It can usually be controlled by medication, so tell your treatment team about any pain.
- Nausea can be caused by many things. Eating small meals may help. You can also talk to your treatment team about medication or dietary changes to manage nausea.
- Lack of appetite is a common problem faced by people with CUP. This 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.
- Breathlessness may have various causes and can feel frightening. If you become breathless, try to get a flow of air from a fan or window moving near your face. Relaxation and breathing techniques may also help.
- Fatigue can be a major issue. It may be caused by anaemia. Ways to manage the tiredness include planning your day, doing gentle exercise and taking a short nap.
- Talk to your treatment team about any symptoms or side effects that you experience.



Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

Staying active – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and what your doctor advises. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

Complementary therapies – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to 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.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and cancer

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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.



Call **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*, or download the booklets from our websites.



Seeking support

Living with a CUP diagnosis

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

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

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

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group (see page 45)
- Cancer Council 13 11 20.

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

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

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 are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety.

Go to beyondblue.org.au or call **1300 22 4636** to order a fact sheet.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. People often feel they can speak openly and share tips with others who have gone through a similar experience.

Many people feel isolated after a diagnosis of CUP, so finding some sort of mutual support group can be especially worthwhile.

In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.



Caring for someone with cancer

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

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit carergateway.gov.au or call 1800 422 737.

Carers Australia is the national body representing carers in Australia. It works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit their website at carersaustralia.com.au. You can also call Cancer Council 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.

●● It is very important that the carer of someone with CUP is given access to all services and support bases available if they require them. The journey can become as much about the carer as the patient. ●● *Dave, diagnosed with CUP*



Useful websites

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

Australian

Cancer Council Australia.....	cancer.org.au
Cancer Australia.....	canceraustralia.gov.au
Carer Gateway.....	carergateway.gov.au
Carers Australia.....	carersaustralia.com.au
Palliative Care Australia.....	palliativecare.org.au
Department of Health.....	health.gov.au
healthdirect Australia.....	healthdirect.gov.au
beyondblue.....	beyondblue.org.au
Australian Cancer Trials.....	australiancancertrials.gov.au
Cancer Voices Australia.....	cancervoicesaustralia.org

International

American Cancer Society.....	cancer.org
Cancer Research UK.....	cancerresearchuk.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
National Cancer Institute (US).....	cancer.gov
CUP Foundation – Jo’s Friends (UK).....	cupfoundjo.org



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- Is there any sign of where the cancer might have started?
- What tests do you recommend and why? How invasive will they be? What information will these tests show?
- What happens if you can't find where the cancer started? How will this affect my treatment?
- Can you explain the results of the tests to me?
- If you find out where the primary cancer is, will my treatment change?
- What treatment do you recommend and why?
- What will treatment involve? When will it start? How long will it last?
- How much will treatment cost?
- Who will be coordinating my treatment?
- What are the likely side effects of treatment?
- What can I do to help prevent or reduce the side effects I may have from treatment?
- What will happen if I don't have treatment?
- Are there any clinical trials available to me?
- Are there any complementary therapies that might help me?



Glossary

adenocarcinoma

A cancer that starts in the 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. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

anaemia

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

antibody

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

antigen

Any substance that causes the 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.

blood test

A test to look for abnormalities in the blood. A complete blood count checks the number of red blood cells, white blood cells and platelets.

cancer of unknown primary (CUP)

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

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

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth. Chemotherapy may be given alone or in combination with other treatments. It can also be used to reduce the size of the cancer and help lessen pain.

clinical trial

A research study that tests new and better treatments.

core biopsy

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

CT scan

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

endoscopy

A type of internal examination or diagnostic test. A thin, flexible tube with a light and camera (endoscope) is used to examine the inside of the body.

fine needle aspiration

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

histology

The study of body tissues and cells under a microscope.

hormones

Chemicals in the body that send information between cells to bring about changes in the body.

hormone therapy

A treatment that blocks the body's natural hormones that help cancer grow. It is used when the cancer is hormone dependent.

lymph nodes

Small, bean-shaped structures that form part of the lymphatic system. They collect and destroy bacteria and viruses. Also called lymph glands.

malignant

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

mammogram

An x-ray of the breast to detect cancer.

medical oncologist

A doctor who specialises in treating cancer with chemotherapy.

metastasis (plural: metastases)

A cancer that has spread from a primary cancer in another part of the body. Also known as secondary cancer. CUP is a metastatic cancer.

MRI scan

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

neoplasm

See tumour.

neuroendocrine carcinoma

A cancer that develops from specialised nerve cells that sometimes produce hormones.

palliative care

The holistic care of people with advanced cancer, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual, social and practical needs.

palliative treatment

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

pathologist

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

PET-CT scan

A positron emission tomography scan with a CT scan. In the PET scan, a person is injected with a radioactive glucose solution that makes cancerous areas show up brighter in the scan.

platelets

Blood cells that help the blood to clot and stop bleeding.

primary cancer

The original cancer. Cells from the primary cancer may break away and

be carried to other parts of the body, where secondary cancers may form.

primary site

The part of the body where the cancer first developed.

prognosis

The expected outcome of a person's disease.

radiation oncologist

A doctor who specialises in treating cancer with radiotherapy.

radiotherapy

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

red blood cells

Blood cells that carry oxygen around the body.

secondary cancer

See metastasis.

side effect

Unintended effect of a drug or treatment.

squamous cell carcinoma (SCC)

A type of cancer that develops from squamous cells, which are thin, flat cells found on the surface of the skin or the lining of certain organs, such as the lungs, vagina and cervix.

tumour

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

tumour markers

Chemicals produced by cancer cells and released into the blood. These may suggest the presence of a tumour.

ultrasound

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

white blood cells

Blood cells that fight infection.

x-ray

A type of high-energy radiation that shows solid areas in the body such as bone.

References

1. K Fizazi et al., 'Cancers of Unknown Primary Site: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up', *Annals of Oncology*, vol. 26, suppl. 5, pp. v133–v138, 2015.
2. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia: An overview 2014*, AIHW, Canberra, 2014.
3. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Unknown primary site*, AIHW, Canberra, 2016.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary



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 Pink Ribbon Day, 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.

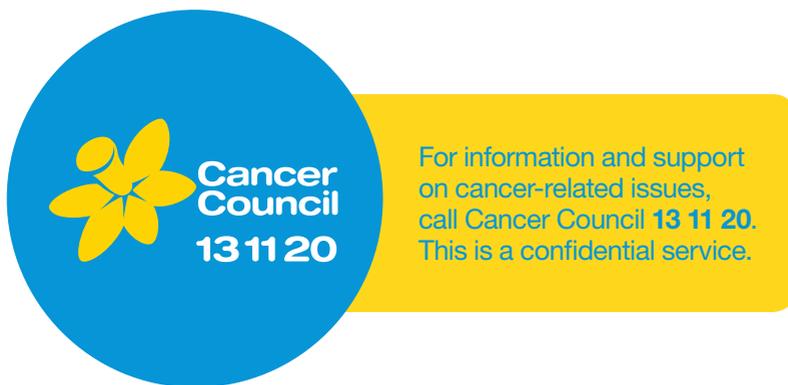
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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, contact us through the National Relay Service.
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.*