

Understanding Gall Bladder Cancer

A guide for people affected by cancer

This fact sheet has been prepared to help you understand more about gall bladder or bile duct cancer (cholangiocarcinoma).

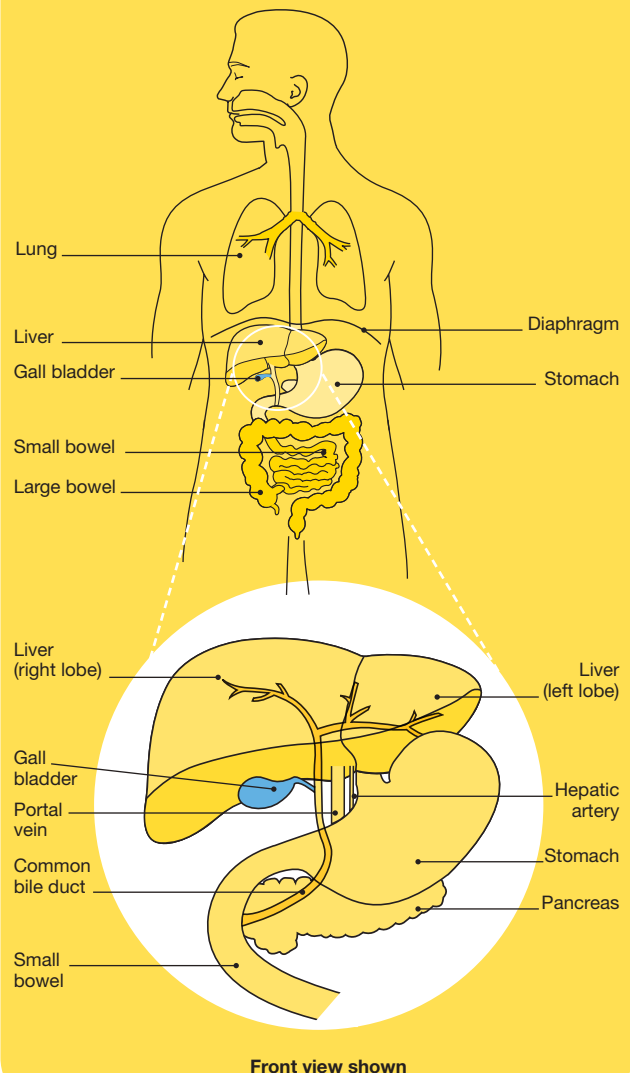
Many people look for support after being diagnosed with a cancer that is rare or less common than other cancer types. This fact sheet includes information about how gall bladder cancer is diagnosed and treated, as well as where to go for additional information and support services.

Many people feel shocked and upset when told they have cancer. You may experience strong emotions after a cancer diagnosis, especially if your cancer is rare or less common like gall bladder cancer. A feeling of being alone is usual with rare cancers, and you might be worried about how much is known about your type of cancer and how to manage it. You may also be concerned about the cancer coming back after treatment. Contacting local support services (see below) can help overcome feelings of isolation and will give you information that you may find useful.

About the gall bladder

The gall bladder is a small, pear-shaped organ on the right side of the abdomen. It is part of the digestive system and sits under the liver. It stores bile that is made by the liver. Bile is passed through small tubes (bile ducts) into the small bowel (small intestine) after eating and helps to break down fats.

The digestive system



Understanding Gall Bladder Cancer

What is gall bladder cancer?

Gall bladder cancer occurs when cells in the gall bladder become abnormal and keep growing to form a mass or lump called a tumour. The tumour type is defined by the particular cells that are affected.

The most common type is adenocarcinoma, which starts in epithelial cells (which release mucus) that line the inside of the gall bladder. These make up about 85% of all gall bladder cancers. Other types of gall bladder cancer include:

- squamous cell carcinoma, from squamous cells (skin-like cells)
- sarcoma, from connective tissue (which support and connect all the organs and structures of the body)
- lymphoma, from lymph tissue (part of the immune system which protects the body).

Malignant (cancerous) tumours have the potential to spread to other parts of the body through the blood stream or lymph vessels and form another tumour deposit at a new site. This new tumour is known as secondary cancer or metastasis.

How common is gall bladder cancer?

Gall bladder cancer is rare. About 891 Australians are diagnosed each year with gall bladder or bile duct cancer (about 3 cases per 100,000 people).¹ It is more likely to be diagnosed in women than men, and people aged over 65 years.

What are the risk factors?

The cause of gall bladder cancer is not known in most cases, but risk factors can include:

- having had gallstones or inflammation of the gall bladder (although the majority of people with gallstones will never develop gall bladder cancer)
- family history of gall bladder cancer can result in a small increase in risk (first-degree relative such as mother, father, sibling or child). The majority of people with gall bladder cancer, however, will not have a family history
- other gall bladder and bile duct conditions and abnormalities, such as gall bladder polyps, choledochal cysts (bile-filled cysts) and calcified gall bladder (also known as porcelain gall bladder).

What are the symptoms?

Gall bladder cancer can be difficult to diagnose in its early stages as it doesn't usually cause symptoms. Sometimes, gall bladder cancer is found when the gall bladder is removed for another reason, such as gallstones. But most people who have surgery for gallstones do not have gall bladder cancer.

Gall bladder cancer is sometimes suspected when there is a large gall bladder polyp (greater than 1 cm) or a calcified gall bladder.

If symptoms do occur they can include:

- abdominal pain, often on the upper right side
- nausea (feeling sick) or vomiting
- jaundice (yellowing of the skin and eyes), causing dark urine (wee), pale bowel movements (poo) and severe itching without any visible skin rash
- general weakness or fatigue
- a lump in the abdomen
- unexplained weight loss
- fever.

Diagnosis

If your doctor thinks that you may have gall bladder cancer, they will perform a physical examination and carry out certain tests. If the results suggest that you may have gall bladder cancer, your doctor will refer you to a specialist who will carry out more tests. These tests may include:

- **Blood tests** – including a full blood count (to measure your white blood cells, red blood cells, platelets), liver function tests (to measure chemicals that are found or made in your liver) and tumour markers (to measure chemicals produced by cancer cells).
- **Ultrasound scan** – soundwaves are used to create pictures of the inside of your body. For this scan, you will lie down and a gel will be spread over the affected part of your body. A small device called a transducer is moved over the area by an ultrasound radiographer. The transducer sends out soundwaves that echo when they encounter something dense, like an organ or tumour. The ultrasound images are then projected onto a computer screen. An ultrasound is painless and takes about 15–20 minutes.

Understanding Gall Bladder Cancer

- **CT (computerised tomography) and/or MRI (magnetic resonance imaging) scans** – special machines are used to scan and create pictures of the inside of your body. Before the scan you may have an injection of dye (called contrast) into one of your veins, which makes the pictures clearer. During the scan, you will need to lie still on an examination table. For a CT scan the table moves in and out of the scanner which is large and round like a doughnut; the scan itself usually takes about 10–30 minutes. For an MRI scan the table slides into a large metal tube that is open at both ends; the scan takes a little longer, about 30–90 minutes to perform. Both scans are painless.
- **Diagnostic laparoscopy** – a thin tube with a camera on the end (laparoscope) is inserted under sedation into the abdomen so the doctor can view inside.
- **Cholangiography** – an x-ray of the bile duct to see if there is any narrowing or blockage and help plan surgery to remove the gall bladder. For an endoscopic retrograde cholangiopancreatography (ERCP), the doctor inserts a flexible tube with a camera on the end (endoscope) down your throat into your small intestine while you are sedated to view your gut and take images.
- **Biopsy** – removal of some tissue from the affected area for examination under a microscope. In the gall bladder, a biopsy may be done during a laparoscopy or cholangiography. Otherwise a needle biopsy is done, where a local anaesthetic is used to numb the area, then a thin needle is inserted into the tumour under ultrasound or CT guidance.

Finding a specialist

Rare Cancers Australia have a directory of health professionals and cancer services across Australia: rarecancers.org.au.

Treatment

You will be cared for by a multi-disciplinary team (MDT) of health professionals during your treatment for gall bladder cancer. The team may include a surgeon, pathologist (to interpret the results of blood tests and biopsies), radiologist, radiation oncologist (to prescribe and coordinate a course of radiation therapy), medical oncologist (to prescribe and coordinate a course of systemic therapy which includes chemotherapy), gastroenterologist (to treat disorders of the digestive system), nurse and allied health professionals such as a dietitian, social worker, psychologist or counsellor, physiotherapist and occupational therapist.

Discussion with your doctor will help you decide on the best treatment for your cancer depending on:

- the type of cancer you have
- whether or not the cancer has spread (stage of disease)
- your age, fitness and general health
- your preferences.

The main treatments for gall bladder cancer include surgery, radiation therapy and chemotherapy. These can be given alone or in combination. This is called multi-modality treatment.

Surgery

Surgery is the main treatment for gall bladder cancer, especially for people with early-stage disease where the gall bladder can be completely removed.

Surgery to remove the gall bladder is called a cholecystectomy. Often surrounding tissue including lymph nodes, adjacent bile ducts and part of the liver will also be removed if gall bladder cancer is suspected. Surgery may be performed as either open surgery or keyhole (laparoscopic) surgery. If the tumour has been found after the gall bladder has been removed for another reason, further surgery may be required.

If the cancer has spread and the tumour is pressing on, or blocking, the bile duct, you may need a stent (small tube made of either plastic or metal). This holds the bile duct open and allows bile to flow into the small bowel again. Stents are placed under x-ray guidance or during an endoscopic retrograde cholangiopancreatography (ERCP).

Understanding Gall Bladder Cancer

The extent of the surgery depends on the location and stage of the tumour. Your surgeon will discuss the type of operation you may need and the side effects and risks of surgery.

- For a free copy of Cancer Council's booklet on *Understanding Surgery* visit your local Cancer Council website or call 13 11 20.

External beam radiation therapy

Radiation therapy (also known as radiotherapy) uses high energy rays to destroy cancer cells, where the radiation comes from a machine outside the body. It is often given with chemotherapy in a treatment known as chemoradiation. It may be used for gall bladder cancer:

- after surgery, to destroy any remaining cancer cells and stop the cancer coming back
- if the cancer can't be removed with surgery
- if the cancer has spread to other parts of the body (e.g. palliative radiation for the management of symptoms such as pain).

A course of radiation therapy needs to be carefully planned. During your first consultation session you will meet with a radiation oncologist who will take a detailed medical history and arrange a planning session. At the planning session (known as CT planning or simulation) you will need to lie still on an examination table and have a CT scan. You will be placed in the same position you will be placed in for treatment. The information from the planning session will be used by your specialist to work out the treatment area and how to deliver the right dose of radiation. Radiation therapists will then deliver the course of radiation therapy as set out in the treatment plan.

Radiation therapy does not hurt and is usually given in small doses over a period of time to minimise side effects. Each treatment only takes a few minutes but the set-up time can take longer.

- For a free copy of Cancer Council's booklet *Understanding Radiation Therapy* visit your local Cancer Council website or call 13 11 20.

Chemotherapy

Chemotherapy (sometimes just called "chemo") is the use of drugs to kill or slow the growth of cancer cells. You may have one chemotherapy drug, or be given a combination of drugs. This is because

different drugs can destroy or shrink cancer cells in different ways. Your treatment will depend on your situation and the stage of your tumour. Your medical oncologist will discuss your options with you.

Chemotherapy is usually given through a drip into a vein (intravenously) or as a tablet that is swallowed. Your medical oncologist will discuss your options with you.

Chemotherapy is commonly given in treatment cycles which may be daily, weekly or monthly. For example, one cycle may last three weeks where you have the drug over a few hours, followed by a rest period, before starting another cycle. The length of the cycle and number of cycles depends on the chemotherapy drugs being given.

- For a free copy of Cancer Council's booklet on *Understanding Chemotherapy* visit your local Cancer Council website or call 13 11 20.

Clinical trials

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

Visit australiancancertrials.gov.au for more information or contact the Australasian Gastro-Intestinal Trials Group (AGITG): gicancer.org.au

For a free copy of Cancer Council's booklet *Understanding Clinical Trials and Research* visit your local Cancer Council website or call 13 11 20.

Understanding Gall Bladder Cancer

Complementary therapies and integrative oncology

Complementary therapies are designed to be used alongside conventional medical treatments (such as surgery, chemotherapy and radiation therapy) and can increase your sense of control, decrease stress and anxiety, and improve your mood. Some Australian cancer centres have developed “integrative oncology” services where evidence-based complementary therapies are combined with conventional treatments to create patient-centred cancer care that aims to improve both wellbeing and clinical outcomes.

Complementary therapy	Clinically proven benefits
acupuncture	reduces chemotherapy-induced nausea and vomiting; improves quality of life
aromatherapy	improves sleep and quality of life
art therapy, music therapy	reduce anxiety and stress; manage fatigue; aid expression of feelings
counselling, support groups	help reduce distress, anxiety and depression; improve quality of life
hypnotherapy	reduces pain, anxiety, nausea and vomiting
massage	improves quality of life; reduces anxiety, depression, pain and nausea
meditation, relaxation, mindfulness	reduce stress and anxiety; improve coping and quality of life
qi gong	reduces anxiety and fatigue; improves quality of life
spiritual practices	help reduce stress; instil peace; improve ability to manage challenges
tai chi	reduces anxiety and stress; improves strength, flexibility and quality of life
yoga	reduces anxiety and stress; improves general wellbeing and quality of life

Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

- ▶ For a free copy of Cancer Council’s booklet *Understanding Complementary Therapies* visit your local Cancer Council website or call 13 11 20.



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

Nutrition and exercise

If you have been diagnosed with gall bladder cancer, both the cancer and treatment will place extra demands on your body. Research suggests that eating well and exercising can benefit people during and after cancer treatment.

If you have had your gall bladder removed, bile made by the liver will no longer be stored between meals. Bile instead will flow directly from your liver into your small intestine and there will still be enough bile produced for normal digestion. You should still be able to eat a normal diet after your gall bladder is removed, but it’s a good idea to avoid high-fat foods for a few weeks after surgery while your body adjusts.

Eating well and being physically active can help you cope with some of the common side effects of cancer treatment, speed up recovery and improve quality of life by giving you more energy, keeping your muscles strong, helping you maintain a healthy weight and boosting your mood.

You can discuss individual nutrition and exercise plans with health professionals such as dietitians, exercise physiologists and physiotherapists.

- ▶ For free copies of Cancer Council’s booklets on *Nutrition and Cancer* and *Exercise for People Living with Cancer* visit your local Cancer Council website or call 13 11 20.

Understanding Gall Bladder Cancer

Side effects of treatment

All treatments can have side effects. The type of side effects that you may have will depend on the type of treatment and where in your body the cancer is. Some people have very few side effects and others have more. Your specialist team will discuss all possible side effects, both short and long-term (including those that have a late effect and may not start immediately), with you before your treatment begins.

One issue that is important to discuss before you undergo treatment is fertility, particularly if you have been diagnosed at a younger age and want to have children in the future.

- ▶ For a free copy of Cancer Council's booklet *Fertility and Cancer* visit your local Cancer Council website or call 13 11 20.

Common side effects	
Surgery	Bleeding, damage to nearby tissue and organs (including liver failure and bile leakage), pain, infection after surgery, blood clots, weak muscles (atrophy), lymphoedema
Radiation therapy	Fatigue, nausea and vomiting, liver damage, bowel issues such as diarrhoea, skin problems, loss of fertility, early menopause
Chemotherapy	Fatigue, loss of appetite, nausea and vomiting, bowel issues such as diarrhoea, hair loss, mouth sores, skin and nail problems, increased chance of infections, loss of fertility, early menopause

After treatment for gall bladder cancer (especially surgery), you may need to adjust to changes in the digestion of food or bowel function, in particular diarrhoea. These changes may be temporary or ongoing and may require specialised help. If your gall bladder has been removed, you can still break down fats in your small intestine. The bile simply flows directly from your liver to your duodenum, rather than passing through your gall bladder first. If you experience problems, talk to your GP, specialist doctor, specialist nurse or dietitian.

Making decisions about treatment

It can be difficult to know which treatment is best for you. Your doctors may discuss your situation at a specialist multi-disciplinary meeting prior to giving you treatment recommendations. It is important that you speak with the specialist team before making your decision. Ask them to give you a clear plan of your treatment options, including written information about side effects.

Some people prefer to seek several opinions before feeling confident to go ahead with the treatment. There is no need to feel awkward about seeking a second opinion and specialists will not be offended if you do so. If you are confused or want to check anything, ask your specialist questions. This will ensure you have all the information you need to make decisions about treatment and your future that you are comfortable with.

You may have to attend many appointments. It's difficult to remember everything your specialist is saying to you so it's a good idea to take someone with you. They will be able to listen, ask questions and remember what the doctor says. It may help to take a list of questions with you, take notes (especially about anything you are unfamiliar with) or ask the doctor if you can record the discussion (many mobile phones have a recording function or you can use the CAN.recall app – for more information visit rarecancers.org.au). There are some suggestions for questions you could ask at the end of this sheet.

- ▶ For a free copy of Cancer Council's booklet *Cancer Care and Your Rights* visit your local Cancer Council website or call 13 11 20. Cancer Council's podcast on *Making Treatment Decisions* is available to listen to at cancercouncil.com.au/podcasts

Looking after yourself

There is no right way to feel if you have been diagnosed with a cancer such as gall bladder cancer. Feeling a range of emotions is normal and you may feel overwhelmed, anxious, fearful, angry, sad or lonely.

Many people need emotional support before, during and after treatment. Adjusting to living with visible scars, changes to your physical appearance,

Understanding Gall Bladder Cancer

changes to your lifestyle and bodily function can be hard and take time. If this is affecting you, or likely to affect you, it's important to seek help.

It can help to talk things through with a counsellor, psychologist, friend or family member. Talk to your medical team or call Cancer Council 13 11 20 about what support services are available.

- ▶ For a free copy of Cancer Council's booklet *Emotions and Cancer* visit your local Cancer Council website or call 13 11 20.

Practical and financial support

There are many services that can help you manage with practical or financial issues caused by gall bladder cancer. Benefits, pensions and hardship programs may be able to help pay for prescription medicines (for example the Australian Government's Pharmaceutical Benefits Scheme [PBS]), transport costs or utility bills. Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

For additional income, you may be able to access your superannuation early in certain circumstances, or claim on insurance policies such as income protection, trauma, and total and permanent disability (TPD).

Managing your ability to work or study, particularly during cancer treatment, is important to consider and will depend on your personal situation.

- ▶ For free copies of Cancer Council's booklets on *Cancer and Your Finances* and *Cancer, Work & You* visit your local Cancer Council website or call 13 11 20.

Life after treatment

Once your treatment has finished, you will have regular check-ups to confirm that the cancer hasn't come back. Ongoing surveillance for gall bladder cancer involves a schedule of ongoing scans, and physical examinations. Let your doctor know immediately of any health problems between visits.

Some cancer centres work with patients to develop a "survivorship care plan" which includes a summary of your treatment, sets out a schedule for follow-up care, lists any symptoms and long-term side effects to watch out for, identifies any medical or emotional problems that may develop and suggests ways to adopt a healthy lifestyle. Maintaining a healthy body weight, eating well and being active are all important. If you don't have a care plan ask your specialist for one and make sure a copy is given to your GP and other health care providers.

- ▶ For a free copy of Cancer Council's booklet *Living Well After Cancer* visit your local Cancer Council website or call 13 11 20.

If the cancer comes back

For some people gall bladder cancer does come back after treatment, which is known as a recurrence. If this happens, treatment will depend on where the cancer has returned to in your body and may include a mix of surgery, radiation therapy and chemotherapy.

In some cases of advanced cancer, treatment will focus on managing symptoms, such as pain, and improving your quality of life without trying to cure the disease. This is called palliative treatment. Palliative care treatment can be provided in the home, in a hospital, in a palliative care unit or hospice, or in a residential aged care facility.

When cancer is no longer responding to active treatment, it can be difficult to think about how and where you want to be cared for towards the end of life. But it's essential to talk about what you want with your family and health professionals, so they know what is important to you. Your palliative care team can support you in having these conversations.

- ▶ For free copies of Cancer Council's booklets on *Understanding Palliative Care*, *Living with Advanced Cancer* and *Facing End of Life* visit your local Cancer Council website or call 13 11 20.



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.

Understanding Gall Bladder Cancer

Questions for your doctor

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

Diagnosis

- What type of gall bladder cancer do I have?
- How far has the cancer spread? What stage of cancer do I have?
- Have you treated this type of cancer before? If so, how many times? Is there another doctor who has more experience treating this type of cancer?

Treatment and side effects

- What are the treatment options for me? What do you recommend and why?
- What are the possible risks and side effects of my treatment? How will these be managed?
- If an operation is recommended, how many times have you performed it?
- How complex is the surgery and how long does the operation take?
- How long will all treatment take? Will I have to stay in hospital?
- Is this treatment covered by Medicare/private insurance? Will there be extra expenses?
- Are there any complementary therapies that might help me?
- Do you know of any support groups or support services I can use?

If you are thinking of taking part in a clinical trial, here are some questions you could ask:

- What are the possible benefits and risks to me?
- What is being tested and why?
- How many people will be involved in this trial?
- If I cannot get onto a clinical trial can I still pay for a drug that is currently in trial?

Acknowledgements

This information has been developed with help from health professionals and people affected by gall bladder cancer. It was reviewed by: Kathleen Boys, Consumer; Dr Julian Choi, HPB Surgeon, Western Health and Epworth Hospital, Vic; David Fry, Consumer; Dr Robert Gandy, Hepatobiliary Surgeon, Prince of Wales Hospital, Randwick, NSW; Yvonne King 13 11 20 Consultant, Cancer Council NSW; Elizabeth Lynch, Consumer; Dr Jenny Shannon, Medical Oncologist, Nepean Hospital Cancer Centre, NSW.

Note to reader

Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, 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 fact sheet.

Support services

- Cancer Council: visit your local Cancer Council website (see below for details) or call **13 11 20**
- Australasian Gastro-Intestinal Trials Group (AGITG): gicancer.org.au or call **1300 666 769**
- Pancare Foundation: pancare.org.au or call **1300 881 698**
- Rare Cancers Australia: rarecancers.org.au or call **1800 257 600**
- Talk to a nurse, social worker or Cancer Council **13 11 20** about what is available in your area.

Where to get help and information

Call Cancer Council **13 11 20** for more information about gall bladder cancer. Trained health professionals can listen to your concerns, provide information, and put you in touch with local services and support groups. Ask for free copies of booklets that may be relevant to you, or download digital versions from your local Cancer Council website:

ACT..... actcancer.org
 NSW cancercouncil.com.au
 NT..... cancer.org.au/nt
 QLD cancerqld.org.au
 SA..... cancersa.org.au
 TAS cancertas.org.au
 VIC cancervic.org.au
 WA..... cancerwa.asn.au
 Australia..... cancer.org.au

References

1. Australian Institute of Health and Welfare (AIHW). Cancer in Australia 2019. Cancer series no.119. Cat. no. CAN 123. AIHW, Canberra, 2019.

A web-based resource for Australians with less common cancers project is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government. Website: canceraustralia.gov.au



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.