

# Biliary cancer

## Your guide to best cancer care



### About this guide

Being told you have biliary cancer (cancer of the gallbladder or bile ducts) or could have biliary cancer can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help guide you and your family and friends through this experience.

### Information and support

**Cancer Council:** For information and support, call Cancer Council on **13 11 20** to talk to a health professional or visit the website [www.cancer.org.au](http://www.cancer.org.au).

**Pancare Foundation:** For information or to talk to a cancer nurse call **1300 881 698** or visit the website [www.pancare.org.au](http://www.pancare.org.au).

**Liver Foundation:** For information or to talk to a liver specialist nurse call **1800 841 118** or visit the website [www.liver.org.au](http://www.liver.org.au).

**Translating and Interpreting Service (TIS):** If you need an interpreter, call TIS on 13 14 50 or visit the website [www.tisnational.gov.au](http://www.tisnational.gov.au).

**Computed tomography (CT) scan.** Computerised x-ray machines are used to take a detailed picture of your internal organs, including the gallbladder and bile ducts.

**Ultrasound.** Soundwaves are used to take a picture of your internal organs, including the gallbladder and bile ducts.

### Referrals

If your GP has concerns, you will be referred to a gastroenterologist, hepatologist, medical oncologist or hepatopancreatobiliary (HPB) surgeon for more tests. Gastroenterologists, hepatologists, medical oncologists and HPB surgeons are doctors who are highly trained in biliary cancer.



### Timeframes

Your specialist appointment should happen within two weeks of the initial GP referral.

If you can't get an appointment within this time, follow up with your GP.



### Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost?

## Initial tests and referral

### Symptoms

Your general practitioner (GP) should do a check-up to see if they can find what's making you unwell. They will ask you about any symptoms you might be having such as: yellow skin, itchiness, nausea, vomiting, weakness, loss of appetite, weight loss, fevers, chills, pain in the right side of your stomach, darkened urine or pale bowel movements.

### Initial tests you may have

**Physical check.** Your GP will check your abdomen (stomach area) and ask you questions about your symptoms.

**Blood tests.** A sample of your blood will be taken. Tests will include a full blood count, liver function and tumour markers.

## Diagnosis and staging

The specialist will do more tests to see if you have biliary cancer. This process of working out if you have a medical problem is called making a **diagnosis**.

You might have one test or a mix of tests:

**CT scan.** If you haven't already had one.

**Magnetic resonance imaging (MRI) scan.** A scan where a powerful magnet and radiofrequency waves are used to make a detailed picture of the body.

**Magnetic resonance cholangiopancreatography (MRCP).** A type of MRI scan that specialises in looking at the gallbladder and bile ducts.

**Endoscopic ultrasound (EUS).** A flexible tube (called an endoscope) with a camera on it is put down your throat to reach your stomach. It uses soundwaves to take a picture of the gallbladder and bile ducts. This is done under light general anaesthetic (you will be asleep).

**Positron emission tomography (PET) scan.** A small amount of radioactive glucose is injected and your whole body is scanned to show where the cancer is.

**Laparoscopy.** Small cuts are made on your abdomen. The specialist puts a small tube with a camera on the end, through the cut, into your abdominal cavity to look at your gallbladder, bile ducts and other organs. This is a laparoscope. This is done under general anaesthetic (you will be asleep).

**Biopsy.** A small sample of your gallbladder or bile ducts is taken to check under a microscope. The biopsy can be taken at the time of the EUS or laparoscopy.

**Staging.** The combination of tests will help determine what stage the cancer has reached. Staging helps to work out the best treatment for you.



#### Timeframes

Results should be available within two weeks from when you have the tests.



#### Questions you might want to ask

- What is biliary cancer?
- What tests will I have?
- How much will tests/appointments cost? (you may need to pay for some tests, even in a public hospital)
- Where should I be treated? Do I have a choice?
- What stage is my cancer?
- What support services are available to me?

## Treatment

There are several ways to treat biliary cancer. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment. Your treatment may be informed by genetic testing, which can be helpful to guide which type of treatment you have.

You might have one treatment or a mix of treatments:

**Surgery** is where the cancer is cut out.

**Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. Radiation therapy may be used with chemotherapy or alone.

**Chemotherapy** uses drugs to kill cancer cells and stop the cancer growing.

**Targeted therapy** uses drugs to attack specific features of cancer cells and stop the cancer growing.

**Immunotherapy** is a type of cancer treatment that helps the body's immune system to fight the cancer.

**Biliary drainage** may be needed to help manage jaundice caused by blocked bile ducts. This may be done via a needle through the skin or using an endoscope to put in a stent (tube).

For more information about treatments visit the Cancer Council's website [www.cancer.org.au/cancer-information/treatment](http://www.cancer.org.au/cancer-information/treatment).

Supportive care (treatment or services that support you through a cancer experience) are also available.

You may be offered to take part in a clinical trial.

#### Clinical trials

Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit the Australian Cancer Trials website [www.australianclinicaltrials.gov.au/about/find](http://www.australianclinicaltrials.gov.au/about/find).

#### Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.



#### Timeframes

Treatment should start within four weeks of the treatment decision.



**You can ask your GP for a referral to another specialist for a second opinion.**



### Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?



### Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be. If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a health professional about financial support.

For more information about costs, visit the Cancer Council's financial assistance webpage [www.cancer.org.au/support-and-services/practical-and-financial-assistance](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance) and paying for treatment [www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment).

## Recovery

Cancer treatment can cause physical and emotional changes.

### Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is after treatment
- what will happen in follow-up, how often you should be seen and what tests will be recommended (and the purpose of these)
- understanding and dealing with any side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other health professionals and community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit the Cancer Council's website [www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment](http://www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment) and the Australian Cancer Survivorship Centre's website [www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship).



### Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

## Living with advanced cancer

### If cancer returns

Sometimes cancer can come back after treatment. It can come back in the same place or can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.



#### Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

### Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your preferences for your future medical and healthcare treatment. This gives you an opportunity to think about, and talk about, your wishes and preferences, in case there comes a time when you cannot make or communicate decisions for yourself. Advance care planning is voluntary, and it's up to you whether you choose to do this or not.

### Advance care directive

An advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit the Advance Care Planning Australia website [www.advancedcareplanning.org.au](http://www.advancedcareplanning.org.au).

### Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.



Speak to your GP or specialist or visit the Palliative Care Australia website [www.palliativecare.org.au](http://www.palliativecare.org.au).

### Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer.

For more information visit the Cancer Council's website [www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment](http://www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment).



#### Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide 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, Pancare Foundation and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

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This resource is based on information from the optimal care pathway for people with biliary cancer. (1st edition), available at [www.cancer.org.au/OCP](http://www.cancer.org.au/OCP).