

A Guide to Understanding Cholangiocarcinoma



Liver Foundation acknowledges the
Traditional Custodians of this land.

We pay our respects to Elders past,
present and emerging.

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How to use this booklet

Hearing the word “cancer” can feel very scary.

Many people feel like this.

You are not alone. We are here to help.

You can talk to:

- Your GP
- Your specialist
- A nurse from the Liver Foundation Support Line.

It is free and private.

You can:

- Ask questions
- Ask a friend or family member to come with you
- Ask for an interpreter

These are your rights

IMPORTANT WORDS TO KNOW

They will help you read this booklet.

Bile ducts	Bile ducts are tubes in the body that begin in the liver. They carry bile from the liver to the gallbladder and the small intestine.
Cholangiocarcinoma	Bile duct cancer
CT scan	This is a scan that uses X rays to take pictures of the inside of your body.
Ultrasound	This is a scan that uses sound waves to take pictures of the inside of your body.
Liver fluke	This is a parasite that attacks the liver.

WHEN TO GET MEDICAL HELP FAST?



Call **000** now

or go to the **Emergency Department** now if you:

- Vomit blood
- Do black, sticky poo
- See blood in your poo
- Have a high fever
- Have strong pain in your belly
- Feel confused
- Feel very sleepy or are hard to wake

What is cholangiocarcinoma?

Cholangiocarcinoma is a rare cancer of the liver.

It starts in the bile ducts.

It is also called bile duct cancer.

Bile ducts are small tubes that start in the liver.

They carry bile from the liver to the gallbladder and then to the small intestine.

What is cholangiocarcinoma?

There are different types of bile duct cancer. It depends on where the cancer starts:

- **Intrahepatic cholangiocarcinoma**

Cancer grows in the bile ducts inside the liver.

- **Hilar (perihilar) cholangiocarcinoma**

Cancer grows in the bile ducts just outside the liver.

- **Distal cholangiocarcinoma (extrahepatic)**

Cancer grows in the bile ducts near the small intestine.

**You are not alone.
We are here to help.**



Why does cholangiocarcinoma happen?

Most cholangiocarcinomas happen after a long time of swelling and irritation in the bile ducts.

This can happen with other liver problems, like hepatitis or fatty liver or a liver disease called primary sclerosing cholangitis.

You may get cholangiocarcinoma if you:

- Have inflammatory bowel disease or diabetes
- Were born with bile duct problems
- Have a health problem passed down in families, like cystic fibrosis or Lynch syndrome
- Have been in contact with some chemicals, especially in commercial printing jobs
- Have a liver fluke
- Smoke

Sometimes people get cholangiocarcinoma even without any known problems.

How do I know I have cholangiocarcinoma?

Many people do not know they have cholangiocarcinoma.

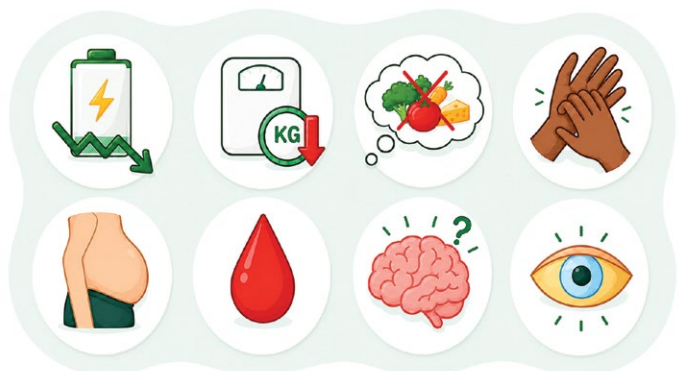
This is because there are no signs at the beginning.

Some people first see their doctor because they:

- Have pain in their belly
- Lose weight without trying
- Have a blood test that is not normal

Other signs:

- Yellow eyes or yellow skin
- Dark wee and pale poo
- Itchy skin
- Feeling very tired
- Feeling sick or not hungry
- Fevers or chills



What to do next

The doctor will ask you to do a scan if they think you may have cholangiocarcinoma. This may be an ultrasound or a CT.

If you have cholangiocarcinoma, you can get treatment.

Chemotherapy can make you feel tired or sick.

Problems with bile ducts can make it hard to digest food.

Talk to your doctor if you are worried or need support.

This is what you can do to feel better.

- 1 Talk to your doctor or a dietitian about what to eat.

This helps your body get what it needs from food.

- 2 Ask if nutritional supplements are good for you.

Check with your doctor or dietitian first.

- 3 Don't drink alcohol.

- 4 Don't use any herbal medicines or liver tonics.

These can cause more harm to your liver.

Check with your doctor before taking anything new.

Healthy living for my liver

New health information can feel scary.

It can be hard to understand.

It is okay to go slowly.

You do not need to do everything at once.

Start with one small step.

How do I take care of my liver?

Easy steps:

- Drink water during the day
- Eat more vegetables and fruit
- Go for a short walk
- Move your body for a few minutes
- Go to your appointments
- Call the Support Line and ask one question





Eating

Pick foods that you like and are low cost.

- Try not to skip any meals
- Eat protein at every meal
- Eat less takeaways, chips and cakes
- Drink less juice and soft drink

If you feel sick, not hungry or stressed:

- Eat small snacks every 2 to 3 hours
- Choose soft foods, like soup, yoghurt or smoothies
- Ask your doctor or dietitian for help

MORE INFORMATION



Scan the QR code to learn more about Cholangiocarcinoma.



Staying active

Staying active is good for your whole body.

It is also good for your liver.

- Being active can help you:
- Stay healthy
- Reduce the chance of diabetes and heart problems
- Improve your mental health
- Keep you strong

Being active is good for you.

Start slowly.

Be active every day.

Staying active means things that:

- Make you a little short of breath
- Help keep your muscles strong, like squats

See your doctor before you start new exercise



Stop drinking alcohol

If you have cirrhosis or advanced liver disease, do not drink alcohol.

If stopping alcohol feels hard, you are not alone.

Talk to your doctor.

You can also call the Support Line for help.



Medications

It is important to take the medications your doctor gives you.

Talk to your doctor if you are worried.

Always check with your doctor before taking:

- Supplements
- Herbal medicine
- Over the counter medications

This is important because some things can make liver problems worse.



My notes

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Contact us

If you have questions about liver cancer or liver problems, you can call our Support Line.

You will speak to a liver nurse.

The nurse is caring and knows a lot about the liver.

The Support Line is:

- **Free and private.**

You do not have to give your name.

It's for people in Australia:

- Patients
 - Families
 - Carers
 - Health workers
-
- Open on weekdays 8am to 6pm
 - Closed on weekends and public holidays



Contact us

- You can talk to a nurse who knows a lot about liver problems

- Phone: 1800 841 118



- Email support@liver.org.au

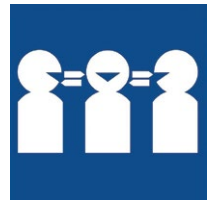


- You can ask for an Interpreter or Auslan.

- Call TIS National 131 450.

Tell them you want to speak to the

Liver Foundation Support Line at 1800 841 118.



MORE INFORMATION



Scan the QR code to learn more about Nurse-Led Support.

What is Liver Foundation?

Liver Foundation is an Australian organisation and we:

- Teach people about liver health
- Promote early testing and awareness of risk factors
- Support research
- Help people get care

The Liver Cancer Nurse Led Support Line:

- Is run by liver nurses
- Is funded by the Australian Government

The Support Line helps people with cancer and cholangiocarcinoma.

It helps people understand the health system.

