

Bile duct cancer (cholangiocarcinoma)

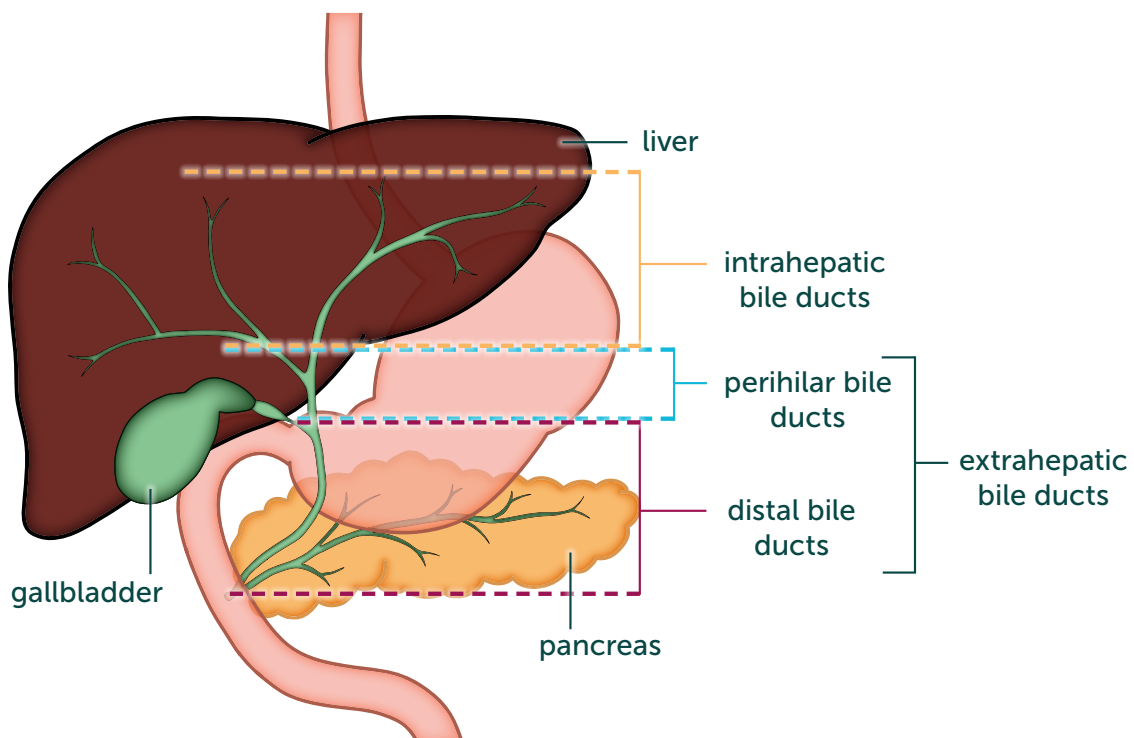
What is bile duct cancer?

Bile duct cancer is also called cholangiocarcinoma (say: kol-an-jee-oh-car-sin-oh-ma).

In bile duct cancer, cells lining the bile ducts start to multiply and grow more than they should. There are bile ducts throughout the liver and outside the liver, connecting it with the gallbladder and small bowel (intestine). They release bile into the bowel after we've eaten. It helps to digest fat.

There two main types of bile duct cancer:

- Intrahepatic – bile duct cancer that starts in bile ducts inside the liver
- Extrahepatic – bile duct cancer that starts in bile ducts outside the liver



There are also two types of extrahepatic bile duct cancer – distal and perihilar.

- Perihilar cancers start where the main bile ducts inside the liver meet.
- Distal cancer start in bile ducts that carry bile from the gallbladder to the intestine.

Bile duct cancer symptoms

Early bile duct cancer may not cause any symptoms. Or symptoms may be vague. You may feel sick or lose your appetite.



If the cancer blocks bile ducts, you may develop jaundice (say: jawn-diss). Your skin and eyes may look yellow, caused by bile salts building up in the body. You may also have:

- itching
- dark wee
- pale, putty coloured poo
- flu-like symptoms of muscle aching, fever and tiredness

Other symptoms include:

- losing weight without meaning to
- tummy (abdominal) pain that spreads to your back

All these symptoms can be caused by other conditions – it's important to see your GP to find out what's causing them.

Bile duct cancer risks and causes

About 2,200 people in England are diagnosed with bile duct cancer every year. But it's still a rare cancer. It doesn't tend to run in families.

We don't know what causes most cases, but there are some things that increase risk. It's a myth that liver cancers are always related to alcohol. In fact, it's unclear whether alcohol is linked to bile duct cancer.

Most people who get bile duct cancer are older, between 50 and 70. Some other liver or gallbladder conditions increase risk because they irritate the bile ducts. People with these may get bile duct cancer when they're younger than that.

Other factors that may increase risk include:

- other liver disease – cirrhosis or long-term infection with viral hepatitis
- being overweight
- having diabetes

Tests to diagnose bile duct cancer

To start with, most people see their GP who may do some blood tests. If there are any concerns, your GP will refer you to a specialist. At the hospital, you may have any of these scans:

- an ultrasound
- a CT or MRI
- an MRI specifically of your liver and gallbladder (MRCP scan)

You may have one of these tests to look at the area more closely and possibly take a tissue sample (biopsy):

- a tube down your throat (endoscopy), to look at your bile ducts from inside the body
- an endoscopy with an internal ultrasound probe (endoscopic ultrasound or EUS)
- an injection of dye into the bile ducts, with a needle put through the skin over the liver (percutaneous transhepatic cholangiography – or PTC)
- an internal examination with a camera put through a small cut (a laparoscopy)

Your doctor will send the biopsy to be checked for signs of cancer. Any cancer cells may be tested for gene changes (mutations). These mutations may be targets for biological treatments. The tests are called molecular profiling.

Bile duct cancer stages

The stage of a cancer means how far it's grown and whether it's spread. Doctors decide on treatment according to stage.

In bile duct cancer, you may hear about TNM staging or number staging. TNM stands for **T**umour, **N**ode, **M**etastasis.

T is the size of the cancer.

N explains whether it has spread to nearby lymph nodes (glands).

M means spread to another part of the body.

There are 4 number stages:

- stage 1 is an early cancer, small and localised
- stage 2 is slightly bigger, but also localised
- stage 3 has grown outside the liver into nearby tissues or lymph nodes
- stage 4 has spread to another part of the body

There are detailed staging systems for each type of bile duct cancer.

Bile duct cancer treatment

The treatment you'll have depends on how far the cancer has grown and exactly where it is. The information below is arranged into treatment for different stages of bile duct cancer.

Treatment for bile duct cancer that can be removed

If you have an early cancer, it may be possible to cure it with surgery.

If you have intrahepatic bile duct cancer, you may have part of your liver removed.

If you have extrahepatic bile duct cancer, you'll have the bile ducts outside the liver and the gallbladder removed. You may need part of your pancreas or small bowel removed as well.

You may have chemotherapy after your surgery, to reduce the risk of the cancer coming back.

Treatment for bile duct cancer that can't be removed

If your cancer can't be removed, your doctor will concentrate on trying to control it and slow its growth. You may have

- chemotherapy
- radiotherapy
- a small tube (stent) put in to allow bile to flow and relieve jaundice

Treatment for advanced bile duct cancer or cancer that's come back

Often, bile duct cancer is quite advanced when it's first diagnosed. Unfortunately it can also come back after treatment. Doctors call this recurrent cancer. Your doctor will focus on trying to control the cancer and relieve any symptoms you have. You may have:

- chemotherapy
- radiotherapy
- a targeted (biological) therapy

To relieve symptoms, you may have:

- a small tube (stent) put in to allow bile to flow and relieve jaundice
- painkillers, anti-sickness medicines or medicines to relieve itching

Bile duct cancer check-ups

After your treatment finishes, your doctor will want to see how you are. So you'll have check ups, or follow up appointments.

After surgery to remove bile duct cancer, you usually see your doctor after a few weeks, then 3 monthly. If all's well your appointments may become 6 monthly after a couple of years. You may have scans or blood tests from time to time.

If your cancer can't be removed, you may see your doctor more often during and after treatment. Or, if things are stable, your doctor may suggest you ring if you need an appointment. You don't have to wait for an appointment if you are concerned or have a new symptom or side effect you're worried about.

Living with bile duct cancer

It's often difficult for people to cope after a diagnosis of cancer. With a rare cancer it can be even harder. You may get tired of explaining your diagnosis. You are less likely to come across people in the same situation as you. Your diagnosis and treatment may take a physical, emotional and psychological toll on you. Added to that, there are practical issues to cope with.

Many of us aren't used to asking for help. But we all need it at times. Your GP can help with organising other services, such as district nurses or a symptom control nursing team. There may be good neighbour schemes in your area or home support from social services. Your treatment centre will be able to tell you about cancer support groups near you, who are a good source of information about local services.

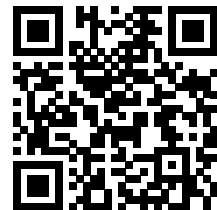
More information and support

Our patient information web pages, nurse-led helpline, support groups and online forum are here to help you, your family and friends, whatever your diagnosis.

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or scan the code with your phone

Call our nurse-led helpline **0800 652 7330**

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