

About Cholangiocarcinoma

Cholangiocarcinoma is a primary liver cancer that occurs within the bile ducts and, for many, it is a devastating diagnosis.

The facts:

- It's the second most common primary liver cancer in the world
- In 2013 it caused 2,161¹ deaths in England alone
- Fewer than 5% will survive one year from diagnosis
- The incidence is increasing, and we don't know why
- It's difficult to diagnose clearly and accurately
- Most are diagnosed too late for potentially curative surgery
- In the western world the cause is generally unknown, most cases are sporadic
- Thailand has the world's highest incidence, caused by eating raw fish infected with a liver fluke (*Opisthorchis viverrini*)

At AMMF we are working to:

- Raise awareness
- Provide information to those who need it, either individually or via our website
- Support research, especially into finding ways to achieve better and clearer early diagnosis

¹Public Health England NCIN/Cancer52
'Rare and Less Common Cancers'

For more information on
cholangiocarcinoma, the work of
AMMF and ways to donate,
see our website:

www.ammf.org.uk



**AMMF – The UK's only
cholangiocarcinoma charity**

**Working nationally and
collaborating internationally for
those with cholangiocarcinoma**

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**The UK's only
Cholangiocarcinoma
Charity**

www.ammf.org.uk

Registered charity no 1091915



In 1997 when Alan Morement was diagnosed with the liver cancer cholangiocarcinoma, there was very little available information and next to no research into this disease. After Alan died in December 2000, AMMF (The Alan Morement Memorial Fund) was set up and registered as a charity. Today AMMF is the UK's only dedicated cholangiocarcinoma charity.

Although cholangiocarcinoma (bile duct cancer) is considered a rare cancer, worldwide it is the second most common primary cancer arising in the liver. However, because it is so difficult to diagnose accurately and early, cholangiocarcinoma (CC) is often advanced by the time of diagnosis and so surgery, currently the only potential cure, is not an option. Fewer than 5% will survive one year from diagnosis.

Over recent years there has been an enormous and extremely worrying worldwide increase in the incidence of CC. In 2013 it was the cause of 2,161¹ deaths in England alone, and the incidence appears to be increasing across all age groups, including younger people. The cause of this ongoing increase is currently unknown, and much more research is needed.

AMMF is dedicated to raising awareness, providing information to those who need it, either individually or via our informative website, and supporting research into the causes, better diagnostic tests and more effective treatments for this devastating disease.

¹Public Health England NCIN/Cancer52
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What is cholangiocarcinoma?

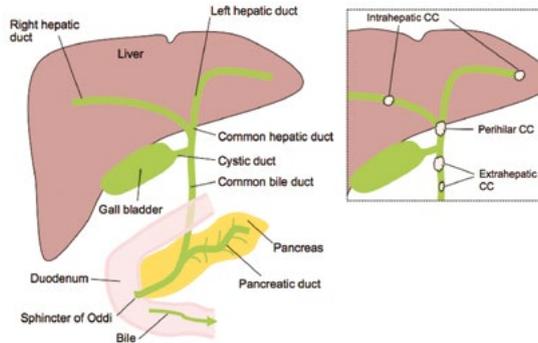
Cholangiocarcinoma (bile duct cancer) is a cancer that arises in the bile ducts in or around the liver. Diagnoses fall into three main categories:

Intrahepatic – affecting bile ducts within the liver.

Perihilar (Hilar or Klatskin) – affecting the junction of the left and right hepatic ducts.

Extrahepatic – affecting bile ducts outside the liver.

This category includes **Distal**, where the bottom portion of the bile duct, near to the connection with the small intestine and pancreas, is affected.



What are the risk factors?

In the western world the exact cause of CC is unclear – most cases are sporadic. Established risk factors, including some illnesses that cause chronic damage to the liver and/or bile ducts, and possibly a small genetic predisposition, are thought to account for less than 30% of all cases. Primary Sclerosing Cholangitis (PSC) is the commonest known predisposing cause.

Other recognised risk factors include gallstones which have remained in the bile ducts for a long time; cysts in the bile ducts; and exposure to certain toxins. Newly discovered likely risk factors include obesity, diabetes and fatty liver disease. However, most people with CC have none of these risk factors, so studies into the causes are a vital area of research.

What are the symptoms?

Cholangiocarcinoma (CC) starts in the bile ducts, so the commonest symptoms are due to blocking of the flow of bile – jaundice (yellowing of eyes and skin), often with dark urine or pale stools, a pain or ache under the right ribs, indigestion and sometimes itching. There may also be unexplained weight loss, general malaise and fatigue. Whilst several of these symptoms can be non-specific and could be caused by benign conditions, they do require urgent assessment (especially where jaundice is present).

What treatments are available?

Surgery to totally remove the cancer is currently the only potentially curative treatment. Unfortunately, by the time most patients are diagnosed, the cancer is too advanced for surgery, so fewer than one third of those diagnosed with CC are operable.

If surgery is not an option, there are several other types of treatment which, although not curative, can help control symptoms and delay the cancer's progression and/or its effects on the body. Following successful trials, the Gemcitabine/Cisplatin chemotherapy combination is now the standard for those with inoperable CC, and further trials looking for more improvements are under way. Other treatments, including stenting to restore bile flow, are available to improve wellbeing.

Full details on cholangiocarcinoma, its diagnosis and treatment can be found on AMMF's website, along with information on clinical trials and research the charity is currently supporting. There is also a discussion forum for patients and their loved ones to share information.