



AMMF

THE CHOLANGIOCARCINOMA CHARITY

EXAMPLE QUESTIONS TO ASK YOUR DOCTOR

The UK's only cholangiocarcinoma charity
Registered Charity no 1198095
www.ammf.org.uk

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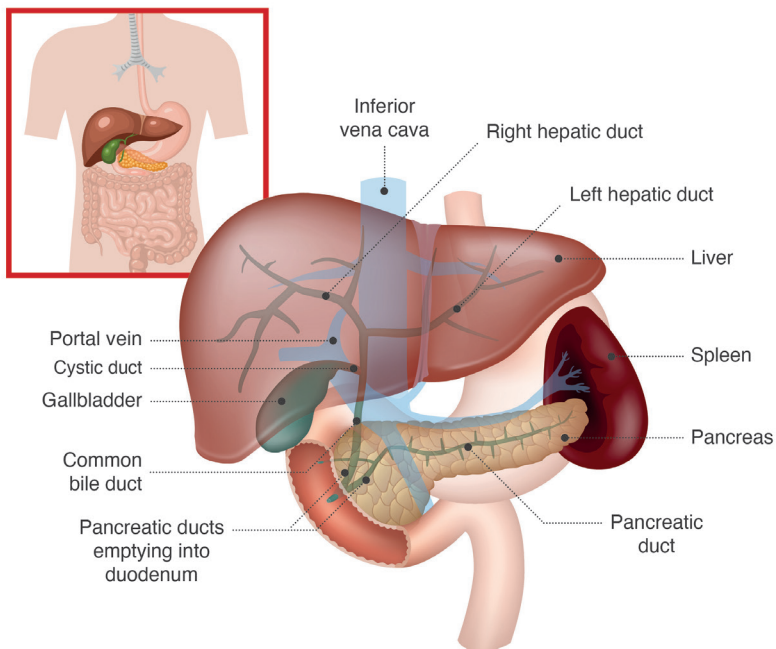
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*For more information on cholangiocarcinoma, including treatments and clinical trials, see **www.ammg.org.uk***

WHAT IS CHOLANGIOCARCINOMA AND WHERE IN THE BODY DOES IT OCCUR?

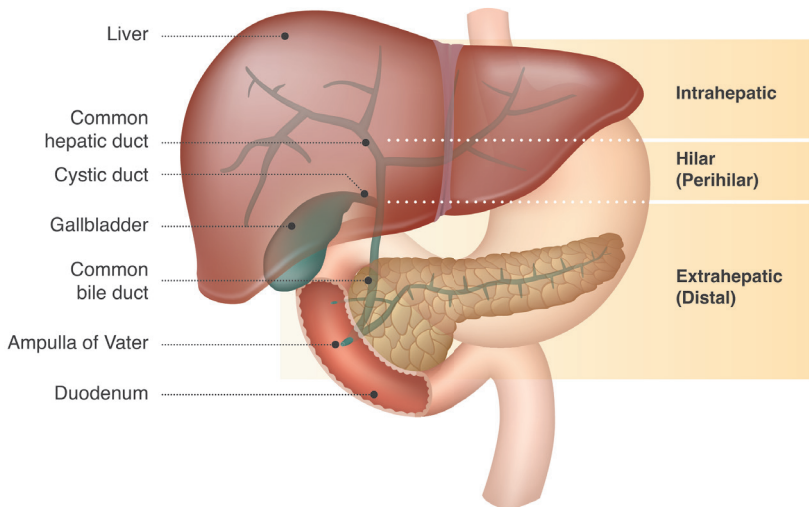
Cholangiocarcinoma (also known as bile duct cancer) is a **biliary tract cancer**. Cholangiocarcinoma (CCA) occurs in the bile ducts and there are three different types: intrahepatic, extrahepatic (or distal) and hilar (or perihilar):

The biliary tract includes the network, or tree-like structure, of ducts within the liver and the common bile duct outside the liver.



WHAT IS CHOLANGIOPHARCINOMA AND WHERE IN THE BODY DOES IT OCCUR? *(continued)*

Cholangiocarcinoma or bile duct cancer, is a primary liver cancer which starts in the inside lining of the ducts of the biliary tree; this is a network of tubes that carry bile from the liver to the gut. Depending on which part of the bile duct CCA develops in, it is categorised as one of three types:



- **Intrahepatic CCA** originates in the bile ducts within the liver
- **Hilar or perihilar CCA** originates just outside the liver, where the left and right hepatic ducts join together
- **Extrahepatic or distal CCA** originates in the common bile duct from just below the cystic duct, which joins the common bile duct and the gall bladder, down to the small intestine. The common bile duct carries bile from the liver and the gall bladder to the small intestine.

EXAMPLE QUESTIONS TO ASK YOUR DOCTOR

Select the questions that seem most appropriate for you to ask your doctor so that you can better understand your cholangiocarcinoma (bile duct cancer) diagnosis and your treatment plan.

AFTER GETTING A DIAGNOSIS

- Where is the cancer located? What type of cholangiocarcinoma (CCA) do I have?
- Is the cancer in other parts of my body?
- What is the stage of my cancer?
- What is my outlook (prognosis)?
- Can my cancer be removed with surgery? If so, what are the potential complications of surgery?
- Will I be cured after surgery?
- If I can't have surgery, what are my other treatment options?
- Do you need to perform any further tests to help with the diagnosis or deciding the treatment plan?

ABOUT TREATMENT

- What treatment option(s) do you recommend and why?
- How many treatments will I receive? How long will the treatment last overall?
- What are the possible side effects of these treatment options in the short and long term?
- How quickly can the treatment begin?
- Will I be eligible to receive treatment as part of a clinical trial?
- Will I be eligible for molecular testing to see what targeted treatments might be available to me, or what clinical trials I might be eligible for?
- Will this treatment affect my daily life? Will I be able to work and perform my usual activities?

ABOUT MOLECULAR PROFILING (TESTING)

When first diagnosed with cholangiocarcinoma:

- Will you be using molecular testing to plan my treatment?
- How soon could we run these tests?
- Can you try to ensure my biopsy sample is large enough to run molecular tests?
- If there is no biopsy sample, or it is not suitable, could liquid biopsy be used?

ABOUT MOLECULAR PROFILING (TESTING) *(continued)*

When offered molecular testing:

- Which gene faults and abnormal proteins will this test look for?
- How might the results help me?
- How likely is it that you'll find a gene fault that we can target?
- How long will it take to get the results?
- How will I get my results?
- What happens if I don't have a gene fault that can be targeted?

When getting your molecular test results

- Which gene faults and abnormal proteins do my cancer cells contain?
- What does this mean for my treatment options?
- Why are targeted treatments not suitable for everyone?
- What are the risks and benefits of the options available to me?

Immunotherapy

- Would immunotherapy be helpful for me?

IF YOU ARE OFFERED A PLACE ON A CLINICAL TRIAL

- What is the purpose of the trial?
- Which treatments will I get?
- What does the trial involve?
- The trial I have been offered is randomised. What does randomised mean for me?
- How will I be monitored for side effects?
- How might the trial help me and others in the future?
- If I choose not to take part, what other options are available to me?

ABOUT YOUR OVERALL CARE PLAN

- Is it possible that the cancer will get worse during treatment or come back after treatment?
- How often will my cancer be assessed?
- What are my options if this treatment fails?
- Should I make any changes to my lifestyle, such as my diet and exercise?
- Where can I get more information and support?

CHOOSING NOT TO HAVE TREATMENT

- Can I choose to not have treatment?
- What would this mean for me?
- If I say no to treatment now, can I change my mind at a later date?
- What care and support can I expect?



AMMF's website has a wealth of information and a range of helpful pages including:

Nutrition

Molecular profiling

Treatment options

Clinical trials

Information booklets specifically prepared for those with cholangiocarcinoma

To view the website, please visit

ammf.org.uk

ammf-eu.org

To contact AMMF please email:

info@ammf.org.uk

AMMF – The UK's only cholangiocarcinoma charity

Working throughout the UK
and Europe, collaborating
throughout the world for those
with cholangiocarcinoma



www.ammf.org.uk

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