

Cholangiocarcinoma

Introduction to Question Guide

Important

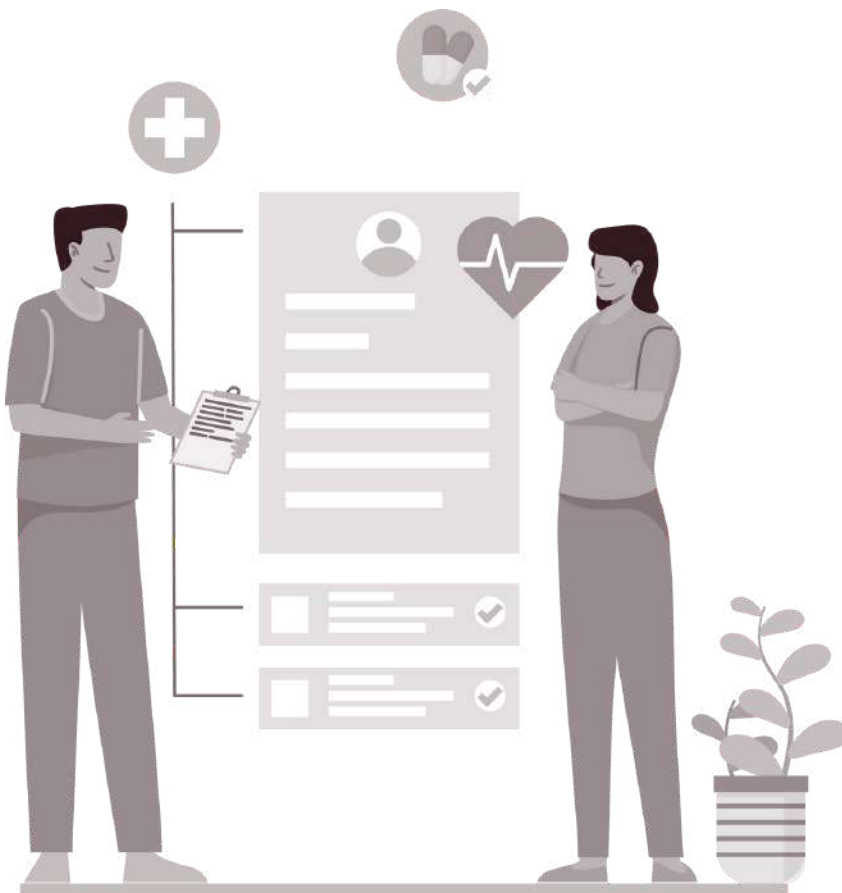
Please read this before your doctors appointment

1. Ensure that your Doctor is aware that you have prepared questions to ask them.
2. When you meet with your Doctor please ensure that you first listen and take in their information and advice before discussing your questions.

How to use this question guide

Hand the question pages to your Doctor who I am sure will be only too happy to help you fill out the answers.

Another options is to record the conversation and write down the answers at a later time.



SURGEON - ONCOLOGIST

About this Question Guide



EXPERIENCED CCA PATIENT & CAREGIVER QUESTIONS

These questions are designed by experienced patients and caregivers to guide you through what you must know

RECORD KEEPING IS VITAL

These answers will form a foundation and act as a simple record to remember when you leave your Doctors office.

PLEASE ASK YOUR DOCTOR FOR COPIES

what will be the best method to obtain copies of Scans, Diagnosis and progress updates

VERY IMPORTANT PATIENT - DOCTOR RELATIONSHIP QUESTIONS

Experience and Expertise can determine
your life and death outcomes.

Do not be afraid to ask questions.

Your doctor is a professional and trained in this.



☐ Do you have current experience with Cholangiocarcinoma?

☐ Are you treating other Cholangiocarcinoma Patients?

☐ Are you OK with me seeking second opinions?

DIAGNOSIS AND TUMOR LOCATION

Questions that need answers

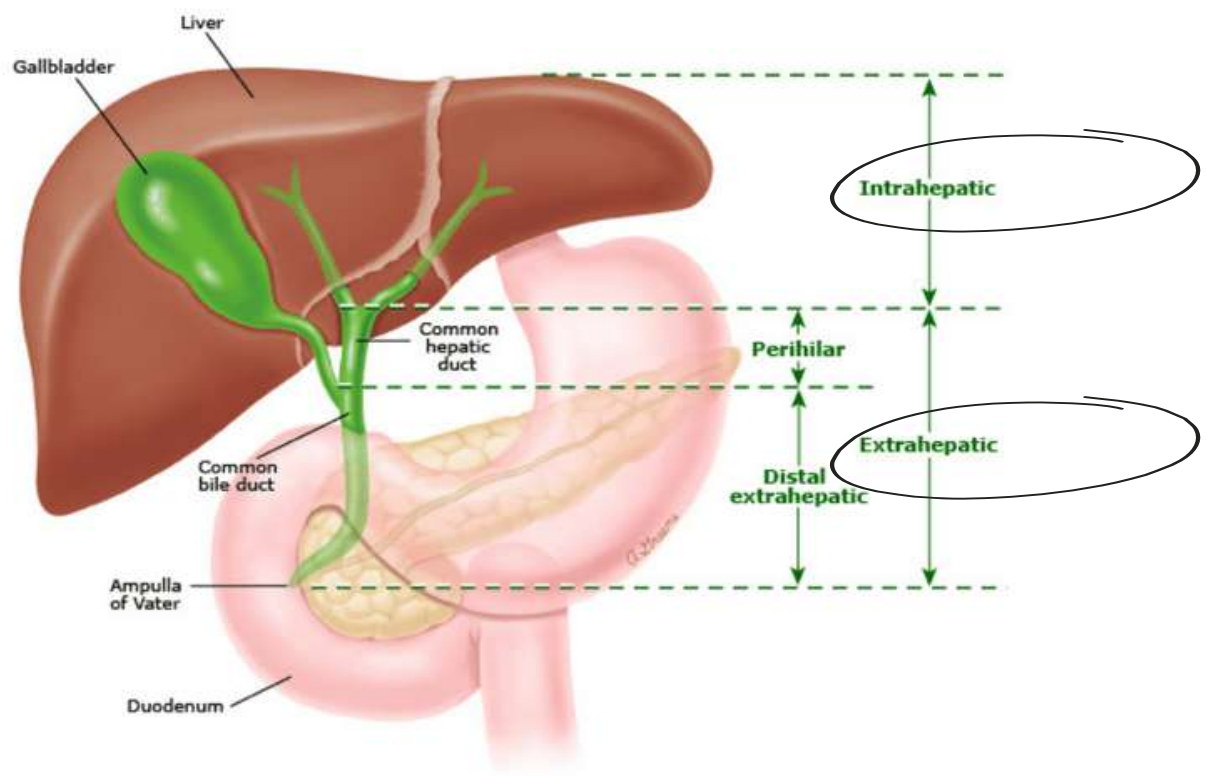
DIAGNOSIS

☐ What is the specific name of my diagnosis?

- ☐ Intrahepatic
- ☐ Extrahepatic Perihilar
- ☐ Extrahepatic Distal
- ☐ Indicate other variables

PRIMARY TUMOR LOCATION

☐ Please indicate the location of the primary tumour



SURGERY

Questions that need answers



SURGERY QUESTIONS

☐ Can the tumor be removed by surgery?

☐ YES

☐ NO (See pages 5 & 6 Surgery Not an Option)

SURGERY IS AN OPTION



☐ 1. What is the name of the surgery option?

☐ 2. Is it a curative surgery?

☐ 3. When will it be scheduled?

☐ 4. What should I know about the side effects

☐ 5. What should I know about recovery?

☐ 6. Will I have adjuvant treatment after surgery

BIOPSY AND TESTING

Questions that need answers



BIOPSY OBTAINED FROM SURGERY FOR TESTING

Tissue sample obtained from surgery is called a biopsy

- ☐ Obtain enough tissue sample for an IHC test and...
- ☐ Tissue sample for Genomic Profiling

IHC TEST (IMMUNO-HISTO-CHEMICAL)

- ☐ Highlight the PD-L1 score
- ☐ Highlight the MSi Status
- ☐ Highlight the HER2 Score

GENOMIC PROFILING - DO I QUALIFY FOR IMMUNOTHERAPY?

A full profiling is essential for Cholangiocarcinoma Patients especially if the IHC Test is not helpful. Please ensure the following are highlighted in the Profiling result sheet.

- ☐ Matching Immunotherapy or targeted therapy options
- ☐ Also highlight TMB score (*Tumor Mutation Burden*)
- ☐ Re-examine PD-L1 score
- ☐ Re-examine MSi Status
- ☐ Re-examine HER2 Score

WHEN SURGERY IS NOT AN OPTION

Questions that need answers

Reason One:

To difficult or dangerous to operate

3 very Important questions too be certain of

- ☐ Can a biopsy still be obtained without surgery?
- ☐ Can Surgery become an option at a later time, after chemotherapy or radiation treatments have reduced the risks?
- ☐ Would you mind if I seek a second opinion on this very important decision?

WHEN SURGERY IS NOT AN OPTION

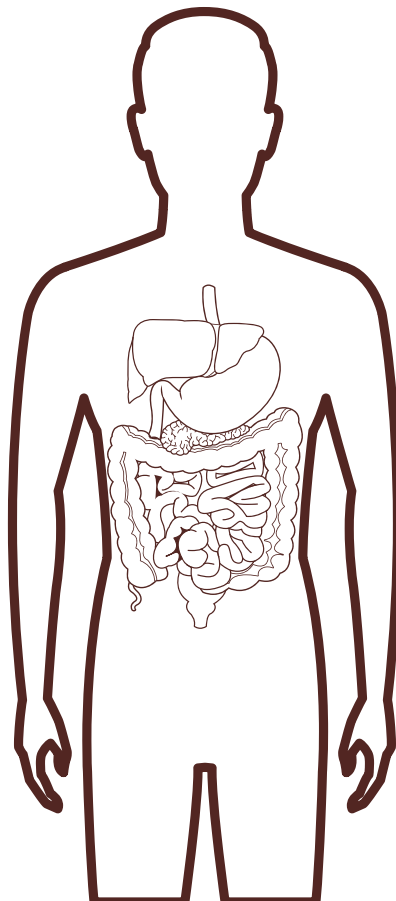
Questions that need answers

Reason Two:

The cancer has spread to other locations

4 very Important questions to be certain of

- ☐ Can you show me where the cancer has spread too.
- ☐ How many tumors in total?
- ☐ Which tumors are the most concerning?
- ☐ Can Surgery be an option at a later time, after chemotherapy or radiation treatments?



TREATMENTS

Questions that need answers

CHEMOTHERAPY:

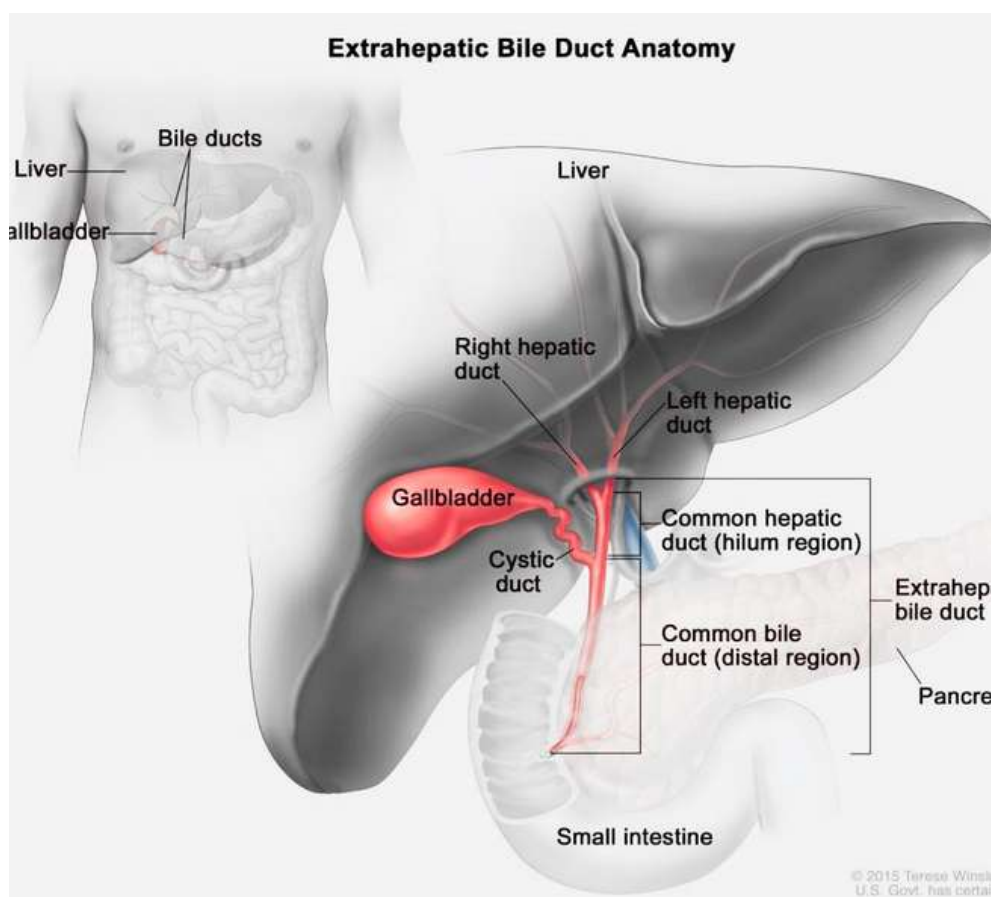
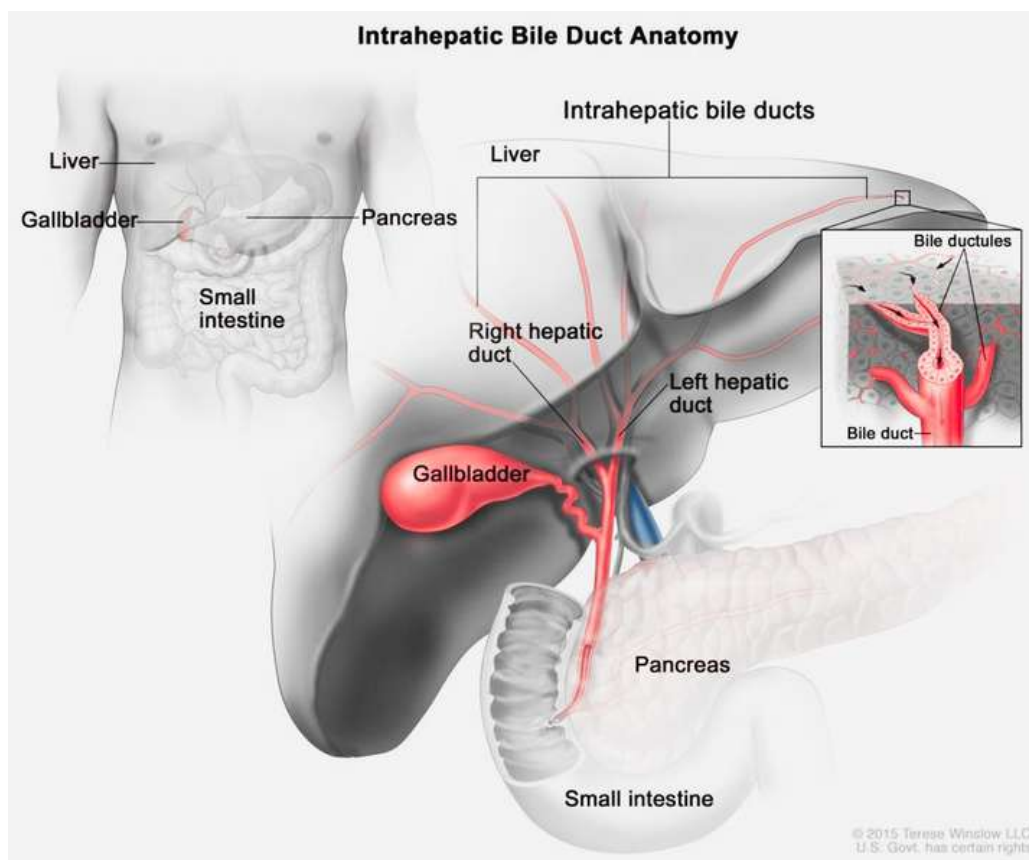
- ☐ What is (are) the name of the treatments?
- ☐ What are the frequency of treatments?
- ☐ How long will I be on this treatment?
- ☐ What are the side effects?
- ☐ What happens after this treatment, is there other options?

RADIATION TREATMENT:

- ☐ What is the name of the radiation treatment?
- ☐ What are the frequency of treatments?
- ☐ How long will I be on Radiation treatment?
- ☐ What are the side effects?
- ☐ What happens after this treatment, is there other options?

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Intrahepatic Diagram



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Notes: simplified



BIOMARKERS & MUTATIONS

- PD-L1: An antigen on the surface of the tumor
- Antigen: A protruding protein on a cell surface that sends or receives messages
- MSI: Microsatellite Instability
- Instability: DNA mistakes that have not been repaired
- HER2: Similar to PD-L1
- TMB: Density of Tumor Mutation Burden occurring in the tumor

TESTING

- IHC: Immunohistochemical: A local test that stains the tissue sample to identify biomarkers that align to immunotherapy
- Biomarkers: Known Indicators (Flags)
- Genomic Profiling: Sequencing the DNA (& RNA) of a tumor
- Genomic: DNA alterations since birth (Environment)
- Genetic: Passed from parent to child (Inherited)
- NGS: Next Generation Sequencing identifies Genomic and Genetic alterations within a tumors cells that is driving the cancers growth.

MORE

- Intrahepatic: Primary is in the bile duct within the liver
- Extrahepatic: Primary is in the bile duct outside the liver
- Primary: Original / first
- Metastasis: Cancer has spread to other locations

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Important for you to understand



As a Cholangiocarcinoma patient you have three very important priorities to pursue thoroughly. Very often you will need second opinion's to achieve this.

SECOND OPINIONS MATTER THEY SAVE LIVES

1. Do you qualify for a curative surgery?
2. Obtain a biopsy for IHC testing and thereafter Genomic Profiling
3. Can you qualify for a clinical trial, in particular Immunotherapy?

Surgery is the only curative option for a Cholangiocarcinoma patient.

Curative means fully clean removal of the tumor

Cholangiocarcinoma has one of the highest rates of mutations that are regarded as targetable for immuno or targeted therapy options - this is good

Immunotherapy is a treatment space that is moving quickly and is beginning to provide Cholangiocarcinoma patients with potential curative options.