Questions to ask your

Oncologist

cholangiocarcinoma FOUNDATION®

SURGERY:

- [ ] Is surgery an option?
- [ ] Should I seek a surgical opinion? If not, why not?
- [ ] Is neo-adjuvant treatment recommended before surgery?
- [ ] What would neo-adjuvant treatment include?
- [ ] When would neo-adjuvant treatment start?
- [ ] Is adjuvant treatment recommended after surgery?
- [ ] When should adjuvant treatment start?
- [ ] What would adjuvant treatment include?
- [ ] Should my adjuvant treatment include radiation?

GENERAL QUESTIONS:

- [ ] What kind of cancer do I have?
- [ ] What is the cancer's stage? What does that mean?
- [ ] Where is my cancer located, has it spread to other parts of my body?
- [ ] How many other people have the same type of cancer?
- [ ] How many CCA patients do you treat per year?
- [ ] Are there any further tests required for my diagnosis? What are they and what will they tell us?
- [ ] What symptoms will the cancer cause?
- [ ] How long do people with my type of cancer usually live?
- [ ] How much do I want to know about my prognosis?
- [ ] Do you encourage second opinions, if so; could you recommend a cancer institute to provide a second opinion?
- [ ] What information do you use to make treatment recommendations?
- [ ] Am I likely to need a biliary stent, and how is the procedure performed?
- [ ] What are the risks associated with biliary drainage and stenting procedures?
- [ ] How do I contact you between appointments (often there are new pains or symptoms, or we are hyper sensitive to any health changes)?
- [ ] What diet or lifestyle changes should I make? Will I have any limitations?
- [ ] Can you provide me with a referral to a Nutritionist and/or Dietician?
- [ ] Can you suggest a mental health professional I can see if I feel depressed, overwhelmed or distressed?
- [ ] What advocacy groups can support me?

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BIOMARKER TESTING:

- ☐ What is biomarker testing?
- ☐ Should I think about genetic testing?
- ☐ How soon will you order biomarker testing of my tissue?
- ☐ Is there any merit in routine blood biopsies? Will these be covered by insurance (my experience is not if you are NED)?
- ☐ What is the relevance of increase (or not) in various cancer markers (CA 19-9 etc.)?

TREATMENT QUESTIONS:

- ☐ Based on my cancer stage, how soon should I start your recommended treatment?
- ☐ What is the goal of my treatment?
- ☐ What would you consider shrinkage of tumors, stability, and progression?
- ☐ What are the chances that my cancer will come back after my treatment?
- ☐ What will we do if it comes back?
- ☐ Do I have a choice of treatments?
- ☐ What are your goals for my treatment?
- ☐ Are first-line clinical trials an option for me?
- ☐ Are second-line clinical trials an option?
- ☐ When do I need to decide on my treatment?
- ☐ Will I be able to work during treatment?
- ☐ What is the next step after this treatment?
- ☐ Does a particular line of treatment exclude other future treatment options (eg. needle biopsy and liver transplant)?
- ☐ Why am I having a CT / PET / MRI scan?
- ☐ How much experience do you have treating this type of cancer with this type of treatment?
- ☐ How long will the treatment last? What will it involve?
- ☐ Where will treatment be done?
- ☐ What do I need to do to get ready for treatment?
- ☐ How will I know if the treatment is working?
- ☐ What are my options if side-effects become too toxic?
- ☐ How will treatment impact my quality of life?
- ☐ How much will I pay for treatment? Will my insurance cover any of it?

SIDE EFFECTS:

- ☐ What might be the side effects of treatment?
- ☐ When are they likely to happen?
- ☐ What can I do to reduce the side effects?
- ☐ Are there any long-term side effects of treatment?
- ☐ Is cholangitis a possibility? What is it, and how is it caused?
- ☐ How will treatment affect my daily activities?
- ☐ What symptoms or side effects should I tell you about immediately?

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Questions to ask about

Clinical Trials

GENERAL QUESTIONS:

- ☐ What is the goal of the trial?
- ☐ What phase is the clinical trial? What does that mean?
- ☐ What are the potential benefits and risks of participating in this trial?
- ☐ Why are you recommending a clinical trial for me?
- ☐ How does it differ from standard treatment?
- ☐ Who will be coordinating my overall medical care?
- ☐ How can I end my participation if I change my mind?

TREATMENT QUESTIONS:

- ☐ Has this treatment been tested before?
- ☐ Have there been other trials similar to this one?
- ☐ Is there any published data on the clinical trial?
- ☐ What are my treatment options if I don't join this trial?
- ☐ What other clinical trials might help me?
- ☐ How long will the treatment last? What will it involve?
- ☐ Where will treatment be done?
- ☐ What do I need to do to get ready for treatment?
- ☐ What diet or lifestyle changes should I make? Will I have any limitations?
- ☐ Will I need special tests or additional imaging scans?
- ☐ When do I need to make a decision about my treatment?
- ☐ How much will I pay for treatment? Will my insurance cover any of it?
- ☐ Will the clinical trial cover any of my out of pocket expenses like travel, missed wages, daycare, parking, food, etc?
- ☐ How will I know if the treatment is working?
- ☐ Are there any reasons I would be removed from the study?
- ☐ If the treatment is working for me, can I keep getting it even after the study ends?
- ☐ If there is a mixed response to treatment, can I remain on the treatment if my physician and I want to continue this treatment?

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POSSIBLE SIDE EFFECTS:

- ☐ How will treatment affect my daily activities?
- ☐ What might the side effects of treatment be? When would they be likely to happen?
- ☐ What symptoms or side effects should I tell you about immediately?
- ☐ How will treatment impact my quality of life?
- ☐ What can I do to reduce the side effects?
- ☐ Are there any long-term side effects of the treatment?
- ☐ Will I be able to work during treatment?
- ☐ How can I reach you if I have any questions between appointments?

PRIVACY:

- ☐ Who will know I am participating in a clinical trial?
- ☐ Who will have access to my data and medical history?
- ☐ Will I get a copy of the results from the study?

SUPPORT:

- ☐ Can I talk to other patients already taking part in the study?
- ☐ Can you suggest a mental health professional I can see if I feel depressed, overwhelmed or distressed?
- ☐ What advocacy groups can support me?

Questions to ask about

Palliative Care

GENERAL QUESTIONS:

- ☐ What is palliative care?
- ☐ Where will I go to receive palliative care services?
- ☐ What symptoms does palliative care treat?
- ☐ Will I have a new physician if I receive palliative care services?
- ☐ What impact does palliative care have on my survival rate?
- ☐ What medications will be included in palliative treatment?
- ☐ What side effects might I experience from palliative treatment?
- ☐ Am I able to receive treatment (chemo/radiation/clinical trials) while receiving palliative care?
- ☐ When should I ask for palliative care?
- ☐ Will my insurance cover palliative care?
- ☐ What out-of-pocket expenses might I expect?
- ☐ What services are offered to my family to support me?

Questions to ask about

Hospice

GENERAL QUESTIONS:

- ☐ What is hospice care?
- ☐ Who arranges for hospice care?
- ☐ How does hospice differ from palliative care services?
- ☐ When is the best time to start hospice care?
- ☐ If I start hospice, can I leave the program?
- ☐ What symptoms does hospice care treat?
- ☐ Am I able to receive treatment (chemo/radiation/clinical trials) while receiving hospice care?
- ☐ Will my insurance cover hospice care? What out-of-pocket expenses might I expect?
- ☐ What services are offered to my family to support me?
- ☐ Do you provide services for getting personal affairs in order, such as a will, power of attorney, advance directive, etc.?