

A Patient Guide to Shared Decision Making

Primary Biliary Cholangitis (PBC)

By now, you are being evaluated for possible PBC, or you have been diagnosed with it and are preparing for treatment. Either way, please remember that **you** are in control and have every right to ask your doctors and nurses questions about the road ahead. In fact, your medical team expects and *encourages* your questions. So don't hesitate. Ask away! There are no silly or trivial questions. Please know that **you** are the most important part of your health care team and need to be comfortable with the care you will receive. To help guide you in "shared decision making" with your clinicians, the following checklist may be helpful, but your questions don't have to be limited to these.

Part 1: Diagnosis: blood tests [ALP, bilirubin] and imaging (ultrasound, liver stiffness measures, biopsy)

Place a checkmark next to the questions that are the most important to you.

- Why do I need this test?
- How long does the test take?
- What might happen if the test is delayed or not done?
- How will I feel during the test? Is it painful?
- How accurate is the test?
- Will I need to arrange for someone to take me home after the test?
- How much does the test cost?
- What are the risks?
- Is there a less expensive test that might give the same information?
- What can the results show?
- What should be done to prepare for the test?
- After the test, what happens next?
- Where will the test be done?
- Do you have a brochure or recommended website for more information about the test?

Part 2: Treatment Options

Place a checkmark next to the questions that are the most important to you.

- What are my treatment options?
- Are these treatments painful?
- How is each treatment done?
- Does the doctor who will initiate and monitor treatment have years of experience?
- Is doing nothing an option?
- How long will it take to recover?
- What are the benefits and risks of each option?
- How will it affect my quality of life?
- What is the goal of each option? Do they work on symptoms only or do they treat the underlying disease?
- When do I need to decide?
- What does the research say about the probability of success for each option in situations like mine?
- Where can I find more information about each of these options?
- How will each treatment make me feel?
- Is it okay to seek a second opinion before we begin treatment?

Notes
