

# 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.*

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|---|---|
| <input type="checkbox"/> Why do I need this test?   | <input type="checkbox"/> How long does the test take?   |
| <input type="checkbox"/> What might happen if the test is delayed or not done?                | <input type="checkbox"/> How will I feel during the test? Is it painful?                                    |
| <input type="checkbox"/> How accurate is the test?  | <input type="checkbox"/> Will I need to arrange for someone to take me home after the test?                 |
| <input type="checkbox"/> How much does the test cost?   | <input type="checkbox"/> What are the risks?  |
| <input type="checkbox"/> Is there a less expensive test that might give the same information? | <input type="checkbox"/> What can the results show?   |
| <input type="checkbox"/> What should be done to prepare for the test?                         | <input type="checkbox"/> After the test, what happens next?   |
| <input type="checkbox"/> Where will the test be done?   | <input type="checkbox"/> 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.*

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

### Notes

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