

A guide to get the PBC conversation started with your doctor



Talking to your doctor at your next appointment may help you feel more confident about managing your PBC.

As a progressive disease, PBC can get worse over time if it isn't treated. Take a few moments to consider the evolution and impact of your symptoms, lab results, and overall PBC journey. Using this guide can help your doctor understand what you experience each day so you can work together on a treatment plan that fits your needs.

Let's get started!

Helping your doctor understand your PBC journey

Tracking lab results and symptoms

Your lab results can give you and your doctor a clearer view of if and how your PBC is progressing. Similarly, your symptoms provide important context about how your daily life and well-being are affected.

1. What were the results of your most recent lab tests?

DATE OF TEST	ALP	BILIRUBIN

2. Are you currently experiencing any of these symptoms?

- Fatigue Itch Bone pain Joint pain Brain fog Abdominal pain
- Other _____

Fatigue

3. If you experience fatigue, how often does it occur?

- Never Rarely Sometimes Most of the time Always

4. How does fatigue impact your lifestyle?

- It limits me at work It limits my ability to do day-to-day tasks I am often too tired to think I am often too tired to bathe or shower
- I do not have enough energy to exercise Other _____

5. How do you manage fatigue as a symptom of PBC?

DID YOU KNOW?

Fatigue affects up to 78% of people with PBC, and it's more than just feeling tired. It can be physically and mentally draining and can significantly impact daily life.

Fatigue can feel like muscle weakness, brain fog, or longer recovery time from daily activities.

Itch

6. If you experience itch, how often does it occur?

- Never Rarely Sometimes Most of the time Always

7. How does itch impact your lifestyle?

- It limits me at work It limits my ability to do day-to-day tasks It affects my social life It affects my sleep

8. How do you manage itch as a symptom of PBC?

DID YOU KNOW?

Up to 70% of people with PBC experience itching and for some it feels severe. Severe itching can be accompanied by stinging and burning, interfering with daily activities. Itching may disrupt your sleep and make you feel tired. However, fatigue and itch are not always connected—you may experience fatigue without itching.

PBC risk assessment checklist

Understanding your risk of disease progression is important. Having one or more of the risk factors listed below does not necessarily mean you are at risk for progression.

Talk to your doctor to determine your risk of disease progression.

ANSWER THE QUESTIONS BELOW TO SEE IF YOU MAY BE AT RISK:	YES	NO
Were you younger than 45 when you were diagnosed with PBC?		
Did you have any evidence of cirrhosis when you were diagnosed with PBC?		
Did you have very high ALP levels at diagnosis?		
Did you and your doctor discuss how much improvement to expect from your ALP and bilirubin levels after 6-12 months of treatment? If so, did you meet those goals?		



“I feel more armored when I go into a doctor appointment with my questions written down.”

Trudi,
living with PBC

Getting answers about PBC

With the information you've gathered about your lab test results and symptoms, you're now better prepared to have a meaningful conversation with your doctor.

Use these questions below to help guide your discussion and get the most out of your visit.

1. How do we know if my current treatment plan is working?

2. What are my treatment goals and how frequently do we need to reassess them?

3. Is there any change to my current treatment plan that may help address my ALP levels and help with symptom control?

4. What can I do to better manage my symptoms?



Visit realpbctalk.com/resources to access additional resources for your PBC journey.