COMMUNITY LIVER ALLIANCE ™
GLOBAL AWARENESS. LOCAL IMPACT.

LIVING WELL WITH PBC

A practical, printable toolkit to help you prepare for conversations and participate actively in your PBC care.

Living with Primary Biliary Cholangitis (PBC) involves more than laboratory results. It can include questions about monitoring, treatment goals, fatigue, itching, daily functioning, emotional wellness, family life, and how to communicate what you are experiencing. This toolkit is designed to help you prepare for those conversations and participate actively in your care.

Name _____ **Date** _____

This guide is educational and does not replace individualized medical advice. Talk with your healthcare team about your specific situation. In an emergency, call 911.

1. PBC: The Basics

PBC is a chronic liver disease that affects the small bile ducts in the liver.

> **ASK YOUR CARE TEAM**
>
> **“What does PBC mean for me right now, and what are we watching over time?”**

My notes

2. Your PBC Care Team

Care team member	Name / Practice	Contact / Next visit
Hepatology / gastroenterology		
Primary care		
Advanced practice provider		
Pharmacist		
Women’s health clinician (when relevant)		
Behavioral health or other supportive care		
Other specialists based on individual needs		

3. My PBC Dashboard

Your care team may follow laboratory results, symptoms, bone health, and other measures.

What We're Following	Current Result / Status	Previous / Trend	Question for My Team
Liver-related tests			
Other labs			
Bone health			
Symptoms / quality of life			
Other monitoring			

4. Treatment Conversations

1. What is the goal of my treatment?

2. How are we determining whether it is working?

3. What results or changes are most important?

4. What happens if I am not meeting treatment goals?

5. What symptoms can treatment improve, and what symptoms may need separate management?

6. What other treatment options should we discuss?

7. What side effects, interactions, or access issues should I know about?

5. Itch / Pruritus: Describe the Impact

Itching can affect much more than skin. Use this tracker to show your care team when it happens and how it affects sleep, concentration, mood, work, and daily activities.

Date / Time	Itch 0–10	Sleep	Skin / Scratching	Daily-Life Impact	What I Tried

6. Fatigue: More Than “Tired”

Fatigue can be difficult to describe. Instead of only rating severity, consider what fatigue prevents you from doing or changes about your day.

Area	No / Little Impact	Some Impact	Major Impact	Notes
Work / school	☐	☐	☐	
Household tasks	☐	☐	☐	
Exercise / movement	☐	☐	☐	
Social activities	☐	☐	☐	
Thinking / concentration	☐	☐	☐	
Mood / emotional wellness	☐	☐	☐	

TRY SAYING

“My fatigue is affecting my life by...”

7. Preparing for a PBC Appointment

- ☐ What has changed since my last visit?
- ☐ Do I understand my treatment goal?
- ☐ Do I have medication, access, or insurance concerns?
- ☐ Which symptom is affecting me most?
- ☐ Do I understand what my team is monitoring?
- ☐ What is my most important question today?

8. Living with PBC

Use this space for notes about sleep, movement, nutrition, emotional wellness, work, relationships, intimacy, travel, and maintaining daily life.

My notes

9. Women's Health & PBC

Women living with PBC may have questions about bone health, perimenopause, menopause, sexual health, medications, and coordination between hepatology and women's health clinicians. The companion guide, "PBC Through Perimenopause & Menopause," is designed to support these conversations.

My questions

10. Caregiver & Family Guide

PBC symptoms may not always be visible. Family members and caregivers can support patients by listening to how symptoms affect daily life, helping prepare for visits when invited, and recognizing that fatigue and itching can have meaningful physical and emotional effects.

How I can help / what I need

11. My PBC Appointment Planner

Before My Visit	My Notes
The biggest change since my last visit	
The symptom affecting me most	
My treatment question	
My test/monitoring question	
A quality-of-life concern	
My top question today	
Next step before I leave	

Acknowledgment

This toolkit was made possible through an educational sponsorship from Ipsen. The Community Liver Alliance gratefully acknowledges their support in empowering patients and caregivers affected by Primary Biliary Cholangitis (PBC).