

“It’s PBC. You
have to **accept** it”

*Believe that
I deserve
more!*



Real PBC talk

Susan, living with PBC

Amplify your voice in your PBC journey

Your knowledge and understanding of your PBC journey arms you with what you need to find the right treatment plan for you. Discover how to involve loved ones and your healthcare team with **Real PBC Talk**. Uncover more details about symptoms, treatment response, and signs of disease progression to help you in sharing your PBC experience.

Visit realpbctalk.com for more PBC support.

What is primary biliary cholangitis (PBC)?

PBC is a rare autoimmune disease in which the body's immune system attacks healthy cells in the liver by mistake.

People with PBC experience liver inflammation and buildup of toxins, such as bile acids, causing liver damage and reduced liver function.

If left untreated, PBC can lead to liver complications, resulting in liver transplant or death. Understanding PBC and talking to your doctor about your treatment plan is the key to staying ahead of and managing the disease.



WHAT CAUSES PBC?

Genetics and environmental triggers can increase the risk of developing PBC, but ultimately the cause is unknown. **It's important for you to know that your diagnosis was not caused by anything you did.**



**"PBC isn't my fault—
this is just the way
my liver works."**

Kathy

LIVING WITH PBC

PBC symptom severity impacts daily life

People with PBC can experience a physical and mental burden associated with the disease. It's important to remember that symptoms can change over time and so you should track both your lab results and your symptoms to identify any signs of progression.

SYMPTOMS VARY FROM PERSON TO PERSON, BUT COMMON SYMPTOMS INCLUDE:



Fatigue

Up to 78% of people living with PBC experience chronic fatigue that is more intense than general fatigue. It can feel like muscle weakness, brain fog, or needing longer recovery time from daily activities.



Severe itching

Up to 70% of people deal with intense itching, leading to loss of sleep and difficulty participating in daily activities.



Brain fog

Memory issues and difficulty concentrating can interfere with daily life for those with PBC.



Body pain

Joint pain and stiffness occur in up to 35% of those with PBC.

Did you know?

Up to 60% of people with PBC do not have symptoms at diagnosis, but symptoms may develop over time and do not show how severe your disease may be. This is why regularly monitoring both your lab results and symptom experience is important.



Visit realpbctalk.com/about-pbc to learn more about tracking your symptoms.

Fatigue is the most common symptom of PBC

People often describe PBC fatigue as an overwhelming sense of tiredness and feeling of exhaustion, which affects up to 78% of people with PBC.

If you're feeling forgetful, hazy, or unable to focus, it may be related to your PBC.

PBC-related fatigue is recognized as distinctly different from regular tiredness—it is often described as a deep, relentless exhaustion that doesn't go away with rest. It has a physical and mental impact, which can make social and emotional difficulties worse.

Even if you're not experiencing other PBC-related symptoms, you may still feel significant fatigue. Sometimes itch may play a role in fatigue, but some people have no itch at all and still experience significant fatigue. **That's why you should work with your healthcare team to examine and manage both of these symptoms separately.**



You're not alone in feeling this way

In one study of people with PBC, about 55% of those with significant fatigue also experienced brain fog.



"One of the hardest parts of fatigue is that people can't see it. You look 'fine,' but inside you feel completely depleted. It's invisible—and sometimes that makes it even harder to explain to others."

Jackie

LIVING WITH PBC

What should you consider when assessing your fatigue?



Keeping track of your fatigue over time

Use a diary or check-in surveys to help you spot patterns and impact on daily life that may be useful to discuss with your doctor. If your PBC-related fatigue is getting worse, make sure you talk to your healthcare team about it.



Ask your doctor about measuring PBC-related fatigue

Your doctor may use different scales to help you describe the impact of fatigue on your daily life. The PBC-40 scale is the only scale specific to PBC—it can help you monitor and track fatigue in a way that helps your doctor measure and understand your experience more clearly.

Examples of questions from the PBC-40 scale:

In the last 4 weeks...

- Has fatigue interfered with your daily routine?
- How often did you have to sleep during the day?



Talking to your doctor about fatigue

PBC-related fatigue is more than just feeling tired. Openly and clearly sharing how fatigue affects your daily life can help your doctor recognize the severity and burden of your experience. You can use the discussion guide on realpbctalk.com to talk with your doctor and work together to manage fatigue in a way that works for you.

The impact of fatigue



2 in 5
PBC patients

Two in five PBC patients feel severe fatigue that affects their ability to function day-to-day.



Visit realpbctalk.com/resources to access a helpful discussion guide.

Monitoring PBC progression

PBC is a progressive disease, which means it can get worse over time.

Slowing progression as early as possible is key to management. By monitoring your lab results and assessing symptoms like fatigue over time, you and your doctor can adjust your treatment plan by identifying signs of progression early.

Some people may be more likely to experience disease progression or poor treatment response

Certain factors could put some people with PBC at a higher risk of disease progression, including:

- People diagnosed with PBC before the age of 45
- Men with PBC
- People of color with PBC
- People with high ALP levels at diagnosis
- People with additional autoimmune diseases

Inadequate response to treatment

An inadequate response means you are not responding to treatment as well as you could be.

This may mean that the treatment is:



Not lowering
ALP levels enough



Not lowering ALP
levels quickly



Did you know?

Most people with PBC are treated with a medicine called ursodiol (ursodeoxycholic acid, also known as UDCA). **Up to half of people with PBC do not respond well enough to ursodiol and may require additional treatment**, so it's important to frequently monitor and keep track of your PBC.

Understanding your liver lab test results

Liver function is measured with a series of laboratory (blood) tests. These tests show levels of substances like **alkaline phosphatase (ALP) and bilirubin**, which can give you and your doctor a clearer view of if and how PBC is progressing.

The impact of your lab tests

The latest PBC guidance recommends getting lab tests done every 3-6 months. Treatment plans should also be evaluated and adjusted every 6-12 months, as needed.

If you would like to review your results with your doctor or discuss your treatment plan, ask to schedule an appointment.

PBC GUIDELINES RECOMMEND



Lab tests every 3-6 months



Treatment evaluation every 6-12 months



An inadequate response to treatment may lead to further disease progression

Make sure you discuss your treatment goals with your doctor early and often to get the most out of your care plan.



Visit realpbctalk.com to see how treatment response can vary for different patients with PBC.

Starting the conversation

Be open and honest with your healthcare team

Disease progression, symptoms, and response to treatment can vary greatly. It is important to explain your unique PBC experience to your doctor and other members of your PBC healthcare team. This allows them to work with you to create a treatment plan that meets your individual needs.

Talk to your PBC healthcare team about your condition:

“
How should we be monitoring
my PBC over time?”

“
What can I do to manage
my symptoms?”

“
What are my treatment goals and how
frequently do we need to reassess them?”
”



Visit realpbctalk.com/resources
to discover helpful resources for
starting the conversation with
your healthcare team and finding
support through PBC organizations.



“I realized life with PBC
can get easier and I
don’t need to relegate
myself to accepting
that nobody will ever
fully understand
my experience.”

Amber

LIVING WITH PBC



Bring your loved ones into the loop

You deserve patience, grace, and understanding—both from yourself and from your loved ones. Sharing your experience with your support system can help ensure you get the care and empathy you deserve, so your PBC journey doesn't feel like a solo venture.



Connect with the community

Getting involved with the PBC community allows you and other people living with PBC to share stories, learn from each other's experiences, and move forward with purpose in your journey with this rare disease.

Start the dialogue between you and your loved ones:

Fatigue due to PBC is more than just being tired.
My fatigue makes me feel exhausted.

Due to my constant itching,
I'm finding it more difficult to
accomplish day-to-day tasks.
If you could do laundry,
that would be a huge help.

Shared experiences that could help you and the wider PBC community include:

- Ways to manage your PBC symptoms, including fatigue and itch
- Ways to share your experiences with your loved ones and doctor
- Tips on staying positive in the face of a PBC diagnosis

At Real PBC Talk, we're meeting you where you are in your journey.

Here are a few points to remember as you consider the impact and management of your PBC.



PBC is a rare autoimmune disease.

People with PBC experience liver inflammation and buildup of toxins, such as bile acids, causing liver damage and reduced liver function.



Openly communicate with your doctor.

Being clear about your PBC experience helps your doctor understand the severity of your disease and find a treatment plan that works for you.



PBC-related fatigue impacts daily life.

Symptoms vary from person to person, but fatigue is the most common and is experienced by up to 78% of people with PBC.



Monitoring your symptoms and lab results is key.

Use lab results as well as your symptom experience to track your disease and any signs of progression.

Ipsen-committed to people living with PBC

Ipsen is developing tools and resources to offer support and empowerment to help you face the unique challenges PBC presents.



**Visit realPBCtalk.com
to learn how to make
an impact on your PBC.**