

PBC CARE

Understanding PBC

What did we explore?

This module explores what **primary biliary cholangitis (PBC)** is, its common symptoms, how it's treated, and the importance of regular monitoring.

Here's a quick reminder of the key learnings:

2

Living with PBC symptoms



Early symptoms include feeling like you have no energy, even after rest (fatigue), itchy skin (pruritus), tummy pain, or aching joints. Over time, symptoms like **weight loss, muscle wasting, and yellowing of the skin and eyes** may appear.

PBC can lead to complications such as **scarring of the liver** (cirrhosis) or **high blood pressure in the portal vein** (portal hypertension). While there's no cure, **early treatment, symptom management and regular monitoring** can help reduce the risk of complications.

1

Getting to know your PBC



It's a **long-term condition** caused by the immune system affecting the liver. **Damage builds up over time**, leading to scarring and reduced liver function.

The **exact cause isn't fully understood**, but researchers believe PBC develops due to a mix of genetic and environmental factors.

The main treatment goals are to **slow down disease progression** and manage symptoms to **improve quality of life**.

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Taking care of PBC



Treatment begins soon after diagnosis to slow down liver damage. **Other treatments may be added or used** if this does not work, stops working, causes intolerable side effects, or if symptoms persist.

Lifestyle choices—such as **eating a balanced diet, avoiding alcohol and stopping smoking**—can help to improve overall wellbeing.

Regular monitoring **tracks how the liver is doing** and can help to **catch complications early**. You should have a care team made up of **various medical specialists**.

Putting knowledge into action

Here are some tips to help you feel more comfortable and confident when talking with your healthcare team.

1 Getting to know your PBC

It's never too late to speak up.

It's normal if you've ever felt overwhelmed or unsure, or found it easier to say you understood even if you had more question. Your next appointment is a chance to get the information you want. Now might be a good time to think about any questions you have, and who on your care team could help answer them.

How did my PBC develop?

How can I reduce my symptoms?

Can I prevent complications?

How can I tell if it's getting worse?

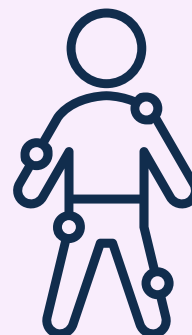
2 Living with PBC symptoms

Find your words, take your time.

It can be difficult to describe the burden of symptoms like being fatigued and having itchy skin.

Your next appointment is an opportunity to help your healthcare team understand your experience with PBC. Now is a good time to prepare by thinking about the words you want to use and collecting examples of how your symptoms affect your daily life.

- ✓ Symptom journal
- ✓ Useful words and metaphors
- ✓ Times you asked for help
- ✓ Real-life examples



3 Taking care of PBC

Be part of your care planning.

When discussing your test results and care plan with your doctor, it may feel like you're being spoken at, not with.

Your next appointment is an opportunity to participate in making decisions; it might be time to ask for a different explanation, the extra support you need, and how you can contribute to your care.

To help you prepare, revisit the questions included in the Understanding PBC presentation before your appointment.

What do my test results mean?



Lifestyle changes



Mental health

How often should I have check ups?

Visit the PBC Foundation or your local PBC or liver patient group for more information.

These materials have been developed by Ipsen with instrumental contributions in concept development and review from the following patient organizations: ALBI España, AMAF aps ets, Australian Liver Foundation, Casa Hunter, Deutsche Leberhilfe, Canadian PBC Society, PBC Föreningen, PBC Foundation © 2025 Ipsen. Some rights reserved. This material, except as identified below, is made available under Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 license, (CC-BY-NC-ND 4.0; <https://creativecommons.org/licenses/by-nc-nd/4.0/deed.en>). Permissions beyond the scope of this license may be available at corporate. communications@ipsen.com but any modifications to the documents will be under user's liability and Ipsen will not be responsible for the content or its accuracy. IPSEN and the IPSEN logo are registered trademarks of Ipsen; other trademarks and logos are used under permission from their respective owners. Trademarks and logos included in the material are not licensed under a Creative Commons license.