



Understanding PBC



PBC CARE

CONVERSATIONS | AWARENESS | RESOURCES | EMPOWERMENT

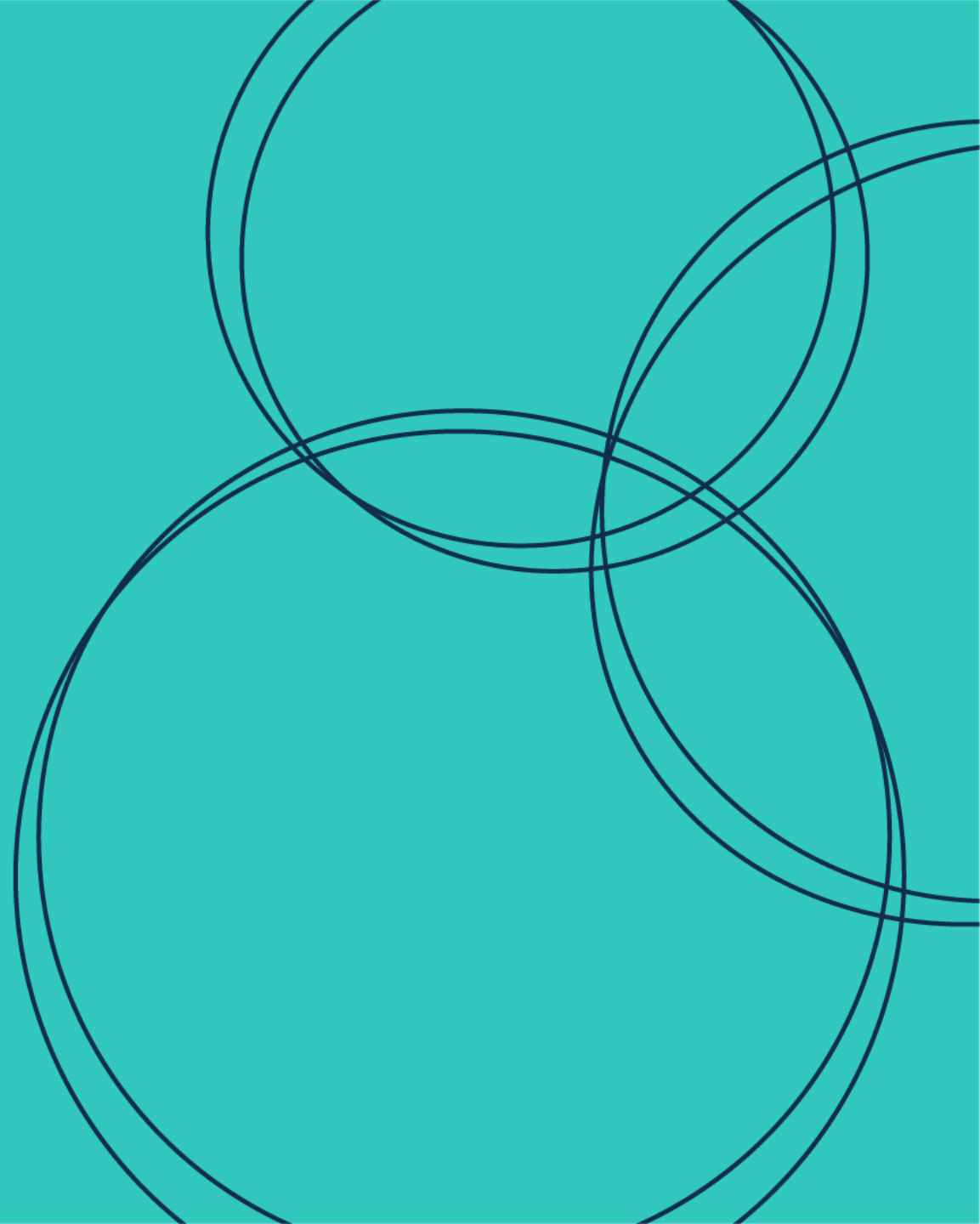
These materials have been developed by Ipsen with instrumental contributions in concept development and review from the following patient organizations: ALBI España, AMAF aps ets, Australian Liver Foundation, Casa Hunter, Deutsche Leberhilfe, PBC Canada, PBC Föreningen, PBC Foundation.

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Understanding PBC: Taking care of PBC



What We Will Cover in Taking Care of PBC



01

How is PBC treated?

02

Lifestyle and supportive care

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Why regular monitoring matters

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What tests might you need?

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Who is on your care team?



A reminder: The goals of PBC care

Slow down disease progression

Slow down rate of liver damage
Prevent progression to cirrhosis
(scarring of the liver) and liver failure

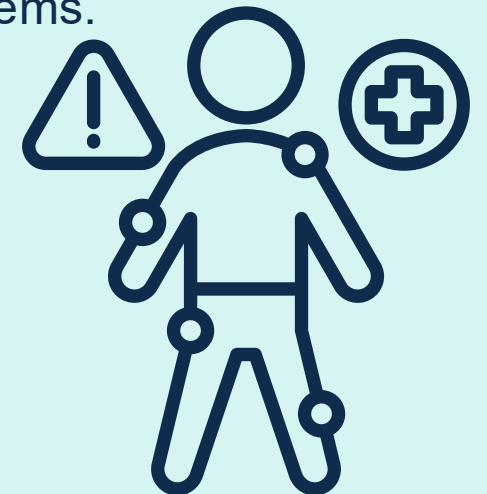
Regular monitoring is important to assess how PBC is progressing and how well treatments are working.



Reduce symptoms to improve quality of life

Reduce symptoms such as fatigue, pruritus (itching) and bone problems.

Certain treatments and lifestyle changes can help to reduce symptoms.





A reminder: The goals of PBC care

Words You Might Hear and What They Mean

Treatment goals	The main things we hope to achieve with your treatment or care to improve health.
Disease progression	How a disease progresses over time. In some cases, a disease can start slowly and become more severe or complicated if not treated.
Symptom management	Ways to help reduce or control symptoms to help you feel better.
Prevention	Steps you can take to avoid getting sick or having a condition.
Treatment pathway	A clear plan that shows the steps and options for treating your condition.



How is PBC and its symptoms treated?

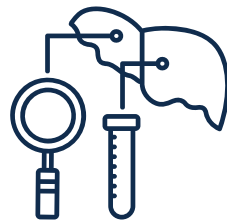
Goal: slow down disease progression and control symptoms



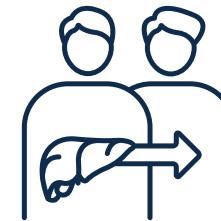
First-line treatment begins soon after diagnosis to slow down how quickly the disease gets worse. It aims to improve bile flow and reduce harmful bile acids in the liver.

Second-line treatment may be added or used instead if the first-line treatment doesn't work, stops working, causes intolerable side effects, or if symptoms persist.

By better controlling bile acid buildup, these treatments can help preserve liver function and some can relieve symptoms such as fatigue and itching.



Treatment for PBC is long-term and requires regular monitoring.



A liver transplant may be considered in advanced stages of PBC (for a very small number of people).



How is PBC and its symptoms treated?

Goal: slow down disease progression and control symptoms

Words You Might Hear and What They Mean

First-line / second-line

The first treatment usually given for a condition / a treatment that may be added later or used instead.

Inflammation

Swelling and irritation that can cause pain and redness in the body.

Liver function

How well the liver works to process nutrients, filter toxins and make important substances for the body.

Disease progression

How a disease progresses over time. In some cases, a disease can start slowly and become more severe or complicated if not treated.

Monitoring

Regularly checking how your condition is progressing and how well treatments are working.

Bile ducts

Small tubes that carry a fluid called bile from the liver to the small intestine.



How is PBC and its symptoms treated?

Goal: Reduce / control symptoms



There are several options available to help manage common symptoms of PBC:



Itching: You can think about lifestyle changes such as choice of clothing, skincare and certain medications can help.



Fatigue: Talk to your doctor about PBC treatment options that may have a positive impact on fatigue.



Dry eyes/mouth: Consider artificial tears, saliva substitutes and good oral care.



Bone health: Vitamin D and calcium supplements.



How is PBC and its symptoms treated?

Goal: Reduce / control symptoms

There are several options available to help manage

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substitutes and good oral care.



Bone health: Vitamin D and calcium supplements.

Words You Might Hear and What They Mean

Fatigue

Fatigue is a chronic and debilitating condition that goes beyond ordinary tiredness, often persisting despite rest or sleep and can have a significant impact on quality of life.

pruritus

Itchy skin that makes you want to scratch.



Lifestyle and supportive care for PBC

Maintaining a healthy lifestyle supports liver health and overall wellbeing

Alcohol consumption	Most people with early-stage PBC can eat a healthy diet without restrictions. If you have issues with fat absorption, you may need to look out for vitamin deficiencies and could benefit from supplements like vitamins A, D, E and K.
Community	Living with PBC can feel overwhelming at times, but it's important to make space for the people and activities you enjoy . If work is affected by fatigue, you may seek reasonable adjustments, like flexible hours.
Mental health	Being diagnosed with a long-term condition like PBC can affect your mood and mental health . If you're feeling low or anxious for more than a couple of weeks, talk to your doctor or nurse—they can support you. You could also seek help or information from PBC patient organizations.
Nutrition	The expert consensus is that people with PBC may consume alcohol 'within safe limits' . However, those with advanced liver disease are advised to abstain from alcohol.
Physical activity	Keeping active is not only safe for people with PBC, but evidence also suggests physical exercise might improve overall energy levels and wellbeing. You might like to seek support to find exercise that works for you.
Smoking	Smoking is known to make liver scarring worse and to increase the risk of liver cancer, so it would be beneficial to stop smoking if you have PBC.



Lifestyle and supportive care for PBC

Maintaining a healthy lifestyle can help you manage your PBC. You might hear your healthcare provider use the following terms:

Words You Might Hear and What They Mean

Healthy lifestyle	Making choices that support good health, like eating well, staying active and managing stress.
Alcohol avoidance	Choosing to limit or not to drink alcohol to protect the liver and reduce damage.
Smoking cessation	Stopping smoking to improve overall health and reduce the risk of complications.
Balanced diet	Eating a variety of healthy foods, including fruits, vegetables, whole grains and lean proteins.
Self-care	Taking steps to care for your own physical and mental wellbeing.
Patient organization	A group that supports people with a specific health condition by offering information and resources.

Smoking

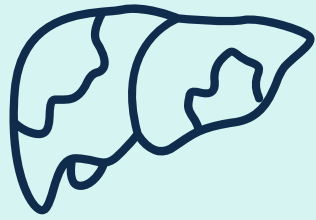
Smoking might improve overall energy levels and wellbeing. You might like to seek support to find exercise that works for you.

Smoking is known to make liver scarring worse and to increase the risk of liver cancer, so it would be **beneficial to stop smoking** if you have PBC.



Possible complications of PBC

Over time, PBC can cause:



Cirrhosis: scarring of the liver, which makes it harder for the liver to do its job properly

Portal hypertension: high blood pressure in the portal vein, which carries blood from the intestines to the liver



If PBC is not treated or reaches an advanced stage, it may cause problems in other parts of the body as well, such as:

Osteoporosis: a condition where bones become weak and brittle

Ascites: fluid in the abdomen

Vitamin deficiencies: including A, D, E and K

Dry mouth or eyes, or vaginal dryness



Complications can happen because PBC damages the liver over time. Early diagnosis, treatment and regular monitoring can slow disease progression and reduce the risk of complications.



Possible complications of PBC

Words You Might Hear and What They Mean

Disease progression	How a disease progresses over time. In some cases, a disease can start slowly and become more severe or complicated if not treated.
Cirrhosis	A condition where the liver becomes severely damaged and scarred over time.
Liver failure	Happens when the liver stops working properly and can't perform its important functions, like cleaning the blood or producing essential proteins.
Osteoporosis	A condition where bones become weak and brittle, making them more likely to break.
Portal hypertension	High blood pressure in the veins that carry blood from the intestines to the liver.

Complications can happen because PBC damages the liver over time. Early diagnosis, treatment and regular monitoring can slow disease progression and reduce the risk of complications.



Why regular monitoring of PBC matters



Catch Problems Early

Spot liver damage or complications early.



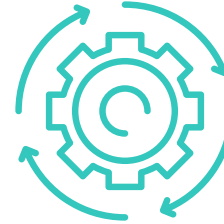
Make Informed Choices

Work with healthcare professionals to stay one step ahead.



Protect Your Quality of Life

Proactive care, especially to manage symptoms, could improve quality of life.



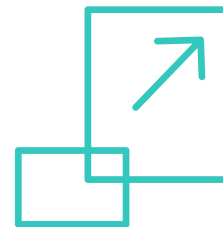
Track Your Progress

See how your treatment is working and adjust if needed.



Stay Connected

Maintaining a relationship with healthcare team could lead to better outcomes.



See the Full Picture

Monitoring overall liver health, not just alkaline phosphatase (ALP) and bilirubin, gives a clearer view of your wellbeing.



Why regular monitoring of PBC matters

Words You Might Hear and What They Mean

Monitoring

Regularly checking how your condition is progressing and how well treatments are working.

Follow-up

Going back to your healthcare professional regularly to check progress and adjust treatment if needed.

Lab work

Tests done on blood, urine, or other samples to check for changes related to a condition.

Biopsy

Taking a small sample of tissue (like from the liver) to look at under a microscope.

Bone density

A measure of how strong and dense your bones are, often tested to check for osteoporosis.

Proactive care – especially to manage symptoms – could improve quality of life.

Monitoring overall liver health — not just alkaline phosphatase (ALP) and bilirubin — gives a clearer view of your wellbeing.



What liver health tests might you need for PBC?

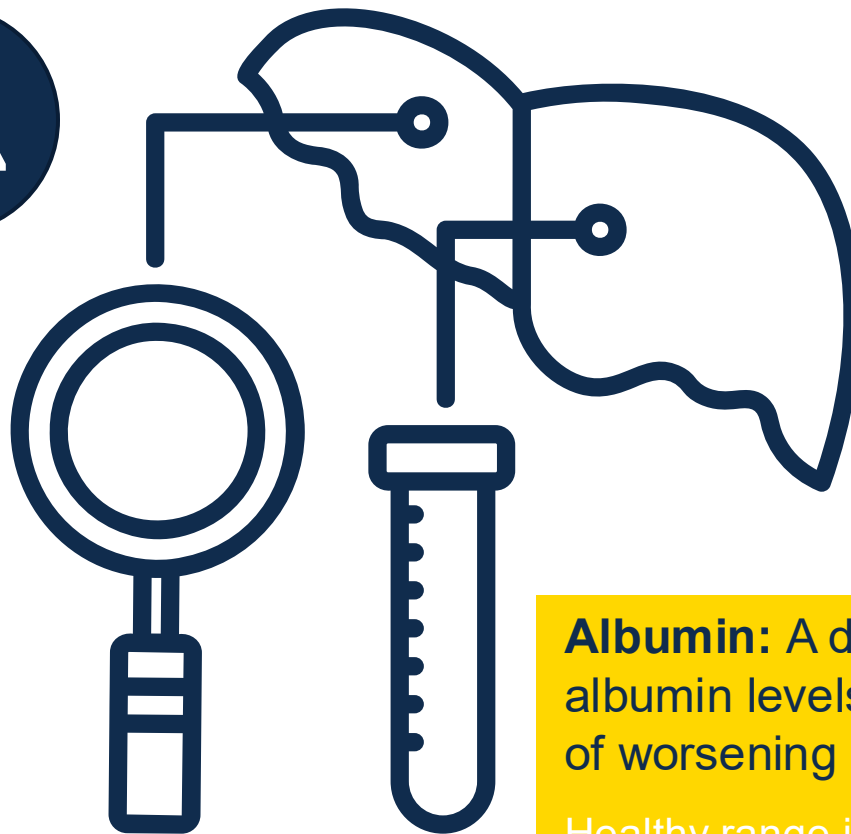
These tests are simple blood tests that can be repeated at each visit with your healthcare team to track your liver health. Changes in results may indicate a risk of PBC progression.

Knowing your numbers is one of the best ways to be in control of your PBC



Alkaline phosphatase (ALP) and gamma-glutamyl transferase (GGT): These tests check for problems with the flow of bile through your liver. If both levels are raised, it can indicate that the disease is not being optimally controlled.

Healthy range for ALP is considered 35- ~140 IU/L and GGT is (iu/L 7-40 female and 9-50 male)



Bilirubin: Shows how well your liver is processing waste. Higher levels might mean your liver is not working properly.

Healthy range is considered <17 $\mu\text{mol/L}$ or <1.2mg/dL

Albumin: A decrease in albumin levels can be a sign of worsening liver disease.

Healthy range is considered 35-55 g/L



What liver health tests might you need for PBC?

These tests track your liver health, so changes might indicate a risk of PBC progression.

Knowing your numbers is the best way to keep your liver in control.

Alkaline phosphatase and gamma-glutamyl transferase (GGT): These tests check for problems with the flow of bile through your liver. If both of these levels are raised it can indicate PBC.



Albumin: A decrease in albumin levels can be a sign of worsening liver disease.

Shows how well your liver is getting rid of waste. High levels might mean your liver is not working properly.

Words You Might Hear and What They Mean

Monitoring

Regularly checking how your condition is progressing and how well treatments are working.

Follow-up

Going back to your healthcare professional regularly to check progress and adjust treatment if needed.

Lab work

Tests done on blood, urine, or other samples to check for changes related to a condition.



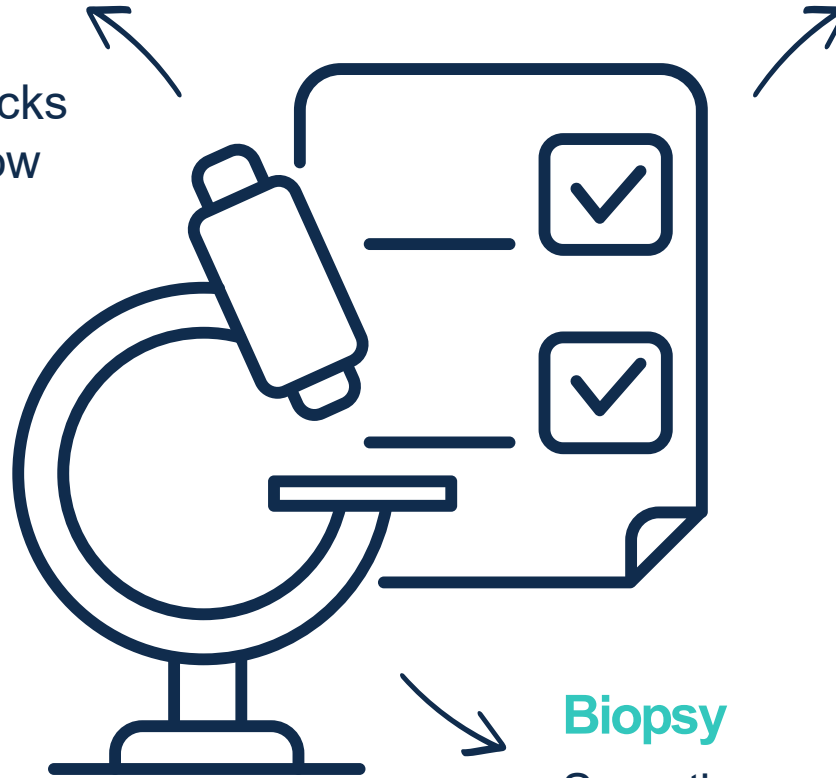
What other ongoing tests might you need for PBC?

Liver stiffness test

FibroScan: A special scan that checks how stiff your liver is, which can show if there is any scarring.

‘Enhanced Liver Fibrosis’ test

The **ELF blood test** measures three blood markers — hyaluronic acid, PIIINP, and TIMP-1 — that rise when there is liver scarring. Doctors may use it to monitor liver conditions like PBC.



Bone density scan

DEXA scan: People with PBC are at higher risk of bone thinning, so doctors recommend a bone density scan — a quick, painless test that uses X-rays to measure bone density.

Biopsy

Sometimes, a small **sample** of the liver is taken to look at it closely under a microscope. This helps understand the extent of liver damage.



What other ongoing tests might you need for PBC?

Liver stiffness test

FibroScan:

how stiff your liver is, and if there is any fibrosis.

'Enhanced' blood tests

The **ELF** blood test measures three blood markers: alpha-fetoprotein, hyaluronic acid, and TIMP-1 — that rise when there is liver scarring. Doctors may use it to monitor liver conditions like PBC.

Bone density scan

People with PBC have a higher risk of osteoporosis, so doctors often recommend a bone density scan, a quick, painless X-ray to measure bone density.

Words You Might Hear and What They Mean

Monitoring

Regularly checking how your condition is progressing and how well treatments are working.

Follow-up

Going back to your healthcare professional regularly to check progress and adjust treatment if needed.

Biopsy

Taking a small sample of tissue (like from the liver) to look at under a microscope.

Bone density

A measure of how strong and dense your bones are, often tested to check for osteoporosis.

Biopsy

Sometimes, a small **sample** of the liver is taken to look at it closely under a microscope. This helps understand the extent of liver damage.



Who is in your healthcare team?

Primary Care Doctor, e.g., general practitioner (GP)

Often the first point of contact for someone with PBC

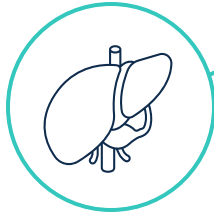
Provides general healthcare, monitors overall health and refers to specialists when needed.



Hepatologist

Specializes in liver diseases

Diagnoses and treats diseases of the liver, like PBC. They monitor liver function, manage symptoms and prescribe medications.



Gastroenterologist

Specializes in digestive system diseases

Diagnoses and treats diseases of the digestive system and biliary organs. They can help manage digestive symptoms of PBC.



Dietician

Provides nutrition / dietary advice

Diagnoses and treats dietary and nutritional problems. They help by preparing diet plans to promote liver function, manage symptoms and support bone health.



Psychologist or Counsellor

Supports mental and emotional health

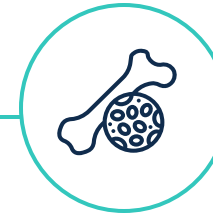
Helps manage the psychological impact of living with a chronic disease like PBC.



Endocrinologist

Specializes in conditions of the endocrine system

Helps to manage any hormone-related complications, especially if there are issues like osteoporosis or thyroid problems.



Rheumatologist

Specializes in autoimmune and inflammatory disease

Helps diagnose and treat autoimmune diseases. Patients may have other autoimmune conditions such as Sjogren syndrome and rheumatoid arthritis.





Who is in your healthcare team?

Primary Care Doctor, e.g., general practitioner (GP)

Often the first point of contact for someone with a health problem.

Provides general medical care and monitors overall health, referring to specialists when needed.

Hepatologist

Specialises in liver diseases.

Diagnoses and treats liver diseases of the liver like PBC. They monitor liver function, manage symptoms and prescribe medications.

Gastroenterologist

Specialises in digestive system diseases

Diagnoses and treats diseases of the digestive system and biliary organs. They can help manage digestive symptoms of PBC.



Psychologist or Counsellor

Supports mental and emotional health

Helps manage the psychological impact of disease like PBC.

Endocrinologist

Specialises in conditions of the endocrine system

Helps manage any hormone-related complications, especially those like diabetes or thyroid problems.

Rheumatologist

Specialises in autoimmune and inflammatory disease

Helps diagnose and treat autoimmune diseases. Patients may have other autoimmune conditions such as Sjogren syndrome and rheumatoid arthritis.



Dietician

Provides nutrition / dietary advice

Diagnoses and treats dietary and nutritional problems. They help by preparing diet plans to promote liver function, manage symptoms and support bone health.

Words You Might Hear and What They Mean

Healthcare team

A group of professionals who work together to provide healthcare.

Primary care

The first level of healthcare where a patient receives general medical treatment, advice and care, e.g., from a GP.

Hepatologist

A doctor who specializes in diagnosing and treating liver diseases.

Dietician

A healthcare professional who provides advice on nutrition and helps manage dietary needs for better health.

Questions To Ask Your Healthcare Team

Example questions: Taking care of PBC

What treatments are available to me?

Are there any side effects of treatment?

Are there any lifestyle changes I could make to improve symptoms?

Are there any supplements I could take?

Are there specific foods or drinks I should avoid?

What foods should I include in my diet?

How often should I have a follow-up appointment?

What tests do I need to monitor PBC?

What do my test results mean for me?



What questions could you ask your healthcare team?

Who in your healthcare team might you ask?

How comfortable do you feel talking to your healthcare team about these topics