



# Primary biliary cholangitis (PBC)

A long-term condition of the small bile ducts in the liver

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Primary biliary cholangitis (PBC) is a slowly progressive autoimmune condition of the small bile ducts inside the liver. It mostly affects women in middle age. Daily ursodeoxycholic acid, taken for life, slows the disease, and people who respond well usually have a normal or near-normal outlook.

## What is it?

In PBC, the immune system gradually damages the tiny bile ducts inside the liver. Bile then builds up and slowly injures the liver. Without treatment, this can lead over many years to scarring and cirrhosis. Its old name, primary biliary cirrhosis, was changed because most people never develop cirrhosis. It is different from primary sclerosing cholangitis (PSC), which affects the larger bile ducts and is often linked to inflammatory bowel disease.

## Who gets it?

- Mostly women, usually diagnosed in middle age
- Close relatives of people with PBC have a higher risk than average
- It often occurs with other autoimmune conditions, such as thyroid disease, dry eyes and mouth (Sjögren syndrome), coeliac disease and Raynaud phenomenon

## Symptoms

- Many people have no symptoms at diagnosis
- Tiredness, which can be marked and does not always match the severity of the liver disease
- Itch, often worse at night and on the palms and soles
- Dry eyes and dry mouth

- Later: yellow eyes or skin, and signs of cirrhosis

## Diagnosis

PBC is usually diagnosed from a raised liver enzyme (ALP) together with a positive anti-mitochondrial antibody (AMA) blood test. A liver biopsy is rarely needed. An ultrasound checks that the bile ducts are not blocked, and a FibroScan measures scarring.

## Treatment

Ursodeoxycholic acid (UDCA, also called ursodiol) is the first treatment for everyone with PBC.

- The dose is based on weight: 13 to 15 mg per kg of body weight per day, taken as one dose or split
- It is taken for life. Do not stop it when you feel well
- It is well tolerated. A few people notice slight weight gain, hair thinning or loose stools in the first months
- The response is checked after about one year with blood tests, mainly ALP and bilirubin
- Blood tests and FibroScan are repeated regularly. If you have cirrhosis or advanced scarring, you will need a liver ultrasound every six months to look for liver cancer, and checks for enlarged veins (varices)
- If the response is incomplete or UDCA is not tolerated, a second-line medicine is added. Newer options include elafibranor and seladelpar, and some specialists use bezafibrate. An older medicine, obeticholic acid, has been withdrawn in the US and Europe because of safety concerns; if you take it, do not stop it suddenly on your own, but contact your specialist to review it. UDCA and the second-line medicines are available in Oman, and your specialist will advise which is suitable for you

UDCA does not usually relieve itch or tiredness, which are treated separately.

## Managing itch and tiredness

- Cholestyramine powder is often tried first for itch. Take it at least four hours apart from UDCA and other medicines, because it stops them being absorbed

- Other options include rifampicin (with liver test monitoring), naltrexone, sertraline and, in some cases, bezafibrate
- Moisturise daily, use lukewarm rather than hot showers, wear loose cotton clothing and keep nails short
- For tiredness: regular physical activity and good sleep habits help, and your doctor will check for other causes such as thyroid disease, anaemia or low mood
- Severe itch that does not respond to treatment should be reviewed by a specialist

## Bones and vitamins

- PBC increases the risk of thin bones. A bone density scan is advised at diagnosis and repeated periodically
- Ensure enough calcium and vitamin D, and do regular weight-bearing exercise such as walking
- A bone-protecting medicine may be added if bone density is low
- In advanced disease or long-standing jaundice, the fat-soluble vitamins (A, D, E and K) can become low and may need replacement
- Cholesterol is often raised in PBC; whether it needs treatment is decided individually

### Get urgent medical care if you have

- Yellow eyes or skin
- Vomiting blood or passing black stools
- Swelling of the abdomen
- Confusion or unusual sleepiness
- Fever with shivering and pain under the right ribs

## Common questions

### Will I develop cirrhosis?

With early diagnosis and a good response to UDCA, many people never develop cirrhosis. Regular monitoring detects any progression early.

### **Should my sisters or daughters be tested?**

Their risk is higher than average. A simple liver blood test may be reasonable, particularly if they have symptoms such as itch or tiredness. Discuss it with your doctor.

### **Can I continue UDCA during pregnancy?**

UDCA is generally continued during pregnancy and breastfeeding. Plan pregnancy with your team, as itch can worsen in later pregnancy. Newer second-line medicines are not used in pregnancy, so tell your team early if you are planning one.

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This leaflet is general information and does not replace advice from your own doctor. Version 1.0, October 2026. Next review October 2028.

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