

# Primary Biliary Cholangitis (PBC)

An information guide



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Primary Biliary Cholangitis (PBC) is a chronic disease that can destroy some of the bile ducts of the liver. This can be widespread in the liver and lead to inflammation resulting in the bile no longer flowing to the gut. Bile toxicity may then occur leading to fibrosis (scarring of the liver), and in 40% of cases, cirrhosis over a 10 year period.

Although relatively uncommon (35 per 100,000), the incidence is rising.

It affects mainly women aged 40 to 70 years old (in 90% of cases) but men are not excluded.

There is no exact cause but it may be due to a familial history; environmental triggers; smoking and it is also often associated with other autoimmune conditions e.g. Lupus; Thyroid disease; Coeliac disease or Rheumatoid Arthritis among others.

## What are the signs and symptoms?

- Fatigue.
- Itching.
- Deranged alkaline phosphatase (ALP) on blood test for 6 months.

### **Less common signs include:**

- Dry eyes and/or mouth.
- Nausea.
- Ache on right side of abdomen.
- Diarrhoea.
- Bone pain.
- Indigestion.
- Bruising.
- Abdominal pain/ bloating.
- Decreased appetite.
- Weight loss.
- Abnormal blood vessels on the face, arms and chest.

If the disease is very advanced or very active, jaundice (yellowing of the white of the eyes and skin) and darkening of the urine may occur.

If the disease has advanced to cirrhosis, there may be muscle wasting, weight loss, ascites (swelling of the abdomen with fluid) and vomiting blood.

### **Diagnosis**

This can be made by arranging blood tests. A liver biopsy is no longer thought necessary.

You will undertake an ultrasound and a fibroscan will also be arranged.

### **Prevention**

You will not develop PBC by exposure to someone else with the disease. It is not thought to be due to a virus and has nothing to do with alcohol.

Although there may be a family link to PBC, at present there is nothing that can be done to prevent it occurring.

## **Treatment**

Once diagnosed, you will be commenced on Ursodeoxycholic Acid (URSO).

The dose will depend on your weight and will be titrated accordingly. The aim would be to halt the progression of the disease.

You will need to have your bloods monitored regularly so that we can assess the response.

You may experience some itching in which case you will be prescribed medication to relieve this.

Fatigue is a common problem and we would encourage healthy eating, sunshine, keeping well hydrated, regular, light exercise and planning your day to day activities.

A third of patients may experience bone problems and we will arrange for you to have a special scan (DEXA). You may then need to take Vitamin D supplements depending on the DEXA results.

In rare and complicated cases a liver transplant is needed.

## **Side effects of Treatment**

- Bloating.
- Nausea.
- Constipation.
- Diarrhoea.
- Flatulence.

URSO is not always tolerated well. It would be advised that you commence on a low dose and build up to the recommended dose. Once tolerated, we recommend you take the whole dose in one in the evenings.

## **Looking after yourself**

It is important to eat a varied and well balanced diet. You should try and maintain a stable weight. If you start to gain weight, you should reduce calorie rich foods such as cakes, sugar and fried foods. Use low fat options and fill up with fruit and vegetables. Ask to see the dietician if you need help or advice.

You may need to consider making changes to your lifestyle such as reducing your working hours or pacing your daily activities to help preserve energy and stamina.

Gentle exercise such as walking and swimming is encouraged but it is advisable to talk to your doctor before taking part in strenuous activity.

## **ANYONE WITH PBC SHOULD NOT SMOKE OR DRINK ALCOHOL**

PBC is a chronic condition and you will be offered structured/ lifelong follow up. Different patients have a different disease course and may require different intensity of follow up.

## **HELPLINES:**

### **UK-PBC**

[www.uk-pbc.com](http://www.uk-pbc.com)

### **British Liver Trust**

2 South Hampton Rd

Ringwood

BH24 1HY

[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)

### **British Society of Gastroenterology**

[www.bsg.org.uk](http://www.bsg.org.uk)

**Notes :**

**If English is not your first language and you need help, please contact the Interpretation and Translation Service**

Jeśli angielski nie jest twoim pierwszym językiem i potrzebujesz pomocy, skontaktuj się z działem tłumaczeń ustnych i pisemnych

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