



**PATIENT GUIDE TO...**

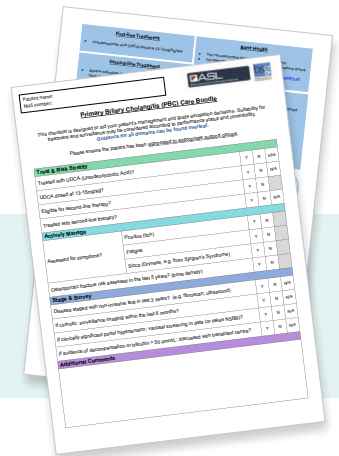
# Discussing PBC with your Clinician

Guidance on discussing your treatment and symptoms with your healthcare team.



## YOUR GUIDE TO...

# Discussing PBC with your Clinician



The **PBC Care Bundle** has been created by BASL and BSG in response to the UK-PBC Audit that identified concerning inconsistencies in PBC care across the UK.

## WHAT IS THE PBC CARE BUNDLE?

It is a standardised healthcare approach for use by clinicians in the NHS, aiming to deliver better care for PBC patients. It includes a checklist of questions that clinicians should discuss with patients at each appointment.

## WHY DO WE NEED THIS GUIDE?

Too many patients still receive suboptimal care in relation to the treatment of PBC and management of their symptoms. While the PBC care bundle aims to address this, patients also have a part to play by taking an active role in conversations and healthcare decisions.

Our patient guide mirrors the clinical checklist so you can better understand the recommended care pathway. It includes additional information to help you answer the questions and prepare for appointments. You may want to use it in discussions with your healthcare team to ensure the questions have been covered and all your concerns are addressed.

## WHAT DOES THIS MEAN FOR ME?

As you go through the questions, it is important to remember that every patient has different experiences with PBC, therefore some of the questions in this guide may not be relevant to you.

If you consistently find yourself answering No to questions, and you feel it is something that needs to be addressed please raise your concerns with your healthcare team. Remember, you and your clinician are a partnership in achieving the best care for you, so feel confident to ask questions, and ask for answers to be explained or repeated as required.

As much as we hope all your appointments will follow the guidance of the PBC care bundle, we recognise that this will not be the case for everyone. For further support and information about anything covered in this guide, please contact the PBC Foundation.

# TREATING YOUR PBC

An important part of your PBC healthcare journey is having the right treatment for you, at the right time.

## 1. Have you been prescribed Urso?

Yes  No

If you have answered **No**, please discuss your treatment with your healthcare team.

**Ursodeoxycholic Acid** (known as Urso and UDCA) is the recommended first-line medication for PBC and should be prescribed to all PBC patients when diagnosed as a lifelong treatment.

Urso is proven to help reduce the progression of PBC in most patients, however it does not alleviate symptoms. For the treatment of symptoms please see question 5.

## 2. Are you on the right Urso dose for you?

Yes  No

If you have answered **No**, please discuss your treatment with your healthcare team.

Your Urso dose is based on your weight and is specific to you. The **optimum dose** of 13-15mg/kg/day is proven to be most effective for the majority of patients. If your weight changes, your dose may need to change too.

Please use the PBC Foundation's **Urso Dose Calculator** to check if your dose is correct.

## 3. Do you require second-line treatment?

Yes  No

If you have answered **Yes**, please answer question 4.

Most PBC patients respond well to treatment with Urso and will not required additional treatments. For those who a) don't have the desired response to Urso after a year of treatment, and b) meet a specific criteria, may be eligible for a second-line treatment such as Obeticholic Acid (OCA) and Fibrates (eg. Bezafibrate).

## 4. Are you treated with a second-line treatment?

Yes  No

If you believe you are eligible for second-line treatment and have answered **No**, please discuss additional treatments with your healthcare team.



Scan for Urso  
Dose Calculator

## MANAGING YOUR PBC SYMPTOMS

Symptom burden in PBC can have a huge physical and mental impact on a patient's quality of life.

It is important to raise any changes, or new symptoms with your healthcare team. It is helpful to track your symptoms so you can share as much detail as possible. A number of symptoms associated with PBC are listed below, these should be discussed with your clinician.

Not all patients experience the same symptoms, so some may not be applicable to you.

### 5. Have you discussed the following symptoms with your clinician?

**Itch**

N/A  Yes  No

Itch is known medically as **Pruritus** and there are a number of treatments available.

**Fatigue**

N/A  Yes  No

Although, there is currently no medication for fatigue, there are non-medical interventions. Your healthcare team can screen for other auto-immune or age-related conditions, assess contributors such as itch and sleep, as well as recommending lifestyle changes.

**Brain fog**

N/A  Yes  No

There is ongoing research looking at how to address fatigue and brain fog. Whilst there are no treatments and limited understanding of brain fog, it is important to tell your clinician about the extent of your symptoms to give them a full picture of your life with PBC.

**Dryness**

N/A  Yes  No

Sicca Syndrome and Sjögren's Syndrome are associated with PBC, causing dryness in the eyes, the mouth and, in some cases, vaginal dryness. Whilst there is no cure, there are treatments for the symptoms and in some cases referral to a specialist team may be required.

### 6. Has your bone health been assessed in the last 5 years?

Yes  No

If you have answered **No**, please arrange an assessment with your healthcare team.

Date of your last assessment: .....

People with PBC have an increased risk of osteopenia and osteoporosis, your bone density should be assessed and in many cases a DEXA scan is recommended for PBC patients.

## MONITORING YOUR PBC

A key aspect of living with PBC is lifelong surveillance.

**7. Has your PBC been assessed in the last 3 years?** Yes  No

If you have answered **No**, please arrange an assessment with your healthcare team.

Date of your last assessment: .....

As well as regular blood tests, the condition of your liver is assessed with an Ultrasound, Fibroscan or ELF test. These are non-invasive procedures and an effective way to assess the health of your liver and whether fibrosis is present.

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### QUESTIONS 8-10 ARE ONLY RELEVANT IF CIRRHOSIS/ADVANCED LIVER DISEASE HAS BEEN IDENTIFIED

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**8. If you have cirrhosis, have you had an ultrasound in the last 6 months?** Yes  No

If you have answered **No**, please arrange a scan with your healthcare team.

Date of your last assessment: .....

Many people who have cirrhosis will remain well with no complications or side-effects; this is called compensated cirrhosis. It is however important to be monitored for any changes or complications with an ultrasound scan every 6 months.

**9. If you have portal hypertension, is your varices screening up to date?** Yes  No

Check with your healthcare team that your scan is in date and/or arrange a screening.

Date of your last assessment: .....

Portal hypertension can increase the risk of complications such as varices (enlarged veins), an endoscopy is used to monitor your condition and identify if treatment is required.

**10. Have you developed complications associated with cirrhosis?** Yes  No

Cirrhosis can cause complications such as varices, ascites, hepatic encephalopathy (HE), or muscle loss - this is known as decompensated cirrhosis. Decompensated cirrhosis and high bilirubin ( $>50 \mu\text{mol/L}$ ) can sometimes be an indication to consider transplantation. A small percentage of patients may require referral to a specialist liver unit for transplant assessment. Remember, your healthcare team are there to support you and answer any questions you may have through your healthcare journey.

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