

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 the British Association for the Study of the Liver and the British Society of Gastroenterology in response to the UK-PBC Audit that identified concerning inconsistencies in PBC care across the UK. Your doctor is able to access this care bundle.

WHAT IS THE PBC CARE BUNDLE?

It is a standardised healthcare approach designed for use by clinicians in the United Kingdom aiming to deliver better care for PBC patients, however it is also available for your doctor to access in Australia. It includes a checklist of questions that clinicians should discuss with patients at each appointment.

WHY DO WE NEED THIS GUIDE?

This guide will help you to take an active role in your healthcare and in conversations with your treating team.

This guide contains information to help you prepare for your appointments. You might want to use it in discussion with your treating team, to make sure all your questions and concerns have been 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.

While your appointments may follow the guidance of the PBC care bundle, you can be assured that your clinician will work with you to determine the best treatment plan for you. For more information and support you can contact the Liver Foundation at liver.org.au, 1800 841 118 or go to the the PBC Foundation website www.pbcfoundation.international.

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.

It is easy to calculate if you are on the correct dose - just divide the dose you are on (in mg) by your weight (in kg). Talk to your doctor if you aren't sure about your dose

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 require 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.

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.

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. DEXA scan is available under Medicare - talk to your doctor if you haven't had a scan in the last 5 years.

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 or Fibrosan. These are non-invasive procedures and an effective way to assess the health of your liver and whether fibrosis is present.

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

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.



The PBC care bundle recommends that clinicians direct patients to appropriate support groups.

The PBC Foundation is the largest PBC patient support organisation in the world. Our purpose is to have a positive impact on the quality of life of every person affected by PBC. Our services are provided free of charge to all registered service users, and include our helpline, website, meetings, conferences and publications.

The Liver Foundation is Australia's peak body for all liver diseases. You can talk to an expert hepatology nurse for more support and information.

www.pbcfoundation.international

helpline: +44 (0)131 5566 811    @PBCfoundation

The Liver Foundation: www.liver.org.au | (Australia) 1800 841 118

Date of your next appointment:

Notes:

IMPORTANT INFORMATION:

Our Patients Guide to Discussing PBC with your Clinician has been designed as general guidance to inform and support PBC patients. It is important to remember that some patients may have different healthcare requirements and in some clinical situations, an alternative care pathway may be recommended.

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