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# Making the most of appointments

## With people living with primary biliary cholangitis (PBC)



No matter which stage of PBC the patient you are treating is at (diagnosis, taking first-line treatment, taking second-line treatment, etc.), they will understandably have questions and concerns. This resource has been developed in collaboration with patients living with PBC and clinicians in the field to reflect their main concerns when it comes to making the most of medical appointments.

It's important to align expectations and ensure the patient leaves an appointment feeling content and cared for. This includes making them feel heard and validated, and that the most appropriate management strategy for their condition has been chosen. The aim is to work together to achieve the best outcome possible. This guide covers a list of considerations that may be helpful when treating a person living with PBC.

Please click here or scan the QR code to view the IQIRVO▼(elafibranor) adverse event reporting and prescribing information. This medicinal product has a conditional marketing authorisation.

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IPSEN IN PBC

IQIRVO®(elafibranor) Patient Support

## When someone has been recently diagnosed with PBC

**This is an extremely turbulent time for many people with PBC — as a key member of their medical team, you play an important role in their support network.**

### Acknowledge their feelings and reassure them

People can react to the news that they live with a chronic condition differently — ask them how they are feeling and if they have anyone to talk to about their diagnosis.

### Ensure they have accurate information

As it is a rare disease, many people have not heard of PBC. To ensure people living with PBC are not misinformed, spend some time explaining the condition to them and direct them to trusted sources of information, such as those included in our **Patient Support materials**.
The **Understanding PBC** guide is a good place to start!

***Please note that these materials may only be offered to people with PBC who have been prescribed IQIRVO®.***

### Direct them to supportive communities

Insights from those living with PBC suggest that people often feel lonely following their diagnosis. Knowing that there is a network of people in a similar situation can help.

Find out about any local PBC patient support groups and direct patients to them as soon as possible. If a local PBC support group does not exist, consider referring them to a national PBC group or a rare liver disease group.

## When a person is starting a treatment for the first time

**Whether starting a first-line treatment or switching to alternative treatments, it is important that patients understand what the treatment aims to achieve and why they should adhere to their treatment schedule.**

### Align on treatment goals

Some people assume that treatment means that the disease will be cured or have other ideas on what it can achieve. When starting a patient on a new treatment, align with them on treatment goals to manage expectations.

Consider describing the treatment from two perspectives: how the treatment helps to manage the disease and how it will affect their daily living. This can be particularly useful in PBC, as some treatments won't have an immediate effect on PBC symptoms but are important in managing liver disease progression. It has been suggested that people who are well-informed about their medication adhere better to treatment.[1]

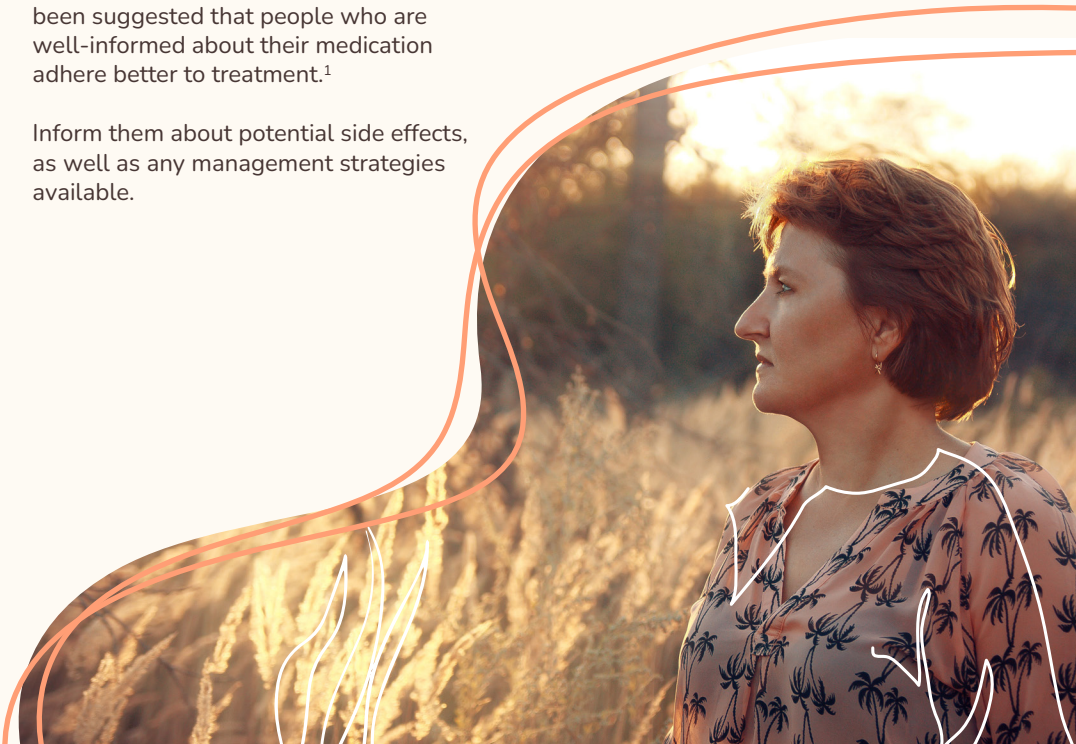
Inform them about potential side effects, as well as any management strategies available.

### Explain the treatment schedule

Ensure patients understand when they should be taking their treatment, and suggest they set up reminders in their phone or calendar.

Let them know what they should expect in terms of monitoring treatment response: how frequent follow-up appointments will be, what sorts of tests will be used, and ways in which the treatment plan may be adjusted based on the response.

Don't forget to speak to them about any other treatment-specific considerations.



## Considering risk assessment

Early in a patient-doctor relationship, it is important to establish the role and frequency of their regular appointments — to monitor the patient's PBC and adjust their treatment plan as necessary. Part of this discussion should include explaining the concept of **risk of PBC progression**.

It is crucial that patients understand that an increased risk only informs if an event is more likely to occur; it does not guarantee it will occur. Calculating risk can allow you to make more personalised treatment plans with the aim of potentially better managing disease progression.

Some patients may ask for more detailed information on risk factors, and this information is included in the **Understanding PBC** guide.

Details you could explain may include:

### Demographics

There could be many reasons behind the correlations between patient demographics and risk of progression,[2] so sensitivity is paramount as these personal factors cannot be changed. Again, stress that these links are only used to inform you about how their treatment and care plan will be adjusted to give them the best outcome possible.

The risk of disease progression has been correlated with race and age:

- **Diagnosis of PBC before the age of 45** is associated with severe disease and a poorer response to treatment[2–4]
- **People of colour** living with PBC often have more severe liver disease at clinical presentation and experience poorer long-term outcomes[5,6]

## Disease severity at diagnosis

When PBC is diagnosed at an early stage, preventative measures can help to limit widespread cholestasis/fibrosis. Due to the nature of PBC, early diagnosis is not a given, so the following risk factors can be used to guide treatment:

- **Levels of alkaline phosphatase (ALP) above five times** the upper limit of normal have been linked to more severe PBC, a higher chance of experiencing symptoms, and a lower chance of responding to treatment[7]
- **An elevated AST/platelet ratio index score** is associated with a higher risk of PBC-related complications[8]
- **A high liver stiffness value** is indicative of fibrosis and a higher risk of disease progression[4,9]

## Serological profile

**PBC-specific antibodies (against gp210 and sp100)** are more common in people with severe PBC and their presence is associated with a poorer outcome.[4]

## Inadequate response to treatment

Evaluating risk is an ongoing process, as the risk of progression can change throughout the course of the disease. An inadequate biochemical response after 12 months of treatment is associated with disease progression and worse outcomes.[9,10]

## How to personalise appointments to the patient's needs

**A personalised approach should be adopted to build a strong relationship with the patients you care for and ensure they get the best care possible. The following suggestions have been designed with patients to help guide you as you tailor your approach.**

**Ask how they are**
It's a small gesture, but it can be powerful in making a person feel seen as more than just a patient you treat. It also gives them the opportunity to lead the conversation.

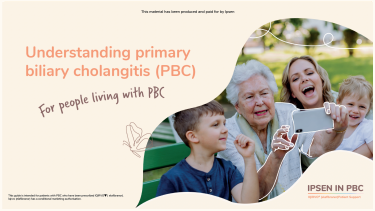
**Ask if there are any immediate concerns**
Many months may have passed since your previous appointment, during which a patient may have experienced worsening of symptoms or challenges relating to their condition or treatment. Explicitly asking them this question can be empowering, especially for those who may be reluctant to speak without prompting.

While some concerns may not have a solution, it is important to give patients the space to speak about their experiences. Ensuring that patients feel heard is valuable and can help to strengthen your relationship with them.

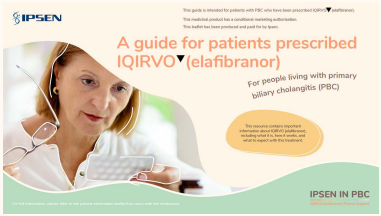
**Ensure they understand the tests**
When going over any liver function tests, briefly ensure that patients understand why they were done. Some patients may prefer to go into their results in more detail, while others may prefer the conclusion.



The IQIRVO® Patient Support Materials provide a variety of resources for people living with PBC. These materials are available for all patients who have been prescribed IQIRVO® and offer disease and treatment education, physical and emotional well-being guidance, and practical tools to help them keep on top of the condition. A summary of the resources available is provided below; you can find the complete list of resources here: **www.ipsen-hub.co.uk/primary-biliary-cholangitis/patient/support/**



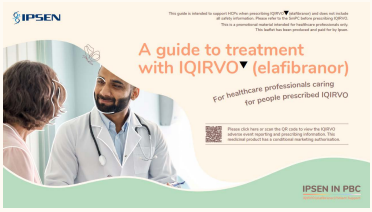

## Understanding PBC
For patients




## Elafibranor guide
For patients



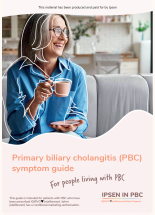

## Family, friends and workplace guide
For friends & family




## IQIRVO guide
For healthcare professionals



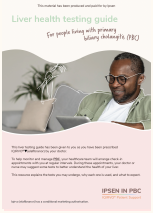

## Making the most of your appointment
For healthcare professionals




## Symptom guide
For patients




## Making the most of your appointment
For patients




## Liver health testing guide
For patients




## Exercise guide
For patients




## Symptom tracker
For patients




## Supporting you through your journey
For patients




## Glossary
For patients

## References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