



Primary biliary cholangitis (PBC) symptom guide

For people living with PBC

IPSEN IN PBC

IQIRVO® (elafibranor) Patient Support

As someone living with **PBC**, you may be concerned about how the condition could impact your day-to-day life.

Symptoms vary between people with PBC; some people won't have any symptoms when they are diagnosed, but they can appear as time goes on.^{1,2}

This guide has been given to you as you have been prescribed IQIRVO® (elafibranor) by your doctor. It summarises common PBC symptoms that might be experienced, either now or in the future, and recommendations on how they may be managed.

It is important to note that the severity of the symptoms you may experience may not be reflective of the extent of liver damage caused by PBC.¹

Please refer to the Glossary if you are unsure of any of the technical terms used in this resource. Terms that are defined in the Glossary are underlined throughout.

What are the common symptoms of PBC?¹



Fatigue



Itchy skin



Brain fog



Dryness of eyes and mouth



Trouble sleeping



Soreness in the abdomen



Dizziness

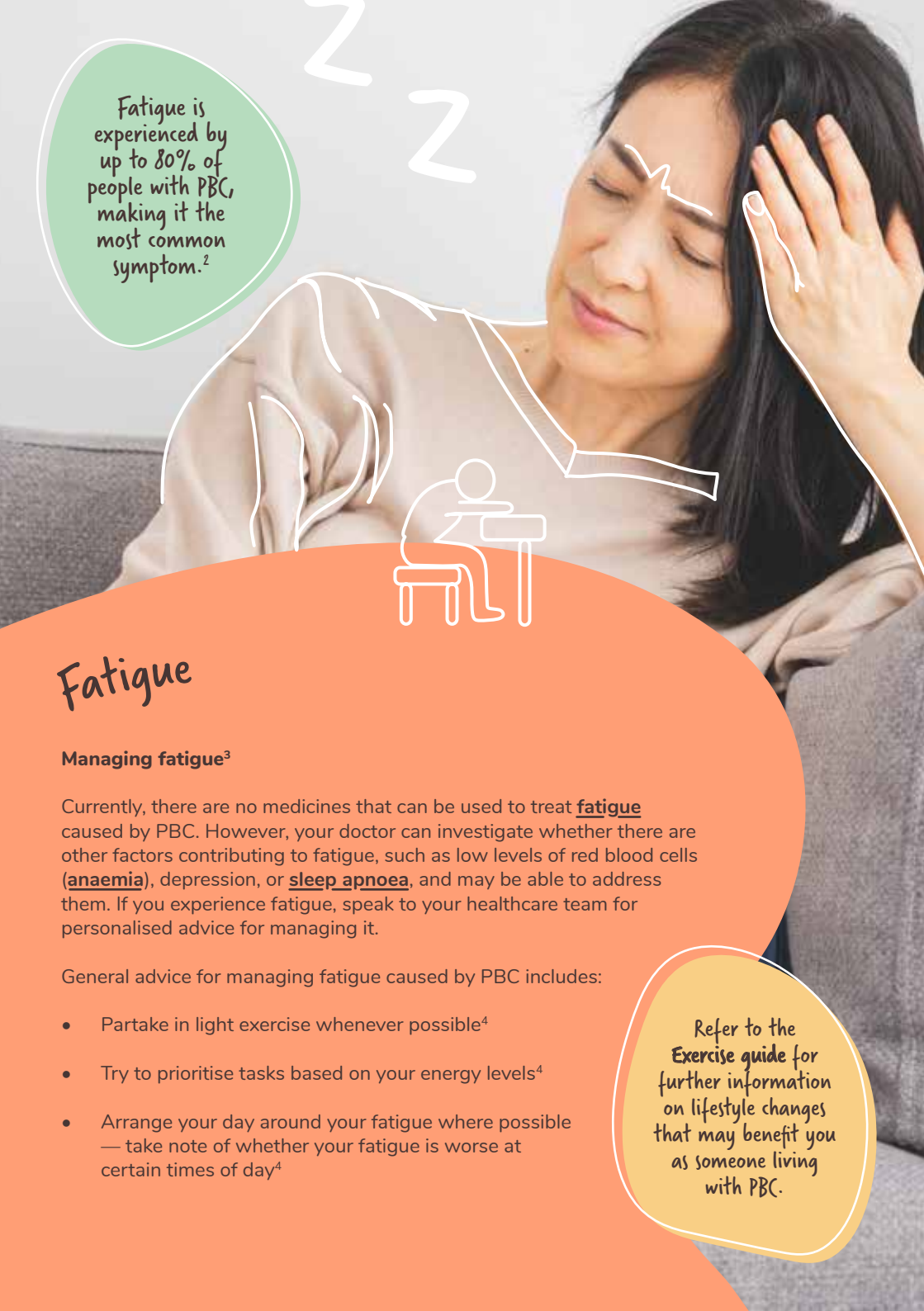


Aching bones or joints

This medicine is subject to additional monitoring. This will allow quick identification of new safety information. If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet.

You can help by reporting any side effects you may get. See www.mhra.gov.uk/yellowcard for how to report side effects.

Side effects should also be reported to Ipsen via email at pharmacovigilance.uk-ie@ipsen.com or phone on 01753 627777.



Fatigue is experienced by up to 80% of people with PBC, making it the most common symptom.²

Fatigue

Managing fatigue³

Currently, there are no medicines that can be used to treat **fatigue** caused by PBC. However, your doctor can investigate whether there are other factors contributing to fatigue, such as low levels of red blood cells (**anaemia**), depression, or **sleep apnoea**, and may be able to address them. If you experience fatigue, speak to your healthcare team for personalised advice for managing it.

General advice for managing fatigue caused by PBC includes:

- Partake in light exercise whenever possible⁴
- Try to prioritise tasks based on your energy levels⁴
- Arrange your day around your fatigue where possible — take note of whether your fatigue is worse at certain times of day⁴

Refer to the **Exercise guide** for further information on lifestyle changes that may benefit you as someone living with PBC.

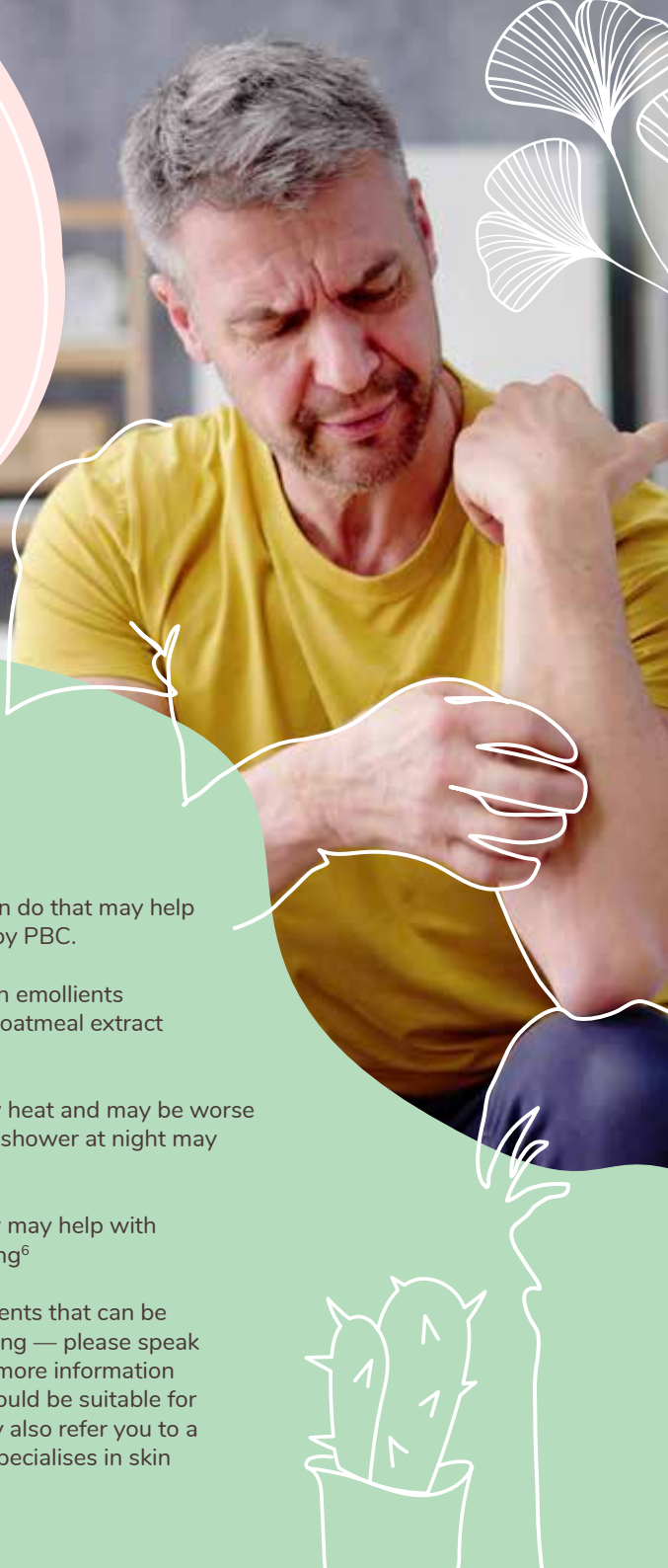
Itching, known as pruritus, is the second most common symptom of PBC, affecting approximately 70% of people with PBC. It can impact your sleep and quality of life.⁵ People with severe itching may also experience depression, social isolation and worsening fatigue.² Scratching can also break and mark the skin.²

Itching

Managing itching

There are a few things that you can do that may help to alleviate severe itching caused by PBC.

- Keep the skin moisturised with emollients — some people also find that oatmeal extract has similar effects^{2,6}
- Itching can be made worse by heat and may be worse in the evening. A cold bath or shower at night may help to relieve itch⁶
- Cognitive behavioural therapy may help with preventing excessive scratching⁶
- There are also medical treatments that can be prescribed to help relieve itching — please speak with your doctor or nurse for more information on these and whether they would be suitable for your circumstances. They may also refer you to a dermatologist, a doctor that specialises in skin





Dry eyes and mouth

Managing dry eyes and mouth³

Your doctor may recommend using artificial tears and/or saliva as they may improve dryness of the eyes and mouth.⁴ A dry mouth can increase the likelihood of tooth decay, so you should visit the dentist frequently.³

A condition known as Sicca syndrome is common in people living with PBC and can cause dryness of the eyes and mouth.^{2,6}





Brain fog is a term used to describe forgetfulness and having difficulty concentrating.^{7,8}

Brain fog

Managing brain fog

There are no treatments available for brain fog,⁷ but small lifestyle changes can be made to help manage it. Setting reminders in a diary or on your phone can help with memory problems. Taking notes more frequently (during work or your medical appointments) can give you something to refer back to during times you have lost concentration.

It is useful to keep track of your symptoms and discuss them with your healthcare team:

The severity of PBC symptoms can fluctuate, so keeping track of them can help build a picture of how PBC affects you over a long period of time.



You may experience other symptoms, which should be discussed with your doctor. They will be able to explain whether they are related to your PBC, another health issue or possibly a medication you are taking.



How can symptoms change with time?

PBC affects people in different ways. Not everyone living with PBC will progress to advanced disease, and some symptoms may be due to other factors unrelated to PBC. If your PBC does become advanced, it is likely to be a long time after your diagnosis. Symptoms of more advanced PBC are shown below.^{1,6}

Regular appointments with your doctor or nurse are there to keep an eye on your health and check if your PBC is progressing. These appointments will ensure that disease progression is spotted early and will provide an opportunity to discuss further treatment options at that point.

Jaundice

(yellowing of skin and eyes)

**Impaired memory and
trouble concentrating**

Ascites

(swelling of stomach caused
by fluid build-up)

Oedema (i-dee-muh)

(swelling of the legs, ankles and
feet caused by fluid build-up)

**Bleeding and
bruising easily**

**Light/pale stools
and dark urine**

Xanthelasma (zan-the-las-muh)

(yellow bumps on the skin, usually around the eyes, caused by
fatty deposits)

If you experience any of these symptoms or any additional symptoms that have not been discussed in this guide, please seek medical advice and discuss them with your doctor or nurse.



Living with PBC symptoms can be challenging, but your healthcare team are there to help. Keeping a record of your symptoms can provide the information your doctor needs to help you manage PBC symptoms as effectively as possible. We recommend that you use the “Making the most of your medical appointment” guide to help you keep on top of your symptoms, including what is or isn’t working for you.

References

1. NHS. Primary Biliary Cholangitis: Symptoms. Available at: www.nhs.uk/conditions/primary-biliary-cholangitis-pbc/symptoms/. Last accessed August 2024.
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