



Understanding PBC



PBC CARE

CONVERSATIONS | AWARENESS | RESOURCES | EMPOWERMENT

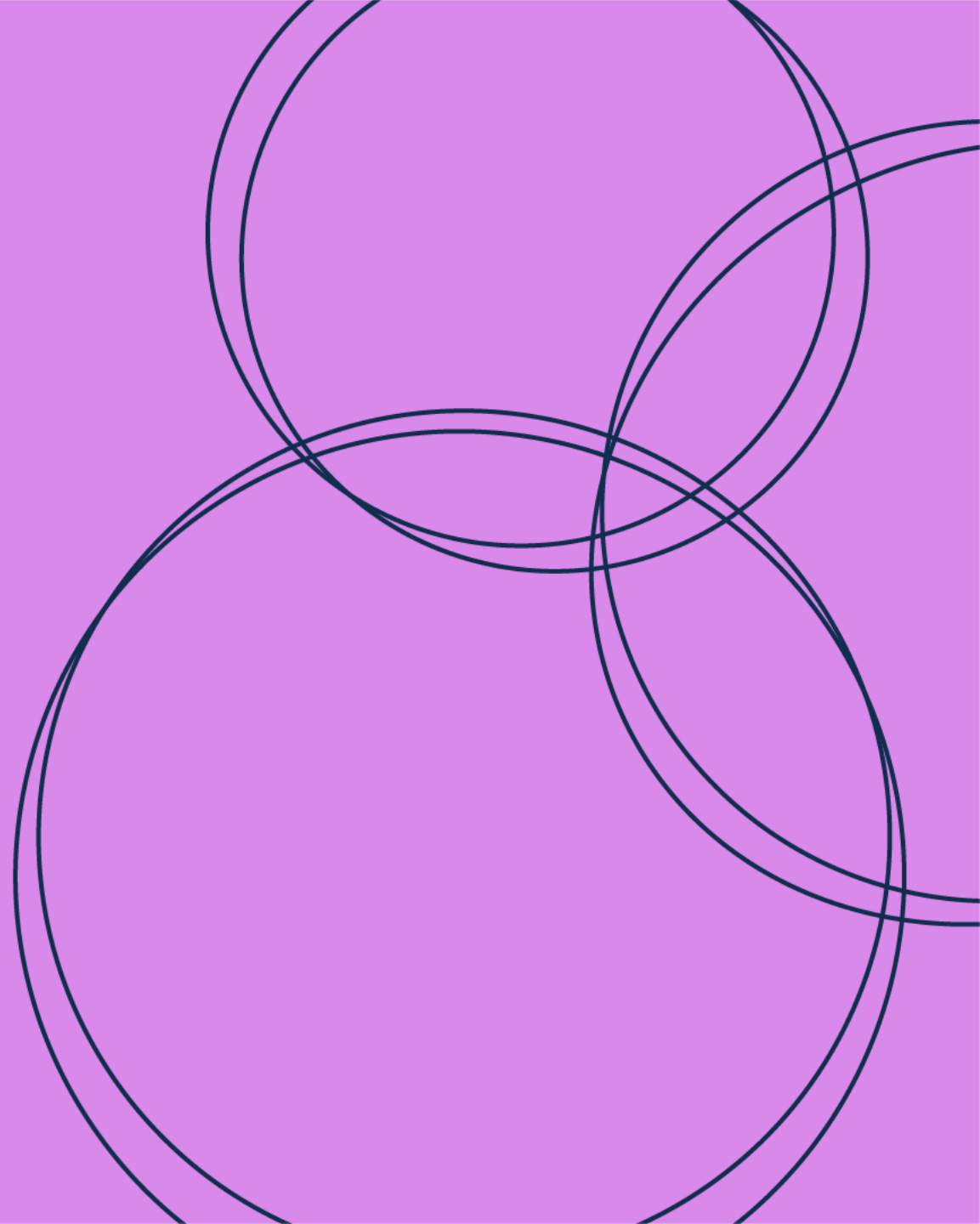
These materials have been developed by Ipsen with instrumental contributions in concept development and review from the following patient organizations: ALBI España, AMAF aps ets, Australian Liver Foundation, Casa Hunter, Deutsche Leberhilfe, PBC Canada, PBC Föreningen, PBC Foundation.

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Understanding PBC: Living with PBC symptoms



What we will cover in living with PBC symptoms

01

Common symptoms of PBC – and how they may change over time

02

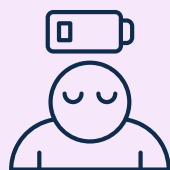
Reducing symptoms of PBC





Common symptoms of PBC

In the early stages of PBC, you may have no symptoms at all, or you may:



Experience fatigue



Sleep a lot



Have itchy skin (pruritus)



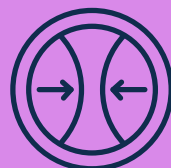
Have tummy pain or discomfort

It may be one of these 'vague' symptoms that prompted you to go the doctor for the first time.

Over time, you may have other symptoms that suggest more advanced liver disease:



Weight loss



Skin thinning / muscle wasting



Tummy discomfort or swelling



Yellowing of the skin or whites of the eyes (jaundice)



PBC can get worse over time, which may be a slow process. Some people will develop symptoms of liver disease – but not everyone.



Common symptoms of PBC

It may be one of these 'vague' symptoms that prompted you to go the doctor for the first time.

In the early stages



Feel
tired

Words You Might Hear and What They Mean

Fatigue

Fatigue is a chronic and debilitating condition that goes beyond ordinary tiredness, often persisting despite rest or sleep and can have a significant impact on quality of life.

pruritus

Itchy skin that makes you want to scratch.

Abdomen

The area of your body between your chest and hips, often called your tummy.

Jaundice

A condition where the skin and the whites of the eyes turn yellow because of a build-up of a substance called bilirubin in the blood.

Over time, you may



Weight loss



Skin thinning /
muscle wasting



discomfort or
swelling



Yellowing of the
skin or whites of
the eyes (jaundice)



PBC can get worse over time, which may be a slow process. Some people will develop symptoms of liver disease – but not everyone.



Ask your doctor about options for managing your symptoms

Finding ways to reduce symptoms could help you maintain a good quality of life. The most common symptoms of PBC are fatigue and pruritus (itching).

To help with **itching**, you could:



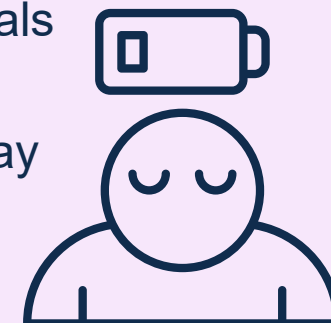
- Share with your nurse or doctor if itching is affecting your quality of life
- Certain medications can offer relief from itching

Have you tried any of these suggestions?

Fatigue affects up to 80% of people with PBC, with up to 20% experiencing severe fatigue.

To help with **fatigue**, you could:

- Talk to your family and friends about how fatigue affects you
- Keep a diary of how you are feeling – there may be time of day you feel better or worse
- Plan ahead to help manage fatigue by scheduling rest breaks between task and setting realistic daily goals to conserve energy
- Keep active, even though you may not always feel like it, but don't overdo it



Reducing PBC symptoms

[Click for definitions](#)



Finding ways to manage your symptoms can help you maintain a good quality of life. Fatigue is a common symptom of PBC (extreme tiredness).

To help with this, you can:



Words You Might Hear and What They Mean

Fatigue

Fatigue is a chronic and debilitating condition that goes beyond ordinary tiredness, often persisting despite rest or sleep and can have a significant impact on quality of life.

pruritus

Itchy skin that makes you want to scratch.

Abdomen

The area of your body between your chest and hips—often called your tummy.

Symptom tracking

Keeping a record of symptoms (like fatigue or itching) to see changes over time.

- Certain medications can offer relief from itching

• Scheduling rest breaks between tasks and setting realistic daily goals to conserve energy



Have you tried any of these suggestions?