



MORE THAN TIRED:

Let's talk about fatigue in PBC

A guide to getting the support you need



Fatigue is **more** than just feeling tired

Fatigue is the symptom most often seen in PBC, and it can be difficult to live with¹⁻⁴

You are not alone....



"It is like walking in a fog where even simple tasks, like unpacking groceries become impossible"⁵

"Fatigue is hidden – I look well, but inside I feel mind-numbing exhaustion"⁵

Understanding how your fatigue affects you can help you take back control

For many people with PBC, fatigue is the symptom that has the biggest impact on their daily life³



Problems with **memory or concentration**⁶



Reduced **ability to work**⁷



Sleep disturbances^{2,6}



Less able to **stay connected** with others²



Finding it harder to stay **physically active**⁶



Feeling **anxious or low**²

There are other medical conditions that can cause fatigue or make fatigue worse. **Talk to your doctor about checking for other conditions**

Taking control of your fatigue: **ASSESS**

Everyone experiences fatigue differently so it's important to **assess how it affects you**. This can also help you be in a better position to discuss this with others

Take time to think about **how fatigue affects the different areas of your life**

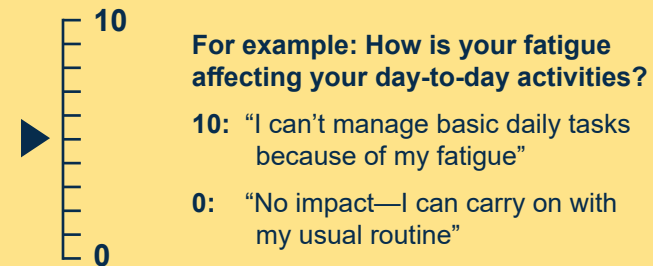
Is your fatigue **worse at a particular time** of the day or **after certain activities**?

How is your fatigue **impacting your job**?

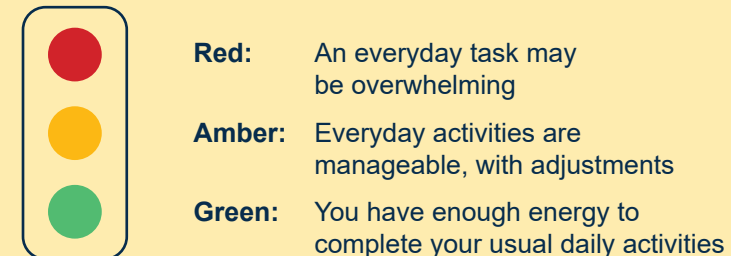
Does your fatigue **stop you from socialising** with friends and family?

Be honest with yourself and others about how your fatigue is really affecting you

You may find a simple 0–10 scale helpful in recognizing how fatigue affects your daily life¹



Another method is to assign traffic light colours to your fatigue on a given day:⁸



Using these scores with your doctor can help them understand the impact of your fatigue¹

Taking control of your fatigue: **TELL**

You don't need to minimise your symptoms - being open helps others understand what you're managing

Fatigue in PBC can make you feel isolated, but reaching out for support can help. Here are some tips to help you start the conversation about fatigue



Friends & family



Work



- Giving real examples (e.g. needing to rest after small tasks) **can help others understand** that fatigue is more than tiredness.



- Be open with your manager about how fatigue **may be impacting your work** (e.g. needing more time for tasks, reduced concentration, or changing energy levels during the day)



Healthcare professionals



- **Making notes** about your fatigue or **preparing questions in advance** can help you feel more confident when discussing your symptoms with your doctor
- Take someone with you, or use a notebook to record important information during your appointment



Support groups



- **Support groups** can provide understanding, shared experiences, and practical tips for living with PBC
- Even if support feels limited, finding a **PBC community** can help you feel more connected
- Fatigue can also impact how you feel emotionally - **speaking to someone** about your mental health can help

Taking control of your fatigue: **MANAGE**

Don't worry if something does not help straight away - it can take time to find what works best for you

Managing fatigue means making small changes every day **so you can feel your strongest**



Try to spend your energy on the things that **matter most** to you



Take **breaks and rest** during the day



Notice what makes your fatigue better or worse



Ensure you are **eating well** and have **good sleep hygiene**

"I think of my energy like a battery pack. It can run low quickly, and I have to stop and recharge"

Listen to your body, as your energy levels may change during the day⁷



Trying to stay **as active as possible** can play an important role in managing fatigue in PBC

What's achievable will be different for everybody – for some this will be walking around the house, others it will be pushing a shopping cart

While gentle movement can help some days, on other days rest may be more important



Speak to your doctor before starting new exercise or lifestyle changes

Top tips for taking control of your fatigue



Pay attention and **keep a record** of how your fatigue affects you and how your symptoms change over time^{1,8}



Talk about your fatigue with your doctor, friends, family and colleagues³



Speak to your doctor and **make a plan** for managing your fatigue



Ask your doctor about available **resources and support groups**

**Remember:
you do not have
to manage your
fatigue alone**





References

1. Koc OM, *et al. Lancet Gastroenterol Hepatol.* 2026;11(1):71–86; 2. Mellis GF, *et al. Hepatology.* 2013;58(1):273–83; 3. Sierra L, *et al. Ann Hepatol.* 2025;30(2):101945; 4. Uhlenbusch N, *et al. Liver Int.* 2026;46(3):e70526; 5. Hale M, *et al. BMJ.* 2012;345:e7004; 6. Swain MG, Jones DEJ. *Liver Int.* 2018;39:6–19; 7. Hirschfield G, *et al. EMJ Hepatol.* 2022;10:22–31; 8. Royal Free Chronic Fatigue Service. The Traffic Light System. Available at: <https://rfcfs.co.uk/Home/Energy-Management/The-Traffic-Light-System> (last accessed July 2026).