



# LIVING WITH PBC FATIGUE

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Much as we would like to, and despite the progress being made in understanding and treating of fatigue, the reality is that fatigue in PBC is a problem than people need to learn to live with. A key component of this is the coping strategies to help minimise its impact. These are entirely in your hands and are really helpful. A mantra that we use all the time is “own the problem and own the solution”. It is your life and you need to make the very best of it that you can

## These are the key things to think about

### 1) Treat energy as a valuable commodity and use it wisely:

Pacing of your activity is a critical element of managing fatigue. It is important not to “wrap yourself in cotton wool”. By the same token, however, using energy wisely allows you to make sure you do the most important things. Think of energy as you would do money. Save it when you can and make sure you get the best value for money when you do spend it.

### 2) Understand and use the rhythm of the disease:

Fatigue in PBC characteristically gets worse as the day goes on. This means that mornings are the best time to get things done. The corollary is that evening working, and, in particular, night shifts can be very challenging indeed. If you have important meetings or engagements try to organise them for mornings. If your work pattern involves evenings and nights then speak to your employer about changing your work pattern. The other aspect to disease rhythm is to accept that there will be good days and bad days. If you are having a bad day be philosophical, don't fight it and focus on the likelihood that tomorrow will be better.

### 3) Exercise is good:

There is now trial evidence to suggest that exercise is associated with a significant reduction in fatigue severity. There are also good reasons to believe it should work based on our understanding of how the muscles are affected in PBC, and how exercise and training might be expected to improve their function. The challenge for people is getting started (“how can I exercise when I feel so tired”). There is also the perception that exercise is all about people with perfect bodies wearing lycra in gyms; an environment and an association that many people with PBC feel uncomfortable with. The good news is that there are lots of ways of increasing exercise as part of daily life. An activity increase of around 10-20% is thought to be enough to have a beneficial effect. Think how you could achieve this. If you can manage 30 minutes of exercise three times a week it will really make a difference. One area of real progress in this area has been the advent of digital technology that helps you keep track of exercise. Tools such as “Fitbit” are very useful, and many smart phones have exercise trackers. This allows you to understand what you are doing and measure the changes you make. Simple steps to increase exercise are such things as walking rather than driving or taking the bus. If you do have to use transport, think about parking a bit further away or getting off a stop earlier. Sometimes people join walking groups (good for the social side as well), take up golf or get a dog! Gyms are, of course, a very good way of doing it and are not at all as most people imagine them to be. The vast majority of gym users, in this day and age, are ordinary people wanting to get fitter just like you. They are very welcoming and

the instructors are really good at tailoring exercise regimes to what you are able to do and what you want to achieve. If you really get enthused then aim for 10,000 steps every day. This is the recommended healthy level of exercise. One piece of advice, particularly if walking is your chosen approach is to watch the speed. The benefit difference between slow walking and fast walking is huge. If you are too slow it is still a good thing to do but it may not be as beneficial as it could be.

One thing that people worry about is causing harm through exercise. This is absolutely not the case. You may feel more tired immediately afterwards (although the tiredness is a healthier feeling one) but as the days go by it will continually improve. Think of exercise as a long-term change. Make it part of your life and aim to be active most days. Always listen to your body, though, and if this is a bad day then don't force it. Tomorrow will be a better day and you can pick it up then.

### 4) Keep your social structures:

One of the really striking findings from UK-PBC was that having fatigue wasn't automatically associated with poor quality of life. In fact, there is a group of people with significant fatigue who feel that their life quality is good despite their fatigue. What this group have in common is strong social networks. In contrast, people who have become isolated feel the symptom much more and their quality of life is worse. What does this mean in practice? What we often come across is people who try to save energy by changing their lifestyle; reducing or stopping their work, not going out and meeting friends, etc. What our findings suggest is that this is almost always a false economy. This may save some energy but there is a price to pay in terms of overall life quality. The message we give to patients is to keep doing things! Adapt what you do to your capability but doing things remains really important. I know a patient who used to go rambling with friends. She found this increasingly difficult with her PBC and that she was being left behind. What she did, however, was not to give up going but to meet people at the end of the walk. Walk a short distance to meet them and then join them for coffee. A really sensible compromise.

Many patients also get benefit from digital media based social networking. This can be of great use to people with profound fatigue and, of course, became a lifeline during self-isolation during the COVID-19 outbreak.

Adapted from “PBC: The Definitive Guide for Patients with Primary Biliary Cholangitis”, 2nd edition published in 2023