

- If talking is not your thing, write. Pen and paper, or a pc, are just as useful when it comes to expressing our feelings. Keep your notes under your control: so keep them password-protected or destroy them.
- Take stock of changes (for good and bad) and observe what is making things better, ensuring these become your choices.

After diagnosis, we tend to get on with handling the physical effects of our condition. We need to learn what it means and to learn intelligent patterns of behaviour that help us manage our symptoms, e.g. fatigue, or eating healthily, etc. Dealing with the physical aspects is often easier than dealing with the emotional effects.

The early stage of emotional distress gradually gives way to a coping routine in most people with spells of what is better described as “low mood”. How much and how often low mood affects us is down to a combination of personality, experience, what is happening around us, brain chemistry and perception. We each have to learn to treat low mood just like any other symptom. Like tiredness, there is a sense in which it cannot be controlled totally but it can very much be made worse by bad self-management. Strategies that prevent the situation getting worse are often the best ways of coping with such symptoms and of improving quality of life. Looking at PBC holistically is the best use of our limited time and energy. What helps one symptom will often benefit another. For example, eating healthily will give energy and also help to counter poor absorption of vitamins. The same can be true when dealing with low mood. We can all understand the mind-body connection between stomach ulcers and anxiety. By being aware of this mind-body connection on how we live daily, we can avoid some of the more unpleasant effects of low mood. We are not powerless. There are strategies to improve mood. There are strategies to regain control.

## Investing in Energy

Let us consider time, money and energy. We spend all three. We occasionally try to save all three and occasionally, if we are being honest, we can even admit that we waste all three.

Time has its own controls. Try as we might, we cannot add to the number of hours in a day or days in a week so we are forced to consciously organise our time and make arrangements within the limits of a 24 hour day. Even putting something off till tomorrow is one such arrangement.

With money, we face similar limitations. What is in our wallet or purse, in our account or credit card, what we have access to in earnings, savings, etc are all limited. We make arrangements to spend within our limits. (And when we don't, we surely know about it!!)

For all that we speak of time, money and energy using the same terms, we don't often consider energy in the same way. We face limitations on our energy (despite

the best protestations of an energetic 6 year old!!). It is easy to take energy for granted and it is only when our energy is limited in a way that restricts our choices that we start to realise that we also need to manage our energy use.

Fatigue associated with PBC can teach us this very harsh lesson. Fatigue can vary from hour to hour, through the day, from day to day, week to week, month to month or even year to year. The key thing is to manage our fatigue (as opposed to fighting it) and a great way to do this is to look at how we spend our energy.

Fatigue is usually understood to have three kinds of causes:

**Physical:** illness, weight, dehydration, sleep

**Lifestyle:** activity, sleep hygiene, overworking, diet (false energy foods)

**Psychological:** stress, depression, negativity, emotional strain

We know there are medical aspects of fatigue within PBC, and that it itself cannot currently be cured: there are currently no licensed medications that can treat the fatigue that comes with PBC. That all said, there are things we can do to help ourselves. For example, a 2% loss in body fluids can cause a 20% reduction in physical and mental performance. So, just the simple act of keeping ourselves hydrated can have a huge impact on our fatigue and our quality of life.

When we look at the three causes, **physical, lifestyle and psychological**, they are all interrelated and cannot be isolated. The good news about this is that we can use this to our advantage. We can use small gains in each of these areas to create a “ripple effect”. Making a small change in one part of our life can influence other parts of our life that seem unreachable. Improving, for example, our movement can increase our energy levels and can give us more chance of doing everyday things more easily.

In the same way that we audit our financial spending, it can be helpful to audit our energy use. As selfish as it sounds, it is important to ensure that what we spend our energy on is for our own benefit. **Only by using our precious energy to look after ourselves can we add value to the lives of those around us.**

We are most aware of the lack of physical energy, so we shall start there. All too often, we continue a pattern of output of physical energy until we can no longer do so. That is the equivalent of spending each and every single penny of our income to the point of bankrupting ourselves. It doesn't make sense to do that. Just as we need to make better choices to protect our own financial situation, we also need to learn to look after ourselves first in energetic terms.

An energy audit starts by looking at those things we do regularly. Do we need to do them? Can we cut down? Do you *really* need to iron the towels? Do you *really*

need to clean out those kitchen cupboards? We all do things out of habit which waste away the energy we have. Be honest: what is your energy extravagance? With what do you struggle in order to maintain “standards”? Is it really necessary? Housework is energy-hungry. Can you afford the “mod-cons”? Washing machines dishwashers, self-driving vacuum cleaners can all save your energy (as can kids doing their own housework!!). Keep everything to hand. Storing the sheets in the bedroom they are used can be helpful. Remember, nobody has ever died with the regret that they didn’t do enough housework!!

There are other ways to save energy: using light plastic jars instead of heavy glass ones; preparing your shopping list so it is in the order of the way you walk round the shop, eliminating backtracking; consider buying prepared foods, salad bags, etc.

The next factor in fatigue is lifestyle. This is often the biggest single factor that we have control over and can improve fatigue. From conferences to self-management sessions in many places around the world, we have been told that taking more control of lifestyle choices has led to improved self-management which then leads to increased quality of life, which is exactly what we are after.

When we look at lifestyle, diet is important. There is an old computing term; **GIGO** (pronounced “guy go”): it stands for Garbage In, Garbage Out. Now this can be said for many aspects of life, not just computing. It can be said about the quality of our thoughts. It can also be said re our food choices. So, to move us away from the notion of fad diets, we are going to speak of food choices, as this has an enormous impact.

Keeping hydrated is incredibly important. There is a huge weight of evidence (albeit anecdotal) that tells us that itch improves when food choices improve. Eating as healthily as possible has a positive impact. We eat unhealthily for many reasons: convenience or laziness, not knowing any better, or just making bad choices. Whatever we have done in the past, it is so important to at the best we can.

Just the basics can make an enormous impact. Cutting out unhealthy snacks can help us physically as well as emotionally when it comes to fatigue. Sugary foods will give us an instant energy boost but then we drop very quickly afterwards as we seek more sugar. It is the same for carbonated drinks, etc. Eating these foods will deplete our energy. We can also feel low because we know we have made the wrong choice, meaning that we have doubled the negative impact on our energy levels with just one decision.

We know that eating the wrong types of fat is bad for us. We know it puts weight on (which doesn’t help our fatigue) and can contribute to other conditions, e.g. Non-Alcohol related Fatty Liver Disease (NAFLD). What some of us might not know is that the synapses in our brain (the bits which send out information along