

Fatigue Management



The Pituitary Foundation Information Booklets

The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families

The Pituitary Foundation is a charity working in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions, their family and friends.

Our aims are to offer support through the pituitary journey, provide information to the community, and act as the patient voice to raise awareness and improve services.

About this booklet

The aim of this booklet is to provide information about fatigue and how to manage this.

You may find that not all of the information applies to you in particular, but we hope it helps you to understand fatigue better and offers you a basis for discussion with your GP and endocrinologist.

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What is fatigue?

What is fatigue?

Fatigue is a feeling of physical tiredness and lack of energy. It is different from 'being tired'. It is complex, with a broad range of physiological, cognitive, neurological and emotional symptoms. The unpredictable nature of fatigue makes it difficult to manage, and can become worse with increased levels of physical, mental and emotional activity, which means stress on the body.

Mild, moderate or severe, the differing levels indicate the spectrum of severity and functional impact on patients. People who have pituitary conditions may experience stronger feelings of fatigue more often and with greater impact.

"Fatigue is the one symptom that affects my life the most. It's the symptom that stops me doing things I want to do and it is the hardest to cope with"
(Quote from a Helpline caller.)

Why can fatigue occur in pituitary patients?

Many of the hormones controlled by the pituitary gland play a role in energy production, such as thyroid, cortisol, growth and sex hormones. The aim of hormone replacement therapy is to mimic hormone production as closely as possible to replicate natural levels. Other things which may cause fatigue, that could be investigated, include a deficiency in Vit D or Vit B12 or if you have sleep apnoea.



Understanding fatigue - 'The human battery'

Everything we do, from the simplest to more complex tasks, requires energy. A drop in energy means that even minimal activity can lead to prolonged feelings of fatigue. It can be compared to having a 'human battery' that has developed a fault.

BUT, how we use the energy left in the battery can affect the symptoms of our conditions. It is tempting to do as much as possible while the energy is there and push past our limits - this 'flattens the battery' even more. When the battery has been flattened, there is no choice but to stop in order to 'recharge'. It is possible to avoid flattening the battery entirely by learning to manage activity and ration energy, allowing opportunities to build energy levels over time. If some energy is left in the battery, it will be used by your body to build up reserves for use with other activities.

So stop before the battery becomes flat, as it is more difficult to recharge, and will take longer.

Activity levels

With fluctuating levels of energy, it is tempting to carry on with an activity until we have no energy left, but this leads to a ‘boom and bust’ pattern emerging. Exhausted, the only option is to do nothing until we feel we have energy again.

Alternatively, by *always* doing very little as we try not to flatten our human battery, we are not allowing our bodies to build up energy reserves - the human body needs activity in order to produce energy. Over time, this can lead to a life that has no meaning. This may result in low mood and depression and our physical fitness reduces, resulting in weak muscles and deconditioned, stiff joints.

Energy is needed for all types of activity - physical, mental, emotional and social tasks, so it is important to become more aware of your everyday life, and how small everyday jobs can affect energy and fatigue. **Activity sheets** are a good way to start to understand how different tasks/activities need different levels of energy and these will be different for everyone. Also it is useful to know that some activities, whilst using energy also energise us, so are important. Eating, having fun, sleep, and achievements, whilst using energy also give us energy back. Let go of some of the ‘have to’ (stress, work, housework, paperwork) and try to create a good balance of activities.

Pacing

Look at your daily life and see where your energy is going each day - break down activities to make them more manageable and find areas where you

can adapt and change. This is known as **pacing**. Setting a **baseline** for specific activities is a good place to start. This involves trying to find a level of activity that can be managed without causing excessive levels of fatigue - a ‘middle ground’ between doing too much and doing too little. Pacing involves:

Planning

- can I break the activity into smaller/different stages?
- can I take regular breaks?
- can I time what I am doing?
- can I do the task differently?

Prioritising

- can I ask for help?
- do I need to complete the task/activity today?
- does this have to be done at all?

Perseverance

- how can I adjust to working to time, not how I feel?
- use your baseline on good and bad days to improve tolerances.

Grading

We use different amounts of energy for things we do, and some will take more energy than others e.g. dealing with stress, heavy physical activity and housework. Making small manageable changes to your activity levels is known as grading. There are various ways to grade, all of which will help preserve energy:

Time - the longer spent on an activity, the more energy will be used. Try setting a baseline for activities for 10, 20, 30 minutes and gradually increase the time.

Distance - useful for any activity which involves motion - walking, driving cycling etc. Stop before you complete the journey, rest and go back - gradually build up the distance covered.

Speed - reduce the speed at which you do things as this will preserve energy.

Strength - muscle bulk decreases through inactivity so try to maintain it by starting with light loads initially and slowly increase e.g. weight of a shopping bag, number of stairs climbed.

Resistance - reduce this as much as possible initially, as the more resistance to a task, the more strength and therefore energy is needed. So, walk/cycle on the flat not up a hill.

Rest - think about quality rest. How you rest is as important as the activity carried out, so consider mental energy as well as physical energy. For example, watching TV or reading are not really resting, as the body uses mental energy for both these tasks. Also, prolonged periods of rest leads to physical de-conditioning, needing more energy to start activity again. *Use rest as a PAUSE within activity.*

Complexity - Focus on one task at a time - the more brain processes that are required, the more

energy is needed, so keep it simple initially and build up. For example, make a sandwich and not a complicated meal, and for mental tasks reduce distractions as much as possible.

It is important to understand that grading activity is like a staircase not a slope - it won't be a smooth line upwards. Make each small increase not too different from your current level and take many small steps rather than one big one and give up.



How to approach activities

The tortoise and the hare - don't race to get to the finishing line like the hare and collapse in a heap, take the tortoise approach of taking small slow steps. It feels slower but a steady approach will get you to the end of the job.

Stopping point - don't wait for your body to tell you when to stop - you have gone too far at that point. Think of it in terms of the stopping distance a car needs to prevent it from hitting a



wall - you have a 'fatigue wall' which you need to avoid.

Combining activities - Maintain a balance between physical, mental and social activities and don't group activities of high demand together. Remember to rest in between to maximise the energy.

Rest

Relaxation and recovery are the purpose of rest. Stopping physical activity and relaxing are not the same thing, and negative thoughts inhibit the body's ability to recover. If you are feeling resentful and frustrated about the things you feel you *should* be doing or could previously do, you will not feel relaxed as your body will be using mental energy. Learning to balance our activities

with quality rest time is as important as the activity we do. Thoughts can be very powerful, so try not to think you are 'giving in' to your condition when you do rest. Try to find a way of introducing a gentle activity like yoga into your daily routine, as it relaxes both the mind and the body.

Initiating movement and activity after prolonged periods of rest and sleep can be difficult as the longer you rest the more difficult it will be to get going again. Our bodies are designed to move, so having smaller amounts of rest between periods of activity is better than taking long periods.

Your body will think it does not need to generate energy if there is no demand, so rest is a positive strategy that helps your body access its natural systems for regeneration and recovery.

Stress and relaxation

Stress is a normal part of life, but having a pituitary condition can inhibit the body's ability to deal with stress. Thus, it can make life more stressful, without the necessary resources to deal with it. The pressures of work, money, and family and health concerns are all stressful factors of life which few of us can escape from, so learning to manage better is the best alternative.

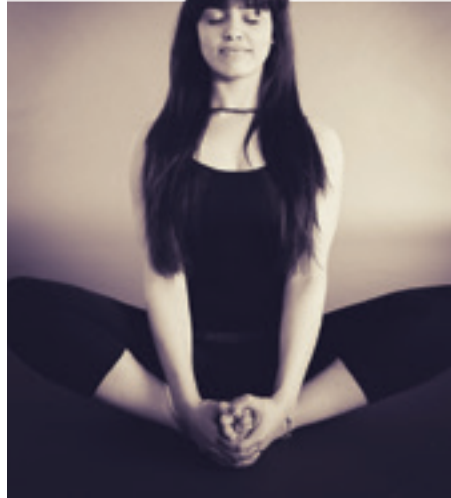
"I see all the things piling up that I feel I should be doing. I worry that I will never catch up. In the past I would be able to do everything with no trouble."

Managing stress will reduce the energy used by the stress response, leaving energy for other things. When we become stressed the muscles in our bodies become tense, which in turn uses more energy, leading to increased feelings of tiredness.

Relaxation is the opposite of stress, enabling you to feel more calm and confident, with reduced tension in your body and mind. Furthermore, relaxation is a skill which can be learned through practice.

Relaxation techniques

- **Simple breathing exercises** (abdominal breathing) - Breathe deeply into the stomach, hold for a few seconds then release.
- **Yoga** - Good for relaxing the mind, and gentle enough for the body, whilst maintaining movement.
- **Pilates** - Similar to yoga, helping to retain muscle tone and reduce stress and tension.



- **Massage** - An excellent way to relax the body and mind.
- **Mindfulness** - You can benefit physically, emotionally and mentally from learning mindfulness or meditation techniques. It can contribute to greater peace of mind, better sleep and more productivity.

• Relaxation CDs

These will need practice, and some may take time to learn, **but remember - any reduction in stress will contribute to a reduction in fatigue.**

Sleep

Difficulty with sleep is common for pituitary patients, but for many people feelings of fatigue are not improved by sleep. Although it may have helped at the beginning of your illness, it may not be helping now. Many patients have



- Loss of motivation and energy when awake
- Reduced enjoyment and satisfaction with life

It is possible to develop good 'sleep hygiene', which will help to balance the demands for energy you place on your body - this is more difficult if sleep is chaotic.

Good sleep hygiene techniques

- Gradually reduce the amount of sleep by getting up earlier (half an hour at a time)
- Avoid napping in the day if possible (it often makes you feel more groggy)
- Replace day time naps with quality rest
- Establish a routine - wind down before sleep- bathe, have a hot milky drink, read, use soft music and/or lavender in the bedroom
- Use bed only for sleeping - don't watch TV, use electronic devices etc. Associate bed with sleep, not stress or an activity
- Avoid stimulants at bedtime - caffeine, nicotine, alcohol
- Consider your sleeping environment - heat, light and sound all impact
- Aim to reduce anxiety - things often seem worse at night, so practice relaxation

the added complication that their sleep pattern has been disturbed for months or years prior to diagnosis due to hormone changes. A common myth is that if you sleep for longer, your fatigue will be 'cured', but this is not always the case. Think about how much sleep you needed to function affectively *before* you developed your condition. The more we understand our sleep difficulties and sleep patterns, the less anxious you will become about them.

If you are sleeping for 12 hours or more, yet still feel unrefreshed and fatigued, you may find it difficult to tell the difference between when you are tired from actual lack of sleep, and when you have actually exerted yourself too much. The consequences of too much sleeping may include the following:

- An increased need for sleep
- The body gets used to excessive sleep and late waking - night becomes day and vice versa
- Inability to concentrate properly - 'brain fog'

These may seem like common sense, but the reality is, we tend not to follow them.

Memory and concentration

We often focus on the physical energy we are using and forget about the internal demands for energy, including thought and mental processes and you may be as distressed about your mental difficulties as by your physical limitations.

Pituitary patients experience difficulties with mental fatigue leading to memory and concentration problems. Energy is needed for brain activity, and as fatigue increases this affects brain processes = 'brain fog'. Concentration is our ability to focus our thinking, but due to fatigue you may have difficulty filtering out necessary information from other thoughts or distractions from within the environment. This impacts on our ability to concentrate.

- Physical impact - significant problem as patients
- Emotional state - fear, distress, anxiety, anger all have a negative impact, whilst being calm and relaxed enable greater concentration and a positive attitude
- Commitment and enthusiasm - decide to do something, and try to focus on enjoyable activities as it will be easier to motivate yourself



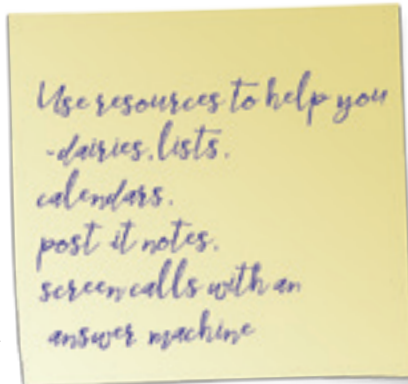
Learn helpful strategies to manage your mental energy

- Skill- try not to take on new tasks, as they take more energy and concentration to learn
- Don't overwhelm your senses - more energy is needed to manage this which will reduce your ability to concentrate

- Don't compare how you are now to previous levels of ability
- Apply grading to mental tasks - set smaller goals, prioritise, plan ahead and take regular breaks. Focus on one task at a time and change activities regularly

- Consider your environment - are there light, heat noise distractions or constant interruptions

- Use resources to help you - dairies, lists, calendars, post-it notes, screen calls with an answer machine
- Rehearse and repeat things you want to remember
- Accept help from family and friends



Physical exercise

Exercise can be treated like any other physical or mental activity as it can be taken in a slow and graduated way. It has many benefits, improving your overall fitness, maintaining muscle strength and bone density (important for pituitary patients) and preventing heart disease. In addition, it will help to lift your mood, reduce anxiety and depression and help concentration.

You may need to prioritise valued activities. Self-care and work-related ones are often prioritised over leisure activities by people with long-term conditions, but engaging in leisure and social activities is important for physical and mental well-being. Making a decision to accept help for essential tasks, and not criticising yourself if planned activities need to be altered or cancelled, will help to develop a change of attitude, leaving you less tired, as you will not be using negative mental energy. This additional energy can then be used constructively to engage in activities you find pleasurable, which will in turn energise you.



Thoughts and feelings

Pituitary conditions create changes in your life which are stressful and upsetting, and they mean adjusting to a 'new life'. This can be difficult, and feelings of frustration, anxiety for the future and anger are all understandable and reasonable feelings. You may experience the loss of employment, social activities and/or your previous role, particularly if you have to restrict things you have always done.

As discussed, negative emotions use a lot of the body's energy, so it will be beneficial for you to change from worrying about your illness and fatigue levels, to taking a more positive attitude. Allow yourself flexibility in relation to what you achieve in a day, practice learning how to relax and conserve energy, and don't self-criticise if you have to change your plans. Shifting priorities within your personal life will help to manage your fatigue, for when energy levels are low choices have to be made about how to use energy efficiently.

Don't underestimate the power of thoughts and feelings. As much as negative emotions rob us of energy, a positive, calm outlook will help sustain energy levels and improve your quality of life.

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is a type of therapy that can help you manage fatigue by changing the way you think and behave. It's often used as a treatment for a range of health conditions.

CBT aims to help reduce the severity of your symptoms and the distress associated with fatigue. It works by breaking down overwhelming problems into smaller parts, and by breaking the negative cycle of interconnected thoughts,

feelings, physical sensations and actions.

Ideally, your CBT therapist will have experience of dealing with fatigue, and treatment will be offered on a one-to-one basis. The treatment will be tailored to your needs and may include some of the following:

- helping you accept your diagnosis
- challenging feelings that could prevent your symptoms improving
- trying to increase your sense of control over your symptoms

The use of CBT doesn't mean fatigue is considered to be a psychological condition. It's often used as a treatment for a variety of long-term conditions.

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A patient's experience of **fatigue**

'Feeling very tired' just doesn't explain how much I was affected by fatigue before, during and after my diagnosis for Cushing's. It took several years and eventual self-diagnosis before I had surgery to remove my macroadenoma, but by that time I was constantly exhausted. I could not walk more than 50 yards before having to stop and rest, my sleep was disturbed so I was not getting good quality rest, and I was struggling to cope with my life as a wife, mum and employee.

Consequently, by the time I had my surgery, I had literally nothing in reserve - no energy to draw on to help me cope with weeks of tests, transsphenoidal surgery or my new steroid-dependent life as a pituitary patient.

Once discharged from hospital I found I could not stay up all day. The need to rest and do nothing was overwhelming, and the progress so slow that I wondered if I would ever feel in control again. My daughter was only six years old, so not being able to join in with her games, bike rides and general fun was heart-breaking. I had always enjoyed an active and fit life, but was reduced to watching from the side-lines as the world carried on without me. My husband had to cope with me coming to terms with my condition and on-going fatigue, whilst also 'running the show' at home, as my energy was so restricted. I also needed to take seven months off from work, as my job was mentally and emotionally demanding - energy I just couldn't spare. When I did eventually return, I could only manage a two day week - something my employers did not appreciate.

In deciding to take back some control of my life, I began to keep a diary. As progress was so slow, it was difficult to see any positive changes on a day-to-day basis, but by comparing weeks, my life looked a little brighter and motivated me to learn more about fatigue and how to better manage it. Over a period of four years, I resigned from my job, retrained for another profession in the healthcare sector, and discovered so much more about fatigue - putting into practice what I was learning. I began to 'pace' myself, learned what was important for my long-term health, and redressed balance in my life. I learned about the importance of relaxation (starting yoga seriously for the first time ever), the importance of 'doing a bit and leaving a lot', and most importantly, leaving enough energy for the nice things - time with my family, afternoons out with friends and treats for myself. Even now I ensure I enjoy a massage regularly and happily book spa days for me to 'recharge' my batteries.

Life is tough for pituitary patients, so explore possibilities, see what works for you, but above all else - make it count. I consider myself to have 'come back from the brink', and whilst I still have days when I have reduced energy and struggle to function, I stick to my management plan and rest appropriately until I feel like my usual self again.

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Join the The Pituitary Foundation today and enjoy the benefits of membership!

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- ✓ Become an important part of the only charity in the UK providing support to pituitary patients.
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Helpline

Monday - Friday 10:00am-4:00pm
0117 370 1320

Endocrine Nurse Helpline

available scheduled hours
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Website: www.pituitary.org.uk

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The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues.

For more information please visit our website, or call our Helpline.

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Working to support pituitary patients, their carers & families