

Energy limiting conditions:

Living With Uncertainty

and long-term effects after being unwell



Developed and delivered by



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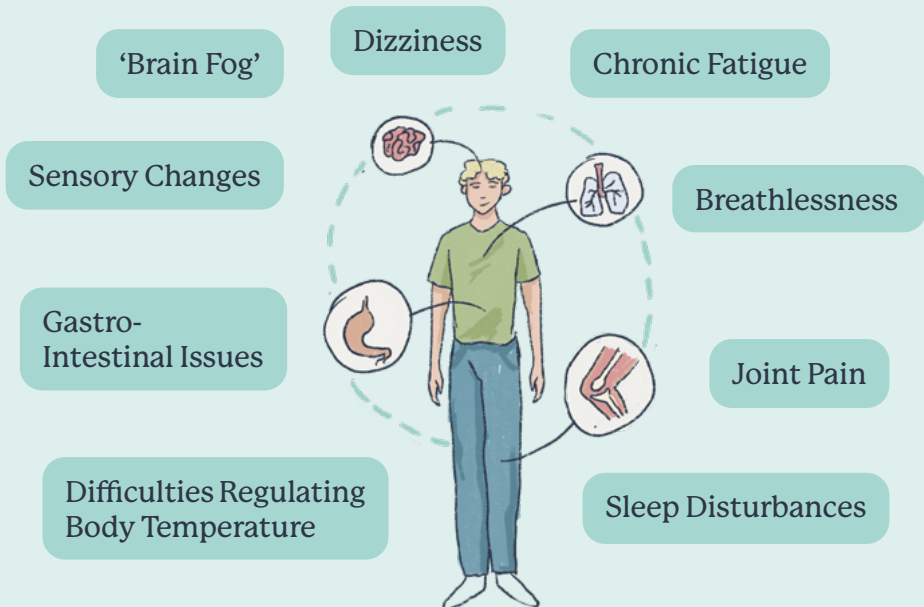
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What is an Energy-Limiting Condition and Why Did I Develop One?

As the name suggests, an energy-limiting condition is an umbrella term for several illnesses that affect the way our bodies creates and uses energy.

These include conditions such as Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (M.E./C.F.S.), Fibromyalgia and 'Long Covid'. Whilst scientists and researchers are unable to give a full explanation as to how they start, it is largely felt that these conditions are triggered by a viral infection which causes the body to remain in a state of persistent malaise.

This malaise can describe a variety of symptoms including:



The experience of living with an energy-limiting condition is unique to each individual however symptoms can fluctuate by the hour, day or week which can make life feel very unpredictable and challenging to cope with.

Whilst the scientific and medical community largely agree with the idea that energy-limiting conditions have a viral origin, other factors that increase our risk of developing one have also been identified including gender, stress, trauma and exposure to certain toxins.

These conditions are also very good at going 'under the radar' as they are not detectable on blood-tests, x-rays or CT/MRI scans, and a medical explanation cannot be reached in the same way that other illnesses are defined. Understandably, this leaves patients and families feeling extremely frustrated.



Energy Limiting Conditions: Living With Uncertainty

Currently, our understanding of energy-limiting conditions such as Myalgic Encephalomyelitis, Fibromyalgia and Long Covid are limited. Research is ongoing to try and work out their causes and to identify curative treatments however no breakthroughs have yet been made.

Whilst some people experience a mild, short episode of illness after suffering from a virus, we know that more complex and sometimes enduring health conditions can develop, and this can be very challenging to live with and have a significant impact on people's lives.

Diagnostic tests can be useful for ruling out particular conditions, but in cases of energy limiting conditions it is not unusual to find that a specific medical explanation cannot be reached in the same way other illnesses and conditions are defined. Understandably this leaves patients and families feeling extremely frustrated.

Some patients report feeling that their symptoms are not taken seriously by a range of people including their families, workplaces or health care providers. People can feel they are not believed by doctors or loved ones, and that their legitimate concerns are dismissed. This can lead to increasing feelings of isolation at a very worrying time.

“What is happening to me?”

“Will I ever be back to normal?”

“Is this all in my head?”





..... “Is this going to get worse?”

There are many questions that are present in the minds of many people suffering with the long-term effects of energy limiting conditions and for their loved ones.

Clinicians may not be able to provide definitive answers which can be anxiety provoking and extremely frustrating. Many people fear they will not return to how their lives were before becoming unwell.

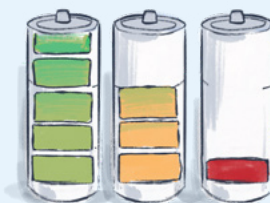
Physical Health Conditions and Mental Health

It is normal for physical health conditions to affect an individuals sense of wellbeing.

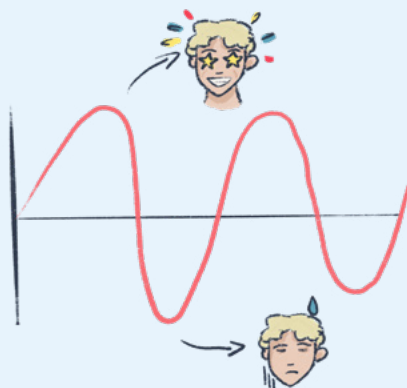
This is true for energy limiting conditions and other conditions as well. This may affect your quality of life and the ability to work. Many people notice they are feeling worried about becoming re-infected, or have concerns about taking up the offer of vaccinations. It can be very unsettling not to know how long symptoms might last or when a return to a normal way of life can be expected.

Symptoms of anxiety or low mood are normal when we face significant change or threats to our health, wellbeing and our lives as we know it. Some individuals may have traumatic experiences of being ill. People can be living with symptoms of pain, fatigue, cognitive changes, and sleep disturbances. Previous mental health and physical conditions may have flared-up again after a period of being settled, and the impact of living with uncertainty can be exhausting.

We know that to understand someone's health condition it is not simply the biological factors that need to be considered, but also the psychological and social factors.



Living with an energy limiting condition often impacts our emotions, and we can experience highs and lows in our mood or anxiety, as symptoms fluctuate.





Starting to discover that your body isn't recovering as you had expected, or that it appears your experience is different from others can be frightening. Whilst research is very welcome and our knowledge of these conditions will increase over time, knowing that medical teams are still in the process of learning how to assess and treat your concerns can be confusing, frightening, and shocking, and can leave some people feeling numb.



Uncertainty and Living with an Energy Limiting Conditions

People who experience prolonged and persistent symptoms may feel uncertain about their future.

Understanding why you are feeling this way, and knowing what you can do to cope, can help you feel more confident in managing your symptoms.

Difficult thoughts arise because the mind is trying to cope with the shock of becoming unwell and to understand what has happened. Alongside these thoughts you may notice feelings of anxiety, loss, anger or sadness. Research has not yet identified any medicines to treat the persistent effects of energy limiting conditions and that can add to the sense of frustration and fear.

Sometimes we try to cope with feelings, such as anxiety about the future, by worrying – by planning and preparing for various possible worst case scenarios. This kind of planning and focused thinking usually helps us to feel better and feel more in control, like planning out a route to a new destination, or budgeting our bank accounts.

However, when we are dealing with uncertainties, worrying or planning doesn't actually reduce the risk of possible negative outcomes. This means that anxiety persists even after countless nights of problem solving, planning or worrying – so we still experience that intense anxiety, alongside a restless night's sleep.



Sometimes we think that we'd be better off knowing things, good or bad; we imagine that this would make it easier to manage, rather than living with the uncertainty or not knowing.

Since learning that living with energy limiting conditions is enduring and complex, you may find that your life has changed in unexpected ways. You may feel uncertain about these changes and you may worry about what life is going to be like. You may

feel unsure about many other aspects of your life. This is called living with uncertainty.

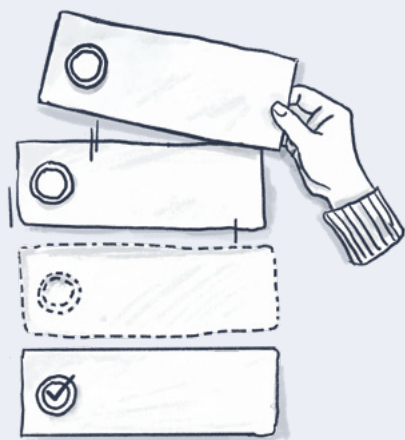
A general feeling of uncertainty in your daily life is common for people who live with a chronic or enduring health condition, that is difficult to manage and understand for ourselves, society and health systems.



Top Tips for Living with Uncertainty

When you are living with uncertainty, you may feel that your whole world has been turned upside and that you have lost your sense of control.

These feelings can be overwhelming and as a result you may find yourself getting less enjoyment from things and stopping yourself from doing things that you would usually do. Uncertainty may be a part of your life now, but it does not have to take over your life. There is no right or wrong way to feel about living with uncertainty. However, there are ways to help you cope with the challenges it brings and that can help you to lead a quality of life that is meaningful for you.



What can I do?

1. **A sense of routine, structure and consistency in our daily lives help us to feel contained and in control.**

You may find your usual lifestyle has changed a lot since becoming unwell or living with unpredictable symptoms. Wherever possible, try to keep a familiar routine to help maintain a sense of normality, even if you are doing that routine differently, to pace your activities.

2. **Make tasks or jobs easier by breaking them down into small, achievable steps and ask for support from other people if you need it.**

When we are worried or overwhelmed, it is very easy to become focused on these intense feelings and before we know it our attention is captured! This can make it much harder to do the thing you needed or wanted to do. Try not to put off or avoid the things you need to get done and reward yourself for your achievements whenever you can.

3. At difficult times it is important to keep a sense of achievement and enjoyment.

Make time to connect with the things you enjoy. You may have to think creatively about how to maintain hobbies or interests when your physical health has changed. Staying connected in the smallest way to the things that are meaningful can help to reduce stress levels and lift your mood.

4. Thoughts and feelings continually change but no matter how bad they get, they cannot harm you.

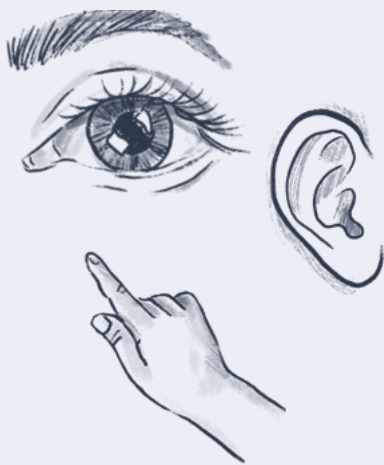
Sooner or later they will change or pass. Distress is normal and it is OK to feel this way. Try choosing to step back from thoughts and feelings, watching them come and go – this will help prevent them from taking over. Practice mindfulness skills to develop this skill of ‘watching thoughts’ rather than being dominated by them.

5. Events, feelings and sensations can trigger automatic habits of thinking, such as “I can’t cope with this”, “If I was in control things would be easier” and may lead to you feeling worse. Tell yourself ‘this is the worry talking’ and ‘searching for certainty may not be helpful for me to focus on right now’.

By becoming more aware of your thoughts, feelings, and bodily sensations, from moment-to-moment, you can become aware of what is helpful for you and what isn’t. This awareness can give more choice to respond in a way that is most helpful for you, rather than staying in ‘auto-pilot’ mode.

6. Try to notice what is happening in the world around you (...simply list 5 things you can see, feel, hear...), and take a break from what is whirring away in your mind.

It can often be easy to forget to appreciate the small things when we are surrounded by uncertainty. Stepping back from the distressing thoughts and feelings can help you to make the most of what you are doing right now.



7. **Think about the things that you value and that you feel are important.** These values are like your compass; your guide for what you focus your attentions and actions on. It is easy to lose sight of the things that give you a sense of purpose when you are stuck in uncertainty. By letting go of the worries you can't control, you can put more time and energy into the things that are meaningful to you.

8. **Set yourself goals to work towards something meaningful.** When your future feels uncertain, often people stop making plans or setting themselves goals for fear of “tempting fate”. However, having something to work towards and look forward to is an important part of feeling good. This can help you to feel motivated and give you a sense of achievement. Remember to take baby steps! Small changes over time will make a big difference.

9. **Practice self-compassion.**

This involves being aware of our own pain and suffering, and understanding that while feeling this pain is hard, it is a normal human experience. Directing feelings of kindness and care towards ourselves, and focusing our attention and energy on how we might alleviate our pain, are important parts of self-compassion.

Can you try talking to yourself the way you would a loved-one, who is struggling with the same feelings? How can you create a sense of comfort and safety for a few moments in your day? Try wrapping yourself in a soft blanket, spending some time stroking your pet dog or cat, or try pleasant smells or tastes that remind you of a fond memory - these acts of self-compassion and care can bring great benefits for our mental health and well-being.



Offers of psychological support aim to help people put this advice into action. We are not suggesting that your symptoms and experience are not real. We understand that people's symptoms and suffering are genuine, and the impact they have is complex and wide-reaching. We offer these psychology services because we know that these approaches have helped others to feel more in control and to move towards the life they want to lead.



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resources, courses, helplines
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Delivered to you by Aneurin
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Managing the 'Control' Dilemma

We often try to control, get rid of, or fight our difficult thoughts or feelings (e.g. trying to find answers to questions such as “will my symptoms get worse?”, “will they come back?”, “what will happen to me in the future?”).

Searching for definitive answers or pushing these thoughts away can help in some circumstances, but thoughts and feelings concerning your health and future often involve no obvious “solution” or “answer”. These things really matter to you and these thoughts and feelings are likely to reappear no matter how many times you push them away. When our usual ‘control’ strategies don’t work this can leave us feeling even more distressed. Using alternative strategies to manage difficult thoughts and feelings can be very beneficial.

When you are feeling overwhelmed by demands, you can categorise these into ‘things I can’t control’ and ‘things I CAN control’ (see the example on next page). Acknowledge that it’s difficult to live with stressors outside of your control, and allow yourself to let these thoughts pass. **Then place your energy and focus on the things in your life that you can control.**



Things I cannot control	Things I can control
What my GP says in our next consultation	Being open with my doctors about how I feel and what I'm most worried about
Not being able to drive at the moment	Helping my son with his driving test by arranging an instructor and going over theory work
Not being well enough to work	Pacing my activity levels so I can assess what work I can do, and how much I can do
Not having enough energy to go to the shops	Ordering an online food shop if I feel too tired to go out
The kinds of thoughts that pop up in my mind	Taking deep breaths when I feel overwhelmed

Giving yourself permission to let go of the things you can't control can help you feel more confident and more able to manage, even if it won't get rid of the worries.



Tolerating Uncertainty with A.P.P.L.E.*

A for aware:

Be aware of, and notice the need for certainty as it comes up in your mind.

P for pause:

Notice the impulse to 'fix' the uncertainty and try not to react to that impulse... Just pause, and breathe.

P for pull back:

Tell yourself... "this is the worry talking" "certainty may not be possible for me right now" "will focusing on this worry be helpful or unhelpful for me right now?"

L for let go:

Let go of the thought or feeling. Tell yourself it is only a thought or feeling. We don't have to believe everything we think. Thoughts are not statements of fact (although we forget this and sometimes treat them that way!). They will pass. You don't have to respond to them. You might imagine them coming and going like clouds in the sky, or like passing cars along the road.

E for explore:

You can explore the present moment, because right now, in this moment, you are here. Notice your breathing, and the sensations of breathing. Notice the ground beneath you, look around you and notice what you see, what you hear, what you can touch, what you can smell. Right now. Then shift your focus of attention to something else – maybe carry on what you were doing before you noticed the worrying thought, or do something else, that you feel is a helpful focus for your attention and actions – and give it your full attention.



Visit www.getselfhelp.co.uk to learn more about these techniques and others, such as 'STOPP: CBT in a nutshell'. These tools are also available as an App, which can teach you how to use them in more detail, and you'll also have them at your fingertips when you need it most.

STOPP

Take a breath

Observe: What am I thinking? What am I reacting to? What am I feeling in my body?

Pull back: Put in some perspective. See the bigger picture. Is this fact or opinion? How would someone else see this?

Practice what works: What's the best thing to do for me, for others, for this situation?



Some people find it useful to have this STOPP card in their wallet or on their phone, so they can follow the steps in moments when they are feeling overwhelmed.

Sources of Support

If you would like further support for coping with uncertainty and the impact this is having on your wellbeing, you can find this from the following services:

- **Melo Cymru** is a local wellbeing online hub and offers advice, access to group support, educational courses, and self-help resources to help you look after your mental health and wellbeing. Visit: www.melo.cymru to find out more about local courses and wellbeing resources
- If you require urgent support, please contact **NHS 111 and select option 2** - this is a 24 hour mental health helpline ran by healthcare professionals who are skilled in supporting people in emotional distress. Alternatively, you can contact the **Samaritans on 116 123**.

- Apps: Search for these apps with your smartphone or device. They are NHS tested and recommended and can help us cope with stress, anxiety, sleep difficulties and improve wellbeing:



Calm

An app for sleep and meditation



The Stress & Anxiety Companion



This leaflet has been developed by the ABUHB Symptom Management Service. If you have any questions, concerns or feedback about this leaflet then please email us on ABB.SymptomManagementService@wales.nhs.uk

