

Question & Answer capture from 'When a loved one has fatigue' event held on 25th October 2023

This isn't a verbatim capture, I've summarised some points and turned some discussions into more explanatory paragraphs in order to help them flow well when read in written form! I hope you find it helpful.

Question: We've been going to bed later at night and sometimes sleeping in. You mention sleep hygiene. Is it really important to have an early bedtime?

Answer: It doesn't have to be a very early night! But our bodies love predictability – so I'd suggest the more important thing is to aim for a consistent bedtime. Whatever time you're going to bed and rising, try and make it more or less the same times each day. This helps your body to establish a lovely predictable pattern which is helpful for so many reasons.

Linked to this, it's been shown that it can be helpful to reduce our access to artificial light after around 11pm at night, if possible. So, it can be beneficial to try to get to bed with lights off ahead of that time, and then keep any artificial light very dimmed (if you need to get up to go to the toilet in the night etc).

Finally, it's helpful for people to consider how much sleep they're getting. If your loved one is sleeping more than around 9 or 10 hours a night this might actually be TOO much. Certainly once their journey has been underway for a while and they've achieved some stability. Rather counter-intuitively I've seen people feel better, not worse, when they shorten the amount of sleep they have and bring it in line with the recommendation of 7-9 hours a night.

Note: earlier in their journey your loved one might need more sleep while their body is performing important healing and restorative functions. I'm skilled at helping people identify when this period has passed, and that reducing their sleep is now going to be helpful.

Question: Several doctors that I know have mentioned that fatigue is psychosomatic – and I do find myself wondering how much mindset work can help. What are your thoughts on this?

Answer: I'm delighted that this has come up during the Q&A because I felt I couldn't give it enough time during the main presentation, due to having so many other things to cover.

I think this is a hangover from the views that formed decades ago when these chronic fatigue type journeys started to get more attention. And some medical experts still share this view. However, in my view it very much isn't only a psychosomatic issue.

It's far more complex than that – although mindset does play a part, it's far from being the only thing to address. I suggest that people look at fatigue as a 'whole system' issue to be

resolved. That means physically, but also cognitively and usually requiring lots of mindset work and nervous system attention...all of these things play a part.

There's something about chronic health conditions – particularly fatigue – that, over time, get our systems into 'threat' mode. They start to over-protect us and perceive most things as a danger and so lock us down in order to try to keep us safe. This can, at a cellular level, put our body into a type of survival mode where it forgets how to thrive, even when the physical issues have been resolved and there's nothing holding it back.

And so, some work to persuade your loved one's system to feel safe again and able to switch back to this 'thrive' mode is usually required. This can be via somatic work, brain training, therapy..whatever works best for that person.

The trouble is that people then think that doing that work earlier on will have just the same positive effects, and therefore that's all there is to it! I think this is where the medical world's view that it's solely psychosomatic stems from.

The very important point to make, is that there is usually a lot of physical healing that has to happen first, as well as a certain amount of careful pacing in order to get your loved one's system into a steadier predictable state. Only then can it be persuaded that things are indeed safe, and for it to feel comfortable accepting whatever help is being provided to get it back thriving again.

A complex topic to discuss briefly but I hope this helps!

Here are some interesting links. Please don't take it that I fully support/agree with everything mentioned in these articles. I share them to provide helpful starting points around some of the theories that I think could explain what's going on to some level. However, these health challenges are so complex and no one yet *really* understands truly what is going on under the surface. If they did, we'd have more answers and successful treatments. But let's hope we get there one day soon:

An article by Dr Myhill about Mitochondrial dysfunction in ME/CFS patients:

<https://pubmed.ncbi.nlm.nih.gov/19436827/>

An interesting explanation of the Cell Danger Response:

<https://www.sciencedirect.com/science/article/pii/S1567724919302922#:~:text=Mitochondria%20regulate%20the%20CDR%20by,cellular%20health%20to%20environmental%20health>

Question: I feel that I'm often holding the hope for my daughter – it's almost as though she feels she has to manage MY expectations. For example, she sent me a link to an article saying that only 95% of fatigue patients recover. It's very difficult and I don't know how to help her change her mindset.

Answer: This follows well from the question and answer above! If your loved one's system is deeply in threat/danger response mosw, then it's much more inclined to believe information

that supports the worst case scenario, rather than accept and believe the more hopeful messaging. Sadly this then further enforces the threat response, and has a negative effect on them emotionally and physically. It's important to try to get this negative spiral moving nicely in a more optimistic direction.

My suggestion is that you and your loved one look for, and talk about, the success stories that are out there. Spend time on the inspirational content that's online – hearing about real recovery stories is giving your loved one's system factual information that it can't dismiss quite so easily. Don't push her to watch these things, but do gently encourage her to. Here are some suggested resources:

<https://www.youtube.com/@RaelanAgle>

<https://www.youtube.com/@HealwithLiz>

<https://www.youtube.com/@suzyboltyogaforlongcovid> (also a great resource for helpful calming techniques! Suzy and I share a lot of mutual clients ☺)

Let your daughter take the inspiration from these stories, but do remember that what helps one person won't necessarily be so helpful to her. But the message to take away is that it IS worth continuing to figure out the helpful blend of approaches for her, because many other people have found theirs and have then achieved wonderful improvements.

Question: I've been impressed by what I've heard you talk about this evening. My son has fatigue – if he was interested in coming to you how do you help?

Answer: First of all, I don't do 'one size fits all approaches' – as discussed, everyone has to identify their own way to get through these sorts of health challenges. However, I do start most people on my Life Rescue Framework, which focuses our initial discussions around the five fundamental areas that I believe anyone with fatigue needs to master. I don't talk about this framework in much detail publicly because of course it's my intellectual property!! But it covers many of the things we've talked about tonight: mindset work, energy management, self care, getting our bodies into a healing state, and understanding the importance of accepting what's going on – while staying hopeful and determined to get better!

How I guide each person through this framework differs from person to person. I often say that I get into their life with them! Because fatigue impacts every person in a unique way, and they need to figure out how to adapt these fundamental areas into THEIR life and specific situation.

Once I've got them to a place where they're coping much better, life feels easier and their symptoms are consistently lower-level, then we move on to my Life Restart Framework which is where we start to talk about what will really help their recovery move forwards.

But we have to start with those important basics! A very important point to make is that your loved one can't outsource their recovery to others. I see people who have spent lots of

time, money and energy on lovely treatments and approaches – but they haven't mastered the basics. And so their system just isn't ready or able to receive the benefits of these external measures. Start with the basics, get into a steadier state, start to feel hopeful about the future again...and THEN explore the exciting boosting options! Here's a blog I wrote about this a couple of years ago: <https://www.pamelarose.co.uk/post/outsourcing>

Other helpful topics that were discussed:

Cold water swimming – this can be very calming to our nervous system (if it can be tolerated!). Rather counter-intuitively it doesn't stimulate our stress response, it calms it.

If your loved one can't tolerate, or doesn't have the energy for, cold water swimming then similar benefits can be achieved by splashing their face with cold water, or rolling an ice roller onto their skin (a Pamela Rose tip!). Here's a link to buy online: https://www.amazon.co.uk/Teenitor-Muti-Purpose-Preventing-Migraine-Puffiness/dp/B07PFG7GNJ/ref=sr_1_5?crid=3S6SPJBLF3XKV&keywords=ice+roller&qid=1698333078&sprefix=ice+roller%2Caps%2C111&sr=8-5

Other ways you can calm and heal the nervous system:

Spend time in nature

Spend time with pets

Breathwork (this one's great: <https://www.youtube.com/watch?v=JfYqWSAMCg&t=309s>)

Humming (tones the vagus nerve)

Singing (also tones the vagus nerve)

Meditation

Spending time with people we love

Mindfulness

I encourage you to make time to do a range of these things just as much as you encourage your loved one to! As mentioned in the presentation, you need to keep yourself healthy and well too.

Medical interventions

In my presentation I mention that fatigue challenges differ from many other serious health issues due to the lack of treatment approaches from the traditional medical routes. That said, there are things that medical experts can and do prescribe and so it's certainly important to explore this thoroughly.

I'm not a medical expert and so felt it was important not to discuss this at length but the medications that were discussed included:

Antihistamines (very specific types)

Probiotics

Melatonin
Beta blockers

We also talked about Dr Glynne – an NHS and private consultant in the UK. In my view, he's the best there is! His website is: <https://thephysiciansclinic.co.uk/physician/dr-paul-glynne/>
Please do mention me if you contact him! He sends many of his patients my way, and has seen first-hand how helpful it can be for them to access the type of help and support I give.

Research:

Serotonin research mentioned: [https://www.cell.com/cell/fulltext/S0092-8674\(23\)01034-6](https://www.cell.com/cell/fulltext/S0092-8674(23)01034-6)

Vagus nerve research mentioned:

https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4479598

ME/CFS research study to explore genetic link: <https://www.decodeme.org.uk>