

My Long Covid recovery journey, and the tools I used.

To all who it may help

I realise we are all on individual health journeys and at different stages along those journeys. This is my story, perhaps some of it resonates. My hope is that it provides a practical toolkit that may aid others to heal or find that missing piece to their own unique recovery puzzle. Whilst I am a doctor, this is not medical advice. In fact, I don't think Western Medicine has the answers to Long Covid yet, (or much of a deep grasp of many of the chronic fatigue conditions). This is simply my journey including tools I found useful from my own research into many modalities.

These pages may seem like a lot of information to absorb, take it at your own pace.

Firstly, I realised (and I hope you do too) I/we must have immense **inner strength**.

Finding myself with this largely unknown multi-system illness, with virtually no medical treatments available, initially gaslighted by medics, poor healthcare support, often misunderstood by friends/family/employers/wider community. Life had changed so drastically for me; one minute I was leading a full active life 'in my prime', the next I had disabling fatigue and brain fog, to the extent it made me housebound, unable to care for my child and go to work. It was an isolating, scary place, having this new mystery illness which rendered me housebound, feeling like I had dementia, with no idea if I would recover, and no treatments in sight.

Living and coping daily with that difficult experience made me realise how strong I was. I found it empowering to have the awareness of this strength. This strength/deep-rooted courage provided a solid base on which to build recovery and maintain the belief/hope that I would recover. I believe keeping hope alive is critical to recovery.

My journey with LC:

- **Autumn 2020 – acute Covid infection**– no chronic symptoms, no long covid
- **2 covid vaccinations Spring 2021** – moderate Long Covid started: moderate fatigue, palpitations, shortness of breath, intermittent dizziness. These symptoms didn't resolve, but they were not yet as debilitating to my overall life. I was still able to go to work part-time and look after my child, slow walk to the village centre (10 min walk) but not much else.
- **Virus/possible Covid - Autumn 2021:** - ongoing severe Long Covid that 'floored' me:
 - **Severe fatigue** – housebound, barely had the energy to cook my own lunch.
 - **Severe brain fog** – couldn't follow sentences, couldn't construct sentences, couldn't follow thoughts through. 'Cotton wool' brain.
 - **Extreme sensitivity to sound, and light and temperature.** I couldn't tolerate background music or people talking anything other than a slow, low whisper.
 - **Hypothermia** - I struggled to get warm even wearing 5 thermal layers. A hot bath was often the only way to get relief.

- **Gut issues** – I was constantly extremely bloated (like I was pregnant!), it felt like my digestion had stopped working and I was unable to absorb any nourishment. This seemed to be triggered by pretty much all foods.
 - **All hormones felt in ‘disarray’**. (This has been confirmed in a recent study from Harvard, that LC affects hormone cascades as well as the immune system).
 - Such as the **insulin hormone** – my **blood sugars** were fluctuating wildly, and I couldn’t control them – I’d feel strange/weak (hypoglycaemic symptoms) before eating but then also hot and dizzy after eating and have to sit down.
 - **Dizzy often** – my BP was very low 85/45, pulse rate low 45. I saw a Cardiologist who thought my body had gone into the ‘freeze’ state of ‘fight/flight/freeze’ (the Sympathetic nervous system) and was stuck there. There was no medical treatment for this. It’s basically a primeval reaction of mammals, such as a Gazelle being chased on the savannah by a Lion, and they play dead to stop being eaten by predators. Except I wasn’t a Gazelle in Africa, I was a woman in her prime with a body playing dead and because it’s under the control of the autonomic nervous system, it’s not a conscious decision and you can’t snap your body out of it. Its running on automatic and there is currently no medical way of curing it. Doctors often call this deranged autonomic nervous system ‘**Dysautonomia**’. It explained a lot of my other symptoms too, such as bloating, deranged hormones, ineffective immune system, hypothermia, as these aspects of the autonomic nervous system don’t work when the body is stuck in freeze mode.
- Spring 2022 – I was also diagnosed with a **new autoimmune disorder** – thought to be triggered by Long Covid. The usual medications used in people without Long Covid have not worked for me, but interestingly, it now seems to be improving (with a lag time) as my Long Covid has improved.

Functional impact of Long Covid:

Unable to work. Obvious financial implications, but also social, and psychological impact of not being able to do the job I love.

Social life – seeing my friends is a big part of what I love about life, but sadly I found this one of the most fatiguing activities. So for many months I couldn’t join in/meet up or even invite friends over for cuppa. After 5 mins it felt too much and I’d have to go and lie down.

Unable to look after my 3 year old. He was in 5 days/week childcare, and when my husband was abroad (he works abroad for 3 weeks at a time regularly), aged grandparents came to help at weekends, and I needed babysitters to help with bedtime. This felt the most crushing, that I didn’t have the energy to put my child to bed (let alone attend to the rest of his day-to-day care). I felt like so much had been taken away, and on my worst days my narrative was that ‘I couldn’t even be a Mum’. Unable to carry out this deep maternal instinct was devastating.

Recovery

It’s been 2.5 years since I was at my worst. It’s been an undulating journey, gradually improving over that time, using the techniques and tools in this resource. By the end of the first year, I was about 60% improved, the end of the second year took me to 90%.

I’m pleased to say I’m now back to regular jogs with the dog, working my part-time job (and increasing sessions), river swimming, weekly badminton, gym, yoga, and thankfully, caring for my child. I’ve just climbed Snowdon in the rain and wind and dark.

My sincere hope is that by sharing the tools I used, you might find the missing piece to your recovery puzzle and get your active full lives back too.

This is my 'Recovery Blueprint'.

I've gathered the tools into 6 areas.

I believe each one of these areas is needed to heal, like a jigsaw puzzle. Some were more helpful/needed at the beginning, some at the end. (I've written them in the order that resonates with me, but I imagine different elements will speak to different people at different times.)

1. Regulating the Nervous system
2. Nutrition
3. Sleep
4. Hormones
5. Exercise
6. Healing mindset

1. Nervous system regulation

The first main thing that helped was to calm my whole nervous system to allow my body to start to heal.

My aim was to reduce the Sympathetic Nervous System or '**fight/flight/freeze**' response (in my case freeze, although I understand a lot of people with LC are in the fight/flight part and the ethos is the same). Instead, enter into the Parasympathetic Nervous System of '**rest and digest**'.

I used lots of different tools to do this:

- **Relaxing music** – I like the **Sensate app**. It has different calming music tracks, designed to enable a 'flow-like state' and calm the nervous system. (There are some free tracks and you can upgrade to access more).
- **Direct Vagus nerve stimulation** immediately changes the nervous system to using the parasympathetic branches. Such as humming, or massaging the vagus nerve near the ear – see YouTube for more info such as <https://youtu.be/LnV3Q2xlb1U?feature=shared>
- **Long Covid specific yoga classes:**
<https://TheYogaForLifeProject.co.uk>
2-3 per week (currently free/donation) was brilliant. The classes are a perfect mix of very gentle movement, breathing, calming techniques in a warm, inclusive group. Also <https://360MindBodySoul.co.uk> (Rest Repair subgroup is for Long Covid, pay a small weekly rate.)
Also, Suzy Bolt from 360 above has some free content on YouTube such as <https://youtu.be/2fD1jdt8vfc?feature=shared>
Attending all these classes regularly was hugely influential on my recovery.
- **A supportive Long Covid community** - having positive, nourishing, kind connection with others in a similar situation counteracted the isolation. It also helped to acknowledge and validate the weird symptoms of LC, knowing I was not the only one.
Examples of this are 'The Yoga For Life Project' Whatsapp group (formed from members of the Long Covid yoga group).
And/or '**Yoga and meditation for gentle Covid recovery with Suzy Bolt**' on Facebook.

There were lots of other Long Covid groups on Facebook, but I deleted any groups that didn't feel helpful/positive for my recovery or mindset.

- **Mindfulness meditation** – I often use the '**Insight Timer**' app which is free and has hundreds of different teachers and types of meditations to suit your style/mood. I especially like Tara Brach. I found the aim wasn't to settle my thoughts (that's just too hard, especially with severe brain fog), but meditation calms the brain into theta brainwaves, which has a healing effect on brain and body (brain scan studies have been conducted to prove this).
- **Being in nature** is hugely calming for me. (I've since discovered this gets the brain into theta brainwave state too). I would access nature in whichever way was possible at the time. Whether it was sitting outside in my garden or looking through my bedroom window towards an old oak tree, or walking slowly in the woods, with frequent stops on a bench. I find being near trees/woods is especially uplifting.
- I tried to reduce my striving/type A personality traits. I tried to cultivate a feeling of letting go of the struggle and being with what is/acceptance. I read that this is healing and leads you to better health ultimately. I found meditations which helped me with this concept.
- Breathing exercises for Long Covid. There are lots on YouTube such as <https://youtu.be/k9-8AG3sUj4?feature=shared>

2. Nutrition

- All my reading highlighted that gut health, and the microbiome are very important in chronic illnesses of any kind.
- Therefore, fermented foods (or probiotics) are important as they improve the microbiome which improves full body health.
- Cheese (especially soft, blue, unpasteurised variety) and live yoghurt count as fermented foods and are easily accessible. As well as kefir, kimchi, sauerkraut, kombucha.
- I personally also drink a shot of 'Symprove' <https://www.symprove.com> daily which is a well-researched probiotic.
- **Avoid ultra-processed foods** if possible (even shop bought bread, unless its artisan sourdough). My aim was/is to eat whole plant foods, basically things that still look like food rather than in packages. This can take a lot of food prep time, energy and planning, and I didn't have the brain power/energy at first, unless someone cooked for me. But now I batch cook and freeze and have become more organised with the weekly shop. For times when I don't/didn't have the time/energy for cooking from scratch,
- I use the **Yuka** app. I love it. You can scan any food label in any supermarket (or personal care/beauty product) and it gives a score out of 100 and tells you what additives are in the different foods/products. It's free, (but if you want to search for items without having the barcode you pay a small annual fee.). This means you can still choose to eat well using packeted food.
- **The Zoe podcasts** <https://zoe.com/learn/category/podcasts> are a brilliant source of free information to learn more about how food affects our health.

- I try to avoid sugary foods and eating lots of simple carbs as they spike blood sugar levels, which causes general inflammation and strain on the body. I'm not perfect with all this, far from it, but these are my general aims.
- I found a lot of foods, especially things like raw vegetables or salad, difficult to digest, especially initially, so I would make dishes where they are cooked more.
- My 'go-to' for lunch: homemade vegetable soups with added seeds, nuts, olive oil on top.
- For dinner; dahl or butternut squash curries with rice; stews and casseroles; one pot roasts with roasted veggies to give some examples.
- For breakfast: porridge with spices/berries; or eggs; or yoghurt/granola/fruit.
- Experts advise we aim for **30 different plants per week**, this includes all seeds/nuts/spices etc. I doubt I achieve this, but it has made me prioritise diversity in my diet, and I add seeds/nuts/spices to anything I can. Even my breakfast porridge has cinnamon, cardamon, ginger, turmeric added.
- **Ayurveda** – latterly I've started learning about this ancient (4000-year-old) Indian way of living. It is filled with wisdom about whole body health and healing. It's taught me many things, including to use lots of spices per day and which ones will work best for me depending on my ailments and my energy type or 'dosha'.
- I have herbal teas every day based on this too. Such a CCF tea (cumin, coriander and fennel seed), which calms my energy type, (and helps me enter the parasympathetic).
- Ayurveda and Zoe podcasts both explain how diet and food metabolism is personal and what foods exacerbate one person may be fine for another, so it's a journey of trial and error.
- **Supplements** – initially I thought these would be the answer and bought every supplement I read on any Long Covid group. I gradually realised they were not the Holy Grail, (and it's better to get the nutrients from food). But I do think boosting your immune system with good quality daily Vitamin D (with K2 to help absorb), Vitamin C (if possible, wholefood Vit C), Omega-3, and organic Turmeric (with added black pepper to help absorb) is beneficial.
- **Intermittent fasting** has become a widespread topic in Wellness Literature. I personally found it too hard to fast when I wasn't well, I think my blood sugars were not stable enough to cope. I now try to fast 12 hours overnight, (7.30pm-7.30am) and plan to increase the length when able.

3.Sleep

Circadian rhythm is important for general health, having the same bedtime and getting up time has helped my energy. I aim to be in bed by 10pm-10.15pm (not always possible but I try!) and aim for 8 hours sleep.

I know sleep disturbance is a common symptom of LC. Both getting off to sleep and waking up in the night.

Wearing **blue light blocking glasses** in the evenings (from an hour before bedtime) has really helped relax my body ready for sleep.

I also use **blue light blocking bulbs** (they are basically red bulbs!!) in the bedside lamps, and landing, and soft lighting in the bathroom.

Avoiding a late dinnertime also helps with insomnia.

Meditations in bed - I always listen to something when I get into bed with the aim of calming my mind and focussing on positive/nourishing thoughts/mindsets rather than fears or worries or to-do lists.

If you think about it, we have 8 hours of sleep on which to ruminate on whatever we were watching/listening to before bed, so if healing is our aim, we need relaxing, gentle, uplifting input to our brains. This includes what you watch on TV in the evenings too.

I often use the **Insight Timer app** and listen to soothing sleep journeys, or calming meditations.

Or I listen to **The Tapping Solution app**, tracks such as 'quiet my racing mind' or 'boost of peace', or any sleep support meditations.

Or calm music/**Sensate app**.

Or an evening or sleep meditation by Joe Dispenza (which is amazing at visualising the healing you want) on YouTube such as

<https://www.youtube.com/watch?v=XbkuE2cYsnQ&t=4311s>

Experts say this state we get into before sleep accesses theta brainwaves which is when the brain is the most open to new suggestions/healing ideas. So, it's a good time to try to visualise/feel what it's like to be healthy, calm, well, grounded whilst I listen to the above.

4.Hormones

My understanding is LC can affect a vast number of bodily processes, including hormone levels.

I've read studies to show there's a higher density of Covid receptors (ACE2 receptors) in the ovaries than elsewhere in the body, so Covid causes more disruption to Oestrogen/sex hormones compared to other hormones.

Perimenopause/menopause has many similar symptoms to LC (admittedly not to the same extent).

Being aged in my 40s (and therefore being in the perimenopause) I didn't know which proportion was attributable to LC and what (if any) was perimenopause. I figured that if the perimenopause was accountable for even 5% of my brain fog or fatigue, then it was worth looking in to. Here's a link to an article I found useful: <https://balance-menopause.com/uploads/2022/03/Long-COVID-and-female-hormones-factsheet.pdf>

I went to see a Menopause & Long Covid Specialist Doctor and I read a lot about the perimenopause. I decided for me, the potential benefits outweighed any risks, and was started on HRT.

I saw a gradual improvement with every dose increase of oestrogen. I realised that my body needed to go slowly and gently with HRT, so it took a year to get up to the dose I'm on now, in small increments.

After a few months, testosterone gel was added which made further small improvements, especially with brain fog.

It's difficult to know how much the HRT helped, as I improved gradually over that year long period whilst also immersing myself with all the other strategies outlined. But I think it is a percentage, and felt small, stepwise improvements each time I increased the dose.

It was a bumpy road, especially when I found the dose increase was too much or too quick. Using trial and error, talking to the specialist, keeping an eye on blood levels, listening to my intuition was all important.

5.Exercise

For many months I **paced** myself carefully, to reduce the dreaded 'Post-Exertional Malaise' (PEM) and prevent the yo-yo of 'boom and bust'. At the beginning, doing too much meant I'd be bedbound for 48 hours.

I know 'Pacing' and the 'Spoons Theory' is taught by OTs, Fatigue Clinics and Long Covid clinics, and I feel it definitely has a place when one is very unwell and for a while after. It calmed my nervous system and paced me, which meant I had enough energy to last the day. I think the problem can come, when one is ready to do a bit more, but the fear of getting PEM, along with conditioning from the LC/Fatigue clinic of the importance of pacing, can hold one back/feel stuck.

For me, being in **nature** is important. I started just sitting on a bench in the woods. I then progressed to a little slow walk as well as a sit-down on the bench. I then increased this very gradually, listening to my body with how much.

Initially, I scoured the Long Covid posts on the internet for **percentages of steps I should increase by**, or heart rates I should stay under, to prevent causing PEM. This meant that during the walk my eyes would be glued to my Smartwatch in case I went over whatever dreaded threshold I'd read. Then I realised this wasn't helping me as the fear of doing too much and bringing on a crash was always in the back of my mind. I changed tack and would listen to uplifting meditations/music whilst doing the short walks and listened to my body/intuition with when to stop. (I think having LC helps us attune to our bodies more than ever, so we can use intuition with more confidence).

Listening to uplifting meditations helped me forget the fear and keep it a wholly positive experience. See my 'Healing mindset' section next – I think our mindset is key.

Gentle yoga was very beneficial. It was very gentle at first when I was very unwell. Lots of restorative poses and very gentle movement whilst lying down or sitting. This was gradually increased to more active poses as I felt able.

Deep breaths in the garden in the mornings (with some gentle standing yoga movement/stretches) helped to wake my brain and body, but also open my heart and mind to healing and positivity, as opposed to feeling fear of the illness/contraction of my life. For some reason it helped me remember that I can do difficult things and I can heal, it helped my mindset for the day.

Cold water therapy helps some people.

I tried gentle river swimming/plunges when I was 40% better but it brought on PEM, even if I bobbed around and didn't swim - so I stopped.

I started again when I was 90% better, and I now find it very empowering physically and mentally. I am careful not to stay in too long and mostly wear a wetsuit (with all the trimmings of booties/gloves/hat unless its summer). The theory is it tones the Vagus nerve which in time makes our Nervous System more resilient to physical and mental stress. Cold showers (or part of the shower being cold) may have similar benefits.

6.Healing mindset

I read a quote "**Where focus goes, energy flows**".

I.e. what I focus on is more likely to come true.

I felt this was key for my recovery and wonder if this is often the missing piece of the puzzle.

I wanted to find a way to not only have awareness of my thoughts/mindset/mood, but also learn how it can be influenced. It's too difficult, unrealistic and unhealthy to be positive all

the time and I wanted tools/techniques that felt sincere. I read a lot about mind-body medicine and investigated many different approaches. Some felt like they fitted better some days than others, so I had an arsenal.

Here follows my own consolidated version of healing tools that helped my recovery:

Gratitude – this felt the easiest way to slide into a more open, healing mindset and out of a fear-based one. At the beginning I used gratitude meditations on YouTube (there's many, I like <https://youtu.be/xfD4HaBBc0I?si=xHlrMy5HTcjjJcga> by Jessica Heslop). I often listened to it whilst walking in nature, so I had a 'double hit' of feeling uplifted (and getting into theta brainwave activity).

The Tapping Solution app was also helpful in opening my mindset if I was feeling 'stuck' in a negative space or thought pattern or limiting belief. I would listen to whatever track spoke to me at the time. If I was feeling anxious, I would tap along to 'opening to peace", or 'releasing anxiety in the body'. It basically involves saying affirmations whilst tapping on acupressure points and is surprisingly well-researched. I liked how each meditation started with acknowledging the negative feelings you may be experiencing, (it seemed amazingly accurate!) which made the negative thoughts feel less powerful somehow, before then opening to the possibility of more helpful thoughts via affirmations.

I prioritised doing things that '**brought joy**' if I could. This is different for everyone, perhaps its art or music or poetry or gardening or being in nature or hobbies etc.

In Autumn 2022 I did a course called the **Lightening Process**. <https://lightningprocess.com> This highlighted any self-limiting beliefs (we all have them, but they are tricky to identify without guidance). The ethos is these may be keeping us 'stuck' in a dysregulated nervous system. It helped to kick start more helpful thought patterns and supported my healing mindset. As it was small group work with follow-on sessions that lasted a few weeks, it helped to maintain longer term change.

I read and listened on YouTube to **Joe Dispenza** and other Personal Transformation coaches. Amongst other things, they all advise to think about what you do want and **visualise** it. (Quantum Physics has now proved how visualising helps that scenario come true.)

So I created a list and visualised myself with those attributes.

E.g. Agile brain, deep energy, physical resilience, strength, freedom, self-belief, empowered. I also visualised how my world would look when I had my health back; playing with my child, running along the beach, my brain working hard at work, partying with friends, climbing a mountain etc.

Depending on my mood, some days felt easier to visualise than others. I found guided visualisations helped me access these practices more easily, so I would listen to a meditation which takes you through the process step by step such as this by Joe Dispenza: <https://www.youtube.com/watch?v=sCnSbROZN-s&t=6s>

Prioritising self. Gabor Mate, amongst others, talk about people who tend to always put others first/are too kind/give too much of themselves, as being associated with chronic ill-health. I worked on improving my boundaries, being more assertive and stopped caring what others think. I try to have more compassion for myself, not listen to the critical inner voice, and prioritise my needs.

I don't like this term, but I have read that 'the victim mindset' is associated with poor health. I think seeing things through a **self-compassionate** lens is more helpful. We still give ourselves empathy with the difficult road we find ourselves on, but instead of feeling stuck and disempowered, we can offer ourselves soothing, loving-kindness for our situation, and

think about our needs in that moment and what would help (a bath, a cuppa, a chat, fresh air). Both ways recognise how crap the situation is, but one is empowering and healing.

It's quoted that **'We are the average of the 5 people we spend the most time with'**. The quality of relationships with those around us can affect our health and wellbeing. I looked into whether counselling would be helpful for any of my closest relationships and considered parent coaching too.

I read that **forgiving** others (and myself) was important for healing and did some forgiveness meditations and exercises I found online.

ACT – Acceptance and Commitment Therapy – I read about this as it can help with getting 'unhooked' from tricky emotions/thoughts. I think it may be especially helpful for people with Type A personalities, for which there seems a higher percentage of Long Covid sufferers – perhaps it's because we tend to push on through??!

<https://youtu.be/OV15x8LwAQ?si=YrHjqKvND2r4zYSN>

To remind myself of quotes, words that resonated, or affirmations, I put post-it notes on my mirror (fridge/wherever works for you) so I could be reminded of them every day.

E.g. **'I Trust my body and brain'** (I think it's quite common with LC to lose confidence in our bodies, so this felt a good antidote to read)

E.g. **'I have all the resources inside me that I need for my life'**. Feeling like the locus of control is within us, empowers us to heal, rather than waiting for someone else to fix us.

To Conclude

Perhaps one thing has resonated or sparked an interest to explore further. I hope my story has given hope, food for thought, and/or practical tools for healing.

There have been silver linings to my Long Covid journey. For example, this journey has shown me:

- my inner strength
- what's important in life/priorities
- to take pauses more often
- to be grateful for everything I have (and not take health for granted)
- a passion to help others with Long Covid
- encouragement to stand tall and aim to thrive
- importance of doing activities that bring me joy/peace/wellbeing
- putting my needs first is important

Extra reading

Nicole Sachs <https://www.thecureforchronicpain.com>
<https://www.youtube.com/watch?v=7eHKbhhBxvs>

Feel better, live more podcast (Dr Rangan Chatterjee)
<https://drchatterjee.com/blog/category/podcast/>

Dr Joe Dispenza book– You are the Placebo