

# Severe ME Day

2021

Gym at 6.30am followed by a G&T 12 hours later. For women who want to live life at their optimum, energy is currency. So, when an illness strikes that robs you of it, you're left feeling not only devastated, but invisible, too. Here, one writer shares how witnessing up close chronic fatigue syndrome or also known as myalgic encephalomyelitis - a condition which many long Covid sufferers now qualify for a diagnosis of

- has taught her that energy is not a certainty, but a privilege.

Sprawled on my bed at home in Lincolnshire, I was thumbing through the newly released Harry Potter And The Half-Blood Prince when I heard a distressing moan coming from my mum's room. Entering slowly, I found her, sweat-soaked duvet cast aside, writhing on the bed as her limbs shook uncontrollably and she tried to fix her frightened eyes on me.

That day back in 2005, when I was 12 years old, was the first time my mum, Liane, then 45, found herself caught in the vicious throes of what was later diagnosed as myalgic encephalomyelitis (ME) - also known as chronic fatigue syndrome (CFS). Initial blood tests failed to reveal why Mum had suddenly become so sick and completely devoid of energy. After six months - having ruled out everything from glandular fever and thyroid problems to Lyme disease and multiple sclerosis - her baffled GP diagnosed her with ME/CFS (the slash is mandatory for medico-political reasons - more on that later) and later referred her to a musculoskeletal and autoimmune specialist.

In the years that followed, I watched as the unstoppable force that was the mum I'd grown up with - the energiser who took charge and galvanised everyone around her to get shit done - became relegated to bed for hours, days, weeks on end. My early teens were spent tiptoeing around our house while she rested. She was forced to turn her back on the 20-year career she'd built as a sexual and reproductive health doctor and my father negotiated fewer hours as an optometrist to try to navigate the dual role of primary carer and family breadwinner. People failed to understand why Mum could be bed-bound by early afternoon because she'd done a food shop that morning.

As the muscles on her slim frame wasted away, every hug became a tangible reminder of how much had changed. And while it was Mum whose body had been taken over, I resented how the illness impacted me, too.

Schoolmates regaled each other with stories of summer holidays, nothing but a pipe dream for me now, and the idea of mother-daughter shopping trips was laughable.

Not only did my day-to-day life undergo a seismic shift, but my idea of my future did, too. Googling the disease a few years later in the hope that I'd hit upon something that might help Mum, I discovered that ME/CFS could be genetic. I was horrified. I'd inherited my mum's natural drive and optimistic disposition; had I also inherited the illness that had quashed them both?

ME/CFS affects 250,000 people in the UK and an estimated 17 million globally. The chronic illness is characterised by tiredness that renders you immobile, debilitating cognitive issues and acute sensitivity to light and sound. The severity can vary, and a quarter of sufferers are bedbound or housebound, often forced to rely on a wheelchair or live in the dark. Others you may walk past in the street and never realise, because it's a 'good day'.

While ME/CFS can affect anyone, it's most often diagnosed in women aged between 25 and 45 and has been described as the worst hangover of your life, multiplied beyond belief, that doesn't fade after a good night's sleep or a Berocca and a fry-up. 'ME/CFS is, on average, more disabling than many other

major conditions, such as rheumatoid arthritis or cancer,' says Dr Luis Nacul, clinical associate professor at the London School of Hygiene & Tropical Medicine. Many of those suffering from long Covid - which, early research suggests, is also disproportionately female - may now qualify for a diagnosis.

At its most dramatic, ME/CFS can cause sufferers' bodies to 'crash' - as my mum's did when I found her in her bedroom. 'In just a single day, my body failed me,' she recalls. 'With no warning, I suddenly felt very faint, my temperature spiked and I experienced disabling weakness.'

Overnight, heart palpitations, aching muscles, difficulty sleeping and trouble getting words out became my new normal - and left me utterly helpless. I'd always been on the go; now I had to choose between using the minimal energy I could muster on having a shower or making a phone call. Doing both wasn't an option.' And while the physical pain and complete lack of energy was debilitating enough, it was the feeling of helplessness that was killing Mum. 'I felt like I was missing half my life,' she remembers. 'I was tired of lying in bed dreaming of all I wanted to do.'

So what's the cause? Frustratingly, scientists don't know, even though ME/CFS isn't a new illness. Diagnoses of myalgic encephalomyelitis were first made in 1955 when, within just four months, nearly 300 members of staff at the Royal Free Hospital in London developed unexplained limb pain, muscle weakness, nausea, dizziness and severe headaches. Official recognition came in 1969, when the World Health Organization classified ME as a neurological disease.

However, in 1970, psychiatrists Colin McEvedy and AW Beard, in a controversial study published in the BMJ titled Royal Free Epidemic of

1955: A Reconsideration, claimed that the condition was 'mass hysteria' on the grounds that tests showed no abnormalities or obvious causes of infection among patients. In an example of contemporary gender biases - and the dispiriting body of evidence revealing how women's pain is often dismissed - the pair also suggested that female patients, who made up the majority, were exaggerating their symptoms. The study was influential and, for decades, the condition wasn't taken seriously, with the media coining the term 'yuppie flu' and sociologists attributing ME (the CFS part of the name was used from 1984) symptoms to the stresses of modern life.

### **Mind vs matter**

So effective was this legacy in cementing the condition as psychological- and thus by the conventional wisdom of the era, not real - that, up until 2016, The Royal College of General Practitioners classified ME/CFS as a mental health disorder, only recategorising it following years of campaigning, scientific findings that showed failings in the McEvedy and Beard report, and the publication of research identifying early physiological markers.

It's such a politicised condition that it requires two names, as many believe the word 'fatigue' downplays how severe an affliction it is.

Now, the NHS and most official bodies refer to it as ME/CFS. Since the term ME was established, scientists have learned that not all cases were caused by inflammation of the brain (what the E of ME indicates), hence the renaming. Still with me?

The lack of understanding around ME/CFS means it has been historically overlooked in medical school (one source received only five minutes' teaching time on the condition) and research funding remains negligible.

In the past year, those campaigning for greater recognition of ME/CFS as a physical illness were given cause for hope when a team at King's College London found a possible link between the condition and an overactive immune system. Lead author Dr Alice Russell explains: 'Our findings in patients with overlapping symptoms suggest there may be a difference in the way the immune systems of ME/CFS sufferers respond to the initial immune or viral attack that triggers their symptoms, compared with the rest of the population.'

What's more, a 2017 Stanford University study found evidence of an inflammatory disease in ME/CFS patients; Columbia University research showed disturbed cytokine (small proteins important in cell signalling) production patterns; and multiple other studies have suggested that the cells of ME/CFS patients are in a state of metabolic hibernation.

I discussed these findings with my mum. They certainly appear to tally with her experience; in the years before her first crash, she experienced an uncharacteristic series of infections. Ever the medic, she's interested in reading scientific explanations for what happened to her body. The more they find out about what could be going on beneath the surface in ME/CFS sufferers, the more I worry about its potentially hereditary nature - but doctors believe that while there is a genetic link, it doesn't necessarily mean that everyone in a family will get it, just like cancer or heart disease.

### **Not seen, not heard**

The condition's physical impact has been highlighted in recent years.

Surfing world champion Tyler Wright, 27, revealed in 2018 that ME/CFS had left her too weak to compete. Similarly, Jennifer Brea - Harvard PhD student and creator of the award-winning 2017 ME/CFS documentary *Unrest* - was a keen skier and cyclist before the illness left her housebound. After catching a virus when travelling in 2011, she sustained multiple infections and never recovered. In one haunting scene, she tells a handheld camera: 'It was like I had died, but was forced to watch as the world moved on. There are some days where I'm just doing a good job by holding it together and not killing myself.'

Indeed, a study published in 2016 found that ME/CFS sufferers are six times more likely to die by suicide than those unaffected by the condition. Energy is essential, and when you're running on empty, the impact isn't purely physical. 'We socially reward people who work and contribute and perceive them as more deserving and more morally upstanding,' explains Dr Tracey Collett, sociologist and associate professor in medical education at the University of Plymouth.

'For ME/CFS sufferers, the roles they perform - as parent, partner, child, friend - are drastically reduced, but they're rarely afforded the sympathy and care that would come with having another, better understood, condition. And to add insult to injury, their contemporaries move on without them, building relationships, having children, developing careers and travelling the world - all things that validate your sense of identity and worth.'

Indeed, I remember watching as invisible clouds obscured my mum's sunny disposition. 'There were times when I thought this living nightmare would never end,' she tells me. 'I was frustrated, low and any remnants of hope I had were drifting away.' Of course, I'd known this. I'd witnessed her in tears. Because I felt her emotional pain so keenly, these incidents left me with tears running down my cheeks, too. 'I never experienced suicidal thoughts because I had good spells,' she adds. 'But had I not - like so many sufferers - I can understand how the pain and loneliness could drive people in that direction.'

### **A life less ordinary**

When it comes to treatment after a diagnosis, ME/CFS patients in the UK are offered a combination of medication, graded exercise therapy (GET), cognitive behavioural therapy (CBT) and 'pacing' (an activity-management strategy aimed at limiting the number of crashes that sufferers experience). Their efficacy? Questionable.

In 2018, campaigners successfully put pressure on the authors of a 2011 study to reveal the evidence that led to their findings that CBT and GET were 'moderately effective' forms of treatment for ME/CFS. It appeared that the unpublished data showed recovery rates had been grossly inflated. Just as long Covid was forcing the scientific and medical communities to take note by autumn 2020, the National

Institute for Health and Care Excellence (NICE) announced they would be removing CBT and GET from their guidelines.

My mum spent 10 years fruitlessly pacing her activity and taking medication to ease the pain, encourage sleep and regulate her immune system. She missed weddings, graduations, birthdays, holidays and funerals, experiencing the sting of unmet responsibility not only to us, but to her ageing parents. 'I felt guilty about being utterly useless as a wife, mother and daughter,' she recalls.

She began to research alternative treatments and discovered functional medicine: a highly personalised type of alternative medicine that aims to tackle the root cause of a problem via tailored lifestyle and nutrition interventions - then nutritional therapist Marek Doyle.

Despite the fact that his qualifications seemed less robust than those of the doctors Mum was accustomed to dealing with, she trusted his identification of several underlying problems, including adrenal issues, gut imbalance and inflammation - none of which NHS doctors had raised - which she believed were caused by her stressful lifestyle as a junior doctor in her twenties.

She began following Doyle's suggestions of dietary changes and supplements to take. 'Over the course of two years, there were ups and downs as my body started to function again,' Mum recalls. 'I woke up in the morning with energy and a clear mind. I could plan my life for the first time in years. A turning point was when I could finally visit London to see you,' she tells me. 'The weather was sunny, we walked and talked and I felt alive and part of the world again.'

Despite my cynicism as the daughter of a doctor, with more than five years behind me as a journalist writing about health, I can't deny that the transformation is astounding. Save the odd crash, I've got my mum back and it's amazing. Girly days out are a joy and our lives no longer feel like they're on hold.

### **Future Facing**

While society's awareness of 'invisible' illness is increasing - something supercharged by long Covid - and science is heading in the right direction, we can't forget those for whom progress is too late. My mum included. She lost 10 years of her life; the career she strived for was over, she had little faith in her own body and she lost out on being a mum - and a wife. There were no date-night dinners as her identity quickly transitioned from romantic partner to someone who needed to be cared for.

Lost. Left behind. Missing. The words that always come up when you speak to women affected by ME/CFS. It makes me marvel that, when I ask my mum to reflect on the years taken by the illness, she shows sadness but no bitterness. 'It's pointless to dwell,' she says. 'I just want to make the most of the future.'

I'm doing my best to follow suit, which is made easier by the fact that we can make new memories now. That little girl with her head buried in a book could not have imagined navigating her teens without the mother she thought infallible. Even more inconceivable was that my mum's health would return, with no need for medication; that one day I'd find us pausing for a break on a full day's sightseeing at my request, not hers.

I lost my mum for a time, and it would be disingenuous to say that I'm not scared it will happen again. She fears that her body may let her down in the future - and so do I. From her research, Mum's firm belief is that lifestyle is more important than any genetic tendency, but that's something you can't know for sure. What is more certain is my belief that good health and plentiful energy are privileges that should never be taken for granted.

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*“Recently my 9 year old daughter and I were talking about the lack of available information to help children understand what it’s like when their parent has M.E and other illnesses.*

*“She took herself off to bed early and came to me the next morning with the following story. I thought I had always put a brave face on things and had hidden how ill I was from my children, but it turns out I hadn’t.*

*“Holly has very little self-confidence and she doesn’t believe me when I tell her how amazing she is. She would like to help others in the same or similar position and I hope sharing her story will help.*

*“Thank you.*

**Chantalle Peretti**

### **My Mummy and M.E. by Holly Peretti**

Before Mummy was ill, I remember her coming out everywhere we went. She did what normal mums who do not have anything wrong with them would do if they were out of lockdown.



Holly with her mum.

She looked happy every minute of every day and always had a huge smile on her face. Mummy always looked strong, barely ever weak, or tired and she was always laughing, joking, and played in the garden with us for as long as we would like her to.

She made me feel very cheerful and welcomed to the family which I loved. Mummy took us to cinemas, playcentres, parks and even other people’s birthday parties. I remember Mummy was very rarely unhappy or upset and she only cried on really, really bad days.

I was always entertained as mummy played with us almost all of the day. That was until something changed...

One morning, we woke up expecting to see Mummy already dressed and waiting for us downstairs, but her bedroom door was closed so we knew she was still in there whether she was asleep or awake watching TV in bed.

Me and Charlie peeked in to see mummy laying there looking weak and tired. Quickly, we rushed over to Mummy and held one hand each, so she felt comforted. She definitely was not in her usual mood. Something was wrong.

We told Daddy as soon as he got home from his night shift as a paramedic. As soon as we finished telling him everything, he quickly helped me get Mummy dressed while Chaz went downstairs and got Mummy’s handbag, coat, and shoes ready, so she did not have to bend down and wear herself out doing those chores.

We rushed Mummy to the hospital, Daddy driving, while me and Charlie sat in the back, keeping an eye on Mummy to make sure she was OK. She already had an appointment, so as soon as we got in we went with the nurse to the room and told the nurse everything that had happened that morning.

The nurses went off and discussed what had happened. They then came back and told us Mummy had M.E. We were all heartbroken.

## **Since Mummy has been ill**

Mummy got more and more ill and got diagnosed with more and more illnesses. She even faints now.

We are used to it but still anytime Mummy faints I still get scared she will not wake up again. We get anxious and Mummy has been fainting for a long time now!

As Mummy got sicker, she could do less and less with us and now it is very rare that Mummy can come out with us because she is too tired and weak. Our lives have been turned around completely.

We used to go to bed feeling very cheerful as we had had a great day out with Mummy and Daddy. Then you wake up in the morning, feel that something is wrong, go to check on Mummy and feel sad for quite a long time. You can imagine how that feels. It is horrible!

I hate seeing Mummy in all the pain, agony, and sheer exhaustion she goes through all of the time. I love Mummy all of the time no matter what she looks like or feels like, but I wish she were better so we could do the things we used to do that we can't do now as she's too ill.

## **What I see and what it means**

On some good days, when she has had a lot of rest over the few days before it, Mummy looks a lot brighter and that means a lot to the family as she barely ever had days where she feels more cheerful and less exhausted.

When these good days do come round, we all feel a lot happier, including Mummy, and it means we can do some extra bits with her.

Throughout the day, we do a few bits with Mummy and then because that makes her exhausted, we go out somewhere or watch something upstairs, just the three of us, while Mummy has a long rest.

Holly and Chantalle – a good day.

Resting does her good and means we can do some extra bits with her the following day.

We then have cuddle time with her – cuddle time in our house is what we call, 'calm down time!' That time is anytime after tea and before bedtime.

It is where we all snuggle and cuddle up together on the sofa and watch something we all like.

I always like cuddling up to Mummy as then I feel that I am safe and that she is too.

Mummy now always looks weak and tired and on those days we know how ill she is. She can barely get up and we all have to help her go anywhere she needs to, or she will have a fall.

## **How it makes me feel**

To see Mummy act and look so poorly makes me really heartbroken and upset as she looks so ill and in pain, that I just want to help her to magically get better, but I can't because I don't know what to do. I sometimes feel angry at myself for not just being able to make her better quickly.

Every time I make a wish, I always wish the exact same thing – that Mummy will get all better and back to her normal, cheerful mood instead of being tired, weak, and in pain every part of every day. I wish she had more energy so she can have more fun with us.

## **How I cope**

I don't actually mind not going to all these places as much as little kids would do, like Charlie. I would prefer to though. I understand that what can not be done, can not be done.

With little kids, they probably will not understand when Mummy's ill, why Mummy's ill and how to deal with it. Like if Mummy fainted for instance, they would be jumping on her lap and tickling her. On the other hand, as we are older we will know what to do. We would take Mummy's blood pressure, hold her hand and cuddle her.

No matter what Mummy looks or feels like, it doesn't mean she is the odd one out. The most challenging bit of looking after her is seeing her in so much agony. It makes me feel bad.

## **How I see the future**

I am not sure if Mummy is going to get better or not in the future. I figured that if we carry on helping her, she will get a little bit better. I do not think her M.E. is going to get completely better, but if Charlie, Daddy, and I carry on caring for her as much as we can, then I think some of her illnesses may get slightly better. No matter what happens, I still love her!

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