

The hidden cost of long COVID

Marc-Andre Bosset on how counselling can support people living with the very real and tangible symptoms of long COVID

In November 2021, I signed a contract with a mental health intermediary agreeing to offer six online sessions of mental health support to individuals who suffered from long COVID symptoms. Over the course of the following 13 months, I supported clients across the UK who mostly held office jobs in companies of varying sizes and within different sectors. These clients had all contracted COVID-19 at least once and none had been hospitalised as a result. By the time I saw them, many had been signed off sick intermittently over the course of a year or less, as they had unsuccessfully attempted returns to work. Some had been on continuous sick leave and others were drawing near the end of their employer's sick pay scheme. Only one of the 36 clients had received an official diagnosis of long COVID.

The clients reported the multitude of symptoms that afflicted them on referral forms, and the most challenging were fatigue and brain fog. However, the least reported symptoms were those that surfaced the most during our sessions – hopelessness, anxiety, anger and shame. I would eventually find out most of them were acutely worried their employer wouldn't take their condition seriously, and that they'd be labelled as lazy, depressed or frauds.

Fatigue

The clients I worked with recounted experiences of fatigue that were disabling and life-altering. The overall sense I gathered is that long COVID fatigue is overpowering, unpredictable and strips sufferers of their sense of agency. These individuals had been deprived of their intentionality and identities. The simplest tasks, from walking across a room to getting dressed, required gargantuan efforts. One said, 'It feels difficult to even hold myself up', while another described how 'Everything feels slow and heavy, like wearing a space suit'. They described how it would take them several hours in the morning to get out of bed, get dressed and have breakfast. The simplest of tasks became huge obstacles, and there's a feeling the whole body is like lead, weighing more than one can carry. As one client said, their body had always been an afterthought, however, with long COVID, it now got constantly in the way.

Boom bust

Contrary to popular perception, most of my clients didn't suffer from a constant sense of fatigue, but rather what felt like an irregular experience of boom and bust cycles. During the boom cycle, they would report feeling

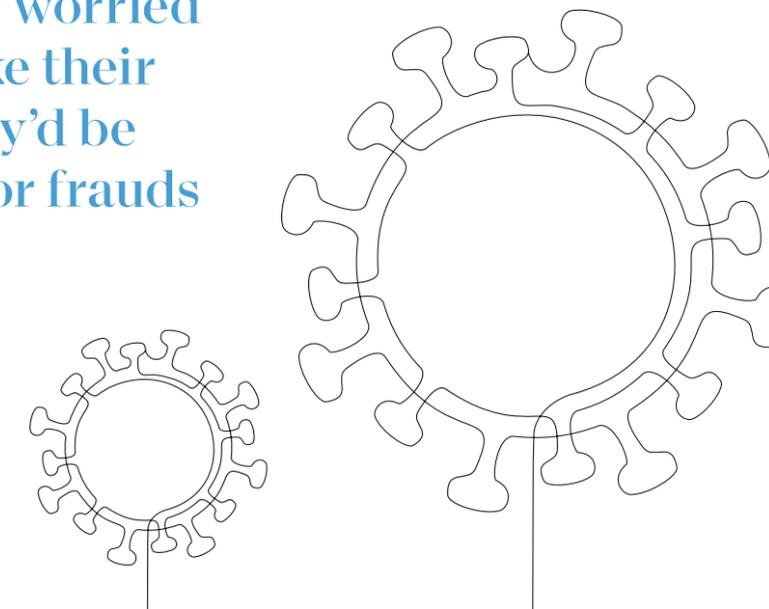
wired and tired at the same time. For some, this occurred in the middle of the night, hence long COVID's associated symptoms of insomnia or disturbed sleep. One described this state as, 'The head feels rested but the body is exhausted... I'm fully awake but in the wrong body'.

Others experienced this boom for brief intervals during the day, while some could have several days of feeling relatively normal. Understandably, they would want to make the most of their moments of newfound energy and pack as much as possible in those fleeting windows of relative normality. They would report feeling high on adrenaline, while others said they almost felt like they were able to 'psych themselves up' for a particular task or activity. Coincidentally, it's this experience of a 'boom' that enabled clients to sit through the 50-minute sessions. I only had to end our sessions prematurely a few times because of a clients' overwhelming fatigue or brain fog. For most of the time onscreen, clients would appear deceptively healthy, a dimension of long COVID which, as we shall see later, is a source of guilt and shame.

However, these boom intervals are duplicitous – they initially provide a sense of hope and elation; hope that recovery is underway, elation that freedom from the

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shackles of fatigue lies just around the corner. However, without exception, there follows a 'bust' cycle, where clients wouldn't be able to get out of bed, sometimes for days at a time. It's worth noting that these affective cycles of elation followed by a collapse mimic the affective contours¹ of the aetiology of shame.²

Brain fog

Fatigue and brain fog are intrinsically related. The experience of brain fog causes fatigue, and the latter exacerbates brain fog. In brain fog, symptoms become manifest in a variety of different ways, such as forgetfulness, difficulty concentrating and impairments in reading and planning. Mundane daily actions that were once so familiar they were executed out of conscious awareness, become challenging labyrinthine tasks that require explicit thinking, time and effort. One client described that while preparing breakfast, they were caught up debating whether they had to get the spoon out of the drawer before the cereal box out of the cupboard, or whether they needed to pour the milk in the bowl before the cereal.

One client reported how they struggled to follow the narrative of their favourite TV series. Clients reported experiencing difficulties with reading and writing, which made them worry they would never be able to

work again. One client recounted a dream where they were reading a book, and the words gradually disappeared from the page, along with their understanding of the content – an evocative representation of one of the challenges with brain fog. As another client put it, the experience of brain fog is like being incapable of making connections between parts and the bigger picture. An avid card player described they now had to look at each card in their hand rather than having an idea of what they have straight away – 'I'm back to a beginner level'. As one client succinctly summarised, with brain fog, it '...feels like someone smashed a part of my brain'. All these individuals found themselves constrained to concentrate on every finite detail for simple or familiar tasks, which not only leads them to feel exhausted, but to lose their sense of self.

Emotional cost

Almost all clients shared an entrenched incredulity about long COVID. Many said things like, 'Long COVID isn't real... I just need to pull myself together'. There was an overarching sense that the symptoms they were experiencing must be of their own making, and that instead of long COVID, they were just weak minded, unable to cope,

depressed or simply lazy. This self-destructive affect intensified ahead of meetings with line managers, insurance representatives and even GPs or occupational therapists. As mentioned earlier, these clients could appear deceptively healthy – only a handful displayed overt physical symptoms, such as coughing, raspy voices or breathlessness. The rest were therefore painfully aware that, without proof in the form of a medical diagnosis, they could be perceived as frauds, both in their own eyes and those of others.

The sense of fraudulence (which one could refer to as impostor syndrome) is also accompanied by a strong sense of guilt – clients felt they were letting down their family and colleagues. They felt guilt for burdening partners who had to take on additional household tasks or colleagues to whom their workload and responsibilities had been shifted. Parents felt guilty for no longer being capable of engaging with their children. And those who were single experienced a greater degree of loneliness and isolation. There was

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equally a sense of abandonment from colleagues and line managers who stopped checking in or cancelled scheduled catch-up calls. As one client told me, 'A colleague was injured and they got messages, but with long COVID, there's just silence'. Many questioned whether they would ever be able to work again. And even those slated for a phased return to work, the fear was that the brain fog would prevent them from working effectively, which would lead them to being eventually dismissed or pushed out of the company.

The symptoms of fatigue, brain fog and their emotional fallout had such an impact on some clients that they no longer recognised who they once were. 'I lost my personality, interests and hobbies... I lost my spark...'. These multi-layered affective states, consisting of guilt, sense of failure, abandonment and loss of identity, amount to an overarching experience of shame. And shame, as we know, is that sleeper emotion³ that underlies so much in psychopathology.⁴ There therefore exists a circular relationship between long COVID and mental health, which exacerbates the symptomatology, an aspect corroborated by recent medical research.⁵

Treatment approach

As I illustrate my treatment approach, it's important to note that I delivered sessions within a broader support package, which included six sessions with a physiotherapist and six with a respiratory therapist. None of the long COVID sufferers had specifically requested mental health support and the greatest majority had never experienced any form of counselling. Consequently, in the first session, I was often met with perplexion and even diffidence – there was confusion about the nature of the call, which got lost among the myriad of appointment reminders these clients had received. But, more importantly, there was diffidence about how mental health support

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could help with the very real and tangible symptoms of fatigue, brain fog or breathlessness. Most therefore accepted to come on the call just to show their employer they were trying their best to get better.

It was an odd position to be in as a psychotherapist – however one for which my past experience of working within the corporate sector came in handy. I consequently formulated my own 'pitch', focusing on a two-pronged 'service offering' – on the one hand, I justified my presence by explaining that some research had shown a strong correlation between trauma and long COVID symptoms.^{5,6} I should add that for some individuals, long COVID felt like it had opened a door on experiences that had remained below the surface, and that using the space to address these, albeit limited to six sessions, could offer some form of relief and support. The other option was a more practical approach aimed at managing day-to-day symptoms, incorporating chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME)¹ protocols, focused mostly on pacing and limiting sensory overload.

Unprocessed trauma

My first client suffered from fatigue, joint pain, breathlessness, insomnia and an altered sense of smell. They had never spoken to a psychotherapist or counsellor before. In our first session, they disclosed how they felt long COVID had opened the gates to issues that had always been simmering below the surface. What emerged was an extensive history of emotional abuse and neglect. Through a therapeutic approach integrating person-centred, self-psychology, object relations and psychological education, by the end of the six sessions, they reported feeling like they had 'more room to spare' in their head. They felt validated and reported that their joint pain had disappeared and sleep pattern had returned to normal. They conceded the fatigue was still there but nowhere near as intense as in our first session.

I'm not implying that, thanks to six sessions of psychotherapy, this client was cured of long COVID symptoms. Nor am I suggesting that we had integrated the split-off parts⁷ of their endopsychic model⁸ – extensive relational trauma doesn't get metabolised⁹ in six sessions. However, it

was quite surprising to see the effect that our limited sessions of psychotherapy had on the intensity of their somatic symptoms, no matter how temporary this effect may have been.

Processed trauma

Although there were predictable crashes following social interactions, physical exertions or sensory overloads, my clients found it close to impossible to isolate triggers that could reliably help mitigate future busts, no matter how hard they tried to structure and pace their day. What seemed feasible one week – such as walking 100 meters, showering or limiting garden work to 15 minutes – would prove impossible the next. So the practical treatment approach first involved validation and education – reiterating that long COVID was a real condition, and that it wasn't just in their head. I would reference research papers, statistics and articles, and discuss the parallels with CFS and other functional disorders. Particularly with brain fog, I would use the more appropriate label of 'disorder of executive function'. We used labelling and education to validate their experiences.

The other dimensions of treatment included transparency and acceptance. I would be honest about the current limited knowledge of long COVID, that there's no known cure for it, and that there's scant predictability in symptoms. I was also transparent about the limitations of counselling in this context; that I couldn't take away their fatigue, breathlessness or brain fog. I validated their pain by being inquisitive and curious about the phenomenology of their experiences. I would tell them how I would hear other clients use similar metaphors when describing their symptoms. Although they were aware that many people across the world were suffering from long COVID, to hear they were not alone seemed reassuring. Consequently, I would encourage them to sign up to the NHS long COVID clinics, which offered online groups, among other things, as a form of support.

From a practical perspective, structuring their experiences and identifying the four types of fatigue (emotional, physical, cognitive, sensory), as per the NHS protocol, proved to be a very helpful technique, certainly more so than the daily diaries clients were asked to complete by other therapists,

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which often resulted in an overload of note keeping that many clients found overwhelming and tiring. In conjunction with CFS/ME protocols, we discussed modifying daily habits with the aim of decreasing sensory stimulation. This would help clients make sense of why they would feel overwhelmed when the TV was on in the room, or if several people were chatting next to them. Although there is no predictability in the symptoms, structuring their experience seemed to help restore some form of agency.

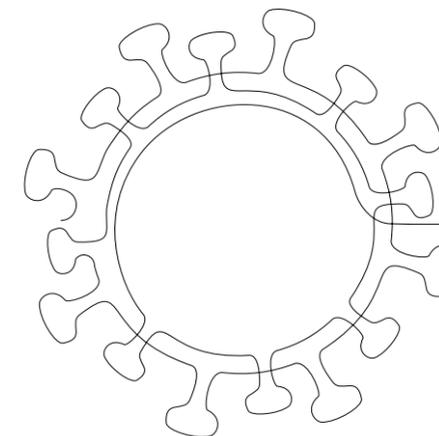
However, the practical goals of pacing and sensory awareness had to be carefully calibrated, particularly when the sense of hopelessness prevailed. In those circumstances, the benefits of social interaction could outweigh the benefits of following CFS/ME protocols. Consequently, by the end of treatment, we usually reached a phase that I labelled 'managing the trade-off' – finding ways to increase wellbeing through social engagement while being aware of the subsequent costs, a balancing act that clients would eventually need to fine-tune on their own through trial and error.

Implications

The emotional cost of long COVID materialises via multi-layered affective states that together constitute an experience of shame. This affective dimension of long COVID is a product of context rather than the condition itself, and it's one that exacerbates long COVID's somatic symptomatology. In addition, as the experience of shame has been shown empirically to be central to many forms of emotional suffering, such as depression, this circular relationship would corroborate the research statistics, pointing to higher mental health diagnosis after infection. And this shame has roots in society's current view of

illness. However, as we have seen with long COVID, illness cannot be defined as a purely physiological condition that occurs to an objective body and that can be measured in mechanistic terms. As Heidegger put it, '...you can never actually measure tears. If you try to measure them, you measure a fluid and drops at the most, but not tears.'¹⁰

The advent of long COVID forces us to at least revisit the dominant notions of pathology. In *The Normal and the Pathological*,¹¹ Canguilhem developed a notion of health that's centered on the ability of the living organism to establish its own vital norms. Illness would therefore be defined as the organism's inability to set new vital norms for itself in accordance with a changed environment or a change in its own organisation. Such a conceptualisation would at least enable sufferers of long COVID, CFS and other functional disorders to be recognised as ill, and therefore safeguard them from the dimension of shame that exacerbates an already burdensome condition. ●



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Marc-Andre Bosset is a UKCP registered and BACP accredited counsellor and psychotherapist in private practice in London. He started his

foray in the field of mental health by volunteering as a Samaritan and obtained his MA in Psychotherapy and Counselling from Regents University School of Psychotherapy and Psychology. He carried out his placement with the South London and Maudsley NHS Foundation Trust as a counsellor for three years before completing a Diploma in Advanced Clinical Practice with the Minster Centre in London. He spent the first part of his professional career in the corporate sector working for companies of differing sizes, from Fortune 500 firms to small start-ups, in Europe and North America.

YOUR THOUGHTS, PLEASE

If you have a response to the issues raised in this article, please write a letter, or respond with an article of your own. Email: privatepractice.editorial@bacp.co.uk

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