

'Everyone wants COVID to be over – but it isn't'

Catherine Jackson meets the practitioners specialising in supporting the growing number of people impacted by long COVID

'W'e are living in a world of denial. Everyone wants COVID-19 to be over; of course we do. But it isn't, and

I think it's irresponsible that those with the power to prevent its spread aren't doing more. Hundreds and thousands of people are becoming chronically ill after exposure to a virus that they are being told is no worse than the common cold.'

So says integrative counsellor and writer Elizabeth Turp, who specialises in working with people with long-term chronic illness and pain, and describes herself as an 'expert patient'. Her concern is the growing incidence of long COVID, which is affecting people even after the mildest of experiences of COVID-19. 'I could foresee this coming right from the start of the pandemic. All pandemics bring post-viral long-term health impacts. People are experiencing what may prove to be permanent disability and no one at Government level is taking it seriously,' she says. 'And in terms of chronic conditions, long COVID is particularly complex because of the multiplicity of symptoms involved.'

What might seem at first reading to be an overly apocalyptic vision surely needs serious consideration when you look at the numbers involved.¹ COVID-19 cases in August 2022 totalled some 944,700 across the UK, well down on the 3.7 million of January 2022, but not so far off the 1.1 million recorded in January 2021. People are still getting COVID-19. They may be dying in fewer numbers, but every case is someone who is at risk of developing long COVID, the effects of which are multiple, hugely complex and varied, potentially very disabling, and

mostly still mystifying medical research as to their causes and, therefore, how to treat them. Omicron is proving just as likely as other variants to lead to long COVID, and long COVID rates are rising rapidly, from almost 1.3 million in January to two million in July.²

And this is when people may turn to counsellors and psychotherapists for help, says Turp: 'They've tried everything else and it isn't helping. Often they are pretending so hard that everything is fine, but it isn't. Our job as therapists is to make space for all the mess – the fear, the loss, the guilt, the shame, the frustration and the anger – so they can begin the work on adjusting to disability and learning how to manage their symptoms.'

What is long COVID?

Long COVID can manifest as any and many of a long list of symptoms, often in combination. They include chronic fatigue, shortness of breath, chest pain, problems with memory and concentration ('brain fog'), difficulty sleeping, heart palpitations, dizziness, pins and needles, acute joint pain, depression and anxiety, tinnitus, ear ache, feeling sick, diarrhoea, stomach aches, loss of appetite, a high temperature, cough, headaches, sore throat, changes to sense of smell or taste and skin rashes. And there's more – hair loss, erectile problems and higher risk of stroke, heart attack and Alzheimer's.

Says Turp: 'Energy levels are low; you can't think straight or concentrate; you may have pain in strange places; your sleep may be poor when you need it most; your appetite and guts don't feel right; you are on an emotional rollercoaster. Much of this is normal following a viral infection as the body recovers and rebalances. The body

needs rest.' Not resting can lead to the condition becoming chronic, she warns.

She believes that some of the symptoms of long COVID may be due to our natural, instinctive threat-survival system, which is largely controlled by the amygdala. This is the part of the brain that sends us into 'protect and survive' or 'fight, flight or freeze' mode, overriding the more logical thinking of our frontal lobes. 'When we experience a serious threat, our brain responds to protect us – it scans for threats. The amygdala may become over-alert or hypervigilant, and this can contribute to physical symptoms in the body such as digestive problems, pain and sleep difficulties,' she says.

The official advice from the NHS is to contact your GP if any of these symptoms are still present four weeks after you have had COVID-19, and you may then be referred on for further tests and possibly an assessment at a specialist long COVID clinic. There are 68 of these in England, where a multidisciplinary team of specialists with expertise in the various aspects of the syndrome, sometimes (but not always) including psychological symptoms, will be able to assess you and recommend treatment. But there's nothing currently available that will lead to a cure. Long COVID remains a medical mystery – no physiological cause for its symptoms has yet been found. And it remains 'long' – some people who had COVID-19 in the first wave are still bed-bound by the symptoms.

According to Government data, some two million people are living with self-reported long COVID – two per cent of the population.² But, given the ongoing rates of COVID-19 infections, the numbers are inevitably accumulating. For some, the

symptoms are lasting a year and more; for 67%, they affect their day-to-day lives, and 20% are affected severely. Those most at risk are in middle age (35–69 years), female, living in deprived areas, working in frontline public sector occupations – teachers and health and social care workers – and have coexisting health conditions or disabilities. Essentially, they are those exposed to the highest viral loads because of their work, those rendered more vulnerable by disadvantage, and (arguably) those carrying the greatest burden of caring for others – who are often mid-life women.

However, research has so far failed to track down the causes of these symptoms, beyond COVID-19's known effects: damage to cardiac and lung function, blood clots and other physiological symptoms that can be identified through scans and medical tests. So, as members of the ME and chronic fatigue syndrome (CFS) community warned early on in the pandemic, people with long COVID are facing the same battles as they did to have their symptoms recognised and treated compassionately and appropriately.

Listen to the experts

Lesley Macniven caught COVID-19 very early on, in March 2020. A leadership development and management consultant and work coach by profession, she co-founded and volunteered to co-moderate a Facebook support group (longcovid.org) for people who were developing the symptoms that have come to be called long COVID. The group has since grown to more than 55,000 people worldwide, primarily based in the UK and US. 'What we want is recognition that we exist, research into why people aren't recovering and into treatments that work, and rehabilitation – there are hundreds and thousands of people severely disabled by this; there needs to be changes at every level to accommodate it,' she says.

It is the case that the majority of the research projects into long COVID funded by the National Institute for Health and Care Research (NIHR) are looking for causes and medical treatments. Only one is explicitly concerned with rehabilitation – working with people with long COVID

themselves to explore what helps them live with and manage the condition. This is the aptly acronymed LISTEN study (long COVID Personalised Self-management support- co-design and EvaluationN), led by Fiona Jones, Professor of rehabilitation research at St George's Hospital and Kingston University, London. Researchers are exploring in partnership with people with long COVID what works for them, and from this will develop and trial a programme to help them self-manage their symptoms. 'Long COVID is similar to other conditions where people feel they're not being listened to by healthcare professionals, or the symptoms that they're experiencing can't be explained by standard investigations, so they get referred to different departments. There isn't this ongoing support, so there's not only the experiences you're feeling but the anxiety that you're not getting the support that you need as well,' Professor Jones says.

But it's a small trial, with nothing like the budget of others. Do we not need more investment in helping people to live with a condition that is disabling so many?

Macniven agrees: 'There are things patients are finding that work for them but we just aren't being listened to. So listen to what we have to say, and we will listen to what you have to say, and we will get the best of both worlds.'

Sarah O'Connell has had ME for nine years; her 11-year-old daughter has had ME for more than three years, and more recently her son, aged seven, got long COVID, combined with PANS (inflammation of the brain that causes a lot of neuropsychiatric symptoms, such as separation anxiety, obsessive compulsive behaviours and emotional dysregulation),

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so she knows all too well what it is like to be faced with medical gaslighting. 'You can be consulting for something quite other than ME, but as soon as you mention the diagnosis, there's this vacant stare and you know what's going through their minds. You just feel helpless and hopeless – hopeless because you realise there's no connection and you can't trust this person and the care you will receive because of their response to the diagnosis; helpless in that you can't educate this person, there isn't time to explain it – you just have to do what you can to get the care you need.'

Professor of biological psychiatry at King's College London, Carmine Pariante has devoted his career to researching the links between mind, body and brain and diseases and disorders like CFS and long COVID that sit at the interface between them. He says, if a patient comes to a doctor saying something is wrong, then there is something wrong. The problem is that medical science hasn't yet caught up with the causes of illnesses like CFS and ME. 'Every psychological phenomenon has a biological substrate. Most psychological mechanisms are driven by biological changes in the brain – brain cells communicating. We know from research into pain that it is profoundly influenced by the cause – the tissue damage – but also by our mental state, our environment, how we interpret the pain, what the pain means for our health,' he says.

'But none of this takes away from the reality of the experience or implies that people invent these symptoms. Accepting that psychological and psychosocial factors influence your experience of the symptoms of your illness does not in any way imply the illness does not exist. It is just that we are behind with the science.'

Says Macniven, 'I would love everyone to have 10 minutes with a therapist just to hear the words, "You are not well but you are not broken." It would be like a drink of water in the desert. If only GPs would simply say: "I believe you and I can understand and I have noted your symptoms on your record and classified you as having long COVID and put you on a waiting list for a clinic, and meantime, what do you find helpful and how can we support you to self-manage the symptoms?"'

Counselling and COVID

Turp argues that every specialist long COVID clinic should include counsellors in the team. 'Everyone with a chronic long-term illness has psychological effects. Of course they do,' she says.

Kim Patel, also an integrative therapist specialising in working with chronic pain and long-term health conditions, summarises the main talking therapies offered in multidisciplinary pain management and chronic fatigue programmes: 'Mostly it's CBT and looking at issues like fear avoidance, and boom and busting; acceptance and commitment therapy (ACT) that's about finding valued goals and working towards them even in the presence of continuing pain or fatigue, and compassion-focused therapy (CFT), where again you are, for example, looking at boom-and-bust behaviours and the threat and drive systems, and bouncing between the two. And there's also the person-centred approach, which is more about self-awareness and self-acceptance.'

'These are all approaches that counsellors can offer if someone isn't getting the multidisciplinary support from a long COVID or chronic fatigue clinic,' she says, 'but they must have specialist training first. And I strongly believe these complex conditions need a multidisciplinary approach, to ensure the complexity of needs is properly explored and addressed.'

It isn't work that a generic counsellor without specialist knowledge and experience of working with chronic conditions should take on, Turp says. So much harm can be done if the counsellor's attitude is negative - and it is common even among counsellors, she says, to believe that the unexplained symptoms of chronic fatigue and brain fog are 'all in the mind'. If a client is led to believe that all they need to do is what amounts to graded exercise therapy - gradually push themselves beyond what they feel is a manageable level of activity - the evidence shows that it can result in even worse long-term illness, she says. 'Some therapists are COVID deniers; some are COVID minimisers - we are human beings, we are no different from the general population, where these beliefs are common.'

'You are not just losing what your body can do; you are losing what your brain can do - it is a complete loss of self. There is a huge grief'

Sarah O'Connell is a firm advocate for counselling. 'It has definitely helped me. It is such a tough thing to go through, when you have a chronic illness that affects your body and your brain. I used to be this articulate person with a career and something to say for myself, and now there are days when I can't even string a sentence together. You are not just losing what your body can do; you are losing what your brain can do - it is a complete loss of self. There is a huge grief - I am still processing it after nine years. It's so helpful to have someone there that you know you won't push away by talking about anything you want to and helping you to prioritise what you can do with your limited energy.'

Karen Rawden, a psychosynthesis psychotherapist, co-founded the Facebook group 'COVID-19 UK & Ireland Sufferer & Survivor Support' in March 2020. She experienced ME in her teens, so knew what was happening when, after contracting COVID, she found herself once more struggling with familiar, continuing symptoms. She started the Facebook group because she realised, having also survived cancer, that what she needed to help her through long COVID was contact with other people in the same situation: 'I had to find others who were going through this, to get solidarity, support and connection.' The group offered weekly peer support meetings, which Rawden facilitated. 'Each session lasted no more than 1.5 hours, with a set format for sharing, connecting and bearing witness to one another without judgment. No one offered advice or suggestions unless it was asked for. Being simply heard gives people who have suffered a sense of autonomy, agency and value.'

Her message to those with long COVID and those working with them is to listen

to their body and trust what it is saying. She says counsellors and psychotherapists have a key role in helping clients to grieve and develop a new relationship with their changed self, including with their body. 'Through therapy, people can find it easier to reconcile their experiences on their healing journey,' she says. 'Very often with COVID, at the beginning when people are immersed in the illness, it is like your emotions fade away. But there is a moment around four months after when the emotions come back in full force - anger, rage and then a low depression and a feeling of general discombobulation that can look like anxiety - a sort of churning inside. You may experience physical symptoms - increased heart rate, sweating, symptoms of a panic attack. So often clients come to me not realising that what they are dealing with is the aftermath of COVID, whether it's long COVID or the reconciliation of what they've been through.'

Rehabilitation

For Anu Garg, keeping foremost in mind that long COVID is essentially a physical condition is fundamental to how she works. She is an integrative counsellor, psychotherapist and accredited EMDR practitioner, and she draws on all these skills in her work with people with long COVID. She sees her role as akin to that of a rehabilitation psychologist: 'I regard what I do as providing the psychological rehabilitation alongside the physical and medical rehabilitation the client is getting elsewhere.'

The main focus for the work is loss, she says - loss of capacity, loss of function, loss of identity, loss of social role, loss of friendships, job, career, relationships. Unlike bereavement, this loss is continuing, gradual and cumulative.³ 'It is a gradual continual loss, going on and on. But in working with loss, we are also working in transition. People are constantly coming who they are now with who they were before, and they generally don't like themselves now. So, we need to explore what they can do now that they value.'

'Fortunately, many people do have some other skill or occupation they can still do within their reduced capacities.'

painting or writing. Some find that their relationships are better because they are not working full-time, so they can spend more time with family and partners. In our work, I will emphasise their improved relationship and how they are perhaps better able to listen and engage with their loved ones. Overall, my aim is to consolidate all that they see value in now, thereby enlarging their value system, but without them devaluing what they were.'

Session lengths may need to be flexible to accommodate the person's capacity to engage with the work, or she may see them once a fortnight or every three weeks, rather than weekly. 'Even half an hour can wipe someone out for the whole day,' she points out. 'You are gradually transitioning them to the new them. It's a slow process because it's two steps forward and one back. They like the new them, but then again, they don't like it because they are still mourning the old them. Once they accept and adapt to the new them, then you can start to focus on the future and how they can maintain a healthy and better quality of life.'

Another important feature of what she offers is pluralism. 'Be very multimodal - don't be precious about your area of expertise, and if you don't have the skills, refer on,' she says. 'Draw on other resources and other professions - occupational therapy resources can be very helpful. Provide them with practical information and resources that they can explore and use.'

Lesley Macniven strongly concurs. 'For people with long COVID, counsellors should always be thinking "Where else can I direct my client?,"' she says. She has established an offshoot campaign group that is looking at the implications of long COVID for people's employment. 'We need psychological support but there's also practical support needed urgently around issues like employment and welfare benefits, especially with the cost of living crisis,' she says. The group (longcovidwork.co.uk) is campaigning for changes to the benefits system and assessments for Employment Support Allowance to recognise the needs of people with episodic conditions like long COVID. Wherever possible, Macniven

says, employers should take steps to enable people with long COVID to stay in their jobs rather than resign or retire early.

Values

Values - identifying and valuing what matters, while also acknowledging what has been lost - also drives the work of Chris Hutchins-Joss, team lead and CBT therapist at DHC Talking Therapies (DHC). DHC delivers IAPT services across Surrey and offers an eight-week groupwork course on 'Living Well with Long COVID', in addition to the usual IAPT offer of one-to-one talking therapy with either a CBT practitioner or a person-centred therapist, or guided self-help. Initially, the specialist long COVID clinics generally included a psychologist in the team. This seems to have fallen away and some local IAPT services have stepped into that space by expanding their existing specialist support for people with long-term conditions to include long COVID.

Around a quarter of people presenting with symptoms of long COVID attend the eight-session group, which is based on ACT. The aim of the group is to encourage people to explore what they are struggling with, physically and emotionally, what they are doing to cope with these symptoms in the moment, and how effective those coping techniques are: 'People talk about worrying about the future, withdrawing from and snapping at loved ones, substance use and overeating - these are all common and very understandable responses to struggling with long COVID. Our role is to help them figure out what is working well and what isn't, with a view to continuing with what is effective,' Hutchins-Joss says.

'Once people accept and adapt to the new them, then you can start to focus on how they can maintain a healthy and better quality of life'

'We talk a lot on the course about how we hurt where we care - and that is because we do really care.' So they will explore what participants miss most that long COVID prevents them doing, and what they can do that might serve that same function and meet those needs. 'You can see the light-bulb moment when they realise there is another way of achieving that same important ingredient in their life. A lot of the work is about shifting our expectations to finding something more practical and feasible in the short term that can achieve it,' he says.

It is also about rescripting their lives. 'We all have certain stories about ourselves that we are hooked into - the story we tell ourselves and others about who we are. So the work is about finding how to unhook from those stories and create new ones about how we are dealing with the way that story is changing because of the effects of long COVID.'

Acceptance and hope

As someone who is disabled, counsellor Emma West believes the profession has much to contribute to the multidisciplinary approach to long COVID. 'I think there is a twofold role. One is helping people manage what is going on at this moment in time and exploring strategies, techniques, lifestyle changes and self-management techniques that work for them. And the second, for long COVID in particular where we know so little about its long-term outcomes, is helping people maintain hope. I am concerned that telling people, "It'll never get better, and you have to live with that," could become a self-fulfilling prophecy. Yes, it's potentially a life-changing loss, so there's some psycho-education to be done about the effects of loss and how it's normal to go through the stages of anger, denial and so forth and come to that place of acceptance. But they don't have to stop there, and people often need support, such as from a counsellor, to then come up with creative ways of doing things differently and living differently.'

Words like 'acceptance' and 'recovery' are highly loaded within the ME/CFS and now long COVID world. Says Elizabeth Turp: 'Acceptance is not the same as resignation. It's not about accepting

that your problem is permanent. It's acceptance of where you are now: "This is what is happening to me at the moment, and I am going to stay with that and process it." I think it's only when they accept that this is where they are that people with long COVID can begin to learn how to self-manage the condition to make their quality of life better or start to heal.'

Kim Patel has personal experience of living with chronic pain: 'Acceptance is courageous, because you have to be courageous to actively accept that this is how your life is now and live accordingly,' she says. It's what former occupational therapist Lydia Rolley calls 'living with the new normal'. She is retired now but worked in a regional chronic fatigue service for 15 years, and latterly trained as a systemic family therapist. She has just published a book about recovery for people living with chronic fatigue, which she hopes will also be helpful for those with long COVID who are struggling to manage fatigue.⁴

The book is a very practical guide to pacing – how, in the early stages, to live within your energy resources and balance your wish to do more with a realistic appraisal of your capacities. 'The whole concept of "new normal" is a good illustration of this whole condition,' she says. 'A lot of people can improve and recover. Where they get to isn't necessarily where they started but it will be better than how they have been. I use the phrase "reasonable hope", coined by Kaethe Weingarten – we want people to have hope but not to ask too much of themselves initially.'

'Just sitting with a professional who believes you is very healing,' says Turp. 'You have to learn how to pace yourself,

'People need to believe they can recover. There is nothing wrong with giving people hope. Without it you fall into learned helplessness'

how to put yourself first and how to ask for help. That is what acceptance is – when you stop fighting, accept that what you are going through is terrible; that it is what is happening to you and there is no point fighting that. But it can take years for some people to get to the point.'

Jan Rothney has recently published a book on recovery from chronic fatigue⁵ that is based on her hypothesis that it is the body's response to an overload of stress, physical and mental, and its way of keeping safe. A former health and social care lecturer who has worked with children with behavioural difficulties, she has had ME twice and so brings personal experience and professional knowledge to formulating her Reset to Thrive recovery programme, which she originally ran as a clinic for many years and now online.

Like Turp, she argues that CFS is a result of the malfunctioning of the body's autonomic nervous system (ANS) – the system that governs how the body responds to threat and danger, whether through fight or flight or immobilisation. The problem is that, when the person is able to start being active again, the ANS has reset the threshold for shutdown at a much lower level, as a safety mechanism to prevent total collapse happening again, she argues. It is then up to the individual to consciously override that new instinctive, self-preserving cut-off, Rothney says.

'We need to train the amygdala that we are safe – we humans have the capacity to activate the higher brain to override the malfunctioning system. Some people are full of self-loathing and frustration – you need to find emotional detachment, to become this little Buddha that just watches what is happening and is curious about it but knows it's your instinctive survival system running amok, stopping the polyvagal system from producing normal healthy functioning.'

She too thinks it is important to nurture hope: 'People need to believe they can recover. Helping them is about introducing them to that belief in recovery, finding excitement in making progress, becoming resilient and changing their expectations of themselves. There is nothing wrong with giving people hope. Without hope, you fall into learned helplessness.'

It is inevitable that, where medical science fails us, people will seek alternative answers. Not knowing and uncertainty about the future are intensely destabilising, as is feeling you have lost control over your life. Concern has been voiced at some of the more experimental, unproven medical treatments that are being sold (at high prices) to the desperate and credulous, such as 'blood washing'.⁶ By encouraging and nurturing people's ability to accept where they are and feel compassion for their changed self and the many losses they have experienced, counselling and psychotherapy can perhaps provide a safe space where they have more chance of finding ways to live within the capacities of the 'new normal' for them. ■

• For further information about pacing for wellbeing, fatigue and post-viral recovery, see www.elizabethturp.co.uk

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