

# How storytelling can help people with long Covid

*‘Body mapping’ involves creating a visual narrative to help convey the impact of post-infectious diseases to family, friends and health workers.*  
**Theres Lüthi reports**

Post-infectious diseases such as long Covid and ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) pose a puzzle to the medical establishment. Patients report debilitating symptoms such as extreme fatigue, shortness of breath or muscle pain, but often show normal results on routine medical checkups. And many sufferers do not look ill, leading some to question the severity of their disease. In the absence of diagnostic tools or an understanding of the pathophysiological processes, many sufferers find it difficult to share their experiences. They lack a verbal language that expresses the true impact of the illness.

Now, researchers from Oxford University are using the technique of “body mapping” to help patients better communicate the physical, cognitive and emotional dimensions of their illness to family, friends and health professionals.

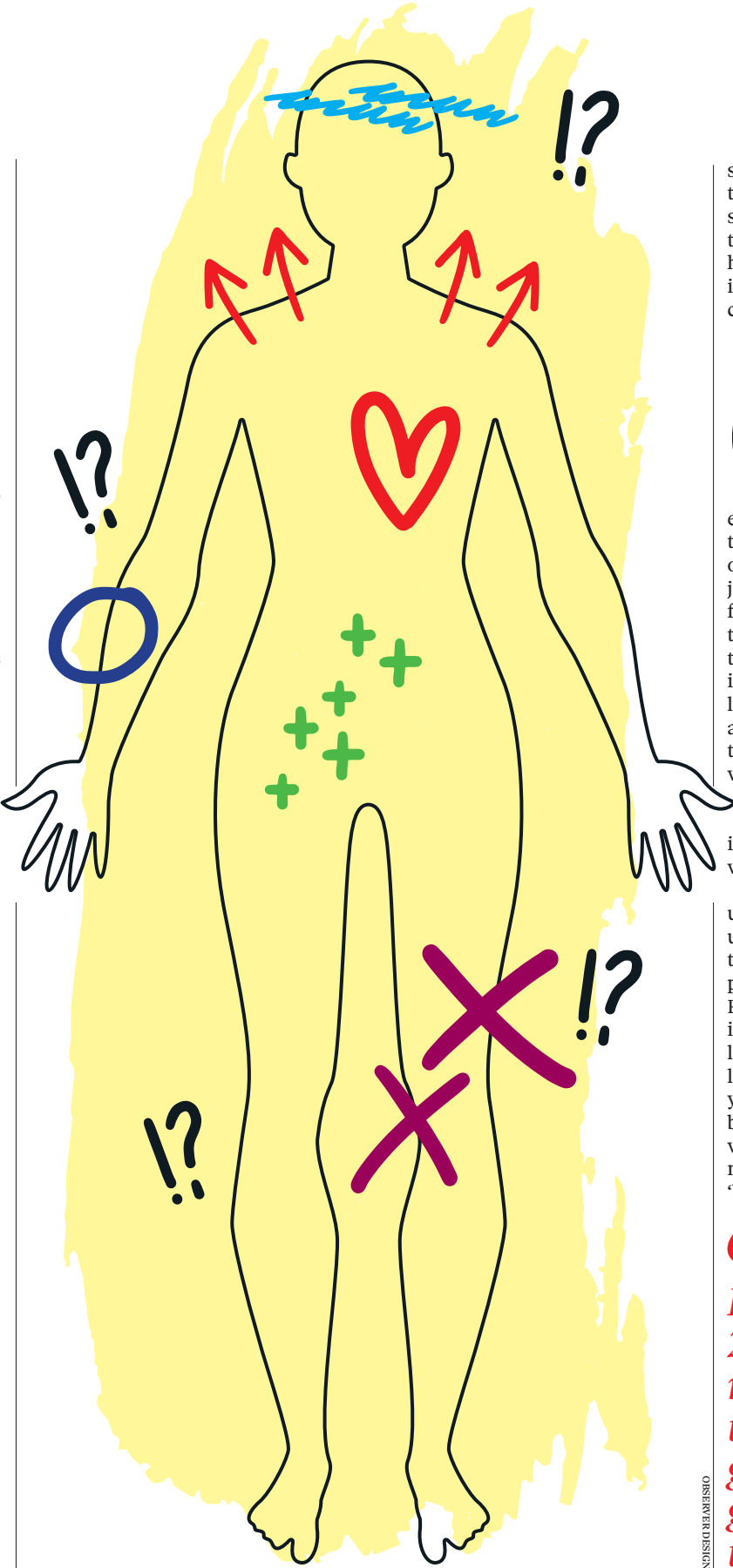
Oxford’s Maaret Jokela-Pansini is interested in how illness feels. “People experience illness in many different ways depending on economic, social and cultural factors

such as age, gender or possibilities to access healthcare,” she says. “When we talk about health and disease, we must always take space and time into account.”

Jokela-Pansini first became acquainted with body mapping when she was working in a women’s organisation in Honduras that ran workshops in prisons. The technique, which involves creating a lifesize outline of a body, aims to capture patients’ experiences and has been used in trauma therapy and with chronic pain patients. “We call it ‘alternative cartography,’” she says. “We think of the body as a map: pain, emotions, experiences, they are all located somewhere in your body, which in turn is seen in relation to a specific environment.”

Last year, she teamed up with the Oxford professor Beth Greenhough and they adapted the method for their project Visualising Long Covid. So far, eight workshops have been organised in London and Oxford with the help of the charity Long Covid Support. The participants begin with tracing their bodies on paper. They are then given a list of questions and asked to draw, write or collage their responses on to the map of their body. How did you experience your health before getting long Covid? What impact has it had on everyday life? What kind of support do you get? How has the illness changed the way you view yourself?

“Body mapping is really about storytelling,” says Jokela-Pansini. Most participants begin with their head or their heart. “Family members are often in the heart,” she says. And despite each body map being unique, there are recurring motifs, such as



shadows. “Participants use them in the sense that they are now only a shadow of what they were before and that they feel left behind. The world has moved on, but they are still living in the pandemic – an experience that can be profoundly isolating.”

Onagh Cousins at Long Covid Support says body mapping allowed her to reflect on how illness is experienced in different parts of the body. Cousins participated in one of the first workshops and later joined the project as a research fellow. “You might ask: where is the pain located? Is it in the gut, in the heart, in the arms? What does it feel like? Is it red, is it orange, is it lots of scribbles, is it soft? And what about going to a clinician and being told: ‘It’s all in your head’? Where would you draw the emotion of that experience on your body?” Body mapping invites lots of different ideas and allows you to share them with other participants, she says.

Cousins finds the vocabulary used in connection with long Covid unhelpful. “Fatigue, ‘brain fog’ – these words don’t do justice to what people are actually experiencing. Fatigue sounds like tiredness, but it is in fact deep sickness. It feels like the worst hangover of your life combined with the worst flu of your life. Your brain and your whole body, everything, feels very, very weak and fragile. You’re not you any more.” The same goes for the term ‘brain fog’, which has an almost cosy

“*I spent my mid-20s waiting to recover. It was time I will never get back. It’s the grief for a life that wasn’t lived*”

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connotation. It doesn't come close to describing how paralysing the cognitive symptoms can actually be.

Cousins is now 29. She had just qualified for the British Olympic rowing team when she contracted Covid in March 2020 and subsequently developed long Covid and ME/CFS. The illness forced her to give up her rowing career. That hurt. But it wasn't the hardest part. "I was in my mid-20s; I should have been in the prime of my health. But I spent them waiting for my body to recover. It wasn't just weeks or months – it was years, time I can never get back. It's the grief for a life that wasn't lived – the things I could have done, the people I could have met, the experiences I could have had."

The researchers have now developed an online toolkit that makes body mapping accessible to more people, including those who are unable to leave their homes due to their illness. "In the coming year, we hope to hold regular online body mapping workshops," says Cousins.

But can this tool actually improve the wellbeing of people with long Covid? Not in the sense that it will heal them, says Jokela-Pansini. But creative research methods such as body mapping allow patients to express themselves differently so that their families, friends and possibly even clinicians can better understand how they feel.

"I think such body maps have utility," says Carolyn Chew-Graham, a GP in Manchester who was not involved in the research. "Asking patients to record their symptoms can be helpful not only for the individual, but it could also be useful to show the body map to a GP and say: 'This is where all my symptoms are.' That then allows them to discuss each body area and symptom and come up with a management plan."

In addition, body maps may give patients more credibility. "Many people with long Covid struggle with family members not believing them," says Chew-Graham. "It isn't just healthcare professionals who can gaslight patients, it's also partners and family members." This can be especially true in some ethnic minority groups where fatigue is often stigmatised, as Chew-Graham recently found in a study. The sense of not feeling worthy of care, as well as low awareness of available support, presents barriers in sufferers of long Covid seeking help.

Jokela-Pansini considers it crucial to include patients from ethnic minorities in future studies. "We have a lot of data for white middle-class women, but we don't have much information about women with migrant backgrounds." When an illness so thoroughly disrupts everyday life, it is all the more important to take a holistic view of it. Social scientists, biomedical researchers, clinicians, patients and carers all have a part to play: "It's important to look at all these different layers, because each one of them contributes to a better understanding of post-infectious disease."

The networker

# John Naughton



## With his toxic revamp, Emperor Zuckerberg is preparing to be Trump's puppet

Years ago the *Economist* magazine had a striking cover in which Mark Zuckerberg, the founder of Facebook, was portrayed as a languid clone of the Roman emperor Augustus. This was inspired by stories that Zuck was fascinated by Gus. On honeymoon in Rome in 2012, for example, he took so many photos of the emperor's sculptures that his wife joked it was as if there were three people on the holiday. The couple even named their second daughter August.

Explaining his fascination for Rome's first emperor, Zuckerberg told the *New Yorker* that "basically, through a really harsh approach, he established 200 years of world peace... What are the trade-offs in that? On the one hand, world peace is a long-term goal that people talk about today [but] that didn't come for free, and he had to do certain things."

He had indeed. And guess what? Last November, Zuckerberg – who had thrown Donald Trump off Facebook and Instagram in the wake of 6 January 2021 – flew to Florida to dine with the US's new emperor, a man who a few months earlier had said that his dinner guest would "spend the rest of his life in prison" if he attempted to interfere in the 2024 US election.

It seems that the Meta boss emerged from Mar-a-Lago convinced that – like Augustus before him – he had "to do certain things". He had already embarked on changing his look. Gone were the jeans, grey T-shirts and hoodies and close-cropped hair of old, to be replaced by a curly mop, relaxed T-shirts in new colours, a shearling jacket and a £735,000 watch. Oh – and chains, lots of them.

But that was just about style. After his dinner with Trump, Zuck tackled substance, namely some of his company's practices that the Maga crowd found infuriating. He spent six weeks closeted with his top policy and communications executives working out the sweeping changes that would be needed to keep Meta out of Trump's firing line. And on 7 January he revealed them in a video.

The company, he explained, would change how speech was handled in its apps, and it would relax restrictions on how people could talk about hot topics such as immigration, sexuality and gender. It would dump its fact-checking



*Curls, chains and relaxed tees... Mark Zuckerberg shows off his new look.*  
Getty Images

### What I'm reading

John Naughton's recommendations

**Take back control**  
Really insightful blogpost by Rob Miller on the renewed relevance of the Luddites' story with respect to creativity in the digital age.

**Essential reading**  
Tina Brown, right, is on Substack, and bloody good she is too.

**Must mute Musk**  
Peter Geoghegan arguing on his Democracy for Sale newsletter why European democracies need to start taking action against foreign interference.



operations and replace them with the feeble "community notes" approach adopted by Elon Musk on X. It would terminate its work on diversity, equity and inclusion (DEI) that was so loathed by the Maga crowd, eliminate the role of chief diversity officer, and abandon its diversity hiring goals.

After that, Zuck spent three hours on Joe Rogan's podcast in which, among other things, he bumbled on about the need for a more macho vibe in the corporate world. "Masculine energy is good," he said, "and obviously, society has plenty of that, but I think corporate culture was really trying to get away from it. I think having a culture that celebrates the aggression a bit more has its own merits that are really positive." You get the drift. The world needs more macho CEOs. More importantly, though, there's a new emperor in town and Zuck needs to keep on the right side of him. But then on 9 January the *Intercept* had a scoop that illustrates how this swerve plays out on the ground. It came in the

form of leaked internal training materials for content moderators on Meta's platforms.

The new guidelines give users new freedoms to post a wide array of derogatory remarks about race, nationality, ethnicity, sexual orientation and gender identity. Examples of what's now allowable (at least in the US) include: "Immigrants are grubby, filthy pieces of shit"; "Gays are freaks"; "Trans people are immoral." The guidance is riddled with contradictions. "Migrants are no better than vomit" is allowed, but "Muslims make me want to throw up" should be removed because it claims that a group "causes sickness". "These damn immigrants can't be trusted, they're all criminals" is OK but "Black people are all drug dealers" remains prohibited. And so on.

On one level these revelations merely confirm that effective "moderation" of content on social media is a Sisyphean task – at least on platforms with business models that prioritise engagement (and therefore extremism) over decorum. But at a deeper level, the tale of Zuckerberg's swerve usefully illustrates what the future holds for the tech industry: when Donald Trump says "jump", Silicon Valley's only question will be, "how high?"