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RECOVERY REPORT

What 75 YouTube Interviews Say About Recovery from Chronic Fatigue Syndrome and/or Related Illnesses

EXECUTIVE SUMMARY

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Executive Summary

Overview

In recent years, the phrase 'recovery is possible' has become synonymous with the chronic fatigue syndrome (CFS) recovery community and for good reason. As anyone with first-hand experience will know, people with CFS are told that they will not recover—including by doctors. According to the analysis of first-hand social media accounts shared in this report, the medical necessity of this messaging is challenged and an alternative set of messages accompanies the experience of recovery.

CFS, also known medically and in the UK patient community as myalgic encephalomyelitis (ME) or more commonly ME/CFS, is represented to the public as follows:

> A long-term condition that can affect different parts of the body. The most common symptom is extreme tiredness. The cause of ME/CFS is unknown. … While there's currently no cure for ME/CFS, there are treatments that may help you manage the condition and relieve the symptoms. Treatments include energy management, cognitive behavioural therapy and medications prescribed for pain or sleeping problems. … People with ME/CFS will need to adapt their daily routine and pattern of activities on a long-term basis. There may be periods when your symptoms get better or worse. (National Health Service 2026)

The National Health Service (NHS) webpage further directs people to the ME Association—a charity that has consistently opposed public discussion of recovery and those who represent its message.[1]

A core finding of the Recovery is Possible study discussed in the *Recovery Report* is that the people who recover from CFS and/or related chronic illnesses have undergone hurt and devastation, betrayal and mistrust, fear and confusion at the negative message of non-recovery stemming from medical quarters. The message of non-recovery is experienced as unbearable. Medically, is it necessary? Not according to the analysis of the accounts of recovery discussed here. Section 2. Onset of symptoms and Section 3. Encounters with medicine make clear that medical ideas about the 'chronicity' (Smith 2005) of CFS permeate the way that illness and recovery are experienced and narrated.

[1] The campaigning activities of the ME Association can be tracked through media representation (through the media appearances of Dr Charles Shepherd), letters of complaint to public bodies (including the Advertising Standards Authority, universities and the BBC), letters of complaint to individual academics and academic organisations (including professional bodies and journals) and of course government bodies and representatives. An example of complaint about the use of the term 'recovery' by recovery programmes and practitioners is discussed in Cupit et al. (2025).

A second core finding is that the people who recover from CFS and/or related chronic illnesses do so of their own accord and also not independently—recovery narratives represent the transformational power of specific kinds of knowledge, relations of support and often non-medical guidance. In the report, these are discussed in Section 4. Mindset as the gateway to recovery, Section 5 Mindset as a recovery practice and Section 7. Forms of support: Care, pedagogy and mutual aid.

According to recovery narratives, negative medical encounters that promise to tank all prospects of recovery catalyse a search for recovery outside formal medical settings. Belief in one's own recovery and having an explanation of the origins of illness and/or symptoms whose explanatory power provides recognition and validation of one's experience and compels a new way of thinking about one's illness/symptoms as recoverable, co-occur across recovery narratives. The role of belief in particular is discussed in Section 6. Recovery mindset: Hope-belief and legitimate optimism. These themes or strands of recovery experience anchor the recovery mindset—a wholesale reorientation towards oneself and one's embodiment in pursuit of recovery. In the interviews analysed for this study, self-determination is the predominant value associated with the recovery mindset.

A third core finding is that recovery from CFS and/or related chronic illnesses is narrated as a personal transformation and that the description of this personal transformation largely in the language of what the report terms 'overextension' acts as an account of the social pressures involved in the developing and sustaining of such illnesses. Discussed in Section 8. Social illness, identity and the overextended personality, this complex and sensitive subject is ethically approached through a careful thinking through of the multiple associations and implications that are represented in accounts of personal change. Boundary-setting and self-compassion are described as key to renegotiating one's sense of self through one's return to health.

The findings of the *Recovery Report* are the result of a social and cultural analysis of 75 recovery interviews produced for the YouTube channel of Raelan Agle. Raelan's channel is one of four focused on raising awareness of recovery from CFS. With a combined reach of 200,000 subscribers and more than 23 million views, these channels act as a central hub for a mushrooming network of online communities and personal social media profiles engaged in redefining CFS not only as a condition from which people can recover, but as at least in part a social and cultural experience. At the centre of this emergent digital culture is the recovery interview, whose mobilising force is best represented by Raelan's channel, home to nearly 300 interviews with people who have recovered or achieved measured improvement in their symptoms. For the newly emergent digital culture of CFS recovery, recovery stories are a staple 'recovery media'—making hope for recovery accessible and providing information, reassurance and know-how to people with chronic symptoms. For research, recovery interviews are

occurring in a 'natural' social context, providing an opportunity to hear first-hand accounts unmatched in scope and dexterity.[2]

The *Recovery Report* is the first publication from the Recovery is Possible study, conducted by Dr Sarah Cefai, Senior Lecturer in Gender and Cultural Studies at Goldsmiths, University of London, and Leverhulme Research Fellow 2024–25. It is published as open access to ensure findings reach people in the recovery community and people affected by CFS or related chronic illness. In the broader Recovery is Possible study, Cefai examines CFS recovery as a cultural and political object—as something that is culturally articulated as well as discursively and institutionally produced, represented and thwarted.

The *Recovery Report* is first and foremost a community report. Findings are also relevant to professional stakeholders including clinicians, policymakers, researchers, and patient communities.

Context

Why this research matters

Recent medical research suggests over 400,000 people are affected by ME/CFS in the UK alone (Samms and Ponting 2025)—a figure that rises to two million when including those living with long COVID (Hasan, Rogers, Tucker and Fraser 2025). With the online recovery community, this report treats long COVID as a related chronic illness. The rapid growth of clinical, healthcare and wellbeing needs resulting from long COVID has stimulated an unprecedented expansion and transformation of post-infectious disease research. This has coincided with the emboldening of biomedical perspectives within the UK government's ME/CFS health policy (Department of Health and Social Care 2025) and patient support and advocacy groups. The doubling down on an exclusively biomedical explanation of illness in representations of CFS is accompanied by a 'chronicity rhetoric', according to which diagnoses such as fibromyalgia and POTS represent these conditions as relatively stable though fluctuating (Cupit et al. 2025; Smith 2005), even if patient perspectives diverge from this institutional perspective. The chronicity rhetoric has taken on a new significance in the era of long COVID research, mobilised to agitate for funding for biomedical research and technology, as seen in the recent award of £4.7 million allocated to ME/CFS genomics (Department of Health and Social Care 2026).

The message of chronicity or non-recovery is not limited to medical discourse but is culturally pervasive and has devastating consequences for those diagnosed with CFS. If first-hand accounts

[2] Relative to the affected population, research on recovery from CFS is scant. A full literature review is beyond scope of this community report. A list of existing studies on recovery narratives is available in the report, and a list of further reading is available on the research website: https://sites.gold.ac.uk/recoveryispossible/.

of recovery from CFS—told predominantly by women—are to be believed, the government's definition of CFS as a long-term condition is simply not true.

The findings discussed in this study reflect what people who have recovered say about their experience of recovery to social media. These findings suggest that the message of non-recovery, if not wholly responsible for the patient outcomes it describes, at least significantly contributes to them. Every account of recovery included in this study implies or directly discusses the belief in recovery as a vital turning point in one's journey to improvement. According to the accounts discussed here, with the right information and support, significantly more people could be recovering from CFS than currently do so.

Recovery interviews on Raelan Agle's YouTube and other digital media are readily accessible to a wide audience, but thus far have not been the subject of policy debate or academic research. Those who have recovered from CFS harbour a potential wealth of knowledge and data towards which, as the first of its kind, the *Recovery Report* can only gesture. Not only are those who have recovered not the subjects of research or their bodies the sources of biological information, the de facto exclusion of recovery from the purview of CFS research is unaccounted for as a limitation.[3] Meanwhile, hundreds of thousands of people are turning to YouTube and the wider online recovery community to learn from 'recovery media'. The accounts taken for this study suggest that both social and cultural research, as well as patients' use of social media, hold much significance for research.

The subject of recovery from CFS or ME/CFS is a contested one. The *Recovery Report* makes it clear that people who narrate their recovery from CFS do so in terms that sit in tension with the existing framework used by the NHS.

Scope and Approach

What the researcher did

The primary objective of the analysis of recovery interviews was to 'give voice' to those who have recovered from CFS and/or related illnesses in formal public discourse. The analysis also sought to learn from those who have recovered, to show how and why recovery stories matter

[3] A recent example of this is the DecodeME study led by Dr Chris Ponting. During the public seminar presentation of findings, Ponting reported that "these genetic signals are not perfect predictors of disease. … They're not able to say anything about recovery. For that, we would have needed to have done a GWAS genome-wide association study) on recovery, on those who have or have not recovered" (Decode ME 2025). In fact, the genetics of people who have recovered have been assimilated to those who have not (some people in the study's sample will have recovered). Building on DecodeME, the UK government recently announced a £4.75 million investment in SequenceME 'to offer new hope' to people living with the condition (Department of Health and Social Care 2026): 'CFS patients in the UK are set to benefit from a world-first genomics study into the condition, also known as ME, which affects hundreds of thousands of people nationwide, the government has announced today.' The announcement does not detail the proposed link between genomes (research) and benefits (for people).

in relation to specific social, cultural and medical contexts. The researcher framed the research process, including the recruitment of participants and their interviews with Raelan, in view of the ethics of reciprocity central to community-based participatory action research (Maiter, Simich, Jacobson and Wise 2008). All of Raelan's interviewees were invited to share their accounts to the study. With their informed consent, following a pilot conducted in the summer of 2024, data analysis began in Autumn 2025. A total of 75 interviews recorded by Raelan for her YouTube channel were included in the final study.

Of the included interviews, 77% (n = 58) are given by people who describe themselves as completely recovered from CFS and/or related illnesses. The remaining 23% (n = 17) considered themselves to be substantially recovered but still in the process of regaining their health and wellbeing.

An ME/CFS diagnosis represents the majority experience, for 63% of participants (n = 47), while 31% of participants (n = 23) were diagnosed with long COVID (some were diagnosed with CFS then long COVID, or long COVID then CFS).

Just over half of participants only discussed their diagnosis of ME/CFS or long COVID, whereas just under a third (n = 23) disclosed one or several more diagnoses, notably postural orthostatic tachycardia syndrome (POTS).

Research design was informed by the following assumptions about recovery: (1) recovery is singularly lived and subjectively experienced and (2) no two participants' symptoms are identical, and neither are their journeys to being well. Analysis of interview data used the textual methods of close reading, 'thinking with', thematic analysis, narrative analysis and critical discourse analysis. Drawing on gender and cultural studies, these techniques of critical interpretation and situated, embodied and partial perspective (Haraway 1991) position data analysis as a material, historical encounter—occurring from within relations of power/knowledge (Foucault 1980; Oakley 1981; Smith 2005). Additionally, the researcher's feminist knowledge of embodiment and affect studies provided a framework for interpreting the social strains and narrative turning points represented in the interviews. The resulting themes were organised schematically, which produced a clear narrative arc that consistently underpins what at first appear to be biographically unique events, experiences and encounters. The key methodological finding of the report is that **recovery narratives cluster not according to their appearance on YouTube but as an effect of the deep social structures that shape the lived experience of CFS and related illnesses, as well as recovery from them.**

A bespoke semantic and sentimental computational analysis using Claude Code (Anthropic) was applied to corroborate the findings of the schematic analysis. A more extended use of this analysis is beyond scope of the *Recovery Report* and has been reserved for future study.

Limitations

The study is based on a very select group of people: firstly, people who have recovered from an illness that is represented as long-term; secondly, people who have put themselves forward to talk about their experience of illness in the online recovery community. Moreover, nearly two thirds of the interviews are with people who started working as non-medical practitioners following their recoveries—as coaches or practitioners of nervous system regulation and other mind-body recovery techniques. Without further research, there is no way to know how the sample has shaped findings. However, the consistency of the findings with pre-existing social and cultural knowledge, as well as the findings of a small number of published studies examining recovery narratives suggests broad applicability (see: Bakken, Mengshoel, Synnes and Strand 2023; Harper 2026, forthcoming; Hasan, Kuyvenhoven, Chowdhury, et al. 2024; Ingman, Chalder and Lawrence 2025; Krabbe, Groven, Bjorbækmo, et al. 2023; Linnros, Andreasson, Norlin and Hydén 2026).

The select group can be understood in a range of ways. In line with the gender ratio seen in the wider community, the group represents a bias towards women's experience—4 out of 5 participants are women. Research design also assumed that the women who speak about recovery from CFS and/or related chronic illnesses are not taken seriously because they are women and that the feminisation of this under-researched condition is transferred to men's experience. The analysis proceeded on the assumption that such accounts should be taken at face value to **allow the integrity of people's accounts to be assessed according to a rigorous social and cultural analysis of what is being said** rather than according to cultural predispositions towards women as subjects of knowledge (disregarded in medicine) or partakers in YouTube (as the social media of young people and the radicalised right).

Undertaking a social and cultural analysis through the lens of gender and cultural studies is also a limitation, insofar as any resulting knowledge could be regarded as inferior to medical science. The study is limited by a lack of funding, itself a reflection of a broader cultural context. Community-based participant action research cannot mitigate against unwanted negative attention that might be directed towards the community as a result of the research.

Key Findings

What the research found out

The *Recovery Report* places emphasis on the legitimacy of the voices of those who have recovered and seeks to contribute to this legitimacy through academic analysis. The below discussion and summary offers a synopsis and quotations from participants' YouTube recovery interviews. Findings have been presented in a horizontal fashion on the understanding that their importance will shift according to the interests of different readers.

1. People's accounts of recovery reveal patterns of experience

Across the 75 interviews, recovery is talked about in recurring ways, revealing a consistent pattern of experience. Themes associated with both developing and recovering from CFS and/or related chronic illnesses are consistent across recovery interviews. Participants' ways of talking make it clear that recovery is not happenstance or spontaneous.

Recovery narratives represent shared knowledge, intelligence and know-how (an 'epistemological community' connected to a 'movement for change'). Accounts of the experience of recovery could provide an evidence base for the meaningful development of CFS research and policy.

2. People's accounts of recovery redefine CFS as a condition from which one can recover

Recovery stories provide first-hand evidence that recovery is possible. Recovery narratives do not focus on recovery as such. Rather, they place emphasis on the reconceptualisation of CFS and related chronic illnesses from the point of view of having recovered, or still being in the process of recovery. Key to the redefinition of CFS as a condition from which one can recover is the reconceptualisation of CFS as a social and cultural experience that is subject to our influence.

3. Mindset is consistently associated with recovery

The narrative arcs represented in recovery stories are organised according to turning points, the most significant of which is the participant's realisation that they themselves can recover. One's belief in one's own recovery constitutes a turning point—a paradigm shift that lays the foundation of a recovery mindset. The recovery mindset is subsequently underpinned by belief in one's own recovery, but is also strengthened through the belief of others.

The shift from an assumption of 'non-recovery' to a recovery mindset is represented across the interview narratives, suggesting that non-recovery is the assumed prognosis and a widespread cultural idea. The recovery mindset is embodied and experienced—a wholesale somatic re-orientation towards oneself, one's body, and what is possible, that is catalysed by:

- encountering a believable explanation of symptoms that is also an explanation that rejects the representation of CFS as an interminable illness;
- encountering others who have recovered, who are able to narrate their experience of recovery first-hand; and
- being activated to deliberately pursue one's own recovery.

4. Self-determination goes hand in hand with a recovery mindset

Across the 75 interviews, self-determination could not be more strongly associated with mindset. Self-determination is universal to participants' recovery narratives, represented in the

decision to get better and the description of taking ownership of one's recovery. Refusing medical prognosis and the advice to accept and manage debilitating illness is a key example of self-determination. Another key example is the consistent reference to self-directed research, the commitment to recovery practices, and the re-orientation to introspective, somatic practices through which participants are led to cultivate a sense of self.

Self-determination is also associated with participants' ways of talking about the role of social and cultural factors in CFS illness and recovery. Self-determination is often qualified in relation to themes of self-identity, personality and social pressure.

5. 'Mind-body' approaches to illness and recovery are central to recovery narratives

Recovery narratives overwhelmingly describe the discovery of mind-body approaches to illness and recovery as a turning point. Participants claim that these approaches provide a believable, reasonable (rational) and sensible (making sense according to the body), account of symptoms and that symptoms can be addressed according to these approaches.

Mind-body approaches represent a paradigm shift for 95% of participants. In this shift, a medical model of biological illness is rejected in favour of a cultural model, in which symptoms are sustained through a complex interaction between biology, the body, the nervous system, emotion and the mind or sense of self.

Among mind-body theories and concepts, nervous system dysregulation is the most prevalent, described in 85% of narrative accounts. Ideas of neuroplasticity and embodied emotion (for example, informed by trauma and chronic pain science and theory) are also cited.

6. Participants' recoveries take place outside formal medical settings

In almost all cases, recovery takes place entirely outside of clinical settings and without medical advice. Four out of five participants report being helped by a non-medical practitioner—coaches, practitioners of nervous system or somatic techniques, and others working for recovery programmes. Some participants describe benefitting from psychotherapy.

The knowledge, intelligence and know-how of non-medical practitioners is viewed as transformative. In contrast, only a handful of participants describe being meaningfully helped by a doctor, and not one recovered in a public health programme. Nearly two thirds of participants describe how they started to work in the field of mind-body medicine, mostly as coaches and/or as teachers of specific emotion and/or nervous system techniques of recovery, following their own recovery. They describe doing this work as a way to help others and stay connected to the recovery community.

Self-determination is counter-balanced by an account of support from friends and family and guidance from non-medical practitioners. Recovery narratives suggest a turn towards extra-

institutional, socially networked and communitarian values; para-institutional knowledge and practice; and forms of practice directed towards providing care.

7. Recovery narratives implicate the whole self

Self-transformation is a key theme of recovery narratives. The cultural concept of self-transformation is apparent in 4 out of 5 interviews, three quarters of which describe a change in self-identity. One representation of self-transformation is through the discussion of personality, illness and recovery—represented in over half of the interviews. Another is through the loss of self-identity associated with becoming ill. CFS is described as robbing oneself of one's identity. Finding oneself is described as a pathway to healing.

The theme of self-transformation is the primary way that social and cultural factors are acknowledged. The theme also extends to ethical reflection, by which participants ask questions of how to live well and how to live with others. Such questions turn on the ethics of being alive today—of being alive in a body (or being a body), with its context of limitations.

8. The message of non-recovery does clinical harm

At least 64% of participants describe a detrimental medical encounter in which a doctor told them that there was nothing that they could do about their symptoms and that there was no way to recover. Participants recount receiving the message of non-recovery with varying degrees of distress. This clinical experience is often described as catalysing a search for alternatives outside medicine.

It is not clear what the clinical benefit of telling patients that there is 'no cure' will be. Instead, this message can act as a nocebo, worsening patient outcomes.

The *Recovery Report* identifies clinical encounters in primary care as a key point of opportunity for public health to provide more effective care.

9. Telling recovery stories is a vital social and cultural activity

Several accounts describe encountering first-hand stories of recovery from CFS and related illnesses, in person and online, as transformative. Recovery stories disrupt the paradigm of non-recovery. According to participants' accounts, recovery stories provide hope, information, wisdom, knowledge and know-how—but also compassion and inspiration. Recovery stories are the pillar of the recovery community and act as a gateway of inclusion within that community.

Key Finding	Data Analysis & Illustrative Quotations
(1) People's accounts of recovery reveal patterns of experience	Recovery is talked about in recurring ways
	I felt like the programme gave me the community. I needed the people that were all going through the same thing as me. —CFS, recovered after 4 years
	I was very focused on, on these external things, and on paper it all looked okay, right. But if I peel that back and I look at my life in hindsight, I lived with a lot of urgency. I had a lot of people-pleasing tendencies, perfectionism, overworking … I was one of those people that I was over-training and under nourishing my body … So now I can see that for me on my journey, the virus, having COVID, that was just the straw that broke the camel's back, and that's what tipped my health off into this other direction. And then I was careened into this whole nervous system dysregulation with all of these wild symptoms that started to come up. —Long COVID + ME/CFS, recovered after 2 years
(2) People's accounts of recovery redefine CFS as a condition from which one can recover	Recovery stories provide first-hand evidence that recovery is possible 77% (n = 58) are fully recovered, and 23% (n = 17) are regaining their health
	And when I went for my follow-up in April, after I recovered and I [had] climbed my mountain and I arrived and people looked at me and said: 'What's different about you?' And 'Did you go on a holiday? You look really good.' And I spoke with my voice, and everyone was shocked, and I think just happy. *This is amazing.* This is amazing, and I just want to shout out in the world and say: *Hey, there is something you can do!* —ME/CFS, recovered after 2 years
	I think my mindset's now changed. I think you can actually be healed from it. And in the process, I mean, I've learned to listen to myself, listen to my body, and I think that's, so yes, there's been a lifestyle change in a way. It's been a journey of getting to know myself, working out what my triggers are, and I think that's been the biggest part for me, is learning what I need to do to keep myself healthy instead of going back. —ME/CFS + fibromyalgia + POTS + Lyme, recovered after 33 years
	I've worked in this nearly 20 years, so I've worked with a lot of people. I've done it full-time all that time. So, thousands of people I've helped recover. You learn from everyone you work with. They're your biggest source of learning. —ME/CFS, recovered after 15 years
(3) Mindset is consistently associated with recovery	The shift from an assumption of 'non-recovery' to a recovery mindset is represented across the interview narratives 61% (n = 46) talk directly about their belief in recovery

It was really like cultivating that belief that I could recover, that people, first of all, just that anybody could recover, and then that kind of trickled into that I could recover.

—ME/CFS + long COVID + POTS, recovered after 2 years

And I started working a lot with my mindset, and the mindset is the thing that took me out of this disease—a lot of other things too, but the mindset has been so important for me.

—ME, recovered after 6 years

I think belief is really important, as is giving yourself enough time. We're so desperate to recover, understandably, we want to end the suffering … [but] because it is such a transformation really that happens in healing, it can't be rushed. So allow yourself the time … allowing it to land in your body properly and allowing your nervous system to feel safe … is really important as well.

—ME/CFS, recovered after 18 years

(4) Self-determination goes hand in hand with a recovery mindset	Self-determination is universal to participants' recovery narratives 63% (n = 47) express making a decision to recover

The moment when I decided to [recover], because in a lot of ways it's a clear decision as well—I am going into this with my whole focus and determination—I use[d] accountability via a Facebook group and a handful of people.

—CFS, recovered after 4 years

And then when I got my focus back and I did some breathing and calmed the whole system down, then I had to prove to the protective brain that I don't need to avoid anything because so much that's taught about chronic fatigue is to 'avoid, avoid, avoid' … I opened the front door, and I took one step outside the front door, and I just said, *See, I don't need you. I can do this.*

—CFS, recovered after 2 years

I decided that I was going to recover because I was just in such a terrible state that I couldn't tolerate the idea of getting worse. It was completely unbearable to me … So I just in the end refused to accept that this was incurable and just decided that I was going to recover. That was really the turning point … It was just an absolute complete resolution. I had to recover because my life was unbearable.

—Undiagnosed autoimmune and immune-mediated inflammatory disease, recovered after 11 years

(5) Mind-body approaches to illness and recovery are central to recovery narratives	Recovery narratives overwhelmingly describe the discovery of mind-body approaches to illness and recovery as a turning point 95% (n = 71) link recovery to new discovering a new paradigm that made sense of symptoms (all accounts within this subset invoke a mind-body theory of illness)

And so as I started to support my nervous system and just do more practices that I felt I needed, I started to heal from the long COVID as well. I started to incrementally train

with movement. I started to incrementally train with grief. Emotions are so intense. So it's like I had to slowly allow these emotions in and then signal safety to myself. CFS + long COVID + POTS, recovered after 12 years

Even though this woman wasn't a therapist, she wasn't a doctor, and I had been a science journalist, so I love science, so she kind of explained the science of what can happen in our brain and nervous system with chronic fatigue, chronic pain, brain fog, with all these symptoms. And it made sense to me. And so I felt like she was literally diagnosing me, which is crazy. She's not a medical professional, but I felt like I can overcome this because it's now a matter of understanding this knowledge, learning how I can calm down my nervous system, start feeling my emotions, start challenging myself more, getting back to more activities to sort of retrain my brain.

—ME/CFS, recovered after 13 years

It told me exactly what was going on in my body and why it had happened [discussing a recovery programme] … I had never considered the nervous system before."

—CFS, recovered after 4 years

(6) Participants' recoveries take place outside formal medical settings	In almost all cases, recovery takes place entirely outside of clinical settings and without medical advice. 83% (n = 62) talk about recovering with the help of non-medical practitioners

And that, again, is that support of the community as well as the coaches … you're suddenly doing it with someone, so you're getting advice and you're part of this sort of very supportive community. And I think that creates a sense of safety.

—Long COVID, recovered after 3 years

I became the person I am, and I am really grateful for that … It's something really truthful to go through, and I believe that there are different ways to achieve knowledge and to grow as a person and through the opposite, through happiness, through joy, through living. … I feel that that's what happened with me, with the chronic fatigue. It really helped me explore and go deeper and live as the person I want to be … more in touch with a life that makes sense for me.

—ME/CFS, recovered after 2 years

(7) Recovery narratives implicate the whole self	Self-transformation is a key theme of recovery narratives 84% (n = 63) talk about self-transformation in the context of recovery

Just being in this place in my life where I'm prioritising myself, challenging myself, I just feel so much happier, so much more confident. I would never have done this right now. I would never have done, never—five years ago me would not believe that I was doing this.

—Autoimmune disease + CFS, recovered from CFS after 3 years

I was reading loads of books. I was exploring my childhood and what I'd experienced and how that caused my brain to develop and my habits that I was living with. Also looking at society and how that impacts how we feel and behave. … So for me, it was a journey of learning about all of, not just me, but also family, society and on a wider scale, how all

of that impacts how we think and feel and how our brain works, because it develops over our life.

—ME/CFS, recovered after 4 years

It's such a big part of people's recovery … learning to be kind and accepting that you need to allow yourself this time to recover, and it's not selfish and it's so important to almost put yourself centre stage, which I think a lot of people find so difficult.

—Long COVID, recovered after 3 years

I never thought that there was another way to live. I just thought everyone had those negative feelings about themselves.

—CFS, recovered after 4 years

(8) The message of non-recovery does clinical harm	Participants recount receiving the message of non-recovery with varying degrees of distress 63% of participants describe a detrimental conversation with a doctor, in which they were told that there was no way to recover

'There is no cure for that. You'll just have to manage your symptoms for life.' I went home planning my suicide. If I'm never going to get better, why would I even want to stay alive? … For me that was the worst suffering of CFS, was the helplessness and the fear of, *What if this is for the rest of my life?*

Doctors said, 'You've got a long-term chronic illness, there's no known cure, and you've got to learn to live with your symptoms.'

—ME/CFS, recovered after 4 years

I was told by the doctors, just: 'You're going to have to learn to live like this' and 'People don't recover from this.'

—ME/CFS, recovered after 8 years

(9) Telling recovery stories is a vital social and cultural activity	Several accounts describe encountering first-hand stories of recovery from CFS and related illnesses, in person and online, as transformative

I just kept reading. And that's what got me through in the end, was, when I had the energy, was just look at other recovery stories. And that was when things really started to change.

—ME/CFS + fibromyalgia, recovered after 7 years

I was in such despair for so long and the thing that made me believe that I could get better was seeing that other people that had very similar things to what I had been through were getting better and had fully recovered. I didn't believe that was possible for a long time.

—Lyme + POTS + fibromyalgia, recovered after 15 years

In that place where many of your listeners will know, where you're in that dark room with the curtains closed and [you have] that sound and that light sensitivity, it was actually your channel and your voice that a lot of times in those dark moments that

> reached me, and these calls, these recovery interviews, these transformation stories, those were such a light in that dark place. They were a lifeline for me. … It was really like cultivating that belief that I could recover, that people, first of all, just that anybody could recover, and then that kind of trickled into that I could recover.
>
> —ME/CFS + long COVID + POTS, recovered after 2 years

Report in numbers

The *Recovery Report* generated numerical representations to highlight the consistency of themes across YouTube recovery interviews. These are presented as percentages for ease of comparison but should be treated as descriptive indicators not statistics. The numbers do not represent a population.

Percentage of participants	Reoccurring Themes Across Interviews
100%	talk about doing their own research
96%	talk about their interactions with doctors
95%	talk about discovering a theory, body of knowledge or paradigm that enabled them to make sense of their experience • all accounts within this subset invoke a mind-body theory of illness
84%	attribute significance to nervous system regulation in their recovery
84%	talk about self-transformation in the context of recovery
83%	talk about recovering with the help of non-medical practitioners
73%	discuss stress as a factor in becoming ill and/or sustaining illness
63%	describe a detrimental conversation with a doctor • 27% were told that they 'would not recover'; 36% were told there was 'nothing they (doctor or patient) could do'
63%	recall making a decision to recover
61%	talk about their belief in recovery
60%	talk about their hope for recovery
52%	invoke a link between their illness, recovery and personality
52%	discuss anxiety as a factor in becoming ill and/or sustaining illness

47%	associate their recovery with knowledge acquired through reading a book
20%	recount thoughts of suicide during their experience of illness
5%	describe being helped by a doctor around a turning point in their recovery
3%	were told by a general practitioner that they would recover from their chronic illness

Implications

If, as is suggested by this report, people who recover from CFS do so outside of formal medical settings, research that focuses on clinical treatment will systematically miss the evidence of recovery. For recovery to be possible in the context of research, research must make it possible—at the level of epistemology and methodology. The experiences of those who have recovered should bear on at least some future research design.

Research disproving recovery from CFS seems to inform the status quo, in which existing public healthcare is more likely to keep people with CFS ill than facilitate recovery. This is an unacceptable situation, for both patients and doctors.

Medicine is focused on treating disease, and the lack of a disease process means that people with CFS are unlikely to be a clinical priority. An alternative to establishing disease is developing existing treatment pathways that work. Without pursuing this alternative, it is likely that public health will continue to fall short of helping those who could recover to recover.

The findings of the *Recovery Report* suggest that social and cultural barriers are hindering recovery extensively. CFS is primarily a women's health issue but is rarely framed as such. The gendered inequality that significantly, disproportionately affects women is massively compounded by excluding accounts of recovery from research. An important framework moving forward is the countering of research and policy protocol that positions women's knowledge as illegitimate.

The digital culture of recovery from CFS and/or related chronic illnesses provides a hub of knowledge and support and acts as a gateway to non-medical practitioners and recovery programmes. This culture is home to a community whose support is cited repeatedly in participants' recovery narratives. Public health has an opportunity and obligation to learn from this collective resource.

Recommendations

1. Direct resources towards recovery research

Research on CFS would benefit from the inclusion of recovery, and CFS research funding ought include recovery as an object of study. Social and cultural research could be brought into conversation with psychology and other disciplines to offer a more meaningful account of the lived experience of recovery.

The existing knowledge of people who have been recovered can be studied and brought into the realm of institutional legitimacy, along with existing non-medical approaches to recovery. Non-medical approaches to recovery should be explored through pilot studies. The experiences of those who have recovered should be objects of research in their own right.

People who have recovered ought to be included as stakeholders in (1) news media, (2) research, (3) health policy and (4) patient support and advocacy.

The focus on a pharmacological solution should be held in balance with the evidence of recovery—not only in the recovery community but held in wider society.

2. Share recovery stories wherever possible

Social and cultural evidence shows that hope is a vital resource, communicated effectively by first-person accounts of recovery. The public sector and patient support groups should share stories of recovery and send positive messages of hope to people who are unwell.

3. Work with non-medical practitioners

If, as these findings suggest, non-medical recovery practitioners are leading the way in knowledge, support and understanding, they should be brought into the research, policymaking and public conversation about CFS recovery. Non-medical practitioners could be invited to work alongside policymakers, healthcare providers and patient support and advocacy groups. Social and cultural researchers and practitioners of the arts and humanities with an interest in health should also work alongside non-medical practitioners.

Clinicians who wish to refer patients to holistic, mind-body or non-medical support should receive public health guidance to do so.

Public health is recommended to play a role in supporting professional standards and identifying other measures to generate public trust, to help guide people whose experience of illness steers them to a largely exploitative and unregulated market.

Non-medical practitioners with a track record of supporting people to recover ought to be included as stakeholders in (1) news media, (2) research, (3) health policy and (4) patient support and advocacy.

4. Give primary care professionals a voice

General practitioners and other primary care professionals should have a voice in how policymakers and patient support and advocacy groups understand the experiences of those who develop symptoms and then go on to recover.

5. Stop associating CFS with non-recovery

If, as these findings suggest, recovery from CFS is not only possible but practicable with the right support, guidance and conditions, non-recovery must lose its pride of place in the public conversation about CFS.

No one can know if, when or how each and every person with CFS will recover. What we can know is that in its current usage, the message of non-recovery causes harm. Associating non-recovery with CFS obstructs improvement by extinguishing hope. Obstructing even the smallest improvement can have the effect of stealing a person's whole chance for recovery. Every clinical encounter matters.

If, as these findings suggest, recovery stories are key to the collective articulation of recovery and can catalyse individual recoveries, then their silencing is a major social injustice.

Claims regarding non-recovery are not supported by good research and should not be used to discredit, misrepresent or vilify the accounts of those who have recovered.

Conclusion

The recovery interview is a lynchpin and mobilising force of digital recovery culture. Recovery stories foster belief in recovery and offer practical advice. They reveal a collective intelligence and know-how, and they epitomise the values of community and pedagogy that are central to digital recovery culture. They also suggest a practice of mutual aid within the recovery community. The popular appeal and impact of the YouTube recovery interview points to the value of recovery stories more widely.

The *Recovery Report* is a catalyst for further research and an invitation to doctors, policymakers and patient support and advocacy groups to engage with those who have recovered. It claims, unequivocally, that the experience of recovery is patterned, and the thematic patterning of recovery narratives provides one way of learning about what makes recovery possible.

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