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RECOVERY REPORT

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

COMMUNITY SUMMARY

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July 2026

Community Summary

This report discusses the stories people tell about recovery from chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME) or ME/CFS, in the online CFS recovery community. It shows that recovery from CFS and related chronic illnesses is not a matter of chance but follows consistent patterns. Moving outside a medical framework, recognising that one can recover, developing self-determination in the face of adversity, gaining new mind-body knowledge and being supported and guided by others are all important turning points in narratives of recovery from CFS and related illnesses.

Why study recovery on YouTube?

If you have been affected by CFS, you may have been told by a doctor that 'you will not recover'. In contrast, 'recovery is possible' is the core message of the online CFS recovery community—a community in which the Raelan Agle YouTube channel plays a central role. The *Recovery Report* examines 75 interviews conducted for Raelan's channel to see what can be gained from a socio-cultural analysis of what people say about how they got better.

Who is the *Recovery Report* for?

(1) People in the recovery community whose stories have the power to change our understanding of the illness or condition known as CFS;
(2) People affected by CFS or related chronic illnesses and who are uncertain about how to navigate online 'recovery media'; and
(3) Stakeholders in the wider community with the power to build meaningful relationships with people who have recovered from CFS and related illnesses.

What did the study find?

Recovery is possible

- Of the 75 people whose interviews were studied, 77% described themselves as fully recovered. The rest describe themselves as having made meaningful improvement.

Belief matters

- Nearly everyone who recovered describes a turning point at which they started to believe that recovery was possible.
- For many, learning about the recovery of others made belief in one's own recovery possible.

Mind-body ideas are the most influential

- Discovering a theory, body of knowledge or paradigm through which people were able to make sense of their experience enabled them to work on their recovery.
    - 95% of participants say they were helped by mind-body paradigms.
    - 84% say they were helped by nervous system regulation specifically.

Mindset matters

- Those who recovered were self-determined in their recovery. They made decisions about their recovery and sought to exercise control over what would happen next.
- Those who recovered maintained a recovery mindset. Recovery became a point of focus. Belief in recovery and a mind-body explanation of symptoms are key.

Recovery involves the whole person

- At least 84% of participants talked about recovery in relation to self-transformation.
- Stress is described as a factor in becoming ill and/or the experience of illness being sustained in 73% of interviews.

Support is essential

- People who recovered felt supported by friends and family.
- People who recovered received guidance from non-medical practitioners.
- People who recovered did so with support outside of formal medical contexts.

The message of non-recovery causes harm

- Being told that recovery is 'not possible' by a doctor is common—reported by 64% of participants. This message is experienced as devastating.
- Participants make no reference to any clinical benefit of this negative messaging, that could be acting as a nocebo (a negative belief that creates a detrimental outcome).

Recovery stories help

- Recovery stories are sources of inspiration, information and practical know-how. They cultivate belief and confidence in recovery.
- Recovery stories are the pillar of the recovery community, acting as a source of support in itself and as a gateway to non-medical practitioners.
- Recovery stories are reinventing public understanding of CFS in a way that directly challenges medical narratives.

What else does the *Recovery Report* say?

Trying multiple treatments might help with aspects of symptom relief. However, it may also prolong the overall experience of illness and is likely to be expensive. Talking therapies are described as helpful when undertaken in relation to other forms of support. Meditation is widely used but not described by everyone as helpful.

What is the research behind the *Recovery Report?*

The Recovery is Possible study uses the tools of cultural studies to analyse and explain the patterns found in interviews about recovery conducted by Raelan Agle for her YouTube channel. The social and cultural affordances of YouTube have enabled a mushrooming online recovery community, with four channels acting as central hubs—CFS Health, CFS Recovery, CFS Unravelled and Raelan Agle. Together, these channels have reached more than 200,000 subscribers and have 23 million views. The recovery interview is a staple of this community—a form of 'recovery media' attracting a growing audience.

The researcher has analysed 75 interviews using a thematic and narrative analysis. Research design was shaped by ideas drawn from participatory research, gender and cultural studies, and a critical approach to ethics that prioritised 'giving voice', to look at:

- how recovery interviews are shaped by **narrative themes**;
- contextual information within these themes about **how people recover from CFS;**
- the **social structures** that underpin these descriptions of recovery; and
- the **new ways of thinking** about CFS and related illnesses in the community.

Whose voices are included in the study?

The majority of participants had a diagnosis of ME/CFS or long COVID. Just under a third disclosed other diagnoses, including Ehlers-Danlos syndromes, chronic Lyme disease/post-treatment Lyme disease syndrome, Sjögren's syndrome, Lupus, coeliac disease, mast cell activation syndrome, fibromyalgia and postural orthostatic tachycardia syndrome. Most participants are white women, British or North American, and educated to university level. Nearly two thirds started work as non-medical practitioners since their recovery.

What does the report recommend?

Share recovery stories wherever possible—they might make the difference between someone thinking that they will never get better and believing that that they will.

Direct resources towards recovery research—research would benefit from including people who have recovered, people who work with mind-body practices, and disciplines beyond science. Funding ought to reflect a more holistic set of priorities.

Work with non-medical practitioners—non-medical practitioners are leading the way with mind-body techniques but are not currently part of the conversation in policy or research.

Give primary care professionals a voice—general practitioners, emergency doctors and other frontline workers who want to point people with symptoms of CFS to holistic, nervous system or mind-body practices, programmes and practitioners should be supported to do so.

Stop associating CFS with non-recovery—telling people that they will not recover cannot help them improve.

> Despite the growing visibility of complete recovery from CFS through the online recovery community, the NHS still defines CFS as a long-term condition with 'no cure'. The association of CFS with non-recovery seems unlikely to change as long as medical research informing health policy marginalises already existing research that provides evidence of recovery and does not consider people who have recovered as sources of knowledge.

For the full report and further information visit: www.recoveryispossible.info