Goldsmiths
UNIVERSITY OF LONDON

School of Media, Communications & Cultural Studies

RECOVERY REPORT

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

FULL REPORT

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Views and any remaining errors are the author's own.

This report is dedicated to the CFS recovery community.

Suggested social media hashtag: #RIPCFS

Table of Contents

Foreword **5**

Introduction: Overview, aims & objectives **7**

Overview 7

Background 9

Aims of Recovery is Possible 14

Objectives: Knowledge in the public domain 15

How to read this report 16

Terminology/nomenclature 17

Method: What I did **18**

Research ethics 18

Research design—Real lives, fuzzy data 19

Research using social media—Theoretical approach 21

Section 1. Report in numbers **29**

1.1 Introduction 29

1.2 Demographics: Who are the research participants? 29

1.3 Illness characteristics 32

1.4 Tools and techniques used by participants 35

1.5 Recovery characteristics 41

1.6 Observations 43

Section 2. Onset of symptoms **45**

2.1 Introduction 45

2.2 Not recovering 46

2.3 Social expectations 46

2.4 The incomprehensibility of symptoms 50

2.5 Retrospective interpretation 52

2.6 Discussion 53

Section 3. Encounters with medicine **56**

3.1 Introduction 57

3.2 Doctors tell patients, “There is no cure” and “You will not recover” 59

3.3 Doctors tell patients, “There is nothing we can do” 63

3.4 Discussion 66

Section 4. Mindset as the gateway to recovery **71**

4.1 Introduction 71
4.2 Rock bottom 73
4.3 Deciding to get better 80
4.4 Self-determination 86
4.5 Practices in the context of a recovery mindset 90
4.6 Self-transformation 101
4.7 Discussion 106

Section 5. Mindset as a recovery practice 108
5.1 Introduction: Mind-body recoveries 109
5.2 Mindfulness 114
5.3 Meditation 118
5.4 Nervous system regulation 118
5.5 Somatic introspection (feeling, sensation and emotion) 122
5.6 Brain retraining 127
5.7 Discussion 133

Section 6. Recovery mindset: Hope-belief and legitimate optimism 135
6.1 Introduction 135
6.2 How belief is located in recovery narratives 136
6.3 How belief is imagined to originate in the evidence of the experience of others 138
6.4 How belief is 'practised' and sustains a recovery mindset 139
6.5 Discussion 140

Section 7. Forms of support: Care, pedagogy and mutual aid 142
7.1 Introduction 142
7.2 Care 143
7.3 Pedagogy 145
7.4 Mutual aid 150
7.5 Discussion 152

Section 8. Social illness, identity and the overexerted personality 154
8.1 Introduction 154
8.2 Overextended personality 156
8.3 Identity 163
8.4 CFS as a social illness 166
8.5 Discussion 167

Section 9. Ethics of recovery 169

Conclusion: Being recovered 175

References 179

Appendices 183

1. Recovery narratives literature 183
2. Literature cited by participants 185
3. Resources guides at the time of publication 187
   - Recovery stories websites 187
   - Recovery YouTube 187
   - Nervous system and recovery apps 187

Foreword

Recovery from chronic fatigue syndrome is an ordinary story. Or is it? Telling people, “I’m doing a study on recovery from CFS” has elicited stories told in brief. As well as, “I know someone who has that,” I have heard, “My friend recovered from that,” and “I recovered from that.” A peek online or at the medical literature tells a different story.

Recovery is a contentious subject. Until I wrote this report, I never understood how controversial my own recovery from CFS—or post-viral fatigue syndrome as it was termed in the early noughties—would be. I recovered incrementally and, as many of this study’s participants did, with the help of a non-medical practitioner. In my case, she was an energy healer. Speaking about my experience always felt speculative, even though it had already happened. Perhaps this is because I was missing the language in which to make sense of my recovery. This is the language of the recovery community—the subject of the study presented here.

By the time I had CFS for the second time, a new context of ‘culture wars’ had taken shape, and things had become differently hostile. Not only did you have to experience the illness, you had to have a position on it. At least that is the message being directed towards people with symptoms. When I was ill the first time round, debates about medical treatment and policy had been taking place in professional and organisational quarters. By the second time, the debate had moved online and was focused on the origins of the illness—of why I was unwell.

Policymakers claim that what’s needed to improve the care of people with ME/CFS is patient voice. Less attention is paid to who is speaking, and how they are being heard. Patient advocacy and support groups act as cultural intermediaries. They claim to be acting on behalf of people with ME/CFS, but are they listening to everyone? Are clinicians, researchers, policymakers and patient advocacy and support groups listening to those who have recovered? If they were truly listening, wouldn’t they go online, to the emergent, vibrant recovery community, where debate about CFS, long COVID and related conditions occurs, in terms set by those with first-hand experience?

Listening to recovery interviews on Raelan Agle’s recovery channel on YouTube as someone with CFS for the second time, I was struck by the nature of people’s recovery stories. What did it mean that people were bringing in their life stories when they were talking about this illness? What did it mean that recovery involved so much creativity, tenacity and biographical difference?

Then I listened to the recovery interviews as a researcher and they truly upended me. Not only did I hear and feel the depths of people’s devastation as they sat there

alone, in a doctor's office, being told, 'there is no cure for you.' I understood, for the first time, why there was no medical discourse on recovery. For medicine to tell the story of recovery, they would have to rewrite the story of ME. Of CFS. Of long COVID. Of so many health conditions. I learned that in the hands of those who had recovered was this other, bigger story. About the power of medicine to shape our lives. About the pain of being alive today. About the ongoing struggle for knowledge, for mind-body medicine, for legitimacy to be accorded to those who know how to help one another recover from CFS/ME.

Listening to recovery interviews as a researcher, knowing that I would be taking care of someone else's story as part of this bigger story was the honour of my life. Not that it is over yet!

I hope that in the *Recovery Report* you will see why. For those who are in the community, for those who are unable to live their lives because they are beset by symptoms, for those decision-makers with the power to change things—for everyone who is trying to change things, who wants to make recovery possible for more people, this report is for you.

Sarah Cefai

Wednesday 22nd July 2026

Introduction: Overview, aims & objectives

> "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)

Overview

The *Recovery Report* presents the findings of a social and cultural analysis of first-hand accounts of the subjective illness experience of chronic fatigue syndrome (CFS), also known medically and in the UK patient community as myalgic encephalomyelitis (ME). It is an open access resource that shares research findings with people who have an interest in CFS and related chronic illnesses. Three features distinguish the study: (1) its emphasis on recovery, (2) its use of a dataset that is taken from social media, and (3) its theoretical and methodological approach, which draws on gender and cultural studies and brings a critical social and cultural perspective to a health issue. Although the methodological and theoretical assumptions of medicine, psychology and health research can be at odds with the account of subjective, social and somatic experience represented here, there is some consistency between the findings of this study and existing research.[1] For example, going back 30 years, a review of 26 studies showed that having a sense of control over symptoms and not attributing illness to physical causes was associated with better outcomes—'the patient's belief in a physical cause of their symptoms predicted poor outcomes in every study in which it was measured' (Joyce, Hotopf and Wessely 1997: 225). More recent studies use the framework of 'recovery narratives' and have identified themes such as mind-body approaches to recovery (Hasan, Kuyvenhoven, Chowdhury, et al. 2024) and the significance of an explanatory narrative about illness (Bakken, Mengshoel, Synnes and Strand 2023) as key to the narrative (see Recovery narratives literature—psychology and medicine in the Appendices). Unfortunately, however, a more socially and culturally rigorous account of what makes recovery from CFS and related illnesses possible is not reflected in UK health policy. Moreover, this report proposes that a significantly

[1] A full literature review and more in-depth discussion of some of the findings have been reserved for publication by journal article.

more extensive research agenda with a more substantive contribution from the humanities and social sciences is needed to adequately understand and represent the social and cultural factors contributing to recovery.

Those familiar with the field will know that existing research and UK policy represent CFS as being under-researched and poorly understood, without naming any gains to be had from conducting research with those who have recovered (see for example, Department of Health and Social Care 2025). The very fact that participants often recover outside of medicine—a key finding discussed later in this report—should invite more serious consideration of the experiences of people who recover or who make measured improvement in their condition, as well as the potential contribution of social and cultural research. This report demonstrates the utility of a social and cultural perspective in understanding recovery from conditions for which there is no established medical consensus regarding the underlying disease process, especially when such illnesses have devastating effects on quality of life, including suicide.

The critical humanities and social sciences approach taken here focuses on yielding insight from a multi-perspectival analysis of recovery narratives. The subsequent findings reflect a sustained and systematic approach to interview data, enabling the researcher to ‘actively listen’ to the collective voice of experience (known as ‘patient voice’ in medical contexts), whose significance might otherwise be dismissed from the realm of public health.

Social media are a context in their own right, but for this study, they are also the mediating infrastructure of a newly emergent culture—a digital culture of CFS recovery. Recovery influencers or digital culture founders are the pillars of a community who not only holds a space for recovery but also actively facilitates the representation of CFS recovery stories. People increasingly turn to the digital culture of CFS recovery to recover. The association of this online culture with the possibility of and hope for recovery is instrumental—possibility and hope offer the potential of belief.

At the centre of this new cultural articulation is the mobilising force of the recovery story. Social media are amenable to the recovery story because of their prime position as social adjudicators. Along with algorithms and other aspects of the technological infrastructure, audiences play a vital role in determining the visibility of particular media content. Each of the interviews analysed in this study has already been subject to these conditions of production; each has been listened to multiple times, commented on, and possibly shared across platforms. The foundations of media and cultural studies help parse meaningful content from a social media form that, while bearing no formal relation to the institution of medicine, is generative of a

corpus of illness recovery data. The focus of the present study is to elucidate the social and cultural themes structuring the interviewees' narratives of recovery. This focus gives rise to a series of themes centred on mindset and mind-body theories of illness and recovery. This approach concretely shows that, while opaque, recovery is not impervious to socially meaningful explanation.

Background

In the UK alone, a likely 402,000 people are affected by CFS (Samms and Ponting, 2025) at a yearly cost of several billion—estimates that do not include those living with long COVID, to which this report refers as a related illness. The UK government's policy paper *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): The Final Delivery Plan* (Department of Health and Social Care 2025) readily admits the need for a better understanding of the condition but limits its own understanding of research to biomedicine. Accordingly, responsibility for research funding relevant to CFS sits with the National Institute for Health and Care Research (NIHR) and UK Research and Innovation's Medical Research Council (MRC). The policy paper at no point discusses recovery from CFS and while prioritising 'research' as one of three 'themes in which we are seeking to encourage change to improve care and support for people with ME/CFS', limits understanding of 'the entire research system' to research funded by the NIHR and the MRC. This framework overlooks the transformations of medical, health and wellbeing knowledge taking place online, in the specific case of CFS, patients' use of social media not only as a source of information but also as a tool for and context in which to experience recovery.

The omission of the CFS recovery arena, including but not limited to digital recovery culture, from the UK government's account and from academic research to date, represents a failure to consider what the recovery community says about how to get better from CFS and related illnesses. Although restrictions of time and resources render such topics beyond the scope of this report, the discussion of first-person accounts included within provides ample evidence of the urgency with which the experiences of those who have recovered should be incorporated into research. This report gives the public sector the opportunity to recognise the importance of these accounts to the CFS recovery landscape, as well as the collective knowledge that is emerging through a mediated and 'mediatised' infrastructure of support.

To say that CFS is a controversial subject is to seriously understate the vast cultural and political landscape that the illness exists within. The evidence of recovery presented in this report stands as a bulwark against the association of CFS with non-recovery, which has become culturally entrenched. It is impossible to extricate a

discussion of symptoms, epidemiology or treatment from the powerful discourses that take CFS as their ‘proper object’, that name and claim CFS as rightfully theirs. In this respect, the subjects of this study are no exception. People who have recovered from CFS and related illnesses and who share their stories of recovery on YouTube also claim proprietary knowledge. Through this knowledge, which includes the knowledge of experience, they seek to guide others as to how CFS and/or related illnesses can and should be understood. The ‘Recovery Is Possible’ study sought to derive broader meaning from these narratives, to uncover what could be learned from those who have recovered when their accounts are subjected to academic scrutiny. The scrutiny applied in this research was not critique but rather critically grounded interpretation, evaluation and validation through the application of social science and humanities knowledge.

According to research, between one third and one half of general practitioners in Europe lack confidence in diagnosing or managing CFS or dispute its existence as a genuine clinical entity (Pheby, Araja, Berkis, et al., 2021). Such figures can only gesture towards the contested status of CFS as an illness and the complex interweaving of medical and social discourse, medical guidance and practitioner knowledge and practice that shapes the clinical context of diagnosis. In response to a request made by Action for ME under the UK government’s Freedom of Information Act 2000, only 28% of Integrated Care Boards (ICBs) and National Health Service (NHS) Trusts disclosed a record of their implementation of the 2021 National Institute for Health and Care Excellence (NICE) Guideline on ME/CFS (Action for ME, 2023). No supplementary information elaborating on what this implementation actually entails or how it is upheld through protocols such as auditing is shared with the public. Further, Action for ME found that:

> Fewer than one in four NHS Trusts/ICBs are able to track their ME/CFS patients and **two thirds of NHS Trusts and ICBs hold no information whatsoever on their ME/CFS patients**. This was reinforced by the fact that only one in ten (21,927) of the estimated 250,000 patients are currently recorded as having ME/CFS in the medical system. (emphasis added; Action for ME, 2023)

To put this more plainly, from the point of view of the UK’s stretched public health service, CFS barely registers.

The *Recovery Report* makes its own contribution to sobering numbers. In their interviews, for instance, nearly two out of three participants divulge an account of a detrimental clinical appointment with a doctor. The research has generated other meaningful numbers around factors important to recovery and perceptions of the

onset of illness. However, the real contribution of this qualitative study is the representation of recovery *in the voices of those who have recovered and those who have made measured improvement in their symptoms.* Its primary purpose is to provide a descriptive, contextual account of the key subjective and social themes that constitute participants' accounts of how they got better. By making stories of recovery available to a wider audience, it is hoped that the report will feed into a larger public discussion about recovery from CFS and related illnesses.

For Action for ME, figures that attest to the piecemeal delivery of medical care 'beg the question, **how many people with ME/CFS are falling through the cracks?'** (*emphasis added*; Action for ME, 2023). While the *Recovery Report* is concerned about the people who fall through the cracks of the medical system, it asks different kinds of questions about recovery:

> When the medical discourse is one of non-recovery and when medical practice is largely one of absence, abandonment and inconsistency, how do people with CFS recover? What makes recovery from CFS possible? Once people have fallen through the cracks, how do they find care? How do they go from being debilitated by illness to flourishing in good health?

The report answers these and other questions in a social and cultural analysis of 75 accounts of people who have recovered or experienced significant improvement from CFS symptoms.

These terms—absence, abandonment and inconsistency—need to be qualified. The author of the report believes that the evidence of recovery narratives points to the benefits of de-medicalising CFS, or, at the very least, offering a non-medical pathway for support and treatment. Public health is absent and inconsistent, in part because of the strain across the service and in part because there is no agreed upon disease to be treated. The resulting statement, 'There is no cure,' is misleading. In the institution of medicine, medical abandonment occurs as a structural problem. One of the encouraging findings of this report is that people who have recovered have a wide range of ideas about how others can be supported in their recovery. Their own accounts also provide evidence of the significance of social and cultural themes to sustained improvement. Further, many of the ideas presented here are inexpensive to mobilise when given the right support from clinicians and policymakers.

National patient groups in the UK shore up their belief in an 'illness biology' framework through platforming and even adjudicating on the funding of biomedical research. Although biomedicine—largely immunological, biomolecular, metabolic, mitochondrial and genetic in focus—is in conversation with the field of psychology

and/or the health sciences in some quarters, this interdisciplinary work is not reflected in dominant citations. Without claiming a complete understanding of CFS recovery, this report calls for the medical, academic and policymaking communities to consider what people who have experienced recovery already know. The *Recovery Report* claims the following unequivocally:

> An emergent community comprising people seeking to recover or who have recovered, people who have recovered who have become non-medical practitioners who are working to help people recover, and clinicians who may or may not have first-hand experience but who have a specialist interest in chronic health conditions is articulating a collective knowledge of recovery from CFS and related illnesses that is of growing influence.

From the viewpoint of public health, there is no cure for CFS, and NICE guidelines warn against presenting cognitive behavioural therapy (CBT) or energy management to patients as curative (NICE, 2021). Unfortunately, the idea that a yet-to-be-identified disease process drives symptoms can be an unnerving, debilitating message with a deep psychological imprint, alienating patients from their own embodiment and sense of agency. In contrast, the findings of this study are that no matter the stops and starts of medical guidance, people can recover without the aid of biomedical treatment. The most troubling implication of the findings of this research is that social and cultural barriers are hindering people's recovery. Findings suggest that with the right information and support, significantly more people could be recovering from CFS than currently do so. Put differently, the status quo of non-engagement with accounts of recovery is compounding inequalities in healthcare—a problem whose structural characteristics will become all the more evident as the private sector grows in influence. The *Recovery Report* shares much needed documentation of the types of information and support that have been instrumental to people's recovery.

Interviews for Raelan Agle's ME/CFS and Related Illnesses Recovery Channel

Growing numbers of people living with CFS are turning to social media for support, and they do so in the absence of medical care. In the recovery community, YouTube is home to CFS Recovery, CFS Health, CFS Unravelled and Raelan Agle, between them sharing a reach of 200,000 subscribers and more than 23 million views. A burgeoning number of other channels, such as those hosted by recovery programmes or non-medical practitioners, share traffic, sometimes exchanging content or signposting one another via hyperlinks. The feeling among channel hosts is cooperative and convivial.

Raelan posted her first video to YouTube on 27 November 2019—'Working out with Chronic Fatigue Syndrome'. Speaking to the camera, Raelan presents her view that after 10 years of illness, while sharing her knowledge that exercise is a "sensitive, controversial and polarizing topic," she "strongly believes that without exercise I would never have recovered" (https://www.youtube.com/watch?v=PAj08-6IAC0&t=988s). The tone is supportive and conversational, and most of the nearly 25-minute video involves first-person narrative rather than a demonstration of exercise. The content is focused on her experience of exercising with CFS as a way of inviting people still suffering with symptoms to consider how they might try a form of physical activity suited to their needs. It was not until 6 months later that Raelan posted her first interview, which she introduces as "a great opportunity for people to get to hear more people's stories out there, as not everyone's gonna start their own YouTube channel" (https://www.youtube.com/watch?v=PAj08-6IAC0&t=988s). Fast forward 6 years and the channel is home to nearly 300 recovery interviews. Although it is centred on CFS or ME/CFS, Raelan also posts interviews with people who have recovered from long COVID and related chronic neurological illnesses, such as postural orthostatic tachycardia syndrome (POTS) and fibromyalgia. As is the case in the wider community, in the study sample many people who had CFS and/or long COVID had been diagnosed with other conditions that tended to cluster. Around half (n = 39) the sample had a sole diagnosis of either CFS or long COVID.

The recovery interview is the staple of the Raelan Agle channel. Interviews are usually 30-45 minutes in length and follow a topic guide, always beginning with the question, 'How did this all start for you?' Content covers 'what worked and did not work', 'what you wish you had known earlier on', 'whether this could have gone differently for you', and 'what you would say to people who are still in that place of illness'. Increasingly, the channel includes interviews with recovery practitioners, medical doctors, and authors of trade books, as well as Raelan's own direct-to-camera content. The YouTube channel is linked to an ecology of networked media, including Spotify, Apple Podcasts, Instagram, Facebook, and Raelan's website. In 2025, Raelan joined her peers in the provision of a recovery programme—*Brain Retraining 101*.

For comparison, CFS Recovery is the channel of Miguel Bautista, who runs the programme *CFS Recovery* from Canada, and content focuses on insights related to his experience and the programme itself. Recovery testimonials linked to the programme CFS Recovery are shared on his channel. Similarly, the CFS Health channel is associated with the programme of the same name that is run by Toby Morrison who lives in Australia, and it includes interviews with people who have recovered using his programme—the programme's 'success stories'. Finally, CFS

Unravelled is the channel of Dan Neuffer, who has a recovery programme called *ANS Rewire*, and his YouTube similarly features interviews demonstrating success with his programme. Raelan interviews a range of people who have different experiences of recovery and was not associated with a recovery programme until recently. The channel remains focused on platforming a wide range of recovery stories while expanding its collection of interviews with people who have recovered from long COVID, as well as medical doctors, researchers and recovery programme creators able to offer further insight.

First-person recovery stories are frequently described by participants as their first encounter with the possibility of recovery and their subsequent belief in their own recovery. Interviews with Raelan are part of a digital culture of CFS recovery in which a community is using social media to collectively redefine how CFS is experienced and understood. The project of redefinition has become central to this community, in part because the experience of having recovered deems the message of recovery as intrinsic to the possibility of recovery. First-person accounts that are a focal point in the communal project of redefinition communicate a sense of ownership. The *Recovery Report* calls on doctors and policymakers, as well as patient support and advocacy groups, to take seriously both the central ideas that are being articulated in the emergent online environment and the specific social and cultural characteristics of recovery from CFS represented in first-person narratives.

Aims of Recovery is Possible

Recovery is Possible is an ongoing study, the first phase of which is represented in this report. The study asks: what can we learn from the stories that people tell about recovery from CFS, long COVID and related illnesses? The Recovery is Possible study takes a novel approach to answering this question by drawing on gender and cultural studies to create a community-based approach to health research and taking seriously the context of recovery interviews produced for social media. Its purpose is to describe the collective articulation of social knowledge around recovery and to represent the value of non-medical approaches to recovery from CFS and related illnesses according to people's narrated experience.

> **Principal Aim:** To undertake a social and cultural analysis of the experience of recovery from CFS and related illnesses that serves the recovery community, people affected by CFS and related chronic illnesses **and** that is accessible and relevant to a wider audience of clinical researchers, multi-disciplinary academics, policymakers and patient support and advocacy groups.

Although no one can know exactly if, when or how every single person with CFS symptoms will recover, we can know that the message of non-recovery, as it is currently framed, causes harm. When looked at collectively, individual accounts provide evidence of consistent themes, collective intelligence and practical knowhow that should be made available for wider reception beyond the newly emergent digital culture of CFS recovery.

Objectives: Knowledge in the public domain

In the shorter term, objectives are focused on deepening understanding of recovery from CFS and related illness and raising awareness of this understanding beyond the recovery community online. In the medium term, the *Recovery Report* hopes to contribute to an evidence base that can be used to agitate for funding: research on recovery; research that takes a critical social and cultural approach to problems of chronic health; and pilot and feasibility studies on alternative, non-medical approaches to recovery from CFS and related illnesses. This report demonstrates that mind-body interventions, such as practices that are somatic, neuroplastic, behavioural and cultural, can contribute meaningfully to recovery. In the longer term, the Recovery is Possible study aspires to help bring about a sea of change in social and cultural attitudes towards CFS, including: a substantial de-medicalising of the illness; an expansion of interdisciplinary frameworks that incorporate medical and non-medical knowledge to better understand the efficacy of mind-body approaches in relation to a better understanding of the pathophysiology of CFS; situating the phenomena of chronic illness in a broader view of ethics, sustainability and planetary repair.

The objectives of the ‘Recovery Is Possible’ study are thus the following:

- Represent the voices of those who have recovered to stakeholders, including doctors, policymakers, patient support and advocacy groups and clinical and academic researchers.
- Systematically investigate, understand and represent the recovery community as:
    - a digital cultural arena of collective intelligence and knowhow, as well as
    - mutual aid, care and pedagogy, and
    - a means to cultivate hope for recovery.

- Understand and represent support for recovery, the social qualities that sustain it and that it sustains, and how these speak to the vulnerability and resilience of people who have recovered from CFS and/or related illnesses.
- Provide the impetus, framing and context to support stakeholders to learn from community-based recovery pathways and envision new approaches to care and welfare.
- Represent the potential role of the critical humanities and social sciences in understanding the social and cultural context of the recovery experiences of those with CFS and/or related illnesses, including the contribution of researchers working in media and cultural studies, as well as others with expertise in representation, to produce academically rigorous and meaningful accounts.
- Create and communicate a new dataset that inspires researchers from different disciplines to devise new research that takes seriously what people who have recovered from CFS and/or related illnesses and those in the recovery community already know.
- Stimulate a research agenda that engages media and cultural studies more closely with biomedical, clinical and health sciences research and centres a cultural perspective on the relationship between digital culture and healthcare.
- Draw on the collective knowledge base of the recovery community to critically appraise the oft cited 5% 'rate of recovery'.
- Produce an account in the form of an accessible report as expediently as possible to communicate research findings to a wide audience, then follow up the open access report with journal articles.

How to read this report

This open access report is the first in a series of planned outputs. Analysis of the thematic content of participants' recovery narratives has been prioritised.

Findings are presented sequentially with a menu to enable navigation between sections.

With broader and accessible access in mind, the report is accompanied by an audio recording of the Executive Summary.

Quotations have been taken verbatim with minimal amendments for ease of reading. In some cases, participants have been identified by their prevailing diagnosis or diagnoses relevant to the study rather than by an exhaustive list.

Criticisms raised should be addressed to the author of the report, not interviewees.

Terminology/nomenclature

The medical literature describes CFS as a clinical picture of inflammation and poor energy delivery mechanisms, describing a serious, systemic, and chronic neuroimmune disease. Health policy, news media and patient organisations represent CFS as a 'biological disease' without a cure. Research efforts discussed in the media and by policymakers are those that are oriented towards the invention of a pharmacological solution. The oft used acronym 'ME/CFS' is inclusive but masks cultural, political and epistemological tensions around these definitions. While sympathetic to the need for language that conveys the debilitating seriousness of the CFS symptom cluster, the author is reluctant to use the term 'ME' when the meaning of myalgic encephalomyelitis ('muscle pain with inflammation of the brain and spinal cord') invokes an aetiology that has been disproven and a misleading classification of symptoms. Recovery is Possible will subsequently examine the cultural debates around nomenclature, and issues of language and representation, but not in this phase of the study. The *Recovery Report* hence does not highlight participants' reflections on the problem of naming the illness.

For brevity and to reflect its use by participants, 'Lyme' is used rather than 'chronic Lyme disease' or 'Post-treatment Lyme Disease Syndrome' (PTLDS).

The use of the term 'recovery' reflects its use by the community. As the purpose of this report is to reflect the subjective, social and cultural reality of participants' accounts, medical criteria have not been applied to assess them. The experience of recovery and participants' understanding of the meaning of the term is not uniform.

The report has been written in the third person for reasons of accessibility.

Method: What I did

Research ethics

This report discusses the findings of an analysis of 75 interviews conducted by Raelan for her YouTube channel (https://www.youtube.com/@RaelanAgle). Videos posted to YouTube are considered in the public domain and as such are available to research without consent. This study took the view that people who had agreed to be interviewed by Raelan had not also agreed to have the content of their interview studied for the purpose of research. This study also took the view that, while produced for public consumption, each individual interview is a deeply personal account, in which a person engaged in significant self-disclosure, sharing intimate aspects of themself and their experience. The process of asking for consent intended to honour that personal disclosure and vulnerability by formally creating research participants. As a result, each interview was listened to as if the interview subject had willingly committed their account to academic research. This approach is an alternative to one that would recruit participants to be interviewed by the researcher. A sketch of the pros and cons of these approaches is outlined below.

The primary ethical concerns raised by the research were: (1) unanticipated consequences of the research process for the digital recovery community, including attracting negative attention from organisations and members of the public, and (2) attracting negative attention to participants. In relation to the latter, all data have been anonymised. Searching for participants online is advised against, as the findings represent a **collective experience** articulated in the voices of individuals. Participants have been identified by length and type of illness—the dominant illness and not the complete list of diagnoses. This retains simplicity while still representing the scale of experience and suffering the study has engaged with.

The Recovery is Possible study was approved by Goldsmiths' Research Ethics Sub-Committee (reference 1833) on 4 June 2024. To recruit participants, all interviewees on the chosen YouTube channel were contacted about the research study by Raelan and her channel producer. Those who replied stating that they would like their interview to be included in the study were subsequently contacted by the researcher with the formal, ethically approved documents. This process recruited 79 participants and excluded 4 from the final dataset because their interview did not substantively discuss recovery from a first-person perspective. Thus, 75 interviews were included in the final dataset.

Nearing the completion of the data analysis, 15 participants participated in four focus groups, in which they discussed the main findings of the study. This provided an opportunity to check the alignment between findings and participants' expectations.

Research design—Real lives, fuzzy data

Given the lack of a complete disease aetiology and the divergence between the representation of recovery in public health and the representation of recovery in social and website media, the study had no intention of representing sufferers of CFS as a population. There was no ambition for generating 'complete' data. The validity of the study's claims is based on qualitative methods, not externalised information. As such, no interview was excluded on the basis of diagnosis. Given the dearth of qualitative research on recovery and the novelty of using full-length social media narratives to talk about CFS, parameters of inclusion were limited to recovery stories told in the first person. The resulting data could be thought of as 'fuzzy'—they have not been cut by the categories of a research paradigm or process. Data were not streamlined to prop up CFS as a medical object or medicine as an institutional discourse (Smith 2005). This means that the *Recovery Report* lacks a certain version of scientific legitimacy.

Instead, the study assumes that the 'mess' of the social world (Law 2004) does not stand in the way of meaningful, empirically valid findings, but must be engaged with as part of the phenomena of illness and recovery that needs studying. Not all participants were living with CFS or long COVID, but most were. Participants were not excluded based on age or location. The researcher did not disaggregate qualitative findings according to diagnosis, with the exception of checking some overall comparisons between the CFS and long COVID group and the 'other' diagnoses group in the generation of some descriptive data. This approach eschews the medicalisation of the illness while also drawing conclusions about the experience of CFS illness and recovery.

Interestingly, the inclusive approach taken to sampling appears only to strengthen the consistency of the findings: narrative themes and arcs are consistent across different geographical locations, age groups, genders, length and type of diagnosis. This finding could inform future research.

In the summer of 2024, the researcher conducted a pilot study with four recovery interviews. A coding scheme was derived through the researcher's review of academic literature, news media and health policy, as well as her prior knowledge. The use of this scheme to code the interview data produced nine themes: cultivation of the self; interpersonal relationships; social pressure; new social encounters;

collective intelligence; counter-discourse; mindset; nonlinearity; doing something; holism. A group of community and specialist advisors that included Raelan and her producer and represented the medical profession as well as the social sciences and humanities shared ideas about topics for analysis. Each of these themes was meaningful within the accounts of recovery.

The pilot informed the final research design in an important way: the researcher decided not to use a coding scheme to mark the interview data for the purpose of a thematic analysis. Without funding, the study lacked the resources to allow for a formal coding of the dataset. Moreover, the researcher decided against the way of 'looking across the data' that such coding encourages, instead deciding to focus on a close reading of the interviews' transformational insights and narrative developments. Similarly, the researcher did not code the tools and techniques discussed by participants. The high level of variation among how such tools and techniques are understood, implemented and evaluated would have led to false equivalences in the analysis. With a likely set of thematic parameters for the corpus in hand, the researcher decided to conduct **a careful and ethical listening to each interview as a whole, with the intention of allowing a representation of each person's story to emerge**. To undertake this step, the researcher used analytical methods of close reading, critical interpretation, narrative analysis, the embodied practice of 'thinking with', and to a lesser extent critical discourse analysis. The researcher also undertook a social scientific schematising of the data—or put more simply, identified patterns within the narrative and across narratives.

The combination of interpretative and social scientific analysis enabled the researcher to examine the narrative articulation of thematic content—consistency in highs, lows and turning points; moments of insight; troubling experiences; and objects of reflection. By creating a thumbnail 'diagram'[2] of each account, this method pulled out each interview's affective arc, accounting for how each narrative is an interaction in a disclosed feeling-world, as well as a mobilising and expressive force. This approach kept the singularity of each account intact and refused generalisation, reflecting an important ethical and epistemological commitment of the study. Equally, this approach implicitly validates aspects of disclosed experience without needing to critique or endorse participants' claims about 'what works'.

[2] Again, a full explanation has been held back for academic publication. To illustrate in brief: philosopher Gilles Deleuze's work on Michel Foucault (1988) reconceptualises his historical contribution as a methodology that diagrams power. The Recovery is Possible study will develop this idea through positioning CFS and related conditions as themselves diagramming power. In relation to the analysis of interview data discussed here, each singular account was mapped as a set of terms, events and crystallisations of subjectivity that are happening at the intersection of experience with power.

In addition to the video interviews, a survey was also designed to obtain provisional biographical and illness experience information, given that interviews were not designed to collect information in a schematic way. In total, 49 valid responses were collected. Survey data have been used to create a picture of the study participants without laying claim to generalisation.

Data analysis began in the autumn of 2025. Where available, transcripts were generated from raw video recordings. This accounted for just under half of the interviews (n = 37). For the rest (n = 38), transcripts were generated from the videos on YouTube. Interviews on YouTube had only been minimally edited with no relevant impact on the final text (e.g. cutting bloopers). Rev transcription software was used to produce individual interview transcripts. Data were collected in Excel and on paper.

Research using social media—Theoretical approach

This study takes data from a 'natural' social context, in which people are not subject to the influence of the research process. People's accounts include numerous details of their lives, making it clear that CFS and/or related illnesses are lived out as sites of entanglement (see also Bakken, Mengshoel, Synnes and Strand 2023; Hasan, Kuyvenhoven, Chowdhury, et al. 2024; Ingman, Chalder and Lawrence 2025; Krabbe, Groven, Schrøder Bjorbækmo, Sveen and Mengshoel 2023; Linnros, Andreasson, Norlin and Hydén 2026). The analysis of social media interviews allows us to produce an account of the experience of illness as the primary object of study. Such a view in no way negates the biological reality of symptoms. Rather, it prioritises knowledge of the body and the body's knowledge over the desire to corral the body into diagnostic definitions that obscure the illness experience in its representation.

Once recruited to the study, participants in no way, shape or form perform for an academic audience. Similarly, the non-clinical environment of YouTube video production means that participants do not assume or perform illness scripts (showing their knowledge of illness psychopathology or expressing other 'unconscious bias'). Numbers generated from the data are descriptions based on self-reporting without prompting. This adds validity in the sense that numbers do not reflect leading questions, although the limitation is that the numbers are likely to underrepresent occurrences insofar as prompting makes people more likely to report on a subject.

While the findings presented in this report read as descriptive, they are informed by the researcher's extensive experience. Critical fields of study challenge convention, speak truth to power and treat 'thinking differently', especially about seemingly

intractable social problems, as a meaningful pursuit. In line with a critical feminist social science, this study approached the collection and analysis of data as part of a project to produce situated, perspectival and partial knowledge (Haraway 1991). The ideas of research collaboration and the values of rapport and reciprocity within power-sensitive conversation were a priority (Oakley 1981). As the author shares the goal of wanting to further understanding and discussion of recovery in the public domain with the community, this study can be viewed as one of 'community-based participatory action research' (Maiter, Simich, Jacobson and Wise, 2008). Both gender and cultural studies link research ethics to the location of research processes in relation to broader social, cultural and political dilemmas and questions. The researcher practiced 'careful listening' informed by extensive training in gender and cultural studies, affect studies and the cultural politics of the body, as central to a method of analysis that could reflect a reciprocal researcher-researched relation. While the resulting analysis discussed here minimises reference to academic jargon, such training provided a means by which the social and cultural consistency of themes underpinning individual narratives could be identified and analysed. The study also adopts many conventions of social science, including mapping patterns in data and mitigating for bias.

Narrative accounts are positioned neither as merely narrative or social fact but as a collective enunciation about how we live, how we become ill and how we become better—rich with the information of collective intelligence and knowhow. This allowed the researcher to be receptive to—as well as to think critically about—the threads of experience shared across the research subjects' lived worlds, whose sense is disclosed through the medium of recorded language. These worlds are social, personal and political, as well as technological and cultural. This approach allowed a representation of each person's singular story to emerge, with particular attention placed on the narrative articulation of thematic content. Although the researcher had listened to the channel as someone in the community—as someone with CFS—listening to interviews in the context of a research process was an altogether different experience. The resulting data tell us about thematic consistency in experience, validating what people with CFS have to say without endorsing their claims about 'what works'.

Thematic analysis

Analysis focuses on the task of **elucidating the complex reality of chronic symptoms** rather than populating established criteria. What matters to this study is **what can be learned about recovery from CFS and related illnesses according to those who have recovered.** Real people's lived experiences, especially of

symptom clusters that are classified as symptoms of CFS, are always singularly specific: no two people's symptomology or experience of those symptoms is identical. At the same time, there is a clear common ground in that experience. In this study, each interview was carefully and closely engaged with through listening, watching and note-taking by hand. Early on, the researcher was struck by the powerful testimony to witness and the prevalence of two occurrences: (1) the profoundly moving expression of participants' vulnerability, grief and suffering, particularly in accounts of the most difficult period in their illness journey, which the researcher labelled 'rock bottom'; (2) the repetition of the refrain: 'I made the decision to recover'. The most closely related use of thematic analysis in existing literature can be found in psychology. Dating back to the 1990s, one study based on the thematic content analysis of 66 interviews similarly identifies a delimited number of 'social stressors' in half of the interviews studied. In this example, cited stressors include pressures at work, in relationships, and the eruption of emotional life events such as bereavement (Clements, Sharpe, Simkin, et al. 1997).

In this study, thematic analysis proceeded through developing a series of around 15 questions applied to each transcript. Questions included: What kind of decision was this? What made such a decision possible? In what context did people start to see improvement in their symptoms or the capacity for movement? When participants talk about a change in 'mindset', what do they mean by that? What precipitates participants' recollection of the most difficult period in their illness journey, or of them making a 'decision' to recover? What is the significance of encountering someone who is able to narrate their own experience of recovery? How do participants' accounts represent the social and cultural conditions of the illness? How have participants reconceptualised CFS according to their experience of recovery?

Further, the analysis looked at the narrative structure of each interview. This produced an account of narrative 'anchor points' reflecting the serial experience of recovery, according to which narrative events accrue the quality of seriality, suggestive of an internal logic and sequence. Recovery stories make recovery intelligible as an arc or trajectory of experience characterised by defined and distinguishable movements and moments. Such qualities point to participants' 'subjugated knowledge' (Foucault, 1997), enunciated collectively as a counter-discourse. Although the representation of the seriality of the recovery experience is aided by Raelan's topic guide (each interview begins with 'How did this all start for you?' and then follows a similar line of questioning), the internal consistency of the narrative's thematic content originates in its lived experience. Close reading, conceptual mapping, thematic annotation and other techniques generated a picture of these anchor points or nubs of experience, including: onset of symptoms; medical

encounters; “rock bottom”; turning points; and recovery milestones. Of note is the significance of mindset, which, while of interest to the researcher at the outset of the study, became more pertinent through the analysis of the onset of symptoms and recovery milestones or turning points.

Interview data were also used to generate numerical data on tools and techniques of recovery, illness and recovery, support from others. Some of these data are available in the Report in numbers section of the report. Although the efficacy of particular practices and programmes remained out of scope, the prevalence of mind-body themes is a key finding. Without evaluating specific mind-body, neuroplastic or nervous system–based tools, techniques and theories, the analysis systematically captures their representation.

Finally, a computational analysis was designed to corroborate the findings. This yielded further calibration of the narratives’ thematic interpretation. It consolidated the affective and emotional patterning associated with the narrative anchor points. Correlating mindset and recovery practices with symptom onset and resolution informed the observation of self-determination as a salient feature of the recovery mindset. The data on the themes ‘rock bottom’, ‘the decision to recover’ and ‘mindset’ were individually schematically reinterpreted. By percolating the ‘fuzzy’ data through a software operating a large language model (LLM) according to bespoke instructions, the computational analysis introduces a further layer of objectivity to the findings.

Participants were initially invited to complete a survey collecting biographical information as well as information about illness and recovery. Information provided by 49 participants was used to clarify interview content and generate an overview of group characteristics. These data are accompanying and illustrative and have not been subject to analysis. The survey was discontinued once sufficient data were collected. The intention was not to produce a secondary body of information but to establish an epidemiological baseline. Some of this information has been described in Section 1. Report in numbers.

A full literature review, certain findings and a more in-depth use of the computational analysis have been reserved for publication by journal article. The section Conclusion: Being recovered discusses areas for further research identified by this study.

Computational analysis

A semantic analysis was conducted to validate observations about the salience of themes, as well as information gleaned by hand to produce representative data

about the sample. Computational analysis was conducted by a research assistant possessing a specialist knowledge in coding and social science research methods. Initially, given the volume of data, the semantic analysis was conducted to help reduce the chances of error in the analysis the researcher had produced by hand. Using Anthropic's LLM Claude and operated through Claude Code (a command-line interface for agentic coding tasks), the semantic analysis followed a five-phase workflow: (1) keyword extraction, (2) LLM-assisted semantic reading, (3) comparison and discrepancy flagging between transcripts, (4) verification by hand and (5) final text report generation.

Claude's models seek to align with academic norms using large context windows and producing responses that have a more discursive style. Anthropic uses 'Constitutional AI' (the use of AI to supervise other AI), with the goal of producing AI that is 'more helpful, honest, and harmless', while also admitting the significant problem that 'so far, no one knows how to train very powerful AI systems to be robustly helpful, honest, and harmless'. In brief, Claude was considered the best option available to which the study had access. The emerging consensus in health research is that LLMs function most effectively to assist analysis at specific junctures in research workflow rather than as autonomous data sources (e.g. Misra 2026).

To pursue my observations around certain thematic and affective relationships within the interview data, a semi-automated sentiment analysis was conducted. Sentiment analysis is a 'subfield of natural language processing whose aim is to automatically classify the sentiment expressed in a free text', and it has become a widespread tool in health research (Denecke and Deng, 2020). Although aspect-based sentiment analysis associates 'sentiment' (codes for affect and emotion) with 'aspects' (themes and topics), the sentiment analysis conducted on these interview data is scaffolded from a prior analytical layer, itself informed by the researcher's fine-grained theorisation and interpretation of the data. The resulting sentiment mapping of the recovery trajectory represented in the interviews forms a novel basis for further analysis. Research on deductive coding reliability shows that coding-focused passages around identified moments, rather than applying codes to entire documents at once, facilitates more accurate classification (Gupta, Ranjan and Singh, 2024).

Close reading identified that participants repeatedly described feeling abandoned or dismissed by the medical system, that 'rock bottom' functioned as a generative turning point rather than only a low and that the relationship between mindset and action was central to how participants narrated their recovery. The bespoke codebook was built on these observations, with the hope that a computational

analysis would offer expediency and further validation. Whereas the researcher's interpretation of the data benefits from but is also skewed by her specialist interest in subjectivity, affect and cultural power, an LLM aggregates millions of data points in part from how people are speaking. The reports generated thus involve a non-human cross-referencing, although the information provided by the LLM has its sources in human data. Importantly: none of the findings in this report have been based alone on computational analysis.

Although the importance of LLMs to future research in qualitative health has been recognised (Eckey, Li, Morrison and Xiao 2025), natural social data beyond comments on social media have yet to be considered. Unlike existing uses of sentiment analysis in health and media research, the approach taken in this study was novel in two regards: the long-form content differs from comment length text found online and in social media (that which is most commonly analysed in health research using this tool). This study's bespoke framework was more granular than a lexicon-based polarity or valence analysis, building on the specific findings of the semantic analysis and a theorised classification of affect based on the researcher's original analysis. Rather than applying decontextualised sentiment, this approach enriched the existing process of interpretation by introducing interlocutory observations about the specific points of focus emerging as the key findings of the study.

Limitations

This study is based on a specific sample, and findings ought to be interpreted in view of this. Those whose narratives are included in the study had already put themselves forward to speak about their recovery with Raelan and then have subsequently agreed to allow their account to be subject to academic scrutiny. Nearly two thirds of participants identify themselves as working to support the recovery of others, which this study discusses in relation to a number of themes in the findings.

While all of Raelan's interviewees were invited to participate, those who were interviewed more recently were more likely to share their interview to the study. Almost half of the interviews are from 2024, with the remaining half shared across 2023 and then the other years from 2020-2025 (2020; 2021; 2022; 2025). Restrictions of time mean that the full potential of the dataset has not been utilised.

Limitations of class and race include the underrepresentation of people from working class (non-university educated), racialised and global majority backgrounds. The lack of prior social and cultural research in this area means that the role of cultural barriers to representation—including class privilege and structural racism—cannot

be adequately assessed. However, the findings of the study suggest some reasons why university educated, white women living in Western cultural contexts might be more prone to being affected by CFS and related chronic illnesses.

As an unfunded study, the researcher did not have the resources to fully code transcripts in Nvivo or do a content analysis of the data. While these methods could have introduced a different order of validity to the analysis, the researcher took the view that her textual analysis in combination with systematic processes of revision and cross-comparison offered a clear degree of reliability. Moreover, the use of a bespoke computational semantic analysis to re-code identified themes and a sentiment analysis based on the findings of the semantic analysis to re-code the identified narrative arc, provided an additional layer of rigour. Given the limited role of numerical analysis in relation to the questions posed by the study, the actual numerical methods applied were deemed more than sufficient. In qualitative, interpretative and embodied studies located by ‘partial perspective’ (Haraway 1991), it is the resulting interpretation that provides the measure of validity and reliability.

One challenge of working with secondary data is that the researcher cannot ask follow-up questions. However, the fact that the researcher was not the person asking the questions became important to the stance they took towards the data. The researcher maintained the position of listening rather than directing the conversation: they listened to the whole conversation as someone who played no part in how that conversation came to be.

In view of the analysis, another shortcoming of the data could be their public nature. Interviews lack the protections of the academic research process, such as privacy and safeguarding. This has at least two drawbacks: (1) the self-selection of people who approached Raelan to be interviewed—and then to have their interview included in the study—might create a class bias towards those with more confidence or more interest in academic research and (2) while telling their stories, interviewees are more likely to encode self-preservation in their speech. This is a complex point, as social media have massively amplified the display of one’s internal lifeworld for the consumption or vicarious experience of others. Moreover, the protocols of academic research in no way guarantee that the very same aesthetics of self-preservation would not be those that are performed for the researcher. Without more research, we simply do not know what the implications of the use of social media data are. The researcher assumes that the existing dataset shows participants’ caution around more painful and exposing subjects.

Recruiting participants solely for the purpose of generating data has the advantage of allowing the researcher to include interview subjects or research participants with

particular social and cultural characteristics or with particular attributes (purposive sampling). As a researcher, one typically exercises some control over the parameters of the discussion, following a ‘topic guide’ (topics and questions for discussion) and building rapport, as well as steering and responding to the conversation according to the needs of the study. Social scientists are also trained on issues such as objectivity and bias, although the idea that social enquiry should uphold a position of neutrality has been significantly challenged (such as through the reflexive turn in the 1970s and the debates on subjectivity and objectivity referred to above). Indeed, when it comes to recovery from CFS, the ideal of objectivity is problematic on many fronts. Much energy has been spent on debates over which studies should be included in medical literature reviews or whether clinical research that has not followed double-blind trial protocols should even be considered relevant, whereas the narratives of those who have recovered suggest that it is time for a wholesale reconceptualisation of CFS (for a corroborating analysis see The Oslo Chronic Fatigue Consortium, Alme, Andreasson, et al. 2023). Policymaking requires a richer understanding than can be provided by evidence based on methods of data collection and analysis limited to qualitative metrics.

Section 1. Report in numbers

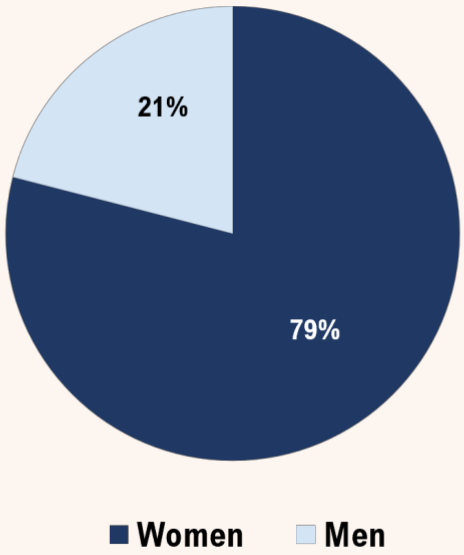
1.1 Introduction

Numbers were generated to communicate some observations with expediency. They should be read as ballpark figures that suggest a picture of the study participants and their experience.

1.2 Demographics: Who are the research participants?

During the research process, a written survey was issued and valid survey responses were collected from 49 participants. These data offer a description of demographic tendencies of the sample. Some patterns described here are consistent with those found in the general population affected by CFS. Namely, the gender ratio of survey respondents was 37 women to 12 men. Equally, 4 out of 5 participants in the study are women (n = 59). Broadly, these numbers are consistent with UK population data showing that 4 out of 5 affected people are women—although rates of incidence differ markedly according to age (Samms and Ponting 2025).

Figure 1. Percentage of participants according to gender



The ratio of heterosexual to non-heterosexual identifying respondents showed a higher-than-average representation of people identifying as sexually diverse (bisexual, asexual, fluid, etc.—though not necessarily gay or lesbian). Existing research does not count sexuality, so the make-up of this study cannot be compared.

There is a distinct lack of respondents from global majority national backgrounds and ethnic and racial categories, with around 85% of respondents identifying as white. Not one respondent identified themselves as Asian or Black. Over 70% of respondents were British or North American, with the former representing the majority.

Relationship status—whether a participant was in a committed relationship or not—tallied with the UK average.

A much higher proportion of respondents than can be found in the general population reported having completed higher education—around 80%, as compared with 50% in the general UK population. The level of education of participants is consistent with their vocational choices, with 64% (n = 48) of participants working as a non-medical practitioner.

These data suggest the gendered, racial, sexual and class characteristics of those who come forward to speak about recovery. However, rather than think about these characteristics in terms of demographics, this study enquires into how they could be positioned as indicative of a structure of identity that underpins how people develop CFS and how they recover. In broad terms, the structure is one of racialised social pressures around gender and sexuality and class aspirations. Given the dearth of research on recovery, there are no population data on the people who have recovered from CFS. Without further research it is not possible to know the role of class attributes, the cultural category of race—namely, whiteness—or sexual orientation, for example, in the experience of recovery.

The analysis also shows that many of the participants who were guided by non-medical practitioners, whether as mind-body coaches, breath work coaches or people working with trademarked psychotherapeutic or brain retraining techniques, themselves went on to train in the practices that helped them. Almost two thirds of participants had started working in the recovery arena following their own recovery. This means, at the very least, that the majority of recovery interviews have been given by people with a substantial commitment to the project of recovery beyond reflecting on their own experience. Most participants had stopped working during their illness, and most did not return to the same line of work once regaining their health. Many people report that this is because they developed a passion for wanting to help others recover. This study identifies this as a theme for analysis—self-education and making the decision to help others for a living is a central pillar of the recovery community. Further research could examine how the self-taught, private enterprise model of care being practiced in relation to CFS and related illnesses

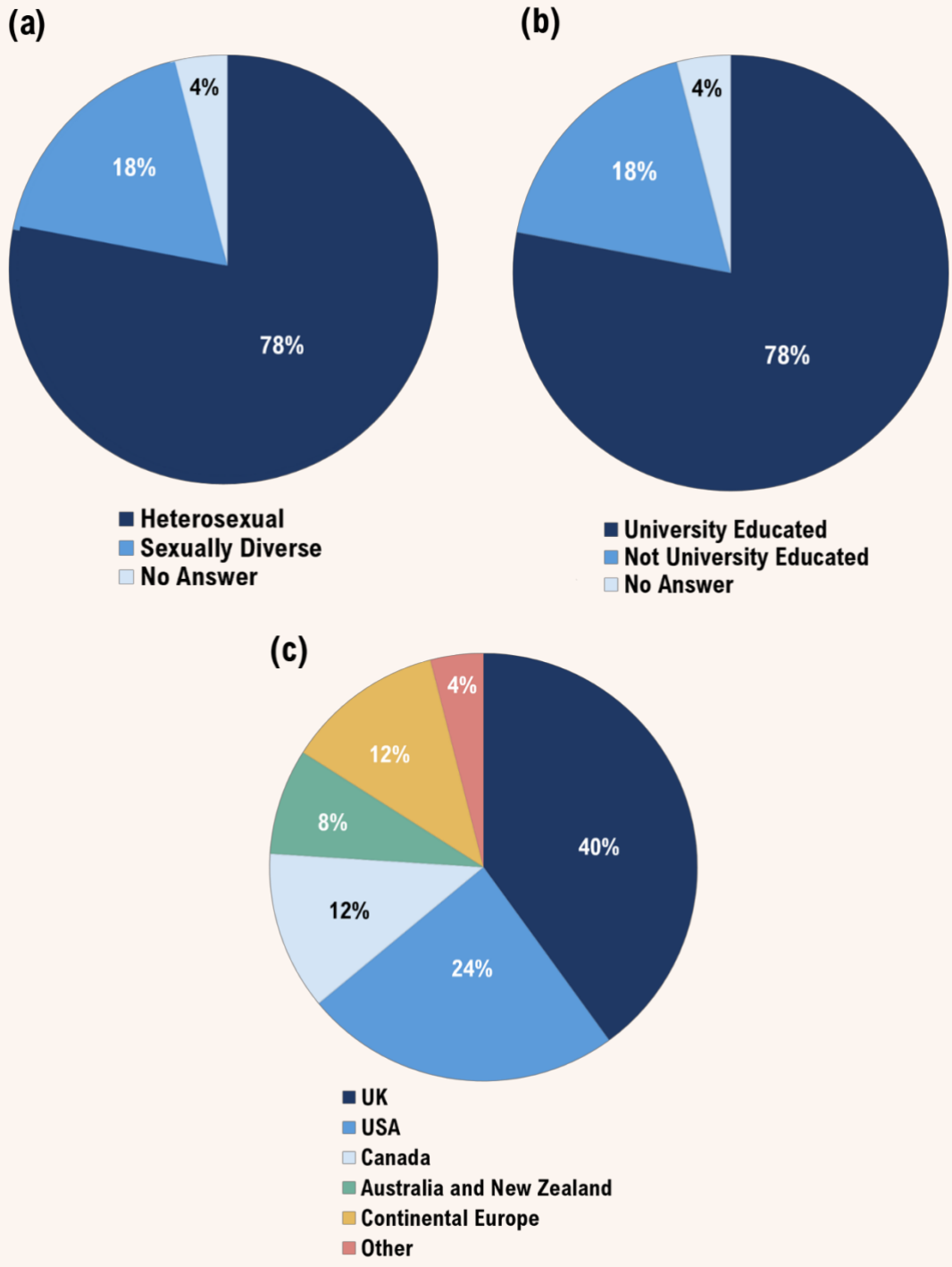
works, and whether it could be scaled up in collaboration with public health to support more people with their goal of recovery.

Figure 2. Demographics for survey participants:

(a) Sexualities of survey participants by percentage

(b) Education of survey participants by percentage

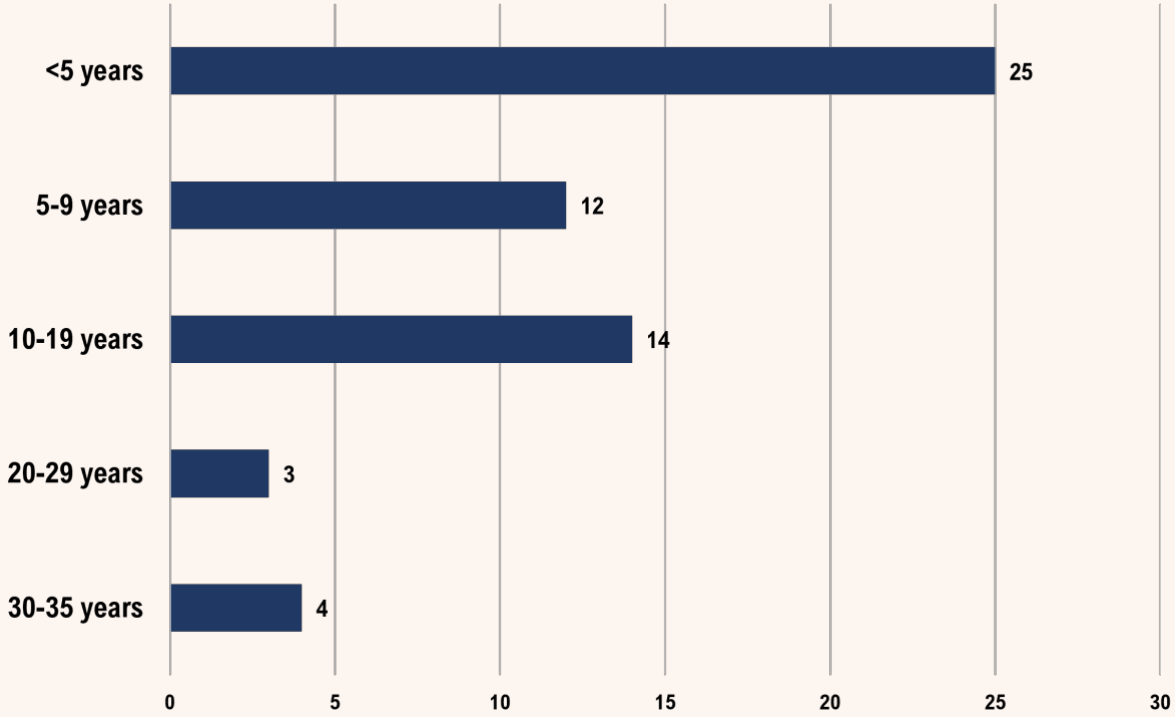
(c) Nationalities of survey participants by percentage



1.3 Illness characteristics

The views represented in this report reflect a combined experience of around 650 years of illness, with recovered participants' years of illness accounting for around 530 years. Given the impression that often accompanies participants' experience of getting better—experiencing wellness and then setbacks, for example—the 'years ill' ought to be regarded as a round figure.

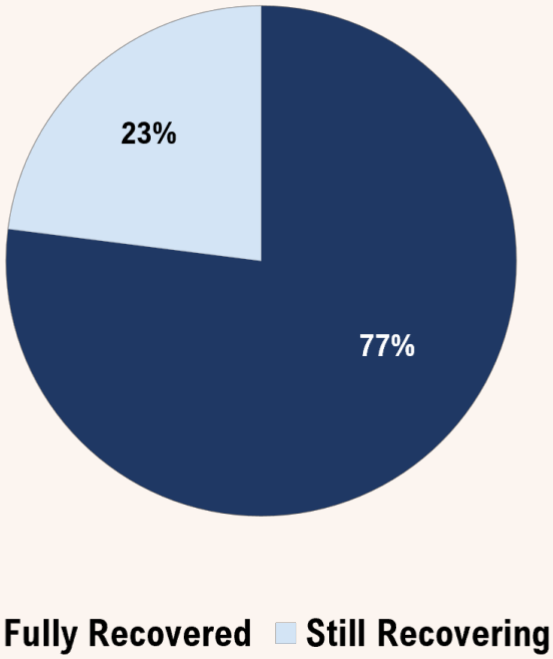
Figure 3. Recovered participants' years of illness



Raelan does not exclusively interview people who have fully recovered, citing audience requests to hear from people who are still in the process of recovering. Raelan and/or the interviewee describe themselves as having recovered or being in the process of recovery. According to their own accounts, most participants are fully recovered:

- 77% (n = 58) of participants self-report full recovery
- 23% (n = 17) of participants self-report recovery ongoing

Figure 4. Percentage of participants who are fully recovered versus still recovering



Some participants who are fully recovered talk about continuing to practice techniques that they had used as recovery tools (such as meditation, breathing techniques or pacing practices) after regaining their health. ‘Recovering’ denotes having significantly improved in health and capacity, while not being completely free of symptoms. Except in relation to the below numbers, the accounts of those who are in the process of recovery have not been disaggregated from those of participants who are fully recovered.

Almost all interviewees say that they were given a diagnosis. One was informally diagnosed by a family member who was a retired GP. Two others say that they discussed a diagnosis with their doctors but that no diagnosis was made. In these three examples, the diagnosis discussed between participant and doctor was used. Based on the findings of the Action for ME FOI request discussed earlier in this report, there is likely to be a discrepancy between patients being told that they have ME/CFS during a clinical encounter and that information being recorded in the public health system. Multiple diagnoses are common and the discrepancy between a doctor discussing a diagnosis of CFS and this being recorded as a matter of public health points to the incomplete medical view of the lived experience of CFS.

Diagnoses have been recorded as follows:

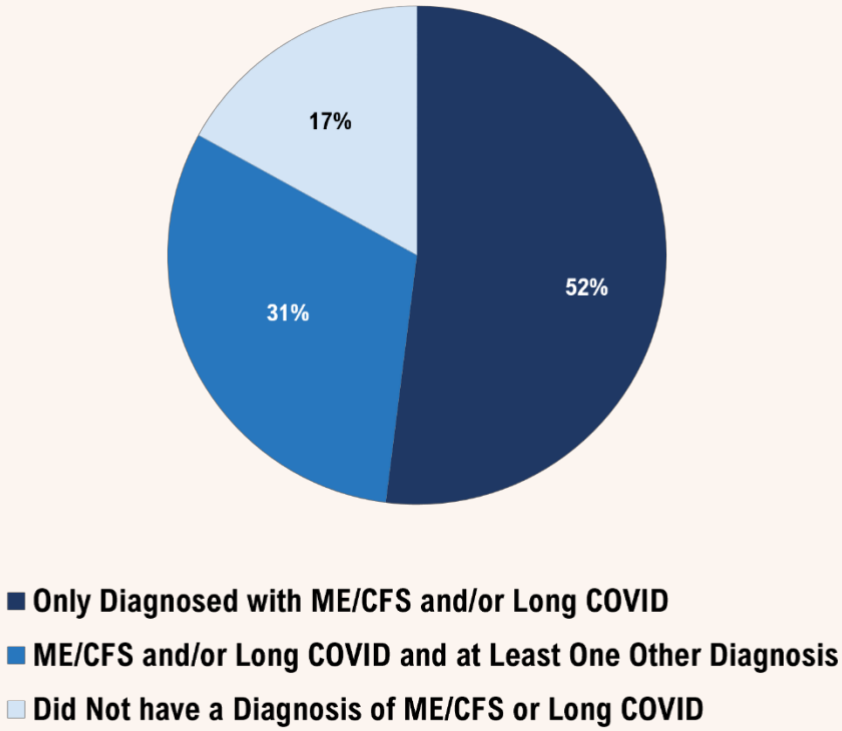
Reported Diagnoses	Percentage of participants
Diagnosed with **ME/CFS***	**63%** (n = 47)
Diagnosed with **long COVID***	**31%** (n = 23)
Only diagnosed with ME/CFS and/or long COVID	**52%** (n = 39)
ME/CFS and/or long COVID and **at least one other diagnosis**	**31%** (n = 23)
Did not have a **diagnosis of ME/CFS or long COVID****	**17%** (n = 13)
Diagnosed with **postural orthostatic tachycardia syndrome (POTS)**	**19%** (14)

*Some participants were diagnosed with long COVID and CFS

**Other diagnoses represented in the sample include: Ehlers-Danlos syndromes, chronic Lyme disease/post-treatment Lyme disease syndrome (n = 6), Sjögren's syndrome, Lupus, coeliac disease, mast cell activation syndrome (MCAS), fibromyalgia and POTS.

Most participants describe symptoms of infection at the onset of illness.

Figure 5. Percentage of participants who have a sole diagnosis of ME/CFS and/or long COVID versus those who have ME/CFS and/or long COVID and at least one other diagnosis versus those who have not been diagnosed with ME/CFS or long COVID

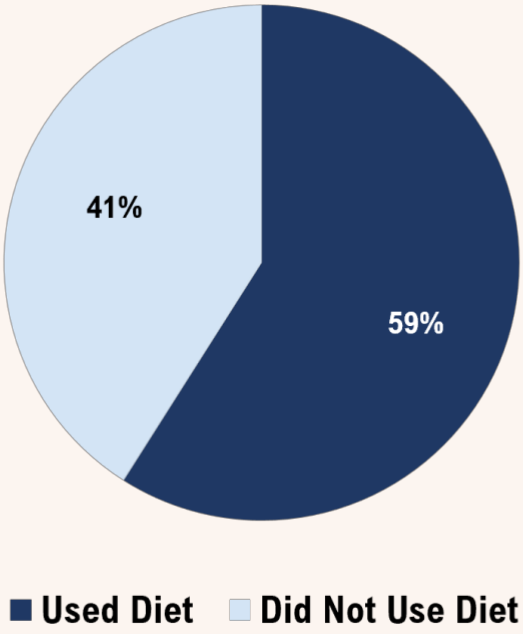


1.4 Tools and techniques used by participants

Interviewees tried a range of treatments and interventions that are recommended in alternative and functional medicine contexts. A measurement of the uptake of treatments and approaches is expressed as percentages for easier comparison. This measurement was generated through coding by hand. Participants report a number of things as having aided their recovery. **These percentages represent uptake—not efficacy.** They might be more likely to reflect exposure to a market in treatment recommendations rather than their success. It is not valid to draw conclusions about the efficacy of these approaches. It is, however, valid to consider how many people report recovery or improvement without having used these treatments.

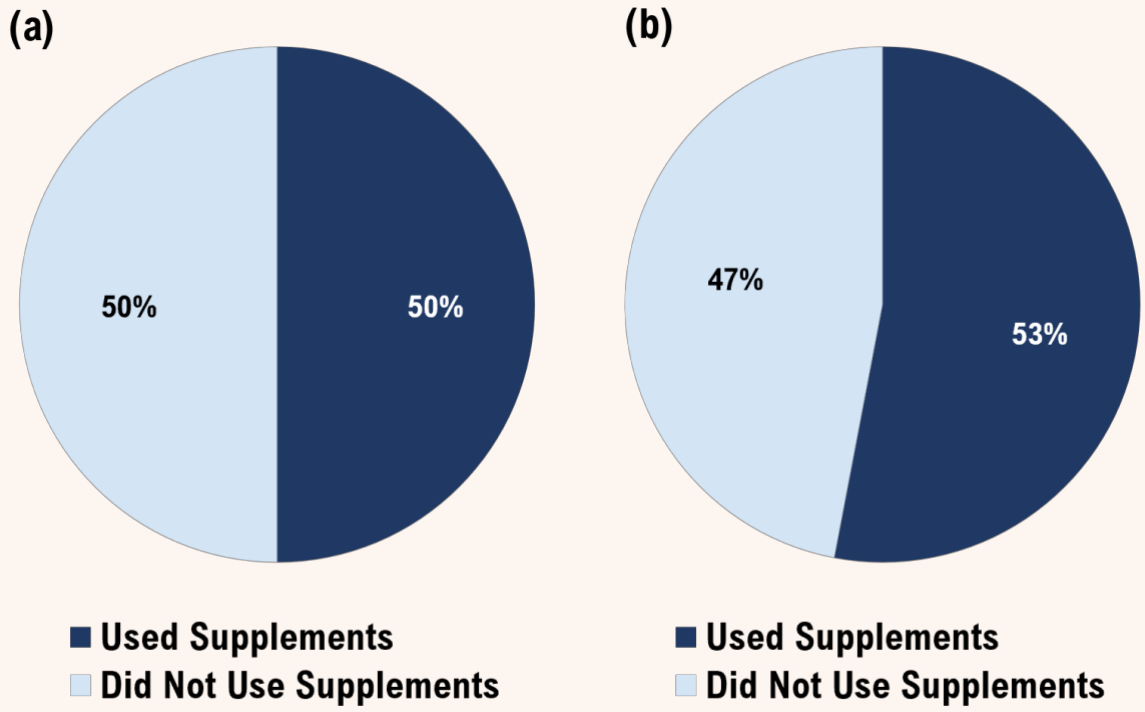
The most predominant tool used by all participants is diet—the percentage of those who used diet is 59% for both recovered and recovering participants. Another way to describe this number is that **at least 40% have seen symptom improvement without making changes to their diet**.

Figure 6. Percentage of all participants who used diet versus who did not use diet



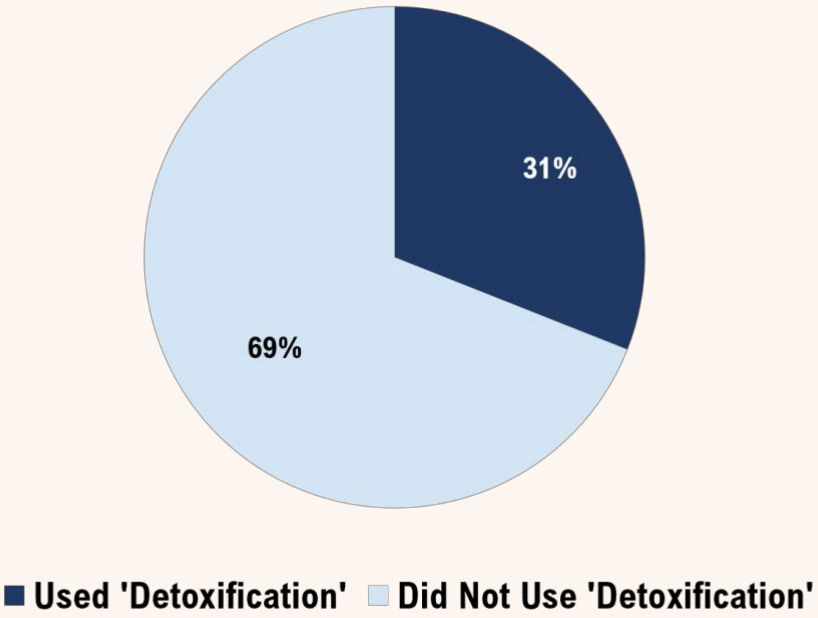
Given the expense, there is a lot of discussion about supplementation in the recovery community. Of those who recovered, 50% used supplementation, compared with 53% of those who are still recovering. Without knowing the efficacy of supplements for individuals or collectively, this does mean that **around 50% of participants have recovered from their chronic symptoms without using supplementation**.

Figure 7. Percentage of (a) recovered participants who used supplements versus who did not use supplements and (b) recovering participants who used supplements versus who did not use supplements



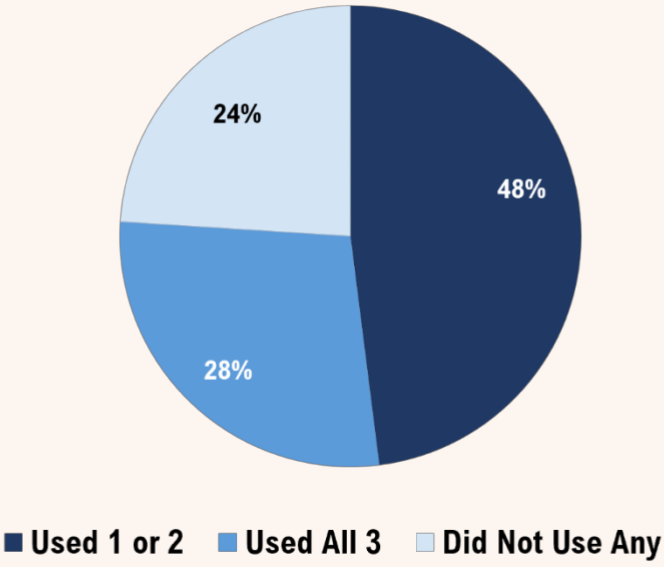
A much smaller number used practices they describe as ‘detoxification’—one in three. **Almost two thirds of participants recovered or have seen significant improvement without using detoxification.**

Figure 8. Percentage of all participants who used ‘detoxification’ versus who did not use ‘detoxification’



Of those who report having fully recovered, **24% did so without using diet, supplementation or detoxification**. While there is a lot of talk about these methods, only 28% of recovered participants used all three. Looking at the interview data in detail: at the time of the interview, only one participant attributed their recovery mainly to diet only, one participant to detoxification only, and one participant to supplements only.

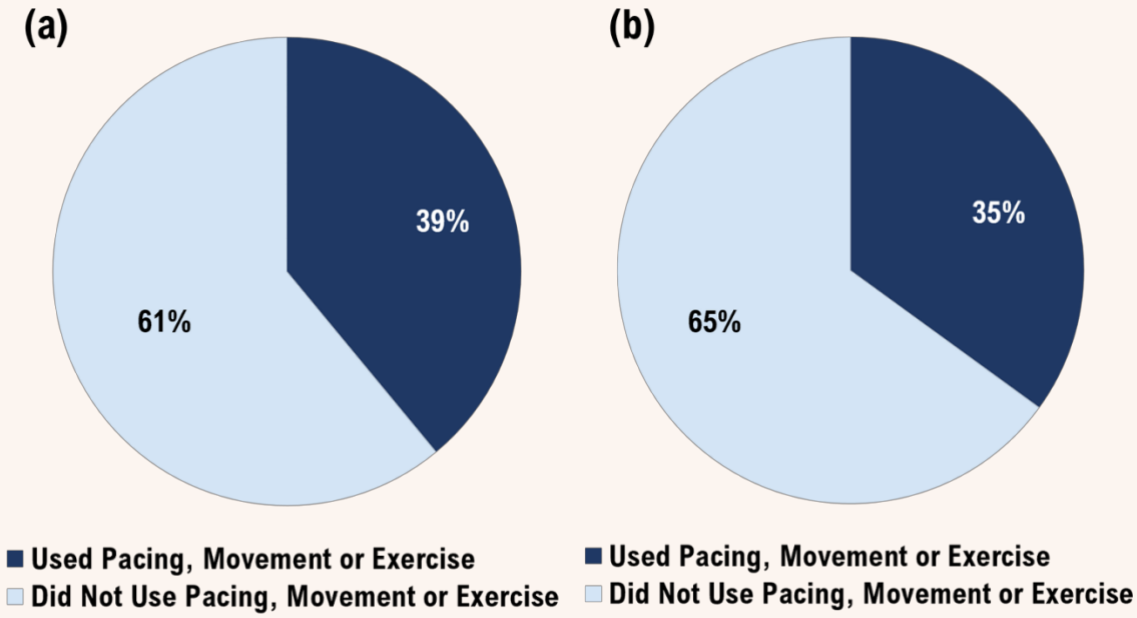
Figure 9. Percentage of recovered participants who used diet, supplementation and/or 'detoxification'



For example, while many participants attribute a key development in recovery to pacing, supplementation receives no such attribution. These data indicate the exposure of people who have recovered from CFS and related illnesses to a series of recommended tools and techniques of recovery associated with alternative medicine.

Given the variability in how pacing is understood and used, the study opted to record any discussion of movement as part of recovery. Even with this capacious definition that included references to movement or exercise (such as, 'going for a walk') as well as using pacing as an approach to energy management, only 39% of participants spoke about this overall, with little difference between those who fully recovered and those who are recovering. The surprising finding is that **around 60% of participants recovered or significantly improved without adopting an intentional practice of movement.** Assumptions around efficacy should not be made, given that for many of the other 40%, movement was reported to have played a significant role in recovery. Moreover, it is possible to pace and increase exercise and movement without defining this as a conscious practice. It is surprising to learn that **only 35% of participants with a diagnosis of ME/CFS adopted a practice of pacing or movement.**

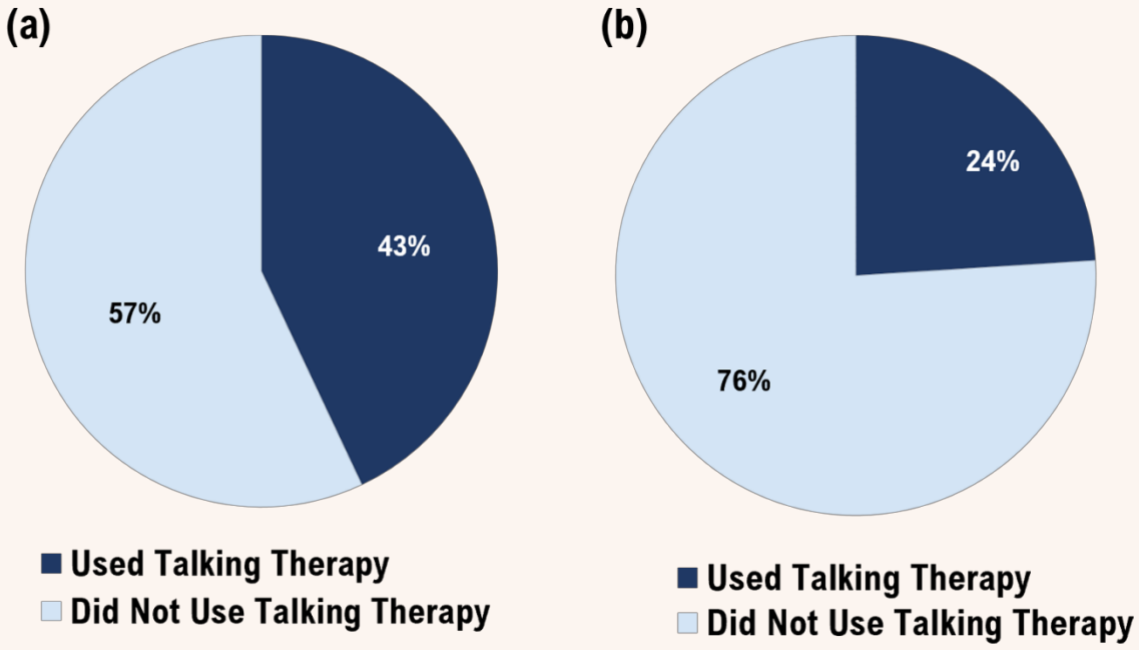
Figure 10. Percentage of (a) all participants who used pacing, movement or exercise and (b) participants with ME/CFS who used pacing, movement or exercise



Again, variability in definition and understanding prohibits a precise number based on these 'naturally' occurring qualitative interview data. Moreover, meditation is ubiquitous in recovery programmes and non-medical coaching and healing sessions; therefore, it might be underrepresented in accounts that focus on different aspects of these approaches. Of those who recovered, **53% report using meditation, and this is higher (65%) for those who are still recovering**. The more capacious notion of mindfulness is reflected in up to 90% of all recovery narratives.

Finally, **37% of participants' accounts include a form of talking therapy**. Here, there does seem to be a discrepancy between the practices of those who are and are not recovered: **43% of recovered participants refer to a talking therapy, in comparison with 24% of those still recovering**.

Figure 11. Percentage of (a) recovered participants who used talking therapy and (b) recovering participants who used talking therapy



The data show that the majority of participants have tried one thing or another: **only 7% (n = 5) did not use any of these lifestyle interventions.** Again, while this does not tell us about efficacy, this does provide meta information about the participants: that they are located culturally in a private market of CFS treatment and that most have tried several interventions before or alongside ones that helped.

1.5 Recovery characteristics

Numerical data have been generated by (or, more properly, extracted from) the interviews to give an indication of certain kinds of reoccurrence. For ease of reading, these are presented as percentages, then qualified below and discussed more in depth in the findings. These numerical data have been derived to produce a shorthand version of some of the themes that the full report outlines in detail.

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

All participants' accounts imply a belief that recovery is possible. Most participants expressly talk about hope and belief (around 60%), but do not necessarily use both terms directly.

No participant claims to have believed in having an intractable illness from which they would never recover at the time of seeing an improvement in symptoms.

While references to a lack of understanding on the part of doctors are widespread, actual recollections of 'not being believed' by a doctor are fewer than a handful.

No participant recovered within a public health medical treatment programme.

1.6 Observations

These data offer a descriptive overview of the following themes that are examined in more depth in the study:

- The gender ratio of participants in this study is consistent with that described in the broader community. While gender and race discrepancies are often noted, existing literature does not include a record of sexual diversity. This study considers the significance of these characteristics from the perspective of identity rather than demography. If the sample represented in this study is a cross section of who is affected by and recovering from CFS and related illnesses, this is a predominantly feminised, educated, white and slightly more sexually diverse group than the general population.
- Diagnostic ambiguity is a significant feature of the experience of symptoms of CFS and related illnesses. While the qualitative analysis reveals consistent themes in participants' accounts of recovery across the dataset, only around half of the accounts are of ME/CFS or long COVID alone. This points to the significance of the social and cultural context of the illness and recovery experience.
- Given the prevalence of pacing as a recommended treatment, it is striking to find that around 60% of recovery stories do not involve a reflection on the practice of pacing.
- Data on tools and techniques of recovery overwhelmingly point to the unregulated influence of a private market in ME/CFS and long COVID recovery. Most of the participants in this study have responded to this market through trying treatments, but almost none of these tools or protocols are accredited alone with symptom improvement or resolution.

- People who have recovered do not report recovery within medical settings. This report offers various forms of evidence of this, including the significant proportion of people recovering with the help of non-medical practitioners (83%) in comparison with those being helped by a medical doctor (5%).
    - This raises concerns about the reliance of medical, academic and clinical research on medical settings as a primary source of evidence.
    - Questions need to be raised about how recovery from CFS and related illnesses can be meaningfully discussed within medical frameworks when the frameworks that people in this study cite as being of significance to them are non-medical ones.
- The knowledge and practices of non-medical specialist practitioners require further research.
- The high proportion of study participants doing their own research suggests that the digital culture of CFS recovery intersects existing self-help, medical and non-medical culture, and that while the mushrooming of the recovery community deserves to be studied in its own right, the cultural rearticulation of existing knowledges and practices is also of significance.

Section 2. Onset of symptoms

> "I was a teacher, a primary school teacher. A stressful job, but you just got on with it … And I started to get these kind of symptoms, which were, I just didn't quite feel right. I didn't really quite feel like myself … I remember at times I'd be kind of sitting in the car, kind of psyching myself up to go into the building, and by the time I went in there, I'd be like, 'Hi! Morning everyone.' And there was a lot of pretending I was okay, a lot of pushing through. And then one day at work, I had a big collapse." (ME/CFS + POTS + fibromyalgia, recovered after 8 years)

2.1 Introduction

This section discusses the social context in which participants describe becoming symptomatic. Such accounts provide important information about participants' understanding of their illness and the significance they attribute to the discovery of a coherent explanatory narrative later on. The effect of medicine on the experience of illness is first marked during the onset of symptoms (discussed in more detail in the following section, Section 3. Encounters with medicine). Crucially, participants' narratives position the medical uncertainty that they first encountered during symptom onset as driving the later significance that they attach to finding a believable, sensible explanation for their illness. Lacking a clear picture of what is wrong at the onset of symptoms is the first hurdle to recovery. Finding a believable explanation stands in contradistinction to the medicalised view of non-recovery without cause and becomes a recovery milestone (see Section 4. Mindset as the gateway to recovery).

Symptoms are described as weird, unexpected and wide ranging—irregular heart rates, breathing irregularities, pains, peculiar and uncomfortable sensations, sensitivity to light and sound, symptoms of homeostatic intolerance, digestive issues suggesting intolerance, headaches and migraines, stiffness and debilitating fatigue to the point of not being able to move. While no two participants' description of the onset of symptoms is identical, their experience outlines a common ground in their symptomology. Participants share the quality of an experiential symptomology—an internal sense of the body not working, of the body being weighed down or getting in the way of what the 'mind', subconscious, person or personality wants to do (such as go out, socialise, work, be normal again). How this seemingly peculiar symptomology intersects with medicine creates an experience in itself.

Recollections of symptom onset universally elicited memories of turning to doctors for answers. What follows is often a lengthy process of diagnosis—waiting for test results to rule out disease pathology, waiting for referrals to consultant specialists or specialist clinics and sometimes being given a misdiagnosis. The consistency of participants' recollections of their medical appointments points to the psychological difficulty of being asked to accept a 'maddening' prognosis: while tests to rule out pathology show 'nothing is wrong', the very lack of a pathology in combination with the symptomology points to a lifelong prognosis. Medical messaging is entwined with participants' accounts of the spiralling of symptoms and withdrawal from family life, study, work and intimacy. The onset of symptoms is described in turn as sudden and cumulative, made possible by precipitating factors. Everyday concerns and activities, such as those to do with intimate relationships, professional pursuits and obligations, form an important part of the repertoire. They provide an overall sense of life at the moment of becoming unwell.

2.2 Not recovering

Many participants use the language of 'not recovering' to describe how they became chronically unwell. At least 24% of participants describe themselves as 'just not recovering', often using the specific word 'recover' rather than 'get better' or 'be well again.' Five participants used the phrasing '*just* did not recover'. The word *just* is an interesting choice, as its effect is diminishment. Its use suggests participants are implying: *that's all it was: a non-recovery*. Participants also used the phrasing 'simply never recovered' and 'never quite recovered'. The strangeness of the illness experience is linked to the ambiguity of lingering symptoms.

> "There were a few things paving the path to that final virus, that after that I just didn't recover." (ME/CFS, recovered after 2 years)
>
> "I had one of my crashes and I just didn't get better." (CFS, recovered after 4 years)

A common theme is participants' revision of their understanding of why they did not recover from an initial infection that seemed to catalyse their chronic illness. This revision often reframes infection as a 'tipping point' within a stressed system or set of interconnected relations rather than an origin in its entirety.

2.3 Social expectations

The perceived relevance of social pressures to the onset of symptoms is a major theme. Some of these pressures are reflected in participants' discussions about their

personality traits, which can be described collectively as participants' identification with an 'overextended personality' (see: Section 8. Social illness, identity and the overextended personality). Rather than locate responsibility for illness in the individual person, participants' reflections on what it means to live in the zone of extension, at the edge and beyond the body's possible means, point to the link between social expectations and corporeal dispositions or 'affective scripts'—the preponderance of anxiety and fear, or in the language of the nervous system: hypothalamic-pituitary-adrenal (HPA) axis activation. The emphasis given to social expectations in recovery narratives suggests a model of embodiment in which social expectations create pressures in and around the person that are interpreted or converted by the body into 'stress' information for the nervous system.

Participants describe life at the onset of symptoms as replete with stressors, such as workplace bullying, the pressures of higher education, the burden of familial responsibilities, the risks of new romantic relationships, the planning of new adventures and, more generally, working, socialising and exercising through each hour of the day. While such stressors are generic to a neoliberal culture that cultivates in each individual subject the sense that competitiveness is central to who we are, participants describe a connection between these stressors and their experience of social pressure that leads them to attend outwards—away from their needs and away from their body. Participants consistently describe a strong work ethic. All participants were in employment at the time of becoming ill. Many describe commitments to a healthy diet and exercise. Sometimes the specific stressor is not detailed, but a participant will outline the effects:

> "I was never taking my foot off the gas pedal, so I experienced that double-edged sword on the outside. I was super fit. I had muscles, I had abs, I could go down the beach and feel great about my physical body, but deep inside things were probably the opposite. I was very, very anxious, especially leading up to that major crash." (ME/CFS, recovered after 7 years)
>
> "I never slowed down." (CFS, recovered after 3 years)

A common theme is reflection on the decision to return to work as soon as possible, with the expectation of being able to work while still being ill and being able to make a full recovery while being at work.

“After about three weeks, I did start getting better, which is as part of the course. But when I started to integrate back into life, go back to work, just look after my son again, I crashed really horribly.” (Long COVID + POTS + MCAS, recovered after 1 year)

“After 10 days I thought, *Right, I’ll go back to work* … by lunchtime, I had to go home … I was just struggling with being exhausted.” (Long COVID, recovered after 1 year)

“I had glandular fever and I had this for a few weeks, and I had the typical symptoms and after that, yeah, I tried to live a normal life again. So I went back to work full time and I exercised again and I really tried to live a normal life, but looking back I can say, *I simply never fully recovered from that initial infection*.” (ME/CFS + POTS, recovered after 15 years)

“After three months, I said to the doctor, ‘I’m not getting any better. Maybe I should go back to work.’ And I went back part-time [and] got worse—and for another year.” (ME/CFS + fibromyalgia, recovered after 15 years)

“That took also a bit my focus away from getting well, because I was so excited to go back to work. I was feeling awful still, but I thought, *Okay, it’s not as bad as the beginning, and if I can work, it means that I am recovered.* It was a bit of a circular reasoning. So, I started that—I think for six months—but I crashed all the time and it was also very stressful, and because I was stressing about crashing, *Oh no, when will be the next relapse? And then I have this file that I can’t do*, but it took my focus away from the illness and also looking for a solution for it.” (ME/CFS, recovered after 2 years)

“I had no idea really what was going on, but something was really not right. And then it wasn’t until we got back to London where we live and I started work again that things went drastically downhill from that point.” (Long COVID, recovered after 2 years)

Like others, these accounts show how participants identify a precise moment at which their symptoms became acute—the moment in which they ‘crashed’ or collapsed. This physiological change is described as happening during everyday

activities, such as while being at work, going outside for a run or driving home from work.

Although not a common theme, one participant tellingly describes how, following an initial recovery from CFS, her symptoms appeared again, in anticipation of the repetition of the initially triggering stressful event:

> "Three years later, I was about to be managed by somebody who I knew to be a bully, and I crashed and burned the Friday before. I should say that first time when I was experiencing distress, I was noticing with the first job I was going downhill, getting very fatigued and just very fatigued, I would say, that I got a virus and just didn't recover from it. So then the second time, I just crashed and burned even without a virus, and that went on for 15 years." (ME/CFS + fibromyalgia, recovered after 15 years)

Having developed CFS initially in the context of workplace bullying, this participant outlines the anticipatory nature of her collapse. CFS arrived the second time due to a scene of anticipation rather than the fallout of an event. This type of detail is wholly interpretive, to be sure. It is consistent with the view that the body or brain (depending on the framework one is using) acts protectively, which is a view that this participant became familiar with and attributes significance to in the process of her second recovery. Another interpretation offered by this illustration is the idea that feeling unsafe is a contributing factor in symptom onset. One participant refers to the idea of the feeling of 'unsafety' in their recollection of how life was when they became unwell:

> "… suddenly, I felt so unsafe at work but also unsafe in my body." (CFS, recovered after 4 years)

These descriptions of returning to work can be viewed as accounts of a period of time in which participants sought to overrule their bodies or their symptoms: to force their bodies to allow the return to work or resumption of activity. This time came to an end when those participants could no longer 'push through' or try to pretend that they were well. Participants' accounts describe the event of having their bodies collapse from beneath them, of being drawn down into unending diminishment, which marked a total transformation in their existence. Almost all accounts are at pains to describe a sense that the whole body, and indeed the whole self, are affected. The body *and* the person can no longer function in the social world, in the world of work, in the

world of education. The body refuses to co-operate with social expectations, which the participants place value upon.

> "When you're working seven days a week and not really resting and not really sleeping much, and you're just so focused on that thing and putting health aside, then your body kind of hits a wall." (ME/CFS, recovered after 7 years)
>
> "That is when my body went, *Time out. We need to stop.* And it just really felt like that. And after that, it took a long time before I really felt anywhere close to being that sort of well, energetic person that I'd been before." (CFS, recovered after 7 years)

The theme of social expectation is articulated across the recovery narrative. Recollections of the onset of symptoms represent a particular pressure point. Participants talk about the difficulty of achieving a healthy life—of finding and maintaining a sense of security, emotional and psychological safety, physical health and mental wellbeing. Later findings in this report (Section 4 through Section 8) outline evidence supporting the view that pressures linked to social conventions and the cultural articulation of the neoliberal political economy (that is, our precarity) are substantive matters in the development of illness. Recovery narratives plot the switch from a chronic illness mindset to a recovery mindset as a change in the way participants are located within and respond to social pressures—both generally and biographically (see: Section 4. Mindset as the gateway to recovery).

2.4 The incomprehensibility of symptoms

One hope of the recovery community is that by sharing and giving visibility to recovery stories, people will more quickly identify the nature of their illness. The experience of not having a credible explanation for their symptoms during symptom onset is described as a significant distress in and of itself. Symptoms cumulate, spread out, take hold, set in. Illness does not appear as a complete picture overnight. Often months go by, sometimes years, without a diagnosis. Insofar as a medical diagnosis of CFS is presented as an admission that nothing can be done, the experience of being diagnosed compounds worry and fear. Participants describe their symptoms as spiralling and a loss of control that is a form of distress in and of itself. People do not want to act in a way that will compound their symptoms, but they are also intrinsically affected by their symptoms. They don't know what to do. They also describe the stress and panic that ensued when doctors could not help them to understand what was wrong.

“I knew I’d been overdoing it, but I wasn’t familiar with what was going on.” (ME/CFS, recovered after 4 years)

“I think there was also an element of denial in there where I didn't want to be associated with ME/CFS because nobody recovers from that. That’s a life sentence, or that was certainly what I thought at the time.” (Long COVID, recovered after 3 years)

“I was having odd symptoms … a bunch of strange symptoms … something was wrong with my body.” (Autoimmune disease + CFS, recovered from CFS after 3 years)

“I just felt like I was running in jelled jelly and it was really uncomfortable, and it felt—my whole body felt like I couldn’t produce enough energy to continue running.” (ME, recovered after 6 years)

“It originally just seemed like it stuck out of nowhere. It seemed like I got this virus and just overnight, my life just completely changed.” (Long COVID + ME/CFS + POTS, recovered after 2 years)

“Not understanding what was going on with my body … fed into more unsafety.” (CFS, recovered after 4 years)

“I just felt very off. I was still able to do my day to day, but I just did not feel like myself at all. I was having to take naps during the day, which was really weird. I was having these kind of intermittent chest pains. I woke up feeling like I’d smoked 40 cigarettes the night before when I don’t smoke. And just emotionally, I felt very off. I was still able to just go about my day. I had no idea really what was going on, but something was really not right.” (Long COVID, recovered after 2 years)

“The doctor just kept saying, ‘I think it sounds like strep throat’. And I was saying, ‘well it doesn’t hurt. It just feels like someone’s strangling me’. *My throat’s going to close at any minute and no one got it.* And so I was put on antibiotics and I was given the spray and no one could do anything. And I think the stress of not knowing—now, looking back—I can see that I was just

so stressed about the whole thing that I think that then made everything much worse." (Long COVID + CFS, recovered after 2 years)

The language of fear is prevalent in accounts of the onset of symptoms. Unexplained and yet all-encompassing, participants describe symptoms as confusing and scary. The word 'terrifying' frequently appears as a descriptor: 20% of participants describe being 'terrified' during the first days of illness. What is described as terrifying is not only the severity of symptoms and their effects but the experience of not knowing what is wrong and the absence of clinical or social support that could provide comfort and reassurance. References to fear appear at other moments in the recovery narrative, such as in descriptions of being afraid of the reappearance of symptoms or of avoiding stressors such as food or activity for fear of having to experience a surge in symptoms. Narratives link fear to the shrinking of life, lessening of confidence, and deepening of social isolation.

2.5 Retrospective interpretation

The location of symptom onset in the social and cultural context of the everyday reflects participants' descriptions of their search for meaning. Told retrospectively, the search for a credible illness explanation is answered by a holistic interpretation that views social and cultural factors as relevant to both illness and recovery trajectories. For a lesser number of participants (<10), the infection that is usually associated with chronic symptoms, such as the Epstein-Barr virus (EBV) or COVID-19, represents the tipping point for a body that, for some time, has been dysregulated. These participants describe prior periods of being symptomatic, a susceptibility to common contagious respiratory illnesses, and being off balance in other ways, often with psycho-emotional implications. These participants take a broader view of illness, seeking to understand what made way for a certain knot of symptoms or errant biology to configure. This retrospective interpretation often involves making connections across different kinds of life events. Examples of this thinking in recovery narratives involve reflections on childhood, early experiences of illness, a lack of safety in the home and loss.

"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 … it just felt like I was hit by a truck." (Long COVID + ME/CFS + POTS, recovered after 2 years)

"Now I think it started in my childhood, but I didn't realise it at the time." (Fibromyalgia, recovered after 11 years)

"I had quite a traumatic kind of teenhood. My dad died when I was 13. I got glandular fever when I was 15. And that was kind of the real trigger point of something happening in my body. And I never quite recovered." (ME/CFS, recovered after 2 years)

"I think I'd had a tough couple of years beforehand and I definitely had a build-up of stress that I wasn't managing. So when I got COVID, it was kind of like the perfect storm … COVID was when my life completely changed. It was just for the absolute worst … I just started to have some really, really scary experiences." (ME/CFS, recovered after 8 years)

2.6 Discussion

It is unsurprising that there is disagreement about the status of particular symptoms as diagnostic criteria around the globe—such as between the Canadian Consensus Criteria, International Consensus Criteria, guidance from the Centres for Disease Control and Prevention, the UK's own NICE guidelines and the definition of ME/CFS in relation to long COVID (for example see, Vernon, Zheng, Do, et al. 2025; White, Abbey, Angus, et al. 2023). There is also disagreement among professions, professionals and patients over how symptoms should be qualified and treated. The interview data in question here have not been analysed in relation to such qualifications even though some are directly in play. Findings point to the scope of recovery provided by community-led, non-medical interventions, implying that further qualification of illness criteria is unlikely to be of immediate benefit to people seeking to recover from symptoms. Findings also corroborate existing research outlining the discrepancy between the complexity of symptom perception experienced by patients and medical reasoning and practice that 'struggles to provide sufficient relief and seems to lack the necessary understanding and tools to help people recover' (Bakken, Mengshoel, Synnes and Strand 2023: 2). We are socialised to make sense of our bodies in particular ways that are culturally specific. The socialisation of our bodies as sites of expression and experience can be referred to as our 'embodiment' or 'corporeality'. Simply, we live in/with/as bodies in ways that vary across time and place, as does our human biology, the biology of disease and, more recently, the sociology of illness. Typically, we are socialised to think of problems with our bodies as disease related and therefore medical in origin. This is a reflection of what

historian philosopher Michel Foucault referred to as the ‘medical gaze’ (1976)—the penetration of medical knowledge into all areas of life. Medicalisation not only presents a way of looking at and understanding bodies, disease and illness, but is a form of power-knowledge that classifies and disciplines subjects—‘individuals’—according to their adherence to a norm. Subsequently, medical knowledge—which includes knowledge in psychiatry, neuroscience, statistics and the health sciences—acts as a social, cultural and legal authority on the body. Typically, medical explanations isolate biological processes from the lived experience of illness at the individual or community level. While illness is our experience of disease, medicine is the science and hopefully treatment of that disease (Sharpe and Greco, 2019). In the case of ME/CFS and related illnesses, the symptomology confounds the diagnosis of disease, which means that the biological integrity of the symptoms–disease–illness relationship cannot be tracked.

Existing research focuses on disease rather than illness. Recovery narratives position the onset of symptoms as memorable. Accounts of symptom onset have an orienting function, inviting the listener into the subject’s illness experience. In the context of the whole interview, the account of how one first experienced symptoms becomes linked to how one improves or recovers. The privilege given to descriptions of social expectations and pressures at the time of becoming unwell suggest that further research (possibly epidemiological) could examine, in more detail, the timing of the illness in relation to periods of study, recent job transitions, new romantic relationships and other common stressors, as well as major life events or traumas. Further research could also tally life circumstances at the onset of illness with structural characteristics, such as gender, race, class, sexuality and family health history. The findings of the *Recovery Report* lay out an agenda for future research into the provision of care to better support people who are seeking to recover from CFS, as well as a more rigorous account of how social differences can be taken into account in that provision of care.

It is unfortunate that current guidance does not direct general practitioners (GPs) to provide more holistic support at this sensitive time of symptom onset, during which participants describe becoming habituated to their symptoms while also struggling to accept their impaired condition. While pathology is being ruled out, participants report feeling kept in the dark or ‘none the wiser’ about what is wrong. Sadly, patients describe how the resulting fear and anxiety aggravates symptoms. Holistic approaches to care, including the provision of social care rather than medical advice, could serve as a vital stopgap within public health services. While this does not fix the lacuna in medical understanding, reassurance from doctors about prognosis and the availability of support—for recovery specifically but also in home and working

life—could provide an alternative framework to the ‘medical abandonment’ described below.

Section 3. Encounters with medicine

Participant: So I came back to the UK and carried on working, um, and it just kept returning and people at work were like, “What is this virus?” And I was like, “I don’t know.” Yeah, it was fluctuating on and off to the point where, soon enough, my weekends didn’t really exist, my evenings didn’t exist, and then a friend of mine kind of said, “Oh, maybe it’s ME.” And I’d never really heard of it. I’d heard of it, but I wasn’t familiar with it, and all I knew was like, *That’s a terrifying chronic illness.* I guess this is something probably some people can relate to: that moment where you’re like, *Oh, maybe I’ve got a long-term illness.* And eventually, [I] went to the doctor’s over about a year, eventually got diagnosed with ME/CFS, and that was where it began to get worse, really. The nocebo effect, perhaps, where the 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.”

Raelan: What did you think when you heard that?

Participant: I was terrified. [It’s] just giving me goosebumps saying that. It’s weird when you’ve recovered and it’s been a while, because you kind of almost forget when your life has become rich again and you are well. But it was horrific. It was like the worst thing. Obviously what I was experiencing was really challenging that you think, *Oh, I’m sick. Maybe there’ll be a route out of it and I’ll be given something.* But what I was suggested to do was pacing, where I had to record how many hours I was kind of active each day, and then if I still had symptoms, reduce those hours. So it was just getting reduced and reduced and it was just like, *Well, what am I learning to live with?* Then at my work, my boss said: “Maybe you need to change careers,” because I was off work all the time. They were incredibly supportive, but hearing that, for me, was heartbreaking. I was in my mid-thirties and I [had] always wanted to have kids, and I thought, *Well, how am I ever going to do that? Because now I’ve been told that I’m just going to basically be in bed and be cared for by my partner and my friends and family for the rest of my life.* It was terrifying. And looking back, that fear really made me worse. I got a lot worse from that point. I think I was living with huge anxiety. I’m sure you can relate to that terrifying feeling.

Raelan: Absolutely. And I just think, *Thank goodness for the Internet*, because at least now when people get that initial message, which I know a lot of people are still getting, I hope … usually we turn to Google and we start searching. *I'm trying to figure things out, and at least hopefully through there we can see that okay, maybe there is hope*. But, for me, that was one of the hardest things when I first got sick, because my mum had been sick my whole life, and I've seen one of the worst-case scenarios played out right before my eyes, and that's all I knew of this illness. So that feeling of, *This is the rest of my life*, was what was the hardest. If someone had told me it was temporary, there was hope, then it would've been different. But just this feeling like, *I can't live the rest of my life like this. I just can't. I'm not up for this. This is not what I want. This is no way to live.*

Participant: Being told that I had to 'learn to live with it', I just felt just terrified, and I got worse to the point where I was pretty, well, I was housebound, pretty much. Every day I would try to go outside. For me, nature has always been healing, and I was really determined to try and continue. But, as I'm sure lots of people have experienced, you just try and walk a few steps, and it's like you're walking up a mountain and you've just run a marathon, and you're like, *I don't understand. I've just been working, so fit and healthy, for years.* It just felt terrifying. And then I just was pretty much on the sofa, and it gets to the point where you can't read. It's difficult to watch TV, have conversations. I've really struggled. Yeah, it's no exaggeration to say I really reached rock bottom. You're just spending all day staring at a wall thinking about what's happened to your life. It's absolutely terrifying. And so, to be told by doctors that 'there isn't really a way out'… I guess I was offered a group session of people with ME, but it wasn't a session for 'how to recover'. It was getting together to [learn] 'how to deal with your symptoms', and I couldn't get there anyway. I couldn't drive, I couldn't get on public transport, and if I had energy, I wasn't using it for that. So, for me, it was just heartbreaking that all the doctors had to offer me was, 'Tough.' Pretty much, that's what it felt like at the time. They were kinder words than that, but they didn't offer me anything substantial. (ME/CFS, recovered after 4 years)

3.1 Introduction

One of the most difficult aspects of listening to CFS recovery stories is having to visit participants' experience of medical appointments. The interviews make clear that obtaining a diagnosis is a meaningful but often obstructive and painful pursuit involving multiple appointments with different doctors and often the navigation of multiple conditions. It takes time for people to realise that symptoms are not going away on their own. Even in the case that a participant has realised relatively quickly (in a matter of months) that the symptoms that ail them are CFS and/or a related chronic illness, time elapses before recovery is contemplated. Participants recount in detail a litany of medical appointments and describe the short-lived satisfaction of receiving a diagnosis of CFS in particular, given the insecurity of its prognosis: a life sentence without cause.

> "[Irritable bowel syndrome (IBS)] in 2012 and then the fatigue came in 2015, actually. And the diagnosis ME/CFS was in 2017, so it was a long span of time." (CFS, recovered after 4 years)

> "I was just getting more and more afraid every time I went to see them [doctors]. And we talked about all these serious conditions and they looked concerned. So at that point, I kind of wanted to do it on my own." (Undiagnosed autoimmune and immune-mediated inflammatory disease, recovered after 11 years)

Existing research and policy document the lengthy, inequitable and cumbersome processes of being given a CFS diagnosis and offered specialist health services. Research also identifies variation in diagnosis by gender, age, ethnicity and location (Samms and Ponting 2025). From a feminist socio-cultural perspective engaged with critical epistemologies such as intersectionality (Crenshaw 1991), standpoint (Smith 2005), identity (Showalter 1987) and materiality (Haraway 1991), the analysis of variability and bias by gender and ethnicity in statistical terms based on patient records reads as quite generalised and abstract and offers little by way of an explanation when it comes to the question of how gender, race, age (and sexuality and class) inform the intersection of epidemiological knowledge and experience understood in cultural, historical terms. While hypotheses around 'social and healthcare barriers to diagnosis' (Samms and Ponting 2025: 7) are welcome, the possibility that CFS arises through historical difference is overlooked.

The CFS community might do well to reframe the culture of disbelief toward people with CFS in terms of the medical establishment's longstanding disbelieving of

women, highlighted in the UK media recently in relation to maternity and neonatal care, menopause and endometriosis, as well as scandals such as the transvaginal mesh implants given to over 100,000 women. While the complex cultural history of this disbelief is out of the scope of this report, participants' accounts show how difficult it is for someone with CFS to feel taken care of by medical professionals. Patient support and advocacy groups often highlight the patient experience of being disbelieved by doctors. However, the relevancy of this claim is not borne out in these data. While interviews often make insider references to a lack of belief on the part of doctors, very few transcripts actually describe being disbelieved by a doctor during a clinical consultation. Rather than speculate on why this might be, the analysis here focuses on what participants do say about their encounters with medicine: that turning to medicine for answers also means turning to doctors for hope, and that patients are being told emphatically by doctors, as if to underpin their belief in the seriousness of the illness, "You will not recover."

3.2 Doctors tell patients, "There is no cure" and "You will not recover"

> "Obviously we need to get a diagnosis to understand what's happening in our body, but also a negative because it was like, *okay, now I have a disease; I have something they're telling me 'there's no cure'.* And from there it was a lot of desperation and a lot of fear for quite a while after that of figuring out what the heck I was going to do about this illness that I had." (ME/CFS, recovered after 7 years)

This study cannot comment on whether doctors 'believe' in the illness CFS or the range of symptoms patients describe. What clearly is distressing for participants is the implication of the diagnosis of ME/CFS: that it is an incurable illness from which one does not recover. These interviews reframe the problem of disbelief as one of the disbelief in the possibility of recovery. This is a structural problem compounded by a lack of research into recovery and a lack of research taking a critical, social and cultural perspective, as well as a failure on the part of national health services to track recovery.

Overwhelmingly, participants recount clinical appointments as negative experiences. As seen below, some 27% (n = 20) of this study's cohort (all but one of whom subsequently fully recovered) recall being told at a doctor's appointment that there was no cure for them. Participants were not necessarily asked to disclose the content of their meetings with doctors but volunteered to do so. As such, the real

proportion of people living with ME/CFS who are told that they have an interminable illness is likely higher.

“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 knew it was incurable … the doctor did say: ‘You are probably not going to recover. Just rest.’” (CFS, recovering after 3 years)

“[The doctor said:] ‘You’re going to have this disease for the rest of your life, and you cannot get well—you cannot recover. It’s only 5%.’” (ME, recovered after 6 years)

“The doctors are saying to you, ‘You can’t recover.’” (ME/CFS + fibromyalgia, recovered after 15 years)

“When they diagnosed me, I was like, *Okay, great, I’ve got a diagnosis. What do I do?* And they were like, ‘Oh, no, no, this is you now. This is you forever.’” (CFS, recovered after 4 years)

“I called a doctor in Harley Street, a chronic fatigue doctor ... and he just said, ‘not many people recover from chronic fatigue syndrome. I don’t think that you’re going to get better from this.’ And I was like, ‘how many people do get better?’ And I think he said ‘5%’ … and he said, ‘If I were you I’d go on Amazon and buy this book *Living with Chronic Fatigue Syndrome* and good luck.’” (Long COVID + ME/CFS, recovered after 2 years)

“He was like, ‘Well, if you keep doing this, one day you’ll never get out of bed and you’ll be stuck in bed forever.’” (CFS, recovering after 20 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)

“He said to me: ‘Well, that’s something that you need to get used to, because you’re going to have this for the rest of your life.’” (Long COVID + ME/CFS, recovered after 2 years)

“Finally, I got a diagnosis. Oh, … guess what? ‘There’s no cure. There’s no cure.’” (Autoimmune disease, recovered after 17 years)

“I have a disease, I have something [where] they’re telling me, ‘There’s no cure.’” (ME/CFS, recovered after 7 years)

“I had a couple of doctors who told me I almost certainly had [multiple sclerosis (MS)] and would probably be stuck in a wheelchair.” (Lyme, recovered after 7 years)

“He specialised in this diagnosis, and he actually said: ‘We don’t know what the cause is and there is no cure, and really, you’re going to have to live with this. I mean, that’s all I can tell you.’” (ME/CFS, recovered after 13 years)

“One doctor, he even told me that I had ‘hypersensitive nerves’ and that I was going to be in pain the rest of my life … No matter what treatment I did, no matter what procedure I did, no matter what specialist I saw, I was just told that this was going to be a forever thing.” (Fibromyalgia, recovered after 4 years)

“All the hope that I had at the beginning, thinking, *Oh, okay, somebody’s recognising this, yeah, it’s something real*, it just completely went away because they told me that I could learn to cope. And I thought, *I can’t. I can’t cope with this. I don’t want to live like that.* And then I told them: ‘What I want is a cure. You know anyone who’s got—’ Well, their answer was pretty much … ‘The sooner you accept that you are ill and that you’ll be like this for the rest of your life, the easier it will be to cope with the symptoms.’ And I was even told that probably I would need one of those disability scooters or, yeah … wheelchair … and that I’ll be fine. ‘You’ll be fine.’ So … well, *This is not fine. I want the cure.* And they said I was ‘delusional’, that I was ‘in denial’, and that that was very, very upsetting.” (ME/CFS, recovered after 2 years)

“My doctors were kind of telling me otherwise, and well, ‘You’re always going to live with X amount of things’ or ‘It’s going to come in waves and you're never going to fully heal.’” (Lyme + POTS + fibromyalgia, recovered after 15 years)

> “I mean I was pretty motivated, but man, just knowing that would’ve just, I was so defeated from day one when a doctor told me: ‘Your life is over.’ And when I was first diagnosed with fibromyalgia and they said: ‘This is it. Your life is over. This is forever.’ And I was—I didn’t want to believe that. Part of me rejected it, but you can’t unhear it. So, it messed with my mind.” (Fibromyalgia, recovered after 5 years)
>
> “He told me the typical conventional medical view though: ‘There is no cure. You can do nothing about it. The only thing you can do is pacing and then you can try some medication, which are not, er, I mean they were not really tested in clinical trials, but you can try them, and that’s the only options you have.’” (ME/CFS + POTS, recovered after 15 years)

The view of non-recovery espoused in these clinical encounters is not only medical in origin but cultural too—a value system that is represented to patients, and that circulates as an effect of discourse:

> “Everything was like, ‘Yeah, you're going to have this disease for the rest of your life, and you cannot get well—you cannot recover. It’s only 5%. And mostly it’s young people or people who only had it for a short while.’ So I was very sad at that time, and I tried to find solutions outside of myself. I went to the doctors and I asked for help, and no one could help me.” (ME, recovered after 6 years)

The above statement highlights the reliance on a 5% recovery rate and the association of CFS with non-recovery.[3] The cultural traction of this narrative reflects its institutional support.

[3] The median recovery rate of 5% is cited to a review of 28 research articles, 14 of which matched the operational criteria for CFS (1980-2003), published in *Occupational Medicine* by R. Cairns and M. Hotopf (2005). According to the Dimensions database, this study benefits from field citation ratio of 66, 359 citations, 7% of which have been made in the last 2 years. Reference to the study occurs in literature that is wide-ranging. The top four cited papers that reference this study examining clinical practice, the natural history of ME/CFS pathophysiology, the role of microRNAs and narrative analysis of the ‘sick role’. The DecodeME genome-wide associations study provides an illustration of this oft cited research, linking the lack of diagnostic testing to interminable illness: ‘There is no positive diagnostic test for ME/CFS, no known cause, and white it can relapse and remit, full recovery is rare, at about 5%’ (Genetics Delivery Team, Boutin, Bretherick, Dibble, Ewaoluwagbemiga et al., preprint). A full review of the citation of this 5% recovery rate has been reserved for publication by journal article.

This report notes participants' accounts of the certainty with which doctors impart the knowledge of non-recovery. What participants' accounts make apparent is the cost of this certainty: the withholding of hope. The lack of research on people who have recovered could draw into question the validity of this certainty. Without a consensus on the disease process—without knowing why people would not recover—and in the absence of a research culture that actually takes into consideration the knowledge and experience of people who have recovered, there is no basis on which physicians could claim to know with any certainty that an individual patient with CFS will not recover. The onus is on medicine to locate documented recoveries and produce more meaningful interpretations of them.

When looking at the interview data, it is impossible to disentangle the experience of not recovering from the medicalisation of non-recovery.

> "For me, it wasn't the only thing, but [it was] one of the things that was contributing to my symptoms, like I said … when the doctors gave me a life sentence, for me, fear was a big factor in generating my symptoms."
> (ME/CFS, recovered after 4 years)

Where evidence of recovery exists, it is ignored and quashed by medicine and society. Any suggestion that non-recovery should be treated as an established, politically neutral fact of medical science should be scrutinised.

Telling patients that they will not recover denies them access to hope for recovery, belief in recovery and, in turn, self-determination, which this study identifies as key for recovery.

3.3 Doctors tell patients, "There is nothing we can do"

A further 36% (n = 27) of participants said that their doctor told them that they 'didn't know what to do' or 'didn't have answers'. Not knowing what to do, or the lack of a treatment pathway, quickly amounts to a message of non-recovery, especially when this message is not accompanied by advice to seek alternative help outside of medicine. Looked at together, 63% (n = 47) of participants—a clear majority—have effectively been given the message that they will not recover. The message participants describe receiving is that recovery is not possible because medicine cannot help. When participants approached doctors, they did so not only to look for treatment but also for validation and support in the form of an explanation of what is wrong. Participants hence recall being told that 'nothing is wrong' and 'there is nothing we can do' as particularly invalidating.

“I kept seeing more doctors, and I’m sure everyone else that experiences this has as well. And they kept saying it was anxiety or I was just worn down, and it was just very hard getting answers at first. So, that’s kind of what it was like when I became unwell … As I went to more doctors and got pulmonologists and all the specialists, they kept ruling things out, and I kept not feeling better … I felt like … me going to all these different doctors and then them having no answers for me just made me kind of like heartbroken.” (CFS + fibromyalgia, recovering after 5 years)

“And they said to me, ‘Look, your chronic fatigue is just going to be … We can’t do anything about it. You’re just going to have chronic fatigue for the rest of your life because you have Sjögren’s.’ And so at this point, what would happen is every day, if I felt a bit better, I’d feel hopeful, and then if I then would crash or feel bad, then I would be like, *Okay, just accept this. Just accept that you’re going to be like this.*” (Sjögren’s with chronic fatigue, recovering after 3 years)

“So I was really feeling frustrated when doctors or people around me were trying to minimise the symptoms, or you can't really blame them because they can't feel it. But so I spent a lot of time trying to explain it but trying not to complain too much about it either. So it was really like a dark lonely period … I felt very anxious and lonely and afraid. And eventually I also, the specialists that did the test and then when they came back normal, they just said, ‘okay, so I can't help you any further.’ So then I had to go back to the general practitioner and the first six months it was a doctor that was really not supportive or anything, but then I switched and she couldn't really help me. She admitted it herself. She said, ‘I really don't know what to do with this.’” (ME/CFS, recovered after 2 years)

“That’s when my journey started with just going downwards from that point on, unfortunately. After I got back from Costa Rica, I got [a] full workup, done cardiology, my doctor read all kinds of [lab work reports] and the answer [was], ‘Oh, we can’t really see anything there. Everything looks fine.’ And it’s really—in a way, it’s a blessing, because you’re like, *Okay, good. Nothing serious is wrong.* And so, then you move forward and you keep going on with life, but then, all of a sudden, you’re starting to have these ups and downs that are continuing. You’re like, well, scratching your head, *How am I fine on*

paper, but I'm not feeling fine? And so that was in 2017, and honestly, I wasn't consistently getting worse. Mine were more ups and downs, and that's how my presentation was from 2017 through 2019, where, for a couple of weeks, I'd be pretty stable. I would still maintain my job, I would be able to do things, and then I would have to call into work for about two weeks because I couldn't get out of bed, and I didn't understand what was going on. And so, the symptoms—what was really interesting is all my systems were starting to pile up. And what I mean by that was initially it was my high heart rate, it was my autonomic nervous system. And then my gastrointestinal system started kicking in, and I started getting the food sensitivities. I started getting the loose stools and intolerances to different foods, and my stomach would be upset. And I just ended up going through so many doctors. We have a very renowned healthcare institution in the area where I live, and they couldn't figure it out. And it was really frustrating. I started losing a lot of time with my children. And believe it or not, even at that time, I was still in denial that this was something serious and [that this was going to be] lasting a very long time." (CFS, recovered after 4 years)

"My primary care physician did not know what to do with me." (Long COVID + POTS, 3 years, recovery ongoing)

The clinical decision to rule things out is necessary but, according to participants' accounts, not couched in terms of medical protocol in a way that still offers patients validation of their experiences.

Unfortunately, according to the data analysed in this study, patient journeys too often involve a doctor turning their attention to the patient's mental health. Some participants shared accounts of being asked by doctors whether psychological explanations of anxiety and depression could contribute to the manifestation or development of symptoms. These clinical encounters did not involve recognised forms of assessment or referrals to mental health specialists. Given the prominence of concerns regarding psychologisation within the literature on CFS, it is notable that only just under 10% of participants (n = 6) volunteer an account of such encounters. These participants each recall being offered antidepressants, and one reflected on the worry that doctors attribute complex physiological symptoms to anxiety and depression. This number is likely to be an underrepresentation given the taboo subject matter, meaning participants are less likely to discuss the intersection of mental health and CFS symptoms at all. A related point is that this 10% only reflects

participants who describe having been openly questioned by doctors about their mental health, not all those who, as patients, felt that their doctor(s) might have made assumptions about their mental health.

> "It took me years of going to the doctor and being like, *Should I be this exhausted all the time? Should everything hurt?* and really pushing them and being told, 'Oh, you've got depression, you've got anxiety. Here's some antidepressants. Just go to bed earlier.'" (ME/CFS, recovered after 8 years)

Across 75 interviews, there was only one example of a GP reassuring their patient that they were 'expected to make a full recovery'. In this example, the patient had the benefit of continuity of care, having been known to their GP over many years. Their account suggests that the GP sought to reassure them that the narrative of interminable illness did not apply to them. At the same time, this GP was still unable to point the patient in the direction of any approach that could support their recovery.

> "And it doesn't tell you anything about exactly, specifically what is happening to you and your body in particular. But yes, I mean, the doctor did say: 'We would expect you to make a full recovery.' Those were words that I really hung on to … And at that time, I had nothing to cling to, so I just kind of clung to that. So, I think pretty soon I just kind of realised that I was going to have to figure this out myself, really. And I guess that's kind of the start of my recovery journey, really." (Long COVID, recovered after 2 years)

This snippet offers three different pieces of information: (1) it is possible for a GP to tell a patient, 'We expect you to make a full recovery', with 'we' referring to doctors local to the patient; (2) as a patient, such words of encouragement become a point of orientation in an otherwise desolate landscape devoid of hope, and (3) such affirmations provided by doctors, combined with the absence of actionable medical guidance, are positioned as the backdrop to subsequent self-determination.

3.4 Discussion

> "Over time, I think probably around the two-year mark, I just completely shut down. So I went into despair, hopeless, helpless, numb. I was disconnected. There was just no connection with anyone. I was just completely closed off because it felt hopeless. No matter what treatment I did, no matter what

> procedure I did, no matter what specialist I saw, I was just told that this was going to be a forever thing." (Fibromyalgia, recovered after 4 years)

In this sample, no one recovers with the message of non-recovery.

Participants almost universally described visiting a doctor immediately following the onset of symptoms. Their accounts describe the vulnerability of turning to doctors for help when all familiarity has ceased to exist. The strong feelings these recollections elicit reflect the socio-cultural position of doctors as figures of attachment. The close-knit relationship between medicine and illness is also reflected through participants' recovery narratives. Western culture has an expectation that when something goes wrong with the body, there should be a medical explanation. According to this schema (simplified for the purpose of illustration), people are socialised to expect a medical rather than a social or historical account of their illness experience.

> "That was the hardest part. That was really the hardest part for me, because growing up, I always thought that I could trust doctors. Doctors are the ones that heal you. They give you the medicine you need to be able to feel better. And with this certain situation, it just wasn't the case." (CFS + fibromyalgia, 5 years, recovery ongoing)
>
> "One of the hardest parts was just no knowing when I was going to get better." (Long COVID, recovered after 1 year)

When patients approach doctors with debilitating symptoms that they do not understand, they are looking for compassion and reassurance. The onset of symptoms is a particularly sensitive time because people are scared for their future. Participants' recollections show great awareness of having entered a space of cultural uncertainty. Sadly, one participant recounts being institutionalised by doctors who disbelieved her at just 12 years old:

> "I was actually locked away in a psychiatric hospital because they really believed that I'm pretending to be ill and in pain to get attention."

Her experience is a painful reminder of the dehumanising side of psychiatry that so many people with ME/CFS have been subject to. The practice of medicine is often represented as a social act of care. Doctors, responsible for the practice of this

care—the treatment of illness—are represented as figures of trust and accountability in a field of attachment in which patients expect to feel safe. Belief in the power of medicine, in the doctor as a figure of certainty and repair, starts young. Parents hold their babies through vaccinations and administer sticky sweet paracetamol to soothe the pain of teething or temperature. When we are young, these experiences disturb us, but we learn to think of them as being in our best interest. We learn to experience medical treatment in the context of primary care, as part of our nurturance. In this cultural context, being told “there is nothing we can do” lands as a lack of care. In the case of ME/CFS, the quality of care hoped for by patients is usually missing.

An irony already observed is that:

> A by product of our ever sophisticated understanding of the biological basis of the human body may be that those people whose illnesses are not medically explained, may actually fare less well today than in times when medical knowledge was less developed because doctors may now be less skilled in providing support and ongoing care against a background of diagnostic uncertainty. Sophisticated technologies may facilitate diagnosis but they also serve to reinforce the boundary between medically explained and MUSs [medically unexplained symptoms]. (Nettleton, Watt, O’Malley and Duffey 2005: 209)

While there may or may not be a ‘failure of goodwill’ on the part of particular doctors or services, the bigger (historical, cultural and political) problem is the deep embedding ‘in the semantic fabric through which we make sense of the world’ of the paradox of an illness-without-disease that CFS carries (Sharpe and Greco 2019: 185). Participants’ descriptions of being told that ‘medicine cannot help' are visceral reactions to this paradox—accounts of medical abandonment made possible by people’s socialisation into medicine as a field of attachment and the account given by doctors that the epistemology and ontology of CFS is unexplained. Participants’ accounts provide further evidence of the claim that:

> The narrative of CFS/ME as an incomprehensible and incurable disease without any available treatment is likely to increase fear, helplessness, and loss of hope. The associate advice to rest whilst awaiting a medical cure both discourages patients from gaining control of their symptoms and creates a barrier to seeking potentially effective treatments, as well as risking worsening of symptoms and reduced quality of life. (The Oslo Chronic Fatigue Consortium, Alme, Andreasson, et al. 2023: 374)

Listening to participants' accounts, there is scant evidence of doctors' considerations regarding the patient experience of receiving test results indicating no identifiable pathology. Patients could be reassured, for example: 'Just because these blood test results are 'normal', that does not mean that all of the biology of your body is behaving as it should. Current testing, however, does not give us more information'. But for patients with chronic illnesses, receiving normal bloodwork results—which would typically be routine and reassuring—is experienced as medical gaslighting, as if the lab work has been applied to establish that nothing is wrong in patients experiencing symptoms that clearly indicate that something is wrong. As such, unremarkable test results are experienced as profoundly alienating.

> "I had 30 symptoms I told her about that day, and she sends me home and she's like: 'You're fine. You're healthy'. I'm like: 'No, I'm not'. So yeah, I was like scream-crying in the car on the way home. That was the worst day. So from that point forward, I never went to another doctor to try and get any validation." (CFS + long COVID + POTS, recovered after 12 years)

Informing patients that they will live with unbearable symptoms indefinitely, without acknowledging the devastating and intolerable nature of what they are experiencing, should be admitted in the strongest terms—as a failure of care that betrays patient trust. Recent research suggests that how general practitioners communicate with patients about chronic symptoms affects outcomes, and that structured communication tools can be of benefit (Abrahamsen, Reme, Wangen, et al. 2023). The problem is however of a more profound nature than one of communication. Despite a burgeoning culture of funded, biomedical research, the current medical diagnosis of CFS addresses the patient as the subject of a mystery illness whose unintelligible disease promises scientific enquiry clues to its 'concealed intelligence' (Damasio 2021). In this way and others, contestation over CFS as a 'proper object' has direct implications on clinical experience, with participants describing being terrorised and left with nowhere to turn.

In the UK, the provision of medical care is informed by the National Institute for Health and Care Excellence (NICE) guidance. It is possible to link participants' healthcare experiences to national policies relevant to their cultural context. In one particularly harrowing account (outside of the UK), an hour-long session undertaken at an ME clinic as part of a social security assessment to work led to a participant's dramatic downturn:

> “That’s when I became my worst. I was severely, severely sick for two months. I was in a dark room, I had ear plugs, I had a face mask, I had no light, no sound. I couldn’t see my kids. They were five and seven at that time. I couldn’t take care of myself. I couldn’t drink or eat. It was horrible. I had a lot of symptoms and I had a headache from hell. I cannot even explain how that felt.” (ME, recovered after 6 years)

The frequency with which patients are told that they will not recover from ME/CFS and/or related chronic illnesses—and that in the case of ME/CFS there is ‘nothing’ that patients can do other than go home from the doctor’s office—requires attention from the medical community. Medical certainty of non-recovery hurts people with CFS. This message provides no treatment, guidance, or support, and can only do harm. It cannot support or contribute to recovery in any way. Acting as a nocebo, it can reinforce expectations of non-recovery and worsens patient outcomes.

Evidence of alienation is abundant. Participants report seeing 10, 20, 30 doctors during their period of illness. They see specialists in all sorts of branches of medicine. They visit clinics that specialise in ME/CFS or long COVID but feel deflated that, despite the specialist attention, the advice of such services does not bear out in much symptom improvement. Across 75 accounts of recovery, medical services are not offering what makes a difference, what opens the door to recovery.

Interview data on the medical encounter can also be looked at another way: as evidence of the opportunity that doctors have to do things differently.

Doctors have an opportunity to encourage patients not to lose hope; to steer patients away from the nocebo effect of the message of non-recovery; to offer information to patients about the social and cultural experience of recovery that is represented in the online recovery community; to point to the many schools of thought on ME/CFS recovery that exist outside of medicine. Doctors have an opportunity to learn from their patients how they are recovering, to develop their own first-hand accounts and thumbnail archives of relevant knowledge. Examples of resources are appended to this report.

Without offering the possibility of hope for recovery or any reassurance that quality of life can be improved, information provided by public health only compounds the fear and uncertainty associated with the illness experience.

Section 4. Mindset as the gateway to recovery

> "I guess I reached a point where I realised that I had to adjust my perspective and I had to maybe consider different techniques and ways of thinking. I guess I'd thought before maybe a lot of things were a bit hippie or wishy-washy, and I was resistant to it even though I was into like alternative medicine and some things, I was just resistant. I guess now I recognise that I was resistant to feeling things and to connecting to myself, which is ultimately what I needed to do to recover, but I was resistant to it. So I reached rock bottom, and then I was just like, *Well, either I'm just facing a life like this, or I just need to start getting curious and asking questions*. So eventually I spoke to my friend's friend who had recovered and [I] discovered that she was real and she had recovered, and it was just incredible, probably one of the most, you know, helpful conversations of my life." (ME/CFS, recovered after 4 years)

4.1 Introduction

According to the analysis undertaken for this report, mindset is the single most consistent factor associated with recovery from CFS and related illnesses. This finding is consistent with existing research that has identified the representation of symptoms, illness and recovery as factors in a patient's mindset (Bakken A K, Mengshoel, Synnes and Strand 2023). This research, based on interviews with 14 participants who had returned to health, also talks about the importance of one pursuing their own healing. Other research, again based on an analysis of 14 interviews, emphasises the importance of hope to recovery (Linnros, Andreasson, Norlin and Hydén 2026) and in turn (in relation to fibromyalgia), the detrimental effect of 'chronicity rhetoric' (Cupit, Finlay, Pope and the PACFiND Team 2025). The recovery narratives represented in YouTube recovery interviews are full of examples of mindset changes, including regarding how participants thought and felt about their illness. From the 75 interviews analysed, this pattern resonates strongly in 95%—in all but four interviews. Reflecting the depth and range of consideration given to mindset, findings are discussed across three sections: this section, Mindset as the gateway to recovery; then Section 5. Mindset as a recovery practice, outlining how mindset is practised—through mindfulness, meditation and nervous system regulation, for example; and Section 6. Recovery mindset: Hope-belief and legitimate optimism, showing how hope and belief underpin all other recovery activities.

This report relates the cultural concept of mindset to foreground mental processes of consciousness and thinking, while implying a bodily register that is somatic, affective and non-conscious. Mindset is not primarily or even necessarily a psychological concept. Many different disciplines and schools of thought, including in philosophy and cultural studies, offer a range of conceptual registers through which to conceptualize the process of thinking itself. The approach taken in this study draws on critical humanities and process philosophy studies of embodiment, within which mindset is constituted by the activities of somatic, affective and non-conscious 'thinking' together with thinking as the activity of 'thought.' This theoretical approach de-centres the privilege given to consciousness—and in other disciplines (psychology, political theory, history, sociology, business studies and so on), to rational consciousness in particular—while retaining an interest in the meaning of thought. Meaningfulness in this context is not solely about consciousness or rationality but involves being and feeling. Mindset is a bodily habituation to illness or recovery informed by and expressive of cultural ideas.

It took the participant quoted above reaching 'rock bottom' before she decided that she needed to ask questions about her illness. Through deciding to reach out to a friend of a friend who had recovered, she was introduced to a recovery programme that she claimed helped her to get better. The participant recounts how the programme taught her "information and knowledge" together with "tools that one can use daily throughout their life to start to connect with their symptoms." Tools include relating to oneself with curiosity and developing a practice of interpreting symptoms. The participant later describes the experience of illness as helping her to "access parts of myself and feel stronger and connected and learn how to create a life that's fulfilling and have stronger relationships."

This extract highlights the idea that recovery from CFS addresses the whole self and that within this understanding mindset is the centrepiece of the self. Recovery must address mindset and is at the same time made possible by mindset.

The previous section provided evidence of the powerful influence of medicine in shaping participants' thoughts and feelings, most centrally about themselves as the subjects of an interminable illness upon which they cannot act. This could be termed the 'non-recovery mindset' that is the result of the medicalisation of the illness. In contradistinction, this and the following two sections of the report provide evidence of a counter-narrative, according to which a recovery mindset mobilised by the recovery community online capacitates people to act on their terminable illness. The report terms this the 'recovery mindset'. The objective of this and the following two sections

is to provide evidence of the difference that mindset makes to the prognosis of CFS and related illnesses.

This section discusses the findings of the narrative analysis that looked at how mindset appears in the interview narrative at key moments of transition. Another way to think of this approach is as paying particular attention to how mindset underpins milestones in the journey to symptom improvement or resolution. The evidence for mindset as a gateway to recovery is outlined according to a set of five themes that typically appear sequentially in recovery narratives: rock bottom, making a decision to recover, self-determination, practices in the context of a recovery mindset and self-transformation. By attending to the narrative structure of thematic content, the analysis can track the momentum and cumulative force of these themes. It is within the narrative structure of mindset thematics that participants reflect on the activities they undertook to recover and the efficacy of their particular recovery practices (Section 4.5 Practices in the context of recovery mindset). Underpinning this momentum is the belief in one's own recovery. According to the evidence of the interviews analysed for this study, this belief is catalysed by the evidence of recovery represented in first-hand narratives and in being given a believable explanation of what is wrong. While the study cannot adjudicate between different explanations of CFS illness, it can demonstrate the significance that certain explanations have for participants.

4.2 Rock bottom

"I could only recover after I'd really hit rock bottom."

"We need to hit a wall, we need to hit rock bottom, we need to see how bad it can get before we decide that we can heal ourselves. And that's like—we've all been in a version of that."

"I just thought, *What is the quality of life? I have no quality of life. I can't do a thing. It's just in bed, not able to do anything, take in anything*."

"I was like, 'My life is over if even my hands won't listen to what I want them to do anymore.'"

"I can't do this anymore. I'm not living. I still get a little bit emotional thinking about that time because it was devastating for my children to know that their mother had given up. So I attempted, attempted suicide and thank goodness I

wasn’t successful. I’m grateful for that every day now because I did find a solution in the end and I kept searching.”

“This probiotic sent me into a month-long, deep depression, really suicidal, not doing okay, and I just wasn’t in the right headspace … I was already not doing so well. It was [at] that point, I said: *Enough. I’m not doing the supplement route anymore. There has to be some sort of other answer, and I have to find some other way out of this*.”

The above quotations illustrate the theme of rock bottom that is prominent in the accounts of nearly one half of the participants (n = 35). Rock bottom is not only prevalent across the cohort but represents some of the most visceral description in the recovery narratives. Rock bottom is experienced as a devastating realisation of the limitations of one’s existence, a truly harrowing encounter with oneself via CFS and/or related illnesses. Differentiated from suffering in general that is represented in almost all of the recovery interviews, rock bottom is represented as a delimited and critical time that is, paradoxically, both an impasse and a lowest point from which one can move forward. In these interviews, rock bottom is a type of suffering that becomes a turning point in participants’ recoveries. The term ‘rock bottom’ is used by 13% (n = 10) of participants in their descriptions.

The previous section outlined the devastating impact of a doctor’s news that symptoms will likely continue for life. Almost two thirds of participants recollect the difficult experience of being addressed in this way by a doctor. Several of these recollections detail the clinical experience as one which catalysed a crisis of the most painful kind—in many cases, a suicidal crisis. In one example already discussed, a participant who undertook an assessment at an ME clinic experienced a total collapse. For most participants, even without the complication of being asked to demonstrate one’s debilitation, being given the message ‘you will not get better’—early in the illness and without an accompanying explanation—is enough to cause devastation.

“‘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?*”

Another participant describes becoming suicidal after being prescribed antidepressants as an adolescent. She notes how the medication label listed ‘suicide’ as a possible side effect, but there was no discussion of this side effect with her doctor. In another interview, a participant describes how a course of iron injections facilitated by a naturopath led to being bedbound “I would say for about a good five months”:

> “When I say bedbound, if I got up to walk from my bed to the bathroom, my heart rate would go up to 180 beats per minute. It was really high. And I would have to hold onto the walls to get to the bathroom. It was so difficult. And showering was extremely difficult. Some days I couldn’t even do it. And so, then I went back to my naturopath, and of course they said, ‘Oh, this shouldn’t be a side effect.’ And so, it was a really difficult time. It was a very dark time for me.”

Across the interviews, there are several accounts of participants’ physical states being aggravated and worsened by the advice of professionals, including doctors, acupuncturists, nutritionists and naturopaths.

An important finding here is that participants’ rock bottom experiences do not tally directly with the severity of their symptoms. There is not one example of a participant attributing the most difficult time that they experienced to symptom severity alone. Even when people describe their symptoms as being particularly hard to bear, ancillary life circumstances inform the experience of being unwell.

The life circumstances participants describe as contributing to their hardest times have a pattern. According to the accounts analysed in this study, these circumstances reveal the types of social pressure that are more likely to push people to their breaking point. The first of these catalysing experiences has been described in the previous section: patients’ encounters with medicine. Two further experiences are prominent: (1) the inability to parent and (2) loneliness.

The descriptions provided by mothers of being unable to show up for their children—unable to be present at a birthday party or care for a child who is unwell—are devastating. The mothers who speak about this experience also relay their absolute determination to recover so that they can be there for their children. Leaving their children without a mother is even more unimaginable than living a life with chronic, debilitating illness.

> “One day, my son needed the hospital. He had a bellyache, and I was so distraught that I couldn’t take him, and it just broke me. And I had a psychotic break at that point, and I no longer wanted to live. I started asking the people around me for knives, and so my partner had to come back from the hospital with my child and then come home and call an ambulance for me.”
>
> “Any person in the world would go to the doctor with that headache because it was so severe. But I didn’t go there, because I couldn’t stand the sound and the lights. So I was lying there and thinking, *If my body wants me to survive this, I will survive, but I’m also ready not for that to happen*. So I was at my totally lowest part of my life. I just couldn’t stand lying there anymore. I couldn’t do anything. I couldn’t even take care of myself and go and take a shower. And so at that point, I told myself that *I have to make a decision*. And the two choices I had: one choice was to end my pain and to end my life. And the other choice was to start living again, because I was just surviving at that time. I was nothing. I had nothing in life. I couldn’t even be with my kids. And they were so small and they wanted to be with their mum and they couldn’t. So I made a decision to continue living because, mostly because of my kids, actually, not so much for myself at that point.”

The third notable social theme to precede many participants’ lowest points is the experience of loneliness and isolation. While people can feel lonely within romantic relationships or tight-knit communities, loneliness features prominently in experiences of social isolation. Descriptions of the impact of COVID-19 during lockdown often relay accounts of social isolation. Other participants talk about the experience of loneliness once becoming ill, a common experience given the decimation of social life by CFS and related illnesses.

People’s loneliness and social isolation become intolerable during personal milestones, such as birthdays. These milestones are culturally loaded with meaning and expectation, signifying the future and inviting people to feel moved by their own hopes, dreams and fantasies encompassed by the social project of optimism. The social pressure here is the pressure to be happy on one’s significant day. The painfulness of the inability to feel happiness as an effect of social isolation is crystalised by these personal events—or non-events—that tip participants into the depths of their despair. Not only is a life with symptoms unbearable but so is a life without the tenderness and affection of other people.

> “I remember on my 31st birthday … it meant to me another year of being ill … I actually got to the point where I decided I was going to give myself 12 months to heal, like 12 months maybe not to fully heal, but 12 months to see significant improvement in my life and my health and my happiness overall, or I was going to end my life.”

Participants’ descriptions of being abandoned to their suffering are heart wrenching. No one wants to end their life. The thought of ending one’s life, or desire to end one’s life, visited participants at times of desperation. Of the 35 interviews in which participants describe reaching rock bottom, 15 disclose thoughts of suicide: 20% of the overall sample. Furthermore, several interviews recount suicide attempts, making clear that for people with CFS, suicide does not stop at ideation. The phrasing ‘rock bottom’ describes participants’ encounters with what they found unbearable about living with illness and without a meaningful life beyond it. In the eyes of participants, what is further unbearable about CFS and related illnesses is the experience of not being able to be present—in one’s life, to others or even to oneself, forced to go on living without access to their identity and to a life beyond illness.

> “It was obviously a really, really distressing time, and I remember just feeling this sense of real despair and basically, I would just kind of cry uncontrollably for, I think at one point I think I just felt like I’d been crying nonstop for three or four days. And it is just that sense of despair that everything has gone—your identity’s gone, your coping mechanisms have gone. You don’t know. The main thing was the uncertainty. You don’t know what’s happening. I didn’t understand what was happening.”

For those who survive it, rock bottom is the low point that becomes the turning point, the difficult time that gives way to a better time. Narrative accounts thus also describe how participants find ways through their own psychological deadlocks. They describe a loosening of bodily dysregulation and dysfunction and an opening to the tenderness they find within themselves. The resilience, perseverance and resolve portrayed in these accounts compels compassion on the part of the listener.

Oftentimes, participants describe rock bottom in phenomenological terms, as being effectively trapped in a room with a screen. This is the time that participants ‘discover’ Raelan Agle and other recovery channels on YouTube. This discovery is made possible by a more open disposition—being open to the unknown, the unregulated and the experimental. The participant quoted above continues:

> “I was really at a rock bottom. The treatment wasn’t working, I wasn’t feeling better. I was suffering. I didn’t see any end in sight to the suffering. I had worked really hard on who I was before this, obviously. I worked on all that work experience and everything, and I felt like I [had] lost it all completely. I just lost who I was. So I was really at a rock bottom in terms of my spirits and everything. As of the last week of February, I cancelled my job. I had no hope. And you would think that four children [are] enough to live for, but I had all these thoughts like, *Oh, my husband should just marry some different woman, and they could take care of the kids and that would be better*. So I just was really at a rock bottom. So I was doing a lot of research online, watching a lot of these videos, watching your [Raelan Agle’s] videos, and I came across something called brain retraining … and my husband forced me to sign up for it.”

Having made the painful sacrifice of stopping breastfeeding her young infant so that, on the advice of a naturopath, she could follow a protocol involving antibiotics and herbs whose effects on breastmilk were untested, this participant saw no improvement. Moreover, she experienced a worsening of symptoms and a deteriorating state of mind. It was from this worst possible place that she started to watch videos about brain retraining—a recovery method discussed later in this report.

Across the dataset, the consistency of the contrast in affect between each participant’s most difficult time and their onward recovery trajectory is striking. It appears as if rock bottom catalyses recovery from within, compelling a new openness to others and ideas. For these participants, recovery begins through a transformation in mindset. Rock bottom clarifies the decision to survive, opens participants to ideas, techniques and methods that might otherwise be dismissed, in part due to the lack of conventional cultural context around them.

Several participants talk about having ‘tried everything’ to get better. More pertinent is the phrasing that they had been ‘open to anything’. Being open implies receptivity rather than striving and attainment. Being open also allows for discretion, a pause for thought and a decision, whereas trying everything might imply passivity and desperation.

> “I got into a pit of despair. I considered not being on this planet any longer, and that was when I had to have a word with myself and say, *Okay, now’s the*

> *time. You're either going to sink or you're going to swim*. So I decided I was open to anything, and that's when I started to really look deep and get some help."

These examples of being catalysed to engage in new practices, to think and feel differently about one's illness, set the scene for a new search for help. What can be observed in the interview data is how a change in mindset prompted participants to re-evaluate their priorities, their abilities, their limits and their opportunities. The process of re-evaluating what it was necessary to do or not do, what participants could or could not do, could or could not control, is described as making them more receptive to forms of support that are not typically valued in contemporary Western understandings of health and recovery. The change in mindset tracks a new state of openness marked by what legal scholar and non-medical recovery practitioner Professor Anna Grear calls a 'willingness to allow'. In this configuration, looking for help is an extension of a profound acceptance of one's vulnerability. Giving up a certain fight is a measure of acceptance. This transition is also described by some participants as one of surrender and holism, in which one accepts and allows symptoms as part of themselves.

> "I remember having a day where the pain was really high and just wouldn't go away, and no matter how much I was fighting it, it wouldn't leave. And so I was like, *Clearly fighting it doesn't work, so why not try something else?*"

Another participant says:

> "I knew I had to be completely at ease with where I was at."

All 35 interviewees who talk about reaching their rock bottom discuss the beginning of their recovery journey in the same breath, and the majority (n = 28) explicitly describe looking for help with a palpable openness to new ideas.

This configuration positions mindset as a method of change—a means of lifting oneself out of one's hardest time, and ultimately, illness. Underlying the theme of looking for help is a receptivity that allows for social interaction, especially with new people. In addition to looking for and accepting help, participants talk about starting a new recovery practice, believing in recovery in a new way, seeing a new practitioner, changing how they are feeling, being taken to help and deciding to get better.

4.3 Deciding to get better

> "She just appeared one day on Facebook and said, 'I've recovered.' And it just—I remember the exact moment. I was actually sitting on the floor, and I was having a kind of like, *I don't think I can do this anymore. I've had it. I can't go on*. And I opened my phone and it was her and it was a picture of her as a child, and she said: 'I've recovered.' And something about it just really, really hit me and I thought, *I know this person. I know how ill she's been,* because one of the things when people recover would be that people would say: 'Well, you can't have had ME because people with ME don't recover.' And I couldn't say that about her because I knew how ill she'd been, and I said to her: 'What? This is brilliant. What happened?' And she'd recovered quite rapidly actually and she had used the Curable app and I hadn't heard of it and I kind of said to her: 'Do you think that would help me?' She said, 'Look, just no pressure, just have a look.' And I opened the app, and the first thing it said was: 'Your symptoms are real. Your symptoms are not in your head. Your symptoms are serious, but your symptoms can get better.' And there was just this big sense of validation that actually no one was saying this wasn't real and so that allowed me to kind of be a bit more curious, and then it went on to talk about the personality traits of people with these symptoms and they talked about people-pleasing and perfectionism and that kind of thing. And I could just see myself so clearly. It was like looking at myself in the mirror." (ME/CFS + POTS + fibromyalgia, recovered after 8 years)

Recovery narratives imply decision-making in all kinds of ways and often in association with recovery milestones. Such is the prevalence of the language of decision-making, and it can be identified as central to the reflexive narrative voice of recovery storytelling—a key expression of agency and an act of self-preservation. Moreover, a clear pattern can be observed across nearly two thirds of the interviews (n = 47): talking in direct terms about the decision to recover at a key turning point in one's recovery. Early on, the researcher was struck by participants' describing their making a decision to recover. This finding represents participants' use of the denotative language of decision-making ('I decided') as well as the connotative representation of decision-making (as in the above example). Decision-making is framed as: refusing to accept a doctor's prognosis; making a pointed use of the first person 'I' to talk about changing one's perspective, researching alternatives, finding a way, accepting the limits of symptoms and believing in recovery. In recovery

narratives, these decisions are pinpointed moments in time, with a before and an after. These decisions are recounted as pivotal to the recovery narrative.

The example above describes a typical confluence—the participant reaches her limit, and while still processing this limit (while sitting on the floor thinking *I can't go on*), turns her attention to the recovery of someone else. Her almost immediate encounter via social media with a story of recovery told by someone known to her introduces or exposes her to a particular tool or technique, social relation and/or form of knowledge. Typical of other accounts, this participant describes the validation she felt when encountering the first tool that would help her—in her case, the Curable app.

In participants' accounts, the decision to recover is always a representation of a confluence of factors. The previous sub-section discusses rock bottom as an event that catalyses an openness to receiving help and engaging with new ideas about recovery, while the following section (Section 5. Mindset as a recovery practice) positions these new ideas within a mind-body umbrella. The previous sub-section also outlines how rock bottom is characterised as the event in which participants reach their limit. Additionally, participants talk more generally about reaching a limit in their tolerance. In the above example, the participant had been symptomatic for many years. She describes reaching a limit within herself. The ongoing situation of chronic illness accretes until its subject reaches a threshold in their existence.

The decision to get better represents a confluence of situation and event. It seems that the only way past the threshold of an experiential dead-end is through a change in mindset. When participants talk about making a decision, or imply the importance of making a decision, they give voice to that change in mindset and place emphasis on the self-actualisation and self-determination that is required to make that change, as will be discussed later in this section.

> "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)

“I was offered CBT [cognitive behavioural therapy] through the hospital and I went to a couple of sessions of that, but it just didn’t—it was group CBT and it just didn’t feel right for me, and I knew that really, I needed to grab hold of this myself.” (CFS, recovered after 7 years)

“It’s time to go for it [brain retraining] … put my absolute all into it. … I decided I was going to do anything to get better.” (ME, recovered after 11 years)

“So, I don’t know, six months in I started to see posts from specific users who almost could be the same person as I was really, and they were doing patient-led research, and they were trialling different medications and different treatment protocols doing different work. And that's when it started to click that *if I’m going to get better, I need to start doing this myself. I need to take charge of my health and nobody else is coming to save me. So, it is time to get on board here and start trying anything and everything I could*.” (Long COVID, recovering after 2 years)

“After the passing of my parents, I felt catalysed to recover. I felt my own mortality coming. I was in my late fifties at that point, and I realised, *I cannot do this forever. This is not what I want.* I was still doing advocacy, and I had this very, very strong urge to choose, choose which one of these lives you would prefer to be in: the sick life, where you’re talking to sick people all the time and advocating for sick people and yourself all the time with very little hope that anything is ever going to make this go away. Or do you want to associate with the healthy people in your life and just accept your limitations, whatever they are? And so, I actually really sat down and had to make that decision, and I decided that it was very important for me to leave the advocacy world.” (CFS, recovered after 33 years)

“Although doctors were saying ‘we don’t have a cure,’ there was something in me that was like, *But this isn’t me. This isn’t my life. This is not how it’s going to go*. … I am never going to give my power away to someone else.” (ME/CFS, recovered after 13 years)

“So I devised this little plan for myself from talking to her for walking, and I just started to feel better. I remember it snowed outside and I was just looking out the window at the snow, thinking about all the times we used to go out

sledging, and I thought, *I'm going to start today*. And I just went out in the snow on the front lawn and just timed it. I was religious on my phone, timed 30 seconds, and just went out on the front lawn and walked in the snow and made footprints and came back in and then returned back to the sofa." **(**Long COVID + CFS, recovered after 2 years)

"But then I thought, *I'm going to Google it again*. Saw one of your [Raelan Agle's] videos and that was it. On that day, I'll be honest with you, first video of yours I watched, I was rolling my eyes because at the end of it you were like, 'You can do this, you'll get better.' And I was like, *Oh god, no worries*. And then I watched another one, I'm really sorry, I watched another one the next day. *It's real.* And I was just like, *Oh, okay, maybe I can get better*. And then that day I sent a group text message to all my friends and family and was like, 'I've been trying to live with this and from this day on I'm going to actively try and recover.' And my whole attitude just switched and it was amazing. And a hundred percent down to your videos. And just seeing that recovery actually is possible." (CFS, recovering after 3 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 [experienced] very similar things to what I had been through were getting better and had fully recovered. I didn't believe that was plausible for a long time. My doctors were kind of telling me otherwise, and well, 'You're always going to live with X amount of things' or 'It's going to come in waves and you're never going to fully heal.' And so that was just my belief for quite a while until I decided that there was another way. … I was personally mentally ready at that time, and what I was ready to acknowledge was my own responsibility for my healing and not looking outside of myself anymore for a doctor to fix me and heal me." (Lyme + chronic fatigue, recovered after 15 years)

"I always said, if I ever find someone that's recovered, I'll just do what they did and I'll get better. And finally I did. I finally had a friend who recovered, so I went, *Right, I'll do what you did and get better.*" (CFS, recovered after 11 years)

> "I was like, *I have to find something. I have to start to do something else. There has to be a different way. Someone has to have gotten better from this.*" (ME/CFS + POTS, recovered after 1-2 years)

Descriptions of the decision to get better often employ temporal and spatial fork-in-the-road metaphors—moving forward rather than going back, turning one way and not the other. These descriptions of directionality diagram a change in one's mindset. Here, mindset takes the form of an affective disposition and phenomenological orientation. The decision to recover is a turning point narratively, associated with a biographical switch point and a movement from darkness and desperation to optimism and light. The decision is an expressive moment that facilitates this—an interruptive self-determination, a re-orientation towards the future.

Temporality is central to the decision. In one of the examples above, the participant had decided in advance that: "if I ever find someone that's recovered, I'll just do what they did and I'll get better" (CFS, recovered after 11 years). When she finally knew someone who had recovered, that is exactly what she did. "I finally had a friend who recovered, so I went, *Right, I'll do what you did and get better."* After spending a hundred thousand dollars on treatments and trying "everything," she learned of her friend's rapid recovery through a practice based on NLP (neurolinguistic programming). In response, she is decisive in her actions. She does what she intended to and describes herself as following through on her intentions. Her resolution conveys a sense of agency and conviction. Her account also highlights the idea that the evidence of someone else's recovery can act as a turning point in the conjunction of one's own decision to recover with new knowledge of a practice that can work.

> "When I was in hospital, … I met a nurse who said, 'Last year, I had chronic fatigue syndrome. I was crawling on the floor. I couldn't get to my son. I couldn't live, and I'm healed.' That was the first indication that anyone had healed and gotten over this. I truly believed, before that point, that the only option was to be like this forever. So that was the turning point in believing that *maybe I could recover on my own*. And this also seemed to coincide with me discovering brain retraining, and that was a real turning point, and that was when I kind of started spiralling upwards in my recovery." (Long COVID + POTS, recovered after 1 year)

> “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 plausible for a long time. My doctors were kind of telling me otherwise—‘you're always going to live with X amount of things’ or ‘it’s going to come in waves and you’re never going to fully heal.’ And so that was just my belief for quite a while until I decided that there was another way.” (Lyme + POTS + fibromyalgia, recovered after 15 years)

There are examples of people for whom the decision to recover leads to an introspective process, as is the following participant’s case, guided by one source alone. Discussing the book, *Recovery from CFS: 50 Personal Stories* by Alexandra Barton (2008), this participant reflects:

> “I studied it and, nice, a lot of stories in there about people who they were a lot better than they used to be, but they still have to be careful, and I thought, *That’s not what I’m looking for.* I was looking for these stories and they were there: stories of people who said that they got better quickly after doing something and they’ve never looked back and they’re better than ever. And so I thought, *I’m going to do that*. And they were all mind-body cures. So I then thought, I switched completely from what I had been focusing on and got a book on ‘reverse therapy’, which was one of the ones that was mentioned [*Reverse Therapy: Chronic Fatigue, Fibromyalgia and Related Disorders* (Eaton 2017)]. And I got better rapidly, really rapidly then, within, well, days and weeks.” (Autoimmune disease + CFS, recovered from CFS after 3 years)

Described here is a multilayered decision process that spurred the participant to look for a practical guide that she could use to help herself. A clear picture of agency, self-determination and self-directed recovery is nestled within this description. In this account, deciding what to look for and what she wants for herself is a means of giving up the expectation that there would be a biological explanation and medical solution for her illness, which she had pursued for nearly two years.

Looking closely at the place of the decision to recover within the interview narrative, there is no evidence for the idea that one can think oneself better or that symptoms are ‘psychological’. Crucially, making a decision to recover is a different type of mental exercise from thinking oneself well.

> "It sounds like we're saying, *If you think yourself well, you'll become well*. But [we're] not." (CFS, recovered after 33 years)

For the participant quoted above, thinking plays a powerful role because they understand the biological experience of symptoms to be driven by neuroplastic processes within the brain. Although these exact processes cannot be assessed in this study, this analysis tracks different accounts of activity that follow the decision to recover: participants reach out to other people, experience self-realisations and reassess the implications of their behaviour. That is, the decision to recover inaugurates in a change in attitude from destitution to openness that enables participants to experience a new form of self-relation and undertake a new combination of recovery tools, techniques and pathways, which are used in ways that are unique to each person.

When participants talk about making decisions in relation to their experience of illness, they are describing the mental inauguration of a new orientation not only towards recovery but themselves. This is memorable for the commitment and determination it embodies. One participant describes their belief in the importance of "just deciding that you no longer want to be in the cycle and you're willing to break free from the old thinking patterns" (ME/CFS, recovered after 7 years), demonstrating that the decision to recover is best understood as a shift in mindset. Looking at the themes alongside one another—rock bottom, making a decision to recover, self-determination, practices in the context of a recovery mindset and self-transformation—allows us to see their relationality and co-emergence, such as the idea that decision-making evokes self-determination. This realisation of a sense of agency, of being able to act on oneself and one's illness, is the narrative journey of recovery stories.

4.4 Self-determination

In the analysis of the interview data, 'rock bottom' and 'the decision to get better' are part of a tapestry of representation that builds up to the theme of self-determination. Looking across the data to examine mindset, it is the theme of self-determination that stands out most consistently. The researcher's initial observation that self-determination is a central theme in participants' recovery narratives was corroborated by the output of the semi-automated sentiment analysis. In both types of analysis (computational and by hand), self-determination was represented as self-directed recovery, agency, self-ownership, self-confidence, empowerment, accountability, responsibility and ownership of their situation. The researcher took the

view that of these representations, self-determination offers the most substantive and critical lexicon for understanding the importance of participants' self-representation in their accounts of recovery. The consistency of the theme of self-determination is one of the most striking findings of the study.

Participants describe themselves as believing that they can recover, as wanting to get better, on their own terms—"I had to find a way out of it" (ME/CFS, recovered after 18 years), "[I need to] find it within myself to heal myself" (Lyme + POTS + fibromyalgia, recovered after 15 years). Participants asked themselves, "What can I do right now?" Participants' refusals of their prognosis offer further clear examples of self-determination. They talk about 'refusing to accept' their prognosis or being 'determined to find another way'. The sentiment of refusal is an important defence against the life sentence given by medicine. Refusal also lays the groundwork for self-determined conviction: "There must be a way." Participants narrate their drive and commitment to recovery practices:

> "I'm not going to learn to live with this." (ME/CFS, recovered after 2 years)
>
> "And at first when they diagnosed me, I was like, *Okay, great, I've got a diagnosis, what do I do?* And they were like, 'Oh, no, no, this is you now. This is you forever.' And I was just like, *What, I, that's crazy. I can't live like this*." (CFS, recovered after 4 years)
>
> "They sent me on a course with the NHS to try and get help, and they did all the tests, the usual tests and things that they did. But they basically said, 'Look, there's not much we can do. You've got to learn to live with it. You've got to just pace yourself, do what you can.' But I've never been one to actually accept that that's going to be the rest of my life." (ME/CFS, recovered after 33 years)
>
> "There wasn't much the medical profession could do as such. I still don't think there's much that they can do. You kind of get a sort of sympathetic shrug and a thumbs up and they give you a few fact sheets about pacing and send you on your way. So I really grabbed hold of it myself." (CFS, recovered after 7 years)

“I also started chasing my dream. I did what I [had] always wanted to do since I was a child, and that just pushed me to kind of get better no matter what.” (ME/CFS + fibromyalgia, recovered after 24 years)

“When it comes to energy disorders—[this] is what I would call this—they [medical doctors] don’t have the knowledge they need to help us recover. They don’t understand it properly. So I realised I had to work it out for myself.” (ME/CFS, recovered after 15 years)

“What would happen is every day, if I felt a bit better, I’d feel hopeful, and then if I then would crash or feel bad, then I would be like, *Okay, just accept this. Just accept that you’re going to be like this*. And then 10 minutes later or a day later, I’d be like, *No, no, no, I can’t accept this. I’ve got to find a way. There are people out there who get better. Why not me?* And those are usually the times where I would watch your [Raelan Agle’s] videos to get that inspiration again, that motivation again.” (Sjögren’s syndrome + chronic fatigue, recovering after 3 years)

“I was not willing to accept that this is my life now forever.” (ME/CFS + long COVID, recovering after 4 years)

“I really refused to accept at that time the diagnosis, which was really, ‘You're going to have to learn to live with this’ sort of dust off, the doctor kind of dusting off their hands metaphorically of me and just like, ‘Go do your thing’. And I was like, ‘I’m not going to learn to live with this.’” (ME/CFS, recovered after 5 years)

In the last example, the participant agitated for a prescription from her GP that finally created symptom relief. Although this was not an end to the condition, it created a reprieve and brought into focus the participant’s need to address a specific aspect of her symptoms (inflammation).

Self-determination is evident in participants’ descriptions of themselves as being “all in,” of “going to put my all into it,” of being willing to do “whatever it takes,” as being “open to anything” and “going to do anything to get better.” Their assertions of their commitment to recovery create a sense of urgency and priority: “I’m going to do what I need to do,” “I’ve got to do this,” “I have to start something else,” “I really focused on recovery.” These expressions of commitment also gesture towards a newfound

reciprocity with the world, discussed later in the report (see: Section 9. Ethics of recovery).

In a few interviews (n = 3), participants describe the conversion of their decision to recover into a commitment before others to whom they sought to be accountable. Watching recovery interviews on YouTube for the first time, one participant recalls:

> "I was just like, *Okay, maybe I can get better*. And then that day, I sent a group text message to all my friends and family and was like, 'I've been trying to live with this and from this day on I'm going to actively try and recover'." (CFS, recovering after 3 years)

> "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)

Such reflections connote a sense of determination and somehow a freedom through the presence of others.

Having an 'accountability partner' is a useful idea that can be extended to the buy-in attracted by recovery programmes that offer support in the form of scheduled social contact. The accountability described here allows the participant to engage with their own emotional investment as witnessed by others. These descriptions suggest that accountability has an enabling function, perhaps helping with co-regulation, encouraging optimism about recovery or simply allowing participants to be supported through the disheartening experience of reoccurring symptoms.

Accountability provides one example of how self-determination is enacted within recovery narratives. However, participants also expressed self-determination through their willingness to challenge established medical explanations and embrace alternative understandings of the body's capacity for healing.

Speaking about her mindset change, one participant describes the power of the idea of the limitless potential of the body. A similar idea can be found in participants' thoughts about the body's innate ability to heal.

> "The massive thing I learned was that energy potentially is limitless—apart from sleep that you need. And it just was a game changer. But it is a lot about

your choices, how you live, I think, what you say 'yes' to, what you say 'no' to." (Autoimmune disease + CFS, recovered from CFS after 3 years)

These sentiments embody a well-known principle of a branch of contemporary affect theory and philosophy—the idea developed in Gilles Deleuze's (1968) reading of Baruch Spinoza, that "we do not know what a body can do." This idea, that places emphasis squarely on the potential of the body and links recovery to an ethics (see: Section 9. Ethics of recovery), echoes throughout the interviews. When participants question the basis of the doctor sitting across from them claiming to know the limits of their particular body, claiming to predict their health outcomes, when they describe themselves as refusing this logic, as never 'buying in to that thinking', they invoke not only their own self-determination but this vital philosophical principle.

4.5 Practices in the context of a recovery mindset

"I changed my environment also to make it be more healthy for me. So I put the wallpaper behind me, the forest here, and I colour[ed] the walls green because it's a soothing colour. I put in some nice pictures and some nice flowers and stuff that I could look at when I was lying in here, because the first time I was lying on a sofa bed. And that was really uncomfortable. So my husband helped me to get a real bed in here, so one of those that you can change the back and the knees and stuff so I could lie more comfortably. We worked on the environment … for my recovery to go better … Very early [on], I understood that I had to go outside and get daylight because of the D vitamins and the energy and stuff. And also very, very early [on] I started moving. So I moved my body on whatever level I was on. So when I was in bed and I couldn't get out of the room, I was wiggling my toes. And that's also one thing that can sound really silly, but that was what I could do. So I did that because at that time, I couldn't lift my arm, but I could wiggle my toes. So that was something. And I told myself to do whatever I could to change. And then I started bending my knees. And when I got up and I could walk, I walked outside on the balcony for two minutes and I did some stretching, and then I went back to bed and I was like there for 23 hours and 30 minutes, and then I went out again before I got my wheelchair. I used my body as much as I could, at the level I was on, with the energy I had. So the nature, the movement, the daylight, the diet, the thought works, the mindfulness and all that stuff took me from, let's say 5% to 40%. And then I found the ANS

> [autonomic nervous system] Rewire programme, and I went [and did] that programme and that took me from 40% to 70% in three months. And I continued that programme for a while, and I saw the movies three times, and I took some notes and tried to really learn everything. And so after that, I started a lot with meditation and brain retraining. And yeah, those are the big things that I did, and the nature was always a big part of my recovery." (ME, recovered after 6 years)

The above quotation illustrates how mindset and self-determination ground the practices of recovery. What strikes the researcher is not the image of someone who is so incapacitated they can barely move—we already have this image of someone with ME/CFS. The image that is striking is one of someone whose effort to get better starts with the energy it took to wiggle her toes. It is an image of courage and ingenuity. This narration tells us about a step the participant took to embody her recovery mindset: she cultivated a domestic environment conducive to recovery through bringing into proximity images of nature, material comfort, care (reminders of being cared for by her partner) and happinesses. Rather than view symptoms as reflections of an intractable illness that could not be treated, this participant describes how she tried to bring life back into her body. Despite being told by a doctor that she would not recover from ME, she recovered after 6 years.

Other examples show how 'taking charge' of one's recovery required embracing what had previously been dismissed—especially mind-body tools and techniques like meditation or emotional expression. In another example, a participant's sense of self-ownership foregrounded their openness to meditation, breath work, grounding, fasting, cold water immersion and sauna therapy. In another, the decision to recover motivated her participation in a recovery programme, approached with "whole focus and determination." Personal responsibility grounded her engagement with ideas about neuroplasticity, self-compassion and brain retraining.

The experience of taking charge put into relief prior experiences of feeling passive.

> "In looking back, there was a part of me that really resented it, because I didn't feel like I was an active participant at that point in my own healing. It really felt like I went to sort of more naturopathic doctors. I thought it was going to be more inclusionary, but in a lot of ways it was still like, 'Okay, either take this medication, [or] take this supplement, take this herb, do this diet', and I just sort of felt like it was being done *to* me. I did have a really

perceptive doctor years later I saw for the CFS, and although he didn't really help me with the symptoms, he helped me emotionally because actually he said, 'You know what? I think you think I'm going to tell you to take a bunch more supplements and more restrictive diets, and I suspect that's actually perpetuating the trauma in which you felt you weren't in control of your body, and now you're just being told what to do with your body by all these medical professionals', and Raelan, I just started crying. I was like, *Someone sees me*, and I didn't even know that's how I felt. But I think for those of us, even if there isn't a trauma, what I find with other people I meet who have CFS is often, if not always, there's a lot of stress beforehand, and there can be a sense then—whether it was existent before or certainly after the diagnosis—of just being so powerless. And so I started realising with diet and everything else, *At some point I have to regain my agency and my power and my collaboration and my healing,* because otherwise I was resenting it. And I think those diets didn't work partly because of that and partly because the root cause of my CFS was not that I wasn't eating enough kale." (ME/CFS, recovered after 13 years)

"Rather than being reliant on doctors or other medical professionals or pills or whatever random treatment you're doing, it's all within you. You've been looking everywhere *but* in here. Ultimately the thing that gets you better is understanding this brain–body–nervous system connection. Once you have that control back, I felt like I could really move forwards." (Long COVID, recovered after 3 years)

This narrative illustrates the view that a negative mindset, one that is passive and that positions the self as a recipient of treatments rather than a collaborator in their recovery, has the effect of preventing a full recovery.

There are a number of further ways that the data suggest mindset provides context for recovery practices. Participants talk about several techniques and practices that became interlinked in a complementary way by their common ground in mindset. One participant, for example, talked about meditation, mindfulness, vagal exercises, yoga, poetry, incremental exposure to activity, celebration of micro-grains and time-limited emotional expression. Together, this participant, who recovered from CFS, understood this suite of mindset practices to disrupt "the feedback loop going back to that malfunctioning protective brain that is sending out these signals." "Having serenity, doing the mindfulness, doing the meditation" created the message of safety,

allowing the body to be nudged into a state in which symptoms were no longer persistent. Looking at these mindset practices together highlights their interconnectedness, discussed in this subsection through the themes of: (a) holistic attitude, (b) momentum and scaffolding and (c) timing (being 'ready'). The prevalence of these themes within recovery narratives echoes the to-and-fro recovery. These themes help describe and account for the stops and starts of improvement.

(a) Holistic attitude

Perhaps because CFS affects the whole body and the self, people draw a range of connections between life experience, illness and recovery. Recovery practices are contextualised in different ways; they are nestled within one another. A key example of this can be found in participants' discussions of pacing.

The emphasis many participants give to 'finding their baseline' is consistent with the way NHS policy understands activity management, with a significant caveat: in the interview data, pacing is contextualised by the participant's mindset. As such, it can be misleading to talk about pacing in a universalising way. Some participants claim that pacing did not work for them when they sought to impose rigid expectations on their activity, or when the model of activity and energy expenditure was at odds with a more holistic mind-body imperative.

> "Pacing was the worst thing I did. Because you kind of learn that you have a limited amount of energy and you deplete it during the day. It totally doesn't work for me like that anymore. You know, I could get more energy if I do something I love and I'll keep going until I'm tired and then it's normal to be tired at bedtime." (Autoimmune disease + CFS, recovered from CFS after 3 years)

For others (n = 9), pacing helped them establish their energy and activity baseline, sometimes over an extended period of time, such as a year. Establishing a baseline means adjusting one's life to accommodate one's illness—learning the limits of one's energy envelop. For the participants that describe this as key to their recovery, this took time. Expectations had to be adjusted: no activity was too small to be counted. For many of these participants, the baseline was the first milestone in the journey to recovery, the place from which improvement occurred.

> “I had to learn what my own baseline was, my energy baseline, how could I pace my energy throughout the day using things like spoon theory, all of those kind[s] of tips and tricks to learn what that baseline was where I could kind of keep the symptoms slightly under the radar … The only exercise I did really in that entire seven-year period was walking, and not much of that to begin with, but that was the thing that one of the markers that I could tell was showing me [was] that I was starting to have those improvements, because the distance I could walk and how I’d feel as a result just became longer and longer.” (CFS, recovered after 7 years)
>
> “And I think what actually helped me recover was coming from a place of *Let’s just see what I can do.* So whatever is within my window of tolerance, baseline, whatever you want to call it, *Let’s see if I can do some movement*.” (ME/CFS, recovered after 8 years)
>
> “I’m in a good place and [do] not push myself, and [I] keep those boundaries and keep looking at my life holistically—not my body, my everything: brain, my nutrition, my outside walks and energy.” (Sjögren’s syndrome + chronic fatigue, recovering after 3 years)
>
> “That is at the start, how I recovered just over time, I guess gently regulating my nervous system without really realising it and getting to a place where I felt okay again. As the relapses went on, that started to work less and less. And one reason I think for that is because I became so strict with it— [I had] so much fear around it.” (ME/CFS, recovered after 18 years)

Rather than accommodate a medical model, the principles of pacing practised by participants are more diffuse. Each participant develops a practice based on self-literacy, their own way of ‘feeling’ into their skin and sensing capacity. One participant said that they liked pacing once “I was able to work out my own way of doing it” (long COVID, recovering after 2 years). A more capacious view of pacing would include participants’ adjustments to bodily activity through techniques of nervous system regulation. The mental representation of one’s capacity requires an introspective enquiry, the cultivation of a language of somatic interpretation—ways to listen to one’s body. In this account of the relationship between sensation and one’s energy envelope, symptoms are not to be feared as signs of irrecoverable illness but listened to for clues as to what the body needs to stop being symptomatic.

> “I think you have to be real in order to heal the complex feeling states that come up inevitably in any complex condition, and I would argue are involved in its genesis in some way or other, to get into that really deep, deep material where change can really happen. It’s not a straightforward thing, and [it] takes considerable empathy with the self. And an important part of that is feeling your feelings and allowing your feelings and not disallowing your feelings.” (ME/CFS, recovered after 33 years)

For this participant, having a holistic attitude means healing what comes up in the context of illness, which can be one’s feeling states. For many participants, this process of healing turns out to be important to their recovery overall. Often these participants narrate that questions of selfhood and identity are important to their emotional wellness and that these issues emerge as underlying vulnerabilities.

A counterexample is the use of wearable devices to provide feedback from the body. Devices are marketed with the promise of bypassing the need for introspection. However, in one participant’s example, the information provided by a wearable enabled a better understanding of their symptoms:

> “With the research I’ve been doing, the data has helped me kind of join the dots, so to work out which bits of possible symptoms apply to me and which bits don’t apply to me. And I also find it easy; I just look at my watch or a wearable or a screen and it tells me what’s going on inside me without me having to feel it. Because what I found is that the numbers change before I feel it, and once I feel it, it’s too late, I’m crashing.” (Long COVID + POTS, 2 years, recovery ongoing)

Overall, though, participants experience symptoms differently and describe different ways of intuiting what is happening in their bodies. The interview sample does not provide enough data on wearables to assess their implications.

(b) Momentum and scaffolding

Participants’ breakthrough moments are associated with symptom relief. This relief not only signals improvement in overall health but also motivates, galvanizes and energises the work of recovery by sustaining positive thinking and belief in one’s recovery. Indeed, one’s belief becomes a conviction with the evidence of symptom relief—participants describe being able to do and feel things they had not been able to do or feel in years. This can be thought of as an affirmative feedback loop.

> “I knew I had to latch on to every tiny bit of evidence that *My body’s better than it was* … I can remember holding onto the wall and just thinking, *This is a good thing*. You’re not completely bedridden. Your body starts to work and [you’re] just seeing every tiny thing as progress and a celebration, and even if I was back in bed again, I lay in bed reciting all the things I had done.” (CFS, recovered after 2 years)
>
> “You have to be willing to listen to your body, you have to be willing to accept setbacks and everything like that. But there is a path forward I think, to figuring out, *Okay, this is what I can tolerate without feeling triggered or symptoms or whatever you want to call it. And then I can make just the tiniest step forward that my body will not even really notice and adapt to that and then continue to add to it slowly over time* … Now I do a mile every day and it doesn’t even feel like it’s a push or something that I’m nervous about doing. It feels like I can take for granted that my body’s going to be able to tolerate it. So it really does add up over time.” (ME/CFS / long COVID + POTS, 4 years, recovery ongoing)
>
> “I built myself up very slowly, very gradually, and it was something I enjoyed.” (ME/CFS, recovered after 8 years)

Feedback often has a rhythm or momentum that can reify the belief that recovery is possible. Recovery often accelerates in stages, although the final recovery can be so incremental that it is almost imperceptible. In the following account, the participant describes a sudden realisation that she had energy to burn, and this was preceded by a positive life experience and perhaps a more imperceptible phase of improvement:

> “It was actually only about a week or two after we got back from the honeymoon and we were sitting on the sofa, and I suddenly got this urge to go for a run … I suddenly felt that not only did I have enough energy, but I actually had expendable energy. I had energy to burn, and I felt this urge … and that’s why I chose that date really as being my point of where I really just thought, *Yeah, I’m back*.” (CFS, recovered after 7 years)

When participants recall the first time a practice made a difference to their symptoms, this shows how self-confidence contributes to recovery. For example, one

participant talks about the difference that a change in diet made and the positive feedback she was experiencing through a newfound emphasis on nutrition. This participant goes on to describe other practices stemming from her successes with diet.

> "First, there was nutrition and that just sense of empowerment that *I'm not like a victim to just fate. I'm not going to have this chronic condition forever. There's actually something I can do. There are a lot of things I can do to help myself.* That sense of empowerment was huge." (POTS, 9 years, recovery ongoing)
>
> "It was like the first time I ever felt like, after I'd done the breathing techniques, I was like, *Oh my god, I feel calm.* I was like, *Is this how you're meant to feel?"* (CFS, recovered after 4 years)

Participants interpreting their recovery through the lens of mind-body theories describe using multiple practices to recover. Each practice is believed to address a particular issue and to also work in tandem to produce an accumulated result. Another participant talks about the importance of finding out "what helps you take active charge in your recovery" (long COVID + CFS, recovered after 2 years) through trial and error with different practices. This participant also advises that "tracking your symptoms and tracking your feelings and how you're doing is super important to recovery." While this study has not analysed the order of tools and techniques represented in narratives, more intensive processes with disruptive elements, like psychotherapy, are not often the first practices that participants embarked upon. More often, participants describe the use of simple techniques designed to enable nervous system regulation, or begin with detoxification protocols recommended by nutritionists, naturopaths or functional medicine doctors, before moving on to deeper or more personally challenging work.

> "When it comes to programmes, it's so interesting because you'd think the best thing is to get a programme that teaches all of this right in one place. But the thing is: it can be really overwhelming. You're not necessarily ready for it all at once. I wouldn't have been ready for trauma work earlier in my illness. First of all, my nervous system was way too activated." (ME/CFS, recovered after 6 years)

> “Breath work was my anchor to bring me back to safety and to bring me [regulation] and feel safe. So it was the tool that I used that meant that all the other tools worked so much better.” (CFS, recovered after 4 years)
>
> “So I have a really tight morning routine. I do a light yoga, my breath work and going to the shower or the ice bath … It’s the best way to help yourself.” (ME/CFS + long COVID, recovered after 20 years)
>
> “Different symptoms and different emotions were requiring different actions to make me feel better, which I found absolutely fascinating.” (Long COVID, recovered after 3 years)

Participants describe the period of time in which they returned to good health as happening over months and years. Rarely did people describe a quicker resolution of symptoms. Raelan sometimes asks participants how they sustained their momentum over the course of their recovery. One participant, who took 4 years to recover, draws out the theme of accountability:

> “I was accountable for everything I did, and that was important for me.” (ME, recovered after 6 years)

(c) Timing (being ‘ready’)

> “I needed that time to just experience life.” (ME/CFS + fibromyalgia, recovered after 15 years)

Several participants talk about the importance of timing in relation to particular practices. Sometimes this is expressed as “not being ready” or “needing the time” to learn and grow. As the participant quoted above puts it, “Something happens in between.” Over time, participants encounter new ideas, new practices and new people who have recovered. The same participant mentioned above cites the importance of ‘mental strength’ and ‘personal growth’. For many, time is essential to cultivating and sustaining a new mindset.

> “I didn’t recover during the programme, but it helped me a lot, and I think I could have recovered during the programme if I had the right mindset.” (ME/CFS, recovered after 2 years)
>
> “That timing is everything too. So I remember two years before I found DNRS [Dynamic Neural Retraining System], I had a psychotherapist tell me about mind-body syndrome, and I literally told her to F off … I wasn’t ready to hear it.” (CFS + long COVID + POTS, recovered after 12 years)

The above participant then goes on to describe how she felt she lacked confidence (perhaps belief) in the physical strategies, “to really pursue it.”

Many participants describe resisting mind-body perspectives for years because of their negative association with the idea that ‘symptoms aren’t real’ or that the illness is ‘all in your head’.

> “I would’ve thought, *They’re not validating my illness. They’re saying that I’m making it up. They’re saying it’s in my head*. I would’ve got quite defensive until I’d done that two years of research and became open to the idea that it wasn’t physical.” (Autoimmune disease + CFS, recovered from CFS after 3 years)
>
> “I’ll say I was really ready. I wouldn’t have been able to just jump into these years before when, for one, I didn’t really believe it and I was bedbound.” (ME/CFS, recovered after 13 years)
>
> “I did have to go through all those years of research and training. I couldn’t just skip ahead to what I know now.” (Fibromyalgia + Sjögren’s syndrome, recovered after 5 years)
>
> “I wasn’t in a place to hear that message, and so I sort of doubled down on … this is my physical body, this is real.” (ME/CFS + POTS + fibromyalgia, recovered after 8 years)
>
> “I was introduced to [John] Sarno at some point during college, but I was like, *There is no way this is mind-body. This is too severe, too full body symptoms.*

> *There is no way this is caused from my brain*." (Long COVID + POTS, recovered after 9 years)

In these excerpts, one can observe how mind-body theories and practices can offer recognition of the complexity and severity of symptoms as they are experienced.

Timing is also significant in the sequence of events that cluster around the change in mindset. A belief in recovery that is prompted by a new idea or theory about the illness or by encountering evidence of someone else's recovery often occurs alongside engaging in a new practice or entry into a programme. For the most part, participants describe a cluster of positive social activity that builds momentum: coming into contact with new people, ideas and contexts at 'the right time'. There is an element of cultural poesis, or bricolage, in the ways people assemble a new context through which to understand their own encounter with their illness and hope for the resolution of symptoms. This encounter is a far cry from the social isolation and destitution of the medical model. The patience that many participants describe as being required links together the theme of timing with the theme of self-determination.

> "I had to change the mindset completely. And then when you get to that point where you just kind of think, *Okay, well, it's all going to happen in time*, you start to relax. Even the pressure, that's enough to keep you in that fight-and-flight state every day, that *it's got to happen. I've got to push*. No, you don't need to work hard. And I think that was the thing I had to learn. *I don't need to work hard for this to happen. I don't need to push. I need to just walk slowly towards the goal, except that there's going to be some quite sizeable rocks in the road.*" (CFS + fibromyalgia, recovered after 20 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)

Several participants recount their use of the affirmations "This is just for now" and "It will get better".

4.6 Self-transformation

> "I've learned to listen to myself, listen to my body … there's been a lifestyle change in a way. It's been a journey getting to know myself, working out what my triggers are … learning what I need to do to keep myself healthy, instead of going back." (ME/CFS, recovered after 33 years)
>
> "Even after the first day of the course, I found myself incredibly changed." (Long COVID, recovered after 1 year)
>
> "The only way I can describe it is it felt like my brain, my soul and my body were getting pulled in three different directions. It was just absolutely horrific. And again, really frightening. I became housebound pretty much straight away, and I couldn't work. I couldn't watch TV. I couldn't listen to music. I could barely parent my son. I couldn't read. I couldn't really do much of anything. It really felt like I lost everything that it meant to be me. I lost what it meant to be a human, to be able to just exist in the world. And especially with the loss of independence as well. It was something I was always proud of, being quite independent, and suddenly felt like that was all ripped away from me. So it was quite horrific." (Long COVID + POTS, recovered after 1 year)

One of the defining experiences of CFS and related illnesses is the loss of identity. This loss is described as hard to convey, even harder to bear and, among those who share the experience, an empathetic common ground that aids recovery. As a result, a number of narratives about selfhood circulate in the interviews, the central theme of which is transformation and change. As the latter quote illustrates, a discussion of identity does not need to precede the description of self-transformation that one associates with recovery. This subsection describes some of the themes accompanying participants' discussions of self-transformation. In other terms, the interviews show that being able to respond to and cultivate personal preference through the pursuit of tools and techniques, theories and concepts, cultures of recovery represented in programmes or by individuals, that speak to the participant, to which the participant finds themselves most responsive, is associated with positive outcomes. The term 'self-transformation' reiterates the theme of self-determination and is used to highlight the positive valorisation of these reflections.

Echoing the claim made by many of the participants, that there is no recovery without a transformation of the self, many of the participants' narratives also link a change in mindset to personal transformation. The theme of self-transformation was

observed in 84% (n = 63) or 4 out of 5 interviews, 75% (n = 47) of which reference a change in self-identity directly, examples of which are provided below.

> “This experience has absolutely changed me forever. … I’m a very different person now.” (Long COVID, recovered after 2 years)
>
> “It feels like the person [I was] before I got sick is a different person to who I am now. … I love myself now.” (CFS, recovered after 4 years)
>
> “I know I’m strong enough to do this and I can change because that’s what I think I need to do. … I’m a different person today.” (ME, recovered after 6 years)
>
> “I became a different person.” (Lyme, recovered after 3 years)
>
> “I was a different person.” (Long COVID + ME/CFS, recovered after 2 years)
>
> “You can’t be the same person after going through something like this.” (Long COVID, 3 years, recovery ongoing)
>
> “I’m not the same person I was before I got sick. I like myself a lot more now.” (CFS + long COVID + POTS, recovered after 12 years)
>
> “I think some people are really keen to get back to how their life was, and I absolutely do not want to do that ever. I want to go forward and it to be better than it ever was. From everything I’m learning through the CFS research, I feel like that’s possible.” (CFS, 3 years, recovery ongoing)
>
> “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)
>
> “What I noticed for myself and for others is this stage of grief, and sometimes we don’t start recovery until we grieve properly the life that we had. And somehow this will change us. It will leave us [scarred], but it’s like: how do we make peace with that?” (CFS, recovered after 4 years)

While it is unsurprising that, given the loss of identity that is part of CFS, participants speak about cultivating a new sense of self, this study finds that the very process of self-cultivation must be considered a part of participants' recoveries. Work on recovery undertaken with individuals, whether one-on-one or through an organisation, to a greater or lesser degree involves work on the self (see: Section 8. Social illness, identity and the overextended personality). It is revelatory and inspiring to hear how participants regain a sense of self from the ruins of their desubjectivation. For some participants, evidence of this work takes on a formal quality, such as through the conventions of psychotherapy, whereas for others, the tone of the work is more cultural, such as through the influence of the genre of self-help. As well as observing participants' accounts of formal and informal techniques for practicing selfhood, the study also identifies how participants link mindset to a sense of self.

Participants' reflections on personality, personal relationships and professional ambition prior to developing illness suggest a working theory that the motivations underpinning social action and behaviour contributed to their volatile physiological state. At least half of the study participants (n = 39) invoke a link between illness, recovery and their personality in their interview. The same number (n = 39) discuss anxiety as a factor in becoming ill and/or sustaining illness. What is being described here is a trouble with the self that participants believe precedes and perhaps precipitates CFS and related illnesses. These themes are discussed in more detail later in the report (see: Section 8. Social illness, identity and the overextended personality).

In the accounts analysed for this study, self-determination brings about a new sense of self. One example of this can be found in reflections on moral themes such as honesty; integrity; authenticity (of selfhood, of feelings); the ability to trust; and the ability to feel safe and settled, as well as loved. Some participants' identifications with being a 'kind' and 'giving' person are reframed around developing knowledge such as 'emotional intelligence', or an intelligence around personal and social 'boundaries', to better enable one to be generous without a personal cost. These identifications are certainly seen in participants' descriptions of how they started to work as non-medical, mind-body practitioners, following their own recoveries. Participants also reflect on developing a new sense of self through reference to more social and ethical terms involving the notion of 'letting go' of prior attachments (see: Section 9. Ethics of recovery).

> “I was always a somewhat spiritual person, but I started meditating and really practising yoga, and I think that sense of spiritual connection to something that was greater than myself really helped. I think it helped with my emotions and helped [me] just feel like there was some hope and there was some kind of broader picture than I was able to see right now.” (ME/CFS, recovered after 13 years)

Taking a broader view of the self, one that focuses on the interconnection between people and indeed all living things, reflects an opening out of the self into social, and in some accounts ecological, relations. The desire to be in nature (and thereby the practice of placing oneself in nature) is a common theme among participants. This is important to highlight, given how practices such as meditation and yoga might be associated with retreat and privatisation (the neoliberal phenomenon of the private self). Many participants talk about learning to become less “focused on external things,” and more interested in cultivating a self-secure, inward-facing sense of identity. For example, one participant says that breath work “releases a lot of energy and helps you connect to your true self more.” Another talks about ‘being kind to myself’ when he knows that he is about to have a more challenging day. Notably, participants did not disclose any feelings of shame or self-blame alongside the sense that their self-identity had in some way contributed to the forming or sustaining of symptoms. Equally, no participant describes having been manipulated into thinking of such associations or refers to these associations between self and illness in any kind of damaging way. Rather, in these data, the theme of self-transformation is one of the most liberatory and galvanising.

> “My biggest stumbling block was me.” (CFS + fibromyalgia, recovered after 20 years)
>
> “I know what it’s like when you lose it [the life you want].” (ME/CFS + long COVID, recovered after 20 years)
>
> “I've learned to trust in myself again.” (Long COVID, recovered after 3 years)

The self-knowledge that is required by the type of symptoms one has also factors into this account of self-transformation. One participant describes themselves being in a ‘better place’ because they know what they’re dealing with and how to manage it. They also describe themselves as “operating within the boundaries of my current

levels" (CFS, recovering after 10 years), showing evidence of introspection and responsibilisation. This sets up an interesting resonance between the idea of physiological and personal boundaries, examined later in the report.

What might be termed a holistic reflection could also be described as a shift to an emphasis on social values and relationality. Participants reference kindness and self-compassion and the difference they experience having replaced, as far as they can, self-criticism with kindness. Participants' willingness to engage in a self-reflexive and introspective mode of self-examination counterposes the issues of identity that they identify as unhelpful.

Some participants invoke the theme of the nervous system as a way to account for the relationship between their sense of self and their progress in their recovery. As one participant who recovered from CFS after 20 years put it, simply, "My body's not going to heal if I'm stressed." Another volunteers this more detailed explanation:

> "We know when we are practicing gratitude that we're activating the frontal lobe, and the frontal lobe and the prefrontal cortex actually counterbalance that amygdala. So the more that we can bring on that frontal lobe, it'll dampen down that over-responsive amygdala response. And so it's actually accessing and lighting up these different areas in our brain that that [are] going to help to balance that out. And that changes the trajectory of our recovery, that changes what's going on neurochemically and all of our neurocircuitry. And so just these things that can seem kind of, and again, I was like, *I don't do visualisations. This is woo woo. This is weird stuff.* But now I understand there's neuroscience behind this stuff, and it's very effective." (Long COVID + ME/CFS + POTS, recovered after 2 years)

Some participants explain this gratitude as an effect of having experienced loss, of having grieved the loss of a liveable life. Speaking about self-transformation in such positive terms invites ambivalence, given the losses suffered through the experience of illness. This seems more like an acknowledgement of the irony or weirdness of being 'grateful' for such a difficult experience of illness, rather than airing a discussion topic on which to dwell. As one participant, who recovered from CFS after four years, put it, "It's weird to say, but I am so grateful for it."

To really understand the gravitas of some participants' narratives, one needs to sit with their whole experience, from their rock bottom to their account of self-transformation.

> "I mean the first time I was suicidal about it was when I was seven … because I was so in pain at seven. But by the time I was 16, it got really, really bad. I actually, I don't say that much on camera, but this time I do: I tried to kill myself, and I'm glad it didn't happen. I'm glad I was stopped and I was put back into psychiatry again this time for good reasons, but wasn't a much better experience, not helpful either, but I had no hope. And actually, I was angry that I had an illness that just tortures. I actually sometimes secretly wished, *Why don't I have an illness that at least kills me in a few years? Why do I have to have this?* That's not going to kill me because it's not a severe illness in that sense, and I just have to have it for how long. And yeah, no, no hope."

It is humbling to fathom that the same person who experienced such extremes of distress also says: "I wouldn't be the person I am today if I wouldn't have had that … of course it was terrible, but I'm grateful because I got through it, and now I can be useful in helping other people."

The preponderance of self-transformation is a reflection not only of the devastating impact of CFS and related illnesses on self-identity but of how participants have recovered from a symptomatic state. The ultimate implication of this finding is that the psychological and emotional ingress of CFS must be understood as part of the illness itself. It is incredibly important for the medical and wider community to understand that how participants feel once they become symptomatic is not epiphenomenal or a secondary emotion. According to this analysis, loss of self is actually part of the CFS symptom cluster, not a second-hand effect of not having the energy to talk with other people or go out or, for example, look in the mirror.

4.7 Discussion

This study did not set out to privilege the theme of mindset: it was one of many areas of interest. Equally, participants describe their surprise at the difference mindset makes to their experience of symptoms. Having realised the substantial importance of mindset as a structuring theme throughout the dataset, the study subsequently approached the analysis of mindset in the following ways. Firstly, it examined the relationship between mindset and key narrative themes. Previous sections, on the onset of symptoms and encounters with medicine, provide evidence of how mindset shapes the experience of illness and changes with the way that illness has been framed in specific cultural contexts. This section delves further into the role of mindset through looking closely at a series of narrative themes— rock bottom,

making a decision to recover, self-determination, practices in the context of a recovery mindset and self-transformation. These relational and co-emergent themes are underpinned by transformations in mindset and link mindset to recovery milestones.

The second approach taken in this study has been to look at the interview data's narrative arcs, where a patterning of affect, emotion and feeling emerges. The semi-automated sentiment analysis corroborated how mindset and recovery milestones are linked through this patterning. When participants recollect their encounters with medicine, especially in clinical settings, they express despair and hopelessness, abandonment and betrayal, fear and anxiety, anger and frustration. When they discover a recovery mindset and the tools and techniques that yield improvement in symptoms, their tone shifts to hope. Another defining moment occurs when participants reflect on their self-transformation, expressing happiness, resolve and contentment—even joy and elation. Interview themes are not only moments in a narrative arc shared across multiple accounts but represent clusters of experience that underpin changes in affective state.

Mindset is not only a gateway to practices of recovery but is itself a practice of recovery that transforms one's sense of self. The interrelation between feeling, affect and emotion, mindset and sense of self that is represented in participants' recovery narratives provides strong evidence of the role of mindset in recovery. The recovery mindset is the outcome of being introduced to a believable explanation of symptoms. This mindset stands in contrast to the mindset of non-recovery that participants who go on to recover have resisted. The interview data show that if one wishes to recover, one must resist the medical discourse of non-recovery. Not only is such resistance possible, but it is also possible to make it available to others. More than resistance, the self-determination expressed by people who recover signifies a wholesale departure from the passivity that medical and societal discourses impose upon the person with CFS symptoms.

The following two sections further expand upon the theme of mindset by highlighting how participants orient themselves to mindset as a recovery practice and by allowing a more detailed account of the role of hope and belief in the recovery mindset.

Section 5. Mindset as a recovery practice

"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. And it was kind of like to me—and I'm not saying this is for everybody—but for me, I felt like I [had] finally heard the truth. This resonated with me with what was happening, and it gave me hope that I could recover instead of just being viruses or faulty genes or mitochondria or things I couldn't do anything about. And after I had that little spontaneous remission and I ran around the block multiple times, I knew I was on the right path. I knew beyond a shadow of a doubt, and that's all it was, was knowledge. I mean, it was just information, which is really crazy. And I think it was her caring. She cared a lot to help me. She spent three hours on the phone with me." (ME/CFS, recovered after 13 years)

"I remember being in that place where I was like, *I just don't understand how this is a nervous system issue and how it can be all of these things.* And then I would come across people … talking about it as a mind-body condition. And I remember almost—not almost—I was actually kind of offended when I would hear people talk about, 'Oh, this is a mind-body issue'. I was like, *Are you kidding me? My hair's falling out. I'm getting blisters on my skin spontaneously. I haven't slept for four days.* And I am thinking, *Here I am this positive person that had been living this healthy lifestyle*. And to say it was a mind-body, to me, at that time, felt like it was invalidating. And it kind of implied that it was all in my head, and that was so upsetting because when we're in this, we're dealing with these very, very real, challenging physical symptoms. And it took me a while to understand … it's almost a language barrier. When we say 'mind-body', what we're really saying … is that we're now saying brain or central nervous system as the 'mind', that's that origin of the thoughts and the emotions. And then when we're saying 'body', we're actually saying more peripheral nervous system, which is all the autonomic

nervous system. And that's what so many of us struggle with too. Whether it's heart rate variability or palpitations or blood pressure issues, all of these kinds of things, that all goes into that peripheral nervous system. So once I could start to understand that, we were kind of saying the same thing: *Okay, it's a nervous system issue, mind-body, but that means brain–peripheral nervous system*. And that kind of clicked something for me. Otherwise, I felt so much resistance to that concept of a mind-body interface or illness, if that makes sense?" (Long COVID + ME/CFS + POTS, recovered after 2 years)

5.1 Introduction: Mind-body recoveries

In recovery narratives, mindset is not only a matter of conscious representation but is also an interplay of cerebral, somatic and affective realities reflected in a reciprocal relationship between a person and their lifeworld. Across the dataset, the vast majority of participants (95% or n = 71) associated recovery from CFS and related illnesses with new knowledge—and ultimately the adoption of a mind-body theory of illness. Participants' accounts place emphasis on discovering new knowledge that 'made sense' to them, describing how a mind-body paradigm enabled them to 'make sense' of their experience for the first time. Given the dominance of the medicalised view in mainstream society, accounts of a shift in mindset universally make reference to a mind-body theory of illness. Interestingly, these accounts tend to cite either an underlying science (involving neuroplasticity or the nervous system) or a somatic psychology of the emotions (such as of repressed emotion) as the explanation for their symptoms that made sense to them.

Participants often encounter mind-body approaches to illness and recovery through first-hand accounts of personal experience. Whereas first-hand accounts are often believed immediately, second-hand accounts are often received with scepticism. In the following example, information comes from a trusted source—a doctor:

"It was so important that my doctor broke it down to a science, and he was like: 'This isn't just some theory I'm making up. This is data. I've pulled from helping literally thousands of people with this' … He's seen people get better from it using the same principles. And he was like, 'Look, this is how your brain works. This is how your nervous system works. These are the steps you need to take to retrain it. And it all comes down to neuroplasticity.' And that was huge for me." (ME/CFS, recovered after 7 years)

Several participants describe the elapsing of a period of time before becoming open to mind-body approaches. In line with participants' understanding of the different theories and practices of recovery they have encountered, interview data represent mindfulness, meditation, nervous system regulation, somatic introspection and brain retraining fairly separately. While this report discusses these in turn, they have also been considered collectively as the practice of mindset, where 'mindset' acts as the umbrella term. This section fleshes out the cultural concept of mindset through a synthesis of participants' accounts of some of these theories and practices, which tell us how mindset is represented and understood in the context of recovery from CFS and related illnesses. Through an interplay of cerebral, somatic and affective realities, one's mindset is sustained. A recovery mindset that privileges ideas about the role of the nervous system or emotion in illness is not a conventional mindset and so must be fuelled and renewed.

"I had actually tried some other brain retraining programmes before. I was really resistant to brain retraining in general because again, there's some really negative spaces online that you can go to related to CFS and they'll tell you that: 'It's a waste of money and it's a scam and they're just trying to basically pull one over on you to take your money'. And what frustrated me about hearing some people talk about it [was that they could not share more because] there's a lot of copyrighted material, a lot of things are proprietary. So it felt like it was really hard for me to know who to trust at that point. *Do I trust the people who are saying, 'Just save your money and don't get scammed?' Do I trust the people who are saying, 'This could be a path forward, but I don't really know what it is?'"* (ME/CFS + long COVID + POTS, recovering after 4 years)

"I was quite resistant to brain training, to be totally honest. I was really sceptical. I am naturally a bit of an analyst. I analyse things sometimes too much—definitely, I would admit that. But I thought, *How could my mind influence my body so much?* I remember looking at some recovery stories and hearing of people recovering, let's say after a week or a few weeks, and thinking that *they mustn't have had chronic fatigue, that can't be real*. Or even someone getting better in two or three months. I was thinking, *That's not—how could that be real?* So, I was automatically discounting that kind of recovery straight away and thinking that they weren't really ill." (ME, recovered after 11 years)

Negativity about mind-body practices is fostered in an unregulated, online environment and is not helped by community standards requiring statistically significant findings from double-blind trials before a recovery tool or technique is greenlit. The latter participant went on to describe brain retraining as the “missing link” that led to his recovery. He said: “I’m a hundred percent sure that that’s the thing that got me better.” Without the approval of formal organisations and sitting outside formal healthcare contexts, participants describe their initial mistrust of recovery programmes:

> “I researched that, and everything I read about it just started hitting buttons. And I was like, ‘Oh, right, okay, this feeling is really familiar,’ and all of my scepticism and my really very strict logic, science-based, not that this isn’t scientific, but this idea that, well, it just can’t be anything about feelings or emotions. All of that started to shift because everything I read, I could really relate to. I was still sceptical when I read testimonials and reviews that people had written about it on the Internet—I just didn’t believe them. They were saying it was ‘amazing’ and ‘I got my life back’ and I just couldn’t believe it. My doctors had said, well, they’d said ‘that wasn’t possible’, and who are you going to believe: somebody on the Internet or the doctor in the uniform?” (ME/CFS, recovered after 4 years)

Interestingly, the language of the nervous system associates mind-body theories with the biological science of the body. In this unregulated cultural context, many participants cite the language of science as being reassuring, as helping to change their mind about mind-body medicine. In particular, the languages of nervous system regulation and neuroplasticity provided a sense of epistemological reassurance. Without assessing the science behind nervous system regulation, or even neuro-linguistic programming, participants describe becoming interested in these approaches because they seem able to offer a scientifically plausible explanation for CFS symptoms.

> “Knowing that this is scientifically possible helped me.” (CFS, recovered after 33 years)

To some in the CFS recovery arena, the language of ‘mind-body’ sounds hopelessly generic, given the differences between different approaches. People might also question whether the significance of mind-body approaches lies in their theory of illness or of recovery—a disambiguation this study has not performed. The language

of ‘mind-body recoveries’ might also be seen as tricky territory analytically given how ‘mind’ means something quite different to a Western analytical philosopher versus a neuroscientist, a psychologist, a healing practitioner of an “Eastern” culture, etc., let alone a cultural theorist influenced by process philosophy.

Notwithstanding such challenges, in the broader cultural context, the language of ‘mind-body recoveries’ that these findings support stands as a clear bulwark against the claim that until medicine discovers a disease process, there is no way to reduce symptom burden or modify the process contributing to the illness. The findings of this study are unequivocal: participants’ accounts are largely of mind-body recoveries that entail sensible paradigm shifts. Remarkably, many participants recount a description of the explanatory power of a mind-body theory alone as reconfiguring. It is humbling to hear participants describe being able to ‘make sense’ of their symptoms for the first time. This is a key milestone observed across recovery narratives.

> “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)
>
> “You can’t separate out your anxiety from your chronic pain or illness. That’s not how we function. Our brain, nervous system, body—they all function together.” (Fibromyalgia, recovered after 4 years)

The frequency of recovery-related concepts expressed by participants very much reflects which kinds of tools, techniques and programmes participants experienced first-hand most often. The concept of ‘nervous system dysregulation’ that frames symptoms as the effect of dysregulated neural pathway is the most widely shared across participant narratives. This is especially true if one looks across all the data and not only where participants talk about encountering a new theory of CFS and related illnesses. Concepts regarding the nervous system are perhaps also prevalently expressed because other ideas about the body and the mind connect back to this system—there is no bypassing the nervous system.

A second cultural imaginary of CFS and related illnesses as mind-body illnesses hinges on the idea of emotions as protagonists of a dysregulated nervous system. Many discussion themes alternate between these ‘emotional’ and ‘neurological’ representations of the symptomatic body. Fear, for example, is talked about both in impersonal terms—as a matter of an evolutionary biology unable to keep up with the

demands of work and personal life in neoliberal capitalism—and in highly personal terms, as a matter of individualised biography and relationships.

The nervous system framework tends to manifest in discussions concerning the switch between the sympathetic and parasympathetic branches of the nervous system, usually illustrated by means of referencing the 'fight-or-flight' state. The idea that 'rest and digest' (the parasympathetic nervous system) is a healing state creates an achievable goal for participants to work towards. Moreover, achieving this provides psychological and tangible physiological feedback to the body. Learning about 'the nervous system' changes many participants' understanding of rest and also, then, pacing. The idea that the nervous system affects symptomatology also offers a way for participants to see the impact of their thoughts on their own bodies. Participants also talk about the vagus nerve, which performs a regulatory function in the respiratory system and other internal organ systems. The invitation to experience joy, of course, affects the brain's neurochemistry but also has a knock-on effect in the vagal and parasympathetic circuitry. Significantly, participants are clear that stress reduction is not achieved by withdrawing from social life, which can, in fact, increase stress through social isolation or by reinforcing 'top-down' instructions to the body that one must first get better before re-engaging socially. Rather, a more introspective communication with oneself about one's expectations or comportment or behaviour, which leads to one showing up for themselves before others, is associated with a more enduring change in how one feels in their daily life (discussed further in Section 8. Social illness, identity and the overextended personality). Equally, practices that regulate the nervous system are seen to provide the opportunity to establish a more centred self-relation. The techniques discussed below help fulfil this goal. For a subset of participants, talking therapy (assumedly psychotherapy—but it is not always clear) provides additional support for the self-reflexive process of introspection.

The principles of evolutionary biology could be a source of comfort and reassurance to someone who is symptomatic. The idea that symptoms are caused by bodily systems that are acting in the interest of self-preservation, that seek to protect the organism, rehabilitates the sick body to an image of health and wellness. This sets up the idea that the body means to work with the self rather than against it. In contrast to the image of a body weakened by irreversible degradation, perspectives informed by evolutionary biology and sociobiology provide reassurance and solace. The mind-body theory of illness is an optimistic one because it is organised around the potential of a mind-body recovery.

> "A big part of it was seeing that my illness wasn't something separate from me. It wasn't a disease that I had to fight and win. It was a part of me that I had to embrace and learn from, which was horrible. It was hard because it was so unpleasant, but I had to just actually go: *This is me. What's it saying? What does it need? What do I need?*" (ME/CFS, recovered after 4 years)

This participant changed the way that she related to and responded to her symptoms.

Mind-body recoveries invite people to address longstanding unhappiness. Another participant talks about the significance of changing her understanding of the origin of her symptoms. She describes speaking to herself—letting herself know that 'I am doing tired'—as a way to dislodge the experience of being subject to a set of symptoms on which she cannot act. By rethinking the idea of illness—that illness is not 'something that happens to you' but 'something that your brain is doing'—this participant offers an example of how mind-body theories of illness reposition the individual as capable of acting on that illness, even if only incrementally or with mixed results. Such examples illustrate the difficulty of disentangling mindfulness from the adoption of a mind-body approach to recovery.

5.2 Mindfulness

> "And then I decided, *Okay, so I'm going to continue living, and what can I do then to get out of this room?* Because I couldn't lift my arm. I couldn't take the glass and drink water. So, *How am I going to get out of this?* It seemed impossible. But the first thing I started doing was working with my thoughts and asking myself: *The thoughts I have—are they true or are they false? Is it for real? What's happening to me right now?* And I started looking at my thoughts [to] see, *Okay, which thoughts do I want to keep, and which thoughts do I want to put aside?* 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)

For the participants, the recovery programme begins within the confines of four walls. This participant in particular had no external reference point, such as a story of someone else's recovery, when she started working with herself to address her symptoms. Mindfulness describes the practice of attention one can give to a range of activities so that they can be knitted together in a new way, be given new meaning, linked to a new sense of being. This participant describes making the decision to

live. For her, the decision to live had to be a decision to recover. This decision was preceded by a terrible exacerbation of symptoms following one hour of physical activity at an ME clinic.

Asking oneself, at the moment of being symptomatic, *How am I responding to this situation and why?* enacts curiosity. Participants report that this type of mindful attentiveness can itself affect symptomology, providing evidence for the idea that symptoms are neuroplastic rather than permanent biological fixtures. References to speaking with oneself as a way to practice and embody a more mindful awareness of how one thinks, acts and feels occur in numerous interviews. Speaking with oneself often takes the form of asking oneself questions, creating the sense that one has agency.

> "When I put that book down, I've realised what I was doing to myself with my thoughts. And I'd been focusing so much on the physical stuff until then, and, like changing my diet … I wasn't focusing as much as I realised I probably should have been on my mind … So I put the book down, and I was like, *Wow, you're just seeing the negative all the time. You're just constantly in 'poor me, poor my life, poor body'.* Yeah, it's not nice going through an illness like this. So you're human and you're going to feel like that sometimes. But there was no positive. I wasn't finding any positive ever. I remember, I was—I got up and I was sitting at the window, and usually my thoughts when I was sitting at the window was, watching the people go to work and thinking, *Well, I can't go to work and they get to go to work and I'll never be able to do anything.* And kind of getting in that frame of mind. And that day, I was like, *Okay, what is here? What's positive here?* And I noticed that the people rushing to work couldn't see the squirrels that were playing in the garden. And they walked straight past the birds and the butterflies and all the beautiful things in people's gardens. They were just there rushing for the bus. And I was like, *Okay, I think I kind of get it. There [are] flows of stuff happening around me that [are] magical and beautiful and wonderful, that even the healthy people, they don't see, because they're so busy. They're so busy with their lives.* And that was a real turning point for me, and I still had bad days and things like that, but it really made me realise where my mind had gone and that I could find some pieces, moments of joy, in each day, and also that would actually help my health because it would help my adrenals and my nervous system." (ME/CFS + fibromyalgia, recovered after 7 years)

> “I started doing a lot of work on catching my thoughts and really paying attention to what my thoughts were, especially if they were negative, to then really reframe them and give myself positive thoughts.” (Long COVID, recovered after 3 years)

These descriptions show how participants brought self-awareness to their thought patterns. What is remarkable in the first quote is the power that the participant attributes to this awakening of a new awareness or sensibility, which we can see loosens her view of her body. Such an illustration positions mindfulness as a way to be more interconnected in the world, as a way to feel into the world rather retreat into a mental or individualising refrain, as the term might suggest. When one tracks mindfulness in participants’ references to self-compassion and openness, the practice of being mindful is clearly associated with self-perception and self-relating, in a milieu of relationships with others.

In moving from a fast-paced mode of living to a slower and more attentive way of being, the participant above describes taking a step back from the daily grind to observe what occurs within relationships, in the detail that we miss by virtue of our habits. This more meditative mindset allows the participant to gain a new appreciation of their own sense of agency and existence.

> “We can, in the moment, just be more present. We can be more patient with ourselves. We can be more accepting.” (CFS, recovered after 9 years)
>
> “Things like meditation just really, really helped me … I kept in mind the things that I was getting well for, the motivation behind why I wanted to recover. My niece and nephew were really young. My nephew [had been] born whilst I was in that relapse, and I really wanted to be able to play with them and be with them again … all of those things together just really helped me, and just focusing on the present movement … mindfulness, it really, really saved me, to be honest.” (ME/CFS, recovered after 18 years)
>
> “I felt like I got to this point where some kind of surrender happened. And I know that sounds really cliché, but it’s hard to describe. I fell into this state of peace. There was actually mental peace, even though I still had the same symptoms, and I kind of was almost observing myself. There would be intense flu-like aching … I felt it in my body, but I was kind of watching it and there

> was this internal state of non-resistance or peace, and it really wasn't something I tried to do, although I had been studying about it, but it kind of happened. And interestingly, that went on for a year. So it didn't actually shift the physical symptoms, but I sort of was—it's not like I wanted them to be there. I mean, this whole situation sucked. It was treacherous. It was gruelling, but at that point, somehow I wasn't fighting it." (ME/CFS, recovered after 13 years)

Pursuing what gave her joy, this participant enrolled in a writing course in which she met someone who had recovered from CFS and whose recovery opened the door to her own recovery.

Significant in this example is that the participant describes a shift in her quality of life that she attributes to mindfulness, even though she still experienced symptoms. She describes an overall shift to acceptance as a kind of 'surrender'. Through this new disposition or attitude, she ceases to 'resist' the symptoms that are also her body. While such an embodiment of 'peace' does not resolve symptoms completely, an improvement in the experience of symptoms provides her with evidence of the overall efficacy of mind-body approaches to recovery. Another participant, who recovered from ME/CFS after 31 years, helpfully points out that "most behaviour is unconsciously driven" and that the body provides a way of "accessing the power of the unconscious mind." In this view, mindfulness provides a way to attune to the circuitous nature of the relationship between the body and the mind, in which the body becomes 'mind' after all (the unconscious), whereas the mind is embodied (affected by neurology, for example).

Participants' reflections on their life circumstances and state of mind at the onset of illness often involve a retrospective reinterpretation of their affective or emotional disposition at this time, attributing significance to how they felt and lived in the everyday as a contributing factor in becoming ill. This is usually imagined as a susceptibility to chronic illness and avoids the attribution of self-blame. Such reflections generate buy-in for mind-body approaches because they resonate with the claim that the nervous system and sometimes specifically emotion are contributing factors in bodily symptoms. Participants talk about "burning the candle at both ends," "rushing to work / to your next meeting," leading a full life that involves work, play and exercise. A life full of activity and commitments to others becomes an object of reflection during recovery. Around half of participants (n = 39) discuss anxiety as a factor in becoming ill and/or sustaining illness, whereas 73% (n = 55 people), or nearly 3 in 4 participants, discuss stress as a factor in becoming ill and/or

sustaining illness. The language of stress and anxiety is used to reinterpret how one was living life, and to position mindfulness as an intervention into these nervous system states. Many of these reflections are unprompted but spurred on by the participant having witnessed mindfulness contribute to physiological change.

5.3 Meditation

A capacious view of meditation might include all the practices discussed in this subsection. Interestingly, the semantic analysis performed with the Claude LLM identified 'meditation' in almost all of the interviews—perhaps linked to the preponderance of elements of meditation within brain retraining programmes. Recovery programmes usually involve a meditative practice as a means of shifting brain chemistry and neurological pathways. For instance, visualisation exercises often are an important brain retraining method in this regard.

Where meditation is discussed by participants, some describe how this practice anchors them in playing an active role in their own recovery. In particular, participants share how meditation is situated within a daily schedule involving other practices. A minority of participants draw out the significance of meditation. For example one participant describes the practice as an "absolute game changer." Several participants who have recovered say that they continue to use meditation even though they are on the other side of their illness.

5.4 Nervous system regulation

> "We all have the power to super choose that relaxation response wherever and whenever we want to." (ME/CFS + fibromyalgia, recovered after 15 years)

The language of 'nervous system regulation' describes the aim of a range of practices that allow a person to affect their body's physiology. The majority of participants have made use of tools and techniques designed to improve nervous system regulation. Some of these practices are described in terms of a specific nervous system element, such as the vagal nerve or limbic system. Others are organised around a technique itself, such as breath work, yoga, cold water therapy, using an infrared sauna or using bespoke practices taught by recovery coaches or through programmes privately. Traditional practices of acupuncture and ayurvedic medicine are also understood to help regulate the nervous system. Participants also talk about modifying their behaviour and placing themselves in contexts most likely to induce a calm or happy state. Participants link mindfulness and meditation to an encouragement of the parasympathetic, or 'healing' state. By observing an inner

sense of calm, and sometimes an early modification in symptoms, participants are able to receive instant feedback that their actions are supporting their body.

Many participants talk in particular about bringing a sense of safety to the nervous system, or brain. This theme cuts across all of the nervous system regulation practices talked about in this subsection. One way in which participants describe bringing safety is through affirmations—short, memorable statements that can be repeated in one's mind or out loud, such as 'I am safe'. While not all participants use affirmations, the language of safety and the reference to the feeling of being 'safe' appear in 55% of the interviews (n = 41). The prevalence of references to safety can be explained in part through the influence of the theory that symptoms are neurological in origin, caused by a nervous system seeking to keep the organism safe. Many participants cite the influence of Dr John E. Sarno and Dr Howard Schubiner, who advanced this theory in their work on chronic pain. In relation to the influence of the vagus nerve within the autonomic nervous system, participants cite Dr Stephen Porges' 'polyvagal theory'. These authors are credited with explaining symptoms "in a biological way" (Lyme, recovered after 7 years)—offering plausible 'biological' explanations for symptoms. Participants describe acting on their symptoms through one of two approaches: (1) a bottom-up approach, in which participants provide a biological message to the body in the form of the parasympathetic state, which then affectively alters their brain's interpretation of symptoms, or (2) a top-down approach, in which participants send a subjective message to the subconscious, in the form of mental messaging, that they are safe, which then alters the symptomatology of the body.

> "You can't heal until your nervous system comes into that kind of the parasympathetic nervous system [state], until that heal and rest and digest state is dominant. We can't heal. It's just physiologically not possible to be in a healing state and racing around at a hundred miles an hour." (Long COVID, recovered after 3 years).
>
> "I started to work on my nervous system again in a different way. We can't brain retrain grief, but we can do things to support our nervous systems as we go through it. And so as I started to support my nervous system and just do more practises 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)

Many participants spoke about the healing effects of breath work. Viewed holistically, one participant (ME/CFS and long COVID, recovered after 20 years) describes breath work as not only a practice that regulates one's nervous system (reduces stress) and reduces inflammation and pain but also one that generates a sense of learning and connection: "It's not on the outside you find healing; it's on the inside, because we all have this ANS [autonomic nervous system]." Participants' references to safety in the context of recovery practices designed to regulate the nervous systems are a good illustration of how participants attribute a subjective value and meaning to their ability to sense their body. This reflects a holistic attitude towards healing.

Several participants single out the affect of fear as a driver of a complex neurobiology:

> "That's one of the really common themes for people who get better is that they realise that the fear is fuel for the pain and the fatigue." (Lyme, recovered after 7 years)

For these participants, "unravelling my own fear response" is supported by nervous system techniques that help create movement in the sedimented emotional and psychological behaviours linked to fear as a 'root cause'. One participant states: "I was in constant fear—fight or flight" (CFS, recovered after 4 years). Several participants talk about their intentional pursuit and embrace of joy as a means of shifting their body's autonomic register. Others describe unravelling the 'fear response' in the context of their symptoms, because this response may not actually register as the feeling or affect of fear. It is through an introspective conversation with oneself that a new ability to think about the presence of fear in one's life emerges. The data suggest that participants associate the more qualitative, subjective valence of fear within the matrix of a person's biographical, emotional life with non-recovery.

For one participant, using devices and other means of gaining impartial data on one's bodily activity helps remove the element of fear from calculating one's capacity for activity on a daily basis.

> “I don’t have that fear of doing anything because they tell me when I’m doing too much and when to rest.” (Long COVID + POTS, 2 years, recovery ongoing)

The theme of self-determination also appears in this example, as the participant explains that information yielded from various devices or techniques is “helping me make decisions rather than controlling what I do.” Participants place a big emphasis on the type of information that enables them to make decisions about their own bodies and recovery.

As described previously (5.2 Mindfulness), participants’ accounts offer examples of working on their frame of mind as a way of altering the physiological habits of their nervous system. Catching one’s thoughts is a poignant description of the self-reflexive activity of modifying one’s internal narrative via an intentional reframing. Such activities are reminiscent of the kind taught by CBT as a form of mind-body work to which she attributes the regaining of her health. She works on her thoughts alongside other practices, including turning her attention to her body to interpret what her body is ‘thinking’ by asking, “What are those messages that my body is sending me?” In retrospect, she believes that her illness was a type of “shutdown” that occurred after a long period of chronic stress. As is typical of people with CFS specifically, she describes herself as being unable to “push any harder,” forced to find another way to think about illness and recovery. This view legitimises a kind of revisioning of the self and of the value attributed to self-care. Now working to support people through their own recoveries, she notes:

> “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)

In other examples, participants link the use of movement to a rehabilitation of the nervous system:

> “Exercise is a form of stress. So if we can build up our tolerance to stress in a healthy way that our nervous system understands, we can then gradually kind of increase what we can tolerate.” (ME/CFS, recovered after 8 years)

Here, we can note how participants situate nervous system practices within an ecology of practices that includes the articulation of a holistic mind-body approach. Within this ecology, the expression of a value system is given as much importance as the description of specific 'tools and techniques' of recovery.

5.5 Somatic introspection (feeling, sensation and emotion)

> "I'm always listening to my body." (Sjögren's Syndrome + chronic fatigue, 3 years, recovery ongoing)
>
> "I realised that I had to work a little bit more with my body and my feelings. *What do I feel in my body? And do I have pain somewhere?*" (ME, recovered after 6 years)
>
> "For so many of us, there's this disconnect between the mind and the body." (ME/CFS, recovered after 15 years)
>
> "I couldn't access how I felt." (ME/CFS + POTS + fibromyalgia, recovered after 8 years)

It is important to talk about somatic introspection separately from other themes to avow emotion and the body in their own terms, rather than through the lens of neurology or psychology. Many participants refer to the idea that the body knows how to heal. For example, one participant says: "I was able to put my body in a state where it could do its own recovery" (CFS, recovered after 11 years). This nexus of knowledge, sentiment and practice foregrounds the somatic response to the pathophysiology of CFS and related illnesses. In this view of the body and of recovery, emotion has a role. It might also be the case that the cultural representation of emotion is part of the reason for what many participants describe as their 'resistance' to mind-body explanations of symptoms. For example, one participant recalls: "I think initially there was some resistance around looking at emotions and what emotions we have that could be linked to the chronic symptoms that we have. I was quite resistant to it" (POTS + small fibre neuropathy, recovered after 3 years).

A range of descriptions involving emotional and bodily knowledge can be looked at through the lens of somatic introspection. Introspection is a practice of inward attention that requires the prioritisation of a person's experience of themselves and their body. Somatic introspection follows the idea that the body has its own language

that one can tune into through different techniques and often with the support and guidance of a non-medical practitioner. Introspection thus also takes the form or expression. In several accounts, there is a close relation between the expressivity of the body (sensation) and mindset practices. This is particularly apparent in what are now termed ‘somatic tracking meditations’:

> “So I would lie in bed when I couldn’t move out of bed, and I would get these incredible sensations of almost being seasick … I suppose a bit like vertigo, but I was lying flat. And actually, I learned just to do mindfulness. I did a lot of meditation. That was a really important part of my recovery … And so I started to notice the symptoms, whatever they were, whether it was the fatigue or the pain or this incredible sickness, seasickness feeling, I just saw them as these incredible experiences, sensations. And when I started to see them mindfully, which in psychology—I didn’t know mindfulness in those days. We used to call it ‘awareness’ in psychology—just becoming aware of things, becoming conscious when I distanced myself from the symptoms and just literally watched them doing what they’re doing … then it took the fear away, and I noticed them just as sensations, and *I’m just going to let all these chemicals do whatever they’re doing, and I’m just going to lie here until it passes*.” (ME/CFS, recovered after 2 years)

These meditations are interesting because they allow the subject of symptoms to experience being symptomatic in a state in which the person is directed to think of their symptoms as expressive rather than as part of a disease process. As the participant quoted above illustrates, the claim here is that such a practice invites one to experience sensation in their body while also disarming the brain or nervous system from its habitual, perceptual mode of being in a threat response—we might say, to nudge the body towards not being afraid of feeling. Experiencing different sensations in the body, such as heaviness, burning or numbness, lets the person know that their body is capable of producing sensation, that there is no need to fear the sensation, and that what have become habitually chronic symptoms such as penetrating fatigue that is also felt as a sensation can be disrupted, even if only momentarily. While this is perhaps the report’s most tendentious challenge to the status quo representation of CFS in UK health policy, it chimes directly with the findings of a recent analysis of 14 interviews (Bakken, Mengshoel, Synnes and Strand 2023). Narrative analysis found that the newformed narrative understanding of recovery, formed through access to mind-body resources and interventions, had two key principles: (1) the idea that ‘symptoms never accurately reflect the nature of

the underlying pathophysiology' and (2) 'it is possible for a person to intentionally influence the shaping of symptoms' (11).

A further reason to discuss the body and emotion on their own terms is the emphasis many participants who have fully recovered from ME/CFS and other illnesses give to the idea of a disconnection between mind and body—"I was disconnected from my body" (POTS, recovered after 9 years). One participant recounts how she "really tried to live a normal life" but:

> "Over the years, my condition became worse and worse, and I got more symptoms and more symptoms. But despite all those symptoms, I was able to work, and I really don't know how this was possible. I think I was totally on autopilot, that was here in my head. And what was going down here [in my body], I didn't want to feel it. Just my body had to work and to function, and if it didn't then I was in a fight with my body." (ME/CFS, recovered after 15 years)

For another, the idea of processing emotion was linked to her mental representation of her body:

> "I call my work 'coming home to the body' because it's about coming home to the felt sense of being in our body. Now when we've got physical symptoms, the body is not a nice place to be, so we learn to avoid and suppress and distract, and we can actually develop quite a lot of fear around our symptoms. When we work somatically with that, we can we can learn … how to process emotion." (ME/CFS + POTS + fibromyalgia, recovered after 8 years)

Consequently, certain practices have been designed to foster a 'reconnection' of mind and body, and these are usually informed by ideas about how to cultivate ways of listening to the body and allowing the body to feel and express emotion. Interestingly, emotion sits across mind and body, requiring input from cognition, subjectivity, culture or consciousness (mind) and affect, feeling and sensation (body). This subsection discusses how participants depict the body as well as participants' descriptions of their embodied experience throughout their recovery journey.

In many contemporary cultures, and in the context of medicalisation, we are encouraged to think of our bodies as passive and as sources of information. In the digital recovery community, it does not take long before you come across the use of medical tracking devices. While they may be used differently by different individuals,

these devices are marketed with the promise that users can bypass introspection, a practice that takes time and discipline. The biomechanical project of ‘curing CFS’ looks for a pharmacological resolution that will bring the body back in line with our cultural expectations for health, including the ability to work and have a family (which are moral and value-laden expressions of social belonging). Wellness culture offers a contrasting fantasy of nurturance and ‘detoxification’ that often treats the body as passive and available for nudging and hacking. Participants’ accounts of gaining insights into themselves through learning to listen to their bodies should give us pause for thought in relation to these fashions and technologies that promise to help users bypass introspection.

> “I can see all the times that my body tried to whisper and I didn’t hear, and they say, ‘Listen to your body when it whispers so you don’t have to hear it when it screams.’ And that’s where I feel I’ve got to—a place where my body has to just say, *Stop now*.” (Long COVID + ME/CFS, 3 years, recovery ongoing)
>
> “I was incredibly depressed because my life as I knew it was over, I was living this kind of half-life and everything was terrible. And yes, I was extremely anxious because I didn’t know what life was going to be like, and I was worried that this was what things were going to be like forever. And I think we talked about trauma earlier—[I was] severely traumatised about partly the length of the illness. And living every day I think with chronic illness is traumatising … As I started to see physical improvement, it was almost like the mental side of it became so much more obvious.” (Long COVID, recovered after 3 years)

Some participants describe having recognised a paradigm that centres on the difference between authentic and inauthentic emotion. This paradigm was helpful because it supported an introspective exploration of how to intuit how one feels, how to recognise underlying issues and opportunities for renewal. One participant who works as a practitioner believes “the symptom state” reflects the “emotional brain’s” way of trying to get our “thinking brain’s” attention, playing a role in CFS, irritable bowel syndrome, fibromyalgia, functional neurological disorder (FND), anxiety states, depression and long COVID:

> “Our emotional mind is going, *No, I’m trying to get your attention to alert you that you need to say ‘no’ to that or ‘yes’ to this*, or it’s actually trying to guide us to create a life that best meets our needs. And it will keep doing it until we understand. So, the way out of this is to learn to listen to those authentic emotions and learn to respond to those appropriately, because when we do, our emotional brain doesn’t need to send symptoms.” (CFS + fibromyalgia, recovered after 15 years)

Some participants are reimagining the body as a series of intersecting systems, knowledges or indeed bodies—as in the idea of ‘the body multiple’ (Mol 2002), according to which the body is produced multiply and therefore exists as a multiplicity thanks to multiple practices. This way of imagining the body as the site of recovery offers a different point of emphasis from the examples of mindfulness discussed above, without contradicting those ideas.

Nearly every participant talks about their body at some point. For many participants, the illness onset is defined by the body reaching its limits. A smaller number describe the onset of symptoms as the body saying ‘stop’ or ‘that’s enough’. Somatic, introspective methods seek to understand what contributed to those limits. We can understand the ‘agency’ of the body as the sense in which the body acts, knows and does things. Some references to the ‘healing state’ express the idea that ‘my body knows how to heal’ (n = 6). Principles such as relinquishing control and being open to the unexpected, ‘trusting the process’ rather than anticipating outcomes, invite this idea. The idea of trust directly counterposes the fear that participants talk about, whether that is the fear of symptoms, the fear of becoming more ill or getting ill again, the fear of emotion or the fear of general daily living. For the participant cited above, who draws on her experience of having worked with more than a thousand people affected by symptoms, what might be termed gut feelings—or what she terms the “emotional brain”—tells us “what it wants”: the individual to be treated well (kindly, thoughtfully, with caring and compassion); to be able to set boundaries that are upheld; to have fun; to voice how they feel. Without cultivating ways to listen to the body, to allow the body to express itself, one cannot intuit how these criteria might be borne out in daily life.

Several participants describe being cut off from emotion as how they feel prior to recovering. These participants believe that the suppression of emotion was a contributing factor to symptoms:

> “I was scared to feel emotions.” (Long COVID + ME/CFS, recovered after 2 years)
>
> “As soon as my body released the pain, the emotional pain, then my physical pain just went … I understand my patterns now. I was very good at repressing my emotions.” (Autoimmune disease, recovered after 17 years)

In participants’ narratives, the themes of emotional expression and integrating different experiences or aspects of identity are connected. In relation to emotional expression, techniques discussed include writing techniques, tension release exercises, hypnotherapy, memory reprocessing and the use of substances that induce mind- and body-altering states.

One participant, for example, talked about ayahuasca—a psychoactive Amazonian plant brew (Ruffell, Crosland-Wood, Palmer, et al., 2023)—as “bringing down the walls between the parts of ourselves that have become fractured.” Another talked about taking a calculated risk by using Kambo (‘frog medicine’) and experiencing the benefits of the detoxification it triggers: afterwards her symptoms were gone. Many of the techniques that are used for emotional processing are drawn from the trauma world and the idea that bodies and subjects can hold onto emotions and emotional pain and whose suffering can be alleviated by allowing them to be processed. Relatedly, participants talk about using visualisation and visualisation meditations, which require the person to generate a mental image with an affective investment to loosen, lift, or transform the person’s current affective state. These latter approaches are frequently found in the context of ‘brain retraining’, a practice that builds on the theory of neuroplasticity to encourage the deliberate cultivation of new patterns of thinking, feeling and responding to symptoms.

In many recovery narratives, somatic introspection was pivotal to a participant’s recovery.

5.6 Brain retraining

> “It’s helpful to be guided where you’re just kind of tracking sensations in your body. So it’s like the fatigue might end up feeling like heaviness through your whole body or say, I would have a lot of burning in my arm, so I would bring my mind into that, but you’re getting these messages of safety. *I’m safe and okay, there’s actually nothing wrong with my body.* So you’re kind of retraining

your brain. And I would do that every day. I would actually do it every night as well. And I feel like it broke the insomnia habit. And I say habit because that's also kind of a subconscious learned behaviour that the bed becomes associated with anxiety. So I would do the somatic tracking and usually a few different meditations every day … At this point, I would just walk a little more and I would notice the symptoms. So as I'm doing it, the symptoms are rising. I'm getting that malaise, and I would just be like, reiterate, *No, I'm okay. I got this. I know what's going on.* And that's how you retrain your brain that you can do these things, which I think a lot of people do anyway, through graded exposure … I would see this coach once a week in the beginning, then every other week, and just started really adding on activities to my life, including foods. I started eating more things that I wanted. And at first, you do have a reaction because your brain thinks, *That's not good for you.* But then within usually a few times, I could just eat it okay. It's crazy. I know. It does sort of seem wild, and I think that there has to be a certain pacing and timing with this … [Then] I started bringing in self-compassion. When I would get symptoms, I would just ask, *How am I feeling emotionally?* Because with this work, you want to bring it back to the emotions because we are so focused on the physical symptoms, but you really want to tend to the emotions which are driving the state of the nervous system. So it's like, *How am I feeling emotionally?* And I would acknowledge, *Well, I'm scared, I'm really scared, I'm really frustrated.* And then I would just kind of be compassionate with myself, and I still am to this day. That's really hard. Just talk to myself. *I'm so sorry. What do you want or need right now?* And instead of just pushing myself, I would challenge myself, but if I needed to back down, I would. And sometimes take a break and just kind of tune in to *What do you want or need?* It just has gotten to be … a much more kind of personal, attentive way of dealing with yourself. I mean, it sounds funny to be talking to yourself, but I think we all do anyway. So it's just doing it in a much more compassionate way, where I used to beat myself up like you had said, for not recovering. I was like, *I'm failing. What's wrong with me?* And I mean that, Dr. Schubiner and others will explain that self-criticism actually does activate the danger alarm signal in the brain and the nervous system, so it actually can feed into symptoms. And so yeah, just being a lot more compassionate with myself, like *This is really hard, but we can do hard things and we'll pick it back up when it's time.*" (ME/CFS, recovered after 13 years)

The description above represents the capacious interpretation of brain retraining shared by many participants. Of all the mindset-based recovery practices, brain retraining attracts the most excitement from participants. In the above excerpt, brain retraining works across the nervous system, one's ability to feel, express emotion, and communicate, imagine, anticipate and show tenderness and compassion. The term 'brain retraining' represents various approaches led by a number of proponents of neuroplastic tools and techniques. John Sarno developed a psychosomatic or mind-body approach to pain in the American public eye, linking the expression of underlying emotions to physical symptoms and representing an alternative to the biomedical view of pain. Howard Schubiner, who builds on Sarno's work, is also a key influence in bringing a mind-body view of chronic pain to a broad audience. The above example illustrates common practices among participants, including interrupting symptoms with new thoughts and showing self-compassion, both of which require adopting a new understanding of oneself.

As in the above example, the capacious representation of brain retraining draws together multiple forms of discourse, including those of the nervous system, subjective experience and emotion.

> "So my life expanded for sure with the brain training, but I kind of got to a point where I think the fear was so strong that I couldn't quite get over that hurdle of doing more. So at that point, I found Mickel Therapy, which—I knew a couple of people [who] had done [it] before … Doing that almost just gave me the permission, just something flipped in me with that. And within three weeks of that, I walked down the stairs for the first time in two and a half years. And very quickly I was using the brain training techniques the whole time. And through that mental therapy I learned about, I really discovered my sense of self, my authentic self, [and I] started to understand about emotions and the effect that they have on the nervous system and how symptoms are acting as messages around emotions that are being ignored and suppressed." (ME/CFS, recovered after 18 years)

Many participants (n = 32) speak about having done brain retraining at some point in their recovery. Participants contextualise this by describing the particular programmes they did, books they read, recovery experts whose videos they watched and techniques they adopted. Techniques include the somatic tracking meditations described in the previous section, as well as visualisations, affirmations, the creation of new habits and the activation of 'replacement beliefs' around symptoms. For

several participants, changing reactions to symptoms was a core element of brain retraining.

> "That was a big one for me. It was realising that if nothing else, I could change my response to symptoms." (Long COVID + ME/CFS, recovered after 1-2 years)
>
> "The only way to convince your brain that you're not in danger is to not respond to the symptoms." (Long COVID, recovered after 3 years)
>
> "Brain retraining is diving into recognising the patterns of behaviours as they're happening, recognising and catching your symptoms as they come up, and reframing that in your mind." (ME/CFS, Lyme + MCAS + POTS + fibromyalgia, recovered after 15 years)

Brain retraining refers to bodily and mental practices designed to interrupt the physiological chain of events that produces the symptom. They often use the subject's mind to access the body. For example, when becoming symptomatic, one participant recalls saying to themselves, "I'm in a setback, but it's okay—my body will recover" (CFS, recovered after 9 years).

In the example below, the participant is speaking about a technique that uses 'tapping' (with the fingers on the body's traditional Chinese acupuncture) alongside other modalities—FasterEFT™ (Faster emotional freedom technique), described on the creator's website as a method of rewiring the brain (https://robertgene.com/). The excerpt shows that while the participant's first attempt with EFT "did not make much difference," using a differently packaged version of EFT, at a different point in time, had a very different outcome. Unlike EFT alone, FasterEFT taught the participant that the mind was playing a role in symptoms, and this message was associated with the purpose and intention of the practice. Additionally, FasterEFT was guided by a friend rather than "one of the psychologists":

> "I kept thinking, *There's something still missing because I can use my brain again a little bit more, but I'm still so ill.* I was struggling every day. I was out of bed after 11 years, but I was still really struggling every day with pain, with insomnia, with all the other symptoms that I had. So what I did eventually was, one of the psychologists I went to, she told me about EFT, emotional freedom technique, when I was very, very depressed. And when I was in that

suicidal state, she said, ‘Try this.’ And I knew a little bit about it because some friends of mine were doing it. So I gave it a go, and I just found it so difficult. It was a lot to remember and a lot to do, and I didn’t actually notice much difference. So I just kind of put it aside, but I understood the concept of it because by this time, I’m really looking a lot at my mind, how my mind’s doing this, and believing that it was my mind that was doing it. And then a few years later, I was telling a friend of mine about the EFT. She was interested, but I said to her, ‘I know that there’s been a lot of progress since then. There’s a lot of other modalities around that are similar.’ And [I] said, ‘Go online and have a look, see what you can find.’ And she found this process called FasterEFT™. She said, ‘This sounds really interesting. He’s talking about the mind and how the mind can heal and how your mind’s causing all these problems.’ And so she went along to the training, and she came back and she said, ‘Can I practise on you?’ I said, ‘Absolutely.’ And at the time, I had to have my knee replaced. My right knee was bone on bone. My surgeon’s been telling me for about nine years, ‘You’ve got to go and have that knee replaced.’ And I finally decided I needed to have it done because I was limping around everywhere worse than when I was sick. When I was really in that crippling pain, I was walking around with walking sticks and spending time in recliner chairs, but now I’m limping everywhere and I don’t want to do that anymore. So she’s using this process on me, and suddenly all my pain’s gone—all my pain of 17 years [was] completely gone.” (Autoimmune disease, recovered after 17 years)

It is important to note that while brain retraining has become a commodifiable object of knowledge, the interview data provide accounts of brain retraining techniques that are derived from many sources, not necessarily a practitioner or trademarked protocol.

“And the minute I opened the door, my body just went into this full-blown terror. And then the ‘reptile’, as I call it in the book, just shut me down. And my legs went and I was on the floor … That was such a pivotal moment, because I know at that moment … (just because I taught psychology; I taught about conditioned responses; I taught Pavlov’s dogs; I taught about panic attacks and how the brain is trying to protect you) … I lay on my floor and I just said, *Do you know, brain? I don’t need protecting. I don’t need protecting.* … So I had to retrain the brain to focus on the right stuff … And I just said, *Do you*

> *know I don't need [you]? You are obsessed with all the times I've had a bad experience.* And I just recited all the times of my life—I have spent years going outside. I've been to school every day. I've walked on the roads, I've walked on the hills, I've been on buses, I've been on trains. I've done this, I've done that. And I just spent maybe 10, 15 minutes just talking … 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.* And then I shut the front door, and I did my little celebratory like, *Yes*, because I've beaten the protective brain … And then after I'd celebrated, then I did another little step and another little step and I just said, *See, I don't need you. I do not need you. I am safe.* And actually, that's what I did for every single thing. So where steps were hard, I just climbed one stair, one step of a staircase, and then I said, *See, I can do it.* … Just do a tiny thing like open the front door and shut it again, but celebrate it. Really celebrate having faced that little thing and overcome it." (CFS, recovered after 2 years)

Another participant who also intentionally interrupted their symptom-association thought patterns, such as 'catastrophising' and 'chastising myself', describes an incremental process of "build[ing] a window of tolerance of being with discomfort, being with uncomfortable sensations" (CFS, recovered after 9 years). The language of working out what 'I' need and what 'my body' needs are both used in this context. Participants often described telling oneself that one will be 'okay', offering a message of reassurance, at the time of experiencing a 'symptom flare' or a 'setback'. Examples are given of this message being directed to the brain or the body or the mind. Brain retraining is a practice of neuroplasticity that assumes the 'rewiring' of the brain can occur in any number of ways but culturally, is advanced as specific sets of techniques. Brain retraining shares some ideas with nervous system regulation, such as the idea that the brain is trying to 'keep us safe'. The approaches described here attribute power and agency to conscious and subconscious thoughts.

Techniques are also discussed in terms of their limitations. For example, brain retraining is sometimes delimited in relation to the emotional and subjective side of the human experience. In the below excerpt, neuroplasticity is viewed as a powerful augmentation of new neural capacities but also not a panacea to the emotional and psychological baggage of a traumatic life that sensitises the nervous system or

creates the vulnerability or susceptibility that is viewed as contributing to CFS and related chronic illnesses.

> "We also have traumas stuck inside of us that we have to deal with, and those are big stressors that we also have to take care of. So it's not enough maybe just to do the brain retraining. We also have to work on what happened before we got sick." (ME, recovered after 6 years)
>
> "[For] some people, just the cognitive piece is enough [for] getting out of the fear-pain cycle. But for me, I needed to do the emotional healing as well. It was a huge part." (POTS, 9 years, recovery ongoing)

Some participants note that, on a practical level, brain retraining was something they could start while severely debilitated.

> "I read Dr. Schubiner's book. I was doing emotional work. I did a lot of brain retraining exposure work, because at that point, I was barely moving. I was isolated to my basement essentially. Didn't move, didn't walk, didn't use my arms. Even when I went on my last holiday, I used a wheelchair. So there was a lot of work to be done." (Fibromyalgia, recovered after 4 years)

5.7 Discussion

This section of the report has introduced the idea that the recovery mindset is sustained through a range of mind-body practices. This study groups together these accounts of 'mind-body recoveries' in reflection of the fact that, to a large extent, participants associate the adoption of a mind-body theory of illness with a wholesale change in how they think about themselves, illness and recovery. While not everyone represented in the study uses or prefers to use the language of 'mind-body medicine / recoveries / illness', this report views 'mind-body' as the most straightforward and accessible umbrella term to encompass the common ground shared by the transformative tools, techniques, theories and concepts that participants talk about.

In their interview, one participant observes: "We're not ill in the traditional sense of the word." This idea is key to the recovery mindset, giving participants an alternative to the illness belief that numerous physiological abnormalities underlie symptoms and cannot be fixed. Mind-body approaches share the belief that whatever is wrong with the bodies of people affected by CFS and related chronic illnesses, it is vital to believe that such changes are not permanent. The concept of 'dysregulation' both

avows that something is wrong and suggests that something can be fixed. In recovery narratives, this new belief is co-emergent with new avenues for healing. Within mind-body practices, imagining a future beyond being ill is an important motif. New beliefs enabled participants to put themselves at the centre of their experience of illness, giving them agency and pathways to action.

Mind-body theories, including nervous system, neuroplastic and somatic theories that pay special attention to the psyche, affect and emotion, have made a life-changing difference to the vast majority of participants whose lives were radically reduced by debilitating symptoms. Participants initially avoided using these techniques due to scepticism about their underlying premise, efficacy and cost, and the evidence of medical research. These accounts draw into question the roles of doctors, policymakers and patient support and advocacy groups in relation to public attitudes and values towards the non-medical routes to recovery active in the CFS recovery community. The report notes that not one participant describes their exposure to mind-body, nervous system or neuroplastic theories as invalidating. On the contrary, these forms of knowledge provided recognition of participants' experiences of illness. The representation of science is cited as a big influence in participants' decisions to try mind-body practices. The availability of 'free' tools and techniques on the Internet creates more accessibility around these practices, although the experiences represented in the recovery interviews show that 83% (n = 62) of participants were guided by a non-medical practitioner.

Over the course of interviews conducted since 2020, Raelan has become a proponent of brain retaining, and her recovery programme *BR101,* developed in 2025, reflects this focus. The efficacy of brain retraining is reinforced by the presence of recovery narratives across cultural contexts, the communication of scientific explanations by individuals with first-hand experience, and the resonance of these ideas within the recovery community.

Section 6. Recovery mindset: Hope-belief and legitimate optimism

> "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)
>
> "I'm just so grateful to be here, and I'm so happy that I can share my story with you all." (CFS + long COVID + POTS, recovered after 12 years)
>
> "I think meeting yourself where you are and taking little baby steps and planting that seed of hope in your brain can be just the most powerful first step." (Long Covid, recovered after 3 years)
>
> "I believe with all my heart that I'm going to recover." (Long COVID + CFS, 3 years, recovery ongoing)

6.1 Introduction

The possibility of recovery is first encountered in stories told by others. Belief in that possibility—or hope for recovery—is then converted into a more concrete belief in one's own recovery. This belief incorporates hope into a deeper commitment and intention. Participants in this study believed in the possibility of recovery. They locate this configuration of hope and belief within their recovery practices and within the shifts in mindset that become turning points in recovery. The Raelan Agle YouTube channel cultivates this belief and provides a place for hope and legitimate optimism. More than a feeling, optimism is an organised, guiding force, encompassing and shaping people's illness and recovery experiences. Optimism might not feel like 'hope' or indeed 'belief' all of the time or for all people. This study uses the term 'legitimate optimism' to describe the mindset of recovery that is cultivated in the emergent online CFS recovery culture. Optimism gives structure to the uplifting content shared to Raelan's channel and the thematic arc of the recovery interview,

and, according to participants' accounts, hope for recovery is most directly communicated through recovery stories.

Participants' descriptions of the discovery of recovery and their subsequent belief in recovery provide compelling grounds for framing the belief in recovery as a decision. Belief does not visit us from the outside, even if it is experienced as such. Belief can only be established within—by a person themselves. By framing belief as a decision, we can acknowledge the deep agency that is required of the self by the body. This agency configures belief within an acting, self-directed subject. The result is a recovery mindset.

Not every participant expressly uses the terms 'hope' and 'belief' in their interview. On the face of it, 60% of participants (n = 45) refer to hope and almost 4 out of 5 of those participants (n = 35) also refer to belief—although one could claim that belief in recovery assumes hope. One believes in a hopeful outcome. The use of these terms is not exhaustive but indicative of the importance of the sentiment of hope to recovery.

According to the evidence of these interviews, recovery is not a spontaneous phenomenon. Recoveries involve narrations of belief, knowledge and intention. Equally, the belief in recovery beds in through the successive and accumulated successes of recovery practices. If belief in recovery is a condition of possibility for recovery, and if hope makes possible belief, hope is a vital resource. Hope is free and transformative, but it is also not available to everyone all of the time—for both 'external' (political, social and cultural) and 'internal' (subjective, biographical and personal) reasons. This section discusses in more detail the representation of hope and belief in the recovery narrative according to three topics: how belief is located in recovery narratives; how belief is imagined to originate in the evidence of the experience of others; and how belief is 'practised' and sustains a recovery mindset.

6.2 How belief is located in recovery narratives

"Having a positive mindset and believing in recovery is what I think ultimately pulled me out of it." (CFS + POTS, recovered after 1 year)

"When I had these limiting beliefs, that there was a possibility I would never get better and I wouldn't ever get out of this. I was in a 'shutdown', and again, it wasn't an opportunity to heal. But when I changed my beliefs and believed, *Oh, maybe I can get better. Maybe there's a way out of this. Maybe I can, instead of taking that road to the left, that is to nowhere, maybe if I mentally*

take that road to the right, and then I can go to more of a place of healing and I can just see myself. I did so much visualisation too." (Long COVID, recovered after 3 years)

"And my whole attitude just switched, and it was amazing—and 100% down to your [Raelan Agle's] videos and just seeing that recovery is actually possible." (CFS, 3 years, recovery ongoing)

"What I really stand by is hope. It's that you can get better, that you don't have to identify yourself with this situation, [that] you don't have to be a victim and that you can have compassion for yourself and there are people out there that can help you find your way. And one of the big keys to that is self-knowing, because I really feel that people do know. My experience was I knew when something was working for me." (ME/CFS + long COVID, recovered after 5 years)

Believing in recovery is described as a pivotal moment in the recovery narrative. Participants directly express the idea that their belief in recovery was responsible for making recovery possible. This way of speaking about belief in recovery mirrors participants' reflections on their decision to recover, so as to suggest that in recovery narratives, belief and self-determination are relational and co-emergent. This chimes well with the association the study identifies between belief and making a decision, given that among the cohort, decision-making is a key means of exercising self-determination. The term 'limiting beliefs' is a useful description offered by many participants who are reflecting on their own assumption of a medicalised culture of non-recovery. It is in the context of this dominant value system that recovery becomes something to believe in.

The conversion of hope into belief signifies the incorporation of recovery into the participant's lifeworld. Participants' accounts reveal two sides of this conversion. The first is this personal side, where belief requires an individual projection—an investment in an 'image' of oneself and life (an image of existence held in one's psyche). Visualisation is one example of a manifestation of that projection and acts to situate belief in recovery habitually. This is also an example of how recovery is made particular to each person. In other examples, the discovery of a mind-body approach to illness is expressed emphatically, with belief. One of the participants cited above states: "I felt like I finally heard the truth" (ME/CFS, recovered after 13 years).

The second side of this conversion is the social location of belief, as a resource that is mobilised in interactions with others who have recovered and in the social interactions that make up digital recovery culture. Belief in recovery is an act of receptivity to an idea and is a significant form of social interaction in the digital recovery culture. The felt positive valence of the idea of recovery is uniquely an opening to other ideas, cultivating a disposition toward otherness. Participants hence describe themselves as becoming more 'open'. Openness is a key idea that distinguishes the recovery mindset. Being open connotes a frame of mind but also a somatic disposition—a willingness to allow oneself to be affected by the ideas of others. The data show that being 'open to anything' can be a way to enact one's pursuit of the recovery in which they believe.

6.3 How belief is imagined to originate in the evidence of the experience of others

In the interviews, belief is reported to originate in an encounter with someone who has recovered from the same or a closely related illness. The data suggest no subjective difference between listening to a recovery story online such as via a recovery video, reading a recovery story whether online or in print, or encountering someone who narrates their recovery in person. After an initial encounter however, participants do describe subsequently pursuing personal contact with someone who has recovered, whether a professional, a friend of a friend or a contact at a recovery programme.

> "I went to 50 doctors and healers over the course of 13 years. I spent hundreds of thousands of dollars, and the thing that helped me was this woman speaking to me, really caring about me, listening to my story, asking what had happened, what stressors [had] happened, kind of explaining the science. And I recovered through that." (ME/CFS, recovered after 13 years)

While this participant's full recovery took over a year, this encounter was so galvanising that she "actually got up and ran around the block," having not run in 13 years. During the conversation above, the woman who had recovered through 'mind-body work' had said to the participant, "You're not sick," and the participant had thought:

> "She kind of alluded, *You're stressed. You've been through trauma, your system [is] stuck in this pattern, but you can get out of it*. And I believed it. I

believed it a hundred percent. I felt it in all of me, and my body reacted with that burst of energy, at least in that moment." (ME/CFS, recovered after 13 years)

In this excerpt, belief is described as a vital matter co-articulated with a dramatic feat.

6.4 How belief is 'practised' and sustains a recovery mindset

Once participants start to see evidence of their recovery, this emboldens their belief that recovery is possible, and that they themselves will get well. Positive feedback affirms not only the body's capacity to heal but the utility and apparent veracity of mind-body approaches. Participants sometimes link the inconsistency in improvement in symptoms to a wavering belief in recovery, describing setbacks and uncertainties. While it is beyond scope to analyse the relationship between each participant's state of mind or framework for thinking and the success or failures that the participant links to a given practice or mindset, it is possible to see examples of participants' own reflections on how their belief in recovery emerged, was sustained, and at moments wavered.

"That was amazing for helping me to kickstart a recovery, but I still had a lot of doubt that it could work." (POTS + small fibre neuropathy, recovered after 3 years)

"So I had doubts, and sometimes thoughts of fear popped into my head as well. And sometimes then I did the technique that I was supposed to do, but sometimes I could feel scared for a couple of hours and then I thought, *Oh no, I'm messing it up again.* I just wanted to say this because I had the impression when I was watching recovery interviews back when I was sick … [and] it also made me feel insecure from time to time because I had the impression … [that] people [just] found the one thing and they had 100% faith and they did it and it worked. And they were thinking, *Yeah, I'm doing it and it's working.* And I thought, *Whoa, I really have to wait for this feeling to come. I had it during the programme then, [and] now I was just waiting all the time [for the moment] when the faith would overwhelm me*, but now I realise that I'm just … very insecure, doubting—full of doubts all the time. It's just there." (ME/CFS, recovered after 2 years)

Given that participants' recovery journeys occur over many years, sometimes decades, the experience of the feeling of hope is likely to be inconsistent. At the same time, many participants talk about the importance of having hope, of not giving up hope—in some ways, encouraging listeners to find ways to 'hope against hope'. Hope can also be the reward or achievement that comes after big life changes.

> **Raelan:** The role of hope is always a common theme that comes up in these interviews. And throughout that journey, where was your hope level at? Were you aiming for full recovery? Where was your head at with all of that?
>
> **Participant:** That's a really difficult question for me to answer because my personal circumstances were such at the time that I was really dysfunctional, and it was very difficult to have hope when you're kind of on the edge. But once I got back from the edge a bit and took dramatic steps to change my life circumstances, I basically took myself off into therapy and I was pretty determined to recover. (ME/CFS, recovered after 33 years)

In some interviews, hope and belief do not stay tethered to the objective to recover but, through the experience of recovery, transmute to a more general outlook or perspective.

> "I have this optimism that I haven't had in years." (ME/CFS + long COVID, recovered after 20 years)

6.5 Discussion

There is a circuitous relationship between hope for recovery and the story of recovery. To believe in recovery from CFS and related illnesses, people need to know that it is possible. In the telling of a recovery narrative, a number of themes are expressed alongside hope. Belief is connected not only to the hope that makes it possible but to making a decision and re-capacitating oneself in one's lifeworld.

The sharing of recovery stories in the recovery community online is represented as upholding the principles of an inclusive social environment in which the values of care, reciprocity and optimism are paramount. Optimism is a condition of possibility of the recovery mindset, and interviews on the Raelan Agle channel actively construct and invest in hope and the belief that recovery is possible.

Learning about the possibility of recovery through encountering the recovery of someone else suggests that the most important way to learn about recovery is

through exposure to accounts told in first person. This renders stories of recovery that are able to catalyse the recovery of other people as ‘political objects’ whose visibility is a site of activism and control. Recovery stories are a key resource for hope and belief in recovery, and the availability of recovery stories is a key cultural issue. By withholding information about the possibility of recovery from public discourse, people with chronic illnesses will be less likely to encounter the information, communities and practices that people describe as having supported their recovery.

The report notes that learning about recovery is quickly followed by a desire for contact with people who have recovered. Except in rare cases, belief in recovery alone will not lead to the resolution of symptoms. Most people who recover do so with the aid of a non-medical recovery practitioner. Recovery programmes and other forms of non-medical support are distinguished by their practitioners’ belief in recovery. Doctors, policymakers and patient support and advocacy groups could each have a role in supporting the contact people with CFS and related chronic illnesses have with those whose work is associated with positive outcomes. The findings of this report suggest that stakeholders should fairly and meaningfully represent the experience of recovery and consider how to bridge the gap between the private provision of non-medical healthcare and public health.

Section 7. Forms of support: Care, pedagogy and mutual aid

7.1 Introduction

Just as no one recovers from CFS in a cultural vacuum, no one recovers without experiencing some kind of support. The *Recovery* Report has already noted that a remarkable proportion of participants—83% (n = 62)—talk about the help of non-medical practitioners and that almost two thirds of the participants themselves have transitioned into recovery work following their own recoveries. These participants (n = 48) report doing private work in the field of mind-body medicine, mostly as coaches and/or as teachers of specific emotional and/or nervous system techniques. Besides studying psychology, the sample does not suggest that the experience of recovery from CFS and related illnesses leads to one entering formal professional training. The recovery stories that we are hearing about in this study thus foreground a certain model and cultural experience of support—support from someone who has themselves previously recovered; support structured by the norms of the private sector; support judged by reputation. The sensibility of this model is captured well by one participant in particular:

> "I went and did a lot more training. 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. Also, from learning to work with your own body." (ME/CFS, recovered after 15 years)

This excerpt nestles pedagogy side by side with healing. The participant themselves recovered with Mickel Therapy, which they heard about while living in Scotland. After years of trying different things, "all the things that people do and just didn't recover," she "went and did it and recovered." Subsequent to this, she worked as a complimentary therapist and trained in the technique she used to recover. The participant's description of how she works with people to recover connotes an image of lateral learning and the ideas of receptivity and reciprocity. Herself having healed, she learned to help others in their healing, whose experience of healing she ends up learning from. This model epitomises the idea of mutual aid that is represented in the recovery community, in which support is linked to learning, care and reciprocity. This section discusses representations of support in the forms of care, pedagogy and mutual aid.

7.2 Care

> “Actually, something Jason [McTiernan] said to me just in the eye, he was like, ‘Don’t give up. You’re totally going to get out of it. Don’t give up. If you try something that doesn’t work, try something else. Do not give up on yourself. Have faith. I believe that you can recover from this. So I know even if you’re having a bad day today, my heart is with you. I know how you feel. You’re not alone in this—and I know it could feel very, very lonely, but you’re not alone.’” (Long COVID + CFS, 3 years, recovery ongoing)

Participants’ narratives are filled with examples of being taken care of by friends, family members and partners. Often many different kinds of support are involved in a recovery narrative. Attention is often given to those offering private care, rather than care in the home or community. Also of note is how participants’ descriptions often link the provision of support to a belief in recovery. It is common for accounts to blend together various different kinds of support and various recovery practices. For example, one participant who recovered from long COVID after 2 years describes her ‘network’ as involving: meditating with the Calm app; working with a fatigue coach; doing a North American brain retraining recovery programme; seeing a nutritionist; being supported by a friend of a friend who had previously recovered from long COVID; and seeing a psychologist who uses NLP and hypnotherapy.

> “So that was also a huge part of my network, I guess, that I assembled to try and help me get through it. I just wanted to mention as well, when talking about the network again, I just felt very fortunate that all my—I had very supportive friends and family and workplace, and I was given the space and time to recover, and I’m acutely aware that not everyone has that. And yeah, I’m just really eternally grateful to everyone around me who just really kind of helped me through it. And my husband in particular, he was a real rock and he had to deal with a lot as well, and he was just kind of unflinching in his support and his care, so that was a really essential part as well.” (Long COVID, recovered after 2 years)

It is hard to qualify differences in care and the experience of having been supported by those providing care versus navigating illness in the absence of care. In the UK, care refers both to the provision of material support, such as having a roof over one’s head, and emotional support, such as having one’s experience recognised by their peers, colleagues, family members and health professionals. The excerpt above

echoes the report's earlier discussion of the recovery mindset—having a holistic attitude towards different healing modalities; experiencing recovery as a journey with a narrative arc that is anchored by threshold moments and that holds together the representation of different aspects of experience; being attentive to the interplay between different opportunities for healing and their interrelatedness. To this finding, the report adds an emphasis on care. Participants portray their recovery narratives as ones of self-determination and also as stories of coming into relation with themselves and others in multiple new ways, such as through the private support of nutritionists, therapists, coaches and others working in the recovery arena. The language that participants recall non-medical practitioners using is loaded with care and confidence, such as: "we're going to work on this, and we are very familiar with POTS and we're going to get your nervous system back in order" (long COVID + POTS, 3 years, recovery ongoing). This type of care perhaps mitigates the exercise of power in formal medical settings that risk patients experiencing failure as well as success in their experience of 'self-management' (Risør and Lillevoll 2021). Indeed, just such concerns about the moral framing of responsibility are levelled to recovery programmes and more broadly to the very concept of recovery. Discourses of responsibility introduce biopower (Foucault 2004). In the narratives analysed here, the online recovery culture provides access to private and community based care. Further research is required to better understand the relationship between the provision of care and support in the form of lifestyle, mind-body, somatic or neuroplasticity based self-directed intervention.

The representation of the socio-economic conditions of care is also limited. Further study is required to develop a full analysis of the socio-economic factors affecting the care received by people who recover from CFS and related illnesses. In the follow example, we see a glimpse of how support was afforded through a parental provision of socio-economic care:

> "I started meditation, because I'm so lucky that my parents have paid for me to have therapy … So, I live on benefits, and there is no way I'll be able to afford therapy. And my parents kindly paid for that. So I've been seeing her now for two years and I love her and she is like a rock to me in this." (CFS, 3 years, recovery ongoing)

Participants often describe time away from work and receiving care from friends and family during periods of symptom severity. The absence of narrative content regarding unsupportive relationships could also suggest that people without support are less likely to be able to recover. None of the participants offer an account of

balancing full-time work with family responsibilities and getting better. Comments posted to the Raelan Agle channel often point to the difficulty of even thinking about taking steps to recovery without personal support or time away from work. Without further study, one can only speculate that a lack of support, whether financial or personal, is a barrier to recovery. Money is sometimes mentioned in the context of the cost of private treatments, providing one limited indication of the financial means of people who recover or experience measured improvement in their symptoms.

The theme of reassurance is prevalent in accounts of care. The family structure, as well as medical and non-medical practitioners, can provide reassurance. Participants often speak about this reassurance as being meaningful to them and sometimes as motivating or helping to sustain a recovery mindset. For some participants, reassurance came through online interaction with people in the recovery community—people who were strangers.

> "With this illness, there's so much anxiety. Right, the fear of the unknown, and every time I would be symptomatic, every time I was having such a bad day, although every day was bad, but if it was even a worse day, I was crying. I was so uneasy and I was so miserable and it was just, *Why me? Why me? Why am I like this? I should be out playing with my kids. I should be doing this.* And it was so nice to have her because I would reach out to her, I would leave her messages crying. And she would call me right away and we would talk about it, and she would put things back into perspective, you know. And she always got me back on that road of: *Look forward, you are where you are right now, but what can you do right now to just get yourself a little bit better?* She always put me back on track." (CFS, recovered after 5 years)

In this account, a stranger became a 'recovery partner' who helped someone with CFS stay in a positive mindset about her recovery. One of the ways that she did this was through helping her to stay accountable to herself, to her intention to recover. This method of providing support is echoed in recovery programmes' provision of peer support, such as through support calls, seminars, coaches and buddies. Some programmes also include peer support for friends and family members who are supporting loved ones.

7.3 Pedagogy

Learning is a major theme of the recovery narrative arc. At the onset of symptoms, participants do not know what is wrong. Rendering the unintelligible intelligible is necessary and requires self-study, patience, support and resources for learning. It is

no surprise that so many participants—just under half (n = 35)—talk about specific books that influenced their recovery. Some of the descriptions of self-education are humbling, such as when participants describe having dedicated the little energy that they had to reading.

> "And I just kept reading." (ME/CFS + fibromyalgia, recovered after 7 years)
>
> "I realise now when I look back, I was actually doing a lot of brain retraining while I was sick. So I was trying to read what I could about people who were recovering. And that's why I love what you do—because I was doing that back then. Nearly 30 years ago, I was reading little *Reader's Digest* stories about people who'd recovered from illness. So I was already training my brain because I was looking, I was looking for a solution. So now I look back, I realise that I think that's what helped me even back then. So I encourage people to do that, to just keep reading the recovery stories." (Autoimmune disease, recovered after 17 years)

Some participants read books, articles or other media with themes of healing, self-help, the body, nutrition, biochemistry, brain injury, brain retraining and psychology. Lots of participants also describe reading recovery stories, not only listening to them on YouTube. This report has discussed how a recovery mindset is shaped by building an understanding of one's illness and taking up some kind of recovery practice. In some examples, learning new ideas almost immediately converts into a new practice. As one participant who recovered from ME/CFS after 13 years said: "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." In the same breath, they represent the issues of learning, understanding and practicing. All of the activities described by participants must be learned. Even personal qualities—those linked to self-transformation, such as self-compassion—need to be learned. Participants also share that recovery programmes position 'education' as the first step to recovery.

The term pedagogy represents the communication of information according to a theory of learning and teaching. This subsection considers the importance of pedagogy to the recovery narrative. If recovery stories are currently the primary cultural means of communicating the possibility of recovery, how can they be disseminated to communicate the message of recovery to others? This report has previously discussed the importance of encountering an explanation for symptoms in

establishing a change in mindset. Participant after participant reflects on the importance of being offered an account that is believable, that chimes with their own experience.

> "I started reading it, got more angry, stopped reading it. And then the interesting part is, *I'm a therapist, right?* So I know that pain and physical symptoms can be produced by the brain and nervous system. I've learned this in school [at university]. We've talked about this lightly. So I know about these ideas, but I was like, *There's no way that that's what's causing it for me.* And I think a few more months went by and eventually I came around, partly because my friends and my partner were just telling me: 'This is what it is. There's nothing else going on here. This is more of a mind-body issue that you're facing.'" (Fibromyalgia, recovered after 4 years)

In the above example, the participant describes a period of self-denial—a theme recounted across several interviews. Interestingly, in this and other examples, the participant represents themselves as becoming truly aware of their illness only after the intervention of other people. In these examples, it is only as a matter of collective concern, shared among the participant and their intimate social circle, that the message of 'mind-body' illness hits home. In this way, the ideas about which the participant was reading in a book are remediated by their interpersonal, social relationships. This remediation points to the role of the social and cultural context in the interpretation of information, showing how the circulation of information via media representation has become a particularly avenue for health communication.

Looked at together, the interview narratives provide an opportunity to witness the recovery community and digital recovery culture as mediating infrastructures that frame the experience of recovery from CFS and related chronic illnesses. Much like the analogue media that preceded them, social media work as mediating infrastructures through their integration into everyday life. Personal influences and the influences of strangers online combine.

The broader cultural context, in which the platforming of recovery narratives on social media intervenes, is negative about recovery. At the time of writing, the search term 'chronic fatigue syndrome' does not yield a single entry on recovery, or CFS from the point of view of recovery, at least for the first 10 pages of Google results (circa 100 results). The same search combined with the added word 'recovery' yields an entirely different set of links, including links to individual stories of recovery. To find recovery online, one must know to look for it. Hence, the interview format used

on the Raelan Agle recovery channel allows for the expanding and sharing of information and understanding at the same time. This form of the interview represents knowledge of recovery as the subject of a personal or biographical enquiry. The fact that the channel, and digital recovery culture more generally, are situated outside institutional knowledge production means that interviews are free to stage an exploration of alternative knowledge without being accountable to an official or professionalised standard. Instead, knowledge otherwise denied or undermined in dominant cultural contexts can be articulated and resulting accounts judged by community standards.

> "I'm going to figure this dang thing out. I cannot be sick for the rest of my life." (Long COVID, recovering after 3 years)
>
> "That was a big change for me, because I was going to people, it's like, *Okay, they've given me this food plan to do these supplements. I'll do the saunas that they tell me to do. I'll do all the things they do. I don't have to read anything. I don't even have to understand what it is I'm doing. I'm just going to do what they tell me*. And that, that mindset change for me was actually to get myself educated." (CFS, recovered after 20 years)

The report's previous finding regarding the self-determination that characterises participants' turn to recovery and the recovery mindset is here re-contextualised according to the vital role of teaching and learning. To get better, one must learn how to do something—usually, many things—differently. For example, one must learn to think differently about illness and symptoms. Self-determination is only made possible by the context in which one finds themselves able to act. In the case of recovery from CFS and related illnesses, one finds themselves in the context of an emergent culture online—a mediating infrastructure of recovery that assumes optimism.

Interview narratives model the idea of pedagogy and reflect the priority given to teaching and learning in digital recovery culture. This report has already noted the frequent use of the term 'science' to imply validity. What is equally valid in terms of movements for social change is the sharing of stories that contradict the status quo—which, in feminist histories, is known as 'consciousness raising'. Raising consciousness is a cultural form of knowledge production that is influential in a range of cultural settings. It is also an important practice for groups working adjacent to and in the interests of transforming the inequities of formal medical culture. The recovery interview is not only a method of telling a story but also a social and cultural device

for generating, collecting and redistributing knowledge that would otherwise remain private or even unspoken. Participants' descriptions of 'doing their own research' mimics this pedagogical structure, where they describe themselves as seeking to develop their own understanding through: Googling symptoms; reading books; reading research articles and reports of medical research; looking for stories of recovery from CFS online, including looking for first-hand accounts on YouTube; doing recovery programmes to learn more about the origins of chronic illness; reading posts and content shared to Facebook groups and other online forums; researching treatments and approaches to recovery; listening to audiobooks on their condition; researching functional medicine and 'alternative medicine'; learning psychology; and watching Raelan's and others' videos. Existing research talks about the importance of 'new resources' (Bakken, Mengshoel, Oddgeir and Strand 2023), sources of information in the media, self-help books and provided by patient advocacy and support groups (Clements, Sharpe, Simkin, et al. 1997; Vogt and Garner 2023) and the general influence of media images and online culture (Linnros, Andreasson, Norlin & Hydén 2026).

Through the lens of media studies, the active involvement of viewers in the programme's discourse might be referred to as 'audience participation'. One further note here: the collective effort of bringing the experience of recovery 'into discourse' does not escape what could be called 'confirmation bias'. Indeed, participants vouch for a plethora of perspectives and recovery narratives that are as singular as they are multiple. At the same time, the socially chaotic nature of recovering from CFS that comes about as an effect of the marginalisation of recovery stories from mainstream accounts fuels a search for consistency. This study contributes to such a search, seeking to make meaning from a heterogenous body of social data and experience and to clarify the ideas, practices and frames of reference that constitute a recovery counter-discourse. However, the intent is not to confirm a single explanation of recovery but to clarify the recurring themes, life experiences and terms of reference through which recovery is understood.

> "And to me, I see you and Miguel [Bautista] and these other YouTubers that are out here doing this. You guys are kind of, you're in the field, you're doing the research on the people that are recovering. You're including our stories into that literature. And I hope that over time, that will continue to ripple out and impact our research that's out there too—again, so this information gets to people sooner." (Long COVID + ME/CFS + POTS, recovered after 2 years)

This quotation comes closest to describing people who are active in the recovery community as practicing a ‘citizen science’. By redefining an illness that affects so many people in such a deep way, this science carries a huge responsibility.

7.4 Mutual aid

The term ‘mutual aid’ could be an appropriate way to characterize the lateral support consistent with aspects of the recovery community. As we have seen, support can begin with telling a story of recovery, with making the possibility of recovery available to others. For this to materialise into a tangible recovery outcome, people need additional support as well. Belief in recovery from CFS is not ideological but material—a belief that is the effect of relations of support. Participants’ accounts situate that belief as a social construct—as made possible by the first-hand accounts of others. If believing in the possibility of recovery requires support and is a defining characteristic of the recovery mindset, the recovery mindset too is one object of mutual aid. The recovery mindset is not freely given but must be actively pursued. The sharing of recovery stories is motivated by and has the effect of producing mutual aid—of helping others, as well as producing representation that might bring about change. The sharing of recovery stories is understood by participants as the giving of support to those who have not yet recovered.

> “She said, ‘I wish you all the best.’ She’s like, ‘Even if I cannot recover, at least I hope you will.’ And yeah, that touched me very, very deep. I met quite a few people that when this illness strips almost everything from you, what is left is pure kindness and pure love. It can be a beautiful thing of connection there.” (CFS, recovered after 4 years)
>
> “Suddenly you’re in a community where everyone’s going through the same thing. You don’t have to discuss it. They just know. 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)
>
> “And one morning, I just thought, *I’m not sure I want to be here if this is what it’s going to be like*. So, I phoned the Samaritans, which is a helpline in the UK for people who are despairing and suicidal, and I just said, ‘I don’t think I want to take my life. I know I don’t want to take my life, but it’s just, it’s not a life I want to live at the moment.’ And I said to them, ‘One of the things I hate is not

being useful, not being a useful member of society.' They said, 'Why don't you volunteer?' So, I did volunteer but not immediately. I said, 'Maybe later.' And I was a Samaritan for 10 years. So that was an amazing experience as well. I spoke to so many people who got these symptoms, you know, and that went on for those 10 years, and it really helped me understand emotions better. It was [an] amazing experience. So, so I had a lot of things happen that helped me understand emotions better." (CFS, recovered after 15 years)

"It's like gratitude goes through the roof when you're fully better, even on path to getting fully better. You're grateful for everything, absolutely everything—for the sunshine, for waking up, [for] feeling good in the morning. Honestly, the first time that I woke up feeling energised in the morning and ready to take on that new day, it was like winning the lotto. It was probably even better than winning the lotto to be totally honest, because there's nothing more important than your health. Absolutely nothing more important than that. And I don't take it for granted anymore … It honestly feels like a totally different life … on the other side of it, it's like I definitely wouldn't be grateful for the suffering that I went through, but I'm super grateful for the growth and all of the experiences that I've had since then. It is worth it. Working on your health and getting better is completely worth it." (ME, recovered after 11 years)

"I just became very passionate about helping others going through the same thing, but I think for me it was more about helping and working with [people], not just, 'Let's focus on your symptoms' … For me, it's that whole picture. 'What's going on?' Because for none of us, when we used to go to the doctor, would they ask you what's going on in your life. 'Tell me what do you do on a day-to-day basis? What are your emotions, thoughts, mental health like?' So it's that whole picture that really, really interests me, and then how to piece that in, into life beyond CFS." (CFS, recovered after 3 years)

"I just want to say one last thing to anybody that's still struggling. I know how difficult it can be, and I really was in that place where I didn't believe I was going to recover. So I would say: *Just trust. Don't give up. Trust life* … It's difficult, but that's what I would recommend is just *you'll find your way and just look, you have the answers*. It is really helpful to watch other people's videos, but we really start to try to replicate someone else's story exactly. Like I did that so many times, and eventually it was like I had to stop watching recovery

> videos almost, and I've gotten what I needed out of them, and then it was like, yeah, *Now it's up to me. I know what I need to do.*" (Long COVID, recovered after 2 years)

In the comments section of Raelan's video posts, people have sometimes commented on the positive bias of interview content. Here is another way to think about that bias. The recovery interview is designed with the intention of sharing people's experiences of recovery. As this study shows, this means not only communicating specific information or anecdotal evidence but inspiring in the audience hope and belief, which this report found to be important to most participants in their recoveries. For hope to be converted into belief, the interview must feel real and credible. The positive bias towards giving is a way of concretising hope and belief as forms of social exchange.

> "I like to work with people in a way that allows them to trust themselves again, because we all lost that trust somewhere along the way. We sought that kind of trust within something else—our medical system, society, et cetera. So we stopped trusting ourselves. But actually, we know what's good for our bodies, because we become so in tune with [them]. We know when we're recovering, we know what nourishes us, what doesn't. So it's allowing people to trust themselves again and to be guided along a path of recovery, but to formulate that themselves." (CFS, recovered after 3 years)

While the concept of mutual aid is not one shared expressly within the recovery community, it signifies a type of non-institutional exchange that is resonant with the types of social and self-relation that many non-medical recovery practitioners describe themselves as helping to instantiate. The idea of trusting oneself is a major theme and complex topic that seems important to the discussion of personality and identity that follows in the next section.

7.5 Discussion

> "It's been incredibly rewarding and I think, I know no one can understand anyone else's experience a hundred percent because everyone's experience of even the same illness is different. But I know what it's like to be so unwell and to be feeling terrible and to sort of lose all hope and to just not know what to do. I think it's really important to me to be offering something that is

> practically useful, that will help people, that will bring them together, bring them into that kind of social space as well, supportive small group environment.” (Long COVID, recovered after 3 years)

Commercial enterprise is entwined with the platform culture of recovery from CFS. In particular, many of those who have spoken publicly about their experience of recovery have gone on to offer support professionally. Commercial interest is a relevant context in which recovery stories are shared on social media—the platforms themselves promote and require this interest for content to work. Private enterprise has grown in lieu of a culture of recovery in public healthcare and much of the material taught in recovery programmes is shared on platforms. However, there is some crossover between the public and private sectors and some participants hope for more—in the UK, this might look like the greater involvement of social prescribing and link workers. Participants who offer professional support describe wanting to help others as rewarding and as offering something meaningful that is in excess of what is being defined as the basis of the exchange. Raelan herself formerly worked as a clinical social worker in medical settings, illustrating the crossover between formal healthcare and public institutional labour, and private work that is linked to social media. Professional, commercial and community-based support are interlinked and made possible by networking and mutual aid. Pedagogy, care and mutual aid are themselves cultural practices that uphold the mediating infrastructure of the recovery community. These elements are not static. There will be moments when mutual aid becomes the mediating infrastructure that holds other elements in place, and there will be contexts in which a commercial element makes the undertaking of mutual aid possible. The consistent thread is the giving and receiving of support.

Section 8. Social illness, identity and the overexerted personality

8.1 Introduction

"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. And so I had all of these external things that, that looked kind of okay, but under the surface internally, there was a lot more that was going on. 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)

"What has been so helpful from this experience is it took away all of these identities that I'd formed that were keeping me stuck, I suppose, or causing suffering in my life. I was eventually left empty. I remember a year into the journey when all of these identities that I had were now gone. It was like, okay, I was a sportsman. I was an active guy. I was doing my studies. I had a girlfriend. Then it was in the middle of this when I had nothing left, I was like, *Who the hell am I?* I remember distinctly one day just thinking to myself, *Who am I now? I don't even recognise myself here. I'm stuck in a house unable to do anything. There's nothing left for me to claim*. But then what happens is, it's the identity forms around the sickness, and that really kept me stuck for a while. It was like, *Okay, well, I'm this guy that's been sick for so long, and this is my identity now.* And then when I got more into the spiritual meditation stuff, there was a lot of talk there about how 'it's all beliefs and identity that's causing all of your suffering.' And then that's what helped me to overcome this as well. It was like I started to look at all the beliefs that I'd formed throughout this period of being sick that were now keeping me stuck and this identity that had formed, then it was a letting go. It was a massive letting go process. It was like, *Okay, I got to let go of that.* I'd let go of my old life. I'd formed this new sickness identity now, and then I had to let go of that, and it was just this

> constant letting go and looking back. That's why this was actually such a beautiful, the way this played out in my life was just like, it's just life just stripped me of all of these escapes and these identities until there was only one way left to go, and it was so liberating, I suppose. So that's why I'm so grateful." (Long COVID, recovered after 2 years)

Given that a substantial number of participants describe themselves as having changed through the experience of recovery, we should question how one's sense of self is involved in the development and/or perpetuation of CFS and related illnesses. The above examples illustrate how the themes of self and identity are represented in the interviews. Self-reflexive reflection about one's identity and sense of self is fairly consistent through the dataset. In view of the limited but indicative biographical data we have about the sample—which shows a bias towards the representation of educated white women and possibly women who identify as bisexual, pansexual, queer or another minoritised sexual orientation—this section brings to the fore an enquiry into what the representation of identity through the themes of personality, emotionality and social connection tell us about recovery from CFS and related illnesses as a social and cultural phenomenon.

The collective reconceptualisation of CFS as a social illness is perhaps most directly represented in participants' reflections on the subject of personality and the self. The study views this reconceptualisation as an enunciation of the illness—a material event, with real people, whose compelling evidence lies not only in the discursive and cultural notion that CFS is a social illness but also in the lived cultural and institutional relation to that concept. We learn from the social movements of the 21st century that this type of enunciation, made from within the context of people's ordinary lives, is precisely that which can lead to cultural change.

In the above example, the participant describes a theory of CFS as "this whole nervous system dysregulation with all of these wild symptoms." Knowledge of the nervous system, derived from the mediatised, neoliberal culture of trauma and self-help that includes neuroscientific ideas, likely informs this assertion. Besides the question of knowledge, such an assertion enunciates people's lived relation to a cultural vernacular of the self. The critical reflexivity of this vernacular draws on a psychologising language of personality, as well as a cultural analysis of the social embeddedness of personality in relation to power. "People-pleasing tendencies, perfectionism, overworking" exist both in the language of personality and as political diagnoses of those who suffer from these problems—why and how. Put another way: not everyone is affected by the stresses and strains of social, professional and family

life in the same way. People's means of processing social pressure are stratified according to gender, race, class, sexuality and other formations of identity.

The *Recovery Report* puts forward the concept of the 'overextended personality' as a lens through which to bring together the participants' observations about the relationship between personality and becoming ill. Following the introduction of this concept, this section turns to speculate on the structure of power that is being described by the overextended personality discourse—identity. This analysis highlights the conceptualisation by participants of CFS as a social illness. All illness is, in some respect, social—our lived experiences of disease are more or less shaped by historical and cultural factors, including access to drugs and healthcare. What the data suggest in relation to this theme is: (a) social factors have a role in how participants recovered or saw measured improvement in their symptoms and (b) a set of factors tallies with a broader epidemiological knowledge of the illness, as well as what different disciplines can tell us about the potential pathophysiology of CFS.

8.2 Overextended personality

> "So, first thing I learned is that I had to stop pushing myself. So, I really would say: *Just really stop pushing yourself*. I was pushing myself when I noticed a little bit of energy. I was basically waiting for energy for so long that I would do everything in one day, that I wanted to do, that I was waiting to do, basically. And that seems to be the pattern for the majority of people as well, is waiting to feel better and then doing too much and then feeling really bad again for so long and being stuck in that pattern. So that's number one for sure. Putting my health and happiness first, that was huge. Instead of putting other people's needs or anything ahead of my own, it's that classic thing of, if you're an aeroplane, you have to put on the oxygen mask on yourself first before you can help someone else. *Stop trying to help everyone. You need to help yourself. You got to get better. When you're better, you're going to be able to help everyone, no problem.* But I was trying to do that, and it was very depleting. I was putting energy in the wrong area." (ME, recovered after 11 years)
>
> "I learned about my needs and how to set boundaries and how to stand up for myself … I couldn't live as I was with the relationship with myself anymore. And that was a huge part of my journey in developing and realising that I needed to be more self-compassionate … the safety that creates in your

nervous system, when you have that gentle, soothing, parenting approach to yourself, rather than hard, harsh and critical. You really need to kind of find that honouring of yourself." (ME/CFS, recovered after 18 years)

"I just had a real realisation about that after being ill, getting better and then thinking, *Actually, I don't want to go back to this way of thinking, this behaviour. It's just not healthy*. And I think perhaps that is some form of stress and anxiety. I'd say I'm definitely a perfectionist. So I think that's got something to do with bringing that on as well. So yeah, that's what I intend to change with moving forward." (Long COVID, recovering after 2 years)

Tendencies in personality emerge as a major theme in participants' reflections on themselves. Participants' reflections share a cogent vocabulary centred on personality tendencies such as perfectionism, people-pleasing, overachieving and overworking. Participants' reflections do not articulate a random set of qualities or an evenly distributed set of personality types. Rather, looked at together, the interview data yield a concentration of terms around one holding high expectations of oneself, participating in goal-oriented behaviour and seeking external validation.

Participants link illness, recovery and personality in over half of the interviews (n = 39). While this figure has been derived through a simple method of denotative identification and counting, its implications are consistent. A more rigorous analysis would yield a higher percentage by taking into consideration a broader, more nuanced and deeply theorised construct of personality, rather than its simple denotation, which is the representation that has been counted here. Personality terms that participants talk about prior to becoming ill include: hypervigilance, working at pace, being ambitious and hardworking, being determined and headstrong, imposter syndrome, a focus on achievement and on helping others.

Added to this is a disclosure of moral values such as kindness. Participants are generally people who show awareness of the needs of others. More negatively framed personality traits are imagined to intersect with positively framed moral ones.

"I had a lot of resistance. Two years into my journey, my first kind of encounter with this work was that my brother gave me John Sarno's book, and it was this book about back pain and I wouldn't even say I read the whole book. I can't even say that I read the whole book and that's a regret of mine now, but I sort of looked through it and there was a lot about suppressed rage and it

> just really—I felt really offended that my brother could think: (a) I thought, *He doesn't think this is real, he doesn't think my symptoms are real* and (b) I thought, *He thinks I've got suppressed rage*, and I had a real judgement around that. I thought, *I'm a kind person. I'm not an angry person. I don't have suppressed rage.* I wasn't in a place to hear that message. And so I sort of doubled down on the, 'This is not suppressed anger, this is my physical body, this is real, this is real'. And I remember having that real sense of trying to validate my suffering as being real and my symptoms as being real." (ME/CFS + POTS + fibromyalgia, recovered after 8 years)

In the above example, we see how a pathway to recovery invites reflections on one's identity and can prompt questions around how one understands oneself. This participant experiences a reflexive process of self-evaluation being foisted upon her. In the interview data, emotion and personality are two ways that this reflexive self-examination is spoken about.

This report puts forward the concept of the overextended personality to highlight the orientation towards care for others that intersects with some of the negatively framed 'maladaptive' tendencies that are also oriented towards others. Participants' concern with the wellbeing of others is interlinked with personality traits associated with conscientiousness and the external world, such as a strong work ethic. Reflections on personality typically appear when participants discuss the onset of symptoms, in accounts of mindset tools and techniques, and within the theme of self-transformation at the conclusion of the interview when participants often volunteer an account of how they feel they differ having engaged in the process of recovery.

Typically, participants represent a nexus of characteristics. One participant was described by the computational sentiment analysis as having a 'driven, push-through personality', which she remedied with self-kindness. Another describes herself as "feeling guilty all of the time" if she did take time for herself (long COVID + CFS, 3 years, recovery ongoing). She describes how, "since childhood I needed to prove myself to people because I thought that people didn't think I [would] ever amount to anything."

Two themes around boundaries—how to better set boundaries in relation to the demands, expectations and interests of other people, as well as how to practice kindness and compassion for oneself, or how to practice self-compassion—are often articulated together. Boundary-setting is viewed as a form of self-care and a means of addressing one's (maladaptive) inclination to put others first (at the expense of

oneself). Participants' reflections on boundary-setting can be interpreted according to the theme of emotional intelligence that runs through many of the interviews. According to this view, one needs emotional intelligence to understand one's own needs. Reflections present accounts of developing a new literacy in the context of emotion and self-identity. Participants develop the skill not only of understanding an emotion in the context of one's sense of self but also of being able to respond and meet the needs of that emotion, or what that emotion represents.

> "If I don't listen to my emotional brain, then my body is going to shout with symptoms. So the way that I keep well is that I do meet my needs. Now I do prioritise myself. I've learned to do that." (Fibromyalgia, recovered after 11 years)
>
> "A lot of us are in the helping industries. Again, going back to putting everyone else first. And I think there's a big fear in disappointing other people or almost a sense of being responsible for how other people feel." (ME/CFS, recovered after 8 years)
>
> "I always did a lot for everyone and I could never say 'no' because I wanted to help, but I was just piling things on myself and I always found that I was putting myself last. I wasn't really doing that much for me. It was always kind of being there for other people and helping them with their lives. So when I had the chronic fatigue, it was kind of, it sounds crazy, but it has been a gift to me now that I'm better because it let me … I had no choice. I had absolutely no choice but to put up boundaries. … Boundaries [have] been a huge thing. And if it wasn't for me becoming ill, having had such a horrible time, I would have never learned to have … I was never good at boundaries. And now that I'm better, I can set them and not feel guilty about it. And I can be there for people in a much better way. I'm not showing up all exhausted and like, *How can I help you?* Now I actually can have some energy and be like, *Right, I can help you now*. It's a big difference." (Sjögren's syndrome + chronic fatigue, 3 years, recovery ongoing)

The idea of overextension, understood as the overexpression of the social quality of extension—how one extends oneself in social relations—is mapped by participants' accounts of boundary-setting. As the latter description illustrates, boundary-setting presents both an introjection of a psychological idea about personality and a moral idea about being a good person. Overextension is extension at the expense of one's

own psychic and bodily integrity—a failure of boundary-setting to the detriment of one's wellbeing.

> "There's a reason that you might not be able to say 'no'—because as a child, you didn't have the choice. So you had to suppress your own feelings in order to have an attachment … we will always choose attachment over authenticity." (ME/CFS, recovered after 8 years) [Discussing ideas of the doctor and author Gabor Maté]
>
> "You won't believe what you can find when you look deep into what you need and why you are the way you are." (ME/CFS, recovered after 7 years)
>
> "That's when I was really grateful for what was happening … I was lying to myself because it didn't just start with COVID. It was like there was lots of stuff I was running from beforehand and emotional repression and not being authentic in friendships and relationships and all that kind of stuff. And this changed everything. It just gave me this opportunity to look inward and learn all of this stuff." (Long COVID, recovered after 2 years)

The idea that we have needs is prevalent in participants' explorations of the themes of identity and the self. The idea 'authenticity' and 'being true to oneself' is used to represent those needs and stands as a counterpoint to overextension. Boundary-setting is also linked to an intension to cultivate a more secure and settled self-relation. This intention is closely related to the idea of safety in the nervous system, which is talked about by many participants. It is also accompanied by participants revisiting their concern with the wellbeing of others—what is motivating this concern, and how can it be acted upon without too much of an expense to the self? What kind of cost is a healthy compromise? The frame of boundary-setting requires the constant revision of one's boundaries by the person setting them. Boundary-setting is described as a reparative act of self-compassion.

> "Unravelling my fear response … understanding my fear response and realising that saying 'no' to people or just saying *what was happening inside of me* was something that was causing a fear response [in my day-to-day experience]." (Lyme, recovered after 7 years)

Trauma release exercises made possible this participant's complete revaluation of their corporeal existence. Boundary-setting, in the form of saying 'no' or being truthful

about one's own internal experience, was something that this participant was fearful of. They did not detail the perceived implications. Being able to say 'no' combats the fear, but it is the trauma release exercise—in this participant's example, an exercise that wills the body to shake—that provides the participant with a new internal self-relation. It is with the confidence of this new self-relation that they are able to take the fear out of saying 'no'. Asking, "What are all the things in the world that make me have a fear response?" is made possible by a somatic practice that allows the body to process fear.

> "The nervous system workshop just made me realise I've rushed all the time, and so I just have slowed down—and I've had to slow down." (CFS, recovering after 3 years)
>
> "Just that routine really kind of keeps my nervous system in check, and I am very aware of my nervous system. I've become really tuned into it. I can feel when it's becoming activated and then I'll use breath work or even singing—the kind of things that trigger the vagus nerve—to calm myself down. That kind of self-compassion, that has been a really big part of me staying in a wellness state." (Long COVID, recovered after 3 years)

The link between self-transformation, personality and the resolution of symptoms rests on the idea that personality traits have a physiological component in the nervous system. This idea is most clear in relation to stress, anxiety and fear, which are associated with the sympathetic nervous system and the evolutionary biology of the emotions. Participants' reflections on their initial lack of boundary-setting and self-compassion point to patterns that could be connected to the pathophysiology of CFS (such as through the HPA axis). It is interesting to consider whether pacing, practiced as a kind of boundary-setting and as part of a recovery mindset that is positive about the body's ability to heal, might have effects on one's neurobiology. One participant describes having become exhausted with hiding her mental health issues. Although they are not represented in the sample, one might expect similar accounts in relation to neurodivergence.

> "I feel like it is a different amalgamation of anxiety. It was anxiety and then it has changed and now it has become CFS. I really, in my gut, feel it is the same thing, just changing." (CFS, recovering after 3 years)

One participant, who recovered from ME/CFS after 7 years, helpfully describes somatic techniques as “a bottom-up approach where we connect with our body, which is so important for many of us, we’ve kind of lost that connection to our body. We’re used to just deflecting emotions or just letting it pass.” The description above of “unravelling my fear response” in conjunction with over a decade of practicing trauma release is a good example of such a ‘bottom-up’ approach. Participants share several different accounts of trauma release somatic therapies that worked for them. In contrast, mindset work, or brain retraining approaches, lead with directed cognitive and affective functioning. For this participant, this approach is “really truly about changing which pathways you’re using in order to make yourself truly into a person who believes they’re going to recover, who sees the hope, sees the gratitude. All the little changes in our brain are surprisingly impactful on our body” (ME/CFS, recovered after 7 years). This reflection takes the analysis from personality through the body and the affect of fear, back to the theme of mindset.

Such examples illustrate the entanglement of affect, emotion and self-transformation with mindset and recovery practices. An important sub-theme here for many participants is the question of how they have processed trauma and adverse childhood experiences (ACEs). Through introspection, many participants seek to understand the origins of their personality tendencies in the formative difficult times they have lived through.

One way of understanding the plethora of affective and emotional experiences of participants is as the ‘truth effects’ of social pressures in bodily realities. Another term that was used by at least one participant is ‘highly sensitive’—being a “highly sensitive person”—imagined neurologically as being “more sensitive to stimuli and stress” (POTS, recovered after 9 years). Personality is a language in which one processes what is happening internally and in the world around us. The kinds of personality tendencies that are described represent what participants call a strong “inner critic” (fibromyalgia, recovered after 11 years), self-beratement with all the “shoulds”.

> “I guess that’s one of the really good things that came out of it is I truly have changed that voice in my head, not all the time, but most of the time.” (ME/CFS + long COVID + POTS, recovered after 12 years)

Around 1 in 2 participants link anxiety to symptoms. Anxiety is not a happenstance affect but is ‘wired’ to ‘make sense’ of a relation. Similarly, fear is interlinked internally within the one’s schemas of perception, including as a co-coordinator of memory,

decision-making, psychic defence and so on. Neuroscience is an important source of information for participants for whom such effects and their dysregulation appears to be consistent with their neurobiology more generally. However, it is clear that neuroscience alone is not of sole benefit. Participants are engaging with neuroscientific ideas in conjunction with other ideas and practices.

> “Internal family systems and therapy was a slow process of just kind of rediscovering myself going back in and kind [of] just rewinding, going backwards. I thought I was fine until I got POTS, but really I wasn't fine and POTS was just the final kind alarm really.” (POTS, recovered after 9 years)

A more general point can be made here—that participants who offer such reflections on the tendencies in their personality (and how these may have negatively affected their health and biology) report being happier to have discovered, through the experience of illness and recovery, that emotionally and psychologically, personally, professionally and socially, they can make changes to their lives and live in a different way. For some participants, what follows is an incremental, possibly even only slight difference, in how they might experience themselves. For these participants, the idea that their personality traits contributed to their illness helps instil a sense of movement, a loosening—not necessarily a 180-degree turn. Other participants describe a more thorough transformation.

8.3 Identity

> “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. For example, as women, a lot of us, myself included, kind of brought up being told to ‘be nice and quiet and not to be angry’. [Anger] is actually a really healthy emotion. Rage, not so much, but anger is really important and healthy, and so it’s important to be able to say ‘no’ and to put boundaries in place and to be able to do that kindly. But I’d never learned that. I just learned ‘Keep all that down and be nice and smile and make sure everyone else is okay, care for everyone else’. 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)

Of the 39 participants who speak about personality, seven are men. This is about one in five, which corresponds to population data on the gender ratio of CFS, as well as the gender ratio of the whole sample for this study. The description above links the repression of anger to rage, understood as an 'unhealthy emotion', to the gendered comportment the participant feels is required of her as a woman. Given how popular culture now readily associates emotional scripts and dispositions with social phenomena, including the restrictions of gender, heterosexuality and class, it is unsurprising to hear how this participant associates the aesthetics of social expectations (to be "nice," to "care for everyone else") with a detriment or cost that she has absorbed as a woman. In this example, the participant's own intellectual exploration of these themes has provided an expanded vocabulary in which to make sense of these associations in the context of her life experience. She describes learning about the theme of overextension and about how she could redraw her personal boundaries in relation to her family and wider society.

Social pressures are a means by which structural inequalities and the demands of living within the performance cultures of capitalist neoliberalism are communicated to their subject. The demands of professional and personal life, particularly for middle-class, university-educated women in the context of increasing precarity, are referenced in the interviews. A critical lexicon around the specifics of race and class is largely absent. Participants talk about their focus on achievement at the expense of all else, but the intricacies of gender, affect and emotion are more all-pervasive than such expressions allow us to see.

> "My life, it was one of those situations that looked good on the outside you could say, but on the inside I was miserable and I had, I woke up with panic attacks and I wasn't doing what I wanted to do and I just felt so trapped. I was [a] student in university and I was studying [subject]. So I was on a path to becoming [profession] ... And this was, I had been under a lot of pressure to become [profession] my entire life, and I didn't think there were any options really. There was also a lot of fear that *if you don't become an engineer, you will suffer, you will struggle.* I really believed this. I didn't think that you could have a happy life on anything else than that salary. … That's what I was taught. And so every day at university, I was like, *This is life or death*, because every assignment felt like literal life or death, because that was the level of a panic and stress I was under." (CFS, recovered after 4 years)

> “Really what you are rewarded for and respected for and valued and judged on is how much you push yourself.” (CFS, recovered after 3 years)

The report has already demonstrated the importance of self-knowledge and touched on the idea of self-trust. The social implications of these ideas become more apparent in the context of identity, understood as that process by which self-knowledge and one’s capacitation in society is structured according to social norms.

The theme of overextension in conjunction with the gendered asymmetry of the incidence of CFS requires further research. Such research should account for the intersections of class, race, sexuality and neurodivergence in the contributing role of gender to the development of CFS. As we can see in the above example from a young woman, class privilege appears to be particularly significant. Participants place emphasis on modelling a certain educated, accomplishment-driven lifestyle and describe a drive to overachieve. The ‘soft skills’ related to mindset work and personal transformation, which are involved in the resolution of symptoms, also attest to an educated disposition—with only one participant’s narrative diverging from this representation of class privilege. Participants’ descriptions of the social origins of chronic stress and anxiety, as well as their descriptions of the environmental comfort needed to rest, recuperate and receive care within family units, need to be better understood in terms of underpinning social structures.

As discussed previously, for many participants the experience of having one’s identity decimated by illness leads to a renewed vision of oneself in terms other than those previously identified. These accounts show how self-questioning is part of a new openness to ideas about selfhood.

> “I did a lot of self-searching, and I looked inside of myself and I found a strength that I didn’t believe I had. So yeah, that was the beginning on my recovery story.” (ME, recovered after 6 years)

> “I had to realise that my value was deeper than that and that people love me. People want to help me. I had to learn to accept that. And it humbled me. Changed me.” (Fibromyalgia + Sjögren’s syndrome, recovered after 5 years)

> “I’ve had a better life because of having gone through that struggle, even though I would never wish it on anyone. It’s created this incredible life for me

> of freedom and joy at having health and just valuing every day that I can go out and live a full life and do fun things." (CFS, recovered after 11 years)

Identity can be used as a critical way to talk about structuring differences that stratify social experience (in other words, that generate inequality) and as a way to talk about shifting attachments through the experience of illness and recovery.

8.4 CFS as a social illness

> "I'm really interested in what fatigue is saying in the light of those broader pressures and what fatigue is saying in the light of the toxins and stresses that come from things like social injustice, the structural factors, not just the individual factors, but the social structural factors like racism, sexism, poverty. Those kinds of things play through into health questions massively and don't often get linked, I think, with fatigue as a condition. So I guess I'm asking *what it is that fatigue is saying. If fatigue is speaking into the 21st century, what is it that we need to hear?*" (ME/CFS, recovered after 33 years)

The content of participants' accounts of self-transformation is social in origin. When participants draw on ideas about attitudes and values as part of their reflection on self-transformation, they also describe a somatic sociology. Within the push-pull of the individual and society, boundary-setting is one example of the transmutation of social conventions according to the shifting needs and capabilities of one's body. It is important to think about the role of social conventions in the experience of illness, as in the words of one participant, "some of that conditioning can contribute to us getting ill, but it can also be unpicked and help us get better" (ME/CFS, recovered after 8 years).

Some accounts of long COVID and CFS in the time of COVID-19 talk about the context of social isolation. Lockdown policies enforced a type of social isolation never experienced before—a break in the usual sociobiology of home and working life. Furthermore, some participants connect their experience with the role of community—or lack thereof, which could be interpreted as a description of loneliness. The report notes that both recovery programmes and recovery culture online centre the idea of community in their forms of communication.

"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)

"What I'd been missing all my life was having a supportive, warm community." (Lyme, recovered after 7 years)

"That was the hardest part for me is finding people who would listen here and there and ask me how I was doing. … Support is very helpful with this as well because you need to feel like you're supported to be able to feel positive and happy and feel better." (CFS + fibromyalgia, 5 years, recovery ongoing)

"You start to realise how loneliness is actually quite a large part of this illness, and it's why I often call this illness a 'mind F' … We isolate ourselves so often because of our sensitivities. I had both sensitivity to light and noise, and I couldn't socialise for very long. So we isolate ourselves. But it is a very core human need to be with other people. By isolating myself, I ended up just getting worse and worse and worse." (ME/CFS, recovered after 7 years)

That not one participant recovered in social isolation is an important social fact. These denotative descriptions of the significance of community can only be taken as indicative of the importance of social relationships to recovery from CFS and related illnesses. The theme of support is linked directly to participants' implicit recognition of the social nature of CFS. These accounts could be further analysed to examine how new forms of work in the arena of non-medical support for recovery are enabling people who have recovered from chronic illness to extend themselves socially in new ways—it appears—to honour that desire to help others and be in relation to others that keeps them true to themselves, while also enacting self-care.

8.5 Discussion

Even before one takes into consideration questions around the relationships between identity, self-transformation, recovery practices and mindset, as this research has done, we can observe that CFS is a deeply social phenomenon. The analysis finds that many of those who have recovered from CFS and/or related illness, or who have seen measured improvement in their symptoms, have come to think of their illness experience as an effect of the intersection of biographical and social conditions with the pathophysiology of the symptoms. The finding of the social and cultural analysis presented here is that: from the point of view of recovery, an

underlying problem that is biographical and social in nature has interacted with the development of symptoms and their resolution.

The concept of overextension is presented to reflect the references to personality that participants highlight in their accounts as well as situate those references within a social and cultural frame. The overextended personality can be accounted for by different schools of psychological thought, such as attachment theory, trauma theory or a more biopsychosocial theory of nervous system dysregulation, as well as neuroscience. Here, the term ‘overextension’ intends to place emphasis on the social nature of the forms of pressure that participants describe themselves as processing or navigating. By contextualising participants’ accounts of self-determination and the self-directed nature of recovery journeys through the concept of ‘overextension’, we take into consideration the social and cultural norms and pressures in relation to which participants are acting. The concept of overextension captures in social theory the biography and psychogeography of exertion that participants recount, the trouble of adjusting to a life in which those forms of exertion have become impossible, and the revisioning of the role of exertion in relation to one’s sense of self post-illness.

Further research is required to understand what social relationships mean in the context of recovery from CFS symptoms and related illnesses. An interdisciplinary account that draws from psychological schools of thought, together with social and cultural explanations of the gendered asymmetry of incidence of CFS, as well as the intersections of class, race, sexuality and neurodivergence within the epidemiological pattern of incidence, is required to better understand how social and cultural factors intersect the pathophysiology of CFS and related chronic illnesses.

Section 9. Ethics of recovery

"I think it means that we start thinking about our own health differently and appreciating the intimacy of the entanglements between our body and our environments. A lot of us on this journey are learning so much about human wellbeing, about human flourishing, about reconnecting with the self, about reconnecting with others in different ways. We are learning all these things. And so this community in a way has unique insights. I mean, many of the people I meet who are utterly inspiring are people who are on this journey or have got to the point on this journey where they're 100% recovered. These are amazing stories of hope. And what it shows is how quickly, given the right conditions, natural systems like the body can find their balance again, find their homeostatic functioning again. And the same is true for living natural environments." (ME/CFS, recovered after 33 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)

"It became more important than the recovery. It was like*, This is bigger than just dealing with these symptoms*." (Long COVID, recovered after 2 years)

"Healing is never ending." (CFS, recovered after 4 years)

Data on recovery are, in fact, data of many different kinds. Recovery narratives tell stories of medical alienation, self-determination and self-transformation. They also tell a deeply social and cultural story about the struggles one faces when they find themselves immobilised by 'medically unexplained physical symptoms'. They attest to the resolve and compassion, the ingenuity and inventiveness, of a group of people finding their way through a maze of protocols, services and advice, all while being symptomatic. What emerges from these accounts of how participants' recovered is a question about how to live. How to live well. How to live well with others. How to live on a fading planet. These types of questions turn on the ethics of being alive today—of being alive in a body (or being a body) in the context of limitations.

> “I guess everyone has to go on their own journey, and you can’t sort of say that one size fits all.” (Autoimmune disease + CFS, recovered from CFS 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)
>
> “I still do that work. I will always be doing that work. That’s something that I've learned from this is these things that we do to recover … It’s a change in the way that you relate to yourself. It’s a change in how you relate to the world and your place in it. And these are all the things that contribute to us getting sick in the first place. So we can’t just drop them and never do them again, and maybe we don’t need to do them as much or whatever. But I still journal all the time. I still meditate. I still do yoga nidra, I still do yoga, I still [do] Qigong. All the things that help me in my recovery are now just a part of my life.” (ME/CFS, recovered after 18 years)
>
> “It does change your life, though. It changes who you choose to hang out with in your social life and how important it is or how not important it is. It can be, there is a mourning period, like a death of your old life … I am still in that in-between space. *Where do I go from here? Where do I find the people, the connections where I want in my work?”* (CFS, recovered after 20 years)

It is the emphasis on self-transformation within a context of social and cultural delegitimation that takes the counter-discourse of recovery squarely into an ethical discourse of self and social relations. Just as no two people are the same, neither are their paths to recovery. This makes the common ground in the experience of recovery that the researcher has identified in this study all the more compelling. By illuminating these areas—participants’ accounts of self-determination, the belief in one’s own recovery and a belief in an explanation of one’s condition and its treatment—we see that the singular nature of one’s pathway to recovery does not contradict the collective basis of its underpinning values. The report offers the term

‘recovery mindset’ as a way to represent the collective value given to who we think we are, meaning also, to how we think.

Questions of language, of nomenclature, are also then questions of ethics. The problem of what to call the illness—chronic fatigue syndrome, myalgic encephalomyelitis, ‘systemic exertion intolerance disease’—is not only one of representation. It is a problem of how best to create an intervention in the world. Naming shapes social landscapes, affecting what can be encountered when we encounter one another. It is unfortunate that the language of mind-body illness, mind-body medicine and mind-body treatment sound less convincing than any conventional biomedical language, whether or not science informs that mind-body language, knowledge and treatment. According to the social and cultural analysis of recovery narratives presented in this report, reconceiving of the body as a body is an important site of experience. The practice of asking, ‘What did my body say?’, ‘always listening to my body’ and asking, ‘How am I feeling emotionally?’ in response to having symptoms is prevalent across participants’ recovery accounts and is an instantiation of a mind-body paradigm. Rather than search for legitimacy, at least some research should be committed to representing recovered people’s own paradigms.

By placing emphasis on the potential of the body and on the body as a site of potential—even of an ill, debilitated body—recovery narratives partake in a holistic revisioning of the illness experience of CFS. This revisioning reinterprets the questions that should be asked in the vicinity of the illness. The *Recovery Report* has hence tracked these questions, although there are many others: What are the conditions of possibility of one’s account of the onset of symptoms? What preceded one’s rock bottom? How does a shared account of ‘making a decision to recover’ challenge what we think we know about CFS and related illnesses? How do recovery narratives represent self-determination? What forms of support are described in people’s accounts of their recovery from chronic illness? These kinds of questions yield answers that are more about quality of life than the termination of illness. They invite the self into the experience of illness in a new way. Importantly, through these reflections and through asking these questions, the self becomes a person who can act on the illness. It is from the position of action—of social action, agency and decision-making—that participants undertake a wholesale transformation of themselves. By newly acting on themselves, they are able to recognise and make decisions within a field of relating. The lens of ethics is the resting place of recovery. ‘How do I live, now that I am better?’

The narrative script on the overextended personality turns on an ethical endeavour when it invites this deeper questioning of who one is in relation to others and how one lives in relation to others.

> "The people who don't accept it are not the right people in your life anyway. The people who do accept it are the people that you need in your life that are the right kind of energy that you need." (Sjögren's syndrome + chronic fatigue, 3 years, recovery ongoing)
>
> "I feel like … everything that was not meant to be just crumbled from my life." (CFS, recovered after 4 years)
>
> "That's kind of my magic pill that I found in myself, along with … a ton of shadow work, boundary-setting, getting out of relationships that weren't serving me or the other person fully, reevaluating absolutely everything and all my perspectives on life." (ME/CFS, recovered after 18 years)
>
> "Once it's tipped over into CFS, then that's an opportunity to change our lives. It's an opportunity to live more like us human beings are meant to live, and you know a much simpler, more nourishing, traditional, less pushy, less people-pleasing, less needing to be more, to have, more to achieve more … because it's not sustainable for us. It's not sustainable for anyone … I really believe this how we're meant to live, and not, like I say, how society wants us to live." (ME/CFS, recovered after 15 years)
>
> "Some people say 'disease as teacher', and it's not a way—I'd rather learn a different way, but when we feel unwell, it's important to look at, well, *What might be going on for me? What might my body be communicating with me?* … I guess for me, it was—a big part of it was seeing that my illness wasn't something separate from me. It wasn't a disease that I had to fight and win. It was a part of me that I had to embrace and learn from, which was horrible. It was hard because it was so unpleasant, but I had to just actually go: *This is me. What's it saying? What does it need? What do I need?*" (ME/CFS, recovered after 4 years)

To claim that people affected by CFS are considerate of others and that this is not the way of the world is not to make a generalisation. It is to say something about the person who becomes symptomatic, who, according to their own narrative, is not a

personality type or a biology or even a biopsychosocial phenomenon. The findings of this study represent the outcome of an analysis that, while adopting many of the conventions of the critical humanities and social sciences, prioritises an ethical practice of listening to what participants have to say.

When participants problematise their tendency to overextend themselves, they are also opening up the possibility of relating to people otherwise. In one interview, Raelan questions where the tendency to please other people comes from, asking why we need to derive a sense of value from others in this way. Participants' reflections on the subject of personality represent a refocus on alternative sources of value and pride. Helping others recover is framed as a way of honouring one's desire to help others while allowing for one's one self-kindness and self-compassion—staying with a recovery mindset.

The practice of drawing boundaries could be a way that many participants shift the need to accommodate the world from themselves to others, to rebalance where accountability lies and to whom one is obliged. This way of setting boundaries redraws who the participant lives in relationship to, that is, with whom they are having relationships. The revaluation of personal and social relationships goes hand in hand with a revaluation of one's professional life. Participants are especially drawn to questioning their ambitions. When they return to work, many choose new career fields, sometimes deciding to devote their work solely to the recovery of others.

> "All these years since I recovered, I haven't stopped learning and trying to understand what made me well and trying to understand chronic fatigue and studying … I felt a very strong call about, *Okay, I'm going to help people in in this situatio*n … I feel very, very strongly that I feel this is my life's work." (CFS, recovered after 2 years)

CFS is an illness of a particular kind. Symptoms are debilitating, calling into question the capacity that people have to act on their own lives. In the absence of the social and cultural capital to which one is accustomed (one's means of accessing and establishing value, including in their sense of self), the experience of CFS can catalyse a deeper reflection on one's sense of self. Many people who recover from CFS describe recovery as a process of self-transformation. While this may sound like recovery involves a retreat to the self, the self-transformation described often focuses outwardly on social questions of purpose and belonging. Hence, these findings suggest that we view the recovery from CFS as involving an ethical dimension. A major implication of the theme of ethical work on the self is that a

pharmacological solution, should there be one, will foreclose the area of ethical revaluation and self-transformation. This should raise questions about the ethics of a pharmacological solution, should the medical community develop one. At first sight, there is everything to gain through a pharmacological answer to an illness whose devastation borders on the unbearable. The findings discussed in this report, from the ‘Recovery is Possible’ study, however, suggest that something very valuable stands to be lost, as well as gained.

Conclusion: Being recovered

> “I had people like you [Raelan Agle] and Rebecca [Tolin], and hopefully people in the future will be even [luckier]. They’ll have stuff in the actual mainstream medicine that there’s not at the moment in the UK really. But I think if I hadn’t have found you and Rebecca and my psychotherapist, I just don’t know if I would’ve ever got better. I don’t know if I would’ve linked it enough without having a bit of information.” (Long COVID + ME/CFS, recovered after 2 years)
>
> “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)
>
> “Listening to people’s recovery stories really was a pivotal moment for me. It was changing my beliefs because I’d really started to believe that recovery wasn’t possible for me, especially the more I read about chronic fatigue syndrome and ME and a lot of the stories online.” (Long COVID, recovered after 2 years)
>
> “The absurd thing was after that, I got a shock. After that I suddenly realised *I don't know what life is without fighting every day*. So it took me another six months to unlearn coping mechanisms and to learn what it is to live without a fight.” (ME/CFS + fibromyalgia, recovered after 24 years)
>
> “I love to share the hope of recovery.” (CFS, recovered after 11 years)

In many ways, the *Recovery Report* has sought to embody the ethical imperative to make the experience of recovery more visible. Taking accounts at face value, it has amplified the experience of recovery in the voices of those who have recovered fully or to a degree. It has conveyed the affective arc of recovery. It has set out the evidence for its findings—that those who recover do so through embodying a recovery mindset anchored by believing in one’s own recovery and discovering an explanation of one’s symptoms that immediately makes sense. Each element of recovery in this sense benefits from the recovery stories of others. Emphasis has been given to the role of self-determination in the recovery mindset, as the interview data show that without the person’s dogged determination to get better, the new

forms of knowledge and practice that have helped others cannot be taken on. Accounts of self-transformation equally point to the importance of self-determination through a period of embodied change and becoming.

The *Recovery Report* has examined the recovery story through a thematic and narrative analysis informed by the critical humanities and social sciences, as well as cultural and gender studies, especially a feminist politics and ethics of listening. Unlike the recovery interview, though, which tends to end on a high with participants celebrating their newfound agility, the *Recovery Report* does not conclude by taking a moment to celebrate. There is too much to do. There is too much at stake. Realistically, the biopolitics of CFS—the way that CFS operates as a technology of biopower (Foucault 2004)—will not be overturned by the findings of one study.

If anything, the findings of the researcher's analysis of the recovery narratives represented here have shown that the way we talk about ME/CFS and related illnesses has implications for the experience of chronic illness. The analysis has shown that the medical discourse of non-recovery, dominant across social and cultural life and not just the spheres of medicine, acts as a nocebo, does harm and falters in the face of recovery with accountability to no one. The analysis also shows however that the limitations of mainstream medicine, including its representation in public health, patient support and advocacy groups, and news media are being challenged in online recovery culture. From the view of dominant culture, the findings of the *Recovery Report*—much like the voices of those who are recovered—may be listened to by no one. Given what participants say about the importance of the visibility of recovery to their eventual experience of it, the prospect of the findings of this study being suppressed to uphold the status quo is deeply troubling.

The medical refusal of recovery is perhaps the darkest aspect of the recovery narrative.

> "Then I had a follow-up in that dreadful hospital place, and I went back. You know, you have to picture me before. When I went to those sessions in the hospital, I was—I couldn't speak. I needed help to walk, and when it was my time to share, I had a little voice, a little voice like that. I really couldn't talk. Nobody knew my real voice. It was one of the most severe cases in that group. We were a group of maybe 10 or 12 people. 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!* And unfortunately it was so sad because I told all the medical staff, everyone there: 'Listen, I've recovered. Please investigate, research, do tests!' You know, 'Use me as a Guinea pig. I'll help you as much as I can. There is a way, and that can help so many people.' And you know what they told me? 'Either we misdiagnosed you and you didn't really have chronic fatigue or maybe everything we did with you beforehand really helped you.' So then on record, they cured me. In reality, [with their treatment], I was worse." (ME/CFS, recovered after 2 years)

Just as this report calls on stakeholders to take seriously these accounts of what might amount to malpractice, it also asks stakeholders to take seriously its accounts of the experience of recovering.

For many in the medical community, a social and cultural study undertaken by a researcher in gender and cultural studies is not one to be taken seriously. Unlike the fields of study that are represented in this report, however, medicine has not been through a reflexive turn. It is apparently still justifiable for medical research to: overlook minority illness experiences even if they affect millions of people worldwide; proceed with research protocols that do not include, let alone foreground, patient voice; show a lack of regard for the interdisciplinary input required by the epidemiological inequity that typifies the illness (most notably, its apparent disproportionate effect on educated white women); and be steered ideologically and according to political influence in contradistinction to the facts on the ground.

For others in the medical community, the findings of this study are desperately needed. GPs and emergency medicine physicians will be the first to share accounts of an overwhelming number of patients debilitated by symptoms but with no known medical pathology that needs treating at the ward or in the doctor's office. Fatigue is one of the most common reasons for primary care visits in the UK and the principle complaint in around 1 in 15 consultations. When faced with patients whose symptoms are more complex and resemble the current diagnostic ME/CFS criteria, NICE guidance advises doctors to help them 'manage their ME/CFS', with no outline of how this help can be provided. Guidance focuses on risk aversion rather than compassion and support for recovery. For these clinicians, the findings of the *Recovery Report* invite new grounds for conversation about how best to support patients presenting with CFS symptoms.

Support is necessary for recovery. Belief alone will not get one better. Neither will learning about the recovery of another—although both are conditions of the recovery that can follow. Just as withholding the possibility of recovery from medical discourse impedes people's recovery, evidence for the type of support that has enabled recovery places responsibility for the visibility and even provision of that support squarely with stakeholders. It is in this spirit, with this request, that the *Recovery Report* concludes its findings.

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Appendices

1. Recovery narratives literature

Joyce, Hotopf and Wessely (1997)	A review of 26 studies showed that having a sense of control over symptoms and not attributing illness to physical causes was associated with better outcomes—'the patient's belief in a physical cause of their symptoms predicted poor outcomes in every study in which it was measured' (225)
Brown, Huszar and Chapman (2017)	Apply anthropological concept of liminality (Victor Turner drawing on Arnold van Gennep) to analyse interviews with 16 people 'claiming to have recovered', described as between health and illness and undertaking 'relentless self-scrutiny, monitoring and pacing' (707)
Devendorf, Brown and Jason (2020)	Deductive thematic analysis of interviews (n = 10) found acceptance of impairment, uncertainty and a belief in making some improvement through coping
Cheshire, Ridge, Clark and White (2021)	Analysis of interviews (n = 19) revealed that recovery is viewed as a nexus between the reality of limited opportunities for full recovery and a strong desire to leave the illness behind and regain a sense of "normality"
Bakken, Mengshoel, Synnes and Strand (2023)	Dialogical narrative analysis of narrative interviews found participants (n = 14)

	established a new worldview and actively pursued their own healing
Krabbe, Groven, Bjorbækmo, Sveen and Mengshoel (2023)	Qualitative narrative analysis informed by phenomenology of recovery in interviews (n = 13) shows that recovery is an interpersonal, contextual, fragile and nonlinear profess involving bodily base self-knowledge
Hasan, Kuyvenhoven, Chowdhury, et al. (2024)	Interpretive descriptive analysis using focused and axial coding of narrative interviews (n = 33) found that fully recovered patients (n < 7) attribute their success to mind-body approaches
Cupit, Finlay, Pope and the PACFiND Team (2025)	Ethnography of fibromyalgia care through interviews (n = 59), observation, document review and stakeholder workshops found that chronicity rhetoric in health and welfare systems inhibits patient recovery
Ingman, Chalder and Lawrence (2025)	Reflexive thematic analysis of interviews (n = 19) looking at the impact of treatment on how recovery is viewed found that recovery is viewed as a personal process involving rebuilding a sense of identity and making changes to ways of living
Linnros, Andreasson, Norlin and Hydén (2026)	Narrative analysis (n = 14) in which there was a turning point characterised by hope and a new understanding of the fatigue condition

Harper (2026, forthcoming)	Reflexive thematic analysis of interviews (n = 8) found that cultivation of a recovery mindset and development of an explanatory narrative about the causes and perpetuations of the illness

2. Literature cited by participants

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3. Resources guides at the time of publication

Recovery stories websites

Fatigue Science Talks
https://www.youtube.com/@FatigueScienceTalks

Living Proof
https://www.livingproof.org.uk/recoverywall

Positively COVID
https://www.positivelycovid.org/

The Recovery Channel
https://recovery-channel.org/

The Recovery Hub
https://www.the-recovery-hub.org/recovery-stories

Recovery Norge (Recovery Norway)
https://www.recoverynorway.org/stories/

Stress Illness Recovery Practitioners Association (SIRPA)
https://www.sirpa.org/im-in-pain/helpful-information/

Recovery YouTube

Raelan Agle
https://www.youtube.com/@RaelanAgle

CFS Health
https://www.youtube.com/@CFSHealth

CFS Unravelled
https://www.youtube.com/@CFSUnravelled1

CFS Recovery
https://www.youtube.com/@cfsrecovery

Nervous system and recovery apps

Calm https://www.calm.com/

Curable https://www.curablehealth.com/

Freeme https://freemehealth.com/

Headspace https://www.headspace.com/

InsightTimer https://insighttimer.com/

Nervana https://www.trynervana.com/