‘Falling between the lines’: Progression to recovery within a contested illness for people with ME/CFS

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REBECCA WALTON

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Abstract

Despite the vast amount of research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), little is known about the lived experience of recovery. ME/CFS remains a poorly understood illness, with unclear aetiology, poor treatment advice and no universally agreed consensus on how recovery should be defined or measured. Because of this, navigating and accessing suitable supports and services for ME/CFS can be a challenging endeavour. This study aimed to explore the lived experience of eight women through personal accounts of recovery, looking at progression over time and what helped or hindered them in their recovery journey. An interpretative phenomenological analysis (IPA) and idiographic tradition enabled an in-depth exploration of each person's situated, lived bodily experience, taking into account the world in which they live. Four recovery phases were identified: Chaos, Confusion and Scepticism, Turning Point, Restoration and Integration and Acceptance and Finding Balance. These phases were intertwined, highlighting what helped recovery progression and the back-and-forth nature of recovery. Recovery for the participants was framed as 'recovery in' rather than 'recovery from', emphasising the possibility of significant improvement while acknowledging the continued need to manage some ongoing symptoms. Recovery is hard work, requiring ongoing bodily surveillance and an in-depth personal knowledge of the illness. In addition, having a recovery-oriented framework based on a holistic approach to health and a belief in symptom improvement that validated illness experience was necessary. Understanding these phases and operating from a recovery-oriented framework can improve health care and treatment options for people with ME/CFS. The approach to recovery, like the illness itself, must be multi-faceted and tailored to the individual, which requires an interdisciplinary approach to the treatment of ME/CFS, allowing for greater possibilities for recovery progression.

Acknowledgements

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The thesis was inspired by my own lived experience of ME/CFS. Although diagnosed 22 years ago now, I have always wondered how people recover, how people define recovery and what helped or hindered recovery for them. This thesis is for everyone who has wondered the same and wants positive stories of recovery progression. To my friends, family, and colleagues, thank you for your encouragement and ongoing support and for understanding my need to tell this story.

Lastly, I thank the women who participated in my research. You shared your hard and raw experiences (from living with this illness) and the wisdom and insights you have gained with honesty and trust. I wish you all the best in your recovery journeys, and know that what you have shared has immeasurable value for others on the same journey. Kia Kaha.

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CHAPTER ONE: ME/CFS An Unpredictable Illness

1.1 Introduction

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, chronic, debilitating illness that affects multiple systems within the body, including overwhelming fatigue that is not improved by rest and affects a person's ability to perform everyday activities (Centers for Disease Control and Prevention [CDC], 2023). There is no universally agreed-upon cause, cure, or definition of recovery for ME/CFS (Adamowicz et al., 2014; Cheshire et al., 2020; Devendorf et al., 2019a). Most of the literature focuses on those who are unwell or remain unwell, with limited research on understanding illness progression and recovery pathways. This introduction will provide the background to the illness and how the illness is currently conceptualised in relation to cause, diagnosis, and symptoms within the current biomedical field. It will also examine the importance of understanding the illness within its entirety, the bodily experience, and the influence of the socio-cultural context.

1.2 Terminology

How ME/CFS is defined has been much debated; for example, in reviewing the literature, the terms CFS, ME, CFS/ME or ME/CFS are used, and it is described as an illness (CDC, 2023) or disease (World Health Organisation [WHO], 2018). These differences are slight but meaningful; within academic research, the acronyms ME and CFS are often used interchangeably for one another (Institute of Medicine [IOM], 2015). In addition, there is ongoing debate about whether ME and CFS should have an independent diagnosis, with ME considered the more debilitating illness (Monro & Puri, 2018). ME was first used in the United Kingdom (UK), and CFS in the United States of America (USA) (National Health Service [NHS]/North Bristol, 2024). ME/CFS, for the most part, is currently used as an umbrella term that most likely covers several different phenotypes and subgroups (Tate et al., 2023).

Part of the problem with the terminology is that CFS or ME, for many people, does not adequately or accurately depict the symptomology or severity of the illness. In a report by the Institute of Medicine, they suggested a new name, Systemic Exertion Intolerance Disease (IOM, 2015). They felt that this name encompassed the illness's salient features, including exertion (i.e., physical, cognitive, emotional) that adversely affects someone's symptomology (Clayton, 2015). However, the term ME/CFS continues to be used in the literature and online.

In the current study, most participants used the acronym CFS for ease of use and understandability with the general public. This thesis will use the acronym ME/CFS and describe it as an illness.

1.3 Prevalence and Demographics

Research has shown that ME/CFS can affect individuals of all ages, genders, ethnicities and socioeconomic backgrounds. Estimating the prevalence of ME/CFS worldwide is challenging due to inconsistent diagnostic criteria, the lack of research in some populations, and limited awareness of the condition. Hanson (2023) estimates the world-wide prevalence to be around 67 million (pre-2020), with an additional 100 million people living with long COVID (Tate et al., 2023). In addition, 91% of people (in America) with ME/CFS are estimated to remain undiagnosed or misdiagnosed, and those who do have a diagnosis often receive inappropriate or potentially harmful treatment (Bateman et al., 2021). Research has also shown that prevalence is higher than other well-known illnesses, such as multiple sclerosis or lupus (Valdez et al., 2019) or rheumatoid arthritis (Gibofsky, 2012). According to estimates from the New Zealand Ministry of Health, it is believed that approximately 40,000 New Zealanders may be affected by ME/CFS (Complex Chronic Illness Support [CCIS], 2023).

Studies consistently indicate that females are more commonly diagnosed with ME/CFS than males. Ratios range from 3:1 (IOM, 2015) to 4:1 of females to men by the National Institute for Health and Care Excellence (NICE, 2021). Although you can be diagnosed at any age, for adult women, it is more commonly diagnosed between the ages of 40–60 (Sandler & Lloyd, 2020). Yet, despite its prevalence and severity, ME/CFS remains a poorly understood and underdiagnosed condition. Most of the research is on women, with very little research on the experience of men with ME/CFS (Snell et al., 2023). One study found that the age of onset was younger in males, and they reported less symptoms and comorbidities (Faro et al., 2016). However, the exact reasons for gender differences are unknown (NICE, 2021). It is possible that differences might be due to symptom reporting, healthcare-seeking behaviours, and societal and cultural influences.

There is some evidence to suggest that different ethnicities may have different prevalence rates, but there is limited research on other population groups, and cross-cultural research is rare. A meta-analysis found that the prevalence rates of Asians were comparable to Western prevalence rates (Lim et al., 2020; Lim & Son, 2021). Other studies looking at

ethnicity found ethnic minority groups had a higher prevalence than Caucasians in the UK (Bhui et al., 2011), as well as for African American and Latinx youth in a study in Chicago (Jason et al., 2020). Greater symptom severity was reported in the USA from Black and Native Americans with chronic fatigue (CF) (Dinos et al., 2009). Because of limited research on different population groups more research is needed on the reasons for the differences.

1.4 History and Classification

Before we can look at recovery, we need to look at what is currently used to diagnose ME/CFS. One of the challenges in the healthcare of people with ME/CFS is that there is no diagnostic test or medical biomarker that can be used to categorically diagnose the illness (although diagnostic criteria have evolved and are making this easier). Historically, the absence of a biomarker has led to scepticism of a biological cause and linked ME/CFS to a psychosomatic cause, leading to debates over diagnosis, treatment and management of symptoms (NICE, 2021; Sykes, 2002). This debate has been soundly argued in the literature, with criticisms voiced regarding various limitations and confounding variables found in studies, in particular with Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET) and the lightning process (Marks, 2022). The ME/CFS community have fought long and hard for the root cause of ME/CFS to be recognised as a physical illness rather than a psychological issue. This has been reinforced over recent years, with many studies showing physiological changes within multiple systems within the body. For example, a recent study in New Zealand demonstrated the physiological changes and biochemical pathways that help explain the diverse symptoms experienced (Sweetman et al., 2020).

A multisystem biological basis for the cause of ME/CFS is far more recognised today (Missailidis et al., 2019); however, a psychosomatic cause persists, and a biological explanation has yet to permeate all healthcare and community settings. This can lead to symptoms being dismissed or misinterpreted, diagnosis being delayed, and patients being offered ineffective treatment protocols, which impede a recovery trajectory. More clinical guidance in diagnosing and managing ME/CFS needs to be provided (Bateman et al., 2021). Tate et al. (2023) state that in the absence of a diagnostic test, a core set of common neurological symptoms form the current clinical case definition of ME/CFS. This approach aligns with the World Health Organization, who classifies ME/CFS as a neurological condition that affects the nervous, endocrine and immune systems (Cortes Rivera et al., 2019; WHO,

2018). In addition, it is proposed that illness severity and illness outcomes are influenced by nature and nature (i.e., genetics, childhood illnesses, and the individual's health profile) (Tate et al., 2023).

1.5 Risk Factors, Triggers, and the Underlying Mechanisms of ME/CFS

The three most commonly reported causes of ME/CFS are infection-related episodes (virus), stressful incidents, and environmental toxins (Chu et al. (201). Although differing percentages are provided, it is estimated that 80% of people with ME/CFS have an infectious episode near the onset of the illness (i.e. Epstein-Barr virus, toxoplasmosis, mononucleosis, giardiasis and more recently coronavirus) (Naess et al., 2010). Other risk factors include childhood illnesses and a family history of an autoimmune or other multisystem chronic disease (Nacul et al., 2020). It is also possible that there is a genetic link or genetic vulnerability, as it has been found that people with ME/CFS can have other family members with a diagnosis (Vyas et al., 2022). In a New Zealand study by Tate et al. (2023), they found that most people had an underlying health condition, of which gastrointestinal issues were the most common (42.4%). In addition, Grach et al. (2023) state that 75%-80% of people with ME/CFS have at least one other disease or disorder. Nater et al. (2011) found that exposure to stressors was more common for people with CFS.

What is likely is that multiple risk factors or triggers overlap, creating susceptibility to contracting the illness in a vulnerable person. This makes sense as the symptoms experienced involve multiple systems within the body. Furthermore, no single mechanism has been found to explain the totality of symptoms or aetiology of the illness (Cortes Rivera et al., 2019). Therefore, a multi-systems approach is required to understand the possible underlying mechanisms of the illness.

1.5.1 Phenotype/Subgroup

As discussed above, several contributing causes, different espoused mechanisms, a vast range of symptoms, and individual health differences make it difficult to compare treatment results. It is believed that there are several different phenotypes/subgroups within ME/CFS; therefore, individualised rather than universal therapies are likely to have the best results. For example, "categorising subtypes/phenotypes based on those individuals who respond to specific treatments may allow treatment plans within a precision medicine framework to be created for each ME/CFS patient" (Tate et al., 2023, p. 6). Looking at specific subgroups and

how they respond to treatment will also be of interest, as any one treatment can have varying results, from improvement to no improvement or worsening symptoms (Castro-Marrero et al., 2017). However, they propose that it is not the trigger that causes the differences but rather the person's unique genetic profile and health history that causes a spectrum of pathophysiological responses that determine differences in illness symptomology and outcomes. Recovery requires a holistic, interdisciplinary approach to health care to address the different symptoms the person experiences. From this perspective, they note that an individualised treatment pathway should be based on the family and personal medical history, genetic or environmental susceptibility, trigger event, immune/inflammatory response and its effect on energy production, microbiome dysbiosis, viral reactivation, immune dysfunction, neuroinflammation and Central Nervous System (CNS) dysfunction. We need to learn more about this illness and the factors that affect its natural history, as few studies have looked at the life course of the illness or symptom fluctuations for recovery over time (Clayton, 2015).

1.5.2 Diagnostic Criteria

There are around 20 case definitions or diagnostic tools currently in use which has been problematic as they have been based on different criteria (Tate et al., 2003). Because of these differences, the Institute of Medicine was tasked with looking at and reviewing several key case definitions and diagnostic tools, such as Fukuda (1994), Canadian Consensus Criteria (2003), revised case definition (2010), NICE clinical guidelines (2007), and International Consensus Criteria (2011) (IOM, 2015). From this analysis, they found a specific cluster of symptoms that typically and universally defines ME/CFS which have been incorporated into key diagnostic tools. Notably, post-exertional malaise (PEM) is now considered a hallmark symptom required for diagnosis (IOM, 2015; NICE, 2021) and inclusion in clinical trials (Kielland et al., 2023). For people with ME/CFS, there is significant detrimental payback following exertion, reducing function and increasing fatigue severity which is known as PEM (Missailidis et al., 2019).

One of the differences between the NICE (2021) and IOM (2015) guidelines is length of time with symptoms before a diagnosis can be sought. For example, symptoms need to have been experienced for six weeks (NICE, 2021) or six months or more (IOM, 2015). Given that an early diagnosis provides a better prognosis, being able to diagnose at six weeks rather than six months is useful (Kingdon et al., 2022). Particularly as diagnostic delays are inversely

associated with recovery/improvement (Ghali et al., 2022). In the NICE (2021) guidelines, all the following symptoms need to be present for a diagnosis for ME/CFS:

- debilitating fatigue that is worsened by activity and not significantly relieved by rest
- PEM which worsens symptoms after activity (which can be delayed)
- unrefreshing sleep or sleep disturbance, and
- cognitive difficulties (i.e. brain fog, memory issues, difficulty with multi-tasking, inability to think, converse or find words, numbers, memory, multi-tasking) (Kingson et al., 2022).

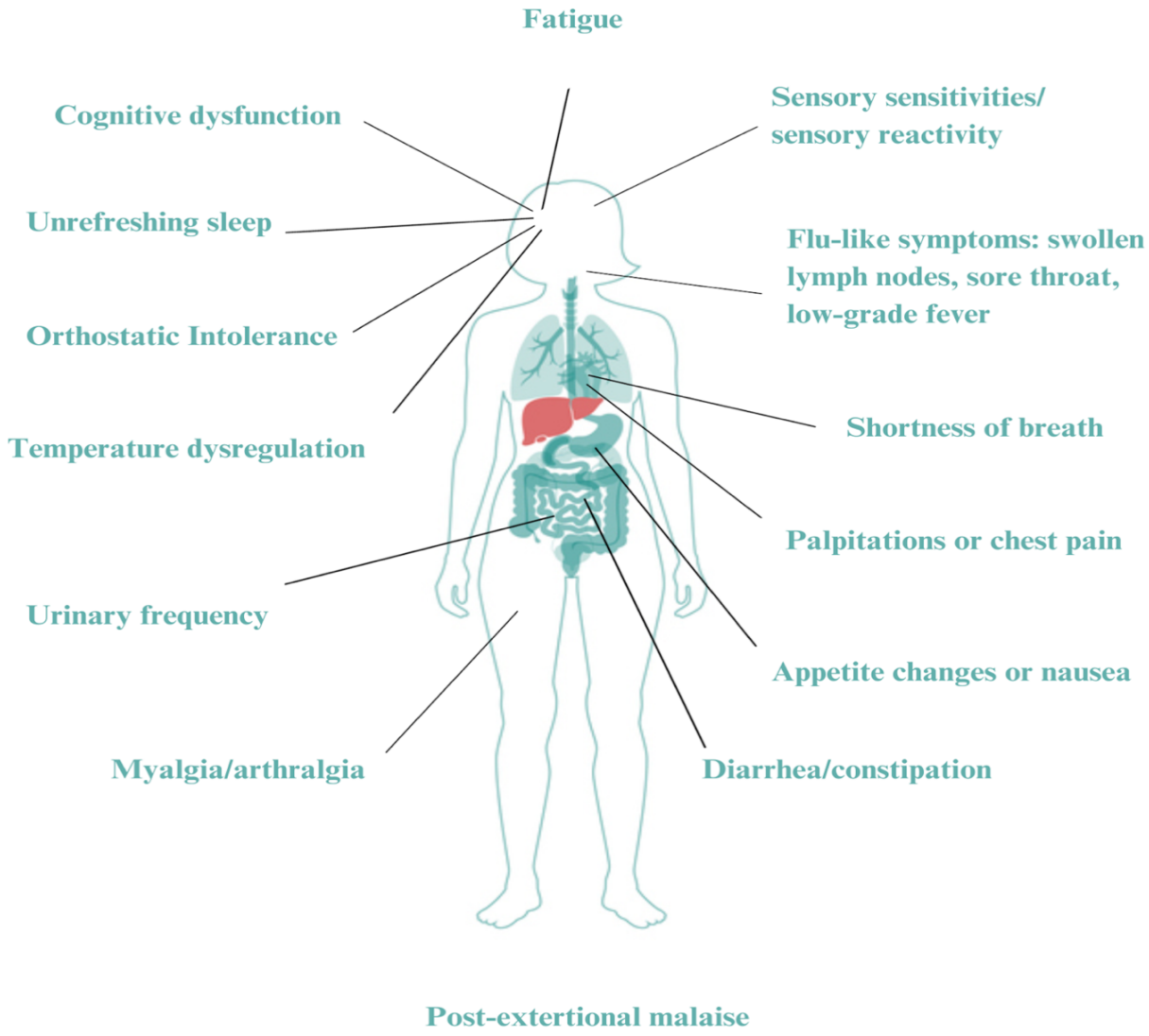
The IOM (2015) guidelines also states that ME/CFS should be a new onset (not life-long) and must contain *either* cognitive impairment or orthostatic intolerance (OI), of which symptomology needs to occur at least half of the time with moderate severity. It is estimated that up to 95% of people with ME/CFS have orthostatic intolerance (prolonged standing or sitting can worsen symptoms), and OI can be objectively measured (Bateman et al., 2021). On the other hand, Sunnquist et al. (2015) does not think life-long fatigue should be a definitive exclusionary criterion because a sudden onset or known trigger is not everyone's experience. They found few discernible differences between those with or without life-long fatigue in both symptoms experience and function. Although there may be small diagnostic differences in prevalent diagnostic tools, fundamental for diagnosis is PEM.

1.6 Symptoms and Categories of ME/CFS

There is a long list of possible symptoms and differences in symptom severity and duration (IOM, 2015). For example, there have been over 100 identified symptoms of ME/CFS (Tate et al., 2003). Some people develop symptoms months after the onset of the infectious illness or from the reactivation of latent infections (IOM, 2015). However, the primary symptoms have been well recorded (refer to Figure 1) and inform the diagnostic criteria above. Other symptoms include impaired ability to engage in pre-illness activities (work, social, education), pain, sensory sensitivities/reactivity, flu-like symptoms (sore throat and tender lymph nodes), shortness of breath, palpitations or chest pain, appetite changes or nausea, diarrhoea/constipation, gastrointestinal issues, myalgia/arthralgia, urinary frequency, neuromuscular symptoms, orthostatic intolerance, and temperature dysregulation (Grach et al., 2023).

Figure 1

Symptom Representation of ME/CFS



Note. This figure is adapted from Grach et al. (2023)

There are four categories of ME/CFS, which are mild, moderate, severe and very severe, with an increased reduction in functional capacity as the person progresses through these categories. The most severe are potentially unable to carry out independent activities and can become bedridden or housebound for extended periods of time (IOM, 2015). Those in the mild category may be able to continue working, although this is often compensated by reducing other daily living or social activities.

1.7 ME/CFS and Long COVID

Of interest for researchers of ME/CFS is the striking similarities found between ME/CFS and long COVID (Wong & Weitzer, 2021). Indeed, several studies have noted that ME/CFS and long COVID are closely related or variations of the same illness as they have many clinical overlaps in presentation (Tate et al., 2023; Wong & Weitzer, 2021) and some of the mechanisms that cause physiological changes are the same (Astin et al., 2023). Many online and community ME/CFS groups include resources for people with long COVID on their websites as many management strategies cross over. Significant resources are going into researching long COVID, which is positive for ME/CFS research, as ME/CFS has traditionally been under-researched. This is timely, as the number of people with long COVID experiencing CFS-type fatigue is expected to rise over the coming years with the expectation that some groups may be disproportionately represented (i.e. Māori) (Ministry of Health, 2022). The World Health Organisation has estimated that at least 17 million people in the European region have experienced long COVID (WHO/Europe, 2022). PEM is also reported by people with long COVID (Moore et al., 2023). Shelley et al. (2021) looked at individuals' experiences of recovery from COVID and found that re-introducing physical activities was often associated with an exacerbation of symptoms and suggested that self-management strategies were not dissimilar to ME/CFS.

1.8 Quality of Life

Dealing with the illness's impact and navigating the biomedical health and welfare system can reduce an individual's quality of life (QoL) and ability to perform or engage in everyday activities, such as; work or education, family responsibilities, and social or recreational interests (Arroll & Howard, 2013). A large survey found a substantial negative impact on the QoL across all life domains for this population group (Vyas et al., 2022). Similar findings were found in an Australian sample (Eaton-Fitch et al., 2020). The lowest scores for QoL have been "associated with unemployment, mental cognition, sensory and sleep disturbances, gastrointestinal upset, cardiovascular abnormalities, changes in body temperature and flu-like symptoms" (Vyas et al., 2022, p. 1529). Managing a long-term chronic illness can place strain on relationships and increase financial strain. For example, family members can experience worry, frustration and sadness (Brittain et al., 2021). It can impact the ability to work, for example Cairns and Hotopf (2005) found that only 30% of people with ME/CFS returned to work and the longer one is sick, the harder it is to return to work. Furthermore,

having to navigate the health system can exacerbate symptoms and add to illness distress (Action for ME, 2016). ME/CFS can affect every aspect of a person's life, from performing daily activities to relationship, financial and emotional strain.

1.9 Why Studying Recovery is Important

There are very few qualitative studies on recovery with scant attention given to the natural history of recovery progression over time (Brown et al., 2017). In addition, the personal experiences of recovery are rarely studied and are an underutilised source of knowledge (Bakken et al., 2023). Most studies seem to focus on those who are unwell rather than on those who improve, whereas positive accounts of change over time can provide rich, powerful, informative narratives. Considering the prevalence of the illness, more research is needed on the lived experience of recovery to increase our understanding of how recovery is defined by participants, and what supports and services they use throughout the recovery journey.

The illness is also known to fluctuate, and the severity and duration of the illness can vary significantly among those with ME/CFS. People can experience periods of improvement or stability followed by relapses, so recovery progression is not typically linear. Symptom presentation and response to treatment protocols will also vary, making this illness difficult to navigate and treat. Despite these challenges, people with ME/CFS do experience symptom improvement; therefore there needs to be a focus on the first-hand experience and knowledge of people with ME/CFS so that we have a better understanding of what might or might not help to improve health and well-being for those living with ME/CFS. Using a critical health psychology lens, allows me to look at other factors that contributes to the progression or burden of the illness and how that influences health outcomes (i.e. bio-psycho-social-cultural context).

1.10 Rationale and Research Aims

This thesis seeks to contribute to the existing knowledge on ME/CFS, enhancing awareness and understanding of this debilitating illness through an in-depth analysis of recovery pathways of adult women with ME/CFS within Aotearoa, New Zealand. Currently, this is an under-researched area with little research looking at the progression of the illness over time with a focus on the recovery experience. This study aims to place the voice of the person at the centre of the research to explore individual recovery trajectories. It is hoped that hearing the personal experiences of recovery and what helped or hindered them in their journey

will be useful for those on the same pathway, health professionals and other researchers. The research aims are:

- Develop an understanding of the lived experience of recovery and how they account for progression from ill-health to wellness over time.
- Explore how people with ME/CFS define and measure recovery.
- Develop an understanding of the different treatment pathways and modalities used.
- Develop an understanding of the supports and services used and their experience of health care within the New Zealand context.
- Advise healthcare professionals about what can improve health outcomes for people with ME/CFS.

CHAPTER TWO: Literature Review

2.1 The Impact of Stigma

Within ME/CFS research, stigma is conceptualised as illness delegitimisation and invalidation (Dickson et al., 2007; Kendrick & Beesley, 2016) and is "defined as the use of power to bring about labelling, stereotyping, separation, and status loss" (Baken et al., 2018, p.7). Stigma is profoundly personal, as it discredits the person and sets them apart as inferior or deficient in some way (Cheshire et al., 2020; Froehlich et al., 2021). This can leave people wondering what is wrong with them (Conrad & Barker, 2010) and can reduce physical, mental and social functioning (Baken et al., 2018). Furthermore, research has found that women experienced higher levels of disbelief and insensitive treatment from healthcare professionals (McManimen et al., 2019). Disbelief leads to extrinsic or intrinsic questioning of the legitimacy of the ME/CFS diagnosis. It is highly likely that a person will face stigma, discrimination, and social isolation at some stage in their journey. These have been found to negatively impact mental health and make the journey of living with and effectively managing a chronic illness more challenging (Froehlich et al., 2021).

Stigma is a complex construct, and is not a fixed entity but socially constructed (Goffman, 1963). For example, the 'sick role' as popularised by Talcott Parsons is governed by social expectations (Parsons, 1951). This places an enormous burden and responsibility for being ill on the 'sick' person. Sometimes, these assigned roles are undesirable and create negative stereotypes that devalue the 'sick' person and what they could contribute, framing them as deficient, a hypochondriac, or unable (even *unwilling*) to perform typical roles or activities (Dickson et al., 2007). These judgements contribute to illness distress, social isolation, and symptom severity. Furthermore, people often hide the illness or mask their symptoms because of disbelief, stigma, and feeling blamed or at fault for the illness, which impacts self-care and management (Pilkington et al., 2020). Within the healthcare system, this can be encountered through victim-blaming discourse, particularly for contested illnesses (they need to try harder or exercise more), which "run counter to the interests and well-being of the chronically ill" (Pilkington et al., 2020, p. 20).

2.2 Health as a Personal Responsibility

Culturally, within neoliberal societies, health is often seen as a personal responsibility (with strong moralistic overtones) (Lyons & Chamberlain, 2017), often failing to reflect wider "physical, social and cultural drivers of health" (Hook & Rose Markus, 2020, p. 643). For example, individual agency and locus of control tend to swing between the person being held responsible for the illness (psychological in origin) or not being held responsible (e.g., for a biological illness) (Kirmayer & Gómez Carrillo, 2019). These attitudes about health encourage blame and stigmatisation and widen health disparities. This often requires individuals to accept help or take active measures to improve their health (Björk et al., 2021); for example, participants in one study were told to 'get fitter' (Strassheim et al., 2021). Unfortunately, this type of advice is both inaccurate and problematic, because overexertion can worsen symptoms (Verrillo, 2012). Negative attitudes or misinformation about the illness affects how the illness is viewed and what care people receive.

The social model of disability would identify systemic barriers, negative attitudes, and exclusion (purposefully or inadvertently) as the main contributing factors that disable people; whereas the symptoms are the impairments which cause functional or physical limitations (Conrad & Barker, 2010). They argue that we must move beyond the biopsychosocial model to one that includes socio-structural phenomena that recognises that illness experience is in part socially constructed (e.g., the bio-psycho-socio-structural approach). For example, stigma or discrimination can lead to reduced demand or engagement in healthcare services (Alameda Cuesta et al., 2021). From this perspective, it is essential to recognise the detrimental effects of stigma on well-being and its impact on healthcare.

2.3 Conceptualising Recovery in ME/CFS

2.3.1 Defining Recovery

Research has only more recently begun to focus on recovery; for example, in a meta-analysis of 34 qualitative studies on ME/CFS, none of the studies focussed on recovery (Anderson et al., 2012). There is no universally agreed-upon definition that captures recovery in people with ME/CFS (Devendorf et al., 2020). In a paediatric systematic review by Moore et al. (2021), they found 11 distinct definitions of recovery, with only five using a personal measure of recovery. There have been several proposed definitions of recovery, for example

Devendorf et al. (2019a) provide an operationalised definition of recovery from a physician's perspective, which is conceptualised as a complete remission of symptoms and return to pre-illness functioning. In a subsequent study, Devendorf et al. (2020) looked at recovery from the patient's perspective and found that recovery may not mean a total return to their pre-illness self. Cheshire et al. (2020) note that recovery definitions are often based on professional rather than patient experience. This is supported by Adamowicz et al. (2014), who found that the voice of the person with ME/CFS was often missing in recovery definitions. Furthermore, Cheshire et al. (2020) conclude that the notion of a total return to the pre-illness self might be unhelpful. Similarly, a qualitative study by Brown et al. (2017) examined recovery and found that 'recovered' did not infer being completely symptom-free; that there was a spectrum of recovery from partial to full recovery. This is reiterated in the first paper to explore children and adolescents' recovery experiences, finding that improvement rather than complete recovery was more typical (Harland et al., 2019). Recovery for some may be the complete restoration of their pre-illness functioning, whereas for others it is seen as a progression towards significant improvement and symptom reduction (Adamowicz et al., 2014; Devendorf et al., 2019b).

2.3.2 Recovery Framework

Although there is scepticism about achieving full recovery, there is more confidence that significant improvement is viable through using different coping or management strategies, including medication (Devendorf et al., 2020). These authors proposed a recovery framework differentiating 'recovery in' from 'recovery from'. This is taken from recovery definitions used in mental health and originally conceptualised by Davidson and Roe (2009). This framework works on the assumption that although complete symptom remission may be less likely (recovery from), the person can live a fulfilling life while effectively managing symptoms (recovery in). Full recovery is the hoped-for endeavour. However, a spectrum of well-being is more helpful in navigating an illness that is known to fluctuate, particularly for those who have had the illness for many years. Specifically, Devendorf et al. (2020) found that recovery was conceptualised as "functioning without fear of relapse, returning to previous roles and identities, and being free of symptoms" (p. 317). One of the concepts touched on is the *fear of relapse,* and it is an essential consideration for recovery. Harland et al. (2019) found that participants wanted to be able to return to activities that were important or meaningful to

them without *payback* – the fear people experience is often associated with the cost of payback and having to weigh up whether the proposed activity is worth the cost.

2.3.3 Measuring Recovery

There are numerous self-report measures used within ME/CFS research and in clinical practice, including pain, energy or fatigue scales, quality of life, changes in PEM, measuring functional improvement, VO2 max, and cardiopulmonary exercise tests (Devendorf et al., 2020; MEPedia, 2023). The challenge in using self-report measures is the fluctuating nature of the illness; for example, if people are limiting their activity, it is unlikely to provide an accurate level of fatigue intensity or energy level. Furthermore, understanding recovery is based on a clear concept of fatigue, but fatigue has different meanings for different people, and the experience of fatigue can be vastly different; for example, in fatigue ratings or functional impairment after over-exertion (Olson et al., 2015). In addition, it is difficult to determine how realistic it is to have a total return to pre-illness health or full health, given changes due to age or other co-occurring conditions. It is unclear whether the pre- or post-illness self is the same given changes in expectations, purpose or meaning, lifestyle goals, functionality and stage of life (Adamowicz et al., 2014). What someone wanted pre-illness and what they want during or after illness might differ significantly (i.e., not wanting to return to their pre-illness activities because these were considered to contribute to their health decline).

Recovery is a highly subjective experience and needs to consider personal meaning-making and what a return to health would look like for that person to inform treatment plans, prognostic goals and patient education. Further research is needed for a consensus definition on recovery; however, until that happens, using self-report measures is a useful guide given the complexity and fluctuating nature of the illness (Moore et al., 2021). An individualised approach to recovery is needed, whereby the person can define recovery, outcomes sought and see tangible progress over time (Loades et al., 2018).

2.3.4 Rates of Recovery

The lack of a consistent definition of recovery means estimating rates of recovery is difficult. A systematic review calculated the median for full recovery as 5% (range 0 – 31%), and improvement was 39.5% (range 8 – 63%), with some people reporting a worsening of symptoms (Cairns & Hotopf, 2005). Another study found that the total recovery rate was 8%

(Ghali et al., 2022). In a systematic review by Moore et al. (2021), they found a range of recovery rates from 4.5% - 83%. People tend to have improvement in symptoms rather than full recovery (no symptoms). The recovery rates can only ever tell part of the story. Obtaining reliable data on the number of people who recover from ME/CFS is challenging (as noted above), so caution needs to be applied when looking at recovery findings because of the inconsistent definitions and diverse methodologies. For example, in looking at recovery studies, there are differences in diagnostic criteria, measures and outcomes used, severity and illness duration, patient selection, treatment and follow-up, making it difficult to compare findings across a particular subgroup or treatment type (Adamowicz et al., 2014; Cairns and Hotopf, 2005). Mudie et al. (2020) recommend using a range of standardised data collection tools by different research groups to better understand existing research on a particular treatment and to help with treatment comparisons within different phenotypes/subgroups. Finally, it is important that people with ME/CFS are informed about prognosis; however, this needs to move beyond statistics to recovery stories and the possibility of improvement as beliefs about prognosis can influence outcomes (Loades et al., 2018).

2.3.5 Phases within Recovery Progression

Often, health and illness are positioned within a dualistic framework that considers people to be well or unwell and finds it difficult to conceptualise an illness that can fluctuate between the two. Brown et al. (2017) discusses the concept of liminality, which refers to falling between the socially and medically sanctioned health and illness categories. For example, in their study of 16 people who recovered from ME/CFS, they found that people are situated within a new liminality between illness and full health. They were neither in one nor the other but somewhere in between. This is reflected in research that has found a partial, rather than full return to health for the recoveree (Cheshire et al., 2020).

Furthermore, people with ME/CFS often go through an identity change throughout the illness journey. For example, Arroll and Howard (2013) found that participants compared their past and present selves, which led to the gradual process of "letting go, building up, [and] the gradual process of rebuilding" (p. 302). The same process is experienced by people who have very severe ME/CFS (who return to health) who go through a "profound narrative shift", and recovery progression is described as "long-time work" in the pursuit of "their own healing" (Bakken et al., 2023, p. 1). Over time, there is a rebuilding of a positive reconstruction of the

self (Whitehead, 2006). In the study by Bakken et al. (2023), they found four phases in recovery progression:

1) Developing illness: in search of an explanation
2) Severe illness: deteriorated and bedridden
3) Turning point: cracking worldview and new discovery
4) Healing: holding on to the new worldview

Making sense of the illness (sense-making) is part of the illness experience; illness itself has been described as a biological disruption with the known life trajectory in sudden disarray (Bury, 1982). This biological disruption is described by Dickson et al. (2008), and is similar to Bakken above. This includes:

- Identity crisis (agency and embodiment), of which participants experience a sense of personal loss and diminished sense of control and agency.
- Scepticism and the self; the fluctuating nature of ME/CFS led to the "dissolution of sense of self" (p. 466).
- Acceptance, adjustment and coping which is fundamental in adjusting to living with and managing ME/CFS, which allowed people to move forward in their lives.

This loss of control or agency from an unpredictable illness creates a disconnect with their body (and life) in immeasurable ways (Njølstad et al., 2019). Following on from this sense of loss is a rebuilding of agency and adjustment that allows for the possibility of post-traumatic growth (Arroll & Howard, 2013). The rebuilding of agency seems to come from a gradual building-up of bodily self-knowledge, where wellness begins to overshadow the state of illness, which slowly fades into the background (Krabbe et al., 2023). From this position, the person tries to understand what this disruption will mean for them. For an illness like ME/CFS, this typically occurs through the slow unveiling of the illness itself, unravelling the implications and discovering what might lessen suffering or symptom severity. One study found that participants went through an initial period of chaos and confusion, then restitution (control over the disease) and quest (agency and personal growth) (Whitehead, 2006). In the quest stage, participants found that, despite ongoing symptoms, they gained valuable insight into the illness and understood the management strategies that worked for them. Adjusting to the illness

seemed to range from small achievable tasks to a complete reappraisal of their past and present lives. This included the re-conceptualisation of personal goals and meaning-making of their personal experience. Recovery, as noted above, is hard work, unpredictable, non-linear, and needs the involvement of experienced professionals and access to relevant supports and services.

2.3.6 Illness Models

There are few qualitative studies that have examined the natural history of recovery in ME/CFS. This includes looking at the patterns of symptom fluctuation, factors associated with improvement, relapses, and remissions, and their implications for recovery (Cairns & Hotopf, 2005; IOM, 2015). Having a better understanding of this is helpful, as people want to be better informed about the prognosis of ME/CFS and what they might expect (Loades et al., 2018). Again, caution needs to be applied as beliefs about prognosis have been found to be a significant predictor of post-treatment fatigue (Heins et al., 2013). One of the few studies to offer a broad epidemiologic overview in the United States is a study by Chu et al. (2019), who found that one of the underexamined aspects of ME/CFS was the evolution of symptoms. This was one of the reasons why Nacul et al. (2020) decided to create a pathophysiological framework from the "pre-illness stage to the final disease outcome" of ME/CFS (p. 8). This framework includes:

- predisposition (i.e., genetics) and triggering of disease, such as an acute infection, which could be a singular or repeated insult;
- prodromal period (initial mechanisms involved, such as the systemic inflammatory response syndrome);
- early disease (failure to return to previous levels of homeostasis or state of balance within bodily systems); and
- established ME/CFS (persistence of symptoms likely due to chronic low-grade neurological and systemic inflammation resulting in physiological abnormalities).

This infers that during the prodromal phase, a return to good health (for those with mild to moderate symptoms) is most likely to happen at the beginning of the illness (typically before the three to six-month period featured in most diagnostic criteria). Early detection to support people back to pre-illness health is therefore essential. They also surmised that the physiological response might differ between those who recover and those who remain unwell.

If this is the case, an important question they pose is what "determines the perpetuation and transformation of symptoms?" (Nacul et al., 2020, p. 6). This transformation is unknown at the current time; however, what is required is a multi-perspective approach that does not just focus on the pathophysiological responses but includes the voice of the person with ME/CFS and an in-depth look at the personal accounts of recovery experiences over time.

2.3.7 Contested Recovery

Being a "recoveree" is a complex process which is precarious in nature because it falls between socially recognised health and illness categories. The recoveree status is often brought into question amongst group members (who remain unwell), where claims of accurate diagnosis incur scepticism (Brown et al., 2017). These authors describe how the recoveree is placed into a position of "unintelligibility", leading to a sense of ostracisation within the ME/CFS community (p. 707). The unintelligibility of the recoveree status is a form of invalidation; a disbelief and devaluing of the recovered person's experience and positionality. Furthermore, for some people, the word recovery is not helpful as it can delegitimise the experience of being ill and remaining ill, and vice versa for the recoveree. This can lead to people feeling reluctant to share their knowledge (if interventions or current status conflict with community knowledge) "for fear of being ostracised or dismissed; often, these conflicts arose around mind-body approaches, which some ME/CFS patients reject because it does not fit their logic model of illness" (Hasan et al., 2023, p. 7). Friedberg et al. (2005) found that "active members of ME/CFS groups report greater symptom severity and less improvement than those who leave such groups, which may indicate a move away from the patient community when symptoms of ME/CFS are less active" (p. 7). It is possible that some groups of people may be more vocal and have more online presence than others within ME/CFS community groups, creating a fragility around the discourse of recovery.

Almost no research has looked at the contested nature of recovery and how that impacts recovery pathways. Due to this lack of research, it is difficult to know whether internet-sourced material distils particular illness beliefs and how this might affect an individual's decision-making process about recovery. Certainly, online resources can be a helpful source of information and social support for the illness (Brigden et al., 2018; Morehouse et al., 2021) and for information on management strategies (Soderlund & Malterud, 2005). However, developing trust online is a nuanced process that is embedded through the lens of one's own experience, background and digital literacy (Brady et al., 2016). Unfortunately, the

contestability of ME/CFS can be seen in the recovery space, which is linked to the diagnostic criteria or treatments used and brings into question the believability of the personal account. Personal accounts are mired within and are part of the complex backdrop of ME/CFS biopolitics and the biosocial identity and beliefs within the ME/CFS community (Karfakis, 2018). Little is known about how this influences recovery or how online groups respond to recovery experiences or narratives, particularly where psycho-social supports are used.

2.4 Illness Narratives

Most of the literature has focussed on the experience of the person who is ill rather than on recovery or improvement, which means there is significantly less research on recovery narratives or stories, particularly from a diverse range of backgrounds. Part of the problem with the lack of recovery narratives is that the focus on the illness can make recovery seem impossible or hopeless. For example, reading the ME/CFS statistics had a negative impact on this individual's psyche: "I was very active seeking information online. And I tended to grab onto the darkest, the gloomiest scenarios that fitted the way I felt… I found numbers and was horrified! No more than two to four out of a hundred ever recovered completely, and many got worse and were bedridden forever! The picture of the future was all dark" (Bakken et al., 2023). Currently, there are limited narratives on hopeful, possible pathways to recovery. This is demonstrated by this participant's retelling of their story: "Nothing about recovery was ever mentioned. Nothing about hope. Nothing about anything we could do to help ourselves" (Mead & Copeland, 2000, p. 1). Given that over two decades have passed since that study, it is with some concern that this sentiment is still reflected in the current literature. Although realism is needed, there also needs to be room for hope. Kalla & Simmons (2020) note the importance of "throwing away horror stories" and focusing on stories which are hopeful that people can resonate with (p. 154). In their poetic representation of seven women's recovery journeys with ME/CFS, they found that participants often experienced a pivotal moment that engendered feelings of hope and agency (the ability to look back to move forward). From this perspective, hope is seen as a psychosocial resource that enables people to engage in behaviours that improve the possibility of recovery (Duggleby et al., 2012). As part of this, participants found ways to reduce stress, increase self-compassion and listen to their bodies to understand their needs.

2.5 Treatment and Management Strategies

Part of the challenge in working out what treatment or management strategies might work for a person is the lack of research on effective treatments. This increases the level of uncertainty, stress and anxiety in managing this illness. Due to the large number of symptoms, there are as many treatment protocols as there are triggers and underlying mechanisms, as each needs to be mapped onto the other. Hasan et al. (2023) describes the cyclic model of intervention selection, which is based on internal factors (symptoms, understanding of aetiology, prior experience with the intervention), external factors (credibility of recommender and validation – understanding of symptoms/experience) and expectation (again based on experience and validation) which often occurs over a trial period of some duration. A comprehensive literature review by Noor et al. (2021) looked at treatment and management strategies used in ME/CFS. They grouped them into four broad categories: behavioural therapy, pharmacological therapy, complementary or alternative medicine, and dietary recommendations. The NICE (2021) guidelines recommend that individualised care should be provided by a multidisciplinary team who has expertise in working with this population and outline specific strategies, such as; energy management and reducing the risk of relapses through PEM strategies, improve physical functioning with the proviso that it does not worsen symptoms (and needs to be done through a specialist), incorporate sleep management strategies, manage coexisting conditions (i.e., OI, POTS or EDS) and add in any other symptom management strategies needed. For example, medication has been found to reduce some symptoms for some people (Castro-Marrero et al., 2017). In addition to what is mentioned above, a study on adolescents with ME/CFS found the most helpful strategies were for orthostatic intolerance, headaches, dysmenorrhea (painful menstruation) and fibromyalgia (widespread muscle pain and tenderness), dietary changes, advocacy, and active involvement in creating an individualised plan (Rowe, 2023).

The key is that each strategy can provide incremental improvements and minor improvements, particularly across multiple domains, add up and help people to keep moving forward with a recovery mindset. Even if there is only a five per cent improvement in any one domain, this will likely be worthwhile to pursue (Tate et al., 2023). For the most part, recovery is not instantaneous but occurs over the years, and will involve a combination of treatments, supplements and compounds (Tate et al., 2023). It is essential that health professionals become

skilled in early detection and the teaching of self-management strategies to prevent developing chronic long-term impairments (Burgess & Chalder, 2011).

A best practice approach is one that works with the individual to form a plan that includes management or treatment strategies for specific symptoms; this requires a long-term game plan with good supporters. Hasan et al. (2023) found that a significant amount of time, energy and money was needed to "identify, try and adapt interventions" (p. 8). They also noted the complex array of internal and external factors that influence treatment selection (i.e., validation, attribution of the cause, and personal illness beliefs). This is reinforced by the IOM (2015), which states that health professionals should validate the person's experience, schedule regular follow-up appointments, address questions about prognosis, assess health needs and provide relevant support. Validating the person's experience is critical for the person and the likelihood they will engage with healthcare services.

In reality, there are no definitive treatment pathways, and for the most part, people with ME/CFS (or their supporters) have to figure out for themselves what works for them. However, some good evidence exists for strategies that make a considerable difference in people's lives. Wilson et al. (2011) state that a person with chronic fatigue or a chronic illness can live well with their condition and lead a meaningful life, although this is typically not without considerable effort.

2.5.1 Case Study – Pacing, Unrefreshing Sleep, Fearful Thoughts and Follow-up

One of the few in-depth case reports focussing on treatment protocols was on an adolescent boy called 'George', who fully recovered (Burgess & Chalder, 2011). It is important to note that there is evidence that younger people have a better prognosis. George was an active teen who caught a stomach bug from overseas (the trigger) and, with the worsening of symptoms, ended up wheelchair-bound with limited ability to sit and talk. The treatment protocol targeted different symptoms within a multidisciplinary approach. It included establishing consistent routines and patterns of activity and rest (pacing), diaries to record sleep and daily activity, improving his sleep routine, dealing with fearful thoughts (using CBT), preparing and managing setbacks, working with the family and building a therapeutic alliance, and consistent follow up by professionals (23 home visits over 19 months). I want to focus on some of these strategies, such as pacing, improving sleep, and extensive follow-up (I address fearful thoughts in the next section).

Pacing refers to understanding your own personal 'energy envelope'; that is, energy is finite, and the person has to use strategies to manage/conserve energy, typically comprising of regulating activity to avoid the worsening of symptoms (O'Connor et al., 2017). The first scoping review on pacing and its effects on symptoms (involving 17 studies) was conducted by Sanael-Hayes et al. (2023). These authors found that the studies were not robust enough to inform treatment practices, and more evidence is needed for evidence-based guidance (i.e., using wearable trackers to monitor heart rate variability to improve pacing practice). However, for the most part, pacing as a strategy is typically recommended and reported to be beneficial for symptom management. For example, increasing rest periods and breaking tasks into manageable chunks can prevent people from progressing to a more severe stage of fatigue (exhaustion) (Olson et al., 2015). Although not commonly reported, one participant in this study became so worried about conserving energy that this approach had a detrimental effect. This individual worked with their doctor to figure out what they could or could not tolerate and devised a plan to only use a certain % of energy. "So, I was very careful and conscious. While I was continuously deteriorating… Later, I've thought a lot about "pacing". I got the advice I was looking for, that fitted my experience. I know it helps some. But I paced myself to bed!" (Bakken et al., 2023, p. 7). Pacing can be tricky to negotiate initially; you can become fearful about pushing the envelope too far, which can cause a relapse or crash. This is an area that would benefit from evidence-based guidance from health professionals.

Unrefreshing sleep is a symptom that people with ME/CFS widely report. Regardless of how many hours of sleep they get, the person will awaken and feel unrested. People report disrupted sleep/wake cycles, difficulty falling asleep or waking, and the inability to get back to sleep. Rowe et al. (2023) note the importance of treating sleep disturbances, as they can have devastating and adverse effects on all aspects of a person's life. Treatment is likely to start with establishing good sleep hygiene (behaviours to help with sleep routines/regulating circadian rhythms) and then move to psychological (i.e., stress/anxiety/fear) and pharmacological support.

George also had intensive support over a long period of time. Ghali et al. (2022) found that more extended follow-up periods were associated with better outcomes. It can be exhausting having to navigate the health system and manage symptoms, for example, keeping fatigue or dietary diaries. Having a health professional who can help you with this is beneficial (Scottish Government, 2023). This is also reinforced by the CDC, who state that routine health

check-ups should continue with monitoring of new illness symptoms (CDC, 2023). Furthermore, interpersonal relationships and supportive professionals can promote well-being. This can be seen in the level of satisfaction with health care professionals, which was related to how much health professionals took them seriously and believed them (Rowe, 2019). Social support could include emotional support, practical assistance (i.e., transport to appointments), and validation of experiences. Many studies have shown that social support can be a protector for health and has mutual benefits for mental and physical health (Umberson & Karas Montez, 2010). Understanding the availability and quality of social support and its impact on recovery can inform interventions to enhance support systems.

2.5.2 Disputed Therapies and the Physical vs Psychological Debate

There are strongly held viewpoints about studies that have a link to the psychological rather than physical. Some authors have argued that the methodology of several studies was ethically unsound or inadequate (Marks, 2022). In particular, this can be seen in the debate over CBT and GET. For example, CBT and GET are no longer recommended treatment options (Bateman et al., 2021; Geraghty et al., 2019; Marks, 2022; Vink & Vink-Niese, 2018), nor is the lightning process (NICE, 2021). On closer analysis (of CBT and GET), studies found that +the data generated concerns about the findings and applicability to ME/CFS (with variability in findings attributed to differences in methodology, diagnostic criteria and healthcare accessibility) (Vink & Vink-Niese., 2020). It was also found that fewer people can work after GET and CBT interventions (Friedberg & Sohl, 2009). The NICE (2021) guidelines state that CBT should only be used as an adjunct therapy (i.e., to manage illness distress). If someone chooses to undertake physical activity, this should be overseen by a physiotherapist within a ME/CFS specialist team and involve the following structure: develop a baseline, reduce physical activity below the baseline, maintain this before increasing activity, and make adjustments as needed while staying within energy limits. The difference between this approach to physical exercise and GET seems to be that GET uses a fixed approach to incremental increases in physical activities, whereas the approach in the NICE (2021) guidelines is individualised based on PEM. Another interesting point of view is that having a physical rather than a psychological basis as the cause of the illness is also a protective measure.

> *"Attributing CFS to a viral cause may be advantageous because the explanation is easy to understand and to explain to others, and it may also be self-protective as it precludes guilt, blame or social stigma that may be associated with alternative explanations.*

However, the problem of attributing CFS to a viral cause is that it may result in feeling helpless around self-efficacy for recovery" (Loades et al., 2018, p. 3).

On the other side of the debate, Sharpe et al. (2022) provide some additional background to this argument and describe how the methodological debate centres on the diagnostic criteria used, the use of subjective self-report measures, and inappropriate application of treatment protocols. They believe the core of this argument stems from a belief that if a psychological intervention improves symptoms, then it somehow disproves that ME/CFS is a physical illness. The authors believe this is the wrong conclusion to draw. They do not claim these interventions are a cure, nor that that ME/CFS is not a physical illness. Rather, they state that different therapies are part of a rehabilitation framework that can assist someone with some of the psychological and behavioural factors associated with living with and managing a chronic illness. This, then, seems to line up with the recommendations of the NICE (2021) guidelines. Certainly, other studies have found beneficial findings in the use of psychological treatments (i.e., CBT). For example, in a literature review by Noor et al. (2021), they talk about CBT as a useful behavioural strategy for symptom management. However, the critical distinction is that they are discussing CBT as an adjunct and not as a cure. In a meta-analysis (of 16 RCTs) of behavioural and psychological interventions (i.e., GET – targeted graded activity adopted for CFS, CBT, rehabilitation and multifaceted approaches), the authors found "sustained beneficial effects on chronic fatigue management, in particular on fatigue severity reduction" (p. 135). Perhaps the important point is how these therapies are used, what they are promising in terms of outcomes, and whether a ME/CFS health professional expert is involved. Regardless of treatment modalities, there is a need to observe one's limits and use pacing-led treatment approaches (Marques et al., 2015). It is interesting that in the case study of George (above), one of the things he needed to manage was his 'fearful thoughts' about ME/CFS. Furthermore, Burgess and Chalder (2011) note that fear of symptoms exacerbation can prolong the recovery process.

The debate continues around sanctioned and unsanctioned interventions; most of the mind-body interventions fit into the unsanctioned category. However, two of the latest articles on recovery from the perspective of the person with ME/CFS found that some people do account recovery improvement to mind-body interventions (Bakken et al., 2023; Hasan et al., 2023). The review by Castro-Marrero et al. (2017) found some positive benefits from holistic treatments (including nutrition and nutritional supplements), and they suggest that an

individualised multidisciplinary integrative medicine approach is used that combines psychological counselling and pacing. In a systematic review of mind-body interventions, they found that "fatigue severity, anxiety/depression and physical and mental functioning were shown to be improved in patients receiving Mind-Body Interventions" (Khanpour Ardestani et al., 2021p. 652). Those interventions included mindfulness-based stress reduction, cognitive therapy and stress management, relaxation, Qigong, Acceptance and Commitment Therapy (ACT) and isometric yoga. One participant notes that if the current debate about the "harmful effects of mentally based interventions" was around when he was recovering, he believes he might still be bedridden (Bakken et al., 2023, p. 9).

Another programme that has been reported to have some benefit is neural retraining (Tate et al., 2023). Two of the more popular programmes discussed online are Ashok Gupta's Amygdala and Insula Retraining Program (Gupta Program) and Annie Hooper's Dynamic Neural Retraining System (DNRS). These programmes are based on neuroplasticity, mindfulness and holistic health and both work on the stress response, which keeps the nervous system and immune system in a state of heightened arousal, causing inflammation (Johnson, 2021; MEPedia, 2024). Although there is no scientific evidence on the effectiveness of the DNRS (MEpedia, 2024), a small eight-week course based on the Gupta Program found that 80% of patients with fibromyalgia improved functionality by 30 – 50% (Sanabria-Mazo et al., 2020). The science behind how mind-body therapies work is expanding, and there is significant research happening with regards to the mind-body connection. On the other hand, people are fearful of being misled or symptoms worsening, and hearing testimonies of people who claim to recover from mental training programmes can cause confusion and resentment. As with most chronic illnesses, there is a psychological aspect to living with or managing a long-term chronic illness. Therefore, both autonomy and caution need to be applied when looking into treatment strategies. As discussed, ME/CFS is a multi-faceted illness that requires multiple tools to support well-being.

2.5.3 The Biomedical Model and Systemic Barriers to Healthcare

Although the biomedical model has long been criticised (Lyons & Chamberlain, 2006), our Western healthcare systems are still embedded in that model, which relies on specific biomarkers and tests for illness validation. Consequently, people with ME/CFS are often dismissed, and their patient testimony is devalued by the medical profession (Blease & Geraghty, 2016). Moreover, illness beliefs are perpetuated and shaped through medical

institutions, which filter into healthcare supports and services, of which doctors are the gatekeepers (Pilkington et al., 2020). Strassheim et al. (2021) explored the lived experiences of five people with severe ME/CFS and found that trying to legitimise ME/CFS within the biomedical model created blame (if it cannot be seen, then you must be at fault). A medical system that privileges what can be 'seen' or 'measured' provides a narrow frame to examine health behaviours and outcomes (Kornelsen et al., 2016). From this perspective, different illnesses hold different positions in the world, creating different illness experiences.

Overall, there needs to be more knowledge among healthcare professionals about ME/CFS and symptom management (Adamowicz et al., 2014). For the most part, General Practitioners (GPs) are the professionals who diagnose and treat patients. Without an adequate understanding of this illness, it can lead to delays in diagnosis and ineffective treatment programmes or management strategies, all of which hinder the recovery process. The downside is that people can be misdiagnosed; for example, Arroll & Senior (2008) found that antidepressants in all but one participant aggravated or worsened symptoms. Unfortunately, most people have to 'shop around' to find a health professional with the knowledge and expertise to treat them (Bateman et al., 2021). It has been well documented that a poor relationship with the medical profession impacts healthcare and creates barriers to diagnosis and engagement with health services (Pilkington et al., 2020; Stressheim et al., 2021). There are also other systemic barriers in managing ME/CFS, such as access to disability benefits, appropriate healthcare, and lack of accommodation in work or educational settings.

2.5.4 Traditional or Alternative Health Pathways

More research is needed on what supports and services people with ME/CFS use, particularly those that are outside of the traditional medical model. However, we know that many people with ME/CFS turn to alternative therapies or medicine to assist them when the medical model is considered unable to help them (Kim et al., 2020). One study found that GPs saw a non-return to the clinic as a success, considering that either the illness was a non-issue or that it resolved itself, rather than the person giving up on the traditional medical model as a means to help them recover. The individualised framework outlined by Brown et al. (2014) is one of the few articles that offer an integrative medicine approach (combining both conventional and evidence-based lifestyle medicine) to managing ME/CFS. Some of the strategies they outlined included dietary changes, addressing nutritional deficiency, increasing physical fitness that took into account PEM, managing stress/central nervous system

dysfunction, reducing environmental toxicity, dealing with gastrointestinal issues (dysbiosis and leaky gut), looking into immunological aberrations (i.e., viral onset or herpes virus), reducing inflammation and oxidative stress, and working to restore mitochondrial dysfunction (impaired energy production).

Finding support is fractured and often expensive, requiring personal resources, health literacy and the ability to fund treatment. There is a considerable financial cost for those who can experiment with different treatment modalities. Most funded healthcare or subsidised medicine is accessed through the GP. Meanwhile, for those looking for alternative approaches to health, this pathway is fully funded by the individual. An Australian study which looked at the direct and indirect costs of ME/CFS found that the annual cost per person was $75,697, of which $71,215 was borne by the person (70% from loss of income) (Close et al., 2020). Treatment costs and lack of income to fund recovery are significant contributors to slower recovery progression.

2.6 Summary

The literature on recovery in ME/CFS highlights the complexity of defining and achieving recovery in this illness. Care needs to be taken when defining and measuring recovery because of the heterogeneous symptoms and varied presentations of the illness (including differing physiological mechanisms, psychological influences, and systemic barriers), all of which can influence recovery pathways and recovery progression. Other possible influences include illness duration, symptom severity, comorbidities and treatment interventions used. While a recovery-oriented framework is recognised as valuable, the evidence for specific interventions is limited, underscoring the need for further research to guide the development of effective recovery-oriented approaches. Recovery-oriented treatments typically include strategies tailored to the individual's unique needs. These may involve pacing, activity management, and interventions targeting fatigue, sleep, nutrition, and psychological well-being. Therefore, it is likely that people will have a different experience of recovery and use different modalities and treatment pathways. Understanding the multi-faceted nature of recovery and addressing the impediments to recovery is essential for improving the management and outcomes of individuals with ME/CFS. By understanding recovery, this research can contribute to the existing knowledge base and help guide future research efforts and recovery frameworks.

CHAPTER THREE: Method

This chapter will begin by describing the methodological principles underpinning this research and how this influenced the research design, positionality and ethical considerations. I discuss my approach to participant recruitment, the interview process, quality criteria, and provide a transparent outline of how data collection and analysis was conducted.

3.1 Research Design

This research used a qualitative paradigm, which includes an interpretative phenomenological theoretical orientation and a critical health psychology lens to explore the recovery experiences of adult women with ME/CFS over time within Aotearoa, New Zealand. This research aims to increase knowledge and understanding of recovery, how it is defined, measured, and understood, and what contributes to or hinders recovery progression at the individual and systems levels.

3.2 Methodological Principles

This qualitative study is underpinned by the tenets of Interpretative Phenomenology Analysis (IPA), which include phenomenology, hermeneutics, and ideography (Smith et al., 2009). Phenomenology is uniquely positioned to explore and reveal insights into how people makes sense of their lifeworld (Langdridge, 2017) as it is primarily concerned with exploring an individual's personal account of a phenomena or event and how they interpret that experience (Smith et al., 2022). In addition, this study uses a critical health psychology lens to examine the systems participants are embedded within and whether they help or hinder a person's illness experience (i.e., ssystemic barriers and structural inequalities). This approach allows the researcher to explore personal experience, traditions, socio-cultural context, and the systems one is embedded in and how these shape our everyday practical experience and sense-making (Oerther, 2020) within the New Zealand healthcare system.

3.2.1 Hermeneutic Phenomenology, Ontology and Epistemology

IPA is underpinned by Hermeneutic Phenomenology, which provides the philosophical underpinnings to explain the theory of meaning and interpretation used within this approach (Suddick et al., 2020). The theoretical perspective is inspired by both Heidegger's hermeneutic approach to phenomenology, which is interpretive and based on 'being-there' or 'ways of

being' in the world (dasein), and Maurice Merleau-Ponty (1962) and his understanding of how our experiences and perceptions are embodied and embedded in the lived body and its surroundings. This is of particular relevance to this study as it is through this interactive bodily existence that participants perceive and express changes in their bodies through their recovery experience (Merleau-Ponty, 1962). IPA is linked with a critical realist orientation, which positions itself between positivist (objective, mind-dependent) and constructivist (subjective, mind-independent) worldviews (Allana & Clark, 2018), which influences how we come to understand knowledge claims and different realities (Finkel, 2014). Critical realism is ontological in that it infers that a reality exists that is "not dependent on observation" and exists "independent of our thoughts about it" (Haigh et al., 2019, p. 3). Our perception of reality involves a multi-layered, stratified approach. The approach uses both positions to help explain how physical and non-physical mechanisms (i.e., thoughts, ideas, stigma) and social or contextual influences can have observable or unobservable consequences on phenomena or events and the way we interpret or interact with the world around us (within the inter-connected and over-lapping domains of the real, actual or empirical) (Allana & Clark, 2018). This understanding of knowledge-making also maps onto the three modes of engagement described by Martin and Sugarman (2001) for Hermeneutic Phenomenology. This includes the *ready-to-hand mode* (unconscious engagement with activity or event), the starting place for inquiry and the grounding for interpretation, the *unready-to-hand mode* (beginning of awareness and interpretation), and *present-at-hand mode* (which looks at the event or activity in an abstract and detached fashion) (Martin & Sugarman, 2001). The researcher needs to be aware of the conscious and unconscious influences of knowledge-making as they explore the personal accounts of participants.

Each person interprets and assigns meaning to their experience, which is shaped through personalised meaning-making systems (i.e., self-awareness, intentionality, social interaction and context) (Grant & Giddings, 2002). Our meaning-making systems originate from our everyday practical activity, which includes our actions and pre-understandings (i.e., knowledge, prejudice, assumptions), which can be conscious or unconscious (Martin & Sugarman, 2001). Furthermore, the meaning we associate with the world we live in is co-constructed, offering a plurality of realities depending on the lens through which it is experienced, defined and understood. Therefore, knowledge claims from this theoretical orientation are not limited to a particular vantage point but take a much wider lens by exploring the object or phenomena of interest and the subjective interpretation of the personal experience

(Martin & Sugarman, 2001). Furthermore, our understanding is not static and changes over time, and the construction of knowledge is fallible as it is open to "challenge and change" depending on the mechanisms and entities we encounter at any given time (Haigh et al., 2019, p. 4). This approach acknowledges that how we make sense of our physical world is a complex, multi-faceted, bi-directional, iterative, interpretative process (Hiles et al., 2017). In order to understand a person's experience, the researcher needs to delve into the lifeworld of the individual by exploring personal narratives and an understanding of the social-cultural contexts in which they are embedded (including language, history, beliefs, attitudes and values) (Lyons & Chamberlain, 2017).

3.2.2 Bi-directionality and Co-constructed Interpretation

As a theoretical orientation, IPA does not see the researcher as neutral and does not believe it is possible to be a detached, objective observer as both the researcher and participant are inter-connected through the process of discovery and interpretation (Packer, 1985). IPA would suggest it is impossible to 'bracket' or set aside all our assumptions or to have 'value-free' research as our unconscious beliefs and biases shape our thoughts and feelings. Hermeneutic Phenomenology provides further insights into this dualistic, reciprocal, co-constructed meaning-making through the constructs of the Hermeneutic Circle and Fusion of Horizons (Pietkiewicz & Smith, 2014). New understandings are developed through building on our foundational knowledge or pre-suppositions through our interactions with others. Concerning research, the researcher needs to understand what the person is saying (manifest) and what they mean (latent) by delving into the narrative and breaking it down into its constituent parts while simultaneously looking at how this fits into the broader picture for interpretative sense-making. This involves fusing horizons, a process by which the researcher and participant merge or reject another person's intelligibility (understanding) with their own (Holroyd, 2007). From this concept, the researcher and participant knowledge claims change and evolve depending on the moment in time and socio-cultural context. In this way, the researcher is not detached or neutral but involved through the process of interpretation.

Applying this theory requires a robust interview process and analysis, whereby the hermeneutic circle is closed when the researcher reaches a 'sensible' understanding, free from the inner contradictions of the event/action being discussed (Laverty, 2003). The participant and researcher are involved in a double hermeneutic process (Smith et al., 2009) in which the participant describes and assigns meaning to their experience and interprets their sense-making.

Therefore, the sharing of our subjective experiences, practical activity, pre-understandings, and interaction with others constantly influences meaning-making through the fusion of horizons, creating a shared or transformative process in understanding the event or experience (Martin & Sugarman, 2001). In this way, the researcher and participant relationship also influences meaning-making throughout the research and interview process (Clare et al., 2008). Phenomenological research should use the participant's own words and a clear link to the narrative, as this gives further evidence that the findings are grounded in the data, providing more credibility to the results. This research demonstrates this by the number of extracts used from the individual narratives.

3.2.3 Idiography

An idiographic study is an in-depth analysis of personal experience (often through a single case study). Idiography looks at each case in its entirety (considering context) before moving on to the next person's experience. IPA does not seek consensus or generalisable findings amongst participant experiences; instead, it aims to highlight the experience (where things align and differ) from an in-depth examination of a phenomenon or event. This approach was used for this research, whereby the first participant's personal account was read and re-read and initial exploratory notes made, which were turned into personal experiential statements, before moving to the next participant's transcript.

3.3 Recruitment and Participants

3.3.1 Purposive Sampling

I used a snowballing technique for participant recruitment and purposive sampling to enable a more homogenous sample. This is in keeping with IPA in that samples are relatively homogenous, so you can capture, delve into and analyse a particular experience or event (Shinebourne & Smith, 2010). IPA research tries to define its sample (including characteristics) as much as possible, as it aims to look at similarities and differences within a particular group of people (in this case, adult women with ME/CFS). In addition, ME/CFS affects more women than men (Chu et al., 2019), and women report more symptoms than men (Noor et al., 2021).

A limitation often discussed when using purposive sampling is that it does not provide generalisable findings and uses a non-representative sample (Robinson, 2014). However, given that the purpose of this research (and theoretical orientation) is not to provide generalisable

findings or use a heterogeneous sample, this limitation is not a significant disadvantage for this research. One of the quality criteria for this research is transparency. Therefore, it is essential to highlight that this study aims to explore the convergent and divergent themes of a particular group of people by using an in-depth qualitative analytical and interpretative process (IPA) in exploring lived experience. The findings and recommendations of this research are not generalisable, nor is the aim to find a consensus about the lived experience of recovery for women with ME/CFS. Instead, this research is about the in-depth exploration of personal accounts of the lived experience of eight women with ME/CFS living in Aotearoa, New Zealand. IPA is about understanding the unique experiences of a particular group of people rather than trying to average data or turn data into formulations and losing the qualitative nature of the personal accounts.

3.3.2 Sample Size

A smaller sample size is in keeping with and helps to maintain the idiographic tradition of singular case studies (Smith & Osborn, 2003). As discussed above, the same idiographic process was applied to additional participant case studies. Given the relatively small sample size, a focus on women provided me with the opportunity for a more nuanced and in-depth analysis of recovery at the individual case level (Smith et al., 2009). This is in keeping with the methodology of IPA, which is about the depth of interpretation on a particular topic and group of people (Shinebourne & Smith, 2010).

Although there is no specific rule to determine the sample size, in general, the number of participants would range from one to ten (depending on the level of research). For example, you might have three participants for an undergraduate study, five participants for a master's research project and up to ten for a doctorate (Smith et al., 2022). My initial aim was to interview between six and eight participants. I ended up interviewing nine people, of which eight participants were included in the final analysis and write-up. The ninth participant was excluded due to illness duration (six months as opposed to an average of 11.5 years for the rest of the participants). This also enabled a more homogenous sample and reduced the sample size to the original proposal.

The initial advertising and snowballing strategy effectively found people who wanted to participate in this study. Participants were enthusiastic about talking about this topic, and it was easy to find people; in fact, I had to limit the enquiries. Because each participant had

between two and three interviews, this generated a lot of data and usable quotes. However, the same idiographic process was applied across all eight interviews, enabling an in-depth understanding and analysis at the individual level and across the data set to uncover themes.

3.3.3 Participants

Nine participants were interviewed, eight of whom were included in the research and given pseudonyms. All participants lived in a regional or major New Zealand city (no one lived rurally). Participant data is summed up in Table 1.

All participants met the following criteria:

- Participants must identify as women.
- Participants must be over the age of 18.
- Participants must reside in Aotearoa, New Zealand.
- Participants must have lived experience of ME/CFS.
- Participants of any ethnicity were invited to participate.

Table 1

Participant Information

Participant	Age	Ethnicity	Length of time to diagnosis	Length of time with illness (up to 2023)
Amelia	44	Asian	3 years	8 years
Charlotte	51	NZ European	2 years	9 years
Mia	51	NZ European	2 years	26 years
Olivia	46	NZ European	10 years	21 years
Sophie	42	NZ European/Māori	6 years	13 years
Catherine	34	NZ European	5 years (until confirmation)	10 years
Emily	40	NZ European	1.5 years	4 years
Hannah	25	NZ European	3 – 4 months	11 years

Participants were also asked to give an indication or rating based on their fatigue at the height of their symptoms and what level they thought their fatigue was now. Using a rating scale - 0 meaning 'no fatigue' and 10 meaning 'fatigue as bad as you can imagine'. Scores are categorised as mild (1–3), moderate (4–6), and severe (7–10). At the height of symptoms fatigue was rated between 8 – 10. Currently participants rated their fatigue mostly 3 and under, however there were fluctuations in fatigue ranging up to 6 or 7.

All participants, apart from one, had a diagnosis of ME/CFS by a health professional. The participant who did not have a diagnosis saw a ME/CFS expert who confirmed she fitted the criteria for a diagnosis of ME/CFS, but she did not seek a diagnosis as the advice given was that she was on the right path to recovery, and her health was improving at that point. Although my research was open to all New Zealanders, the participants were predominately New Zealand Europeans apart from two participants. This is likely because advertising through university and personal networks will inadvertently reflect on the researcher's positionality. For future research, it would be advisable to go further afield to hear the voices of other ethnicities, including those of Māori. All women identified as cis-gender (she/her).

For this research, I have defined my sample as adult women with ME/CFS over the age of 18. Initially, I contemplated limiting the age to 45 years because I thought illness changes might be confounded by age and menopause (Chu et al., 2019). However, most studies have not found age associated with poorer outcomes or impacting prognosis. The study by Matthews and Komaroff (2007) found that physical function tended to improve even though people were ageing, and that being older at the age of onset was associated with better outcomes (Ghali et al., 2022). In addition, the typical onset of the illness for adults is between 30 and 39 years (Grach et al., 2023), and the average wait for diagnosis is five years. Recovery progression is estimated to take between three to nine years (Cairns & Hotopf, 2005), although it should be noted that not everyone recovers. An often-cited article estimates that around five per cent recover and 40 per cent achieve a substantial improvement (Devendorf et al, 2019a). Although there is a wide variation in illness severity and duration, recovery or improvement, changes typically occur over years rather than months. Given this, it was decided to leave the age band open.

3.4 Interview Schedule and Procedure

A semi-structured interview guide interview was developed (refer to Appendix C) using open-ended questions to answer the research aims. IPA favours semi-structured interviews because of the dynamic co-constructed role of the researcher and participant. This research used semi-structured open-ended questions in a face-to-face online interview. A semi-structured, participant-led approach to interviewing enabled me to be responsive and flexible and use follow-up questions to generate a greater depth of understanding about recovery progression (Magnusson & Marecek, 2015). This type of interviewing is in keeping with IPA, which elicits rich data through the in-depth interpretation of meaning-making (King & Hugh-Jones, 2019).

Each potential participant was sent an information sheet and consent form (refer to Appendix A and B) prior to agreeing to take part in the research project. In addition, before the initial interview, I had an online meet-up with each participant to get to know one another, build rapport, and review all the documentation (consent, information sheet, and research aims). I clarified this was a no-obligation meet-up and that participation was voluntary. This meeting helped to build some connections between the participant and researcher prior to the first interview.

If the participants were interested, they sent back a signed consent form. Although my preference was for face-to-face interviews, all the interviews were conducted via Zoom. I felt that face-to-face interviews would help with reading participants' body language and creating rapport, and this might be less accessible using an online format. The reason for participant interviews taking place online was participant location and preference. Only one participant lived in the same city as me, and they choose to have the interview online as it saved time and energy in getting to a physical meeting venue.

Given the length of time people can have this illness, I allowed for two one-hour interviews, with the possibility of a third shorter follow-up interview (if needed). The transcription of each interview was completed before the following interview. At the start of the second and third interviews, I clarified any points that were not clear from the recording or transcription. I also emailed participants if I needed a point further clarified. Having two (or, in some cases, three interviews) contributed to the depth and rich data I ended up with for analysis. It was also helpful in building rapport, which developed over the interviews.

All interviews were conducted online, and participants were offered the option of having the interview through Zoom, Microsoft Teams, or a video call (through their PC, Mac or phone). Dual recordings were made using the online platform and Otter.ai (purchased for its transcription service). This meant I had a backup in case there was an issue with the recording or the recording quality. I gained verbal consent to start the interview once participants indicated they were ready. Due to the possibility of fatigue or energy issues, I ensured a five-minute break was taken during each one-hour interview. Participants were asked to let me know if they needed additional breaks and if the interview length needed to be adjusted. Each participant was offered a koha for participation in the research, which all participants accepted. The koha was paid via a bank transfer.

3.4.1 Timelining Tool

A graphic elicitation (timelining) tool was used to help draw out deeper, richer discourse in conjunction with the semi-structured interview questions. There are several benefits in using a timelining tool in qualitative research; predominately this is to deepen storytelling and allow for greater participant control, reflection, and contemplation (Sheridan et al., 2011). It also helps anchor and focus the interview on critical elements while visually representing the participant's story (Marshall, 2019). This is important, as previous research involving recovery narratives of young women with ME/CFS found the storytelling jumped back and forth (Krabbe et al., 2023). My purpose for using this tool was threefold: first, because narratives were retrospective and could potentially cover an extended period of time; therefore, using this tool helped participants think about key memories or events at different moments of time. Secondly, because of the length of time participants could have this illness, the timeline helped with the flow and focus of the interview. Finally, it gave a visual representation of their journey, which assisted with storytelling and rapport. During the initial meet-up and consent process, participants were asked to create a timeline of their recovery journey, noting key events or moments in time. Given that energy may be an issue for some participants, there was no expectation of how this would be created. For example, written on a piece of paper and a photo taken was perfectly fine. Refer to Appendices E, F, and G for examples.

3.4.2 Interview Questions

The interview guide was developed following the guidelines outlined by Smith and Osborn (2003), who noted that interview questions should be open-ended, neutral, jargon-free

and relate to the research question/s. Notably, Smith et al. (2022) state that the researcher needs to ensure they are not leading a person to answer in a particular way. This requires care and consideration by the researcher, as follow-up questions also need to follow the same open-ended structure. Using statements such as, “Can you tell me more about that?”, “When you said …. what did you mean by that statement?” or “How did that make you feel?” and “What did you think about that?” were helpful in eliciting information without leading the participant. A closed-ended question was used where clarification of a point made was needed. Given that the interview was participant-led, I used the schedule as a guide, and skipped questions where I felt they had already been answered.

A pilot interview was conducted with another colleague for feedback on the interview questions. This was considered part of ethical due diligence, particularly given the contested and stigmatised nature of the illness. The interview questions were considered adequate with the provision that I sought the participants’ definition of ME/CFS early in the interview, given that there were considerable differences in definition and diagnosis.

3.5 Procedure for Data Analysis

The study followed a similar process to IPA data analysis, as described by Smith and Eatough (2007) and Smith et al. (2022). A summary of this includes keeping good records, familiarisation with the data, identifying initial themes from individual accounts and organising themes into clusters; themes are then refined, condensed and re-examined across the data set, finally creating a narrative that accounts for the key themes across participant experiences (including similarities and differences). In practice, this analysis of transcripts involved:

1. In-depth familiarisation of the transcripts

The first participant interview was transcribed (adding in pauses, stops, starts, and intonation), and a column was added for exploratory notes (refer to Appendix H for exploratory note excerpt). Each transcript was read multiple times so that I could become immersed in each participant’s narrative. At the same time, key passages were highlighted, and initial notes made. After at least two readings, free coding was used to note down emotional responses, salient features, and I wrote exploratory notes and made reflections (Larkin & Thompson, 2011), which were turned into experiential statements (summarising the meaning of key text). This process was followed for each participant so that an idiographic tradition was maintained.

2. Initial themes generated and organised into clusters

The first participant's experiential statements (from their transcripts) were initially written down onto pieces of paper so that I could move these around and see where they fit with one another. A visual process was initially attempted so that I could move the experiential statements into individual personal experiential themes (PETs). However, in the end, an Excel spreadsheet was used as it was less confusing, easier to navigate and a more visually useful way to display the data. I also found it easier to see themes across the data set using this format. In the literature, there is no 'right' way of doing this. How you do this is less important than making sure you have truly immersed yourself in the data. Ensuring you have taken the time to ponder and delve into the sense-making of the personal accounts provided. The Excel sheet enabled a visual representation of where individual experiential statements mapped onto each other, forming personal experiential themes (PETs). Refer to Appendix I for PETs excerpt.

3. Themes are refined, condensed and examined for connections.

After identifying the PETs for each participant, I looked at what might make sense to group together across the data set and looked for convergent and divergent patterns. This enabled the creation of group experiential themes (GETs). Throughout this phase, the participant quotes that mapped onto each theme were put together and closely examined. I not only wanted to look for convergent or divergent patterns, but also to ensure the experiences and perspectives of each participant were captured within the analysis. It also provided a sense of the importance of different themes, depending on the number of quotes and participant's perspectives within the data. Although not all the quotes were used, this approach enabled me to feel ethically confident that a participant's account was not inadvertently privileged over another. The Excel spreadsheet allowed me to move PETs into GETs relatively quickly and to visually see the data. Refer to Appendix J for GETs excerpt.

4. The consensus of general themes is finalised.

This process required numerous edits to reduce the number of participant quotes, deciding which themes and quotes were most relevant in answering the research questions. The data was then arranged into a narrative flow and structure that made the most sense to the findings. This also illustrates the practical application of the hermeneutic circle and the fusion of horizons within the research process (Smith et al., 2009).

5. A narrative of the findings is written up that includes the participant's personal narrative and researcher's interpretation.

Once the key GETs were decided and the participant quotes were highlighted, the structure and flow of the thesis narrative was created. This needed to make sense to the data and the research questions. Again, this required reading and re-reading and numerous drafts to add in the interpretation from the data and personalised quotes used. In some of the participant quotes, in the findings section, a word is underlined to emphasise stronger intonation by the participant.

3.6 Ethical Considerations

Due to the sensitive nature of this topic and the potential for distress, a full ethics application was made through Massey University Northern Committee. Approval was granted by the Massey University Human Ethics Committee on the 12/05/2023 for Application OM1 23/11. Underpinning this research are the quality criteria (below), the Massey University's Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2017) the Treaty of Waitangi and the key principles of partnership, participation and protection. Should a participant identify as Māori, I would adhere to 'Te Ara Tika', the Māori ethical framework for research (i.e., including whānau in interviews) and follow the guide for working with Māori participants which was developed as part of the full ethics application.

3.6.1 Privacy, Autonomy and Informed Consent

Participants were fully informed about the nature and purpose of this research, its risks and benefits, and were supported in making decisions regarding their voluntary involvement. It was reiterated that at any point, they could decline to answer questions, ask for more information, or withdraw from the research. All records, including consent forms and transcripts, were secured to prevent third-party access.

Before the first interview, the participant was sent the Information Sheet which included information on consent, confidentiality, participant rights, and how data will be used and stored. For the most part, the consent form was signed before the first interview; one participant could not send a signed consent form, so consent was verbally recorded. Before agreeing to participate, each participant had a pre-interview meeting, which allowed them to go through the consent and information sheet and ask or clarify any questions regarding the

research. Each interview was set up at a time and location convenient to the participant. Consent was considered open-ended in that participants had the right to withdraw at any point throughout the research process.

Due diligence was given to the possibility of identity within a small community like ME/CFS. Therefore, it was considered important for participants to amend or clarify their transcripts, and any potential identifiers were removed or de-identified. All interviews were transcribed using voice recognition software (i.e., otter.ai). Verbal or written consent was obtained from participants for authority to continue to use the data from the transcripts upon transcription (refer to Appendix D for authority to release transcripts). Transcripts were downloaded into Word documents, which were used for the analysis. All transcripts were destroyed upon the completion of the study.

Pseudonyms were assigned to protect the participants' anonymity. Participants were initially assigned numbers as pseudonyms; this was later changed to women's names as this created a warmer narrative in relation to participant quotes. Before the second interview, the transcript was checked for accuracy, and those who requested their transcripts were sent an anonymised copy via email. All participants were given the opportunity to check the accuracy of the draft findings which included the quotes that would be used in the thesis. The master list of participants was held on a password-protected computer and destroyed following the completion of the research.

3.6.2 Exclusion Criteria

Consideration was given to the possibility of post-exertional malaise (PEM) from involvement in the interview. To mitigate this each participant was asked if they considered themselves to be in the mild, moderate, severe or very severe category as outlined in the NICE (2021) guidelines. No participant identified as being in the severe or very severe category. Most participants considered themselves in the mild category, although flare-ups could move them into the moderate category.

3.6.3 Distress to Participants

Sharing personal narratives provided me with an intimate glimpse into participants' lifeworld's, which can include a variety of experiences and emotions, including trauma, sadness, joy, loss, and restoration. The interview, therefore, needed to be approached with care,

and I needed to be mindful of their body language, using empathetic listening and neutral and non-judgemental language. Because of the personal topic of the interview, it was important that I created a 'safe place' whereby participants felt empowered (and valued) for sharing their narrative and journey (Hydén, 2014).

For this research, the participants' energy levels also needed to be considered, which, from the my perspective, was part of providing a high level of ethical care. Therefore, a break was included in every interview (mid-way through), and additional breaks, emotional support, or early interview termination was also offered at various points throughout the process.

At the beginning of each interview, it was reiterated that should a participant become uncomfortable or distressed during the interview, they would be given the option of pausing (to de-escalate), skipping distressing questions, or stopping the interview. One interview was terminated early for one participant who was struggling with energy levels and also shared a distressing moment in her account. After checking in with her on multiple occasions, we decided to finish the interview early. I followed up with an email and check-in before conducting the next interview. Additional national support organisations were also included on the last page of the information sheet.

3.6.4 Risk of Harm to Researcher and Insider Status

Risk of harm was minimal in terms of physical safety; however, thought was given to my status as an insider researcher and the possible benefits and risks associated with this positionality. Given that all interviews were conducted online, and no public locations were used, this mitigated the need for strategies to safeguard my physical safety. What I did need to consider was the potential impact of being an insider researcher. I made my position known in the advertising material that was sent out. Because I have lived experience of ME/CFS, I felt there was a possibility that interviewing people on this topic could trigger an emotional reaction in me. I scheduled regular check-ins with my supervisor and had access to other support services at hand.

I believe that being an insider researcher did enable a level of relationality that deepened the trust participants felt in disclosing personal information about their experience of ME/CFS. However, being an insider researcher also poses challenges. I was mindful that researching something meaningful to me might influence my understanding and interaction with

participants. An insider researcher brings their pre-understandings to the research, many of which may be unconscious (Frost & Bailey-Rodrigues, 2019). IPA talks about *bracketing* these pre-understandings and putting them to one side (Kornelsen et al., 2016). However, it is impossible to completely 'bracket' these pre-understandings as they implicitly and explicitly influence our thoughts, actions and behaviour. Given this, I wrote down my own experience, acknowledging my assumptions through a reflexive journal and purposefully sought clarification by asking follow-up questions to ensure I had understood how they made sense of their own experience. I also reflected on how my perceptions and assumptions changed through this subjective reflexive process and the fusing of horizons from shared experience (Horrigan-Kelly et al., 2016). A reflexive journal is a valuable inclusion within the research process as this can note how 'understandings' change over time due to the researcher-participant relationship and the sharing of knowledge and experience (Shaw, 2019). Refer to Appendix K for a reflective journal excerpt.

3.6.5 Cultural Considerations

This research was open to all people who reside in Aotearoa, New Zealand. In relation to working with Māori, in conjunction with academic and cultural supervision, I also sought consultation through personal networks (a lived experience lead working for the Māori Health Authority who has experience with Tiriti dynamic and whānau-led campaigns). This included the creation of a guide for working with Māori participants, which included recognising the diversity of Māori and clarifying individual cultural needs (Herbert, 2012). The guide included Māori research principles (from Te Ara Tika) as well as ways to minimise the risk of harm and maximise benefit. This included the use of Te Ao Māori and tikanga, taking time for whakawhānaungatanga, using the hui process as an interviewing technique, including whānau in the interviewing process, ensuring findings goes back to the community, understanding the importance of spirituality, whakapapa, the connection to the land and the inter-connection between mind, body and spirit for health and illness. In addition, the principle of Te Tiriti underpinned my research (partnership, protection and participation) (Hudson et al., 2010). An essential part of honouring my participants' contributions was through the gift of a koha. This is an acknowledgement of and respect for sharing their stories and the time given to do so.

3.7 Quality Criteria

Given that there has been and continues to be much debate over the robustness of qualitative research, it is important to apply quality criteria to research. There are 'set' quality criteria for qualitative studies; the researcher must decide on and apply principles that make sense to their research design and research aims (Frost & Bailey-Rodrigues, 2019). By applying key quality criteria throughout the research process, the researcher demonstrates *rigour* and a way to appraise the trustworthiness and credibility of the research design in answering the research questions (Brocki & Wearden, 2006; Stenfors et al., 2020). Applying these quality criteria increases the usefulness of the research. The following criteria were adapted from Frost and Bailey-Rodrigues (2019):

Transparency: A key quality criterion is transparency, as this enables the research to be replicated and provides a clear outline of your research design and positionality (Etherington, 2007). To assist with transparency, I kept meticulous record-keeping throughout the research process, including decisions around research design, theoretical orientation, data collection and analysis. This included using reflexivity, where changes in direction, knowledge and understanding were recorded. Records were made of exploratory notes, PETs and GETs, and visual mind mapping to work out themes and narrative flow. Quotes from the transcripts were used to underscore the connection between the raw data and thesis findings. Transcripts were made available on request, and participants were given the right to review any quotes used in the findings section of the thesis.

Coherence: (using IPA and following an idiographic tradition provided a coherent methodology) for the research design which used a qualitative framework, a phenomenological theoretical orientation, and a critical health psychology lens. This framework is appropriate for a small-scale research project looking to explore the lived experience of recovery for adult women with ME/CFS and the socio-cultural context in which they are embedded.

Value or contribution: the findings are expected to inform the ME/CFS community about recovery progression, increase knowledge within the medical/health profession of what can help or hinder progression, reduce the inequity and stigma of 'contested illnesses' and offer valuable recommendations for better healthcare.

Reflexivity and positionality: One of the quality criteria for Hermeneutic Phenomenology is reflexivity (Laverty, 2003). Spence (2016) states that reflexive practice is

part of the hermeneutic circle, which evolves as one listens to personal accounts and delves into exploratory notes and experiential statements by reading and re-reading transcripts. The interconnection and reciprocity of the researcher and participant relationship influences knowledge-making. The researcher does not live outside the data but is entangled within it. They are intricately involved in building the narrative through this bi-directional interaction, analysis and interpretation. Reflexivity is not a one-off process but needs to occur as a self-critical process from the start of the research design to the conclusion of the analysis and write-up.

One of the underpinning principles of critical health psychology is the notion of power and power relations (Lyons & Chamberlain, 2006). Again, eliminating power relationships is almost impossible because they are often culturally and contextually situated. For example, the interviewee and researcher relationship has an innate power imbalance. This was mitigated as much as possible by giving participants agency over where the interview was held, the right to amend their transcripts and the ability to disseminate findings back into their communities. I was also aware of how much this illness is contested and stigmatised not just by the medical profession but also by families, work colleagues and friends. Therefore, I needed to validate and create a safe place for participants to explore their personal accounts.

CHAPTER FOUR: Findings

This chapter begins with a summary of the themes (Table 2) followed by in-depth discussion of each theme in turn. The themes outline the recovery pathway of a *"unpredictable and unreliable illness"* and demonstrates how participants move from the initial challenges of becoming ill, through to experimentation (trial & error) of different treatment modalities to an in-depth understanding of what recovery means for them and how they live with and manage this illness.

Table 2

Summary of Themes

Theme	Theme Headings	Sub-themes
One	**Being Believed and the Challenges of an Unpredictable Illness**	1. No one knows how to help me 2. It's all in your head 3. Being doubted makes me doubt myself 4. Being believed is integral to a recovery mindset
Two	**Trial and Error and Finding a Pathway Through**	1. Working out the puzzle 2. Systemic barriers 3. Trial and error
Three	**Understanding Recovery**	1. Recovery in (not from) and the paradox of being 'healthy' 2. Recovery progression within the ebbs & flows of an unpredictable illness 3. Acceptance and personal growth

4.1 Theme One – Being Believed and the Challenges of an Unpredictable Illness

This section is about the importance of belief and the impact this has on recovery. In effect, being believed is pivotal to moving into a recovery mindset. This theme also focuses on the experiences that help or hinder the thought of recovery. For all participants, there were periods of not knowing what to do or who to go to for support, plus a lot of poor advice. The participants all experienced a range of symptoms and extensive disbelief, stigma, stereotypes and a general lack of understanding. Once participants felt they were believed, this played a pivotal role in changing a person's mindset (which often coincided with finding the right professional) and moving them into a recovery pathway. ME/CFS is not well understood, so symptom management and recovery trajectories are complex.

4.1.1 No One Knows How to Help me

Every participant started their journey to recovery in a place of uncertainty, confusion, and doubt, with their predicted life-course trajectory in disarray and an illness pathway that is anything but predictable or linear to navigate. Participants did not know where to find information or who could help them.

> …for chronic fatigue, there's not a clear. There's, you know, it's not publicised; it's, you know, like, I mean, even for myself, I struggled to understand what I've got (Sophie).

> ... you can't find it [information], and you don't know it exists, so you don't know how to look for it. And the biggest block would be it's all in your head, or, um, you know, you don't actually have a real condition to look into (Charlotte).

Part of the difficulty is that the word fatigue means many different things to different people. Telling someone you feel *fatigued* does not do justice to the embodied experience, functional limitations and lack of bodily control that happens to someone who has ME/CFS. These differences are clearly described by Charlotte.

> ...[there are] different levels of feeling tired, different meanings of the word tired. That's what my friend and I have decided. Yeah, there's so many different definitions to the word tired that people without chronic fatigue don't understand. Yeah, it can, it can mean, yeah,

> everything from, I'm a bit tired. I need to take things a bit slowly, to, yeah, I'm so exhausted that if anyone talks to me right now, I'll cry.

This is further supported by Mia, who believes it is hard for people to understand what fatigue feels like unless they have experienced it. She describes it as "*when you don't know what pain's like until, say, childbirth [laughs], and then you understand it. And it's like, you don't know what fatigue is like until you have experienced chronic fatigue*". Emily and Amelia provide powerful descriptions of fatigue, describing their bodies shutting down, their feelings of helplessness and their loss of control to make their bodies obey.

> ME is about, not just feeling exhausted, it's more than that, it's actually… paralysis. It's cataplexy. It's…. a feeling of being trapped within your body and you have absolutely no control, and you feel really helpless (Amelia).

> [Fatigue is] extreme, so debilitating, it's not like a tiredness where you just haven't slept well, is it? You know, it's that kind of, you just can't … even … move; you can lie there and tell your body, right, it's time to get up, but your body's like going, nup, not even listening. I'm in hibernation mode. And nothing you say is gonna make me *actually* move (Emily).

The embodied descriptions of fatigue illustrate how ME/CFS can lead to failing bodies, trapping people in a body that is out of their control. There is an evident lack of understanding about the levels of functional impact and symptom severity of ME/CFS by medical professionals. This includes understanding the embodied experience of 'fatigue', a symptom often dismissed, not taken seriously or misdiagnosed. This adds to the burden of the illness as it can add years to getting a diagnosis.

> It was about two years later from my first getting, um, glandular fever. Two years of being pretty unwell, with nobody being able to tell you anything (Mia).

In addition, at the beginning, participants did not have the words, health literacy, or understanding to advocate for themselves. This makes adjusting to the illness more complex, which again slows down any possibility of moving towards recovery.

> … [People with ME/CFS] suffer through adjustment disorder because there's just so many unknowns, and no one is actually helping them throughout that, you know, throughout that journey... well, I don't have a health degree, my career is in commerce and I, I never got sick,

> I never even went to the GP ... So, I didn't have the language to even describe my experience, um, at the beginning of my illness (Amelia).

> …because no one knows what to do. Like there's no, there's no cure, and no one explained to me exactly what it was, and I never had a GP sit down and say, "okay, well, these symptoms can be contributed back to chronic fatigue" (Sophie).

Olivia describes that even when she did have a diagnosis, the GP often did not know what to do, which left her floundering. She cynically asks if they have "*something on my file that just says, just take her money and push her back out the door, because there's nothing we can do for her*". Even when there is something that shows up on a blood test that would warrant further investigation, the diagnosis of ME/CFS can get in the way. The rheumatologist told Emily, *"Um, plus, you've got a chronic fatigue diagnosis, and it doesn't respond to immunosuppressants. So, there's no point in us doing anything. I think even on the letter, it says something like, there's no treatment for it*." This lack of understanding fuelled doubt, confusion, frustration and loss of faith for participants, particularly with the traditional medical model. All the participants felt similarly to Mia and Olivia due to negative medical experiences.

> What I've found is it's really difficult facing GPs who have no understanding of this illness (Mia).

> I've really lost my respect for GPs. All they are is general practitioners; they can just deal with people who have a cold, and nothing more complex. Yeah. I can google just as much as they can. I've sat there while they're googling (Olivia).

Negative medical experiences were primarily around being dismissed and not being believed from different medical experiences. For example, Catherine talks about some nurses who were dismissive of ME/CFS and that other nurses "*absolutely, um, accept that it is a real illness, a real disease"*. This is echoed by Charlotte, who was told to "*toughen up", from a GP who came from another country, a war-torn country who said, "You know, your problems you're telling me are nothing compared to what I've seen*". Because symptoms were often dismissed and needed to be better understood, participants were often given inaccurate advice that was detrimental to the management of ME/CFS. This was a common experience for all the participants, and the poor advice ranged from diet, exercise and medication, which the participants attributed to a need for more education on ME/CFS. Hannah said, "*Yeah, education*

is a huge thing that's just lacking". Being told to exercise is one of the misdemeanours for this illness, as exercise can worsen the illness and increase fatigue.

> There's always an emphasis from doctors to say, "Oh, look, you probably just need to get out more and do more exercise". And that's always the opposite of, of, what you actually need to do. His advice was just so inappropriate to be honest. If I had taken his advice and gone and worked out at the gym, I would have been bedridden, for sure (Mia).

Several participants eventually did find a good GP, and these GPs either had lived experience, were experts in the field or were Integrative GPs working from a more holistic approach. Participants who did find a health professional who believed them found this pivotal to their recovery.

4.1.2 It's All in Your Head

All the participants, at some point, grapple with the question of whether ME/CFS is a physical or psychological illness. This is caused by the contested nature of the illness (i.e., there is no biomarker) and the long battle for ME/CFS to be recognised as a physical rather than a psychological illness. For all but one participant, getting a diagnosis for ME/CFS was fraught because blood tests didn't turn up anything; participants were made to feel it "was all in my head". The average length of time for diagnosis for participants in this study was three and ¾ years.

Amelia tells me how the history of ME/CFS makes it harder for people because there is so much stigma associated with the illness. She ponders how much the stigma of the illness impacts people's progression/prognosis:

> And historically speaking, ME/CFS has had such a bad rap. A lot of times, people with ME have been put into the malingering bucket. Yeah, so ... if history could be erased, and if we could start afresh, and maybe... we started during the time of COVID and did not have that kind of stigma, then I think, people with ME would have better progression, um, prognosis, I mean (Amelia).

The stigma attached to ME/CFS reinforces the popular notion that symptoms were "all in their head" (five participants used that phrase). This is more prevalent at the journey's beginning but rears its head throughout their collective experiences. Olivia remembers:

> …reading the note from the psychologist or neurologist, whatever it was, the way it was written. You know, it was basically, they're like, she's just, it's just in her head, she just does too much, she just needs to do less.

After chatting to a mum who was a GP at her daughter's school, Mia remembers thinking:

> She's got nooo understanding of it, no idea, and she was quite a person that's a no-nonsense sort of super-organised person. I can't remember what she said, but it was pretty much, she was like, just sort of, "Ah yeah, it's all in your head," you know? (Mia)

The following excerpts demonstrates the lack of knowledge of the medical profession to recognise ME/CFS, typically privileging a mental health diagnosis, particularly depression.

> I felt like I was dying, and I was just getting worse, and his advice was just like, "Ah, I think you're depressed". And I knew I wasn't. I had a touch of depression in 1995. And I knew in myself that this was not depression (Mia).

The problem with prescribing anti-depressants, particularly for three participants (Emily, Sophie, and Amelia), was that it made symptoms worse. Amelia found selective serotonin reuptake inhibitors (SSRIs) useless and felt that they did not help fatigue at all, which is similar to Emily's viewpoint (below). Participants are talked into taking anti-depressants, even though they know they are not depressed, doubt it will alleviate their fatigue, or have concerns it is making things worse.

> My doctor kept saying, "Ooh look, I think we should try you on an anti-depressant". And I said, "But I'm not depressed; I'm just exhausted. And I'm frustrated that I'm sick" "I'll put you on amitriptyline," and I'm like, "I hate amitriptyline. We've tried it before. It just makes me too tired". And <u>you</u> know, it's not going to help (Emily).

Sophie describes a painful experience where her GP talked her "*into going on anti-depressants*" and was told to "*just push through and go for a walk*". And that the medication would "*alleviate it*" [the depression].

> Like just being in tears in the car, wanting to take my life. I just, it just felt like everything was too hard. And I just had no joy in life anymore. And I mean, we drove back home and stopped at the GPs... and I said to her, "Look, you've asked me before if I had suicidal thoughts, and I didn't, but now I do". I said, "You know, you've got me on this medication

now. And I feel like it's not helping. I'm, I'm just fatigued. I just can't get out of bed in the mornings". And that's when she diagnosed me right on the spot (Sophie).

Participants also found if they had been on anti-depressants previously, this seemed to create strong assumptions that this must be the cause of their current symptoms. This association between present symptoms and mental health was attributed to increasing the delay in diagnosis. It is, therefore, not surprising that the debate about whether their symptoms were caused by a physical or mental illness ended up being questioned by the participants, as shown by Olivia.

Was I imagining it? Maybe I'm looking into it too much? Maybe I'm too sensitive? Maybe… I mean … and maybe it's just in my head. Maybe it is in my head, you know? Like, it's like, if you tell someone you've got a dicky heart, they'll keep focusing on that dicky heart, and they'll find loads of things wrong with their heart. And I just thought, maybe I'm just, maybe I need to just sort of let this go, maybe it's just the way I am, and I'm making this mountain out of a molehill, and it's nothing. You know. I doubted myself.

Participants talk about a connection between what happens in their bodies and their mental or emotional selves. Although they believe ME/CFS is a physical illness, the fatigue (and other symptoms) are so debilitating that they have a psychological impact. Hannah states that the psychological impact is a "*reaction to life being completely withdrawn from you; this has an effect on the psyche. There's no doubt about it*". In addition, it is exhausting to be constantly challenged and have to *"justify your health [and] I do see that it's connected [mind: body]"* (Charlotte). It's clear that although participants believe that ME/CFS is a physical illness, they also feel there is a psychological impact. There is a historical context to the physical versus psychological debate, which Catherine does not see as one against the other: "*This idea, of it being psychological. Like, I don't agree that it's psychological. But, I think, there's a bi-directional relationship happening."* She goes on to describe how she *"definitely became depressed once I got the fatigue... and so yeah, the lack of energy with the CFS made, the, made me feel more depressed".* She talks about how there can be so many different things going on in the body (i.e., stress) and:

Somehow, your body is expected to just ride it out. But you know, we're not an unlimited machine [our bodies break down].

The entanglement of physical and psychological symptoms and facing down negative beliefs lead to feelings of self-doubt, poorer mental health at times, but also an increased bodily awareness. This growth in bodily awareness continues to strengthen throughout their recovery journey, with Amelia describing how she can differentiate between ME/CFS symptoms, depression, and other illnesses. This reinforces that ME/CFS is experienced differently in the body from other mental health or physical health conditions.

> So I, I know how to distinguish it from other similar conditions like, you know, mental conditions like depression or even just burnout. It's not a mental condition. But, you know, it's something that's experienced psychologically and somatically, so I, I also know how to distinguish it from just normal flu (Amelia).

> I feel that I probably was more exhausted from having to justify my health and recognising [different levels of fatigue] has helped me to go… this is actually, just where I'm at mentally, or, you know, I'm having really low, down days, this isn't depression, this is, I'm really tired, and when you're really tired, it's really depressing, and that's going to make you MORE tired (Olivia).

4.1.3 Being Doubted Makes me Doubt Myself

For all the participants, not being believed made them doubt themselves. Given the lack of clear information, differing viewpoints, the fluctuating nature and the invisibility of the illness, it is not surprising this led to self-stigma and self- doubt. There were also strong societal stereotypes of being a malingerer/not trying hard enough that participants had to contend with.

Invisibility

Participants found that friends, family, and medical practitioners often made assumptions about their health from their appearance or how they presented themselves. There was little awareness about the energy (or toll) it took to do an activity that others took for granted. Mia, Sophie, Amelia and Emily talk about how ME/CFS is "not visible. And if you're symptomatic, people don't see you at all because you're just in bed" and "they don't really recognise that you are actually really suffering" (Amelia).

> Oh, you look well. Well, I feel like [shit]... but yeah, thanks, you know. Couldn't be more unwell on the inside. You know… It was just like, you know, because you do look well. Sometimes. And sometimes, I would look terribly grey, real chronic fatigue thing, you know,

> lose all colour, but in general, because it's such an invisible thing, they can't see what's going on, on the inside. It's frustrating. And if you're there [at school pick-up], they'll go, oh, so you're feeling much better? Oh, that's good. No. Just today. Just in this moment. I've found that energy [laughs] to get to this thing (Mia).

The participants found it more challenging when family and friends did not believe them.

> The public have a stigmatised view of it. And it's, it's one thing to hear that doctors don't believe you, but to hear that your friends and family don't believe you. I found that harder to deal with (Hannah).

Because of the stigma, invisibility and lack of validation, participants tended to mask what was happening to them, which also added to the misperception and inaccurate picture of health others had of them.

> If you entered into that inner space, where I took my mask off [you would see a different me]... I would try and like say to people, like, I'm really struggling, and then not really feeling like anyone's taking any notice. Um, but then at the same time, I was also disguising it… and not letting people see what was going on (Catherine).

Stereotypes and Moral Judgements

This lack of understanding and knowledge led to participants' subjective moral judgements based on the pervasive disbelief of others. Notably, in the early stages of this illness, there was an unreciprocated negative effect between how the illness was perceived and how participants saw themselves. For example, participants were told they were “weak”, they “brought it on themselves”, “couldn’t cope”, and “were malingerers” or “hypochondriacs”.

> Because [ME/CFS] is stigmatised, it's got that connotation of, you're sort of a malingerer. You're always complaining; you're unwell. You're always saying, you know, you're just always trying to explain how unwell you are… It's taken a couple of them [family] just a really long time to really, um, accept what I have. And that it's real (Mia).

These types of moral judgements moved seamlessly into the world of work. Charlotte's boss "*thought I was, you know, slacking off. That became extremely stressful and, um, and contributed to me really, really struggling. And, um, yeah, not doing well. And getting very, very stressed and depressed and anxious*". This had a powerful effect on how participants saw

themselves in the world. The greater the level of disbelief a person encounters, the greater the loss of faith in oneself.

> I think, they think that I'm … just a bit weak or, you know, just a bit precious. And I hate that, like, I've never been that kind of person prior to this... but then on the flip side of that, I wonder how much I'm sort of projecting onto other people because I think that I'm weak because I can't do these things (Sophie).

The basis for these anecdotes was that there was something inherently 'wrong' with them or that they got themselves into this because of the type of person they were. Charlotte was told by one professional that people with ME/CFS are those that "*try to do too much. Like kind of overachievers or, you know, like they have a constant to-do list*".

> A lot of times, there's a bit of a stigma when you say that you have ME or CFS because people start thinking, "Oh, do you also have like, um, borderline personality disorder or something, you know, some of those personality disorders or Munchausen syndrome [a factitious disorder]" (Amelia).

In addition to the stereotypes of either being an overachiever or malingerer or having comorbid mental health issues, being a woman was also linked to perceptions of ME/CFS. Emily's doctor told her that *"It's really common for people, kind of, you know, your age, um, you know, white female, working and studying, all that kind of stuff [to get ME/CFS]".*

> As a woman, to get it taken seriously, that there was a problem. Having that problem acknowledged, um, was the biggest challenge, rather than it being put down to, well, you're a new mum, or, you know, you've had a traumatic birth or um, you're a woman and you've got heavy periods. You know, those kinds of things. That was the challenge… I had to take my husband with me; that was the first time I got listened to. For him to, to speak for me, then I got listened to. I took him to the GP as well, from then on, until I saw my CFS specialist. And he came to my first one with him as well to add that clout (Olivia).

This caused a lot of personal confusion, stress and distrust in their own embodied experiences, leading to feelings of fraudulence, shame and guilt. For Sophie, being constantly doubted made her distrust what her body could do:

> How can I expect other people to understand it when I don't understand it? I don't know what I'm going to be like every day. I, I feel like I've got real trust issues. But a lot of it's because I can't trust myself. And I can't, I guess, with this, it's like, I can't trust myself to get up in the mornings and do what I used to do (Sophie).

Eventually, participants had to make conscious decisions about what they did with these negative personal beliefs and judgements. The impact on the participants from being dismissed and invalidated was clear and often very negative. However, all the participants worked on self-talk to push back against the disbelief. Mia would tell herself, "*Don't worry what people think. You know, people will say all sorts of things, but just don't listen to them*". This is reiterated by Catherine, who says, "*You have to not let them, their beliefs, like, impact on your recovery because that could very well be the case. If they [beliefs] are sort of preventing you from your own recovery*".

Being believed moves the participants from a position of powerlessness into a position of authority and ownership, where they feel trusted (and can trust themselves) about what is happening within their bodies. While self-belief is seen as vital to recovery, validation from others is also essential for shifting from an illness to a recovery identity.

> Belief actually plays a lot in rehabilitation outcomes. A lot of times, people with ME are trapped in an illness identity because they try so hard to be believed that they are ill, and they get trapped into that mindset. And that becomes a barrier to the individual. If you can't switch off the illness identity, how do you switch it into a recovery identity?... It becomes harder because, um, if you're constantly trying to persuade people that what you're feeling is actually real, it's not all in your mind... I guess, circling back, belief is really integral. Having people not distrust or second guess or doubt, doubt your experience, is a key ingredient in actually switching into a recovery mode (Amelia).

> Yeah, just having that validation, I think, probably makes or breaks your, your opportunity to recover. Because if you don't have someone validating you, then where do you even start? It's sort of that that makes that real in a way. When you're not believed or validated, it makes you doubt yourself. Is this all in your head? And that's not a healthy place to be in. Like, because then, you're doubting yourself and your own reality (Catherine).

For all participants, finding a health professional they could trust and who believed in them was pivotal to their mental and physical well-being. Importantly, it provided hope that there was

something they could do to regain their health; it made them feel empowered and supported to find an empathetic listener. Charlotte talks about finding her Integrative GP (who worked with a naturopath) who had *"utter belief in me and in it being fixable"*. Olivia shares how empowering her specialist was, "*He was different from all the others. You know, the empathy was there, and the language used, it's like, ah, that felt very empowering and very emotional*." For Catherine, validation came from a visit with an ME/CFS specialist who was also a GP:

> [She] was very positive about recovery herself. And she was like, it looks like you're on the road to recovery. So just, like make sure you pace yourself and don't overdo it and end up with a huge relapse. But yeah, she was quite positive and reaffirming. So yeah, I think that was, really for me, for my own benefit. But it helped in that sense that a medical professional was actually saying, "Yes, like we've seen this with patients, and your history matches up, and this is a good explanation for what is going on" (Catherine).

While it was important for medical professionals to believe them, participants did need to find a level of self-belief in their bodies and themselves that things could get better. For Mia, this change happened about a decade into having the illness, at a point when she had moved beyond just surviving. She deliberately worked on changing her "*mindset about recovery*" from disbelief she would ever recover to believing she could improve and regain her health.

> [I] really started to make some progress. Um, because for years I was just thinking, I don't think I'll ever recover from this. I think I'm stuck in this forever. And then I changed it to, I am going to recover, or I will recover, and I just keep telling myself that I will. Yeah. So, it was just a whole shift in, um, in the mindset, was really what clicked for me (Mia).

A recovery mindset was not 'mind over matter', but rather a belief that there were things they could do that would improve their lives and reduce the severity of symptoms. This mindset is not always easy to have or maintain, particularly because of the unpredictability of the illness. On really bad days, Charlotte said she did struggle, saying "*positive thinking is bollocks*," but on the flip side of that, *"thinking you're not going to get better is not going to help you get better, regardless*." This was reiterated by Catherine, who believes that what you think about recovery is important.

> [Recovery is] a bit of a double-edged sword because... I think to some extent, you do need to be open to recovery as well. If you don't believe that you're going, like, not that I believe that positive beliefs can change the illness, definitely not [laughs], but it does close off some

possibilities, if you're like, like, I'm not going to recover until they find a biomedical, you know, or the pathology of the disease, then in a way you've closed yourself off to that possibility of recovering in other ways or making some progress (Catherine).

4.2 Theme Two: Trial and Error and Finding a Pathway Through

This theme is all about finding the right pathway (supports and services) as well as the trial and error of experimentation each person goes through to find out what works for them for recovery. This is also about moving from a state of confusion into a growing understanding of self/body and a holistic approach to health (moving beyond the medical model), which are all important for recovery.

4.2.1 Working Out the Puzzle

Participants move through the initial stage of uncertainty, doubt and confusion into a clearer picture of ME/CFS and how it affects their bodies. It is from this position that participants begin to experiment to find out what might help them regain their health. Several participants likened this stage to a jigsaw puzzle. Each participant tries to find the individual jigsaw pieces that will help explain the whole picture (i.e., causes and triggers), and over time, "*a few puzzle pieces have just fallen into place*" (Sophie). It is also a time of experimentation (trial and error) with different parts of the puzzle, such as medication, symptom management and lifestyle interventions. To move beyond merely surviving, participants start with finding a building block or foothold that allows them to build a scaffold for well-being. It is through this tumultuous process that participants begin to gain knowledge of where to go for support and a deeper, richer self-awareness of their bodies. This requires a holistic approach to health, summarised by Charlotte, who says she "*had to work on my, my physical health and my thoughts and my beliefs and everything. I've had to work on everything*".

At the beginning of the puzzle, there was a lack of control and a sense of helplessness (over their body and finding someone or something that might be helpful). Ultimately, participants tried lots of different things, some of which were helpful and others were not. Sophie was, "*just grasping at straws, not knowing what to do, so you kind of just sort of throw money out at anything that was going to potentially help*". However, as Mia states, there is no fix-all*: "Nothing is going to be the perfect cure thing that's gonna get you well*". Further to

this, Charlotte talks about finding an alternative pathway to the traditional medical model, which has helped her regain her health.

> It's now talked about in scientific literature that, you know, western medicine can't fix it. So, therefore, it's incurable. And therefore, all the support sites echo that, right? Because to be, because the current fashion is to be science-based, and science is the only law. Which I know is not true because otherwise, I wouldn't be well. Whilst there's no recovery or no known cure for CFS… but, you can do these things [symptom management tools] to help you feel better (Charlotte).

There were two initial pieces of the jigsaw puzzle for participants: determining the cause and triggers of ME/CFS and working out personal responsibilities. Assigning or determining the cause of ME/CFS was important as this helped frame a recovery pathway. This was not straightforward, as participants often felt there were several pre-disposing factors that made them vulnerable or susceptible to getting this illness. Seven of the nine participants considered the cause to be viral; one participant considered Ehlers-Danlos Syndrome (EDS), and another participant was unsure but considered stress as a probable cause. There were several common co-occurring conditions; for example, four participants had a diagnosis of fibromyalgia (a high co-occurring pain condition), and seven participants had issues with their gut or bowels. Most participants felt that pushing-through, stress or childhood trauma played a role in either heightening susceptibility, exacerbating symptoms (i.e., work stress) or resulting in less personal reserves to deal with trauma (this could be with the illness itself or with other trauma that happened before or during the illness).

Participants talked very medically about the potential causes of their ME/CFS, illustrating how much personal research the participants had done. For example, Amelia discusses the "*many hypotheses as to the causality of ME/CFS*" (i.e., neuroimmune framework, vascular hypothesis, mitochondria dysfunction) of which she falls "*into the classification of Myalgic Encephalomyelitis, and that's the neuroinflammatory paradigm of this particular illness"*. For Mia it was a combination of "*a virus plus ongoing stress/trauma caused damage to the amygdala"*. For Charlotte, the cause/trigger was gut issues and "*inflammation is absolutely key. And, and, you know, all the environmental triggers*" as well as "*my pattern of overworking for years, and my pattern of fear and anxiety, and then trauma as well... created a cumulative effect, I feel, and then a tipping point*".

While the participants had clear ideas about the causes of their ME/CFS, which were mostly external to them, there was considerable underlying personal responsibility for becoming unwell or causing a 'crash'. Participants talked about assumptions that they would make mistakes and get them wrong, particularly in relation to overdoing them. This is seen through comments like "*I was obviously doing too much, as you do*" (Emily) or I "*made another stupid decision, as only I do*" (Hannah). Amelia said, "*What I do struggle with, unfortunately, is just some old habits die hard; as they say, I actually work hard, play hard, and even up to now, I catch myself*." Mia said, "*I just feel I got this illness in the first place because of lots of stresses and toxic things around me. Yeah. I mean, the junk I used to eat at that time, and the crazy hours and the hard work! I was just ridiculous to myself"*. Several of the participants talked about the Kiwi mentality of pushing through and then causing yourself harm. There's a belief "*that everything can be fixed with duct tape and number eight wire. Go on, everything can just keep running, just keep doing it, you'll be fine"* (Hannah). Conversely, becoming more aware of their patterns of behaviour helped them break the 'boom and bust' or 'push and crash' cycle known to ME/CFS, which can cause relapses or crashes. Participants acknowledged some of their behaviours which were problematic. This required a greater self-awareness of their bodies, an understanding of what made symptoms better or worse and changing unhelpful patterns of behaviour to help minimise symptom severity.

> And the worse I felt, the more I kept pushing-through with my usual pattern that got me in this place in the first place of, I can sort this out, I'm in control, I can manage it, I'll just keep doing it, and it'll get better. Um, and the other key thing that was not helpful for me was my patterns and not knowing my patterns at the time. So, my patterns of persistence and persistence beyond when it's useful. Yeah. And control and perfectionism around that (Charlotte).

Catherine was the only participant who did not feel she pushed herself too hard and considered this a contributing factor to being able to regain her health. The difference for her was that she had learnt to listen to her body while going through therapy in the lead-up to contracting glandular fever and used those skills when she became unwell.

> I've never actually been bedbound. And I think that probably, um, it was because of a tendency to be like, I know there's something wrong with my body. I'm going to do something about it. I'm not just going to ignore these symptoms. I don't know really why, why I had that, but it did seem to feature a lot... listening to your body, and so I think I was

> sort of in tune with my, oh, I need to listen, like this is not, you know, this is not about me saying to my body just step into line, it's trying to tell me something. What is it trying to tell me? (Charlotte).

Given the conflicting and negative external and internal beliefs about this illness, it is not surprising that participants blamed themselves. What helped people to move beyond this was a clear understanding of the cause and triggers, validation and finding the right professional, pulling the puzzle pieces together and a willingness to try different treatment strategies and by building a high level of bodily self-awareness.

4.2.2 Systemic Barriers

A large part of working out the ME/CFS puzzle was factors that were outside of the participant's control but caused significant distress, delays to diagnosis and finding knowledgeable healthcare and support. There are systemic barriers that affect an individual's recovery or treatment pathway, including diagnostic criteria, ME/CFS not being seen as a disability, financial support, the cost of recovery, and the impact on work. For Amelia, the diagnostic tool used could be a barrier; for example, she talks about how the Canadian diagnostic tool was considered a more stringent tool for determining a diagnosis of ME/CFS (over the Fukuda). The challenge for Amelia is that if you are diagnosed with a different tool, or what might be considered the 'wrong' tool, it can delegitimise your illness or recovery experience (i.e., did you have it), prevent access to support and reinforce the contestability of the illness. Amelia says that the "*diagnostic criteria in itself is also, you know, a gatekeeping system*. *In addition, GPs are actually the gateway to additional support. So, it's actually the GP who will give the referral for a NASC, Needs Assessment Service*". This means that unless you have a "*very understanding GP*", you can be denied access to services or support. Furthermore, getting financial support is challenging. ME/CFS is not typically recognised as a disability in Aotearoa. Amelia was the only participant who was medically retired and received a disability benefit. Hannah outlines the challenges:

> WINZ doesn't really accept chronic fatigue syndrome as a diagnosis to be on the disability benefit, and you have to be on the job seeker with a medical deferral, which is, piss all. I know I've been here as an adult; I was on the benefit as a medical deferral (Hannah).

In addition, four participants had challenges with getting medical insurance as it "*doesn't cover ME/CFS*" (Amelia,) and Olivia says she "*couldn't get insurance for, you know, being sick*

because this [ME/CFS] was on my record". Although participants could get some costs covered through the disability allowance, it did not typically amount to much, and for one participant, it took about three months for a decision.

> [It goes to] some kind of special um team who decide whether, um, the treatments fit with, what's important. They actually used the word important, if it was important enough... Okay, so we're not important enough, apparently? [They] declined me everything apart from my doctor's visits, which gave me $3 a week for disability allowance. I had like, $1,000 worth of health expenses. And they then turned around and went, we're gonna back pay $3 a week. Brilliant. Thank you. So that wasn't helpful at all. That was a real barrier to accessing the help that I needed (Emily).

Five participants at some point received a benefit, and the four participants who did not either used their savings or were supported by family to take time off work/school for extended periods. Having to navigate the benefit system used up energy reserves that would have been better spent on their recovery. For Mia, the monthly interviews to access her support just "*added stress that I didn't need, you know. Keeps you stuck. It stops you moving forward, all those sorts of stresses*". This is reiterated by Sophie, who says although getting financial aid was helpful, it was "*anxiety-provoking as well because you have to try and prove it [ME/CFS]*". Amelia ended up on a benefit and had to use her KiwiSaver just to survive. This heaped untold stress on top of her and added to the burden of the illness. She tearfully recounts the following experience:

> For me, the stress was just so high, and I was constantly thinking, I don't want to become homeless. And actually, at that time, um, I know, I have an acquaintance... who actually taught me how to do, um, well, what's the term? Um, like, garbage dump diving [dumpster diving] ... when, um, you would, we did that ... I just remember going back home and just crying. And it makes me still makes me cry, just to think, just to get how close I was to, to, just not being able to survive [tearful]. You know. I was earning six figures. And then, suddenly, I'm dumpster diving. I just, because, in a sense, that was so traumatic for me (Amelia).

Unfortunately, participants describe a vicious cycle, for example when they have the finance, they cannot get the help, and by the time they find help, they do not have the finance. Often, when participants still had an income, they did not have a diagnosis, and then later, when they

ended up on a benefit, their ability to fund treatment and financially support themselves was severely affected.

For the first couple of years, when I didn't really know that it was chronic fatigue, I spent a small fortune, really, just to try and make myself feel better, and nothing really worked. We got to the point where we financially just couldn't afford more treatments outside of our doctor (Mia).

Participants recount how much money they spent, particularly in the beginning (when knowledge was limited), on things that did not really help. Knowing what to try and where to spend your money for the best results was challenging. Amelia says how important it is to get good information, as in the beginning she relied on Facebook and *"the algorithm, gives you like, all of the quack doctors, all this adrenal fatigue, um, solutions, supplements, whatnot. And that's not. Yeah, it's not evidence-based, first of all, and I wouldn't have known that* [until I had done my own research]".

Charlotte recounts how much money she thinks she's spent:

> SO much money. Thousands, I haven't even added it up. It would probably make me cry. Thousands and thousands and thousands of dollars in doctors, supplements, counsellors. Yes. Yes. But anyway, you don't have much choice, because it's your life, right? If you don't have your health, you don't have anything, that's what I realised.

The other part of the financial puzzle was medication costs. Both Amelia and Emily talk about the prohibitive cost of some off-label medication because some medications are not funded by Pharmac (i.e., LDN). For Amelia, it was costing around "like $1 per pill".

> If I hadn't printed off information about the success of the medication (LDN) and taken it to my doctor, I don't think I would be on the medication today. So that's probably my best advice is do your research, take it into your appointment, and go, "Here's some stats, here says that people improved, um, here's where you can actually buy the medication and what they ask to be put on a prescription for it. Can we just give it a go?" And that seems to help (Emily).

The other system that worked against recovery was workplaces and employment law. ME/CFS impacted every single participant's ability to work; this initially started with having

to take more and more sick leave, extended periods of leave, and finishing work completely. As Sophie outlines, "[there is a lot of] *financial pressure as well for people to keep working. So, you keep working through being sick because you need the money. That's a really real part of it".* This makes it harder to look after your own health and well-being. On top of trying to keep working, there was the additional challenge of trying to return to paid work while still managing fatigue levels. Amelia talks about the stigma and challenges of finding work and provides an example of when she "*disclosed that I have chronic fatigue syndrome, that almost immediately just crosses me out of the list*" (Amelia). She clarifies this with:

> Employment law is very ableist because if you get sick during the first three months' notice period, first, you don't get sick leave, and second, if you have to take time off because you become unwell, it places the job at risk of termination. If you have to take leave, then there is no income, and how can you pay for anything? (Amelia).

4.2.3 Trial and Error

The journey to recovery was described as being full of experimenting on themselves and making sense of their bodies, with three participants using the phrase 'trial and error'. The participant's willingness to experiment on themselves was in the hope of finding some symptom relief.

> It's such a complex picture, and you have to know, you have to, you have to work out by trial and error what bits work for you … Um, because, yeah, you can say, here's the jigsaw pieces, but it's a long road of trial and error to try the things that work for you. So, if you didn't have any resources to get a professional, that's what you'd have to do. You'd have to say, okay, here's the 30 things that might work. Pick one, you know, one every three months or something to try. The challenge is that it's costly. It's exhausting. There's not a lot of hope [at the beginning] (Charlotte).

> Oh, recovery, you know, it's like an onion. And you have to peel away each layer. Each layer is a symptom. And you've got to work at each thing and take and peel it off. Take it away, um, and then you'll get to sort of the core of it. Ah, the harder things to work through, you know, the layers get thicker in an onion. You cry more; it makes you cry dealing with that inner core of the onion. And so I've always just had that in my mind as well. And just been working with him [her Integrative GP] over the years, healing my onion (Mia).

A big part of trial and error was finding the right professional. It typically took time to find the right health professional whom the participant had confidence in and who had the expertise to advise them on treatment best practices. All the participants saw different specialists who often just ruled out that it was not in their realm of expertise. "*We just thought that maybe they could have something that I could piece together, to add to, um, how I can kind of fight it*" (Hannah). "*Going to see so many practitioners who tried their own thing but didn't, didn't know what it was and didn't get the whole pictur*e" (Charlotte).

Another important facet of trial and error was finding something that could give the participants 'breathing space' or a 'foothold' to move them out of merely survival to building a scaffold for well-being. Mia talks about finding the first bricks (i.e., diet, stress, retraining the brain) to build the "*foundation to support your wellness"*. Charlotte talks about how the prescription medicines gave her:

> that little bit of space, that little building block, that foot-up, because, yes, I was very much in survival mode. I don't know how I, how I survived in the past... It was all just too, too much. So yeah, it's buying yourself that space. But that also came through education as well, not just through the medication... So there was lots of little educational insights and not trying to fix everything all at once. Because you can't as well (Charlotte).

Participants had to work out what they needed to do for symptom management, and this started with an understanding of pacing. Pacing is a self-management system to manage post-exertional malaise (PEM), which is a hallmark symptom of ME/CFS and includes triggers such as physical activity, cognitive and sensory overload (Chu et al., 2018). "*But pacing is the main, the main thing that... just makes everything kind of fall into place a wee bit*" (Emily). The participants felt if they pushed too hard, that contributed to or worsened symptoms, so learning about their bodies and how to avoid crashes was part of all participants' journeys in managing this illness. There came a point where all participants figured this out. In order to do this, participants learn to listen to their bodies and learnt what their individual limits and boundaries are. As Mia says:

> knowing what your boundaries, or discovering, your sort of baseline, where you can operate... where you can function... [stay out of the] danger zone as I'd always call it... sometimes it's whispering at me, you know, through little aches and pains and sometimes it's shouting at me because you know, I've over-done it and yeah, so I think that was an important part as well as learning to listen, because I never, I just used to charge around, you

know, burn the candle at both ends. Be a really yes person. A bit of a perfectionist. Always push, push, push myself (Mia).

All of the participants talk about energy management in some form. Each participant had to decide how to manage demands and whether to engage in an activity or not.

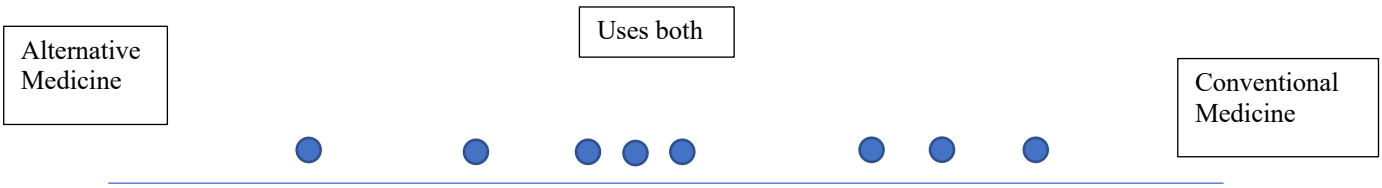
> The Spoon Theory… a really important thing to learn is that everything takes a little bit more. And if I do extra in my day, I'm probably borrowing from tomorrow's spoons. And yeah, that's um, that was a really important part of understanding what I had. What was, and how I should start to live my life as a bit more self-aware about how much energy it takes to do everything. And that was a really important step (Hannah).

> Managing a bank account and having your working account and your savings account. And when you've got extra in the working account, putting it into the savings account rather than just spending it and sort of, that's sort of what you do with your energy (Sophie).

Participants also talked about needing to have professionals who could work holistically and provide regular follow-up appointments. As Charlotte said, without follow-up, it "*jeopardises improvement*" and delays recovery. Most participants had poor experiences with the medical profession before finding someone they resonated with, who they believed had the tools and knowledge to help them (Figure 2).

Figure 2

Preferences for Alternative or Conventional Medicine



Five participants ended up meeting with or having ongoing involvement with an ME/CFS expert, three of whom had lived experience (one was a GP, one was an Integrative GP in a holistic health centre, and one was an alternative medicine practitioner). The other two were conventional medical practitioners (one was a specialist at a hospital, and the other a GP expert). Of these five, one had a supportive GP from the start. Of the three remaining participants, one used a GP reluctantly, one used an Integrative GP who worked with a naturopath, and one had

a supportive GP who, although not knowledgeable about ME/CFS, was willing to listen and try different medications. The continuum shows the participant's preference in relation to using alternative or conventional medicine.

Supportive practitioners were found in both conventional and alternative medicine. When participants found a key health professional, they often described themselves as 'lucky', 'fortunate', and feeling 'grateful' to have found them.

> It wasn't just about the acceptance; it was just he got it. He understood. And he, he was the first person that I felt who showed me some respect for what I was going through (Olivia).

Having a supportive professional who is curious and open-minded was important. Medical professionals do not need to know everything, but they do need to be open to exploring something that might be outside their realm of expertise and offer practical advice.

> But yeah, so, I mean, my GP was amazing. I have to admit, like she didn't really know what to do... I did bring in my own research (on LDN) ... and although the GP was initially hesitant to prescribe LDN, she spent that evening looking at it herself, and then she sent me a copy of all the highlighted bits that she'd done. And then she said, "Yeah, I think, let's figure out a way to get it prescribed to you". So she went out of her way, which was amazing (Emily).

Ultimately, what participants used to assist their recovery was individualistic, based on identified causes, triggers and a mix of both conventional and alternative medicine. "*I've got three circles that are intertwined, and I've got what can I do from my mind, my body and my soul?" and then I asked myself, "What will help me or hinder me*?" (Mia). This approach maps onto a biopsychosocial approach that also included spirituality as a way to support a return to better functionality, fatigue levels and mental health.

Seven of the eight participants trialled medication (often multiple drugs) at some point for symptom reduction or management. All these participants had either negative side effects from a drug or a drug did not provide symptom relief. Of all the puzzle aspects participants engaged with, medications had the potential for the most physical and psychological distress.

> It was horrendous and caused anger, anxiety and a racing heart, and then I've had the racing heart since … and I haven't been able to drink red wine since. Um, which is just one more bloody thing... fecks sake... Um, but yeah, just got to a point, like, this isn't, this is not, this

> is definitely not who I want to be. It's not worth it. I don't want to be taking... stuff for someone to trial and then, ah nah, you need to take this, for these symptoms, and now take this for these side effects and these side effects (Olivia).

On the other hand, through this period of trial and error, some participants found medications that were *game changers* for them; in particular, this was in relation to medication that assisted with sleep and fatigue levels. Some of these are referred to as off-label medication. Four participants used LDN (one with only a small improvement, one who stopped it due to cost and preferred medicinal cannabis, and two who believe it has made significant differences in their lives). Most participants had sleep issues at different times in their journey and medication was one thing that did help for some (i.e., unrefreshing sleep, insomnia, sleeping too much or dysregulated circadian rhythms). Poor quality sleep impacted the participant's quality of life and ability to cope with day-to-day functioning. Participants often describe a kind of 'wired but tired' feeling which had both a cognitive and physical effect on their bodies.

> So sleep is absolutely fundamental. So yeah, it (the medication) supported that, which then supported my whole life getting better. You know, instead of waking up in the morning, dragging myself to work, almost in tears, because I'm so exhausted... I was very anti-medication. Very, anti it, generally. And, but, I tried for so many years to get better on my own (Charlotte).

Most participants used a mix of alternative and conventional medicine that supported their health (with seven out of eight participants using alternative medicine). A part of the puzzle was experimenting with natural supplements, using alternative practitioners (i.e., acupuncture) and using a wide variety of lifestyle interventions (i.e., diet). The most common supplements were melatonin, magnesium, B vitamins, CoQ10 and other supplements that supported energy production, electrolytes, d-ribose, slow-release vitamin D, antihistamines and B12 injections.

All participants had to prioritise where they spent their energy as this impacted an individual's cognitive load and subsequent fatigue levels. Sometimes, this meant reducing socialising to a minimum and then adding people back in as their energy increased. Hannah has to consciously think about whether "*I have the mental capacity and energy to go and have coffee with this person. Because you take on everything that they've got as well. And sometimes you just don't have the strength, you don't have the resources*" (Hannah). Olivia describes it as

having to manage it like how you would "*treat someone with concussion is what I have to do all the time to look after my brain"*.

> It is physically fatiguing but also mentally fatiguing because you need to be switched on mentally when you're engaging with people. It's, um, taking a huge toll on my body in a sense that, um, I easily get fatigued, um, I am less coherent in forming words, my vision fails at some point, there's um, sensory processing sensitivity. Yeah, so there's, it really is an embodied experience for me (Amelia).

When participants were experiencing extreme PEM or significantly impaired cognitive function, time moved slowly. Several participants who were unable to leave their homes for long periods of time have found recalling events and memories of those times are hazy and blurry, and there were gaps in recall. These moments in time were painful to remember.

> There are a lot of months that I have no recollection of because I just spent my time between bed and the couch and TV. I wasn't actually doing anything. Yeah. That's the saddest part about my chronic fatigue journey is how much I don't remember. And how much time is, just lost now. Because, yeah, nothing happened (Hannah).

Participants had to make conscious decisions about who they spent time with, and ultimately, friends were lost because they had to balance the energy they used with personal responsibilities (i.e., raising a family, work, and time for key relationships).

> Lost lots of friends, well... I just stopped because I couldn't come out... that means I miss out on family time for weeks. So I lost, I've lost so many friendships because I can't join in, and then they think it's because I'm, I think I'm above them, or they're not good enough for me, and it's like, that's not what it is (Olivia).

Another part of trial and error for the participants was finding a key person who could keep them afloat and accept the illness. Mia states that you just need one:

> <u>soul supporter,</u> that friend that you know that you can, that just is really there for you. And you know I've got two or three friends that I must say have really tried to understand it... What I'm going through... When I think about it, you just need one person. Like one, more is better. But just to have one person, and that was my mum, just helping me with food,

> helping me with this… Yeah. So she was that for me and a couple of friends. That was amazing (Mia).

However, they also recognised that people were "*never really going to understand unless they've been through it themselves*" (Hannah). So, there were tensions about social support; it was seen as very important, but difficult as it was not always easy to maintain these relationships.

Fatigue can also come from additional emotional stressors on the body, including emotional triggers, challenging interactions and "*the trauma of being unwell*" because it's like "*boom, you're gone, like kind of throw your life away*" (Emily). It is difficult to connect with the world when you feel trapped within your own body. Amelia describes this*: "You're trapped within. You, you can see the outside world and yet cannot be part of that world*". Part of working out the puzzle of ME/CFS is working out a way through this embodiment of grief and trauma, dealing with the loss of an imagined life. Amelia goes on to talk about her grief and trauma because of ME/CFS. She describes what the grief was like and how she moved through it to a place of peace.

> Grief... it's a self-protective emotion because you're losing so much. And so you actually don't want to let go, of what, you know, what's left. And so that that, for me, is, yeah, is my description of grief. The feeling of grief was just like… descending into the abyss, and you feel that there's tonnes of pressure of water… you're just in constant freefall... To transition out of grief was just me crying. For hours, days, weeks, and just allowing myself to cry. And I remember we had this exercise where, you know, you… dig a hole and just whisper to it. And just tell them everything that I'm mourning, and I would create rituals for myself like I would do origami butterflies… on the pieces of paper, I would write everything, all my heartbreaks, and then I would put those origami butterflies into the bushes outside and then when the wind just picks up. It goes, you know, to the heavens or whatever. I guess if you were, if you're, romantically inclined. Yeah. So that's my transition.

Participants strongly believed that there was a bi-directionality between their mind and body: "*I think, you know, there's this grey area with psychological versus biological illnesses, and I think, um, certainly, there's a relationship going on between the two*" (Catherine). Mia focussed on reducing her "*maladaptive stress response, and really getting stress under control and trying to stay out of the fight or flight mode of the nervous system"* by adding in relaxation activities

and exercises into her day. Amelia says that because emotional reserves are low, you are susceptible to other mental health conditions, such as:

> … PTSD. I think because of the chronic fatigue syndrome. I, I consider myself as a highly resilient person. So I guess if I didn't have the chronic fatigue, I would, um, with what happened to me, I would have just been able to bounce back. I couldn't because of the illness [and describes it as her] window of tolerance decreased significantly (Amelia).

There is a psychological aspect in managing a long-term illness that can end up trapping participants because of fear; fear of the unknown, fear of becoming unwell, fear of becoming well. The challenge for participants is that managing the psychological impact of the illness requires energy and reserves that they do not always have.

> And so, I did liken the whole recovery process to thinking about my life in terms of, like, boxes of things. And keeping the box on a shelf; if it was too much at the time, and that could be a box of anything [i.e., spirituality, music, family, friends]. And just like taking them out as I had the time and energy, to, I guess, to sort of work through those things (Catherine).

Several participants found that 'retraining their brain' was useful for overcoming some of the fears attached to ME/CFS. It was easy to get stuck in the negativity of the illness, which limited how they approached the illness and what calculated risks they were willing to try. Hannah feels she has learnt how to stop herself from jumping to unhelpful conclusions about becoming unwell, and she realised she had a lot of "*trauma… from being sick*".

> If I didn't have that kind of strong mentality about CFS, I would live my life a lot... what's the word?... more cautiously than I do. It gives me a lot of freedom. And a lot of, just the ability to not be scared about, um, what's around the corner, which is really nice… So yeah, it's very freeing to accept that you've got this part of your life, that could pop up at any time, but to be okay with it. And just take it as it comes. If it comes. That's the, it's the, if, not the when (Hannah).

The last part of the puzzle for many of the participants (five of eight) was spirituality, to support their well-being. Two of the participants returned to a Christian faith, although this tended to be adapted to suit their situation (i.e., watching videos rather than attending a church service). For others, it was embracing a wider concept of spirituality, including Eastern and

Māori models of health, yoga, mindfulness practices, and other practices that supported relaxation (i.e., breathing techniques for stress relief). For Charlotte, restoring her health required a holistic approach that incorporated mental, physical, social, and spiritual healing. Finding purpose and meaning was also important, particularly as a means to motivate her and a reason to keep going. It is important to know you are *"part of the bigger picture, if that makes sense. That's, that's been sort of what's helped and given me compassion for myself and also, in a sense, given me a reason for going on"* (Sophie). Hannah feels similarly in that:

> you need something that gets you out of bed every day. Yeah, and that's an, it's a, also a tell-tale sign of when I'm crashing is if I don't have the energy to go see the animals and I know, like, we're moments away from disaster. Yeah, because I could have given up everything else in life. Could stop my studies. Stop work. Stop all this stuff. If I, couldn't go and see the animals, shit's serious. Really.

Surrounding themselves with nature was also highly therapeutic and was something that most participants tried to do (this mostly did not involve exercise), which grounded them in the now and provided moments of beauty, clarity, and a calm mind. And some activities were simply to incorporate, like going "*barefoot on the grass or sitting outside in the sunshine getting vitamin D"* (Mia) or "*being by the water... just appreciating that sunshine. I can still see things even though I might be tired. I can still feel the sun even though I'm tired. I can still um hear the wind and whatever*" (Olivia).

There were some commonalities among the participants in working through the puzzle, for example, being believed (addressed in Section One), understanding the cause/trigger, finding the right professional and health pathway, sorting sleep and reducing fatigue levels through medication, using supplements, changing diet, and finding the internal resources to take more control of the process and their health. Participants also described cognitive impairments where they had difficulty with memory, executive function and information processing that required trial and error to work through. Systemic barriers are problematic and can add to the burden of ME/CFS.

4.3 Theme Three: Understanding Recovery

4.3.1 Conceptualising Recovery

This theme is about participants exploration of what recovery means to them, how they conceptualise recovery and what helped them to live with and manage an unpredictable illness. It is important to note that the word 'recovery' could be problematic. This was mostly to do with how the participants conceptualised recovery alongside how the word was viewed by the wider ME/CFS community. Amelia does not use the word recovery herself, and prefers the word 'rehabilitation', "*because it's more an active word and it's, you know, it has a sense of agency to it, whereas recovery is more like, it's just a passive participant*". Whereas for Charlotte, the word recovery "*gives you a sense of hope and forward movement, even if it's, even if it's not necessarily full recovery*". Mia thinks, "*restoration is a good word; you're trying to restore your body back to health again*". Whereas Catherine thinks "*recovery should be conceptualised as learning to live well, in spite of your body having these limitations*". Emily and Olivia comment that recovery means:

> living with an absence of CFS, I think. Because you can't, you know, for most of us, we're going to have symptoms forever. But being able to live a full and enjoyable life, in the face of, you know, some undesirable symptoms (Emily).

> I'd say a good day is a day when you get up, you wake up... and you're able to function [throughout the day] without issues (Olivia).

For some, the word recovery provided a sense of hope, a point on the horizon to move towards, whereas, for others, it delegitimated their experience because some people do not recover and remain unwell. This can make the discussion of recovery problematic within the ME/CFS community. For Charlotte, a belief in recovery is necessary; otherwise, the word recovery becomes a swear word.

> If you don't think you've got any hope of recovering, recovery is not a word you even want to hear. It's like a swear word... You're not going to get well if you don't believe; that's a challenge (Charlotte).

The length of time you have the illness and stage of life also affects how recovery is conceptualised. For example, Amelia reflects that the older people she knows have a different attitude towards chronic fatigue syndrome and are:

> … pessimistic about the word recovery because they have not experienced that in their lifetime. And unfortunately, for this peer group, there was not much information about chronic fatigue syndrome when they first experienced it. There's a lot of dismissal, stigmatisation and just, ohh, you're too complicated. Not even going to work with you. So yeah. So it just leaves years and years of that sediment, you know, a layer of sediment has coloured the way they see recovery, and they have a very negative response to the word recovery (Amelia).

COVID-19, interestingly, has influenced the narrative around recovery for ME/CFS. Several participants reflected on the historic differences between ME/CFS and COVID-19. They felt that COVID-19 had less stigma, had a stronger recovery narrative, and had more research, which they believed might have a positive impact for people living with ME/CFS.

> There's not that history of, of stigma, and like, you know, lack of validation [with COVID], whereas with ME, they have decades of being, you know, blamed. I'd probably say that they have been blamed. And there's a lot of, yeah there's a lot to, I guess, unpack. Um, and that's probably why it interferes with the stories of recovery. Because if it hasn't worked for them. Them personally. Um how do you, sort of resolve that conflict, really. For someone who has recovered by some of these other methods. Does that make sense? (Catherine).

The other aspect of recovery is there are always shifting goalposts that change as you age, which complicates the idea of recovery. Ultimately, you become the person you are from the experiences you have, and this is important to note when thinking about recovery. The other challenge for those trying to define recovery and find answers is that "*there's very limited research on recovery"* and *"no operational definition of recovery*" (Amelia). This is further complicated by the various different versions of the term ME/CFS.

So, while most of the participants did not object to the word recovery, they wanted to clarify that recovery was a journey and that the end result might be a partial rather than full return to pre-illness health. Hannah had heard of people who fully recover, but this has not been her experience and finds the concept difficult*:*

> I'd just call it bullshit. Honestly, I don't think that's, that's possible. And I know I talked to [a chronic fatigue specialist] about that. She said that she's had high performance athletes go back to what they're doing. But I, I don't know if there's ever going to be a... whether I will never ever have a crash again in my life. I could. But I, I don't believe in that. I don't believe it... and some people might, and that's cool. But I always think there's always going to be a little chip on my shoulder. It could, it may not be for the next 20 years. But it could come back (Hannah).

The road to recovery for all the participants was complex, linked to the length of time with the illness and context, which is tied up with a "*whole element of personal personality and purpose and friends and hope* (Sophie). However, it was noted that all the participants have come to a place where the goal is to live well or live a life that is meaningful to them and to do this despite living with and managing some of the ongoing symptoms of ME/CFS. This meant to Catherine, "*an important part of recovery, you know, is just being able to live a life that is meaningful to you*", and Hannah:

> We all define *living well* differently. It's different for everybody. And some people may never... I, quite, quite frankly, I may never have a full time job. I might never be able to deal with that. But then other people would be able to, and then, some people, the thought of having to work more than eight hours a week would be unbearable. They couldn't do it. And we would all classify ourselves, at a certain point, as recovered (Hannah).

Overall, conceptualising recovery is very individual as it depends on personal experiences and the end goal for each person. As Catherine says, "*I'm not entirely sure the limitations fully go away…. recovery is respecting that*". Thus, the narrative constructed by the participants was that it is recovery in, not from and that there were different phases within recovery that overlapped one another and were not linear in progression.

4.3.2 Recovery In Not From

Recovery for the participants can be conceptualised as 'recovery in, not from', and they talked about recovery in relation to "*being able to live life again*", being able to "*function back into life*", being able to "*return to work*", and "*live with an absence of suffering rather than an absence of symptoms*" or described by Amelia:

> I've decided that I don't really have to aim for recovery-from, because I think that's really just like, you know, a cure is elusive. Recovery-from, is elusive. So I've found peace and acceptance in just, you know, framing my rehabilitation journey around recovery-in (Amelia).

It is well known that ME/CFS is a widely contested illness with no medical biomarker and is not well understood by the medical community, but what is less known is how much recovery is contested by ME/CFS groups. Recovery was, therefore, complicated for the participants as they had both an insider with outsider status - an insider because they have ME/CFS, but an outsider as they are living in recovery. The participants found it difficult to find information about recovery, and they attributed this to how contested recovery is within ME/CFS communities and that talking about recovery was problematic. Some participants used online chat groups for research purposes but found these groups largely negative and not a place to discuss recovery.

> But if people posted in the New Zealand ones, the one I see the most, if people post in there about recovering or being well, it tends to be more of a response like, well, that's okay for you. You had it less severe. Maybe it wasn't CFS, you know. Yeah. So, yeah, there's very much the people who are really severe and really suffering and literally can't get out of bed every day. And then when you have less severe symptoms or are perhaps recovering or recovered, then yes, it's, it's not, it's not, a really welcoming space, so much (Charlotte).

Some participants chose not to engage with online or in-person groups because the interactions or material being read was depressing and made people feel despondent. A lack of positive recovery stories made the participants doubt their experience. Another participant found the ME/CFS Facebook page quite depressing and negative. Still, she would go online for research purposes (i.e., LDN), but she had to make sure she turned off her notifications:

> I guess when you become ill, you become part of the club. You know, this unofficial club of sick people and it's not helpful when it's all you're surrounded by miserable people throughout, you know. (Amelia)

> … because all my newsfeed would just be filled with, I'm still sick, what's wrong with me, all these kinds of posts that, you know, you just, it makes you think, oh my gosh, I'm never gonna get better, these people don't get better. But, um, but also find it really brings your

> mood down. I found them really helpful for gaining knowledge about how to help myself. But I had to be really selective about what I went in there to do, a search for something, and then I'll get the information. But I wouldn't, I wouldn't, or had to keep kind of making sure I wasn't getting the posts in my newsfeeds because it really, kind of brought me down (Emily).

Catherine describes the pushback on people who get better and theorises that talking about recovery could diminish a person's experience if they remain unwell.

> And yeah, there's a, there's, a bit of a pushback for any, anyone else who gets better or, you know, recovers sufficiently. Um, I think there's a... hmm, perhaps an assumption that it somehow diminishes their own illness if they don't get better, and so, well, that's what I seem to pick up... But, um, the reality is, sometimes people don't get better, but that doesn't make their illness any less valid... I think what's helpful for people in that space, is perhaps not a message of recovery at this stage in their lives but a message that their illness is valid (Catherine).

It was not just online groups that were not always helpful. Olivia attended an in-person group a couple of times and found she could not continue, and it was not inspiring, saying, "*and all the people were really... empty. They just sat there. And... I was just like, if I hang out with these people, I'm just gonna get worse."*

Because there was so much negativity about ME/CFS prognosis, when participants found positive recovery stories, this provided hope. For some of the participants, there were not a lot of recovery stories around, particularly for those who were diagnosed with ME/CFS more than a decade or two ago. There are also tales of caution: "*You also have to be wary about the miraculous stories you read about. I think, absolutely, recovery stories give hope; they also need to be real. Not these, I mean, some people, I guess, seem to have had spectacular recoveries, but it does need to be real*" (Catherine). Mia reinforces this idea that people have to be selective in what they consume:

> Just be careful of information out there, that you're not reading a whole lot of negative stories online of people who say you can't recover. Just read the positive recovery stories (Mia).

Ultimately, the participants revealed a tension about talking about recovery experiences. This is summed up by Catherine, who says that recovery stories need to benefit the ME/CFS

community, not harm them. "*And that's quite a responsibility and, ah, very tricky.*" There is a need for spaces and places to talk about recovery within a recovery-oriented framework that supports recovery progression.

4.3.3 Recovery Progression Within the Ebbs and Flows of an Unpredictable Illness

One of the most significant challenges for all the participants was the unpredictability of ME/CFS, making it challenging to navigate and manage. Thus, a second important concept for recovery is understanding that ME/CFS has different phases and how understanding these phases could help form a recovery framework. The participants described phases as having "*long, long ebbs and flows*" (Sophie), making it an "*unmanageable*", "*unpredictable*", and an "*unreliable illness*". "*That it's not linear. Like it's very up and down, up and down, up and down, recovery*" (Mia). You can feel better for a time, and then "*the boom and bust phrase… you know, you start to feel a bit better. So you do more, and then you wear yourself out, and then you collapse for a while*" (Charlotte). It can be an "*unpredictable uphill battle every day... keeps you on your toes, takes the wind out of you, when you least expect it... it's not predictable. You know, I can be thriving... and then two months later, I can't suddenly. So flips, you know*" *(*Olivia). Emily also describes it as a:

> very unpredictable, unreliable illness, that can be completely disabling one minute, and just reasonably bothersome the next. But changes, changes, and you can never plan anything in your life or commit to anything. So, you just never know what will happen from one day to the next (Emily).

This unpredictability leads participants to doubt their recovery, which also leads to a fear of the illness and uncertainty over how to manage it.

> Yeah, there's a lot of doubt around it... and fear, there's a lot of fear as to whether it will ever go away, but I think a large part of is, is this all in my head is because of the ebbs and flows, that some days, feels unmanageable and other days, I feel like there's no problem whatsoever. And it seems to be a massive spectrum (Sophie).

It is important to note that recovery as a concept needs to acknowledge the phases and the nonlinear nature of recovery progression. This was understood as having both good and bad days, but that the bad days would get further and further apart.

> But yeah, usually, a bad day is when my brain fog is so severe that I can't concentrate on anything. I'm so tired. I really, really don't want to move and don't wanna get out of bed. I certainly can't, you know, just about, if it's a really bad day, I probably can't work. But they're getting so few and far between I probably had two really bad days in the last two months. Whereas for me, it was two weeks on, two weeks off, kind of thing (Emily).

There were two notable tools that participants used to measure their progression over time: recording a symptoms diary (noting progress or new symptoms) and using a rating scale. For the most part, participants used a rating or percentage scale to help illustrate where they thought they were in their recovery journey. This is not a formal scale, but one the participants used based on their own embodied knowledge. For example, Charlotte mentioned she uses *"a scale of one to ten"*. Others used percentages, such as Emily, who said*, "probably the brain fog is still there about 10% to 20%. On a bad day, it gets bad, nothing like it was*". Others based this figure on functioning, ability to go to work, or fatigue levels. This required the participants to know their bodies well and to know what good versus bad feels like. This required constant vigilance and self-surveillance and maintaining strict boundaries as they constantly checked in to figure out what their bodies were "*trying to tell me?"* (Catherine). As a consequence of this monitoring, participants have grown in confidence about their knowledge of their bodies:

> [I know my] body better than a doctor who has done maybe an hour lecture on CFS maybe a decade ago, two decades ago. I know more about it than they do. And kind of just trusting my knowledge. Yeah, I've talked to more doctors about it than they have (Hannah).

Participants felt they could also differentiate between other illnesses or symptoms from ME/CFS.

> So it's like, you know your body and all aspects of it. It's not just the chronic fatigue... It's, you know your body in detail, that you know, this sort of stomach pain is fine. Whereas, this sort of stomach pain, it's not fine... And again, it's something that you know, just in yourself (Hannah).

Over time, participants talk about getting better with symptom management, "*it's a bit like having kids, every day is easier than yesterday because you've learnt something else … you do find better ways to manage it, which becomes a more limited lifestyle, as you go on*" [because you know there are limits to what you can do] (Olivia). This self-knowledge was critical for preventing crashes or flare-ups and enabled participants to return to or engage in new activities

that created a meaningful life. This constant bodily surveillance can be quite anxiety-provoking. Hannah talks about a feeling she has, a type of anxiousness when you know you could crash:

> Dancing on the edge of something quite dangerous. It hasn't, I haven't gone over the edge in a wee while, which is quite nice, but you still get that kind of impending doom, um, feeling. Um, it's not nice, but it's at the point now, where I, I know what that feeling is, and I know why I'm feeling that [and what to do about it] (Hannah).

Two of the keys to managing this illness were understanding your own "boundaries", which is "*one of the most important things you have to do"* (Charlotte), and maintaining strict routines, as this helps prevent crashes. The participants said that you have to understand what this means for you (as each person is different), and it also depends on what phase of recovery you are in.

> You know, when you're at the beginning, you have to adjust to the illness, but then, when you're recovering, you have to adjust back to being functional... So, just adjusting back to being a normal human being and re-calibrating the parameters wherein I can actually work and function but still honour my limitations (Amelia).

Recovery is *"hard work"* that required persistence, sacrifices, and responsibilities weighed up in relation to energy level. This might require adjustments to every part of life and being willing to change things within the fluctuations (ebbs and flows) of recovery progression. Olivia talks about having to make sacrifices:

> Choose your sacrifices... wisely, I guess, I don't know. I feel you have to, um, to survive it. You have to accept it and accept your position and how you contribute to it. No one's going to solve it for you. A pill is not going to make it better. Um, you have to make your choices (Olivia).

Participants had to be mindful of stressors (the impact of colds and flu, how much they work or socialise, and constantly keeping themselves on the wellness side of the fatigue rating scale). Sometimes, it just feels too hard, but participants keep plugging at it, trying to get it right so they can keep moving forward and rebuild their lives. Catherine notes that recovery is "*a constant job. I can't just give up and be lazy about it".* Sophie describes needing to keep up the

motivation which can be hard because sometimes an "*I can't be arse factor kicks in*". Charlotte says that recovery is:

> really, really hard. And it's not a one-off, right? So it's a practice. Wellness is a practice and, and accepting that you're not perfect. And that you don't get it right every day. That's a journey too, right? Like, really early on, someone told me about, you know, you have to do the work. Plus, I mean, there have been a lot of times, where I've not wanted to go on. Um, but it's not that easy to not go on, right? You can't just go oh, no, I'm not going to do it anymore. And just stop (Charlotte).

There came a time for all the participants in their recovery journey where they felt ready to experiment with pushing the boundaries despite the risk. The steps towards 'risk-taking' were managed in increments within their embodied knowledge of ME/CFS. Sometimes, a risk was determined to be worthwhile in order to do something that was meaningful to the participant. Hannah frames how she lives her life with ME/CFS as living a life of "*low risk*" and constantly makes decisions about doing something for her "*own enjoyment*" while knowing it could lead to a "*massive spiral*". She goes on to describe a friend's very busy weekend:

> Like I would never ever plan a weekend like that. Even if it's something I absolutely loved. The thought of me doing that is terrifying. Still terrifying. Because I know that that would turn my low-risk into a very high-risk situation. So, my normal life is not the same as someone else's normal life, but I could still go out and do stuff on my weekend... [the difference now is that she has in place] a series of steps that I know have worked in the past, to kind of get my body into a better state (Hannah).

Mia would think about her day in terms of what will help or hinder her in her recovery. For example:

> When it came to exercise, or having, you know, a friend call, "Hey, do you want to meet up this afternoon?" I'd straightaway think, how, how am I feeling today? Is that going to be helpful going to her this afternoon, or is that going to hinder me going and talking for an hour and a half? (Mia).

Although Olivia would say she functions reasonably well, as she is able to maintain working (which is essential for paying the mortgage), the sacrifice comes in having to live a quiet life:

> We don't socialise much. We don't have people over. We don't do many things, we can't, we have friends that do so much in one day, and we can do one thing. Because that's all I can do (Olivia).

Olivia then reflects on pushing the boundaries and then the consequences when she goes to the movies with a friend:

> [I will] pay for it. But sometimes it's like, ah, I just want to do this, and I will... minimise stuff for the next week and, you know, kind of counteract it. You know, And I'm not functioning as well today, as a result, but you know, occasionally, once in a blue moon, I'm gonna break all the rules. And, I know, that always reminds me that this is what happens when you break the rules. I need to go back to the old rules. So, diet, and sleep, the routine (Olivia).

Another important factor in managing recovery in ME/CFS for the participants was the mental energy required to do the recovery work. Participants talked of mental fatigue, which was overwhelming when they were trying so hard to remain well. Several participants felt they were "*being just too hard, you know, being too driven in my own recovery, that I actually have come to a point, that I burnt out, just trying to fix myself, like fix my health*" (Amelia). Participants talk about the need to find balance in living with and managing this illness. This is reiterated by Mia who was:

> trying so hard. So, hard with the diet, that it can bring on anxiety, so I have to really stand back sometimes, um, because that's not good either. Just being so focused and so driven to have the perfect diet, you know, yeah. It is finding that balance (Mia).

Recovery narratives did support the idea of phases for a recovery framework. Charlotte also specifically mentioned research from the USA that supports this:

> [An organisation in the USA is] building the case for research base recovery from CFS, or from fatigue, I think they call it. But he talks about the phases, right, the phases of recovery. And, and it's a phased approach. And being aware of the phase you're in and aware that it might be two steps forward and one step back (Charlotte).

The phases were different for the participants in terms of time, but consistent in terms of their experiences, which are reflected in the themes. The first phase, Chaos, Confusion and

Scepticism, starts at the beginning (Theme One), and is caused by the confusion of a unpredictable illness and lack of validation. Phase two is the Turning Point. Pivotal to this is being believed and finding the right professional (Theme One). Phase three is Restoration and Integration, which involves building up of bodily self-knowledge through experimentation and trial and error and finding a pathway through (Theme Two). Phase four is Acceptance and finding Balance (as described below) (Theme Three). These phases are bi-directional, intersecting, non-linear and require persistence and hard work.

4.3.4 Acceptance and Personal Growth

The third important aspect of recovery in ME/CFS for all the participants was a level of acceptance, and all talked about the ME/CFS journey as a huge learning experience. "*I think [recovery] is like a journey. Like this isn't, yeah, this is, a journey, and you just learn something every step of the way about yourself*" (Sophie). Some participants can look back on what they have gone through and find that they would not want to be the person they were, nor would they expect to return to their pre-illness life. The illness has taught them so much about themselves and about what's important to them. They have found a way to accept the illness (with its limitations), to stop fighting it and adjust to it, using strategies that prevent the boom and bust, and finally, to find self-compassion and gratefulness in the life they have. Mia, Hannah and Charlotte discuss this:

> And it's just been such a learning curve, such a, almost just grateful that this has happened, you know, I couldn't have said that years ago. But I think as you move towards, um, wellness and out the other side, it's just taught me so much (Mia).

> It's not like my boyfriend's normal life... but it's my normal life, and I'm very grateful for my normal life... it's not what you imagined your normal life being, prior to diagnosis. Is it? It's hard. My life is not the same as some of these people walking down the street (Hannah).

> Did I say this to you? That I'm actually thankful for it. I'm actually thankful for this illness because it took me to rock bottom. And I've had to learn how to change myself. Or give up [laughs]... And it's taken a long time to get there. But given that I am recovering, I am grateful for it because it's made me work towards accepting myself as I am. Yeah, like, still a way to go. Not perfect... you're the only one that's going to be left at the end of your life. So you need to be happy with yourself (Charlotte).

In order to move into a recovery pathway, the participants also reflected that you have to find some self-compassion because it is not an easy illness to navigate. This meant different things to the participants. For Emily, this was mindfulness:

> This is what I've got, and this is what I've got to deal with. That kind of mindful acceptance has helped emotionally... Yeah, cos you're not, you're not fighting anymore, and you're not kind of like, oh, I just need to... push through, or maybe I just need to... you're just like, well, this is it. This is what it's like and whether it's like this for today or this month, or whether it's like this forever? It just is what it is. And the more I try and fight it or cure it or figure it out, the more stress that puts me under. So, I guess it's just about being really kind to yourself. And just, you know, just knowing that you'll get through it no matter what it looks like for you, really (Emily).

For Olivia, it is not just about managing; it's about surviving "*the challenge every day. Because you mustn't, in my mind, you mustn't give in. So, you have to survive it. I think it comes down to, um, accept it"*. This is reinforced by Mia, who says you have to find acceptance but also moments of joy:

> Accept this illness and accept that's where you are right now. Yeah. In order... you can't move on, make any progress, without accepting it. Need to say, okay, I've got this chronic fatigue. Yes, it's terrible; I feel like death. But I've got it. I've put myself in this, you know, I'm at rock bottom. The only way is up. And this is what I need to do to move forward to move up. Just accept the illness. And in the process, just be really kind to yourself. And try and do some things that bring you joy because I never did that back then; just little things. Anything, just things that you enjoy, just try and start doing them. Even a couple of minutes and build that into your day (Mia).

Personal acceptance was important to the participants, but what was an ongoing challenge was sharing with outsiders. Recovery-in provided a level of self-acceptance that meant participants were able to unmask and tell others about what they struggled with. For example, it has only been in the last year that Sophie has felt she can tell her work colleagues about her cognitive issues and jokingly says*, "Look I'm, I can't be left to work on my own kind of thing [laughs*]" because I won't remember from one week to the next, "*I will be coming to you for questions. And a lot of the time they understand. I don't think... not everyone understands*". This was also linked to learning to take control and be in the driver's seat, which the participants

framed as being important for self-determination and autonomy. Mia decided she needed to *"pilot my own plane really, that's what I sort of think for wellness, I need to be in the driving seat*" (Mia).

Being able to navigate recovery, including systems that can come with immense barriers, required participants to take control, feel confident in their knowledge and speak up for themselves. The challenge for participants is that advocating requires energy; fighting a system that is against you takes energy that sometimes participants do not have. As Amelia says, the lack of energy from the illness "*is already hard to contend with. And then you have all those other things, as additional challenges, amplifies the fact that you just don't have the energy to actually deal with those bigger bureaucratic things*". As Charlotte says, at times it just too hard:

> So, you know, you are often not in the best position, if you're then having to struggle and fight on top of that, it's a HUGE extra load... energy is something that you don't have when you have the condition, and as it gets worse, you've got less of the energy to fight. And like I was saying before, when something as simple as getting out of bed, and making breakfast is hard. Then yeah, going to fight a conventional doctor or something. It's just too much. (Charlotte)

Participants did suggest there are times when you need to have other people who can advocate for you, but this, again, can be tricky when you have limited social support. But as Hannah outlines, having the resources to advocate for yourself can be a sign of recovery. For Hannah, "*a really strong point of recovery is self-advocacy. So when you're in the thick of it, you need someone else. And when you can actually take it on yourself, that's a really strong indicator of recovery*".

In summary, understanding recovery for ME/CFS was contested even with the word recovery, but promisingly, despite this contestation, participants did create a narrative of recovery-in, not from, ME/CFS. The participants identified phases and key aspects of recovery that could be used in a potential recovery framework. However, the ebbs and flows of ME/CFS mean the narrative of recovery is not a linear, straightforward or easy one, requiring sacrifice, balance, and self-acceptance.

CHAPTER FIVE: Discussion

This study aims to contribute to the existing knowledge of recovery in ME/CFS by exploring individuals' lived experiences of recovery progression over time. Few qualitative studies have looked at the embodied experience of recovery, how it is defined and measured by the participant, and what helps or hinders their journey. I begin with a summary of the findings, followed by a discussion of these in relation to the current literature.

The findings of this study support the recovery framework proposed by Devendorf et al. (2020) that recovery should be conceptualised as ‘recovery in’ not from (a partial rather than full return to pre-illness health). There needs to be a recovery-orientated framework based on a holistic approach to health that believes substantial improvement is possible, validates the illness and illness experience and creates a safe space (and place) to talk about recovery. This validation is important because recovery can be contested, particularly within the ME/CFS community space. The contestability of recovery is linked to the heterogeneous nature of ME/CFS, widely varying recovery rates, diagnostic criteria, the treatment used, and illness beliefs. It was found that participants moved through four recovery phases: ‘Chaos, Confusion and Scepticism’, Turning Point’, ‘Restoration and Integration’ and ‘Acceptance and Finding Balance’. This process is not linear, and the first stage can be shortened through a validation of the illness and finding the right health professional. There are a number of different possible causes and triggers, and a treatment pathway typically matched the participant's belief of the cause and triggers. This supports the proposal of different phenotypes/subgroups and that treatment plans should be individualised (Tate et al., 2023). Although there is no 'cure', plenty of things can be done to improve health and well-being and symptom management. Participants used a mix of conventional, alternative and lifestyle medicine and a range of treatment modalities across the physical, cognitive and emotional domains. In addition, health professionals need to be cognisant of the fear of relapse on moving forward. Increasing uplifts, incorporating meaningful activities, decreasing non-social hassles and having a soul supporter were all considered to be important for recovery. Finally, we need to improve medical professional education and awareness of the illness, diagnosis and treatment options, which will help to remove barriers that increase the burden of the illness.

5.1 Defining Recovery

The findings from this study support the recovery framework outlined by Devendorf et al. (2020), who conceptualised recovery as 'in' not 'from'. Full recovery has been defined as not experiencing PEM for at least six months and "complete remission of their baseline symptoms" as well as being able to "perform their premorbid levels of physical, cognitive, social and occupational functioning without pacing strategies or taking medications" (Ghali et al., 2022, p. 3). Although the participants in this study do not fit the definition of fully recovered, they all felt they could live well with this illness despite some ongoing challenges. Given the stringent criteria for full recovery, it is no wonder that statistics only report between 5 – 8% as fully recovered (Cairns & Hotopf, 2005; Ghali et al., 2022). Some participants believed or hoped that full recovery was possible, but this has not been the experience (so far) for the participants in this study. Participants felt that substantial improvement and management of symptoms was more realistic than a complete return to pre-illness health. As Catherine says, "*I'm not entirely sure the limitations fully go away ... recovery is respecting that*". Despite various ongoing symptoms, they all believed they were recovering or a 'recoveree' in terms of identity, where the good days outweigh the bad. This reinforces the individual nature and meaning of recovery. Furthermore, returning to a pre-illness state of health may not be realistic, given the length of time a person has the illness and their age and stage of life. On top of this, many co-morbidities can also influence the state of health and well-being of a person.

5.2 Recovery-Orientated Framework

A recovery-orientated framework works from the premise that substantial improvement is possible, which aims to improve a person's ability to manage their symptoms and maximise well-being and functioning (Freidberg et al., 2023). Several vital principles help to create a recovery-orientated framework, including working from a client-centred approach involving collaboration, dialogue and agency, which engenders hope, and treatment should be relevant to the symptoms experienced (Pavlo et al., 2019). This research highlights that having a positive approach and dialogue around recovery is crucial for four main reasons. First, it helps to uphold the belief in a better tomorrow. ME/CFS is an unpredictable illness with no medical biomarker or cure and a lack of effective recovery pathways or treatment protocols. Although technically, this statement is true, it provides a bleak outlook and ignores the many things that people with ME/CFS find helpful for symptom reduction and management. This research not

only highlights that recovery progression is possible, but that there are many tools available to help reduce symptoms (medication, nutritional or dietary supplements and lifestyle medicine).

Second, ME/CFS is a heterogeneous illness with varying symptom profiles and severity levels. A recovery-orientated framework must be based on individualised treatment plans that address specific symptoms within the various bodily domains affected. By tailoring interventions to the unique needs of each individual, using a multi-disciplinary and holistic approach, there is a much higher chance of positive outcomes and improved quality of life. Charlotte's statement, *"a range of mental, physical and emotional and spiritual healing",* sums up the "intra-action and entangled back and forth" of all those domains (Groven & Dahl-Michelsen, 2022, p. 5). Thus, we need to move beyond the biopsychosocial treatment approach or disease model, as it is too narrow (Noor et al., 2021), and recognise that illness experience and beliefs are a complex "interplay of biological, psychological, social and cultural aspects" (Bakken et al., 2023, p. 13), including structural stigma and discrimination (Conrad & Barker, 2010).

Third, focusing on recovery encourages the use of subjective or objective measures to track progress over time (i.e., tracking PEM by using heart rate monitors). This is important not only for health care professionals but for the individual themselves, as it enables them to have tangible proof of improvement. Baselines assist with knowing your safety zone and seeing progression as you rebuild your health (NICE, 2021). Even if the improvement is slight (5%) in several domains, this adds to incremental overall health improvement (Tate et al., 2023). The most straightforward yet helpful measures are self-reports on fatigue (or energy levels), overall health or well-being, physical capacity or function, quality of life, and recovery phase. This captures the widely varying impact and illness severity experienced by people with ME/CFS.

Fourth, a recovery-focused approach can drive research into understanding the mechanisms of improvement and recovery. Most of the research has focussed on finding the biomedical marker rather than on those who improve and looking for group differences (including different pathophysiological changes in the body). There may be essential clues within this group of people that will be useful for the rest of the ME/CFS community.

5.3 Contested Recovery

One of the interesting findings is that recovery can be contested (within the ME/CFS community) and that the language of recovery is also contested. This brings the personal account of the recoveree into question (Hasan et al., 2023). The recovery experience can be discredited based on diagnostic criteria, treatments, and illness beliefs, and can diminish personal experience. Several participants talked about how tricky it was to talk about recovery because everyone experiences the illness differently. Brown et al. (2017) discuss in their findings how people who improved and had knowledge of living with ME/CFS found themselves in an awkward no-man's land, where they fell somewhere between health and illness. This is echoed in the current study, with participants actively refraining from commenting about their health status, particularly in communicating with people who are still ill or have not improved. For some participants, this meant pulling away from the ME/CFS community and using online groups for specific purposes (i.e., for information or research). Brown et al. (2017) note that the end of the illness experience and re-entry into a new liminality that is positioned within the "well world" comes about from exclusion or hostility from "formerly supportive contacts within the ME/CFS groups" (p. 706). This is similar to this study where participants no longer fit in the world of the very ill, nor do they fit entirely in the well world, but somewhere in between.

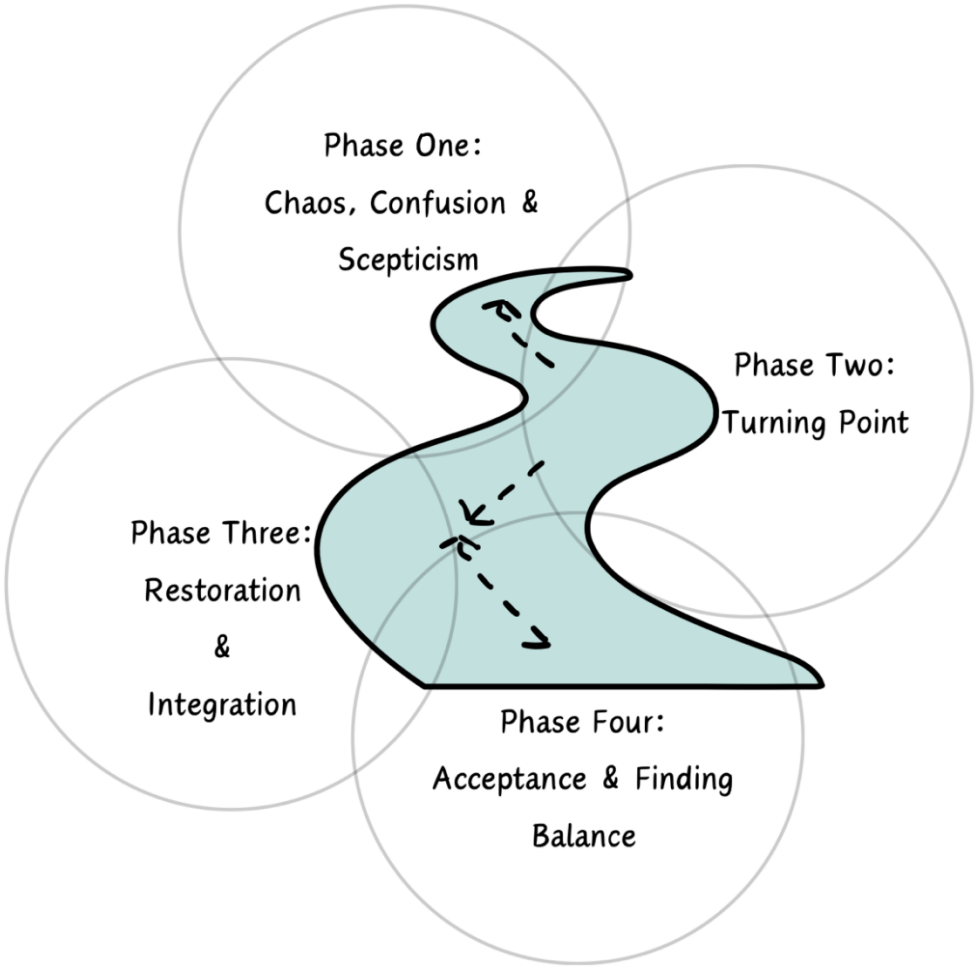
People who are recovering need spaces and places where recovery can be talked about without fear of invalidation (of the recoveree or the person who remains unwell). Participants mentioned the importance of having a formalised space to talk about recovery, for example, within a well-regarded publication or by a respected ME/CFS specialist. This must be balanced with the need for care – to consider the needs of people at all stages of recovery and not to reduce or minimise their experiences. Two well-known websites support recovery from ME/CFS and other similar illnesses, and these were mentioned by the participants. These are CFS Health in the USA and the Optimum Health Clinic in the UK (Integrative Medicine for Fatigue). Both organisations post helpful blogs, videos, and podcasts, which are free. They also have programmes with a financial cost, including individual coaching and support and access to an online community actively involved in recovery.

5.4 Phases of Recovery

The phases of recovery have some similarities with the re-building of identity through initial identity crisis, scepticism and the self, and acceptance, adjustment, and coping (Dickson et al., 2008), and Fennell's Four-Phase Model of chronic illness, which includes chaos and crisis, time of stabilisation, resolution (beginning to construct a new self) and integration. As people move through these stages, they can construct a new concept of self that includes the illness, allowing people to "participate as fully as they can in as complete a life as their physical condition permits" (Fennell et al., 2021, p. 3). This is similar to the process of recovery for participants in this study and maps onto the findings (Figure 3).

Figure 3

Phases of Recovery



While Figure 3 depicts recovery as a journey, with four overlapping and intersecting phases, recovery is not linear and does not typically follow a straight line, nor can there be time periods attached, as this will depend on a range of factors, including symptom severity, duration, age and stage of life. Participants described recovery as two steps forward and one step back, making small gains initially, which increase as relapses and crashes get pushed out further and further. The participants referred to recovery as healing all domains (emotional, cognitive, physical, and spiritual) and that *"healing is not a straight line, but is up and down, back and forth".*

5.4.1 First Phase: Chaos, Confusion and Scepticism

The first phase refers to the initial stage of the illness, when the individual (and medical professionals) often cannot understand the symptoms, leaving individuals open to scepticism and self-doubt. One of the most significant challenges participants faced was knowing where to go for help or what to do. Participants felt there continued to be a general lack of education about ME/CFS within the medical system. During this stage, people can experience severe crashes or relapses as they push themselves too hard and go through what is known as the 'boom and bust' or 'push and crash' cycle (CDC, 2024). At this point, people need to rest and repair, as pushing through tends to worsen symptoms (Stussman et al., 2020).

Belief and Validation

Importantly, being validated helped people move into a recovery mindset, whereas questioning the legitimacy of the illness exacerbated suffering and added to the burden of the illness. In addition, some of the stereotypes and associated stigma are damaging, mainly where they are personified (i.e., a malingerer, lazy, works too hard, it is all in your head), which creates feelings of anger, anxiety, confusion, and embarrassment. Not only is the illness brought into question, but so too is the credibility of the person with ME/CFS (de Boer & Slatman, 2023). Being invalidated or de-legitimised affects illness beliefs, illness experience, level of care, and follow-up received. This invalidation hinders the acceptance of the illness, engagement with health care services (Lobo et al., 2014), and self-care practices and is associated with reduced self-esteem and greater levels of depression (Bontempo, 2022). It is also likely that this phase can be shortened and illness distress lessened if the illness is validated, enabling someone to enter more quickly into a recovery mindset and recovery pathway.

5.4.2 Second Phase: Turning Point

The second phase involves a turning point, often in relation to being 'believed' and finding the right professional who can help them navigate treatment options. Being believed or having the illness validated was such a pivotal turning point for all the participants in this study. Validation may or may not occur at the time of diagnosis, although diagnosis can also be a pivotal turning point. At this point, they have assigned a cause (i.e., viral) and mechanism (i.e., mitochondria dysfunction or neuroinflammation) and are beginning to understand the different triggers that can exacerbate symptoms. In this study, people described a range of causes and triggers (both nature and nurture) that they believed contributed to their susceptibility to getting ME/CFS. The causes suggested were an overseas stomach bug, a virus (most commonly glandular fever), trauma, workload burdens, stress, and personal characteristics such as pushing too hard or perfectionism. Understanding the cause and personal triggers is essential as it helps them understand their symptoms and formalise a treatment pathway.

At this stage, the individual begins to experience some stabilisation of symptoms as they begin to understand how ME/CFS personally affects them. Ideally, participants will have established a baseline and begin to use pacing techniques and found some treatments or management strategies that have given them the space to build a scaffold for well-being (i.e., sleep, changes in diet, supplements, or medication that can help with pain or fatigue). As Tate et al. (2023) mention, this might only make a slight difference (5%), but working across several domains, all those differences build up to make incremental changes. Importantly, individuals first lay a foundation before moving into a rebuilding stage where they can increase basic daily activities.

Finding the Right Professional and an Integrated Approach to Care

Being believed often coincided with finding the right professional who validated their experience and provided empathy and a belief that there could be a better tomorrow. Validation plays a critical role in choosing a health professional (Hasan et al., 2023), and a "good" service tends to be one where the person has been "seen and understood" (Kielland et al., 20243, p. 1191). Validation created a shift in thinking from 'no one can help me' and feeling 'trapped in my body' with little control to a position of agency and self-belief. Addressing the stigma faced by people with ME/CFS is vital for facilitating movement towards a recovery trajectory.

Participants felt a general *"lack of understanding training, knowledge, awareness, interest by the GPs or any medical specialists"*. In a recent literature review in the UK, Pheby et al. (2020) found that up to half of GPs "did not accept ME/CFS as a genuine clinical entity and, even when they did, they lacked confidence in diagnosing or managing it", resulting in diagnostic delays which have a detrimental impact on prognosis (p. 1). Contributing to this problem is that people with ME/CFS often see numerous doctors before receiving a diagnosis (Chronic Fatigue and Immune Dysfunction Syndrome [CFIDS], 2014). Therefore, it is unsurprising that many people are dissatisfied with their medical care (Dickson et al., 2007). One of the keys to successfully navigating ME/CFS is having health professionals validate the seriousness of the illness and acknowledge that the patient is genuinely ill. There needs to be greater awareness and understanding of the illness amongst healthcare professionals. Poor medical care, length of time to diagnosis, misdiagnosis, and lack of treatment options not only contribute to the burden of the illness but delay a move into a recovery identity and pathway. Education and accurate information are also needed for the general public to improve validation and support for recovery.

The Importance of PEM

Particularly in the early stages of the illness, all participants experienced crashes or relapses and often could not pinpoint what had 'gone wrong', but most of the time, it was associated with pushing themselves too hard or overdoing it. Overexertion is linked to the push and crash cycle people often experience at the beginning of the illness when they are figuring out their baseline. PEM does not just mean physical exertion but can result from cognitive exertion and emotional upheaval (Chu et al., 2018). It can occur from daily living (walking, cooking, reading), will vary between individuals, and may differ from day to day. For participants, understanding PEM by knowing their triggers, baseline, and how to operate within their safety zone or energy envelope was fundamental to supporting well-being. This required a lot of trial and error and focussed attention on the body, which is linked to theme three.

5.4.3 Third Phase: Restoration and Integration

The third phase is about regaining some control over the body by building up bodily self-knowledge. At this point, participants could advocate for themselves and begin to demonstrate agency over choosing treatment protocols that they believed would work for them. This typically takes time and involves trial and error through experimentation to figure out

what might provide some symptom relief. Participants typically used a mix of conventional, alternative, or lifestyle medicine. Other studies have noted that people with ME/CFS are more likely to use alternative medicine than those without ME/CFS (Jones et al., 2007). The likely reason for this is dissatisfaction with the traditional medical system. To find the right treatments or protocols, participants had to experiment with different treatment modalities (self-management or lifestyle strategies, nutritional or dietary supplements or pharmaceuticals). It is important to note that when participants experimented with pharmaceutical medication, they did not always work. In addition, the adverse side effects of some drugs meant they had to be discontinued. The trial and error of this stage is not without potential harm and can take time, money and energy. It is therefore imperative that health professionals 'do no harm', and that people with ME/CFS have access to knowledgeable professionals. As they move through this stage, participants might still experience crashes, but they are beginning to be further and further apart. They are building more strength and stamina by developing in-depth bodily self-knowledge.

Body Awakening

Participants in this study often went through a *body awakening* in that they came to know their bodies so intimately that they could differentiate illness symptoms (i.e., depression or the flu) from ME/CFS. They could anticipate when a crash or relapse might happen and what they needed to do to avoid or mitigate the impact. This is similar to the findings by Krabbe et al. (2023), who explored the narrative accounts of young women experiencing recovery and found they paid attention to bodily signs and reactions so they could make adjustments to retain balance (Krabbe et al., 2023). This requires a high level of vigilance, ongoing bodily surveillance and a high degree of body awareness to retain health and well-being.

5.4.4 Fourth Phase: Acceptance and Finding Balance

The last phase is acceptance and finding balance, which sees the individual moving beyond fighting the illness and counting symptoms to accepting the illness and how to live with it. Acceptance has been identified as a key for therapeutic interventions to succeed, which also requires a level of safety (Soderlund & Malterud, 2005); this could be physical or psychological safety. Given the delegitimisation of the illness, this is an important concept to bear in mind when supporting recovery for people with ME/CFS. In the study by Devendorf (2020), recovery meant functioning without fear of relapse and returning to previous roles and identities. This

also holds for the participants in this study, although there is a residual underlying worry that they will never live a life without ME/CFS; this sits in the background rather than front and centre of daily life.

Over time, there is a shift in identity from a state of ill-health to a recovery identity. This new identity allows people to push out personal boundaries and re-integrate activities. Initially, this is a scary thing to do because of fear of payback (what it would cost them). Rebuilding is done through a holistic approach to health (mind: body: soul), building of bodily self-knowledge, strict routines and boundaries, and working through the psychological aspects of living with a chronic illness. Living with this illness means that you have to accept, adjust and make *sacrifices*. This meant prioritising activities and weighing up the costs for the participants; for example, meeting a friend might have a detrimental impact on quality time spent with family. Participants had to think about what they could and could not do and what might exacerbate symptoms (i.e., how much socialising or work they could do). Recovery was framed as a *"constant job"* that was *"long time hard work",* with *"ebbs and flows".* Importantly, participants found a level of self-compassion for themselves and despite managing ongoing symptoms felt resilient and empowered through their in-depth bodily self-knowledge.

Uplifts and Goals

The participants in this study described how important it was to incorporate small goals or an activity that was meaningful or gave them joy, which they say was essential to do, even at the worst of their symptoms. This could be choosing low-effort, non-social activities as these tend to be less fatiguing or energy-depleting (i.e., sitting in the sun for five minutes or mindful drawing). If people perceive they have some improvement, even if modest, or experience more uplifts (minor pleasant events) and fewer non-social hassles or stressors, this is associated with reduced fatigue and better functioning (Freidberg et al., 2023; Freidberg & Sohl, 2009). It might be helpful for other health professionals to understand that reducing the physical or emotional impact of hassles can promote well-being. In particular, participants found that navigating supports and services within New Zealand (i.e., the benefits system) increased symptomology and stress and the overall burden of the illness.

The findings alongside other best practice guidelines suggest the following recovery framework (summarised in Figure 4) and could be used by health professionals and people with ME/CFS to move towards recovery in.

Figure 4

Recovery Framework for ME/CFS

1. Medical Check-Up & Diagnosis

The earlier the diagnosis, the better the prognosis. There is no diagnostic test for ME/CFS. The following symptoms should be present for a minimum of six weeks in adults for a diagnosis:

- Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion and is not significantly relieved by rest.

- Post-exertional malaise after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time that may last hours, days, weeks or longer.

- Unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia.

- Cognitive difficulties (sometimes described as 'brain fog') may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

Make sure you get a full blood and urine test done to rule out other illnesses. Check for common co-occurring conditions, such as; Orthostatic Intolerance (OI) (use the 10-Minute NASA Lean Test), as well as Hypermobility and Ehlers-Danlos Syndrome (EDS), fibromyalgia, coeliac disease, allergies or food intolerances, Irritable Bowel Syndrome (IBS) and small intestinal bacterial overgrowth (SIBO).

2. Post-Exertional Malaise (PEM)

Upon immediately suspecting ME/CFS, start pacing. Triggers for PEM include over-exertion from physical, cognitive, and emotional activities. Recovery from over-exertion can take days or weeks.

1. Keep track of symptoms through an activity or fatigue diary.
2. Practice activity management or pacing (also known as The Spoons Theory or the Energy Envelope).
3. Know your safety zone (what you can do without causing PEM).
4. Avoid the push/crash cycle (know your baseline, and initially reduce activity below the baseline before reintegrating activities). Over-exertion for some people could be part of daily living activities (i.e. walking, cooking, reading).
5. Identify and recognise warning signs and triggers (what might make symptoms worse).
6. Find ways to make tasks easier.
7. Consider wearing a heart rate monitor.
8. Talk to a physiotherapist or ME/CFS professional to help you develop a plan to rebuild or re-integrate activities back into your life.
9. Be patient; recovery requires persistence and consistency.

3. Understand the Cause & Triggers

People can experience multiple pathophysiological changes in different bodily domains, for example, immune system abnormalities, cellular metabolism abnormalities (i.e., energy production), neuroendocrine disturbances, and blood pressure or heart rate regulation abnormalities. There are a number of triggers, such as infection/viral, stressful events or emotional trauma, environmental factors (i.e., chemical sensitivity) and a genetic link that increases susceptibility.

4. Develop & Implement a Personalised Plan

Although some people do fully recover, most people have to manage some ongoing symptoms (i.e., cognitive overload). However, by setting boundaries and using self-management tools, it is possible to live well with ME/CFS. Most people use a holistic approach to health (mind, body, soul) and a mix of conventional, alternative, and integrative medicine (including relaxation and mindfulness strategies). Some tips are:

- Recovery is not linear; ME/CFS is described as an 'unpredictable illness' with ebbs and flows. Use self-report measures to track improvement in fatigue or daily functioning.
- Find your 'soul supporter' - someone who can support you on this journey.
- Find positive recovery stories that you resonate with.
- Build a scaffold for well-being. First, rest and repair. Second, find a health professional who validates your illness experience and can provide guidance. Third, start with laying the foundation by finding symptom relief (even if the change is small initially) (i.e. sleep/gut issues and removing stressors) (see below). Fourth, figure out what works for you, implement strategies, re-integrate activities (using PEM strategies) and deal with trauma (past and present), including fear of relapse.
- Begin by creating small achievable goals; build something into your day that has meaning to you or is an enjoyable activity.
- Build bodily-self knowledge about your triggers and how to avoid a crash or relapse.
- Some common medications used include pain and sleep relievers, medicinal cannabis (inflammation, sleep disturbances, and pain), Low Dose Naltrexone (LDN) (pain, fatigue, stress, and inflammation), gabapentin and pregabalin (pain and restless leg syndrome), fludrocortisone for OI/POTS, long-acting melatonin for sleep, and anti-histamines (allergy relief). Weigh up side effects.
- Dietary and nutritional supplements are typically recommended. Some of the common ones include Vitamin B12 injections, Co-enzyme Q10 plus NADH, Magnesium, Omega 3 and 6, electrolytes, d-ribose, B-vitamins, riboflavin, Acetyl-L-Carnitine, N-acetylcysteine.

5. Follow-up

Schedule regular follow-up appointments, maintain routines, set boundaries and continue to use self-management strategies (i.e., pacing).

The information in this guide is based on the following sources:

- Participants in the study on the Lived Experience of Recovery for Adult Women in Aotearoa
- The National Institute for Health Care and Excellence (NICE): ME/CFS Guidelines (2021).
- ME/CFS Primer for Clinical Practitioners (2014).
- Centers for Disease Control & Protection (CDC) - ME/CFS.
- Vallings (2017). The Pocket Guide to CFS/ME: Key Facts and Tips for Improved Health. Calico Publishing.

5.5 Psychological versus Physical Debate

One of the most polarised debates in ME/CFS research is the physical versus psychological cause and subsequent treatment options. Kielland et al. (2023) describe these as the “bio-psycho-social side" and the "bio-medical side", which are often diametrically opposed (p. 1191). Meanwhile, for the participants of this study, recovery is not found in one or the other but in the complex entanglement of all of these things. This public debate adds to the burden of recovery (Bakken et al., 2023), as it is confusing and divisive, whereas the focus should be on the recovery experiences of those living with the illness and the results from those experiences (Groven & Dahl-Michelsen, 2022). It is often touted that people are reluctant to admit a psychological role to their illness (Chu et al., 2018); however, this was not the case for this study. Participants openly discussed the importance of working through the psychological and emotional aspects of the illness for recovery, which was essential to moving forward. Importantly, this is enabled when the illness experience is validated (Chu et al., 2018).

All the participants in this study needed both bio-medical and *psychological* support for their recovery journey, some of which included the ‘re-wiring’ of the brain to help participants move beyond the imminent fear of payback that kept them from expanding personal boundaries or re-integrating activities. The fear of relapse has been found to have a physical impact on the body by producing more adrenaline (resulting in panic attacks) and negatively impacting recovery (Groven & Dahl-Michelsen, 2022). Furthermore, living with a chronic illness will have its own emotional impact, and the person may need to work through maladaptive behaviour, dysregulated stress responses, the trauma of the illness and negative thoughts and feelings. Participants felt they had to work *“on everything”* in order to recover. This process helped participants gain intimate self-bodily knowledge that enabled them to take some calculated risks in order to re-engage or re-integrate activities into their lives.

5.6 Other Important Factors for Recovery

5.6.1 Getting a Diagnosis Early and Training of Health Professionals

Currently, diagnosis is often delayed due to the lack of knowledgeable medical professionals. Most people have a long wait for a diagnosis, which is problematic because the literature tells us that the earlier the diagnosis, the better the prognosis (Ghali et al., 2022). One study found that the wait time for diagnosis was five years (Grach et al. (2023). In this study, the average wait time for diagnosis was three and 3/4 years. In the latest update, the individual

only needs to experience the symptoms of ME/CFS for six weeks before diagnosis (NICE, 2021). Previously, it was six months, then three months, and now a six-week recommendation. These are important changes, as the earlier the diagnosis, the quicker the person can move into a recovery mindset.

5.6.2 Navigating the Systems, Work and Money

All the participants either reduced work considerably or stopped work altogether. Some participants have been able to add work back into their daily lives as their health has improved. In a study by Soderlund and Malterud (2005), all participants with ME/CFS could not continue with education or employment. Furthermore, employers often did not know how to accommodate or support someone with ME/CFS so they could retain employment (even if hours were reduced). Although this study was in the UK, it echoes the concerns of people with ME/CFS in this study. If you cannot remain employed, you need a diagnosis to access the benefits system. The problem is that diagnosis, for the most part, is not quick; it can take years, meaning the person may not access health and disability support services until well into their journey. All participants who ended up on a benefit felt that the benefits system added to the burden of the illness. They describe this experience as also being invalidating, having to prove they were ill (ME/CFS is not recognised as a disability). This is further complicated because GPs are the gatekeepers for referrals and accessing other supports or services (Pilkington et al., 2020).

Most of the costs of treatment were self-funded as they were outside the GP-subsidised medicines (i.e., alternative medicine, acupuncture or supplements from a naturopath). This can impact people's recovery as the cost is prohibitive and can delay or prevent individuals from working out what works for them. Participants felt you should be able to pick and choose between Western and non-Western medicine to find "*the best kind of toolkit to fight [with]".* Combining conventional and alternative medicine seemed to create the right kind of toolkit for most participants, and a holistic approach was consistently seen as important.

5.6.3 Finding your Soul Supporter

Participants also talked about how important it is to find your "*soul supporter*" or one or two good friends who can support you throughout the journey and who try to understand the illness. It was also seen as helpful to have "*some supportive, enthusiastic professionals behind*

you". The participants also talked about people who were not helpful and had to be avoided, if possible, particularly as some people or professionals depleted energy levels.

5.8 Future Research and Limitations

Although having a homogenous sample is preferable for an IPA study, this sample was predominately European. The findings from this study are not generalisable to the wider ME/CFS context and are situated within the New Zealand health system. The sample size of this study was small (n= 8) and excluded the severely ill and those who had newly acquired the illness. Therefore, there may be views and experiences not covered in the analysis. Furthermore, the age band for this research was left open (over the age of 18), and it might be useful to explore differences in age stratification and the length of time with the illness or time to diagnosis on recovery progression. Future research needs to look at the lived experience of recovery from various backgrounds, ethnicities, and geographic locations (to ensure all voices are heard). In addition, more research using indigenous methodologies would also be beneficial.

There are many possible future research suggestions. More research is needed on the natural history or progression of recovery to explore and further unpack the phases of recovery. This could include more qualitative research, even with people who identify as not recovered or resistant to this discourse. Quantitative research to explore both biomedical and psychological variables at each phase could also be done to validate and create a model for health professionals to use. In addition, more research is needed on what treatments people with ME/CFS use and how they contribute to recovery from both a quantitative and qualitative perspective to contribute to guidelines. Research could look at treatments in relation to phenotype/subgroup so differences can be compared across groups. And research could explore the use of a recovery-orientated framework in clinical practice.

A consensus agreement on the definition of recovery is still needed that considers age and stage of life, co-occurring conditions and whether a return to pre-illness health is realistic or possible (in relation to the definition of a total return to health). Research is needed to explore the contested nature of recovery and what contributes to its contestability (including online experiences), and research could look at where people recover (what spaces and places are used to do this). More positive recovery stories are also needed from a diverse range of backgrounds that resonate with people with ME/CFS and inspire hope.

5.9 Conclusion

The focus for ME/CFS is often on full recovery, whereas this research highlights that recovery is possible; however, it might not be to the same level as one's pre-illness health. 'Recovery in' was positioned as a good discourse to capture the complexities, the phases, and the hard work that goes into recovery. Recovery and the illness itself remain contested, so it is essential to have a recovery-orientated framework based on a holistic and multi-discipline approach to health, the belief in symptom improvement, and validation of illness experience. A recovery framework for ME/CFS emphasises the possibilities of symptom improvement while remaining realistic while providing hope. The recovery-oriented framework suggested by this research is based on four phases within recovery progression; these were not linear and overlapped and intersected with one another. Participants moved from initial confusion to agency and self-belief and from an illness to a recovery identity that included self-efficacy. There is a need for better-trained physicians who understand the illness, diagnosis and treatment options. The keys to moving forward included validation of their illness experience, understanding the cause and triggers, finding the right professional and health pathway, understanding PEM and how to re-integrate activities, being able to experiment with a range of different treatment modalities to determine what was right for them, finding a soul supporter', and consistent follow-up. There needs to be a multidisciplinary, comprehensive, and integrated approach to treating ME/CFS that is recovery-focused, explicitly focusing on alleviating symptoms *and* improving overall well-being, functioning and quality of life.

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Appendices

Appendix A: Information Sheet

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

The lived experience of 'recovery' for women with Chronic Fatigue Syndrome (CFS)

Thank you for your interest in this research project. My name is Rebecca Walton, and I am a student in the Masters of Science (Health Psychology Endorsement) programme at Massey University. I am inviting women aged over 18 years, who reside in Aotearoa, New Zealand to participate in research about their recovery experience (over time). This is an area of research that is of interest as someone who has lived experience of CFS.

Project description

The aim of this research is to explore the lived experience of adult women with CFS and their 'recovery' experience over time within Aotearoa, New Zealand. It is intended that insights from this project contribute to a greater understanding of recovery, how recovery should be defined, and what supports, and services women utilise throughout recovery progression.

What is CFS?

Chronic fatigue syndrome (CFS) is a long-term multi-faceted multi-system illness that affects a person's ability to perform everyday activities. People with CFS experience extreme tiredness that doesn't go away with rest and can't be explained by other causes. CFS and ME (myalgia encephalomyelitis) are often used interchangeably for one another (also referred to as ME/CFS).

Who can participate?

The study welcomes 6 - 8 adult females who self-identify as either having recovered or are in the process of recovering from CFS. Although the term recovery is being used, recovery is not well defined for people with CFS. Recovery may not mean a full return to health but rather people living well and managing the symptoms of CFS within their everyday lives. Therefore, we are looking for people who consider themselves to be recovered or in recovery and excluding those with severe or very severe symptoms.

If you choose to participate in this study:

If you choose to participate in this project, you will be asked to think about your experiences of recovery over time and across your illness experience. You will be asked to attend two one hour interviews. Interviews will be face to face where possible and scheduled for your convenience. I will send you a copy of the questions prior to the first interview and be available to discuss any questions you might have.

For example, I may ask about your understanding of recovery, how you have experienced recovery, who in your life supported you through recovery, and how the ill-ness changed over time. What you talk about is up to you e.g. symptoms, physical or social activity, coping strategies, relationships, work, supports and services, and lifestyle changes.

The interviews will be recorded using an audio recorder. You will be asked to create a graphic time-line prior to the interview, which will help you describe or highlight key experiences or transitions within your recovery journey (that can be added to). You can choose to bring/show photos (or other items) that help reflect your answers to the time-line. They can also be used to help me understand what is important to you and how you make sense of your experiences. To assist in this process, I will ask that you come to the first interview with a pre-prepared timeline (this could be a straight or wavy line, points on a page or a brain dump with dates!). How you create the time line is up to you. This enables you to think about the relevant points you wish to include. With your consent, I will take a photograph of your timeline to assist in the data analysis process. This may also be used within the thesis and/or the final presentation. All identifying material will be removed.

We will meet in a private, quiet location, such as in a community meeting room that will ensure your privacy. I welcome anything that makes you more comfortable (including a friend, whānau member or objects and items to support you). If we are unable to meet in person, we could meet via Zoom (or another online method). In acknowledgement of your personal time given, a $50 koha will be provided in the form of a voucher or paid direct into your bank account.

What happens after the interview?
The interview audio recording will be transcribed by Rebecca Walton (the researcher). The transcript will be sent to you and you will have two weeks to read and amend the transcript or discuss anything that needs clarifying. Interview data will then be analysed using an established method of analysis called Interpretative Phenomenological Analysis (IPA). When the project is complete you will be sent a summary of the project findings. You can pass these on, as well as discuss with me about who you would like the study's findings sent to.

The benefits and risks of this research:
This study will give you the opportunity to voice and share your experiences of your recovery journey, and it is hoped that you will enjoy taking part. This research will contribute to an enhanced understanding of what recovery means in Aotearoa, New Zealand. Interviews will contribute to health practitioners knowledge and engagement with women with CFS and a clearer understanding of barriers to navigating the health system.

As this research is discussing your ill-ness experience, the stories that you choose to share may be quite personal and could bring up unpleasant feelings or thoughts. However, this is a small risk, and I will ensure that the interview balances both positive and negative experiences. You have the right to decline any question that you do not wish to answer. Moreover, all identifying information will be omitted to eliminate the risk of being identified. This includes your name, names of others, and places of residence and work. Information of some support organisations are at the end of this sheet.

Please know that if you want to stop the interview at any time, you can. You do not have to explain why you want to stop, pause, take a break or resume the interview. I will record our conversations so that I can remember what we say and so I can transcribe it into a written document. A couple of weeks after our interview, I will arrange for us to meet again and show you the transcript or email it to you. You will be able to change it if you want. I will provide you with a summary of the research findings.

Data management
Your confidentiality and privacy are important and all names or identifying information will be removed from the transcripts, data and write up of the research. I will use pseudonyms when transcribing our discussion and will store the transcripts within a password protected file on OneDrive (on a password-protected computer). Once you have approved the transcript, I will delete the audio files. I will digitise consent forms, with your real names on them, on a password-protected Massey University storage system. Upon completion of the research project, all identified data will be destroyed including transcripts and consent forms. All de-identified data will be kept for a maximum of 7 years and then destroyed following Massey University's document destruction policies.

Participant's Rights
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *decline to answer any particular question;*
- *withdraw from the study up to two weeks after your second interview;*
- *ask any questions about the study at any time during participation;*
- *request amendments to the interview schedule to align with your requirements and needs, including cultural needs (i.e. bringing a support person):*
- *discuss with the researcher if you would like certain questions changed in the interview schedule (changes can be made where possible);*
- *ask to take a break at any time during the interview;*
- *ask for the recorder to be turned off at any time during the interview;*
- *bring a support person/whanau member(s) to the interview;*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*
- *review and amend your personal transcript within a designated two-week period;*
- *be given access to a summary of the project findings when it is concluded;*
- *request a copy of all your data (audio recordings, transcripts) following project completion;*
- *attend in person or virtually a results presentation when the project is completed.*

Committee Approval Statement
This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 23/11. If you have any concerns about the conduct of this research, please contact A/Prof Louise Brough, Chair, Massey University Human Ethics Ohu Matatika 1, telephone 06 356 9099 x 84575, email humanethics1@massey.ac.nz.

Contact details
You are free to email or call me with any questions or concerns you have about the project at any point. You can also contact my research supervisor is Dr Kathryn McGuigan, Senior Lecturer at Massey University, Auckland.

Rebecca Walton	Dr Kathryn McGuigan
Researcher – Masters of Science (Health Psychology Endorsement) programme	Senior Lecturer at Massey University
[redacted]	k.mcguigan@massey.ac.nz
Mob: [redacted]	School of Psychology Massey University/Auckland Campus Private Bag 102-904 North Shore, Auckland 0745 +64 9 414 0800 ext 43116

Support information
If you find the interview distressing, please use your existing support services. It can also be useful to talk with your GP or other medical professional that you have a good relationship with. You can also contact or use these resources:

- **Need to talk? Free call or text 1737 anytime, 24 hours a day.** A mental health helpline for people who are feeling anxious, down, overwhelmed or that you need to talk with someone.
- **The Depression Helpline** (0800 111 757) or text 4202
- **Healthline** (0800 611 116)
- **Lifeline** (0800 543 354)
- **Samaritans** (0800 726 666)
- **The Lowdown** or free text 5626
- **Health and Disability Commissioner** - consumer rights.
- **Mental Health Foundation** – support groups.

Appendix B: Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

The lived experience of recovery for women with Chronic Fatigue Syndrome (CFS)

I have read and understood the consent form/information sheet provided to me. I have had the details of the study explained to me. Any questions I have had have been answered to my satisfaction and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time up until two weeks after the second interview.

1. I agree/do not agree to participate in this study under the conditions set out in the Information Sheet.
2. I agree/do not agree to the interview being audio recorded for transcription and the content used for analysis, final thesis and results presentation (all identifiers will be removed/replaced with a pseudonym).
3. I agree/do not agree for a copy of my drawn timeline to be photographed by the researcher and used in the analysis, final thesis and results presentation (all identifying material will be removed).
4. I wish/do not wish to review my transcript following transcription
5. I wish/do not wish to have a summary of the project results emailed to me
6. I wish/do not wish to have my recordings returned to me.

Declaration by Participant:

I [print full name] hereby consent to take part in this study.

Signature: Date:

Please provide the following information if you are comfortable to do so:

Age:

Gender:

Note: This project is open to people who identify as female – if you would like to define yourself further within this identity (e.g., Cis or trans) please say so here:

Ethnicity (please indicate which applies)

	European
	Māori
	Pacific
	Asian
	MELAA (Middle Eastern, Latin American and African)
	Other

Please describe:

This information will be used for [Researcher] to contact you and will be kept confidential:

Contact number:

Email address:

Appendix C: Semi-Structured Interview Guide

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

The lived experience of recovery for women with chronic fatigue syndrome (also known as ME/CFS)

Greeting/opening
Kia ora name is Rebecca Walton and I am a postgraduate student in the Masters of Science (Health Psychology Endorsement) programme at Massey University. As you know, part of my postgraduate qualification involves doing a research project. The aim of this research is to explore the lived experience of adult women with CFS and their 'recovery' experience over time within Aotearoa, New Zealand.

Today I would like to ask you some questions about your recovery experience. The interview will take approximately 60 mins, but you can stop at any time if you are feeling uncomfortable or you would like to take a break. Your interview will be audio-recorded, transcribed and then this data will be analysed.
Before we begin, is there anything else you would like clarified, or ask me about?

INTERVIEW ONE
Introductory questions/getting to know the participant

- Can you tell me a little about yourself?
    - Where do you live?
    - How do you spend your day?
    - Who do you spend your day with?

Before we turn to your timeline and look at the specifics of your recovery experience, can you give me an overall sense of what your journey has been like?
Framing recovery

- From your experience how would you describe CFS or ME/CFS?
- How would you describe your recovery journey over time? What does recovery mean to you? How do you conceptualise it? And what do you think contributed to recovery over that period?
- What symptoms have you experienced (or continue to experience or associate with it)?
- Describe yourself before CFS, after contracting this illness and where you are at currently? What has been the greatest change from the beginning to now?
- How long have you had CFS or how long was the period of time you were unwell?

Timeline
Before coming to today's interview, you were asked to construct a timeline, starting from when you first experienced CFS symptoms (until the current date) and to highlight any key points/significant moments throughout your recovery progression. You could also bring in (or show) other mementos (photos or other items) to help explain what was happening to you at different moments in time.
Let's look at your timeline together. You can choose to start at any point on the timeline.
Note: The timeline could depict key transitions or significant events (i.e. diagnosis, changes to symptoms, work, study, relationships, social or physical activity), key supports and services (both helpful or unhelpful) and lifestyle changes you might have made.

Note: We are unlikely to get through all of the timeline in 60 mins, we will decide when to finish for this session and where you would like to start for the second interview.

Go through each timepoint using the following points as questions/prompts:

- Can you tell me about what is happening at this point on the timeline?
    - Tell me about this time-point/memento – what is happening (who, what, where)?
    - Why is this important?
    - Why did you pick this time-point/image?
    - How does it relate to recovery?
    - How did it effect recovery?
    - How does it make you think/feel?
    - How did you work through this situation?
    - Why do you think you responded in this way?
    - What did other people do? Or say?
    - Did this experience have a lasting impact upon you? If so, how?
    - Did a key person or support agency play a role here?

The interview is coming to an end. Before we finish:
- Is there anything else you would like to add/comment on?

Thank you so much, and I look forward to seeing you again to finish the time-line. Please feel free to add to your timeline before the next interview.

SECOND INTERVIEW
Welcome the participant back. Check in if there was anything they wanted to add, clarify, discuss from the first interview.
Finish off the timeline (if not completed) with the questions above.
Over-view of timeline:
- Now that we have gone over all the points on the time-line I want you to look at everything that is written and tell me about:

    - What were the most helpful or unhelpful supports and services over time i.e. this could be both traditional medicine (i.e. GP) or contemporary/alternative medicine?

- What have you found to be the most significant challenges in navigating the New Zealand health system (if any)?
- What was the most significant change for you over time and how do you account for this change (i.e. physical, social, emotional, spiritual)?
- What have you learnt about recovery? If you could go back to a time when you were unwell what would you say to yourself or to others now? Looking back, is there anything you would change/do differently if you could?
- What would you tell someone who is newly diagnosed with CFS about the experience of recovery?
- How should recovery for people with CFS be defined/framed? Is 'recovery' the right word? What is useful for people with ME/CFS to know about recovery?
- What should the future look like?

The interview is coming to an end. Before we finish:

- *Is there anything else you would like to add/comment on?*
- *Once these interviews have been transcribed you will have a chance to look at the transcript and make changes, should you choose to.*

Closing

Thank you so much for you time today, I really appreciate it. I hope that you enjoyed our time together. I will email you a transcript of our interview in the coming few days and you will have two weeks to make any changes to it. I will be in touch in one week (after each interview) to just check in and see that you are ok. If you have any questions at all, please feel free to email me ([redacted]) or call me ([redacted]). Thanks again.
Turn audio-recording off.

Appendix D: Authority for the Release of Transcripts

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

The lived experience of recovery for women with chronic fatigue syndrome

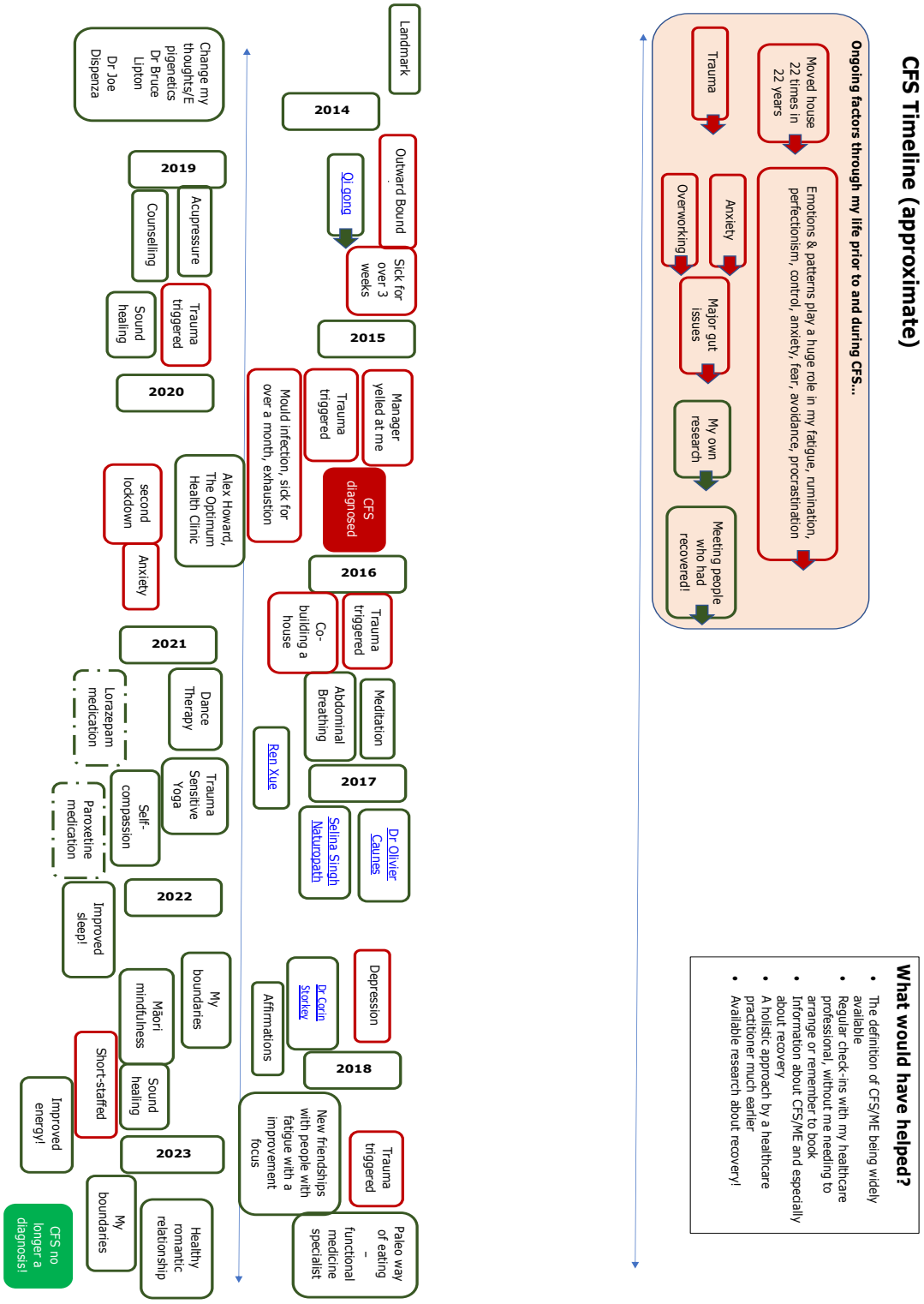
I confirm that I have had two weeks to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in the researchers thesis, in presentations, reports or publications arising from the research given that all material is anonymized.

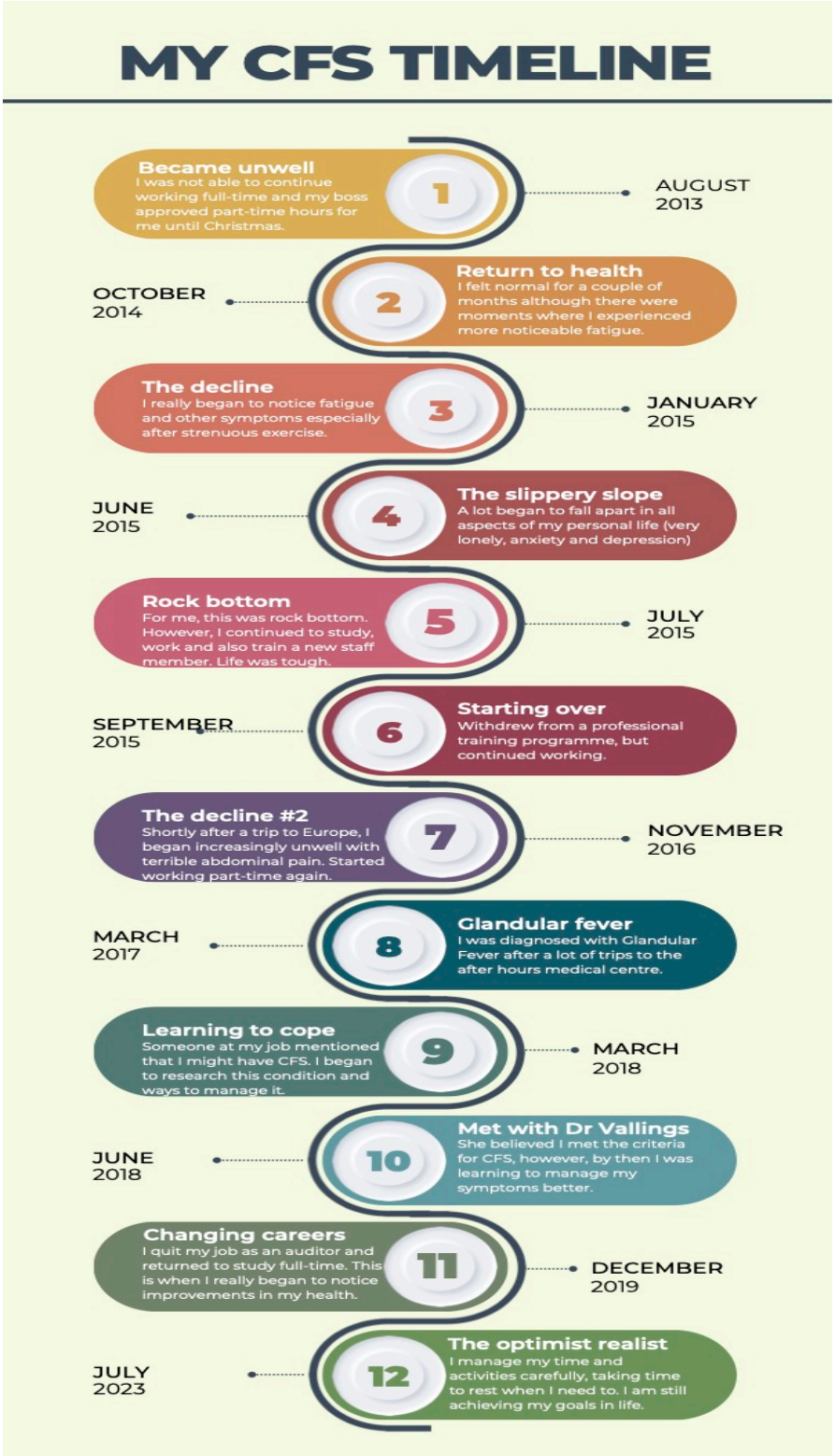
Signature: ..... **Date:** .....

Full Name - printed .....

Appendix E: Timeline Example One



Appendix F: Timeline Example Two



Appendix G: Timeline Example Three

Timeline

March 2012 - 14 y/o year 10. indistinguishable viral infection (boils on face, armpits etc. fatigues and swollen lymph nodes. [Kept training]. Never went back to school until T4 (half days)

Mid year - GP suspected CFS (he had had it) but sent him to a specialist (don't remember who) and was tested for a number of things incl. Lyme.

Was able to attend half days for half of term 4

December 2012 was pretty "okay", still required a lot of rest etc. but was able to get back into [training]. I was a bit obsessed.

2013 suffered significantly with recurring sinus issues and infections, antibiotics 6+ times, consistently taking time off school - ended with getting a Septoplasty. Finished NCEA 1.

Summer 13/14 [training]. Beginning of bad fatigue. Migraines started - Recovered enough to do a half season before reaction to trial med for migraines caused very high HR.

Approx April 2014 (16y/o, yr 12) another viral infection did not recover from, exacerbation of CFS symptoms migraines persisted - trialled lots of different meds via paediatrician @ [public] hospital.

Again summer 14/15 [training] season AGAIN.

The worst crash fatigue wise - needing 16+ hours of sleep per day. Slowly added to daily activity and progressively was able to do more and more in my day. Dec 2015 first job.

2016 - completed level 2 via correspondence school as an adult - still working on my health and being stable.

2016 - 2018 was still largely controlled by physical activity limits, mini dips in health.

2018 - rheumatologist diagnosed Undifferentiated Connective Tissue disease - meds (due to pain in hands/wrists/Raynaud's/chill blains.

Sept 2019 holiday [overseas] - came back and had a very large crash. Referred to Dr. Rosamund Vallings.

Diagnosed with mill hypothyroidism – meds.

Dec 2019 went to see naturopath - cut out gluten - started on Fibroplex Plus (BEST THING).

Jan 2020 Auckland to see Dr. Vallings - confirmed the previous CFS/ME diagnosis and started me on a B12 injection regime - very successful.

LOCKDOWN 1 (during a 1 sem study cert).

July 2020 started [another job].

Dec 2020 another health crash.

Knew the required actions to get myself better.

July 2021 started university.

Jan 2022 moved to [another town].

Dec 2022 massively swollen lymph nodes in atypical places, another fatigue crash medium.

Testing through to May 23 - not cancer most likely CFS/ME or UCTD related.

Note: For anonymity I have removed any identifiers and replaced with [….].

Appendix H: Exploratory Notes (excerpt)

encephalomyelitis and that's the neuroinflammatory paradigm of this particular illness. And So what I have experienced as my symptoms as you will see here, I was often getting sick. Migraines is definitely my most. Dominant symptom. And it's not just like ordinary migraine, it's it's like my whole brain is burning. And when that happens. I go into **paralysis** in the sense. And …	Considers herself to have ME and neuroinflammation was a key trigger from head injury.
Rebecca Walton 38:37 Is it both a cognitive and a physical paralysis?	Migraine. Not ordinary. Not typical. Migraines major symptom. No relief. Different.
P2 38:44 Yes, it's, um, I definitely. I could not think. My eyesight fails me. I, I can barely focus the I I wouldn't be able to stand up. I would be crawling on the floor. There was one episode. I can't remember when this happened, but luckily. My friends were there to help me because at this, at that point my really my **long term relationship already failed.** And I was living on my own and struggling with this fatigue illness, but thankfully I had friends who helped me and at one point my headache was just so bad that I was so nauseous. You know, I would be keeled over the toilet and just trying, you know, trying to relieve the pressure that way. And I guess because. You know the the headache as well as just the vomiting is actually very you know it's you expend a lot of energy. My friends, when they when they came to my house, they found me just on the floor, lying on the floor in the water closet. And yeah, I I don't. I don't really remember how long. I was lying face down on the floor at that point. But yeah.	Paralysis – body in shut down, trapped. No one knows how to help her. Stressor long term relationship failed. Cannot see, cannot stand, body not working. Has to crawl on floor. Nauseous. Vomiting.
Rebecca Walton 40:36 Did they know to come and find you? Or was it just a circumstance that they came, they found you?	Description of what this feels like in her body. Embodied Experience. Lost time.
Sherryl Gibbs 40:43 Ohh yeah, when I started having the headaches I rang them. I for I rang my friend and said that I that it was just different, that my headache was different from the ones that I would experience before and I. Yeah. And then she very kindly offered to come and and bring me food because at that point I haven't eaten. So yeah, that must have compounded the this symptom. I haven't eaten. Yeah. So she said she should bring me food. And and that's how…	Friend helped her and gave her food – she could not get off the floor. She needed help with food.

Appendix I: Personal Experiential Themes (excerpt)

	Recovery / Treatments	Recovery is possible - depending on how it is defined ...	Conceptualisation of recovery/defining recovery	What works/managing symptoms/Physical, Emotional, Social and Spiritual Strategies?	What's needed/future direction?	Turning Point/Mindset (finding baseline and scaffolding)	What's unhelpful/What doesn't work?	Key Supports	Pacing/living within boundaries or limits/Cost of this
P1	1/P14. Only person who perhaps sees a full return to health is possible, but she is only about 7 months in and does not have a diagnosis		Back to pre-illness health.	Mindset (nice quote on how her mindset shifted (p.9), coping with it differently. Not always positive but remains hopeful (p.).11). Lowering expectations and not feeling guilty (p. 1.12). Having a plan, finding her baseline, being proactive (1.12).	Being able to choose between conventional and alternative medicine in relation to subsidised costs of appointments/medicine.	Lowering her expectations, finding her baseline and having a plan.	None of the supplements so far have made a sign.	Family - husband and kids	Pacing is key.
P2	P2. 1/p.19. Understanding there are different stages of recovery (of which age/length of time with the illness can have an impact). Length of time creates different mindset as does age and stage	P2. 1/p.19. Understanding negative responses to the word recovery; P2. 1/6.21. Prefers the word Rehabilitation as it is discourse. P2. 1/p.18. Bringing in MH research into butterflies). Emotional (counselling). 2/p8 does use some essential oils. P9. Prefers CFS recovery space.- Davidson & Rowe. P2. 1/p.19. somatic experiencing like EMDR, retraining her vagus nerve and narrative therapy Using a recovery framework. Davendorf - rather than recovery from, it's recovery in (more hopeful), P 2.3/p.4 people get trapped in a illness identity, try so hard to be believed, need to switch to a recovery identity (great quote).	P2. 1/p.20. The word recovery is problematic.- acceptance (no longer feels grief p.1/10). Knows what to do (symptoms no longer aggravated by confusion and uncertainty). So confusing. 1/p14. Have to do your own research and experiment with off label meds. 1/p14 Spiritual (origami combined with dance movement therapy) So more somatic based). P.10. Uses mindfulness practices such as Fisura logic breathing.	P2 Getting a diagnosis and having a name for it. Game changer. Biggest change is connection through the vagus nerve (encompassing neurology and psych). Also refer to symptoms medical as integrative. 2/p.12 feels both despondent about the power of advocacy groups (not funded enough) and also (refer 3/p.1) how useful they are in providing information and advocate and change her condition to survive advice. 3/p.6. - little health literacy/ill-informed needed someone to help guide her on the journey. Need a regulated body to oversee the journey of people with acquired disabilities (give evidence based information) (great quote).	Recovery is about understanding the mind/body connection	Getting a diagnosis and no longer feeling grief (1/p.9). Taking the LDN was a 'game changer for me', but had to stop because of cost, also game changer was medicinal cannabis which she still takes (1/p.7). 2/p.8 keys were medication, counselling and narrative therapy. 3/p.5 had to be her own	Having the wrong diagnosis of depression and being told to exercise (among other unhelpful tools). Started supplements for adrenal fatigue and spending money on quack doctors (p5). Also mentions this 2/p.8 -quackery adrenal fatigue supplements. 2/p.9 does not rate CBT (good quote makes her feel sick), being so ill-informed and spending loads of money on 'quack doctors' (3/p. 6).	Single - navigated on her own, has some good friends who support her. but navigating this illness on her own was very hard. 2/p.5 she did all the research on her own, their was a ME Support Worker (who had CFS) who was also good and knew what it feels like in your body (p10).	Pacing is key. Decided to not have children. 2/p1 great quote (in green) about honouring and understanding her limitations to say well. if pushes too hard, ends up with headaches and chronic pain.
P3	2/p.9 Feeling better, improving your life? Or to hell with it and just focus on recovery	P3. 1/p.3. Describes the exp. (quote). Defining fatigue is problematic. P3. 1/p.5 Used a self-rating score. 2/p.8 Recovery not a word everyone like to hear, like a swear word. 2/p.9 Feeling better, improving your life? P10: - just call it recovering from CFS and to hell with people that don't think you can recover." (Great quote). 2/p.10 being aware of the different phases of recovery and it being one step forward, two backward and the boom and bust of CFS (great quote). 2/p.17 has to be holistic that involves mental, physical, emotionally and spiritual healing. Is an individualised journey, and it's not a straight line, with stages to pass through, getting good support and knowing your not alone (including professionals).	P3 She did a bit of her own research and meeting other people who had recovered. New integrative Gp and naturopath, stool sample and supplements based on that. ie. overgrowth of certain bacteria, high levels of lactic acid in gut. Changed diet in early 2019 as got really out of balance. OAT test, liver metabolism out of whack. Having regular follow up appointments. Don't going back to old patterns 1/p.15 Need for an integrative team. Also involved with Qigong and Landmark meditation (were useful in changing perceptions/mindset 1/p.20). P3. 1/p.6. Also 1/p.18. Sarah Myhill on mitochondria not hypochondria and finding people who will support recovery (recovery stories) Dr Corrin Storkey/Alex Opbonmum health etc P3 1/p.18.- Friends with other ppl with CFS huge help (ref p 10). P3. 1/p.17. Need for an individual plan which cover the multi-faceted nature of CFS - key to recovery. 2/p.1 having interdisciplinary team, follow up appointments, getting gut back into shape, somewhat helpful was the paleo diet, having a holistic approach, reading recovery stories and doing own research and knowing your triggers. 2/p.2 medication made a difference - paroxethine and lorazepam were game changer for sleep and PTSD. Getting a restful sleep helped with everything (great quote p. 3).	Regular check-ins with my health care professional without me needing to arrange or remember to book, information about CFS/ME and especially about recovery, a holistic approach by a healthcare practitioner much earlier, available research about relationship (has enough energy). Need a regulated body to oversee the journey of people with acquired disabilities (give evidence based information) (great quote). Solinn Health. Need for an individual plan which is multi-faceted 1/p.17). 2/p.10 need for researched based recovery and understanding the different phases of recovery. 2/p15 need GP's to have better awareness as the treat the problems and give hope - need to be knowledgeable about insomnia and PSM. 2/p16 whats need is a flow chart to map continuity of care from first displaying symptoms, diagnosis and treatment	The definition of CFS/ME being widely available.	In 2018 she had been sick since 2014, functional GP. Did a stool test and that was the beginning of the change. 1/p. 9. 2/p.20	Up until 2019 when she changed GP's she had done lots of supplements and wasn't getting any better. Too many doctors and no answers. No holistic picture 1/p.16). Patterns of persistence beyond what was helpful and perfectionism 1/p.16). Good quote. Hard to find info1/p.18. Pretty negative and depressed prior to becomin unwell (1/p.16). 2/p.1 - 'persistence beyond limits', pushing through, perfectionism, some supplements did not work, melatonin.	New integrative GP and naturopath in 2018. Also acupressure mat and counsellor. Did more tests and tried different supplements after stool test. 1/p. 9. Connecting with others who are recovering and other professional practitioners who have supported people through it. 2/p.6 need to hear stories of recovery for hope. To know that recovery is possible. 2/p.12 meeting Dr and naturopath who believed it was fixable and believed me.	P3 1/p.8 Relationship breakup - commit to CBT. 2/p.9. - spent 100s and 100s of dollars but what choice do you hope - trying to figure out what you needed and sorting out your health ? if you don't have your health, you don't have anything. Need to test boundaries to move forward but need good education so you not overdoing it and crashing. 2/p. 11 Some things are universal (like pacing) and others individual.

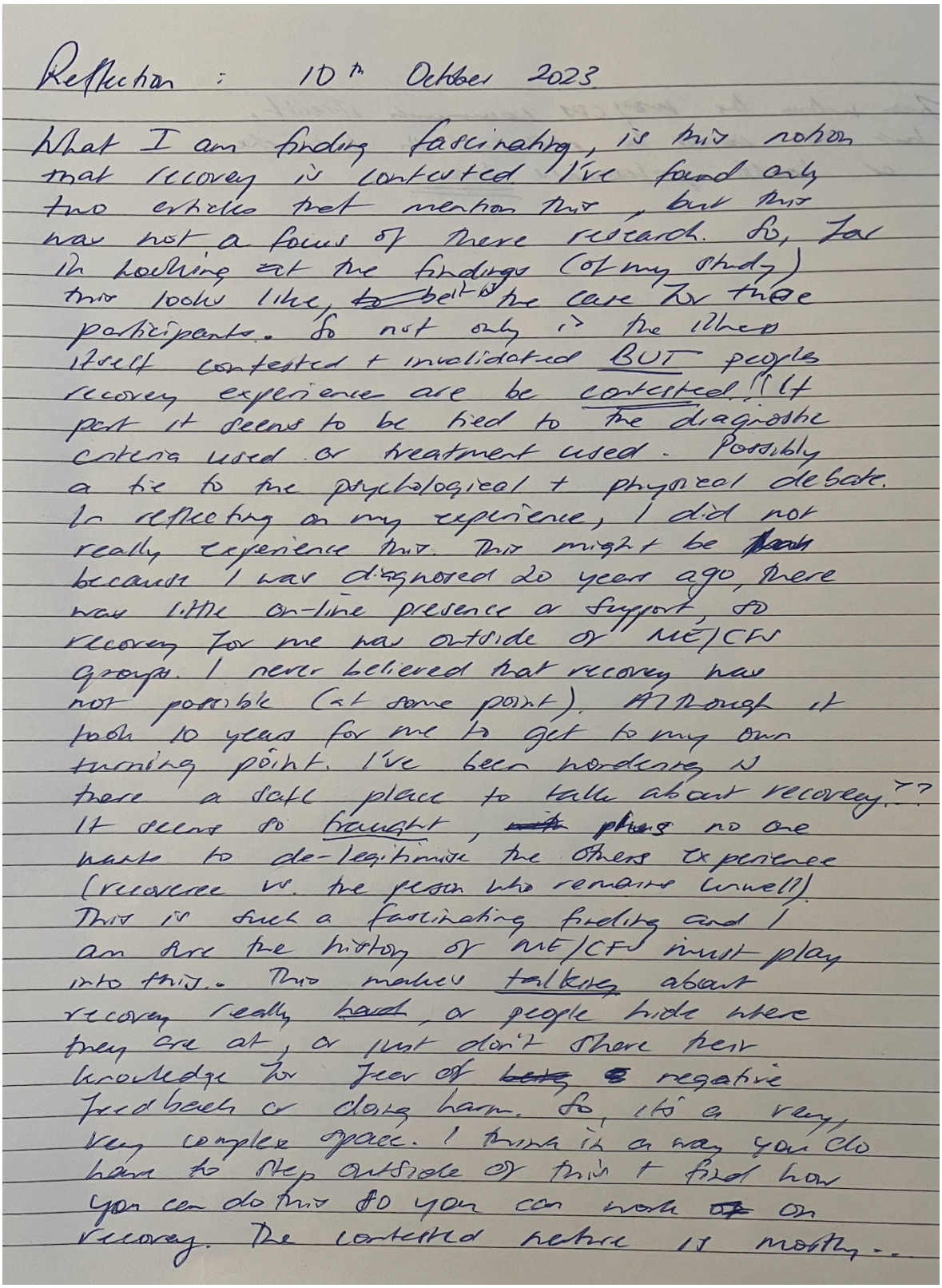
Appendix J: Group Experiential Themes (excerpt)

Table of Group Experiential Themes (GETS)

#	Group Experiential Themes (what's happening at the group level)	Sub-themes (based from PETs and experiential statements from transcripts)
One	**BEING BELIEVED AND THE UNPREDICTABILITY OF SELF-BELIEF**	*1) Being doubted makes me doubt myself* You look fine/nothing's wrong with you **P2** People do not understand my suffering (invisible) 3p.3. **P3** Didn't know what was going on for her. P 3 2/p.13 terrible run in with a GP all in your head/toughen up. **P5** 2/p.8 Sometimes people just say were all fatigued, get on with it, with no understanding. **P6 & P7** You look fine - P6 1/p.19, + 2/p.2 **P6** Medical org didn't believe in CFS (2/p.13). **P6** What you look like and how you feel are two different things (2/p.2). **P6** Good quote about people thinking you're making it up (1/p.6). I don't understand it so how can I expect others (nice quote) (1/p.4). **P6** 2/p.2 hard to understand as the illness had ebbs and flows. Really hard as people see you as fine. **P7** Expected to wear a mask/no one knows your suffering (1/p.4-5). **P8** Great quote about being dismissed, Covid not being a thing, navigating WINZ (1/p.21) **P8** People's perceptions beat you down (2/p.13). **P8** Husband 'doesn't really get it because it's invisible' 2/p.7. **P8** No one sees you sick/no one believes you (1/p.4) **P9** GP's don't believe you or you are dismissed (1/p19). Multiple experiences by participants refer to no one knows how to help me. **P9** Hardest when family does not believe (1/p.13-14)

		Being doubted makes me doubt myself (a no-win situation) P1 Questioning if it is a mental or physical thing P1 1/p.6. P4 Invisibility of illness creates perception issues – P4 2/p.17 P5 Doubting yourself effects your mental recovery P5 2/p.1-2 (great quote) P5 Is this CFS or something else like menopause? Disagrees with this, but still doubts at times. P5 1/p.9. Feels like a fraud, having to use the benefit system, others struggle more etc.... P6 Is this symptom real or not, is it mental health, CFS or something else? P6 2/p.6 P6 If I don't understand it, how can others? – P6 2/p.10. P6 After diagnosis did not feel like a hypochondriac. Relief wasn't going crazy. P6 1/p8-9, 1/p. 12. P6 + P7 Being told you're a fraud makes you doubt yourself (powerful quote) P6 2/p.19. Also P6 Your told you are a fraud and end up feeling fraudulent (2/p4) P7 Doubting herself/imagining symptoms (1/p.16 & 17). P8 Other conditions are dismissed because of CFS diagnosis i.e. POTS, infertility P8 1/p.13 (and others)
		2) It's all in your head – the entanglement of physical and psychological symptoms **P2** Your just depressed 3/p.2 P9 Misdiagnosed with depression (1/p.19), also P2 misdiagnosed/suicidal/adverse effects to medication … and others. **P2** Having the wrong diagnosis of depression and being told to exercise (among other unhelpful advice). **P2** 2/p.9 does not rate CBT (good quote makes her feel yuk). **P3** Got symptoms of depression but was not depressed (1/p.12). **P4** Doctor thought she was depressed but she knew the difference. Does not consider herself to have been depressed during the illness (but managing the illness is very hard - great quote bottom of page about how debilitating it was) (2/p. 8). **P5** 2/1 'I don't have depression, but I definitely have down downs' which is made worse by constantly being challenged about what is going on for me. How you think mentally has an impact. 2/2 Great quote on how being tired is depressing but you're not depressed. Differentiates tiredness from depression.

Appendix K: Reflective Journal (excerpt)



Reflection : 10th October 2023

What I am finding fascinating, is this notion that recovery is contested. I've found only two articles that mention this, but this was not a focus of these research. So, for in looking at the findings (of my study) this looks like, ~~to~~ be the case for these participants. So not only is the illness itself contested + invalidated BUT people's recovery experience are be contested!? It part it seems to be tied to the diagnostic criteria used or treatment used. Possibly a tie to the psychological + physical debate. In reflecting on my experience, I did not really experience this. This might be ~~that~~ because I was diagnosed 20 years ago, there was little on-line presence or support, so recovery for me was outside of ME/CFS groups. I never believed that recovery was not possible (at some point). Although it took 10 years for me to get to my own turning point. I've been wondering is there a safe place to talk about recovery?? It seems so fraught, ~~with~~ plus no one wants to de-legitimise the others experience (recovered vs. the person who remains unwell). This is such a fascinating finding and I am sure the history of ME/CFS must play into this. This makes talking about recovery really hard, as people hide where they are at, or just don't share their knowledge for fear of ~~being~~ a negative feedback or doing harm. So, it's a very, very complex space. I think in a way you do have to step outside of this + find how you can do this so you can work ~~of~~ on recovery. The contested nature is mostly...