A Home That Works for You, Not Against You: The Therapeutic Landscape of the Home When Homebound with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome.

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ABSTRACT

People living with ME/CFS often spend most of their time at home, either as a preventative measure to protect their limited energy levels, or due to symptom severity where they cannot leave the house. Despite varied experiences of being homebound, little investigation has been done into the lived experiences of how the home supports their ME/CFS management. This project utilised the therapeutic landscapes framework to explore the built, natural, social, and symbolic elements of the home for people with ME/CFS. The aim was to see how participants made their home work synergistically to foster a therapeutic environment. Photo-elicitation semi-structured interview were used to gain experiential insight into how they adapted and experienced their homes as therapeutic in relation to their ME/CFS management. Five Aotearoa based participants with ME/CFS took part. The findings mapped onto the four therapeutic landscapes domains as: sectioning the home, simplifying the environment, symbolic and practical role of nature, and enriching their world. Their contributions created rich insight into how their homes are symptom responsive, provides places of both rest and activity, enriches their lives, encourages participation in hobbies, is a place of safety and comfort, and is an environment which works for them and not against them. Participant contributions were additionally illustrated through researcher-made response paintings as a means of representing experiences beyond words. This project contributes to knowledge on therapeutic landscape literature alongside valuable insight into the lives of people with ME/CFS.

Key Words: Therapeutic Landscapes; Myalgic Encephalomyelitis; Chronic Fatigue Syndrome; Homebound; Chronic Illness; Researcher Response Paintings; Lived Experience.

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I also extend gratitude to my supervisor, Dr Kathryn McGuigan, for trusting in me from the beginning and encouraging me to pursue a project where I could also paint. Thank you for your continued endorsement of me, your compliments when I have felt anxious, your empathy when I have felt worried, and ultimately your reassurance that I had all the capabilities to get this done.

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PREFACE

This project has not waned in interest since I first reached out to my supervisor, Kathryn:

I have started exploring the concepts around therapeutic landscapes, though I am more specifically interested in domestic therapeutic spaces (home and health). This has stemmed from two personal reasons: I have spent a lot of time at home due to health challenges and the curation of my domestic space for my health/wellness was very important. I also hold a painting practice, and my work explores visual themes of domestic interiors through a feminist lens (see website if you wish). Maintaining the creative streak is important for keeping me engaged! (J Philbrick, personal communication, February 24, 2023).

After skimming through the therapeutic landscapes (TL) literature I discovered an exciting opportunity to build on the concept by using it in a setting with people who have a chronic illness and are homebound. TL looks at the relationship between person and place, with a specific interest in health outcomes. In recognition of the profound impact my home environments have had on my healing, I sought to collect more stories from people in Aotearoa New Zealand (hereinafter Aotearoa) on how the home can be therapeutic for their myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). In using TL as a point of ignition, I have been able to collaborate in an inspiring photo-led interview project that gives space to the stories of five people who navigate their home-space for the management of their ME/CFS and illustrate lived experience beyond words through researcher response paintings.

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This project was a means to better understand this illness and connect with others in my ME/CFS waka (boat). My academic scholar and my artistry have taken this investigation beyond one of academic merit, but one of shared experience between myself and my participants, and future audiences. I have been able to give this project my empathy, curiosity, and creativity. This project has been inspirational to work on as it shares positive experiences of the home for those living with ME/CFS in Aotearoa. It is valuable that as you read this thesis you are immersed into the embodied experiences of living with ME/CFS to give honour to the daily endurance for people navigating their health within the walls of their home.

CHAPTER ONE: INTRODUCTION TO ME/CFS

Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) is understood as a chronic illness impacting multiple systems in the body (lymphatic, muscular, nervous, immune, digestive, and cardiac), all of which shape the body's ability to produce and manage energy levels (Cortes Rivera et al., 2019; Sweetman et al., 2020). The illness is characterised by relapses of debilitating fatigue disproportionate to any physical, emotional, or cognitive exertion. Fatigue is often delayed in onset (by hours or days), is not alleviated by rest (sleep or otherwise) or nutrition, and can last for days, weeks, or months after activity. This cycle of an energy crash is referred to as post-exertional malaise (PEM) and is the hallmark of ME/CFS (National Institute for Health and Care Excellence [NICE], 2021; Valdez et al., 2018). While it is not terminal, there is currently no known cure for ME/CFS, largely due to unknown aetiology. The recovery rate is estimated at 5% and severity can vary across someone's lifespan (Cairns & Hotopf, 2005). This illness has profound impacts on one's ability to carry out their daily living due to irreversible life limitations.

1.1 Terminology and Diagnosis Impact

ME or CFS are two diagnostic labels for the same illness. They are often used interchangeably, but each label is typically informed by public health organisation use (ME used in the UK and CFS in the USA), medical professional use, or personal choice. ME/CFS is generally used as an umbrella acronym, though slight differences between CFS and ME can occur; the latter supposedly being a more 'severe' account of the illness (World Health Organization [WHO], 2025; Tate, 2023). Diagnostic labelling for this illness has been under ongoing debate for some time, as each label can impact the understanding, representation, and treatment of ME/CFS. Additional debate has been on whether to refer to this as illness, syndrome, condition, disease, or disability. Aotearoa uses ME/CFS, as informed by NICE, who are a public body providing evidence-based guidance to the Department of Health and Social Care in the UK. Aotearoa currently refers to ME/CFS as a chronic illness, despite ongoing efforts to have it recognised as a disability (Associated New Zealand ME Society [ANZMES], 2024; Hannah, 2022; Complex Chronic Illness Support, 2023a). I will use ME/CFS and illness in this document to reflect the participants who identify either/or and are comfortable with the term illness.

The importance of echoing one's chosen label lies within the ongoing stigma this illness carries. Variations of labels have impacted how the illness is discussed, validated, and treated in the medical and layperson space. I had experience of this impact when recruiting for this project via Facebook on a ME/CFS page. My advertisement material used the acronym CFS/ME (opposite to how it is now used), the prioritising of CFS over ME was distressing to several members in the support group, who referred to the use of CFS as a derogatory term. CFS can be understood as derogatory because it can be considered reductionist to prioritise the symptom of 'fatigue'. Fatigue can be wildly misunderstood as a generic experience of being tired, rather than encompassing the debilitating effects experienced by this illness accompanied by the myriad of other symptoms (Institute of Medicine [IOM], 2015). It can result in people potentially not taking the illness seriously. There is also a risk that fatigue gets misdiagnosed as other illnesses or conditions with this symptom. While CFS is sometimes preferred because of a layperson understanding of fatigue, many find using ME holds more power as a medical label due to its difficult pronunciation and roots of the term; myalgic (muscle pain), encephal (of the brain), myel (spinal cord) and itis (inflammation); capturing more of the symptom experiences (Hanson, 2023; Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, & Institute of Medicine, 2015). Another proposed label has been *systemic exertion intolerance disease* to capture the impact on multi systems in the body (Clayton, 2015).

1.2 Diagnostic Criteria

Lack of clarity and unionised agreement on terminology and conceptualisation can trickle down into challenges with diagnosis and treatment. Many people choose to self-identify with the illness, as medical diagnosis can be difficult to obtain due to ongoing debate on diagnostic guides (Wojcik et al., 2011). The most common cause for debate around the illness's label shapes whether it is understood (and diagnosed as) a physical health condition or a neurological one, contributing to stigma around ME/CFS being an illness of the mind (Spandler & Allen, 2018; Underhill & Baillod, 2020). It is estimated that people experience an average wait time of five years for a diagnosis since symptom onset, despite the recommendation that intervention within the first six months improves prognosis (Avellaneda et al., 2009; Grach et al., 2023; Kingdon et al., 2022; NICE, 2021). This could be attributed to the constant changes in diagnostic criteria and medical knowledge, unsupportive medical staff, underreporting of symptoms, and illness stigma (Dickson et al., 2007; Kingdon et al., 2022; Wood et al., 2024). A medical professional will only provide a diagnosis in the absence of any other illnesses with similar symptoms. As ME/CFS does not have current biomedical markers or tests for diagnosis, diagnosis largely relies on patient symptom reporting over time and meeting a set of criteria, see Table 1 (ANZMES, 2024; Haney et al., 2015).

Table 1

Diagnostic Criteria for ME/CFS: Required to be Present for Six Months.

All Required Symptoms	**At Least One Additional Symptom/s**
Substantial impairment or reduction in ability to engage in pre-illness activities: education, social, personal, occupational; accompanied by extreme fatigue that is not alleviated by rest.	Cognitive impairment: *brain fog,* challenges with thinking and comprehension, memory, concentration, speech difficulty, and executive function.
Post-exertional malaise (PEM): worsening of symptoms after exertion, lasting for days, weeks, or longer. Onset typically 12–48 hours after the activity.	Orthostatic intolerance: a worsening of symptoms maintaining an upright position. Usually indicated with increased heart rate, lightheadedness, nausea, or increased fatigue.
Unrefreshing sleep: not feeling better or less tired after sleep, with no alteration to sleep patterns.	Physical exertion intolerance

Note: IOM, 2015; NICE, 2021.

NICE (2021) recommends that symptoms only need to be present for three months to qualify for a diagnosis; asserting the immediacy of the illness, as early intervention can assist in illness management (Kingdon et al., 2022). Although the criteria used for diagnosis is valuable for homogeneity, it is not helpful for someone experiencing out of the ordinary symptoms. Additionally, ME/CFS does not fit the traditional biomedical disease model used in most Western healthcare settings, generally leading to an unexplained illness resulting in exclusionary outcomes for those with ME/CFS, and general dissatisfaction with healthcare services (Dickson et al., 2007; Melby, & Nair, 2024). The ongoing discrimination from medical and healthcare professionals, and wider society, makes it difficult for people with the illness to authenticate, advocate for, or understand their experience (Strassheim et al., 2021).

Aotearoa follows the International Classification of Diseases (ICD) for clinical coding standards, which is an Australian adaptation of the World Health Organization's (WHO) ICD in which ME/CFS is still within the chapter 'Diseases of the Nervous System' (Culver, 2022; WHO, 2025). While the nervous system is bound to physical experience, the term nervous prevails into the neurological conceptualisation of this illness. It is common for people with ME/CFS to be labelled as having psychological difficulties or somatisation, but the ME/CFS community continue to push for validation of a physical health condition.

1.2.1 My Diagnosis

I received my CFS diagnosis November 2023 (age 27), despite experiencing symptoms for months prior. A sleep disorder was first noted in 2021, general malaise recorded in March 2022 and again in April 2023, symptoms became exacerbated following a COVID-19 infection in July 2022 while I was recovering from my second periacetabular osteotomy (hip) surgery, with CFS finally being recorded in November 2023; but only noted as short-term until February 2024 with recognition of its chronic state. The change in diagnosis status came alongside a change in GP. During my early consultations with GPs about my battles with fatigue I was met with anxiety management plans, diagnosis of depression, or a general wait and see approach. I can recall similar conversations were had with GPs in my early 20s where I asked, "how and why can I be this exhausted?" but had my experience explained on mental health grounds.

1.3 Symptoms

According to Tate et al. (2023) and IOM (2015) there is a list exceeding over 100 symptoms contributing to ME/CFS. The diagnostic symptoms in Table 1 are the hallmarks of this illness, additional common symptoms include flu-like symptoms, shortness of breath, chest pain, changes in appetite, gastrointestinal issues, food intolerances, increased pain, sensory sensitivities (light and sounds), temperature dysregulation, and neuromuscular symptoms (Grach et al., 2023; NICE, 2024). Symptoms typically present themselves on a continuum, becoming more severe during a period of PEM, but returning to an individualised *baseline* following sufficient rest.

1.4 Quality of Life, Symptom Burden, and Severity

It is suggested that those with ME/CFS have a lower quality of life (QoL), poorer prognosis, and higher symptomatic burden than those with other serious illnesses/medical conditions such as cancers, stroke, schizophrenia, lupus, multiple sclerosis, autism, or HIV/AIDS (Cairns & Hotopf, 2005; Falk Hvidberg et al., 2015; Valdez et al., 2018). The impact on one's QoL is largely determined by severity, number of symptoms present, personal factors, and understood by the comparison to their pre-illness self (Dickson et al., 2008). QoL areas impacted include family relationships, financial security (due to employment limitations, with only about 30% of people with ME/CFS returning to work), daily routines, self-care management, hobby maintenance, and general life stamina (Cairns & Hotopf, 2005; Pendergrast et al., 2016). Being unwell can have many negative psychological impacts as one adapts to their body changes, self-image, challenged relationships, financial stress, and degrees of loss of autonomy and independence (Corbin & Strauss, 1988; Falk Hvidberg et al., 2015). As McQuoid (2017) indicated, people with chronic illnesses experience ongoing tension between living a meaningful life while also restricting themselves to manage their symptoms. All symptoms impact QoL as the unwell person is in a constant fluctuation of symptoms and being unwell (Eaton-Fitch et al., 2020; Vyas et al., 2022).

Due to symptom variability, categories of severity are used in NICE guidelines. Those with **mild** impact are typically less active in the areas of leisure but can continue to work, often part-time, and complete most domestic tasks and self-care, amongst prioritising rest periods. Those with **moderate** impact are more restricted in the general everyday activities and often stop or reduce work hours, need some support with domestic tasks and self-care, and require significant rest periods. Those who are **severe** have stopped working and can only perform minimal daily tasks, needing support with daily living, and are often homebound. Lastly, those who are **very severe** are classed as bed or wheelchair bound and need complete assistance with their daily life (Conroy et al., 2021). Research has investigated categories of severity to better understand the differences in ME/CFS management and treatment, though most concentrates on those who are moderate to severe as those who are very severe are unlikely unable to participate in research (Conroy et al., 2021; Cox & Findley, 2000; Montoya et al., 2021; Pendergrast et al., 2016; Strassheim et al., 2021).

1.5 Embodied Experience: What This Illness Feels Like

Describing the embodied experience of living with this illness, rather than just a list of symptoms, is more valuable in capturing the impact this illness can have (Hsu, 2024). While I cannot cover the variability of ME/CFS experiences, I can offer some descriptions on how this illness can show up for someone. Noting, my understanding is largely informed by my experiences with mild-moderate CFS. I have been able to continue employment, study, and light exercise, with daily symptom challenges and periods of PEM lasting days or weeks.

The biggest discretion in understanding symptom impact is reconceptualising fatigue. This is debilitating exhaustion across your physical, mental, and emotional capacity; not just feeling tired (Palacios et al., 2023). As Sirotiak (2023) described in their narrative piece, the unrelenting fatigue is like "having a battery that is at a maximum of 10% full, draining quickly. Once the battery is drained, I cannot charge it." (p. 1254). They were previously an athlete and now find a simple walk burns their muscles and results in hours of physical rest. The biggest change when living with this illness is realising that any activity not typically associated with exhausting you, or you could easily manage pre-illness, now triggers PEM.

> *It's like having glandular fever, taking your glandular fever on an all-night drinking binge, then taking your glandular fever and your hangover and doing a 30km forced march over the Brecon Beacons. The way you would feel at the end of that is how it feels to have ME every day. It is like being on a carousel: you have ups and downs, but you can never get off.*
> (Sam, Action for ME, 2025).

It can be struggling to eat, think, or move, as your body has been depleted of its energy resources for your basic functioning, directly impacting your ability to conduct your daily tasks and take care of yourself, for days, weeks, or years on end. I often say that it feels like your muscles are pumped with concrete and poison. You feel heavy, sluggish, and on delay like a computer waiting to be re-booted. While burnout or exhaustion are common, for people with ME/CFS this is a daily occurrence, week after week, month after month, with no respite from sleep or rest, and no end in sight. We have not had a laborious week at work, are met by a day of the blues, or have a clear medical explanation for our symptoms, yet we have various exhausting symptoms permeating our bodies every day. It feels like a cycle of punishment on the mind and body for attempting to complete tasks of daily living.

For those with mild-moderate symptom impact, they are in a constant state of cost versus benefit analysis to decipher which basic tasks to prioritise: Do I shower or cook for myself? The constant negotiation of *energy mapping* exhausts limited cognitive and emotional energy resources and oftentimes the things being sacrificed are basic self-care practices, further impacting health. For those who are severely affected they often have long periods of being bedbound and become non-verbal, as that is the only volume they can tolerate and mental exertion they can utilise, they *"just lay there, you know, and I could not do anything, I did not think much. For ages I just lay there in a darkened room and existed"* (Cecilia in Krabbe et al., 2024). For those as severe to very severe, this can last for years, potentially intubated to be fed and hydrated and reliant on others for survival needs (Baxter et al., 2021).

Alongside symptomatic impacts, this illness effects one's vision for their life; disrupting career and study goals, athletic goals, relationships, and hopes for a fulfilling life. Grief and hopelessness envelopes into daily challenges, putting many at risk for suicidal ideation or death by suicide (Johnson et al., 2022).

1.6 Demographics

Is it estimated that in Aotearoa *at least* 25,000 people are impacted by ME/CFS (ANZMES, 2024), with an additional 10% of the 300,000 people with post viral long COVID meeting the criteria for ME/CFS (Complex Chronic Illness Support, 2023b). Worldwide ME/CFS is estimated to impact 0.42% of the adult population (Strassheim et al., 2021) and growing with the rise in COVID related cases (Mirin et al., 2022). Children and adolescents can have this illness too (Krabbe et al., 2023; Valdez et al., 2018), and many people suffering are undiagnosed, making the true prevalence unknown (Orji, et al., 2022; Wood et al., 2024). ME/CFS is often comorbid with *fibromyalgia* or other chronic conditions (Fall et al., 2024).

Around 10–25% of those with ME/CFS are reportedly in the severe category of this illness and are homebound, wheelchair bound, or bedbound (Conroy et al, 2021; Strassheim et al., 2021).

More women than men are diagnosed with ME/CFS (Lim et al., 2020; Valdez, et al., 2019). While gender is not a risk factor for this illness, over-representation of women in this ME/CFS space has placed a female typecast of the illness, potentially explained by the phenomenon that women tend to seek health support earlier and more often than men (Lim et al., 2020; Lyons & Chamberlain, 2006; Valdez et al., 2018). However, women can often be dismissed for their symptoms being in their head, despite wide recognition of the illness as a physical one, reminiscent of the hysteria era (McLean & Anderson, 2009; Springer-Sullivan, 2005; Underhill & Baillod, 2020). Some research indicates that people with ME/CFS have a history of anxiety, depression, and maladaptive perfectionism, which have historically been associated with traits of hysteria (Pereira et al., 2022; Valero, 2013; Wright et al., 2021). While research explores a higher prevalence of anxiety related disorders in women than males, this *does not* equate to women being more prone to ME/CFS because of anxiety but instead suggests that a history of anxiety can impact one's ability to manage their illness (McLean et al., 2011; McLean & Anderson, 2009; Wright et al., 2021).

No international research indicates socio-demographic differences in prevalence (Avellaneda et al., 2009). However, underdiagnosis is likely in Māori and Pasifika people in Aotearoa (Tate, 2023). With the aetiology of the illness remaining inconclusive, socio-cultural views of the illness remain important in considering the under-reporting and diagnosis of ME/CFS. Given the severity of symptoms for some people, and diagnostic barriers, there could be significantly more people living with this illness, and growing, as it overlaps with Long Covid diagnoses (Komaroff & Lipkin, 2023; Vernon et al., 2023). Therefore, it is important that research around this illness remains person-centered and not overly reliant on medical diagnosing (Hsu, 2024; Hunt, 2022).

1.7 Risk Factors

Research continues to explore the aetiology, pathophysiology, and risk factors for this illness. Identified mechanisms contributing to development include genetic susceptibility (family members with ME/CFS or other autoimmune disorders), childhood illnesses, other underlying health conditions, followed by an additional trigger such as increased exposure to environmental stressors (e.g. farming chemicals), viral or bacterial and infections (e.g. Epstein Barr or COVID-19), trauma or significant life change, or adverse reactions to medical interventions, or major surgery (Chu et al., 2019; Fall et al., 2024; Lacerda et al., 2019; Moss-Morris et al., 2013). Different theories propose different accounts on how this illness develops: infectious theories, immunological theories, or neuroendocrinological (Avellaneda et al., 2009). It is suspected that overlapping risk factors impact the body's ability to bounce back from any significant stressor.

1.8 Treatment and Management

As symptoms differ between individuals, there is no single line of treatment or management for this illness. Noting, treatment does not refer to cure, but minimising symptom burden. It is recommended that a comprehensive and individualised plan is crucial for the care and support for people with ME/CFS (Culver, 2021; IOM, 2015; NICE, 2021). A plan that encompasses a focus on key symptoms, short-term and long-term management strategies, identifies key supporters, and one that validates the individual's experience of illness.

Management plans have traditionally been:

1. **Cognitive behavioural therapy** (CBT) is offered to those who want to reduce illness distress (anxiety and depression) and explore behavioural symptom management; it is not a cure and ought to be prescribed with caution to not exacerbate mental exertion nor encourage the conceptualisation of ME/CFS as an illness of unwanted cognitions (Geraghty & Blease, 2016; NICE, 2021; Noor et al., 2021; Maas genannt Bermpohl et al., 2024).
2. **Graded exercise therapy** (GET) is a behavioural treatment plan designed to physically challenge the person incrementally. GET is paired with the assumption that exercise is a health-promoting activity (Strassheim et al., 2021). However, newer research and anecdotal accounts are declaring that this approach is damaging given physical intolerance for someone with ME/CFS and NICE has declared GET as harmful (Twisk & Arnoldus, 2012; Vink & Vink-Niese, 2022).
3. **The lightning process** involves retraining nervous systems responses as an extension of CBT ideas of cognitive restructuring. It is not supported by NICE and is criticised as being a commercialised treatment proclaiming to offer a cure through psychological intervention, which does not align with contemporary research on how this illness manifests and functions in the body (Vallings, 2022).
4. ***Pacing*** is generally considered the go-to for symptom management. The PACE trial originally encapsulated pacing, GET, and CBT, with a reported 22% recovery rate (Devendorf et al., 2020; White et al., 2013). However, this trial has been scrutinised for their protocol and outcome measures. It was assumed that GET saw some improvements for employed individuals with ME/CFS as an adaptive pacing approach (Zličić et al., 2023), but as Tuller and Vink (2023) breakdown, the PACE trial presented poorly collected results. Thus, the concept and operationalization of *pacing* has expanded from

this trial's approach. Olson et al. (2015) and Sanal-Hayes et al. (2023) describe pacing as increasing rest periods, breaking down tasks in relevance to one's *base-line* symptoms, and caution around PEM triggers. There is one theory that people with ME/CFS should not be elevating their heart rate above a personal threshold, (often 100bpm), as a method of pacing and avoiding PEM (Clague-Baker et al., 2024).

The *spoon theory* was introduced as a metaphor for pacing where spoons operate as energy currency. Those without ME/CFS are allocated unlimited spoons each day, while those with ME/CFS are allocated a varied number of spoons each day (e.g. 20). Throughout the day, each task costs a certain number of spoons, with tasks being more expensive for those with ME/CFS than those without (e.g. a shower costs five spoons). The spoon theory illustrates the energy cost of living with ME/CFS and if one uses too many spoons in their day that is when they will enter their cycle of PEM (ME Support, 2023). This theory is reminiscent of the *Energy Envelope Theory* (Jason et al., 2013).

5. **Alternative health treatments** such as naturopaths, holistic medicines, supplements, acupuncture, and others, are often self-funded or self-sought as they tend to operate outside of the traditional medical realm of what GPs can refer or be subsidised.

None of these management plans offer a curative outcome and in many cases their effectiveness is inconsistent for many markers of one's life (Bateman et al., 2021; Marks, 2022; Tuller & Vink, 2023). It is not uncommon for people with ME/CFS to go through many periods of trial and error with each health strategy, specialists, management plans, and timelines before they can figure out a functional pacing plan.

1.8.1 Home-based Healing

For many, pacing includes spending a significant portion of time at home to best manage symptoms and prioritise rest. It is estimated that 10–25% of people with ME/CFS could be homebound due to the severity of their symptoms (Conroy et al, 2021; Strassheim et al., 2021). While being classed as homebound with this illness is typically reserved for those as being severely affected by ME/CFS, the experience of being confined to your home occurs with the fluctuation of symptoms. Some may have extensive periods of being homebound, while some may only need to retreat to their home at times of rest (Conroy et al., 2021; Pendergrast et al., 2016; Wiborg et al., 2010).

The choice to stay home, though not strictly being homebound by symptoms, is typically a choice to protect oneself from exacerbating symptoms when leaving the home as a method of conserving spoons and pacing. Some argue that this decision is made through a fear-induced negative feedback loop, leading to social isolation and increased anxiety (Boulazreg & Rokach, 2020). However, research supports the conservation or mapping of energy can reduce symptom flares, leading to modest gains in functioning (O'connor, 2019). Additionally, research on the construction of therapeutic spaces in the home aids in creating coping strategies and mitigating the negative effects of extensively staying at home, as I will explore through this research.

1.9 Research Rationale

As was witnessed during the COVID-19 lockdowns, being confined to the home meant people faced many disruptions in their daily routine, in-home relationships, and operated from a place of health consciousness; experiences that someone with ME/CFS encounters every day (Sehmbi et al., 2024). Research over the years has looked at experiences of being homebound, or home as a key site of healthcare when living with a chronic illness or disability (Anderson &

Bury, 2024; Corbin & Strauss, 1988), but not much research investigates the experiences of those with ME/CFS who spend a significant proportion of their time at home for symptom management. Little research is also given to the first-hand experiences of people living with ME/CFS. This gap revealed an opportunity to explore experiences of home for management of ME/CFS, one which valorises their experiences.

This project does not categorise participants by severity, but it does investigate a homogenous setting for those with ME/CFS and that is the home. Home is a vital site for illness management and healing, whether someone is strictly homebound or not. I have experienced this myself and thought it was valuable to investigate how the home operated as a therapeutic site for others with ME/CFS to deepen the understanding of experiences of living with ME/CFS. In valorising their experiences, we can better understand how to support them, better understand the role of the home in illness, and potentially reduce stigma around how and why people with ME/CFS carry out their days in the way that they need to.

My research aims to contribute to the growing literature and understanding ME/CFS management and healing alongside the therapeutic landscape (TL) literature theoretically grounding this project. The aim is to use the TL framework on the home environment to understand the relational experience between person and place one health outcomes relevant to ME/CFS.

1.9.1 Research Questions

How is the home experienced as therapeutic for symptom management when living with ME/CFS?

The sub-questions delineated from the structure of the TL concept:

1. How is the built environment of the home-space experienced as therapeutic alongside ME/CFS?
2. How is the natural environment of the home-space experienced as therapeutic alongside ME/CFS?
3. How is the symbolic environment of the home-space experienced as therapeutic alongside ME/CFS?
4. How is the social environment of the home-space experienced as therapeutic alongside ME/CFS?

CHAPTER TWO: LITERATURE REVIEW

Therapeutic Landscapes (TL) is a conceptual framework pioneered by geography researcher Wilbert Gesler in 1992. Gesler's framework contains four categories used to examine a landscape: the natural environment, built environment, social environment, and symbolic environment. Gesler proposed that these operate synergistically to maintain a site of healing across time, space, and diverse people through their material, functional, symbolic, social, and relational components (Gesler 2003; Rathmann, 2021; Williams, 2007). Any environment (landscape, space, or site) that has a relationship with health (physical, psychological, or spiritual) can find itself available to the application of the TL framework.

Since 1992 the framework has been used to understand the therapeutic and healing impact of spaces such as hospitals, birthing centres, hospice settings, end-of-life care, alcohol and drug groups, retreats, spiritual sites, communal sites like baths, settings in nature, and other informal settings of care, such as the home (Colins, 2007; DeVerteuil & Andrews 2007; Gesler, 2003; Gesler, 2018; Knapp, 2020; Moore et al., 2013; Williams, 2007; Wood et al., 2015). The expansion of the concept has been used in health geography, anthropology, and psychology fields as a tool for understanding relationships between person and place in the context of health and well-being outcomes. Throughout these fields, TL is theoretically informed by humanism, structuralism, cultural ecology, and sociology (Gesler, 1992; Williams, 2007). Other terms used synonymously with TL are healing places or environments, therapeutic environments (Knapp, 2020), the division of *blue/green/gold/dark/white spaces* (Azevedo, 2020; Bell et al., 2018; Smith et al., 2022), or *third spaces* (Glover & Parry, 2009). Other related concepts are ontological security, place identity, place attachment, and social spaces (Banham, 2020; Knapp, 2020; Nagib & Williams, 2018).

There are five fundamental pieces of writing I have read and found best to be up to date with the application and understanding on TL since 1992: Gesler's *Healing Places* (2003), Allison Williams' edited volumes *Therapeutic landscapes: The dynamic between place and wellness* (1999) and *Therapeutic landscapes* (2007), the scoping review by Bell and colleagues (2018), and Rathman's *Therapeutic landscapes: An interdisciplinary perspective on landscape and health* (2021). These texts will be woven throughout the following literature review, especially texts from William's 2007 volume, alongside complementary research to explore the development of TL, related concepts, its future directions, and its relevance to this project. The 2007 volume may seem out of date but is a cohesive and comprehensive collection of the literature on TL and an excellent place to springboard from with ideas. In my early stages of reading on TL, it was revealed that TL is commonly applied to settings where health outcomes reach a level of resolve, often as a cure (Gesler, 2007). However, the framework has been applied to settings where cure is not available, such as palliative or hospice care, or in the case of my project, non-curative chronic illness management in the home (Moore, et al., 2013; Nagib & Williams, 2018).

As the focus of this project is on the home for chronic illness management, I have chosen aspects most applicable to the research focus and to remain close to Gesler's original ideas. The sections that I have broken this review into are based on conceptual applications of TL throughout various settings and fields of research. Sections will break down Gesler's ideas, discuss terminology and concepts within the TL literature, such as *health* and *healing*, and explore developments relevant to this project. TL is a dynamic concept that can be applied to a range of health settings beyond how it has been understood here.

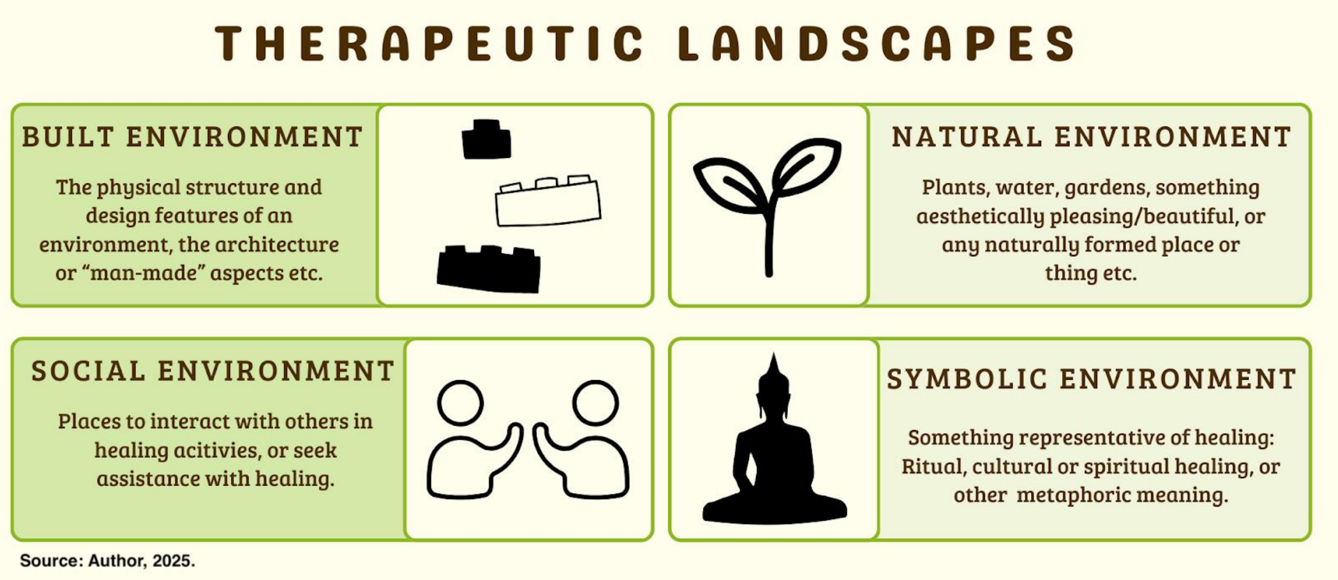
The aim of this review is to impart knowledge on how TL is used as a relative, contextual, and subjective framework for analysing the relationship between person and place alongside health outcomes. The review will link to my research question on how this framework can be applied to the home setting alongside a chronic illness where the relationship between health and place is constantly re-negotiated without the purpose of a cure. The essence and functionality of the TL framework will also give you a sense of why it has been chosen for my project to support methodological choices around relativism, person-led investigation, and arts-based tools.

2.2 Gesler's Design

Gesler set out this framework as a way of looking at places typically reserved for some form of healing or treatment (Gesler, 2003). By looking, Gesler meant deconstructing the elements of an environment which made it therapeutic. He grew curious about the properties of places reputed for their health benefits and the elements which connected such places together. After years of geographical research, Gesler settled on four categories that connect healing environments: the natural environment, built environment, social environment, and symbolic environment (see figure 1; Gesler, 2003; Gesler, 2007). Gesler drew upon these categories as he reflected that they were each encompassing various functional, material, and symbolic elements reputed for positive impacts on health. While the categories can be used collaboratively, some landscapes lend themselves to one category more than another, e.g. a retreat in the mountains aligns with features of the natural environment, but overlaps into the built, social, or symbolic environments depending on the site's activities, designs, and health outcomes.

Figure 1

An Infographic Summarising the Key Traits of Each Category in the TL Framework.



THERAPEUTIC LANDSCAPES

BUILT ENVIRONMENT

The physical structure and design features of an environment, the architecture or "man-made" aspects etc.

NATURAL ENVIRONMENT

Plants, water, gardens, something aesthetically pleasing/beautiful, or any naturally formed place or thing etc.

SOCIAL ENVIRONMENT

Places to interact with others in healing acitivies, or seek assistance with healing.

SYMBOLIC ENVIRONMENT

Something representative of healing: Ritual, cultural or spiritual healing, or other metaphoric meaning.

Source: Author, 2025.

2.2.1 Built Environment

The **built environment** (BE) refers to the physical surroundings and boundaries of a site or landscape, e.g. rooms or buildings. Within the physical space, features such as architectural structures, tangible materials, building layouts, design features, artwork, building history, and more, are examined as traits of the BE (Rathman, 2021).

Features of a BE are typically man-made and created with the purpose of an environment's health intent. Human *intent and outcome* become the point of focus to review the therapeutic outcome within a BE. For example, a hospital contains specific design features prioritised for health and well-being impacts, such as interior colour choices, religious symbolism, therapeutic gardens, or window placement (Collins, 2007; Dinu Roman Szabo et al., 2023; Willis et al., 2019); while other physical features may be prioritised for aesthetics or function of space, such as choice of artworks, home-like features, or disability access (Caspari et al., 2011; Collins, 2007). Not all design choices are for the purpose of health outcomes, of course, but certain sites reputed for healing can apply this framework for understanding how particular physical features contribute to the actualisation of a therapeutic or healing landscape. In doing so, we can explore the relationship between person (patient) and place (hospital) and the relevant health impacts, such as how design features influence patient comfort or safety. The BE elements may be stand-alone features impacting health, but oftentimes the BE features work in conjunction with the other categories of the TL framework as they can carry social and symbolic associations.

2.2.2 Natural Environment

The **natural environment** (NE) encompasses the non-human world featuring flora and fauna, naturally formed places or objects, woodlands, parks, gardens, or something aesthetically pleasing and beautiful (Gesler, 2003). A natural environment is typically associated with an expansive landscape, or the outdoors (Marcus & Sachs, 2013), but in the TL framework, it can also include man-made gardenscapes, indoor plants, or design features resembling nature. The use of man-made nature has been extensively investigated in the context of hospitals where green spaces or garden spaces have been inserted for their therapeutic benefits (Collins, 2007; Dinu Roman Szabo et al., 2023; Gesler, 2003; Garg & Dewan, 2022; Haggard & Hosking; 2003).

Gesler included the natural environment in the TL framework for the long-standing metaphor that nature heals and has long been a part of healing environments (Bell et al., 2018; Gesler, 2003). This poetic piece by Leaño (2021), 'How can we turn to the healing power of nature?' where she seeks solace in nature during a time of distress, demonstrates this. There is extensive and various research on the role of nature in healing, which I cannot cover within the scope of this thesis. Instead, I offer a summary that there are long standing beliefs across and between cultures that the healing properties of nature can be found in plants (such as medicinal plants; Singh, 2006), food opportunities (Shostak, 2017), access to land, use of water (practically and symbolically; Foley & Kistemann, 2015), the role of animals (Gesler & Kearns, 2005), and various activities carried out in green spaces, such as yoga or therapy programmes (Delaney, 2020; Schuh & Immich, 2022). Research explores the reciprocal relationship between humans and nature for health, where physicians even prescribe some time in nature for symptom relief (Doughty, 2023; Delaney, 2020; Knight, 2020; Loder, 2020). Often nature spaces are viewed as pristine or tranquil, an escape, or point of difference from our modern urban living, and thus as a therapeutic escape (Bell et al., 2018; Conradson, 2007). Gesler includes the natural environment to not only reflect the history of these beliefs and findings but highlights the *biophilia* hypothesis that humans are comforted by nature (Gesler, 2003).

Nature provides health benefits through medicine, health promoting activities like walking, hiking, swimming, and lends itself to spiritual benefits of healing by offering spaces of tranquility and comfort. The natural environment seems to offer these health benefits implicitly, but the benefits experienced from nature are more about one's use of them. Looking at the role of nature in a TL is an examination on the how and why of people engaging with the traits of the NE for health. The NE lends itself easily to the social environment, because it comprises the activities in nature shared between people, and the symbolic environment for the spiritual experiences often reported alongside the metaphor of nature as healing.

2.2.3 Social Environment

The **social environment** (SE) involves interactions between people within a place through the delegation of social roles which play a role in healing. SE's that invite healing can also be referred to as therapeutic communities or settings of care (Andrew & Holmes, 2007). The social networks in settings of care can be separated by hierarchical or heterarchical networks. The most obvious example of the hierarchical is the role of a practitioner in a medical setting: they have a service/s and skill/s to offer for healing or treatment in which a patient is reliant on for health outcomes. This social dynamic has been extensively researched to explore how this relationship can be helpful or harmful in relation to health outcomes, especially when contextualised through gender, culture, class, marginalised communities, and patient-practitioner power (Briones-Vozmediano et al., 2017; Came et al., 2021; Curtis et al., 2007).

A less formal setting to examine patient versus caregiver relationship is in the home where the unwell person is dependent on social services, an in-home caregiver, or nursing staff (Donovan & Williams, 2007; Williams, 2002). Other hierarchical roles include that of group leaders, activity facilitators, medical staff, carers, or anyone else who holds the treatment power for an individual or group. Alternatively, heterarchical social networks in settings of care could include shared collaborative activities between people engaging in a therapeutic space, such as group walks, public and communal spaces, community-led projects, or the relationship between people and their pets.

Social environments are not just physical spaces where treatments or activities take place, but socio-cultural trends between people and across time around health behaviours and values (Crawford, 2006). Gesler's inclusion of the SE is pertinent to the relational experiences of people using spaces, what it means to them, and the impact these social relationships have on desired or actualised health outcomes.

2.2.4 Symbolic Environment

The **symbolic environment** (SyE) refers to the visual cues with associated meanings inscribed into an environment or elements of that environment. In this context, they are places or things one encounters that communicate meanings of healing (Taheri et al., 2021). For example, a hospital building carries common meaning as a site of medical healing (Gesler, 2003; Gesler et al., 2004). Inside a hospital are further visual cues for healing, such as the physician or medical equipment, as symbols for medical care. Outside the medical setting, symbols of healing could be religious iconography, elements of nature (such as water, symbolising purity and cleansing; Gesler, 2003); symbols of home (Caspari et al., 2011), cultural symbols (Bell et al., 2018); anything which indicates to someone that this is a site of healing in whichever form they are seeking.

The SyE is the intersection between the physical and the social environment as symbols are drenched in metaphorical meaning-making created by the process of interpretation and evaluation (Taheri et al., 2021). Each category carries with it a symbolic understanding of why that place or thing is therapeutic as symbols exist in physical structures, nature, social relationships, and as metaphors of health to a person or group.

2.2.5 Framework Reflection

When considering an environment through this framework, we are looking not just at the physical bounds of a place, but many layers of an environment that encompass how a space is used and experienced. It is the atmosphere of an environment that includes the psycho-socio-cultural ongoings between person and place, forming meaning-making of that environment into something perceived and experienced as healing, or not (Williams, 2007; Winchester & McGrath, 2017).

The conversations on the relationship between person, place, and traits of health, are prevalent across disciplines. Environmental psychologists have been curious about the relationship between person and environment for some time (Williams, 2002), health psychologists make use of the socio-ecological model to contextualise a person's health behaviour to their wider environments (Giesbrecht & Crooks, 2016; Moore et al., 2013; Reyes et al., 2023), occupational therapists interest on home design to navigate illness and disability (Nagib & Williams, 2018), architects (Frisone, 2024), and much more. Given the large overlap in theory, research, and beliefs around healing environments, it is important to clarify that the TL framework is not a prescriptive model for what constitutes a healing place or not. As such, Gesler insisted on the term therapeutic rather than healing as therapeutic overlaps values, concepts, and tools between various observed therapeutic spaces (Gesler, 2007). The framework is simply a lens one can use to explore the relationship between person and place in the context of the therapeutic (or healing) potential of an environment.

It is important to unpack the impression from the TL literature about the framework largely being conceptualised in a positive setting, or a curative setting, where improved health outcomes have been achieved (Gesler, 2007). Already noted as a limitation, Gesler and Williams assert that TL is not a model to guarantee health outcomes and ought to be used in settings where health outcomes may not gear toward the positive to examine how an environment can be both *healthful* and harmful (Bell et al., 2018; Gesler, 2007; Williams, 2007). To address this, the TL framework ought to be used with relationality and examine a range of experiences occurring in supposed therapeutic spaces (Conradson, 2005; Rathmann, 2021).

Gesler's framework remains a useful lens to examine an environment through the chosen four categories as it allows us to pose questions on where, how, what for, and why are people using a space frequently linked to health and what meanings are created through those experiences to associate the landscape with something therapeutic and/or healing (or not).

2.3 Traditional Healing Environments

Williams (2002) describes traditional landscapes of healing as places people associate with rejuvenation, restoration, relaxation, and peace; imagined or actualsied. Gesler frames TL as actualised places with an enduring reputation for their health outcomes.

2.3.1 Gesler's Sites

The traditional inception of the TL concept was used for reputed sites of healing, such as beaches, mountain-scapes, retreats, hospitals, and other places that assumed an innate essence of healing (Gesler, 2003; Williams, 2007). Landscapes were chosen because they offer a place where intervention, treatment, or experience commonly results in a specific positive healing outcome. Used by a variety of people, they are often rendered as healing regardless of who and how it is used. Within these spaces are many key features understood as therapeutic across space, time, and context, such as: natural lighting, access to nature, organic features, soft furnishings, artworks, and symbols of health and healing (Caspari et al., 2011; Gesler, 2003). These features tend to operate on this sense of innate healing with the assumption that if an environment utilises such features, it will automatically lend itself to the associated healing benefits.

Gesler explores this in his early work with the TL framework, in his studies on Asclepian Sanctuary at Epidauros, Greece; Marian Shrine at Lourdes, France; and Roman Baths at Bath, England (Gesler, 1993, 1996, 2003). These sites were chosen because of their enduring reputations to continually offer the purpose and promise of healing, often through divine intervention.

The Marian Shrine at Lourdes carries a history of offering *miracle cures* explained by the older Catholic belief that ill health is God's punishment for sin. People would make religious pilgrimages to such sites for the purpose of redemption to cure their biomedical ailment. The mix of social and spiritual beliefs became a foundation to the meaning associated with Lourdes as a site of healing. The built environment of Lourdes is a grotto with a shrine (statue) of our Lady of Lourdes, a symbol of a saint and the presence of God, offering a symbol of spiritual healing. Religious buildings, such as the basilica and monuments, have been built around the grotto to expand the area to accommodate more pilgrims. Various taps have been installed to access the water within the surrounding esplanade, as Lourdes is reputed for its spring water, containing healing properties when consumed. There has been a long history of experiences and events that have taken place at this site as a communal place of worship, as a social function of healing. Contemporary use of Lourdes is somewhat compromised by commercialisation with the rise in tourism, but the reputation and use of Lourdes has rested in the believers, and those who have inscribed meaning to the place as healing (Gesler, 1996; Gesler, 2003).

Epidauros was chosen for similar reasons to Lourdes, in that the natural landscape and religious setting are what gave the site its effectiveness in healing. Its remote location, tranquility, and again associated myths of healing powers from Asclepius (God of medicine), led to the reported history of healing diverse people. Both sites had baths which contained healing water. Thus, the Roman Baths at Bath carries similar spiritual meaning. The purpose of baths is so that the body can soak the healing properties of the water to purify their soul and ease their ailment/s. Each of these locations contain features within the built, natural, social, and symbolic environments understood across time as healing, not simply due to the presence of these traits, but in the meaning-making through person-place relational engagements on creating health outcomes (Bell et al., 2018; Rathmann, 2021).

2.3.2 Hospitals

Gesler believed that a hospital, or any formal site of healing, ought to carry holistic values of healing, offering healing of the physical body alongside social and emotional health. Extensive research and investigation into hospital design has taken place across time to examine the therapeutic properties beyond physical health outcomes (see Maiocchi & Shafieyoun, 2022 on *emotional design*). Many design choices such as lighting, colour, noise, space, nature, home-like qualities, artwork, window placement, and gardens are inserted for therapeutic benefits aside from, but assist with, medical recovery (Collins, 2007; Frisone, 2024; Khaleghimoghaddam, 2023; Knapp, 2020; Wood et al., 2015).

Casapri et al. (2011) shared research on the aesthetics of hospitals that echoes Gesler's sentiments that aesthetics of a space is correlated to health outcomes through their psychological influence of experiencing space; one's emotional experience of place. Gesler's consideration of aesthetics has been largely with the *natural beauty* of a setting, while Casapri and colleagues explored how consultation with interior designers and architects builds the necessary interdisciplinary team to create aesthetic-therapeutic experience within a hospital.

Maggie's Cancer centre explored how architectural atmospheres impact health outcomes and experiences (Frisone, 2024). Maggie, a designer diagnosed with cancer in 1998, sought to create a healing atmosphere for those with cancer so that no one else had to experience the sensation of the hopeless sterile hospital office. Inspired by Chinese gardens and the healing temple at Asclepius, Maggie and husband Charles pioneered a more tranquil place within the Edinburgh hospital for patients to experience a more peaceful environment when receiving treatment. The concept of a hospital room transformed into an off-site non-institutionalised centre, with the priority of making patients feel at ease, valued, and more dignified during their treatment or dying trajectory. The belief being that the tranquil environment invites psychological flexibility, opening a positive experience of a health challenge, ultimately improving their sense of well-being. The improvement in psychological experience reportedly has a positive impact on sadness and anxiety, mapping onto one's immune system responses, which is vital to healing (Sternberg, 2009). The Maggie cancer centres around the world are now all designed with an architectural brief encompassing these values and design features; values and features which have been largely informed by patient feedback and experiences.

This consideration of making medical settings more pleasing and responsive to patient well-being needs is also explored in Collins (2007). Collins explores that it's not just the insertion of artworks that make a hospital more beautiful, but it is the type of artwork, who it is made for or made by, is important for the aesthetic-therapeutic experience. Surveys in Collins research indicated that patients felt large scale installations were impersonal. Artwork or decoration created by patients and staff tended to have a more domestic and personal touch to them, resulting in a more therapeutic environment due to a sense of comfort and familiarity; compared to top-down decorative decisions, which led to a sense of an inauthentic space. Patient or staff-led design features are more commonly being adopted in hospital spaces for the therapeutic benefits of familiarity, collaboration, and a sense of belonging (Payne et al., 2015).

Prioritising patient-led design has deepened the understanding between person and place in the context of hospitals because therapeutic values are curated by patient health experiences. This continues the idea that the mere presence of something classed as therapeutic may not guarantee an experience of healing, but it is the meaning, the aesthetic-therapeutic relationship associated with it, that creates the function of healing. This catches on to Gesler's holistic outlook that sites of healing encompass social, emotional, and symbolic experiences for the full therapeutic picture.

While the TL framework is still structured on advised or common features known for therapeutic outcomes, use of the framework must incorporate the relational experience between person and place to truly examine the nature of the TL, rather than an algorithm of a healing environment (Rathmann, 2021). A place that is healing to one, may not be healing to another. Just because a space has a beautiful natural landscape it cannot be assumed that a person or group engaging in that space is guaranteed a healing experience simply because it is there. One would need to be seeking healing, to some degree, and the benefits of the chosen environment would need to be corresponding to the healing need. Delineating what kind of healing is sought is linked to how health and healing are conceptualised.

2.4 Health and Healing: Context, Cure, Holism, and Negotiation

There is a rich history of debate between cultures, classes, disciplines, and fields of study around the conceptualisation and operationalisation of health and healing and how the terms are used in context. It is beyond the scope of this thesis to cover all history, but I will briefly explore how health and healing is conceptualised in TL literature. As expressed, the initial impression of TL is that healing is primarily understood or experienced as curative and positive, but that the TL framework can and certainly should be applied to places where certain health outcomes may not be guaranteed or are compromised.

The Cambridge Dictionary (n.d.a) describes healing as "the process of becoming well again" with the results being 'healed' as the ailment has 'ended'. Therapeutic, often used synonymously with healing, is described in the Cambridge Dictionary (n.d.b) as "relating to a cure of" physical ailment or to make one "feel happier". Both descriptions lend itself to the notion of cure or riddance of what was bothersome. Thus, the reputation of a healing environment has been achieved when upon leaving the environment, one or a group of people feel cured or alleviated by their ailment. It entails a sense of relief, reprieve, or freedom from a physical, psychological, or spiritual symptom. Healing is understood here as a destination or result of a cure.

Despite this assumption of curative healing in TL, Gesler insisted on attributes of healing, sharing that "getting well is not limited to a physical cure" (Gesler, 2003, p.3). He used concepts such as wholeness, connectedness, and references the *body-mind-spirit,* which is a concept coined by Janet Quinn in 1997 and carried through to contemporary holistic nursing training (Zahourek, 2012). Referring to not just healing of the body, but one of emotion, identity, connection, and soul.

WHO's definition of health states that "Health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (WHO, 2025). Somewhat problematically, this quote still denotes the complete state of something or a destination, with no more work left to improve, leaving little space for disabled people or people with chronic health conditions. But what is promising is that WHO's and Gesler's holistic understanding moves beyond just the body, which is permeating modern Western society's approach to health as we start to recognise various variables of one's health and well-being, in models such as the biopsychosocial model and Indigenous models of well-being. This multidimensional approach is utilised in socio-ecological models of health, often compared alongside the TL framework, as it is used to examine a person or group's health behaviours within a given context to capture experiences and understandings of health outside of just the body (Moore et al., 2013; Williams, 2002). The holistic integration combines traditions of

Western medical health systems alongside alternative practices and modalities of health (Torkelson & Marienau, 2022).

The traits of holism have been integrated in Aotearoa's health system with the introduction of a Māori health model, *Te Whare Tapa Whā*. In this model there are four pillars of health: *Wairua* (spiritual), *Hinengaro* (Mental), *Tinana* (Physical) and *Whanau* (Family) (Durie, 1998). These four pillars are interdependent to uphold the balance of someone's whole health. Such a model of health places a person's health in their wider context, beyond the body. Gesler's TL framework carries similar traits to Durie's model in that a TL contains spiritual, mental and physical health, and social relationships. While's Gesler's TL framework is not a model of health, it offers many crossovers to this model as it examines relationships between person and place, holistic health variables, and the meaning-making process within this all.

Despite these values, these conceptualisations of health potentially propose that with the right ingredients one's health goals can be achieved. But life is messy, and not all contributors to health or wellness are guaranteed to line up and achieve this goal. As Rathman (2021) indicated, health can be better understood on a continuum. With the flexibility of health on a continuum, it means that health outcomes can be conceptualised for people with chronic health issues/illnesses. It is incredibly unlikely for someone with a chronic or terminal condition to achieve cure or a guaranteed health outcome, even when all their pillars of health are filled, or all conditions of a supposed TL are present, which is a valuable consideration for this project.

This makes the TL framework open to the question I have for my research because it places healing not as a cure but as a subjective outcome or state of desired health. For the chronically unwell, healing or health does not mean cure, but can mean an ease of symptoms, a not worsening of symptoms, an improvement in their *baseline*, or improvement on their quality of life, *while still being unwell*.

2.5 Beyond Gesler

Moving away from Gesler's traditional locations, the framework moved from being used in the geography space and into the anthropology space and has been applied to settings such as retreats and the home to show how several layers of meaning ought to be present to create a therapeutic space (Rathman, 2021). Deconstructing the use of the framework opens an exploration of meaning-creation and curation of space (as therapeutic) for interpreting the myriad of symbols in a place which suggest that it is a healing. As such, contemporary applications have captured ideas of escapism, curation of space, places of health negotiation, and the tension between harmful and helpful spaces. This paved the way for the heterogeneity of how a place can be experienced as therapeutic or not; encompassing what type of healing is occurring, the environment of choice, who is in it, and the why and how they are using it.

2.6 Escapism in Nature

The idea of escaping to nature was established as a therapeutic value in Gesler's examination of Lourdes (Gesler, 1996). While this originated from a religious value for purity in nature, escaping to nature is continued in contemporary applications of therapeutic places. This is seen in the role of retreats to people finding or creating their own form of escape in nature's elements. The value in escaping to nature is for the elimination of one's usual stressors to be replaced with experiences of tranquility, privacy, stillness, distraction, safety, peace, quietness, and breaking the monotony of life. These provide one with psychological relief or reflection, aiding in a step towards better health or well-being.

The role of nature in the TL literature is much more than just the concept of escapism, however, this is the concept I've chosen to focus on. Escapism opens ideas on how nature has been commodified as a therapeutic experience, why people may seek it out, and how it can be adapted for people and spaces not in an outdoor natural landscape, how elements of nature are appropriated for escapism in the everyday, and the accessibility of who can or cannot escape to nature gain the benefits of this experience.

2.6.1 Stillness

Conradson (2007) looked at two Monasteries as sites of escapism to nature as a therapeutic site and experience. Alton Abbey and Elmore Abbey are lauded for their carefully manicured grounds for a landscape of tranquility, an environment which encourages just *being* rather than *doing* (achieving), a commitment towards silence (for *stillness*), and a place of spiritual contemplation or worship. Unlike the Monks who reside there, who cultivate an environment of stillness as a by-product to their worship practices, the Monasteries are a therapeutic getaway somewhere else for the guest (described as British Westerner), with "the assumption that stillness is most easily attained in locations beyond the sites of everyday home and work" (Conradson, 2007, p. 34). Guests seek stillness through holidays, retreats, or escapes, and these sites give permission for one to be unproductive inviting self-reflection, calmness, and restoration.

It is not an uncommon practice to see stillness as a healing experience, especially as practiced by Buddihsts, with the belief that stillness invites psychological and spiritual liberation and inner-balance (Vesely-Flad, 2022). The emergence of this therapeutic experience for Westerners is seen in the uptake of retreats adopting therapeutic mind-body practices like Yoga or Tai Chi, or in the increase in mindfulness practices in therapeutic settings (Bien, 2006). These stillness practices invite an escape from everyday life allowing one to focus on their healing intentions without distraction with the aid of the healing techniques at such sites (e.g. a specific programme; Dutton et al., 2023). The idea is that one leaves these sites in a more restorative state (psychologically or spiritually) than when they arrived, achieving the reputable healing outcomes. These places map onto the TL framework as their physical surroundings, spiritual offerings, social engagements, and their connection to nature cultivate a positive health experience through relaxation and reflection. The therapeutic experience is primarily psychological and spiritual, understood as achievable in locations where one can escape.

2.6.2 Adoption of Nature's Stillness

Seeking health outcomes elsewhere suggests that the healing properties of stillness in nature cannot be offered without the escape. People escape to nature in many ways. The adoption of nature indoors, nature in the city, or gardens and gardening, in urban settings, communities, homes, and in hospitals are used to create elements of escapism in nature without going elsewhere. Bringing elements of nature to spaces they are not commonly in increases accessibility to the healing properties of nature. Easy access of nature, when not being able to escape, was noticed during the COVID-19 pandemic. Engagement in nature from nearby surroundings (e.g. canals in the city; see Smith et al., 2022 on urban blue spaces), or within the home (e.g. gardening; Marsh & Williams, 2023), held impacts on well-being as it enabled one to exercise, be in the fresh air, feel connected, be safely social, and maintain their place-attachments (Doughty et al., 2023; Guzmán et al., 2022). Placing elements of nature near one’s everyday life means that escapism to nature can be easily achieved.

Turning to nature as a resource for coping and healing is not a novel phenomenon. What is interesting about how escapism, or creating stillness, is understood is in the intentionality and curation of something therapeutic in a place where nature's elements might not normally be. A curated escapism is relevant to this project as people who are homebound by illness often create their own forms of escapism within the confines of their home, such as the use of indoor plants. Deconstructing this curation opens a dialogue on meaning-making of the creation and labour behind a TL.

2.7 Constructed Place

In creating something therapeutic, decisions are made by people through religious practices, architectural trends, science-based spatial design, specialty knowledge, or socio-cultural trends. This reiterates that TL is constructed through labour and transformed into a therapeutic place by the intentions and experiences of individuals or groups (Collins, 2007; Rathmann, 2021). This is an important consideration because it connects back to the relationality of the TL framework as it continues to be about the how and why the space is being used and not in something innate. This is exactly how this research uses the framework to explore how the home is *created* as a TL. The curation, or construction, of a healing place is valuable to deconstruct as it reveals healing intentions (what is the desired healing outcome), healing tools (materials, spiritual practice, ritual, medical etc.), and the success of these outcomes based on human experience of this place (their meaning and reported outcomes). Examining this sequence has been traditionally explored in sites that clearly delineate a purpose of healing, such as retreats, hospitals, or spiritual sites, as it is easier to trace the steps between site interactions and healing outcomes.

Deconstructing the relationship between health outcome and place experience becomes more complex and nuanced when a health outcome is not guaranteed, and not in a site traditionally designated for specific healing outcomes, such as the home. The home is typically reserved for one’s everyday experiences, and not as a site to escape to for health outcomes. When the site of healing holds many other psychological, social, emotional, spiritual, and health experiences the relationships are more complex. Fortunately, the four categories of the TL framework can be used regardless of the setting, if there is a health outcome to focus on. However, health intentions and outcomes need to be contextualised in a direct relationship to the TL framework to explore the function and success of the TL on health. Only then can the framework help to explore what things are being created and used by the person/s in that space for the desire health outcomes.

The framework can open valuable discussions around how complex sites may be contested in the health outcomes they offer. This contesting of space is applicable in the home, as home is considered an ordinary site, not a retreat, idyllic escape, medical setting, or utopian imagination of healing, and thus brings with it intricate layers of meaning and experiences beyond the purpose of the environment to heal. The TL framework can be used to analyse the therapeutic experiences, and health outcomes, of a complex site because of its capacity to be contextualised and used relationally. This is how the framework will be applied for this project.

2.8 The Home: A Site of Care

Use of the TL framework in the home has been a part of the contemporary development of the framework to understand sites where healing is not often curative, specific treatments or healing practices may not be offered. This includes traditional homes, shared living environments, or apartments; a setting in which one carries out domestic duties, sleeps, dwells, and is a primary site for their everyday life. There is a wealth of literature and scholarship detailing the relationship between person, home and health; across this literature are shared conceptualisations that home is understood as a multidimensional site affecting one's physical, psychological, social, and spiritual health (Dyck et al., 2005; Despres, 1991; Hadjiyanni, 2019; Hiscock et al., 2001; Krasner, 2010; Mallett, 2004; Relph, 1976). The values created in the home are often of one's life and identity, privacy, safety/security, comfort, and control, which are all understood to have positive influences on one's health and well-being.

The TL framework has seen how the home can operate as therapeutic when the home becomes a site of rehabilitation and care, usually because someone becomes significantly unwell or disabled. When becoming a site for care, the home often undergoes changes to its build environment (home modifications, medical equipment), its social environment (relationships in the home, caregivers), its symbolic environment (rituals for health, religious or spiritual connections), and the natural environment (adopting the outdoors to the indoors), to adapt to the new experiences of home and health. Unlike how the TL framework has been applied to popular and public spaces, where a sense of universality in their meaning for healing has been surmised, healing in the home shifts into a private individualised sphere. Moore (2013) and Krasner (2010) described the home as an embodied experience, intertwined with the unconscious every day and when someone becomes unwell home often shifts from meaning a site of homeliness and self-expression, to a place entangled with unique experiences of health negotiation. This research intends to disrupt the everyday embodied experience of home by thinking and discussing why and how the home reflects the categories of TL.

Table 2 summarises the literature of how the TL framework has been used in home settings with various health challenges. These texts stretch Gesler's ideas to deepen the understanding of how a space is curated and utislied for therapeutic benefits, even when healing (cure) is not available. These texts inform the following sub-chapters on the material, social, and symbolic changes a home landscape experiences when the home becomes a site of care through a thematic summary of ideas relevant to my project. However, all texts uniquely explore how a home is understood and cultivated pre and post illness, capturing an understanding of home beyond the material environment, but one of the socio-ecological environment of the unwell individual.

Table 2

Key Literature Looking at TL in the Home.

Author	Title	Key Ideas
Alaazi et al., 2015.	*Therapeutic landscapes of home: Exploring Indigenous peoples' experiences of a Housing First intervention in Winnipeg.*	Experiences of Indigenous homeless assigned housing via a Housing First Project. Through an Indigenous conceptualisation of TL, broader socio-cultural understandings of 'home' and 'housing' are examined.
Allen et al., 2017	*How People with Dementia and Their Carers Adapt Their Homes. A Qualitative Study.*	Experiential insight into how people with dementia and their carers access information about home adaptation, how they use these adaptations, and how they feel about these changes to *remain at home* while unwell.
Corbin & Strauss, 1988.	*Unending work and care: managing chronic illness at home.*	Explores the trajectory of changes in care over the course of supporting someone with a chronic illness. Concentrating on home care, the balance of everyday tasks, medical requirements and the social and psychological impact of managing illness in the home.
Donovan & Williams, 2007.	*Home as Therapeutic landscape: Family caregivers providing palliative care at home.*	The caregiver's perspective of adapting the home to facilitate the needs of the unwell person while maintaining as much normalcy as possible. The transformations of social relations, material and physical spaces, and financial impact influenced the healthful or unhealthful experience of the home.

Doyle et al., 2000.	*Palliative care in the home.*	A guide on providing specialist care in the context of the home for family doctors and nurses. Covering emotional, physical, spiritual, and social challenges in the face of ongoing care, emergencies, ethical issues, and communication within the team of carers.
Dyck et al., 2005.	*The home as a site for long-term care: Meanings and Management of bodies and spaces.*	Experiential insight from people receiving paid in-home care services. The negotiation of the home as a site of a vulnerable body in need of new body knowledge and support. Relationships with the homecare and medical care providers are pivotal to the social interactions in healthcare beyond medical needs.
Espeso, 2022	*From safe places to therapeutic landscapes: The role of the home in panic disorder recovery.*	Understanding how the home transforms to an 'affective sanctuary', a TL, during panic induced spatial fragmentation from the unwell persons perspective.
Giles-Vernick et al., 2016.	*Home care of children with diarrhea in Bangui's therapeutic landscape (Central African Republic).*	An investigation of the experimental choices of caregivers made to treat childhood diarrhea at home to avoid expensive or inaccessible medical intervention. The investigation of the TL of this geographic and political location reflected through caregiver decisions to inform future public health interventions.
James, 2019	*Home, space and place: A review of Māori and Indigenous literature contributing to dementia-friendly housing design.*	A Māori and Indigenous perspective of redesigning homes to increase the safety and cultural needs of elderly/Kaumatua with dementia.

Karasaki et al., 2017.	*Orchestrating home. Experiences with spousal stroke care.*	In-depth interviews with spouses who cared for their partner post stroke and how undertaking care responsibilities and use of technology impacted spouses and how the changing material, practical and symbolic elements of home facilitate their partners' needs.
Moore, et al., 2013	*"I Am Closer to This Place"—Space, Place and Notions of Home in Lived Experiences of Hospice Day Care.*	A Heideggerian phenomenological approach to understanding 'homeliness' in hospice care to explore the creation of meaning-structures in hospice settings for patient psychological comfort and wellness to create feelings of being 'at home'.
Nagib & Williams, 2018	*Creating "Therapeutic Landscapes" at Home: The Experiences of Families of Children with Autism.*	Experiential insight on the home modifications made to accommodate a child with autism. The therapeutic nature of the home through modifications became about alleviating challenges which increased safety, comfort, and wellness experienced in the home.
Patel et al., 2023	*End-of-life care at home as a therapeutic landscape within a compassionate communities approach.*	Lived experience insight from people receiving end-of-life care and their family and caregiver perspectives of the TL of the home through compassionate social interactions between formal and informal care providers.
Williams, 2002.	*Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space.*	Investigation into place-identity from informal caregivers in the home. The shifting meaning of home to accommodate for someone's illness and related struggles for the informal caregiver to adapt to.

2.9 Home Modifications

The home undergoes a handful of significant changes when someone becomes unwell to accommodate new meanings and needs as a healthcare site. A large portion of the TL home literature explores home as a therapeutic environment for palliative care, dementia patients, rehabilitation, mental illness, and disability. The focus on home is partly due to increasing homecare as a cost-cutting tool, keeping people out of hospitals, but to also allow people to manage illness in an environment most comfortable to them (Dyck et al., 2005; Patel et al., 2023). TL modifications made within the home address not only medical or physical needs but also changing social relationships and identity within the home. The TL framework is used to discuss a site of healing that does not offer a cure and is entangled with experiences of everyday life.

2.9.1 Physical Changes

Physical modifications are intended to meet new socio-spatial arrangements for daily activities, including medical requirements, ease for caregivers, and improve the unwell person's quality of life. Most physical changes happen through medical urgency or through trial-and-error over time. Each change is in response to a particular symptom or health challenge, such as grab-rails or stair-lifts to decrease the risk of falls and impact on pain, keeping areas clean to avoid cognitive confusion (Allen et al., 2019), installing ramps for wheelchair access, widening doorways, installing larger windows for daylight and visuals of nature, communal areas as sites of rehabilitation rather than entertainment (Karasaki et al., 2017), and changes in sleeping arrangements (Abshire et al., 2021). Physical modifications such as these create new routines and bodily engagements with the everyday space of the home, not merely material differences in space, formulating new meanings on how the home is being used and understood (Dyck et al., 2005). Despite changes, it is a trend in the literature that physical modifications attempt to maintain as much familiarity of the home to preserve the essence of the pre-illness home. This benefits the unwell or disabled and others in the home by reducing the association of home as a healthcare site.

Nagib and Williams (2018) offer experiential insight on the physical modifications made in the home to accommodate Autism and foster a TL. Physical changes made within the home were using soft furnishings, removing dangerous objects, installing gates and fences, and creating sensory responsive spaces. Most of these changes were considered for safety, but as a byproduct, they reduced stress in the home which contributed to a stronger QoL for the child and their family. As a result, there was an increase in positive psychological experiences for families by providing peace of mind by limiting the risks around challenging behaviour. These changes helped maintain the essence of home outside of health modifications.

All the other literature in Table 2 deal with modifications made to the home in a similar manner. Physical changes are made to reduce risk, reduce challenges, ease symptoms, increase a sense of safety, and make home a comfortable environment amidst health challenges. Physical changes in the home are understood as therapeutic because of the positive impacts they have on the unwell or disabled and the people around them; the home becomes a place of healing for everyone in the home.

2.9.2 Symbolic

Maintaining familiarity and preserving the essence of the home is a common goal to preserve home identity. When the home shifts to a place of rehabilitation and care, the original associated therapeutic traits of home are compromised or challenged by the introduction of meanings of health negotiation, change, uncertainty, changing relationships, and in many cases, fears alongside chronic or terminal illness. Familiarity can also be symbolically maintained through aesthetic features, routines, social interactions, and being able to remain in control of the environment as the carrier of meaning-making interactions in the home. Maintaining familiarity in the home is not only to preserve the occupants' identities and home expression, but for those with dementia or other cognitive health challenges, it is to not escalate cognitive confusion (Allen at el., 2017; Patel et al., 2023). Familiarity in the home functions as a symptom-responsive need and a psychological one.

This can be seen in James (2019) on Indigenous design of dementia friendly housing in Aotearoa, where therapeutic housing is not just about accommodating illness, but about meeting symbolic needs of home that maintain someone’s sense of self. In this case, cultural symbols and practices were considered vital to create a therapeutic environment responsive to a Māori individual with dementia. Familiarity with the environment was not only to reduce cognitive confusion but maintaining a symbolic experience of home unique to individual cultural understandings of home.

Symbols of home can be complex and are important to contextualise to an individual’s understanding of home. In Alaazi et al., research (2015), housing was offered to homeless Indigenous people in a Housing First Project. Home was not simply achieved by providing shelter, as these people’s understanding of home was in their familiarity of home in the streets. For some residents there was an increase in ontological security (privacy, ownership, control, and stability) which helped create therapeutic benefits on health (such as restoring self-worth); but for others, their sense of home remained in the streets or wider community as this is where the symbolic features of meaning, routines, and social interactions were held. One participant, Karina, shared “I am too now isolated and living with people who I am not used to” (p. 34) as she was away from her community and self-made family. It was mentioned that the regulations around guests in the building contradicted Indigenous cultural behaviours around having large family and friend gatherings, leaving residents feeling lonely. This research highlights the socio-cultural elements of home, not just the material, which is also explored in other research on *homeless housing* (Bridgman, 1999). The qualities and symbols which make a place feel like home are much more than the physical bounds of a housing structure.

The takeaway here in using the TL framework to explore the symbolic elements of home (geographically or metaphorically) is to examine the symbols relevant to the persons using the space. When making any adjustments in the home to accommodate illness or disability, the maintenance of symbolic familiarity helps to keep the home from one of just a healthcare site and supports a therapeutic experience by maintaining one's sense of self and offering positive psychological experiences.

2.9.3 Social: Caregivers

Much of the literature on TL in the home is dedicated to the caregiver experiences to understand how caregivers are providing (predominantly medical) support, or how spouses and family members are coping with the changes to their environment, relationships, and experiences of home. As the home transforms to a space where illness is being managed, rather than where life is being experienced, social relationships in the home undergo significant changes as responsibilities and routines change, formulating new symbolic creations of therapeutic meanings in the home.

For caregivers, there is physical and emotional labour invested into fostering a therapeutic environment. In many cases, a degree of sacrifice for the partner or caregiver on markers of home are made as they now live with symptom-responsive elements of the home, e.g.

not allowing loud noises, living with large medical equipment, no longer sharing a bed with their spouse etc. These adaptations to the home space impacts psycho-social connections to accommodate illness (Donovan & Williams, 2007; Dyck et al., 2005; Karasaki et al., 2017).

Spouses, who commonly become primary caregivers, are negotiating new responsibilities and expectations, such as financial changes, or changes in parenting and employment, to allow for them to provide care for the dependent. This can create tension in many relationships, but not always. Donovan and Williams (2007) indicated in their research on caregivers providing palliative care, that people reported their relationships "generally strengthened throughout the dying trajectory" (p. 205), made possible by having a strong relationship prior to illness. It is surmised from a few of these texts that a caregiver's effects to maintaining familiarity in the home is one of the ways a caregiver contributes to the health-promoting factors of home as a site of care and maintains the strength of their relationships.

Karasaki et al. (2017) indicate that social connections preserving the home were not just in spousal efforts, but also in the wider community of caregivers, family and neighbours, the health system, and medical staff; creating *compassionate communities*. A community of caregivers are paramount in providing accurate and supportive healthcare practices in the home to foster a network of people as a resource for both caregivers and the unwell or disabled. A participant of Dyck et al. (2005) described receiving daily visits from both nurses and a homemaker for assistance with medical checks and domestic duties; a beneficial resource for their medical needs and maintaining their sense of home. The extension of community and healthcare workers expands the home from just a private dwelling, to one that is dependent on wider socio-ecological factors impacting health in the home (Giles-Vernick et al., 2016). These factors are reflective of one's economic, political, cultural, and social environments outside of the home.

The therapeutic benefit in these formal and informal relationships is social well-being, a sense of belonging, and a sense of community inside and outside the home, maintaining the familiarity of the social world, beyond experiences of illness or disability for the unwell or disabled and others experiencing the home.

2.10 The Unwell Person

Explorations of home through the TL framework do not tend to focus on the experiences of the unwell or disabled, but instead on how caregivers re-experience home, the creation of a medical space, and how others adapt to changes (Abshire et al., 2021; Donovan & Williams, 2007; Dyck et al., 2015). The conceptualisation of the unwell or disabled tends to be someone who has a chronic, incurable or terminal illness, or disability where they are dependent on others to foster their therapeutic and healing environments; as they may not have the ability to modify their home, escape to retreats, manage their medical needs, and personally carry the responsibilities of their own care. However, there are many people who are unwell or disabled and are not highly dependent on others, and therefore, hold the capacity to create their own therapeutic experiences; a perspective that this research adopts.

Research by Espeso (2022) was the main text within the TL literature which valorised the unwell person's experience and creation of a TL. Participants had panic disorders with a symptom to become disoriented and dissociated from *phobic spaces*. In response to this they created an *affective sanctuary* within their home for therapeutic benefits. Therapeutic traits in their sanctuaries, such as symbols of self-expression, emotional regulation tools, self-care tools practices, and isolation to process reconnection to their environment, they could effectively reconnect to their surroundings during times of spatial fragmentation. This space in their home is offered as a safe space in comparison to phobic places and is a site they can retreat to for healing, a place of therapeutic escapism.

Being unwell or disabled at home can have many negative psychological impacts as one negotiates their body failure and deterioration, disrupted self-image, disrupted relationships, financial stress, loss of dignity and privacy, loss of autonomy and independence, and hopelessness (Corbin & Strauss, 1988; Søvde et al., 2021; Staats et al., 2020). Therefore, being considerate of the perspectives and experiences of the unwell or disabled provides valuable insight into their actual needs and creation of a therapeutic environment for them. There are some discussions on how well intended attempts (by others) to maintain therapeutic or health-enhancing elements in the home can create *un*helpful outcomes, when they have not been reflective of the needs of the unwell individual. For example, while social engagement is understood as health-promoting psychologically, it may be health-detracting if visitors are not informed of health boundaries of the unwell person (Donovan & Williams, 2007). People who are unwell or disabled are constantly impacted by how they can or cannot control and govern their own body, or who and what is within their environment, which can be distressing (Donovan and Williams, 2007; Gesler & Kearns, 2005). Being dependent on others puts them at the mercy of others making decisions on their behalf, decisions which may not actually be in their best interest. As the participants in Espeso shared, needing to be alone is greatly beneficial to regulating their panic, and unplanned or unwanted guests would greatly disrupt an important feature of their therapeutic needs.

This research wishes to honour the complex role of the home from the perspective of the unwell person with ME/CFS to better understand their experience of what is health enhancing and therapeutic.

2.11 Compromised Spaces

TL's that contain both healthful and harmful potentials have been categorised as *compromised, ambiguous,* or *contested spaces* (Williams, 2007; Bell et al., 2018). Ideas of compromised spaces are explored inside and outside of the TL literature. Collins and Kearns (2007) discuss the comparison of the health benefits of being at the beach: positives were being outside, exercising, socialising, and experiencing happiness; while health risks such as sun damage, exhaustion, heat stroke, or drowning place tension on the assumed therapeutic benefits of being at the beach. In DeVerteuil & Andrews (2007) on surviving *unhealthy places* and in Geores & Gesler (1999), the atmospheres of early asylums were contested as actually being therapeutic (helpful) to those with mental health challenges. McQuoid (2017) explored how achieving the full therapeutic experience of places assumed to be therapeutic is compromised for someone with health challenges as they need to renegotiate how the place of leisure is used alongside the limitations of their mind and/or body. This renegotiation of space is echoed in Janicki (2018), as specific landscapes facilitate the spread of Lyme disease and then consequently people with the chronic illness renavigate their surroundings as a result.

The home can be a compromised space of health given to concept of healthy versus *unhealthy homes*. In Aotearoa, research has been exploring the impact of damp and mouldy homes contributing to allergies in unwell children, or the ontological security of our housing crisis and renting (Howden-Chapman, 2015; Telfar-Barnard et al., 2019). Issues which disproportionately affect our unwell, disabled, elderly, and Indigenous populations (Brown &

Johnson, 2021). While housing and experiences of home offer health-enhancing benefits, they can become a compromised space when intertwined with housing standards and policies contributing to unhealthy homes. This carries us back to the tension of the TL framework as a utopian notion. The concept often holds a promise of cure or positive health outcomes, despite how many environments can contain health compromising elements.

2.12 Homeliness in Other Therapeutic Settings

Features of *homeliness* have been applied in settings outside of the home to mimic the positive experiences of the home. This has been seen in the hospital (Gesler, 2018), isolation rooms, residential care homes, therapy rooms (Knapp, 2020), and other institutional settings like hospice care (Frisone, 2024; Moore et al., 2013). Features of homeliness is valuable to explore to understand therapeutic features of the home inside and outside of the home.

Knapp (2020) looks at the effects of familiar features of homeliness in a therapy office impacts patient comfort, belonging, and security, to facilitate healing outcomes. These are not features of someone's home, but idealised features of home, such as soothing colours, indoor potted plants, soft furnishings, natural lighting, access to nature, or other decorative elements. As Knapp describes, the familiarity fosters positive emotional associations and psychological connections of safety, supporting healing. Knapp (2020) made use of the *tripartite* model in their research to breakdown **the person** (who is in this place), **the process** (how they are using this space) and **the place** (what site is being used) and how this inter-relational exchange manifests into the meaningful bond between a person and place; much like what is exampled in the meaning-making process in the home and in the relational understanding of the TL framework. This model is not an explicit function for the TL framework but is valuable to track the creation of meaning between person and place through investigation with *place identity* and *place attachment* theory.

The features of homeliness in this setting circle back to Gesler's insinuation that a therapeutic environment which holds meanings of self-expression, comfort, and safety; a place which is welcoming, lifts the spirit, and is safe, can aid in illness recovery (Gesler, 2003). Thus, many features of homeliness are used in various health settings to facilitate such psychological experiences and enhance positive health outcomes.

Summary

The TL framework is a flexible tool for looking at a variety of environments open to an analysis of the relationship between person and place on health outcomes. Some environments hold a clear delineation between environment and health, such as hospitals, while others are more complex in their relationship to health, such as the home or compromised spaces. In the early assumptions that a TL offers healing or cure, it assumes that one who benefits from such as place is mobile, can walk/see/hear/talk, has financial or geographical privilege to access certain sites, can modify their home, is in control of their health decisions, and has access to socially and emotionally safe environments and people; arguably ableist and utopic. However, contemporary use of TL explores how sites can contain therapeutic potential alongside the potential to be harmful or compromised, making the framework more applicable to people and places with complex health experiences.

This research takes the site of the home, as a compromised site, and ME/CFS as a non-curative illness, to further the use of the framework with health outcomes that are not curative. I am not only expanding the use of the framework in ways which William's has recommended, but I am also demonstrating the relational use of the framework, its function as a dynamic analytic tool for exploring how a TL is successful, or not, and ultimately addressing my research question to better understand ME/CFS illness experience. Lastly, the collation of first-hand experiences of the home as therapeutic from people with ME/CFS reiterates the importance of priotising the unwell persons perspective to better understand what is therapeutic to them within their homes.

CHAPTER THREE: METHODOLOGY

This chapter is dedicated to outlining procedural and philosophical decisions of this project. This includes choices around research design, methodological principles, participation criteria, ethics, and researcher positionality. All steps of procedure remained congruent with the research question/s, epistemological alignment, and relational values of the TL and prioritised quality research, participant well-being, and transparency.

3.1 Research Design

This experiential research made use of semi-structured interviews informed by TL, supported by photo elicitation, for a phenomenological exploration of therapeutic experiences within the home for these participant's ME/CFS management. The use of participant photography and researcher-made response paintings responds to the aesthetic-relational element of TL and took the analysis beyond words.

3.2 Methodological Principles

A complimentary blending of tools and concepts from the family of phenomenology as a philosophy have been used: phenomenology (as experiential accounts), hermeneutic phenomenology (as interpretation of meaning in experiential accounts), and visual phenomenology (as interpretation beyond verbal descriptions in experiential accounts). Underpinning all sub-groups of these phenomenological tools are shared assumptions of ontology and epistemology, which prioritises first-hand accounts of experience, positions participants as knowledge bearers and co-creators, and that insight and understanding can be achieved through non-positivist measures (Brinkmann, 2017; Suddick et al., 2020; Larsen & Adu, 2021; Laverty, 2003).

3.2.1 Phenomenology: Epistemology of Subjectivity, Intentionality, and Embodiment

Husserl's phenomenological philosophy is grounded in epistemology as a "descriptive science of the lived experience", as *posteriori knowledge* (Suddick, 2020, p. 1). It investigates essences of a practical experience within the world (a chosen phenomenon of interest) from an intuitive (unconscious) way of being. A phenomenological investigation pierces into an interaction between person and object to unpack the unconsciousness doing (activity) and bring awareness to the meaning of that activity, offering insight into a taken-for-granted experience (Laverty, 2003). The aim is to capture how the world appears to individuals, as already infused with meaning and values unique to them, rather than informed by theory-laden a priori sense making (Larsen & Adu, 2021; Packer, 1985).

Merleau-Ponty describes this epistemological positioning as the interior subjectivity being linked to the exterior world, a *mind-world* dyad, grounded by one's perception (Larsen & Adu, 2021). Meaning, phenomenon is linked by the relational happenstance between person and object; blending subjectively lived experience in an objective world (Brinkmann, 2017; Laverty, 2003). It is perception and experience that gives objects a relational presence, a meaning, and purpose to them. Merleau-Ponty describes this relationship as one of a sensory experience, "people's relations to things are always mitigated by the body's sensory capacities, and therefore people cannot conscience of anything that they cannot also somehow perceive" (Larsen & Adu, 2021, p. 16). Essentially, experience is not only one of consciousness and thought (psychology), but unconscious embodiment in physiological sensations. This could be understood as the habits of behaviours and values people build around phenomenon, which inhabit bodily experiences without conscious awareness of the creation of meaning. Such unconsciousness habits create a *protentional* experience, an embodied anticipation of outcome (Fuchs, 2024). But, through a phenomenological investigation, we can interrupt the unconsciousness happening and bring a spotlight onto what is happening (the activity) and ask what does this mean?

This epistemology allows us to unpack the intentionality and subjectivity of an unconscious experience in the meaning-making process when interacting with the world. It is in unpacking these embodiments that descriptions of realities can be procured, and interpretive meaning can follow (Laverty, 2003; Palmer et al., 2010). In this instance, it is the embodied lived experience of ME/CFS within the home and the meanings within behaviour which bring forth the therapeutic. As identified, it is in assessing the intentions behind use and creation of a TL which procures its meaning as such, hence the relevance of this epistemological position. Additionally, prioritising embodiment and sensory experience is valuable to this project as the home is understood as an embodied experience (Krasner, 2010; Moore, 2013). In looking at a location such as the home, where so much of the commonplace occurs, much of the meaning of home-as-therapeutic is resting within the unconscious and automatic. The embodied experience of home becomes the epistemological context for investigation. By intercepting the activity, we can gain insight into the taken-for-granted or unconscious experiences underpinning the therapeutic experiences in relation to one's ME/CFS management in the home. How the participant's experience their bodies in their home, in relation to symptoms, is valuable to the relational experience and creation of a therapeutic space. It is not just about how they think and feel about their home space, but the physiological impact their home has on their experiences, their symptoms, and health outcomes, to reveal the phenomenon and impact of the therapeutic.

In applied phenomenological research, *lived experience* is the catchphrase of operationalisation. Through conducting interviews, I was able to bring forward verbal descriptive accounts of an activity within a phenomenon (home as therapeutic), piercing into their everyday experiences. The conversation functions as an entry point of locating the not-yet-conscious attributes of their behaviour and meaning-making (Fuchs, 2024). It then invites an unpacking of their activity and meaning on a more conscious and reflective level (through interpretation).

Phenomenological research is interested in capturing the *eidos* of phenomenon, the essential nature of it. To do this, it was pertinent to document *idiographic* accounts and bring cases together to merge experiences to identify shared values of a therapeutic home in relation to ME/CFS. Marrying together a sample of ideally homogenous experiences, merges several individuals and surmises an experience of a shared phenomenon, taking it beyond the individual and captures its essentialist attributes (Larsen & Adu, 2021). The interviews and interpretative phenomenological analysis (IPA) retroactively create links between instances of shared experiences and create meaningful links with the contextualised phenomena (Fuchs, 2024; Palmer et al., 2010).

3.2.2 Ontology: Hermeneutic Interpretation: Access to Understanding and Meaning

Moving beyond the shared descriptive accounts in phenomenological research is the unpacking of shared meanings and wider implications of ways of being in the world from an ontological position. A key difference between phenomenology and hermeneutic phenomenology (HP) is that of description (Husserlian) and interpretation (Heideggerian) (Brinkmann, 2017; Suddick et al., 2020). HP is a natural flow-on from phenomenology that transforms accounts of the what to the why; similarly seen in understanding the meaning-making process of TL.

Heidegger understood phenomenology as one of ontological inquiry, disclosing an ontological being (*Daesin* way of being), not just an epistemological position of investigation (Suddick et al., 2020). Dasein is understood as the essence of being, that humans in their everyday contain existential ontologies, created through one's affectedness, understanding, and articulation of meaningful action (Brinkmann, 2017; Suddick et al., 2020). Essentially, humans have the capacity to be affected by situations, operate through self-reflection and awareness, generate values and meaning, act through intention, and communicate those experiences to others. Such communication can occur with interviews. Thus, interviews remain a popular tool for collating data in qualitative research for their ontological standing by collecting experiential data on meaning-making behaviours (King & Hugh-Jones, 2019).

Dasein experience is understood to occur in the unconscious and just as Husserl's phenomenological epistemology aims to bring forth unconscious meaning-in-activity, so does hermeneutic investigation of Dasein ways of being. The existential ontology in HP raises the question of meaning behind being, the possibility of self in existence, interpreting being in the world and relating to things, within a given context, not only meaning in activity (Daly, 2016; (Larsen & Adu, 2021). Again, capturing the relational experience between person and place or object, revealing a process of meaning-making in both activity and existence.

This ontological position is most relevant to the process of interpretation for participants (in making-sense of their experience), and the researcher (in making sense of the participant's sense-making), leading to co-constructing meaning of experience for the purpose of research outcomes (Larkin et al., 2018; Smith, 2009). The interrogative means of inquiry presented by HP is in the *double hermeneutic* process. While attempting to remain as true to a phenomenon as possible, as a researcher, the challenge is in re-presenting experiences that are not our own. The researcher is not in the experience of the participants, but in a representation of the experience conveyed via the interviews.

During the interviews the double hermeneutic sense-making is introduced as I, the researcher, examined their experiences. The back-and-forth process to reach a shared understanding was created by inviting participants to review their transcript and confirm initial points of comprehension. Transcript revision is both a common gesture of collaborative ethics and a hermeneutic value in fusing horizons. Another ethical and hermeneutic consideration for research, continued in a researcher reflective practice, through journaling and reflexivity (Ortlipp, 2008). Reflexive note taking happened immediately after each interview to record initial impressions and present-moment interpretations. Further reflexive thinking occurred during transcription editing, as a form of data closeness, as I paid attention to the participants' experiences via tone, involuntary vocalisations, utterances, pauses etc. (Oliver et al., 2005); ultimately leading to a process of IPA. Each stage of reflection, interpretation, and analysis acted as further hermeneutic interpretation as I made sense of my subject's experiences within the context of the research question.

3.2.3 Visual Phenomenology: Representing Experiences Beyond Words

An additional methodological choice was to include art-in-research (photo elicitation and researcher response paintings). Art can be used at any stage of a project to enhance the understanding of the research and as a phenomenological tool to diversify perspectives (Wang et al., 2017). Arts-based methods (ABM) approaches allow for the researcher to get closer to participant experiences through means of empathy, reflection, and meaning-making; by supporting different means of expression, beyond words, allowing for an understanding of symbolic and emotional interpretation (Brown, 2022; Fish, 2023; Leavy, 2009). ABM are commonly adopted in health-based research to acknowledge the limits of human language to express sensory and bodily experiences, such as pain, and that human experiences are fundamentally embodied (Brown, 2022).

Gesler (2004) denotes that the experience of a TL is highly aesthetic and given the many research connections to the aesthetic-relational experience of various TLs, it seemed appropriate to give attention to the aesthetic-relational experiences of the home. While this relationship could be described through words, Brown (2022) emphasises the capacity for ABM to capture experience beyond verbal descriptions. Given the research intention is to investigate experiences occurring in a visually stimulated and embodied environment, the experiences ought to be captured and described in a similar manner; the aesthetic-relational world. Brown (2018) is well versed in using ABM for research with participants with chronic illness, as seen in their research with fibromyalgia where participants were asked to create an *identity box* representative of their illness experience. I took inspiration from this methodological tool to capture a more metaphorical and visual account of meaning making through symbols, colour, shape, line, gesture, in my paintings.

My research was also inspired by the work by Sperling and Decker (2007) with their use of photo elicitation for the purpose of aligning the participants as the key recorders of their experience. Participants were asked to photograph places which contributed to their overall health and well-being, with a TL described as places which made them feel good. This facilitated data collection from the *insider's* perspective, a delivery of the participant's horizon. I took inspiration from their use of semi-structured interviews as complementary to the photo submission as a tool for contextualising photographs with interview questions.

I chose to turn our conversations and photographs into response paintings as visual metaphors of their experiences of home humans use metaphorical expressions to compensate for the limitations of language (Brown, 2022) and Gesler (2003) describes TL as being metaphorical. I am also an artist (already painting *homescapes* in my practice), I was able to bridge in a skill of artistic interpretation to represent participant experiences through a sensory means. The aim is that the participants should be able to feel their experience of home in their painting, reminiscent of the described feelings and photographs captured. The paintings act as a visual point of data representation, illustrating the research beyond words. It is hoped that the paintings also provide the readers of this thesis, and viewers of the paintings, an insight into the emotional, sensory, and aesthetic-relational experience of these people's homes, and ultimately a visual narrative of living with ME/CFS beyond the descriptive words of experience.

An artist who has inspired my paintings is Edward Hopper, who captures what looks like stills from private life (see Appendix A for further thoughts on artistic inspiration). This essence of stillness of moments in the home is something similar I try to emulate in my paintings. My paintings will concentrate on the domestic space where these participants' experiences of fatigue take place to capture an emotional interior landscape which captures the ambivalence, nuance, and negotiation of space within the home when living ME/CFS.

3.3 Researcher Positionality

The researcher is integral to the interpretive process through the double hermeneutic process. I act as the catalyst to the interpretive process through instigating this research, facilitating interviews, and conducting data analysis. I am given a platform of authority over someone else's experiences and representing them as authentically as possible. As a means of inviting trust with participants, my positionality is not only as a qualified researcher (health psychology; qualitative researcher) and artist, but in my own lived experience with ME/CFS. My lived experience operates as my horizon which contains shared attributes with the participant's horizons. While positivist research posits that one's own experiences could create interference with objective representation, it is welcomed within qualitative research as it is an enabling condition for research through inviting connectedness and situatedness to the phenomenon of interest (Darwin Holmes, 2020; Dibley et al. 2020).

As described in the introduction to ME/CFS, many people with this illness face stigma and misunderstanding. By being transparent with participants on my own experiences it allowed an opening with the participants for shared understanding and comfortability, allowing me to feel confident in the nuances of my participant's experiences, providing advantages in accessing a hard-to-reach population. I had many shared experiences with my participant's, acknowledged through statements such as "I totally understand" or "Yes, I have been through that too". It was comforting to share these moments together.

An insider's perspective is not without its limitations or criticisms, such as unknowing biases or overconfidence with knowledge (Darwin Holmes, 2020). I adopted practices of reflexivity and meditative thinking to remain open to the new possibilities and understandings from the merging with participants' horizons to best mitigate this, such as recording some of my assumptions and journey of thinking via One Note (see Appendix B). My methodological and ethical choices also continued to prioritise the participant's voices, so that my insider's perspective did not cloud their narratives.

3.4 Recruitment and Participants

3.4.1 Purposive Sampling

To gain information-rich cases for IPA analysis, purposive criterion sampling was used to capture a willing and homogenous sample (Willig, 2022). This method of sampling is to target recruitment among groups or individuals who are most likely able to speak on the phenomenon of interest (Palinkas et al., 2015). This was achieved by advertising the call for participants on a populated Facebook page ME/CFS Support Group NZ (1.5k members). I am a member of this group and made a post from my personal Facebook account which included a recruitment poster, a caption providing brief information on the project, a link to a screening questionnaire, and my contact details (see Appendix C). This group was chosen as members of this page actively share and communicate about their ME/CFS experiences and were likely able to be reflective and informative participants for such a project.

My recruitment post was met with some animosity, especially around the acronym of CFS. Additionally, members commented on my post expressing confusion and distress around why this research was important, describing their home as a prison and not therapeutic. I was messaged by an admin member of the group and was asked to remove my post within 24 hours. I had fortunately already received positive interest and feedback, with many people keen to discuss the way in which their home has been therapeutic or supportive to them.

3.4.2 Sample Size

As this research is exploratory and not generalizable to the public or large population groups, five participants were chosen as appropriate for this project as smaller sample sizes (one - 10) are used to maintain an idiographic and homogeneous approach (Smith & Eatough, 2012). This allowed for a manageable timeline to maintain a health-conscious approach for myself and the participants. Participants were selected on a first-in-first-served basis. I received 23 expressions of interest, contacted ten, and secured five participants.

3.4.3 Participant Characteristics

The characteristics of the participants were chosen to best homogenise the sample and best answer the research question. This did not mean each person automatically had knowledge of TL, but the participants instantly had something to say about the role of their home for their healing. The project was open to all ethnicities, cultures, religions, and gender, though a screening questionnaire (Appendix D) was utilised and outlines the inclusion criteria. I limited the age to over 18 only for ease of recruitment and ethics, though younger people can have ME/CFS. It was important to let people self-identify with ME/CFS due to difficulties with getting diagnosed but also have experienced symptoms for at least six months. Participants were advised on the risk to PEM, and it was suggested to only participate if they felt able to. Participant demographic data is summarised in Table 3 and participant cases are described in Chapter 4. Five participants were interviewed and given pseudonyms. While most of the interest in the project came from females, the research project did not have a focus on gender.

Table 3

Participant Demographics

Pseudonym	Gender	Age	Ethnicity	Length of illness in years	Diagnosis Y/N	Length between symptom onset and diagnosis in years	Living situation	Employment status	Amount of time spent at home
Lily	Female	45+	Pakeha	2-5	Y	5+	Home owner - Married	Self-employment, working from home	80%
Kara	Female	35-45	New Zealander	10+	Y	2-5	Living with parents	Contractor, on a break	95%
Samantha	Female	45+	Pakeha	10+	Y	5+	Home owner - Married	Medically retired	Typically leaves the home 2 days a week for 3 hour periods
Scarlet	Female	35-45	European	2-5	Y	.5-1	Home owner - Married	Part-time work from home	90%
Oleander	Agender (Non-Binary)	35-45	English	2-5	Y	.5-1	Renting - Living alone	Unemployed	99%

3.5 Procedure and Interview Schedule

Participants, who either contacted me or completed the screening questionnaire, were sent an information sheet and consent form (Appendix E and F) to read over before agreeing to participate. A visual timeline was offered in their information sheet for an alternative/easier mode of understanding their commitment, as reading can contribute to cognitive strain. Following this, a non-obligation pre-interview via Zoom was set up with interested persons as an opportunity to discuss the project details, involvement, and interview needs (health, cultural or otherwise). A pre-interview was not only to build rapport but to also assist the participant to pre-think about their contribution to the project. This was to allow them extra time for the cognitive task, one they have likely not thought of before in such a way. It was important that the participants did not feel overburdened during the interview for health reasons (exacerbating cognitive PEM) and to ensure they could remain active and present to contribute rich answers.

If the participant remained interested, they were then instructed to photograph their home space and submit their images and signed consent form via a secure OneDrive folder. Participants were offered a description of Gesler's four categories and were asked to photograph parts of their home which best reflected each category of TL in relation to their ME/CFS experiences (Appendix G). We then scheduled an interview at a time that best suited them. They were given the option to split the interview into two sessions if their health required. Interviews occurred over Zoom for the ease of access to people across the country and to provide less of a cognitive burden on both researcher and participants; as travel and face-to-face interviews would not have been possible given the limitations of this illness. It was not deemed important to access the participant's body language or meet in person for rapport or for the purpose of the research question. Submitted images were screen shared during the interview to assist in the participant being present with the image they selected and not having to rely on memory recall. The interview followed the format of the TL categories to remain easy to follow.

Interview audio was simultaneously recorded via Zoom and Otter.ai, in case one technology failed. A preliminary transcript was created by Zoom. Transcripts were edited for coherency and accuracy, making use of Jefferson's notation. This was chosen to blend naturalism and de-naturalism for an idiosyncratic representation (Matheson, 2015; Oliver et al., 2005).

3.5.1 Interview Questions

Research questions were guided by wording of the TL literature and categories of interest; they remained open-ended, so as not to lead the participant in any direction, such as "Can you describe why you chose to photograph these as a representation of the built environment of your home?" (See Appendix H for interview schedule.) Each category had the same sub-set of questions so that participants knew the direction for each category and to treat each section equally. This also allowed for the participant to take lead on which category sparked more relevance to them. I used the interview schedule as a guide and chose to skip or rephrase questions where an answer had already been provided or was not relevant. My approaches to my questions and schedule were informed by suggestions in The Great Interview: 25 Strategies for Studying People in Bed, by Hermanowicz, (2002).

A practice interview was carried out with a friend for feedback on the questions to check their relevance, ability to invite rich responses, and remain within an appropriate time frame. The practice interview yielded a positive outcome with minor tweaks made to question wording or ordering. Questions were reviewed by the Ethics board and by my supervisor.

3.6 Ethical Considerations

Ethics are not only a procedural requirement, but one responsive to the well-being of everyone involved. This project required a full ethics approval as distress and/or harm was identified for the participant, due to the sensitivity of the conversation (discussing health) and the potential impact on participant's health (cognitive PEM).

This research met the criteria for full approval outlined in the Massey University's Code of Ethical Conduct for Research, Teaching, and Evaluations Involving Human Participants (Massey University, 2017). Approval for this research was granted by Massey University Human Ethics Committee on 15/04/2024 for application OMI 24/12. Procedural ethics are detailed below in alignment with the code of conduct and general expectations of ethical qualitative research (King, 2019). Included are ethics of responsiveness to the *Te Tiriti O Waitangi* (Treaty of Waitangi) for cultural competency, which were responded to with reference to *Te Ara Tika*, Māori ethics (Hudson et al., 2010). Beyond ethics of procedure, values of relational ethics were considered to maintain the social responsibility to the well-being of the participants.

3.6.1 Relational Ethics

It was inherent that my ethical decisions included a responsibility to my participants well-being and the prioritising of their experience. In maintaining relational ontology, I adopted values of a heterarchical relationship between researcher and participant, through steps of transparency and collaboration (Hopner & Liu, 2021; Daly, 2016). This meant empowering participants in their contribution, adhering to withdrawal and privacy procedures, being transparent about my position of lived experience, and utilising empathy during our conversations to remain aware of their emotional experience and health needs. It was my intention that my participants felt like equal creators and collaborators in this research. It was important that participant’s felt heard and respected, that their health was not compromised by participating, and that they enjoyed the experience. Without them, this research could not have produced the meaningful results that it has.

3.6.2 Consent

Due to the relational nature of this project, consent was an ongoing process. Consent was formally secured via a digitally signed consent form before interview commencement, through verbal consent was obtained prior to an interview, at the start and end of the interview, and in transcript revision (via email). It was important that participants felt they had a choice throughout the process and felt enabled to amend their contributions if they shared something they no longer wanted on the record. During interviews I monitored moments of sensitivity or discomfort and offered a gentle reminder that they could take a break, withdraw, or could omit a distressing piece of information if needed. Participant’s generally felt comfortable with all the information they shared, deeming the sensitive information value to share. Further consent to release their content was obtained via an *Authority to Release Transcript* form (Appendix I).

3.6.3 Privacy, Confidentiality, and Autonomy

All consent forms, transcripts, and other personal files remained accessible during the project to the participant via their OneDrive folder. Consent forms were shared to my supervisor for secure storage for five years as per ethics requirements. Transcripts and interview recordings were only heard and read by me and the corresponding participant. All transcripts and photographs will be deleted after the final grade of my thesis is returned.

Participants were informed on the limitations and rights of their confidentiality, privacy, and autonomy. It was noted in the information sheet that they would be anonymous with pseudonyms, (which they were invited to choose, not all did). Transcript extracts were anonymised with their pseudonym in the Word documents used for coding and analysis. They were reminded that their photographs may be included in the final thesis and to not include obvious identifying information of themselves or others (e.g. a family photograph). They were informed that due to the personal nature of their contributions, people who know them intimately may recognise their contributions. Spouse names and locations were omitted from the transcript to preserve autonomy, and they were not relevant. Participants were offered to conduct their Zoom interviews without video, to preserve privacy and autonomy; no participants required this.

Participants were informed that the painting produced in response to their interview would be made visible on my artist website and titled as *Untitled Painting: Therapeutic Landscapes Project, 2024*. Participants have also all agreed to share their paintings as a part of a public exhibition, this was optional. While it would be difficult to associate identity with the final paintings, they were reminded that someone who knows them intimately may recognise it as theirs, especially in conjunction with the anonymous blurb describing their painting and experience at the exhibition. All participants were enthusiastic and supportive of having their paintings exhibited.

3.6.4 Right to Withdraw

Participants were offered a timeline of their involvement, and many check-in reminders of their right to withdraw parts of their contribution, or entirely, without reason/s. They were offered four weeks following their transcript confirmation as their withdrawal window, noting that after this time their contribution would have already been too valuable to the project to remove. Adjustments to their contributions could be considered after this time, but not full withdrawal. No participants withdrew any contributions.

3.6.5 Participant Health and Safety

Participants were advised on the health and safety concerns of this project in their information sheet. Namely, they were advised and guided through options in response to the health impact of participating, cognitive exertion, and PEM. To address this, participants were offered to split the interview, offered various breaks in the interview and were guided to think about a self-care activity after the interview. They were also advised to conduct the interview in a place of comfort, even if laying down, so as not to exert themselves physically.

There was identified risk in potential distress from discussing health challenges, for which I adopted empathetic and counselling language and skills and held a plan to guide them to seek support from a trusted person or support services (counselling or national helplines). It was hoped that in sharing my lived experiences with the participants and conducting a pre-interview that participants felt they were in a safe, validating, and supportive environment to share their experiences. Participants were able to have a support person in their interview if needed; with their identity and contributions omitted. Participants expressed gratitude and appreciation for their participation.

3.6.6 Researcher Health and Safety: Insider Experience

A risk of cognitive strain during and following interviews was also considered for myself. It was important to engage in self-care prior to an interview so that I could be present and have my cognitive resources available for conducting a sound interview. I utilised meditation skills prior to interviews and scheduled a cognitive break for the day following the interviews. A risk of distress in discussing health challenges was also a concern for myself. I reflected with my supervisor that while I felt incredibly grateful to my participants, and validated through their stories, it was unexpectedly upsetting to hear some of their experiences and the mirroring of my own. I took some time to honour and comfort my distress.

Naturally, my anonymity was not secured during this process, as my identity was revealed through posting from my personal Facebook account during recruitment. However, I remained cautious of my identity and safety by communicating via a university email address and not sharing personal contact details. No issues with messages occurred on Facebook, though due to some of the uncomfortable responses to my recruitment post on the ME/CFS Support Page, I did choose to remain inactive on the page for a period, as my name would have been linked to those who had a distressing experience from my post. I did not feel comfortable sharing or commenting on the page for some time afterwards, which I found unfortunate, as I am also a ME/CFS community member. I discussed this discomfort with my supervisor to de-personalise the experience.

3.6.7 Cultural Considerations

This research was open to all ethnicities and people who live in Aotearoa, within the recruitment platform. As per ethical requirements, the project incorporated the minimum standards for Māori ethics detailed in Te Ara Tika (Hudson et al., 2010). This includes an obligation of responsiveness to Te Tiriti o Waitangi for Māori partnership, protection, and participation. This was preserved through care (*aroha*), autonomous participation (*mana tangata*), and justice. It also involved being reflective of my position as a *Pakehā*. I hold a cultural competency certificate (received from MauriOra in 2021), knowledge in cultural responsibility, and basic *Te Reo* Māori.

Should I have had Māori identifying participants, I was able to offer a version of the interview which included *karakia* (participant or researcher chosen) and use of basic Te Reo;

also offered in their information sheet, email correspondence, and the pre-interview. A pre-meeting interview is a part of the protocol to incorporate *Whakawhanaungatanga* (process of relationship building) for all potential participants. The interview questions were designed to be *mana-enhancing* (empowering) to all participants, including Māori. All participants were also welcome to have a support person present during the interview; for Māori participants this is *tikanga* (cultural practice) to have a member of their *Whanau* (family) or *Iwi* (tribe) present. Whanau or Iwi member/s were also welcome to read over the information sheet and consent form and offer a version of the research project for dissemination within their community and the painting could be displayed at any site of their choosing. Offering this sharing of materials and process of collaboration is twofold: to maintain the relational ethics of this project and to uphold values of Māori participation.

3.7 Data Analysis

Analysis made use of IPA principles, chosen as a popular tool within the hermeneutic focus and health psychology to keep the analysis as participant-led (Brinkmann, 2017; King & Hugh-Jones, 2019). IPA contains the aim of investigating how people make sense of their experiences and that without hermeneutics and interpretation, phenomenon cannot be accessed (Eatough & Smith, 2017; Larsen & Adu, 2021). IPA's purpose is to elucidate the meaning of lived experience otherwise not captured and represented. Thus, the analysis had an *inductive* approach to allow the participant data to guide the analysis. While there is not a clear prescription on how to do IPA, as it occurs rather intuitively, ongoing interpretive and reflective processes, paired with qualitative quality control guidelines, keeps the focus on the subject's lifeworld and content (Larsen & Adu 2021; Smith, 2019).

The initial stages of analysis involved analysing the transcripts individually with notations (adding pauses, emphasis, and intonation), researcher margin comments (for exploratory notes), highlighting of key passages, and summarising experiential statements (offered in the participant transcript review). Following confirmation from participants, transcripts were read multiple times for familiarity, further notes and highlights were made for initial organised coding, leading to identified sub-themes and themes in individual transcripts. Then, each transcript as a data set, was compared and integrated into *superordinate* themes, to create a shared representation of participant's collective experiences.

3.7.1 Theme Refinement

Collective themes were drafted in a table document to group ideas and insert transcript extracts for reference. Transcripts were re-read with initial themes in mind to explore any expansions or discover more supporting evidence. Themes were then reviewed and refined, by exploring their overlaps and relevance to the research question. All themes were finalised on their relevance to all participants, though some participants were more relevant in one theme than another or had stronger expressions of their experience within that theme.

Themes were then written into a narrative format, in response to the research question, and various quotes were selected for best representation of the experiential account of the participants. This required many revisions to ensure the representation of participant experiences remained as close to their accounts as possible, alongside framing their expressions into the context of the research. Final themes reflect a blending of their experiences, my interpretation, and mapping onto the research question. There was a challenge in creating separate themes from the interviews as a) things could have been discussed specifically through the TL categories and

b) everything within their home was incredibly interlinked. Built environments impact their social environments, natural environments impact their symbolic environments, and so forth.

3.7.2 Painting Design Process

Painting interior home spaces has long been a focus of my art practice. What feels important to my work in painting domestic spaces without people is that the viewers can project their vision onto the space. I continued this liminal trait in the paintings created for this research to allow visual room for viewer projection and interpretation. However, these paintings contained core details and colours to capture an essence of the participant's home. The paintings were created based on my interpretation to reflect my representation of the data.

The primary thought for the painting's design came to me during or shortly after each interview. I felt it was important to note down key points and generate a rough sketch before conducting the next interview. I drafted most paintings before analysis of the transcript and found that the transcript confirmed the instinctive design I had while providing some additional information for colour choice, details, or objects to be included. At the end of the interviews I asked participants if there was anything in particular they wanted in their painting (a specific room, object, or colours) and while most were happy with whatever interpretation I conjured, their concluding reflections of the interview confirmed initial thoughts I had during the interview around which room/space was going to be most important or which object or narrative would be valuable for their painting. The participants were not invited to review sketches or collaborate on the artworks; thus, no insight will be provided on how accurate or resonant each painting was for the participant.

The paintings were offered as a *Koha*/gift for participating in the project, and participants were generally art appreciators, which I believe contributed to their interest in participating.

3.7.3 Quality Criteria

My identification with the quality of my research (outside of tick-box requirements) is in my relational ethics: to be responsive to the needs and well-being of my participants to be reflexive on my skills as a qualitative arts-based researcher and remain transparent and authentic. Quality criteria tools I adopted were contextualising the design decisions to the actual research question, researcher positionality, transparency, coherency, reflexivity, and ensuring the relevance of the research to the community of interest (Braun & Clarke, 2024; Frost & Bailey-Rodrigues, 2019). My research remained related to my ontological and epistemological positioning, to the relevance of the TL framework and literature, to health psychology research, and to the health context of ME/CFS.

In most qualitative projects, the researcher cannot remove themselves from their analysis and interpretation, but they can be reflective and conscious of their presuppositions and to what extent that plays into their understanding (Brinkmann, 2017). I described above my positionality as a researcher, artist, and lived experience with ME/CFS and that being reflexive to my entanglement with the process was in alignment with hermeneutic values of knowledge-making. This included reflection with my supervisor as an advised step for quality control (Dibley et al. 2020).

Transparency meant involving the participants in every stage of the process; making knowledge as available to them as possible by sharing the research interests and aims, sharing their transcripts and initial interpretive points, and not withholding information or deceiving them. Coherency was maintained through the consistency of ontological and epistemological position and tools. As detailed in my methodological principles, each research tool was in alignment with philosophical positions of bringing the unconscious forward for a phenomenological investigation. This was consistent with the relational values of TL and in my ethical choices.

Coherency did not automatically mean easy interviews. Interviews are carried out for a purpose, and the lens in which an interview is conducted shapes the type of information that is brought forth (Brinkman, 2020). While questions aimed to be open-ended to encourage participant's leadership in answering, they still needed to be contextualised to the research question for coherency in context. For example, I could not just ask "tell me about your house?" as that would not invite insight into the therapeutic experience of their home, nor to the categories of the TL framework. Therefore, my interview questions went through various draft stages, discussion with my supervisor, influence from relevant literature on generating good interview questions (Jacob & Furgerson, 2012), and a practice interview.

CHAPTER FOUR: PARTICIPANT CASES AND PAINTINGS

I have included a case description of the participants with their paintings to provide insight into their varied experiences of ME/CFS, highlight the therapeutic value of their homes, and to preface the findings with the visual context of their homes. See Appendix J for reflective notes on paintings.

4.1 Lily

Lily (she/her) identifies as a Pakeha, aged 45+ with a diagnosis of ME. She has been living with acute symptoms of ME for 2–5 years since receiving her diagnosis, though has lived with ME symptoms for 5+ years prior to diagnosis. Her symptoms include significant brain fog, night sweats, food sensitivities and anaphylaxis, fatigue, non-restorative sleep, inflammation, conjunctivitis-like symptoms, rheumatoid arthritis, aches and pains, and flu-like symptoms. She takes 57 pills a day to keep functioning (medication and supplements). Lily is a homeowner and lives with her husband and cats. Lily shared that it was the *"the wairua or the spirit of the place"* which drew her to this property she moved to in 2012, for her health needs. She is self-employed, working from home; having made these employment decisions upon becoming unwell and work-place changes following the pandemic. Lily spends about 80% of her time at home, partly because of work, but because ME significantly impacts her ability to be away from home and safely manage her symptoms.

In our conversation, Lily relayed significant gratitude for her living environment, describing her home as a safe space. Her property consists of an AirBnb, and her main two-bedroom dwelling, which has her home office. They are on four acres of land surrounded by 400 fruit trees, a triple UV water filter system, a veggie garden, a green house, a spa, and birdlife. Lily described at the end of our conversation:

I didn't realise how helpful my home was before doing this… I'm really grateful for you to for the opportunity to do this, because it's highlighted some major things for me about how I can utilise my home more and why, why, I've gotten worse this year, which is because I haven't been home. (Lily)

Lily's painting (Figure 2) depicts a collage of spaces and objects which have been meaningful to her daily life, experience with ME, and supportive of her healing. The colour palette for this painting is informed by the soft blues of the river nearby, greens of nature, and sunset colours. The nature-detailed wallpaper is both reflective of her feature wallpaper in her dining room, a place she loves to share meals with others, and a symbolic ode to the surrounding nature on her property, which she finds so healing. The fireplace comes from her photograph of her cats laying in front of it; it is a romantic symbol of her relationship with her husband, and given that Lily struggles to stay warm, anything which gives warmth to her physical body or her spiritual soul, has been important. The adjacent space is her office, with attention given to her view, artworks on the wall, memorabilia/gifts, and the word "inspire", which helps to keep her motivated and at ease. The combination of these two spaces indicates key elements which support her: access to nature, symbolic details of her home, and an inspiring office.

Figure 2

Expansiveness in the Home.

4.2 Kara

Kara (she/her) identifies as a New Zealander, aged 35–45 and has been living with CFS for 10+ years since the age of 12, with a diagnosis occurring 2–5 years after symptom onset. Kara currently spends 95% of her time at home. She has been taking a six-month break from flexible contract work as an occupational therapist.

During her teen years and early 20s, Kara was bedbound by CFS symptoms, though had significant improvement in symptoms around age 27, and is no longer bedbound. However, she continues to spend most of her day in bed, especially on days where symptoms flare up. Kara's primary symptoms include significant fatigue, brain fog, chronic pain (primarily from old injuries), body temperature control (too cold), and disrupted/unrefreshing sleep. Kara lives in her childhood home with her Mum, who also has CFS, and her two dogs.

She schedules her days, getting up about 9am with a *forced break* from 12:30–3:00pm, with the afternoon usually consisting of a relaxed activity like watching TV or reading, before heading back to her bedroom around 6pm to rest for a few hours before falling asleep. This structure reflects the decline in energy throughout her day, saying that something she could do in the morning she cannot do by the afternoon, due to brain fog.

Kara has lived in her own homes prior to moving back to her family home when the pandemic hit and describes gratitude for how her family home has constantly adapted for everyone's needs. Kara describes her living situation as supportive, privileged, comfortable, and is very grateful to how it supports her CFS management.

Kara's painting (Figure 3) captures her bedroom space, as this is where she describes spending most of her day, and her most comfortable place to be. Her bedroom has been a crucial site for rest, healing, and a sense of safety when she is encumbered with CFS symptoms. Kara’s biggest battle is the overwhelming sense of fatigue and chronic pain, and her bedroom is a supportive place to rest. Her bed is mechanical and can be moved up and down to support various positions, for better physical support. Next to her bed, (not depicted), is usually her iPad and other technologies to keep her entertained and connected to the world. Behind her bed are little lights which are all kept on timers to minimise the cognitive effort of deciding when to turn the lights off. The little unicorn on her bed is a hot water bottle, to give her warmth and give a little bit of playful magic to the space. The small dog on the edge of her duvet cover is to symbolise her pet dogs. The Buddha sculpture which sits in her bedroom is symbolic of a mindset which keeps her grounded and mindful. The conservatory space outside her bedroom is taken from the downstairs area of her house to capture the two spaces of her home that are of importance to her: her bedroom and her living room. The view of the garden and conservatory is what she can see when she is seated in her chair in the living area downstairs. The garden keeps her connected to nature and helps her to feel sheltered in her home from surrounding properties. The garden is something which her Mum enjoys and thus represents the relationship between the two of them in the home.

Figure 3

Safety and Tranquility in the Home.

4.3 Samantha

Samantha (she/her) identifies as a Pakeha aged 60+ who has lived with ME symptoms for 40+ years, receiving a diagnosis only five years ago once symptoms worsened. Samantha is originally from the United States and now resides in Aotearoa in her own home with her husband and dog. Samantha medically retired in late 2017 and spends most of her time at home. She will typically spend two days of the week, in three-hour slots, outside the home for an activity; symptom dependent, she may leave for a third outing during the week. She describes the cognitive impacts of ME as what ultimately drove her out of employment, with difficulty in processing new information and reading.

Overtime, her main ME symptoms have been the typical PEM cycles of significant energy crashes and fatigue 3–5 days following an activity. Other symptoms have included insomnia, sleep disturbance, tinnitus, body temperature control (too hot), flu-like symptoms, increased sinus issues, irritable bowel, and general body aches and pain. Samantha and her husband moved into their current home because of her health needs, describing moving as *"heartbreaking. It was necessary, but it was heartbreaking…the fact that we had to move when we did… is down to my having ME"* as the need for a more modern home outweighed the love they had for their previous home. Though, at the end of our conversation, she reflected gratitude for where she now lives.

The positive attributes of her new home include having easy visual and physical access to her garden and having an easy-to-manage space. Samantha's home is both practically and emotionally supportive through the care of her husband and her dog, described as her nurse. She refers to her home as therapeutic and helpful by not making symptoms worse, but not as healing, as her ME cannot be healed.

Samantha’s painting (Figure 4) depicts her open-plan living space (without her furniture) with her kitchen bench on the left-hand side. Cooking is an activity that she still loves to do, and her connected living area means she can still spend time with her husband while being in the kitchen. It was also important to her that she could see the outdoors from where she sits in the living room. She loves sunsets, so a sunset and outdoor plants were painted outside her patio doors. Many of her submitted photographs included her dog, one she describes as her nurse and companion. Thus, her dog is a key feature in this painting as a vital detail of her home experience. There is an artwork on the wall, copied from her photograph, though her home is decorated with many important artworks, as it has been important to her to showcase things from her travels. The colours of this painting, colder blues and neutrals, were chosen as they were the described colours of her bedroom as she tends to run hot and needs a cooler environment for her temperature control.

Figure 4

Ease of a Modern Home.

4.4 Scarlet

Scarlet (she/her) identifies as a European aged 35–45 who has been living with ME for 2–5 years. She received her ME diagnosis in 2021 having experienced symptoms for 6–12 months prior. Her early onset of symptoms meant she was practically bedbound, but she now spends roughly 90% of her time at home and takes great pride in her now improved symptoms. Scarlet's primary symptoms include severe migraines, lightheadedness, balance issues, flu-like symptoms, disrupted sleep, and describes her (good) daily symptoms as what someone may experience if they were to call in sick to work.

Scarlet lives in a home she owns with her husband, dogs, cats, and birds. She has resided in this home for almost 10 years and during our interview has noted many adaptations have been made since having ME. Her home is spacious, with four bedrooms, dining room, living area, kitchen, a book-nook (formally art studio space), conservatory, vegetable garden, and a porch. Her and her husband have separate bedrooms, because of how ME impacts her sleep. Another of the bedrooms is her office, where she works part-time from home, 15 hours per week. Scarlet describes her home as healing and therapeutic as it enables her to easily retreat to places of rest and restoration when symptoms flare. Scarlet loves her home and reflects that our conversion helped her realise how many changes have been made in the home due to ME, especially in making things easier to access:

I don't think I've actually thought about until I did the photographs, how… I-I sort of I-I put together things for ease of access. (Scarlet).

Scarlet’s painting (Figure 5) is a depiction of her day bed, which was described as her most social space to be in the house and her favourite. This space is a social one because it allows her to remain openly connected to the rest of the house (adjacent the kitchen and a living room area) and is a space she shares with her dog (hence the paw prints), and where she can engage in her range of hobbies. This is an active place for Scarlet but also remains one of rest and relaxation. It means that she can do her activities from a place of ease without exacerbating her ME symptoms. The colour palette of this painting is to honour her interests in antique colours and textures. The red lace curtain represents her bohemian style and joy for having different textures around the house and appreciation of the colour red. The bookshelves are adorned with books which represent her interests. Of importance is the inclusion of The Holy Bible, which honours her spiritual beliefs and experiences, which gives her comfort and hope during difficult days with ME. Above the bookshelves there is an orchid plant, which was her late Father's plant. This plant symbolises this relationship. Above the other shelf is an artwork (located in her bathroom) to symbolise her love for art and colourful paintings, especially ones of nature.

Figure 5

Creative Place to Rest.

4.5 Oleander

Oleander (they/them) identifies as English, aged 35–45 and has been living with ME symptoms for 2–5 years, receiving a diagnosis after 6–12 months of having symptoms. At the time of the interview, they were living in a rented self-contained cabin on their friend's property, with a cat and fish. They are almost entirely homebound, spending 99% of time at home in their bed; having only left home a small handful of times for important medical appointments or small events in the previous two years. They are financially assisted by the supported living benefit from Work and Income New Zealand, as they are unable to work. Oleander's primary symptoms include increased heart rate with mild movement (such as standing up), chronic pain, loss of muscle mass/strength, insomnia, and extreme fatigue, which are exacerbated by having postural orthostatic tachycardia syndrome (POTS) and attention deficit hyperactivity disorder.

Oleander moved into this cabin recently after needing to leave what was described as an abusive and unhealthy living environment with their maternal parent. The cabin has been made self-sufficient with creative *Macgyvering* of a bathroom (composting toilet in a pop-up tent), kitchenette and bathroom sink (recycled and second-hand shelving, water container funneling to a bucket, mini fridge), a bed, and mobility aids (rolling chair). This set-up has enabled them to be independent and safe. Having everything physically close to them has benefited their ME and this new living situation has improved their QoL. Oleander is proud of their living space and describes their environment as healing and therapeutic because it creates ease of access to all things they need for daily symptom management, safety, enrichment, and is a place they can rest to eventually heal (go into remission) from their ME symptoms.

Oleander's painting (Figure 6) is an illustration of the self-contained cabin they were living in at the time of our interview. It was important that the painting capture their view of nature through their window and sliding door to honour their appreciation of easy access to nature for someone who is homebound. The interior space includes their bed, as this is where they spend most of their time and is a key site for rest and includes elements of their make-shift setup along their wall. This set up includes their blue shelves with their refillable water tank, which flows into a bowl, and then down into a wastewater bucket. This acts as their sink for both kitchen and bathroom purposes. Next to the shelves is a brown cupboard, which is a little pantry space. There is a small painting resting on top of it, which is a painting made by their Mum. It was important to include this painting as their relationship with their Mum was discussed during the interview in reflection of a complex relationship and a history of a lack of care. Next to the cupboard is a fish tank. The fish are company and friends but have been a symbol of care / lack of care that Oleander has received during their time with ME; mentioning the cycles of neglect that the fish went through under their Mum's care. Next to the fish tank is a small fridge, upon which is a small red mouth-like object, which Oleander described as a gimmick object that gives them joy. There is also a plant to refer to the handful of houseplants in their cabin which have assisted in making the space feel more like a home, not a sterile box. On their bed are two Switch controllers to represent how they spend their time in bed, to remain stimulated, but also to symbolise the social connections they have through gaming. As someone who is homebound, this is how they stay connected to the rest of the world.

Figure 6

A Place of Playfulness and Joy.

CHAPTER FIVE: FINDINGS

This section illustrates the core ideas expressed during the interviews. Ultimately, these themes capture how these people have made their home space work *for them, not against them*. Their homes have been symptom responsive and have allowed them to live a life beyond the limitations of their illness. The essence of the themes is summarised in Figure 7.

Figure 7

Infographic Summarising Theme Ideas.

THEMES

MAKING THE HOME WORK FOR YOU, NOT AGAINST YOU: A HOME-LIFE BEYOND ME/CFS.

SECTIONING OF THE HOME

Creating sections or areas in the home for sites of rest, activity, and emotional expression, for the spectrum of ME/CFS experiences.

SIMPLIFY THE ENVIRONMENT

Creating simple systems, non-disruptive, spaces to share with others, and introducing technology for health monitoring, and easy access to tools.

ROLE OF NATURE

Having easy access to nature, inside and outside the home, embracing the symbolism in nature to connect to memories, nurture something, and to use activities in nature for healing.

ENRICHING LIMITED WORLD

Bringing 'outside home' experiences into the home and creating reminders of joy around the home.

Source: Author, 2025.

5.1 Theme One: Sectioning the home

Sectioning of the home captures how participants managed their symptoms and emotional experiences within their built environment. The two sections designated as a site of rest and emotional release (typically the bedroom), or site of activity (living area), were the most prominent reflections of symptom response on the built environment in the home. These sat alongside other active spaces which they engaged in, such as gardens and kitchens.

5.1.1 Sectioning for Rest: Bedrooms and Beds

All participants expressed that **if they are in bed that they are having a bad day.** A bad day is what could be described as a *crash*, flare-up of symptoms, or PEM. All participants experienced different dominating symptoms, but a bad day typically encompassed high levels of exhaustion, brain fog, inability to concentrate, or talk, sensitivity to light and noise, potential inability to eat or shower, and some level of bodily pain. On days where their symptoms were more acute, having a place which was dark, quiet, and isolated proved most helpful because it supported rest. Managing this required the bedroom or the bedspace to be sectioned off from everything else. Within bedrooms, decor, textures, lighting, and assisting technology were all set up in preparation for rest periods. This included dim lights, remote controlled lighting, soft colours, soft blankets, and a general sense of coziness.

Kara expresses how important her bedroom is to her day as it offers a place of comfort and isolation to fully rest (Figure 8). This is why Kara's bed was chosen as the focus for her painting.

My bedroom pictures are probably the most important to me. Um, that's the space where I spend most of the time, my time, and that's the space that is solely mine… This is my cosy, my cosy spot. (Kara)

Figure 8

Kara’s Bedroom

She described it as a space which belongs just to her, meaning that she was able to curate it how she needed, and the ownership of the space means she can experience it how she needs to at any given time. This allowed Kara to have control over her site of rest specific to her symptoms.

Like what Kara expressed, Scarlet described how important the bedroom space is to retreat to as a place of rest and privacy.

My bedroom is my sanctuary when I'm having a bad day, and I can retreat you know, and and and then, like, I've got the different areas of my house for the different levels of energy. (Scarlet)

Scarlet has echoed Kara's experience very closely by expressing how her bedroom operates as that sanctuary away from everything and everyone else. It is a place of isolation for the purpose of rest and low stimulation or energy output. Scarlet noted that she does not share her bedroom with her husband, so that she can curate the space to her rest and aesthetic needs. She also uses her bedroom to engage with her spiritual tools, such as prayer, and meditation, via an iPad located next to the bed. Both Kara's and Scarlet's bedrooms are a place of sanctuary, safety, and comfort where they can use tools to rest and recover in peace. Importantly, they are spaces reserved just for them where they can curate the space to meet their own rest and restoration needs.

Having an isolated place for rest was complicated for Oleander, whose bed is in their main living space rather than a specific room. Their bed is the primary place they spend their day, which is why it was included in their painting. Their ME is compounded by symptoms of POTS, making their physical mobility very limited. Their bed is the easiest and safest place to be as the bed typically does not make symptoms worse. Oleander keeps many things within arm's reach of their bed so that they are not needing to change locations or positions when resting saying, *"I guess it enables my management in terms of like, um, ... everything being like physically close to me, so that I can reach it"*. Much like Scarlet and Kara, Oleander was able to curate the area around their bed so that it best suited their rest and recovery needs, by having things they need within arm's reach. Meaning that once they are in their beds they are not needing to exert extra energy to access tools or comforts that they need.

In contrast, Samantha notes that they try to avoid spending too much time in their bed, reserving it for their sleeping hours (and thus was not referenced in her painting). With that said, on the more difficult days, it has still been important that the bedroom is again an accessible place of rest.

The beds gotta be comfortable. It's gotta look nice when I go in there. Yeah. I- I try to be out of bed by 9am, every day. I don't say I succeed every day, um… but…I need that for me, right, to know that I'm not getting worse, that I'm not bedbound. (Samantha)

What Samantha is expressing here is how the bedroom, that site of rest, is directly reflective of what kind of ME/CFS day they are having and the marker of severity of their illness. This creates a significant symbolism around what their beds and bedrooms represent as not only a symbolic place of rest and escape, but also a place where they experience some of the worst of their symptoms and health challenges. This place, which is reserved for rest, which ought to be cozy, is also met with the tension of being a place where pain and suffering is experienced.

Prolonged and undisturbed rest is one of the key recommendations for managing ME/CFS symptoms, particularly for PEM. Therefore, having control over one's environment, especially the place of rest, has been vital to their symptom management. These participants were able to curate their bedspace to be reflective of what they physically and symbolically needed most when experiencing acute symptoms. Their space of restoration and repair included a comfortable bed, tools for reading or engaging in spiritual practices, and other comforts, like soft teddies, soft bedding, supportive pillows, gentle or no lighting; as well as any other things to create a quiet, dark, safe, and low stimulation environment. These modifications to their built environment, through the curation of their rest site, created therapeutic benefits in relation to their ME/CFS because it allowed them to engage in the key symptom management tool, which is rest. These spaces are adaptations to their built environment which met the need of sectioning off a restorative and restful space designed just for them.

5.1.2 Sectioning Spaces for Emotional Release

While all participants appreciated the comfort and privacy their bedrooms provided for bad days, or times of rest, it was also noted that the bedroom was often a place where the emotional spectrum of coping with their ME/CFS was experienced. ME/CFS is usually described as an invisible illness, and it is common for those with ME/CFS to *mask symptoms* and anguish when in the presence of others. The additional function of the privacy of the bedroom was that it became a place where they would be able to experience the emotional spectrum of their illness without feeling like they needed to hide their experience or disturb others. For many, this was being able to process their grief around being unwell, but also sadness, anger, discomfort, and spiritual grounding. For Lily, this was particularly important to truly experience a grief cry in private.

When I'm at my worst I just need to be alone, and the different buildings…. So it gives us enough space that I can just be on my own um, particularly he, he knows when I'm at my worst, what I need to do is is cry…… I need to give my body that release. (Lily)

Lily described how having many different rooms, and even different buildings on their property, meant that she could have an isolated escape to somatically release her grief when needed, without disturbing her husband. Lily describes the importance of emotional release to process the grief of this illness, so not to bottle it all up. Similarly, Scarlet describes the use of her bedroom (separate to her husband's) as a space to process her darkest emotions, as a means of healthy recovery.

My bedroom is probably the place where I do most of my thinking and when I'm really I'm unwell, and probably the place where, if I'm going to pray or connect it's my bedroom, because it's usually when I'm at my lowest, if it makes sense?... that's also been the really big help for my recovery or my journey as well as, like us having our own bedrooms because it means I can truly relax, not worry about whether keeping him awake…. But it's it is a big part of my health like it really is important me to have that space. (Scarlet)

Both Scarlet and Lily are married and describe how valuable it is to have private spaces within their home to process their ME/CFS. They both describe how emotional release is a part of their healing and management to help maintain a hopeful mindset, which is easiest to achieve when they are alone. Scarlet says *"just getting those big feelings out and to the universe into the world, into whatever… that's cathartic, and that to me is important to part of my healing."* While it can be upsetting to process bad days in isolation, it can be incredibly helpful and having the private and supportive space to do so has been a part of the sectioning of their home. Their bedrooms, or private spaces, symbolised a place of peace which assisted in creating a comforting environment for emotional expression but also an environment to engage with spiritual tools for further emotional processing.

Both Scarlet and Kara use their bedrooms to engage with a level of spirituality. Scarlet uses prayer, and Kara's is through her appreciation of Buddhist values and mindfulness; represented by the Buddha sculpture in her bedroom featured in her painting. Kara uses these spiritual tools for the processing of the hard days, reciting *"the saying, 'this too shall pass', is one that I reminded myself for ever and ever."* This process of feeling what they are going through has become a part of their living with ME/CFS and their PEM recovery periods. Their isolation rest spaces become places for emotional sanctuary alongside a site of symptom respite.

Thus, this sectioning of their home is symbolic of not only the physical challenges and management of this illness, but the emotional management too.

5.1.3 Sectioning for Activity

As these participants identified as being predominantly homebound, their situation creates a very limited physical world and sense of space, and thus having different spaces in the home is vital for their sense of well-being. So, alongside their site of rest they often have a site of activity which enabled them to participate in everyday life. This was typically living room areas, which often featured a comfortable chair that they could rest their body in while being able to engage socially (with family, friends, or pets), or carry out various hobbies (like watching TV, knitting, or puzzles). Other sections of their home such as kitchens, gardens, or home offices, are sections where they have energy to engage with others, the capacity to feel joy, engage in hobbies, and are usually reflective of days when they have less symptom complications. In creating sites of activity, they can participate in the wider world, within their home, and not be isolated to their bedroom, when their symptoms permit.

Kara described her experiences of being in the living room as one where she is involved and gives a sense of business to her day.

It's really important to have that second space to go, I know it's not much, it's not much of a change in terms of what day to day people have in terms of changing environments, but ***it's significant because it is a change in environment.*** [Emphasis added]. (Kara)

Kara expresses the value in having different needs-based spaces under the one roof of her home for the importance of variety in her day. Considering she is unlikely to leave the home for consecutive days, or weeks, having different environments within the home is pivotal to meeting various daily needs of engagement, social connection, stimulation, and purpose. Having a social space gives Kara an opportunity to maintain social connections to her family, as her sister often visits, which assists in not feeling as isolated by her illness.

She goes on to say, *"even though I'm not in my room, I'm probably still not feeling very well, so it still needs to be a supportive space."* Despite having a space where she is more active, it remains a place where comfort is prioritised so as not to exacerbate her symptoms of fatigue and pain. To enable this, she has a lazy boy chair with massage features in her living room and is typically not up and about around the room. Samantha described something similar:

If we've got people over and I'm in the kitchen doing something, I'm directly connected to that social area..... I've got a towel rolled up to use for lumbar support in the seat I sit in, and [dog] is on the, um, mat on the sofa next to me. (Samantha)

Scarlet described a very similar sectioning of her home, with having her daybed as her active, but restful space, adjacent to the living room and kitchen area. Scarlet loves to use the kitchen and said, *"if I start feeling wobbly while I'm cooking, I can go to my day bed and lie down.... it's just to make make it easier to be able to go, um, and rest or relax."* This means that when Scarlet's energy permits, she can engage in regular household activities but is supported by an easily accessible place of rest in a communal area.

Oleander's experience of sections in the home is different as they live in a one room cabin.

I'm in a rented cabin. So it's just like a single room. Yeah. So my bed that you will have seen us on one end, and then my little sort of toilet slash kitchen is thing is on the other end...And then just across, as like my combination bathroom sink, slash kitchen. So again, it's *just keeping things close… because of it's all like close you know, it gives me the independence to be able to do all this myself.* (Oleander)

Sections were very much still present within their space, having the space divided by the bed space (for rest), the kitchen space, and a pop-up tent for a private bathroom space. They are set up to all be near one another to limit exertion when using each space and having quick and easy access back to a place of rest when needed, just like the others.

For all participants the delineation between a site of rest and site of activity is directly reflective of their symptom experience that day. Having a place in the home where they can be comfortably more active means that they can have a more engaging day, through hobbies or social interactions, when their energy permits. This is valuable to their sense of self and sense of purpose, as this allows them to participate in everyday experiences of life, and things which bring them joy. Curating their site of activity to include tools of rest provides a level of reassurance and safety in the home because they know exactly which section or room they can use as per their symptoms at that moment. If they are feeling capable of cooking and baking, they can be in the kitchen; but if symptoms start to flare, they can easily move to a site of rest.

Summary

These participants modified their built environments to have spaces for their toughest and their better days; reflective of the ever-changing and unpredictable nature of ME/CFS. Spaces for rest were curated in ways to have as close to zero impact on symptoms as possible and invite emotional release, while other more active or social spaces in the home were modified to remain easy to access while minimising symptom impact. The active sites encourage engagement with pre-illness hobbies, or anything else which brings them joy; while the sites of rest encourage restoration and emotional release, assisting in coping with this illness. The therapeutic value in having different sites in the home means that the home is not only a site of healthcare and caution, but one of joy, safety, connection, and normalcy. The different sections allowed them to act in response to their fluctuating symptoms and emotional needs, enabling safety in their symptoms and safety to be themselves.

5.2 Theme Two: Simplify the Environment

Specific changes in spaces were made to make areas easy and safe to access, to keep them organised, include tools of healing, tools for independence, and tools to continue engaging in activities of interest. The simplifications of physical systems, social systems, and the role of technology not only minimised impact on symptoms but it also enabled engagement with pre-illness activities, hobbies, and things which bring them joy and connection from a place of ease, comfort, and safety.

5.2.1 Simple Systems

At a basic level, participants described an organised home as incredibly helpful, especially on their cognitive load. For someone with a symptom like brain fog or memory disruption, a trivial task of locating something can become incredibly taxing.

Kara expressed that keeping things consistent in her home, especially her bedroom, has been incredibly helpful "*the thing that makes me think of this is it's always the same, I really, really like consistency.* ***Consistency helps me manage my symptoms…"*** [Emphasis added]. For Kara there is a benefit to her cognitive load by keeping things the same as she is not exerting unnecessary effort to re-arrange or find anything. She describes this of her bedroom space mostly, where all her devices and tools are kept in the same location; when she enters her room for rest, she is not taking extra time and energy to set things up or find something. Kara said her current bedroom layout is almost identical to how she had her bedroom in her previous homes, indicating that she has created a set-up that has served her well over time and across spaces.

Scarlet describes something similar of her kitchen where everything is in an easy to access location that stays the same (Figure 9).

Everything I need to cook with is in one place… So everything is literally within just a turnaround, and use, and turnaround and cook… so I can cook without without utilising too much energy or needing to move around too much, and, um… it's here just set up to be make life easier, so I can still enjoy cooking without, um, using extra spoons. (Scarlet)

Figure 9

Scarlet's Make-shift Butler's Pantry

Scarlet loves to bake. She specifically set up this space to have her appliances at a usable height, to avoid lifting heavy appliances in and out of a cupboard and installed a power socket in the cupboard for these appliances to be used on the shelves. She keeps all related appliances in this one area, so they are ready to use and do not need to be set-up each time she chooses to bake. This is to avoid exacerbating physical intolerance. Scarlet also keeps her ingredients organised with labelled containers and jars; pantry shelves are grouped e.g. breakfast foods are kept together. This adds to the simplification of her whole kitchen system, so that when she is in this space, she uses as little physical and cognitive energy as needed. What both Kara and Scarlet discuss here is how helpful it is to have everything set up just the way you need it to reduce any unnecessary cognitive or physical load and make engagement with important activities significantly easier.

Oleander echoes these sentiments in their description on how helpful it is to have things within arm's reach:

So that's kind of a key thing so that I can physically reach things, even if I'm… doing, not doing well… But it's all, um, just accessible, you know, like and I've got a little table at the base of my bed, that's got my laptop and other things, and then I've got, you'll see in other pictures, I've got my sort of bedside stuff. (Oleander)

Having things consistently within arm's is a specific decision given their mobility and fatigue challenges. When getting out of bed can be a nearly impossible task on most days, it is vital that such items are consistently nearby. Another adjustment Oleander made was to install a pop-up tent in their cabin to house their compost portable toilet. This modification of the space enabled easier access to a bathroom (instead of needing to walk into the main house) but also created a private toilet space. Given Oleander's physical limitations, being largely bedbound, or confined to their cabin quarters, accessing a bathroom nearby is vital to their independence, dignity, and to avoid a PEM flare up simply for needing to access a bathroom. Oleander's modification to their space to make a system easier to avoid unnecessary symptom burden and the ability to carry out a task of daily living unassisted.

So because if I didn't have stuff in here I would need help to leave to go, you know, to the loo and stuff, whereas because of it's all like close you know, it gives me the independence to be able to do all this myself. (Oleander)

Setting up and organising spaces in the home for ease of use is not uncommon, but for those with ME/CFS, the key difference is how much this can impact symptoms. Such simple tasks, like lifting a mixer from a cupboard, takes many more spoons (energy portions) than someone without this illness. By limiting unnecessary exertion through simple systems, it makes the task more attainable, enjoyable, and reduces the PEM activity cost. This becomes an element of their therapeutic space as it helps to maintain their independence, sense of self, and enables a functional use of a space rather than preventative.

5.2.2 Simple Social Systems

Creating a simple social system in the home that caters to guests without disrupting the needs of the person with ME/CFS was also helpful. As Lily's illness makes it difficult for her to go on holidays or to host guests, their on-site self-contained Airbnb means that people can visit without it disrupting her need to keep her home space consistent for herself *"it gives me the holiday and gives them a holiday without me having to leave my space and my comfort…"*

Lily discussed how valuable it is to be able to spend time with friends and family, and such a setup makes it possible without burdening her symptoms. She can keep her home the same and separate, so it remains a safe place for her illness management and her guests have all their needs met, relieving her of host duties. There is no extra or unnecessary effort for Lily, aside from the increase in social engagement, which can be tiring enough.

Samantha expressed a similar sentiment with having a guest room and bathroom already set up. There is no extra effort required, aside from social engagement, to have guests over. This means saying 'yes' to such an activity becomes much more likely as Samantha is not having to count out the costs of setting up a room; everything is ready. Scarlet describes something similar of her day bed area, next to the living area where guests spend their time, *"I can be sitting there* *resting and still be engaged with people"*. Scarlet can engage with guests from the safety of her day bed, a space which is very much hers, while her guests have a space (the living room) they can use without disrupting Scarlet's rest system. Kara has a similar set up with her comfortable lazy-boy chair she can recline in when guests (family only) are visiting in the living room. For Lily, Samantha, Scarlet, and Kara, these are systems and physical arrangements which enable their social needs to be met, without altering the systems they have put in place for themselves and, importantly, without needing to leave their homes.

For Oleander, their social system functions differently as they are too unwell to have guests (aside from support workers). Their social system operates predominantly via the internet through social media and gaming networks, which I will discuss below with the role of technology. Notably, it is from the comfort of their bed that they use these social connection tools; once again a simple system, that includes rest, has been created alongside the purpose of social connection.

All participants discussed these modifications in the manner of being therapeutic because it made their lives easier, alongside encouraging important social engagements and hobbies. These simplifications meant that they could utilise spaces, such as the kitchen or have guests over, with the comfort of knowing their home is already set up to support the activity in response to their illness, and they know how the space will impact their symptoms. This takes their home space from one of a cautionary healthcare site, to one of participation, consistency, trust, normalcy, and engagement beyond their illness.

5.2.3 On-going Changes

Making adaptations or modifications to the home space to simplify the home has been an ongoing venture for most of these participants. Modifications have been ongoing in their homes to reflect the fluctuations of their symptoms, recovery journeys, and constant re-negotiation of space in relation to illness. This is not just about the changes that have been already made, but also in knowing the potential for the home to be an ever-changing landscape as per changing needs. The home acts as an ongoing symbol of support.

In Kara’s case, she has moved between many different homes while being unwell, but is now back in her family home, which she described as a dynamic space continually reflective of the needs of the household. Kara lives with her Mum who also has CFS.

If if something didn't work, we would change it. We would fix it or get rid of it or would do something to make sure that it was. So, there's nothing that's not healing in the environment…. The environment, ***we can adapt and change the environment to work for us rather than the environment working against us***. [Emphasis added]. (Kara)

What Kara said above was one of the best summaries of these interviews I came across. Being adaptive to ME/CFS and making things work for and not against them is a key marker of what makes their home therapeutic to them. The ability to modify their environments has meant the difference in making things safer and/or easier for them and making the home as therapeutic as possible.

The symbolic identity of their home has become about being an environment which works for them, and a space where they can imagine and actualise the changes they need for their health. Lily, Samantha, Kara, and Oleander all moved into their current homes because of their ME/CFS needs, seeing the potential of their new home to support them. Lily and her husband purchased a massive property which could include a vast garden, a home, and an Airbnb. They made significant alterations to the property since purchasing it, for the purpose of easing Lily’s illness burden, and the visions she had of a therapeutic environment. They changed a guest bedroom into a home office, so that Lily could work from home, and they installed triple UV water filters so that Lily could access clean water. As Lily described, the home setup created a significant sense of safety "*I know everything in this building is there to support me or or, yeah, nothing's gonna hurt me.*" They have gone to great lengths to ensure that every corner of their property is a space that Lily feels safe in her ME/CFS experience.

Samantha left their previous older home, and into a more modern home to lessen the load of house repairs needed. When moving into their new home she said *"One of the first things we had to do when we moved in was strip out some very busy wallpaper that was in the master bedroom. I'm like, 'how would that ever be a restful place?'".* She changed the bedroom decor to cooler tones, in reflection of her symptom of often running hot, to create a more calming space when she uses it for rest. Her painting reflects these cooler tones.

Scarlet has lived in her home for 10+ years, including years prior to illness, and made modifications to her daybed area after becoming unwell, *"it was a very active space before, and now I've changed it to a restful but active space, because it's where I it's where I do stuff, but I do it in the very restful way…"* She spoke fondly of the many other ways her home has adapted overtime to her ever changing ME/CFS needs.

These descriptions of renovations and modifications over time demonstrates the fluctuation of this illness and the need for an adaptive environment, one that can easily change alongside one's health needs. Big alterations to the built environment created different needs-based spaces, while little decor decisions contributed to the aesthetic experience of their therapeutic environments. These changes, big and small, were all made to create a more therapeutic and supportive environment which assisted, rather than hindered, their daily needs. If you are to consider the impact their homes would have on their levels of exertion if these changes were not made, their homes would be an environment that they were constantly working against. Knowing that the home can constantly be updated, modified, altered, and changed in reflection of their illness and/or recovery journey, creates a sense of safety and comfort because their home environment will always be there to support them. Given the homebound nature of these participants, being able to have this level of control over your home environment creates hope in how they experience their home positively, and therapeutically, as opposed to one of negative health challenges. It gives their home the symbolic status of a place of healing.

5.2.4 Role of Technology: Integrated in the Environment

The use of technology has been inserted into the home to make things function easier. I debated whether to make the role of technology a standalone theme, because technology has enabled many things beyond just physical changes to the environment. But I have included it within this theme because of how technology has been integrated and adapted into their environments for the key purpose of making systems or spaces simpler, in direct relation to their symptoms. Through its function to make things easier it has provided these people with agency, control, support, safety, and better symptom management. The range of technology in these spaces spans from lighting, placement of power sockets, adjustable beds, to use of iPads. As with all the modifications these participants made, technology has been a unique insertion to adapt their spaces for their individual health needs.

Returning to the bedroom, Kara describes how technology has enhanced the simplification of systems by providing tools to her environment which assist with pain management.

[We] will see that technology and how I've adapted the environment has made a really huge difference on day-to-day function. But it's fully adjustable [the bed], it has massage

> *function, it has USB ports, it has its own lights, it's got a remote control [laugh]. So it's, it's a major part in managing my health, because with my pain… just lying in one position on a flat mattress, you've got what? 4 positions right side left side on your back, on your stomach, um, whereas this bed, I can adjust the head or the legs, to sort of whatever position that I need.* (Kara)

As Kara had indicated, she spends most of her time in bed, especially on days with symptom flares. In our interview, she described some of her past beds in comparison to one she has now and says her current bed with *"all its technology"* has made her life significantly easier and more comfortable, it has made management of her chronic pain easier by being able to position herself with more variety in her bed. The additional features of massage support her physical symptoms and relaxation, while the USB features mean she does not need to get out of bed to find charging ports for devices. Kara shared that the lights in her bedroom are all on timers, so that throughout the evening they slowly dim down as sleep time gets closer; this eliminates the cognitive load of deciding when to turn lights off, and the physical load of getting in and out of bed. It may seem like a simple action, but when faced with depleted energy, such a small thing can feel monumentally difficult and potentially painful to do. This little action can also cost someone with ME/CFS a spoon, whereas someone without ME/CFS would not be impacted.

Lily describes having six Alexa Echo Dots around the house as essential. One use for these is *"I use it to tell me the time, because it feels like too much energy to move my wrist";* reiterating how helpful technology can be to eliminate the extra exertion of a bodily movement when faced with crippling fatigue or pain. Lily uses the Dots for voice control, making alarms to limit the cognitive load of remembering things, to play music, and sometimes for it to tell her a joke during the day as a little pick me up. Lily describes having the Dots as *"like a constant support for me*" as they exist in most rooms around the house, enhancing consistency. Lily can keep the same system running throughout the house and not be disadvantaged in one room versus the other, making home simpler and less burdensome.

Another very valuable role of technology for these participants has been the use of Kindles, iPads, and their mobile phones, for easily accessing reading material, YouTube, the internet, social media, and communication with others. These technologies enable a range of activity and connection without major home adjustments. As noted earlier for Oleander, it has been vital to have tools of connection and stimulation right at their bedside, as this is where they spend most of their day. They shared that they experience the symptom of orthostatic intolerance and limited muscle mass, making it difficult to continually hold their body upright (sometimes using a rolling chair to navigate their living space), which impacts their ability to use a laptop sitting up. Having a mobile phone that they can hold in their hand while resting on a pillow has been vital to stay connected, entertained, and resourced.

> *But the phone is like the hugest thing, because it's in my hand and it means I can access the Internet without having to manage the laptop. And it's how I access support groups, how I access just other human beings full stop and how I'm accessing, [laugh] you know, talking to you now and that's my heart rate monitor is accessed on my phone and, um, everything is via my phone.* (Oleander)

For Oleander the use of technology is vital to their daily experience. They use it to access communication channels, to access the internet (for ME/CFS research or support forums), to be able to game and virtually socialise with others, and to monitor their symptoms. Oleander uses gaming to connect with others online and to be entertained during the day, as such stimulation cannot be experienced by a bedbound person otherwise, *"So video games was actually like a massive part of how I managed to stay sane, being soo restricted."* For Oleander, they can be social and connected from the safety of their bed but can also choose to quickly disengage from the technology if they need rest. This is significant because of the proximity and integration of this technology in their world, meaning that they can dip in and out of using it, as per symptom presentation and personal need: they do not need to travel, or leave the home to meet this need. Many of us use technology in our homes and daily lives, but for these participants with ME/CFS technology is a major contributor to their home setup and aid in their symptom management.

Technology has not only been scattered around the home to make spaces easier to use and aid with symptoms but has provided a vital tool for health management without needing to leave the home or require other medical assistance. Oleander has been able to track their heart rate through a monitor connected to their phone and know exactly which activities elevate their heart and exactly when to sit down and rest. By using a heart rate monitor, they can track this without the need for hefty devices, medical intervention, or guesswork. Such a tool offers them control and knowledge of their body from the comfort of their home.

Further, use of phones, iPads, and similar technology is used by other participants for various health needs. Scarlet describes *"... probably my biggest tool for spiritual things is my iPad because that's where I do my Yoga Nidra sessions, my meditations, watch videos that are uplifting and that kind of thing."* Scarlet can access tools for spiritual healing from the comfort of her bed, meaning she does not need to leave the home to attend community gatherings for such experiences. Scarlet's use of an iPad echoes that of Kara's: it sits next to their beds so that they can easily access tools for resting, restoration, and entertainment.

These tools of technology have been inserted in their environments very intentionally, with direct relevance to their symptom management, either for symptom tracking or tools for well-being. Just with the other home adaptations, technology has been integrated into the environment to enable an ease of access to things and activities, to lessen impact on symptoms, keep things simple and organised, and support engagement with meaningful activities. Importantly, it is not just about the act of using technology for these purposes, but the curated choice to have this technology integrated into their environment contributes to their experience of a therapeutic home as it enriches and simplifies their lives.

Technology enabled all these interviews to take place. It was helpful to both participants and me, as a researcher with CFS. I would not have been able to travel to these people's homes for these interviews, nor them to me. Using online tools meant we could be more flexible with times, interview durations, limit our social energy needed for interaction, and easily schedule in rests.

Summary

The combination of simple systems for themselves and systems for social engagement, means less of a burden on their symptoms because things are consistent, easy to maintain, and ready to use. These systems are uniquely shaped for their specific symptom experiences and specific personal needs. For Kara and Oleander, the system around the bed is of most importance because this space is where they spend a lot of their time and the worst of their symptoms; for Scarlet her system was about making engaging in activities easier for themselves, such as baking; while for Samantha and Lily, it was about making it easier to be social in ways that did not disrupt the systems they have for themselves. All these adjustments mean a lesser impact on cognitive and physical load because everything is exactly how and where it should be. By intentionally creating simple systems, incorporating technology, and having a home-space which is adaptive means they can carry out daily tasks or activities without extreme caution. They can also participate in things with as much normalcy as possible and they are less likely to be disabled or disadvantaged in their home. These modifications impact their experience of their social and symbolic environment as therapeutic because it opens experiences that enriches their relationships, sense of self, well-being, independence, and QoL.

5.3. Theme Three: Symbolic and Practical Role of Nature

One of the TL categories the participant's photographed was the natural environment. When we discussed nature in and around their home, every participant had something positive to share about its role in their healing or sense of well-being, and how valuable it has been to have easy access to nature in some way or another.

5.3.1 Easy Access to Nature

What is commonly described by those with ME/CFS, who are mostly or entirely homebound, is how small their world becomes. Having access to things beyond the home becomes difficult to engage in, but by having elements of nature on their property means nature is literally at their doorsteps. All participants expressed that having a beautiful garden, or some indoor houseplants, has meant that they can stay connected to something they find healing and enjoyable, without needing to leave their property.

In the search for Lily's current home, she shared *"my thing was to be surrounded by as much nature as possible"* later sharing that *"It's definitely the natural that… has the biggest impact on me psychologically".* Lily's home is surrounded by acres of land, 500 fruit trees, gardens to explore with various wildlife, and expansive views of nature and a river. Lily states that living around so much nature is healing as *"it creates a connection to the rest of the world which helps me feel connected, even when I'm having to disconnect".* Lily's appreciation and need for nature around her keeps her connected to parts of the world she would not otherwise have access to, especially during times where her symptoms keep her cooped up in the home.

Samantha expressed a similar sentiment *"I need that connection to the outside, because I don't spend as much time out there anymore."* Samantha can view her outdoor patio space and small vegetable gardens from the comfort of her lounge chair. Kara described a similar set up, where she can see her conservatory and outdoor garden from her living room chair. Both Samantha and Kara can be in a place of rest, their living room chairs, while experiencing the benefits of being close to nature.

Oleander describes their backyard outside their cabin as like having a park right at your front door.

> *It's got an amazing garden like looking out. It doesn't look very impressive in that in that, you know, this time of year, [laugh] but it's it's genuinely like looking at, it's like, be, it's like a park like if you're outside, it feels like you're in like a little park. And that so that view was has been really [laugh] quite a big thing for me.* (Oleander)

Oleander added that they grow up rurally and continually having access to an expansive sense of space with nature is important to their sense of well-being and feeling grounded. Much like Samantha and Kara, Oleander often enjoys this view from the comfort of the indoors but can take a few steps to sit on a lounge chair outside when their symptoms permit. Having easy access to nature has had a valuable impact on their psychological health.

For each of the participants their personal attachment to nature has meant very specific things to their therapeutic environment. For Oleander, it is that connection to memories of rural living, and for Lily and Samantha it's about staying connected to the wider world. For Kara, her connection to the nature of her property is about experiencing the tranquility of the garden space, as it has a positive impact on her symptoms. Kara shares that she lives in a city and the nature surrounding her property keeps her sheltered from neighbours and works as a sound buffer from city noise pollution. Noise sensitivity is a common symptom for ME/CFS, as it takes the body's energy to process various noises. For Kara, this has a big impact on her fatigue levels, *"the busy-ness affects my fatigue. So being somewhere quiet, um, is hugely beneficial because it doesn't take as much as my processing up, so then I don't get as tired."*

Having nature easy to access and engage with creates a quick access point for those who are homebound and does not compromise their health or exert unnecessary energy to engage with. Easy access significantly lessens the burden of exertion, as they can access features of nature while remaining close to their places of rest, when needed. Much like other sections in their homes, their gardens are a section they can be in when their symptoms permit. Their easy access to nature means that they can continue to be a part of things which bring them joy, not burden them, and offer experiences of healing from the comfort of their home.

5.3.2 Symbolic Role of Nature

Nature not only provided healing opportunities through joy and psychological benefits, but also symbolically. For these participants, bringing nature indoors, through indoor plants, not only enhanced their living spaces aesthetically, but invited a symbolic reflection of their healing journey and important relationships in their lives.

Oleander shared that having indoor plants in their environment has been integral to making their cabin feel homely and more like a therapeutic environment *"having the plants in my room really turned it from being just kind of like a box with a bunch of junk in it to like to* ***feel like a home****...."* [Emphasis added]. Oleander shares that having plants indoors was the key difference to not feeling like they lived in a sterile box. For someone who is 99% homebound, having a space that is enjoyable to be in is essential to QoL.

Scarlet expressed a similar appreciation for indoor plants, noting that she does not always have the energy to get outside, and thus enjoys experiencing nature while indoors. Kara echoes this by saying that her indoor plant wall (Figure 10) has *"been really refreshing to have some greenery on the inside"*.

Figure 10

Kara's Indoor Plant Wall

Indoor plants have the capacity to brighten up one's experience of a place they spend so much time in. It brings them joy and aesthetic pleasure. In addition to the aesthetics, Oleander notes that having the plants indoors also gives them something easy to care for, and that many of the plants have become a symbol of their own care over the years; the cycles of neglect and bouncing back, reflecting their own journey of care. Oleander photographed a bandaged plant (Figure 11) as a part of their symbolic environment, which opened the discussion on how they have continued to nurse and care for plants, even during their ill phases. They reflected that this level of persistence in their plant care is symbolic of the care they wished they had received from others. Oleander uses their vision of care for themselves to care for their plants (and their pet fish).

Figure 11

Oleander's Bandaged Plant

Scarlet described something similar of having low maintenance and resilient indoor plants, like cacti, as it meant they could forgo their watering and care for some time but still survive. Scarlet described this as very symbolic of the cycle of ME/CFS flares where you forgo a lot of your self-care routines while you bounce back from flare ups. Both Oleander and Scarlet described that due to the symptom of brain fog, they simply forget to water their plants. The plants which symbolise neglect is an inspirational symbol for those with ME/CFS, as it suggests that even without proper care, one can bounce back and fight through the worst days of their illness.

The symbolic manifestation to the cycles of living with ME/CFS, a cycle of patience and hope, was also discussed by Lily in observing the natural changes in seasons, the cycle of life, within her garden:

> *It links back to that, that changing season, that it reminds me that it's in a season and that even when it's cold and dark, then eventually the light comes again… I've been here before on this grey day, and then it's changed. Yeah. And it's the the [natural] environment is the the tangible manifestation of that.* (Lily)

In addition to the symbol of care these plants bring, some indoor plants held other personal meanings. For Scarlet, she has an Orchid in her daybed area which belonged to her late Father. Orchids are notoriously difficult plants to care for, though despite this, she remains very fond of the Orchid as it holds important memories. Another one of her indoor plants is her wedding flower. Scarlet's inclusion of indoor plants is not just about having quick access to nature indoors, but also the memories of people these plants connect her to.

Similarly, Lily shared that a handful of plants and natural elements in her outdoor garden are odes to people in her life. She has planted a clipping of some pink roses from her late parents in law, and she has a large flock of doves that fly over her property which were gifted by a friend of hers who passed away. By having these memories connected to these elements of nature Lily can hold onto dear memories and connections to important people in her world, from the comfort of her home. For people who are homebound, filling the home with sites of connection and memories becomes a way to remain connected to people outside of your home or those who have passed, without needing to visit outside-the-home locations, such as memorial sites.

The symbolic role that nature plays is deeply reflective on how the participants have understood their collective healing journeys and state of mind about accepting their fluctuating symptoms. For Oleander this was significantly symbolic for the type of care (lack of care) they had received in the past, for Lily it is about the coming-and-going of bad days, for Scarlet it is about remaining connected to something joyous. Plants and nature have this anthropomorphism and embodiment of their care and healing journeys, and staying connected to nature has meant that they can stay connected to their peace of mind and a more expansive sense of the world beyond their illness. The symbols and meanings connected to nature in the home is a personal embodiment of their respective healing journeys and thus valuable to their curation of a TL.

5.3.3 Practical Use of Nature

In addition to such symbolic experiences, nature has also brought about very practical uses for the management of their health. Gardening has been an activity to share with others in the home and the creation of food sources. Many participants described that caring for the garden was a shared responsibility between themselves and someone else in the house. For the unwell person, they tended to be the picker of the produce, while their counterpart was the primary gardener. For Lily and Samantha, this was shared between themselves and their husbands.

> *So [husband] does the digging and planting, and then I'm pretty much responsible, like through the summer for making sure it gets watered, and things get picked on a regular basis, and that sort of thing. The division of duties on the garden.* (Samantha)

Lily shared that while her energy does not permit participation in gardening, she has immense pride for what her husband has achieved across their property, and it is a shared joy to experience their expansive garden, saying, *"my husband and I have a thing of making sure we point things out things in the natural environment to each other".* This distribution of duties between the couples is a valued part of their relationship experience and illustrates how their partners care for them by taking on the heavy energy parts of a task while they can both equally share in the joyous outcomes of the garden. Kara shares this experience with her Mum, who also has CFS. Her Mum, who loves to garden, has taken charge of beautiful landscaping around the property for her and Kara to enjoy, *"I really I really don't enjoy gardening, but I do like going out and picking all the vegetables [laugh] and eating them".* Much like the couples above, there is a distribution of duties and experiential use of the garden, but both parties get to enjoy it in ways they find healing.

One of the greatest joys and impact on health to come from their shared gardening is the ability to grow their own produce. These participant's not only take great pride in growing their food, but also find that producing organic and easy to access fresh ingredients is a vital contribution to their diet, as a management tool of their health, *"And that is therapeutic, I mean, it's food, and it's good for us, and, um… yeah, it's nice to know that you're eating what you're eating and what it's had applied to it."* (Samantha)

Lily and Samantha both have a very limited diet due to digestive, inflammatory, and allergic reactions contributed by ME/CFS, so it has been important to both of their diets and symptom management that they have control over what they are consuming.

There is not only the value of fresh ingredients and having a healthy diet, but also the capacity to have control over something in a very uncontrollable illness. The access to garden space, and sharing garden duties with someone, means that these people can continue to utilise a level of empowerment of choice and control over their symptoms. The value of having this in and around the home aids in the therapeutic experience as they do not need to leave the house to seek this part of their healing.

Summary

Nature has played an important role in the TL framework and literature (Conradson, 2007; Gesler, 2003; Gesler, 1996) and has shown up as valuable in these interviews too. The healing value in having elements of nature in and around the home spanned from the simple enjoyment of being close to nature, the ease of access to nature without needing to leave the property, the ability to create food sources, the sense of tranquility it brings, and the symbolic nature of having something to take care of. The role of nature in the participant's environments was one of the more important and multifaceted parts of their home, being discussed in relation to the symbolic, social, and built environments, as it had impacts on all facets of their world. The features of the natural environment in and around their home both practically and symbolically provided independence, self-sufficiency, and control over symptoms, contributing significantly to their sense of a therapeutic and healing environment.

5.4 Theme Four: Enriching a Limited World

All the previous adaptations in the previous themes culminate in an actualisation of enriching their limiting worlds. Adaptions have kept them connected to important things in their life, all while keeping them safe and comfortable. Though, there remain many other things typically sought outside of the home that have had to be brought into the home, permanently or briefly, to make something accessible to further enrich their environments.

5.4.1 Bringing Activities to the Home: Getting Creative

Bringing certain activities to the home was highlighted during the interviews as a valuable experience to participants as it helped them to feel more included in the wider world. Two key expressions of this were shared by Lily and Oleander.

One captivating story that Lily shared was of her birthday where she wanted to attend Karaoke in the nearest city. But due to her illness, the trip into the city would *"just, you know, take up so many spoons that I don't have".* So, her husband got creative!

My husband went and bought a portable karaoke machine for the B and B and got my best friends to come down for the day. And we did karaoke in the B and B, and it's just become one of the assets of the B and B to have a karaoke machine there if you if you want it. (Lily)

What is striking about this anecdote is the creativity and adaptiveness to Lily's illness in a way that meant she did not have to miss out. The touching part of this story is her husband's involvement to prioritise Lily's health while also meeting her social needs and birthday wishes and her friend's adaptiveness to the situation. This story encapsulates her illness management, and the creativity required to make things accessible, but it also signifies the importance of supportive relationships to make things happen. A part of Lily's therapeutic environment is not just having access to things that she enjoys but sharing her living space with someone who cares for her and understands, to the best of their ability, her illness.

This notion of not taking things away from someone, just because they are homebound and unwell, is a core experience for Oleander who uses video games (and the internet) to stay socially connected. While being connected virtually is not a unique concept, for someone who is homebound with ME/CFS it is potentially their only source of human interaction.

OLEANDER: *... in a really big way that I get social interaction is through twitch streams. Um, where somebody is live streaming them doing something typically playing a game. …if you go to a if you find like a relatively small twitch streamer who, um, you know, seems cool, ahh, if they don't have like a huge amount of followers, it means that you can like chat a lot more easily… And they'll ask her how you are, you chat about what they're doing, or just about like* *random things, and it's more of like a real, it's like… for the brain it feels like a more substantial social interaction than just like typing to other people. Cause you can see people react and hear people react…but like there's something that you capture in these small streams where it is like a group activity that you'll all do like experiencing together.*

JESSICA PHILBRICK: *It's like being able to turn up somewhere without actually having to turn up somewhere.*

In the streaming conversation Oleander was able to experience something they might typically seek outside of the home (a group social activity) virtually. While I have already discussed Oleander's social connections through technology, what is key to this anecdote is about the specifics of the platform and content being engaged with. Oleander is not leisurely browsing random streams but is making conscious decisions about who and what to engage with because of the outcome of social connectivity it brings and having access to more real-time reactions. It shows incredible self-awareness about their personal needs amongst their illness and empowerment of choice by being selective about who and what they engage with online.

Other simple ways that activities have been brought to the home for the other participants is by having friends or family over for dinner, rather than going out; by creating holidays at home with having guests stay, rather than going elsewhere for a holiday; and for all of these participants, by having pets in the home to give them low-energy companionship, given the amount of time they may spend alone.

Bringing stimulating and enjoyable things into the home is not just about mere entertainment but about continuing to meet someone's basic needs for connection and enrichment. Both Lily's and Oleander's tales illustrate very intentional and creative adaptations with specific reference to their symptom presentation and personal desires. These situations of bringing outside activities into the home, enriches their environment by aiding in the therapeutic components of meeting social needs. Again, alluding to the importance of accessibility by being creative in the ways in which something can come into the home and enable someone with ME/CFS to participate in life as much as possible.

5.4.2 Finding the Little Joys: A Sensory Environment

The previous theme describes significant gestures of bringing enjoyment and connection to the home through an activity. But throughout the interviews, the participants spoke fondly of the little details around their home which brought them joy throughout their day, particularly in ornaments or objects. These finer details of personal significance are often found in people's homes but are extra important to people who are homebound because it keeps their environment stimulating, interesting, and important.

Oleander, and others, described that having simple things which give them joy around the home is significant to creating an environment that addresses your senses. Oleander mentions a little frog ornament, which was a gift from a friend.

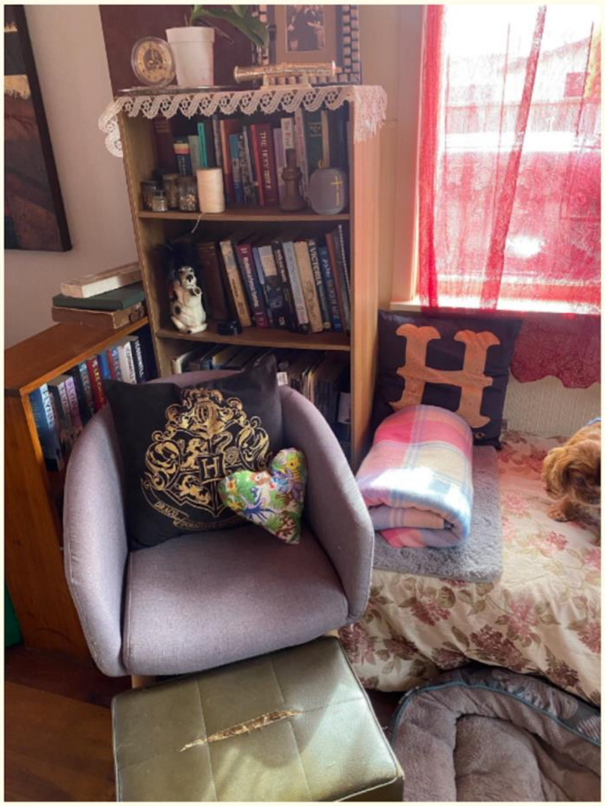
Which is a just kind of [laugh] a whimsical [laugh] thing, and it's, you know, like I do I do often get for myself just like little whimsical things. Just to kind of give myself some fucking joy in life. (Oleander)

Oleander's sentiment here is about having things around the home which bring you joy amongst an illness which so often strips you of joy due to experiencing debilitating symptoms of fatigue, or pain, and the immense grief which chaperones this illness.

Samantha's home is adorned with art works collected from around the world during their travels and living abroad, she says *"I like that I've got memories here that are visible on a daily* *basis."* She likes to be reminded of the wonderful experiences she has had in her life as it keeps her grounded on the difficult illness days. Scarlet offers a similar sentiment, *"I like old old books that I like to collect that make me happy [laugh]*." (Figure 12). Lily shares that she has a favourite candle she lights in her office and that scent makes her happy. These objects have given them something joyful to look at, to touch, or to smell, making for a sensory filled environment.

Figure 12

Scarlet's Bookshelf



Having things around the home which bring about joy creates a therapeutic space because these objects enrich their spaces and give a little spark to their day. As they are not getting the variety of experiences elsewhere, these small details create an environment which attracts and engages all the senses, so that the environment does not feel restrictive and limited. This is important to the symbolic components of their therapeutic environment as it symbolises a home of joy, not only a space of challenge.

5.4.3 Employment

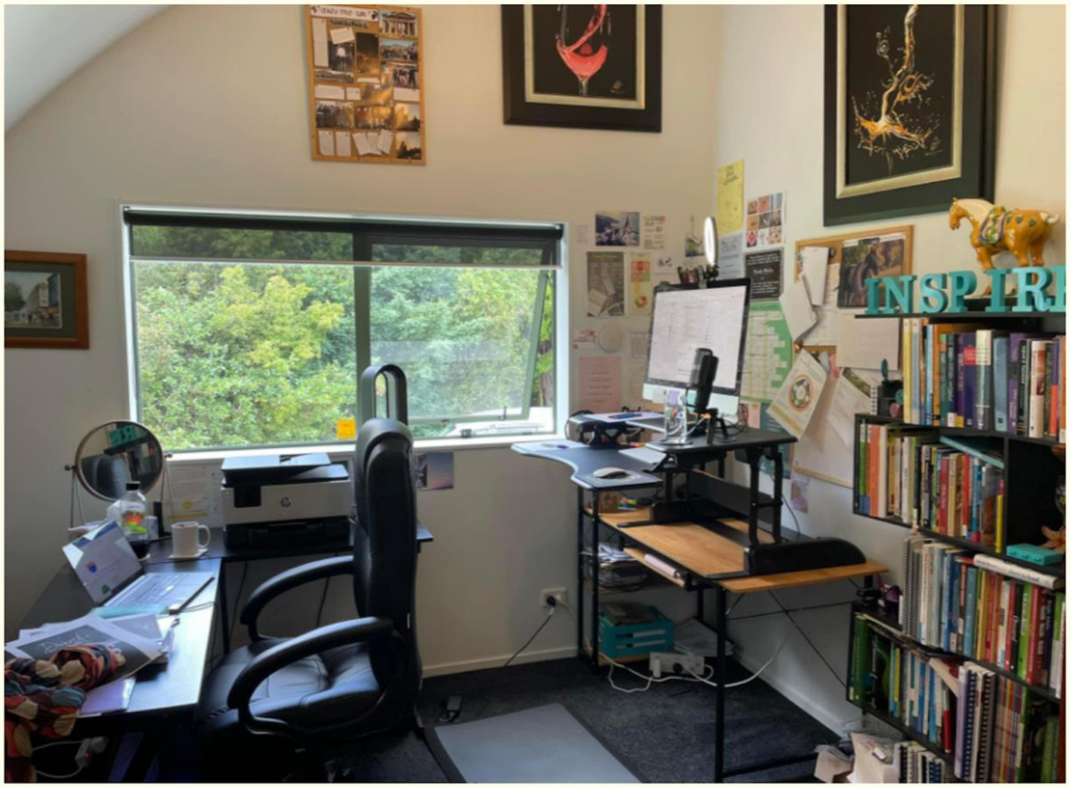
Being able to bring employment to the home offers many practical benefits, namely, financial stability, but also maintaining a sense of self or purpose.

Both Lily and Scarlet were able to continue their much-needed income streams by working from home. Scarlet said, *"I cannot, I would not be able to cope with a job where I actually have to leave the house."* Working outside the home would require too much energy exertion for it to be a successful endeavour for Scarlet. Like Scarlet, Lily decided to base her employment from home and described that *"the home office environment has meant that I can still make that difference in the world that my brain wants, and my heart wants, but my body, doesn't let me."*

Her home office not only allows a safe and accessible environment for maintaining an income, but it has allowed Lily to continue her passions for teaching and helping others. As she says, she has passion projects and interests that she wants to pursue, but her body limits her capacity to do so. Just like the karaoke machine, Lily got creative and adaptive to find a way to bring something important to her into her home environment so that she could continue her sense of self, and not let her illness restrict what she is able to do. Lily's office was one of the spaces she photographed for the interview and depicted in her painting (Figure 13).

Figure 13

Lily’s Home Office.



The details in Lily’s office illustrate how adaptive the space has been to accommodate her illness. She has a range of desk heights, as per her physical needs, a yoga mat on the floor for relaxation, a comfortable chair; and is surrounded by inspiring content on her walls, such as letters from previous students. This office space has not only been about maintaining an income stream but about allowing Lily to continue the things her heart treasures. Lily describes this space as being able to *“remind me of the difference that I can make, when I take care of myself”*. This space is highly symbolic of the manifestation of prioritising one’s health needs but also being creative about keeping important things in their home-world that remind them of who they are outside of their illness.

Summary

By getting creative and intentional about bringing things from outside the home into the home has aided in their therapeutic environment by maximising joy in an otherwise unenjoyable illness. Bringing things to the home has helped maintain a sense of purpose, productivity, identity, and participation within their limited worlds, all from a safe and symptom supportive space. This is significant so that they have not felt like ME/CFS has overtaken their lives or stripped them of all things of importance to them. Bringing employment into the home also enriched their environments by once again allowing an element of control, empowerment, and independence within an uncontrollable illness.

CHAPTER SIX: DISCUSSION

The discussion of these findings connects the identified themes from the interviews with the TL framework, for the purpose of contextualising the research focus. I will then discuss how these findings are relevant to areas of healthcare application, further research, and other considerations. Overall, these findings and these stories are valuable contributions to understanding and valorising lived experiences of those who are homebound with ME/CFS. The findings revealed participants created and found positive experiences within the home amongst a challenging and unpredictable illness, highlighting hope for those living with ME/CFS. Despite the overarching positive focus of this research, there are still unrelenting challenges in living with ME/CFS and being homebound not shared here.

Making a therapeutic home required labour and intentionality as effort was required physically, emotionally, and financially to create the required adaptations. Largely led by the participants' own creation and instigation, they created environments which have allowed them to have experiences beyond their illness, symbolising a type of healing: they are not cured but are able to live meaningfully despite their illness. These findings substantiate the values and function of the TL framework (Gesler, 2003) as the collaboration of the built, natural, social, and symbolic environments of these participant's homes created therapeutic experiences in relation to their ME/CFS management and healing. Their homes are therapeutic through providing positive experiences across their physical, emotional, and spiritual areas of health in ways that offer improvement of symptoms, alleviating challenges, improves psychological well-being, and QoL. These findings reiterate that a TL does not need to be a space which offers a cure, or a geographical destination, but can be one embedded in everyday spaces, when adaptations are made.

6.1 Built Environment

Modifications to the environment noted by these participants maps onto how other TL's have been understood to adapt to illness or disability in the home. A priority of home modifications is often to ensure safety and comfortability alongside preserving the familiarity of home (Donovan & Williams, 2007). The findings from this research mirror those priorities as these participants made physical modifications to their homes for symptom relief, physical and emotional safety, and to maintain normalcy with their home. Ultimately, the healing capacity of their built environments meant that they did not need to navigate their home with caution but could trust in their home to support their health needs.

What has been noticed in the TL literature on how the home (or other sites) are adapted is that physical modifications are made with specific symptoms or limitations in mind, such as grab rails to prevent falls. Nagib and Williams (2018) explored how changes to physical space were made to alleviate symptom-related challenges for the child with Autism. The goal in this instance was having spaces in the home which did not need to be navigated with caution but instead a sense of ease and safety in the home for the person with Autism and anyone else in the home overseeing that person's care. Such changes are echoed in these participants' modifications to their environments, where changes were made in aid of their challenging symptoms, so that they did not need to worry (as much) about how that space would impact them.

ME/CFS symptom responsive adaptations were primarily noted in the creation of rest spaces. These participants created symptom-safe spaces in their bedrooms, through comfortable beds, assisting technology, quietness and isolation, and other decorative features. The bedroom was a part of their home and was a space they did not need to worry about how to navigate symptoms. Sites of rest were spaces that were spaces of sanctuary, as similarly seen with participant's creation of affective sanctuaries in Espeso (2022). This meant that rest could be prioritised, and energy preserved. My participants created symptom-alleviating spaces in their homes where the core values of home could be maintained (safety, comfort, and control) while also being responsive to health needs.

In addition to being symptom-safe spaces, rest sites acted as a therapeutic escape, without needing to leave the home. The participants were able to utilize the component of escapism within the walls of their bedroom, and retreat to a place of stillness and distance from their everyday life. With an energy-limiting illness like ME/CFS, rest is vital for symptom management. To rest, one tends to be still or quiet (physically, cognitively, or emotionally), so as not to exacerbate any symptom by exerting further energy. The stillness of their designated rest space gave permission for them to be unproductive, as was discussed by Conradson (2007) in the concept of stillness at Monasteries. Stillness was achieved through the physical rest in their beds or chairs, cognitive stillness through reducing activity or engagement with others, and emotional stillness through releasing emotions for psychological relief.

The safe rest spaces created in the home were not just for physical symptom safety, but also emotional safety. As Gesler asserted, one's emotional or psychological state is greatly considered alongside physical health (Gesler, 2003). Nagib and Williams (2018) found the symptom of emotional dysregulation in autism was helped with low-sensory spaces. Espeso's (2022) research found that people with panic disorder greatly valued the creation of their affective sanctuaries to support a therapeutic experience when coming out of dissociation, emotional distress, and reconnecting to self. For these participants, their bedrooms were a low-sensory or low-energy output space which meant they could also unmask the emotional spectrum of their ME/CFS and be in an environment to safely express any emotion relating to their experience. The participants highly valued their emotional health for coping with this illness and curated safe spaces to support emotional expression and regulation.

Creating designated safe spaces within the home, also meant that the rest of the home could maintain as much physical familiarity and use as possible. The rest of the home did not need to become an overly symptom-responsive or cautionary space, because they had their rest site they could retreat to. This was seen in the designation of shared spaces within the home where others could use the home as needed without disrupting the health needs of the unwell person. But more importantly, there are days where their symptoms permit them to experience their home in an almost-normal capacity. There are days where they can engage in gardening, cooking, and socialising, and it has been beneficial for them to have places within the home that continue to support being active and engaged in a familiar way.

These spaces usually had a few adjustments made to minimise their impact on symptoms, but they maintained their functionality for full activity use and engagement for the person with ME/CFS and others in the home-space. Maintaining familiarity in the physical environment was also evident in how the participant's prioritised organisation and consistency. Consistency also helps those with dementia or other cognitive decline illnesses, as it limits cognitive confusion and cognitive strain (Allen at el., 2017; Patel et al., 2023). Maintaining familiarity and consistency is a symptom-responsive need for therapeutic opportunities as it limits impact on cognitive strain and makes the environment easy to navigate and less burdensome. Thus, separating and creating spaces for different purposes enables one to participate in regular home activities when their symptoms permit.

6.2 Natural Environment

Participants expressed gratitude for their easy access to natural surroundings, and the way nature was symbolically utilized in their homes. Access to nature gives experiences of tranquility and peace, as discussed by Conradson (2007) at Monasteries, and Gesler's discussion of Lourdes and Epidauros (Gesler 1992; 1996). The tranquility of being in nature provides an escapism from everyday life and can aid in symptom relief (Bell et al., 2018; Conradson, 2007; Delaney, 2020; Schuh & Immich, 2022). However, many escapist experiences in nature require one to leave the home. For the participants, having nature easily accessible in and around the home meant that they could access the escapism and tranquility of nature, without leaving their property as their energy levels make leaving the home challenging.

All participants echoed the general sentiment that having access to nature helped them to feel like their worlds were not so small and gave them a slice of tranquility. Connecting with and being in nature helped participants feel a part of a world more expansive than the walls of their home. Nature had the power to create feelings of escapism within the bounds of their home (whether indoors or outdoors) which had a positive impact on their psychological health.

Most participants had great appreciation for their surrounding garden not only for its aesthetic beauty, but for the capacity to engage in gardening related activities, predominantly for harvesting food. For most of the participants this was a shared activity with someone else in the home, due to energy requirements. Gardening has long been understood as a therapeutic practice, especially when shared with others (Marsh & Williams, 2023; Pitt, 2014). In the Monasteries, groundskeeping was a task carried out by the Monks, as a practice of worship in maintaining an aesthetic and therapeutic gardenscape (Conradson, 2007). Beyond this practical activity, the practice of gardening for control over health has long been practiced and observed as a therapeutic health practice across cultures; especially in the concentration of food as medicine (Singh, 2006).

For these participants, their gardens gave them access to growing food and gave some control over their diets, as they could oversee how the food was grown, the soil, the chemicals, and focus on crops that they needed most. For Lily, who experiences a wealth of food intolerances related to ME/CFS, it has held a significant impact on her health management to have more control over what she is consuming. Having access to the garden within their own property meant that they did not need to leave the premises to access this part of their healing. Gardening gave them some control over an aspect of their health, their diet, but also gave them social connection through the act of gardening. The therapeutic outcome of having their gardenscapes was in positive social experiences, symptom management, and healing through food.

The adoption of a slice of nature indoors as a trait of a therapeutic space has been used extensively in interior design choices for hospitals, retreats, and other therapeutic spaces (Collins, 2007; Dinu Roman Szabo et al., 2023; Gesler, 2003). As Gesler expressed, humans tend to find elements of nature comforting. Therefore, features of nature have been utilised in indoor spaces to create an aesthetic-therapeutic relationship to foster feelings of comfort, peace, homeliness, and make spaces less sterile. This has been seen in hospital green spaces (Garg & Dewan, 2022; Haggard & Hosking; 2003) or how indoor plants have been recognised as an aesthetic feature of homeliness in therapy rooms (Knapp, 2020). These participants have used nature indoors for similar reasons. The use of indoor plants for these participants was to bring a slice of nature indoors and to make their space more homely. Having indoor plants has beautified their space and ultimately created a more comfortable and enjoyable environment. Comfort is a massive contributor to the experience of a therapeutic space and aids in one’s healing journey (Knapp, 2020; Moore et al., 2013). Some plants symbolised their healing journeys and managing their symptoms, such as having low needs plants or having plants that are a bit damaged - both reflecting and symbolising what it is like to have ME/CFS.

The participants used nature in several ways to create therapeutic spaces, reflecting the many associations nature has with healing. The participants chose homes that had gardens or views of parks and gardens, they tended to gardens and indoor plants when their symptoms permitted, providing them with positive psychological experiences, and used indoor plants for beauty and comfort to create a sense of homeliness. The participants made their worlds feel more expansive and enjoyable through their use of and engagement with nature.

6.3 Social Environment

In the TL literature on the social environment, much of the research looks at roles of caregivers (formal and informal) and their adaptations to changes in the home environment, particularly regarding caregiver sacrifices (Allen et al., 2017; Donovan & Williams, 2007; Karasaki et al., 2017). The participants rarely mentioned the role of any caregivers. Three of the participants lived with their husbands but these people were discussed as supporters, partners and not caregivers. This was perhaps due to the self-management capacities they held so there was no sense of needing to be cared for by another. Oleander did mention utilising support workers, but this was not discussed in depth in our interviews. The little conversation held around the role of others for these participants could have been due to the isolating nature of ME/CFS and the extensive reliance on self to manage symptoms.

The identified engagement with a social environment that was most noted around having places for guests in their homes without disrupting their health needs and set ups. Participants found that having social spaces in their home that did not disrupt their own sites of rest was pertinent to be able to actualise these social ongoings. This is important because social engagement can be unhelpful or even harmful to the unwell person when guests do not understand the taxing nature of such an engagement (Donovan & Williams, 2007). These participants had set up ways for people to be social in their home without massive disruption or taxation to their illness by having ready-made spaces they can use. The modification of spaces to accommodate both guests' needs and their rest needs, means less negative impact on the unwell person, while also having access to the psychological benefits of social connection. This allowed a sense of remaining in control of and empowered in their symptom management when engaged in a taxing task such as socialising. All participants did note that guests were very limited to family and close friends in their homes; sharing that other social engagements would be too taxing.

The curation of a space for socialising was an initiative led by the participant. This further suggests that it is the unwell person who best knows the limits of their health and are therefore the ones to shape their environment in response to their needs. This focus from the unwell person's perspective was modelled by Espeso (2022), which detailed how their curated spaces supported them with their panic disorder; a space which could not have been created by someone else. This is an important point for this research as well as the understanding of the impact this separate social space has on ME/CFS symptoms can only be understood from the perspective of someone who it was created for. This returns to the relational nature of TL in which we can deepen our understanding of the therapeutic experience, and success of a health outcome, from the perspective of the person/s the health outcome was intended for.

A part of these participant's social worlds were their pets. This has not been discussed extensively, but their pets provided them low-energy companionship and comfort. Pets have long been considered as therapeutic, benefiting mental health (Hawkins et al., 2021; Orr et al., 2023)

6.4 Symbolic Environment

Symbolic elements of a TL are understood as the visual cues that indicate a place of healing. The symbolic environment is difficult to isolate as symbols operate throughout all categories of a TL but can be understood as the intersection between the physical/material and the social/emotional worlds (Taheri et al., 2021). The traditional discussion of symbolism in the TL literature is about how the environment provides symbols of a particular healing or treatment practice (Gesler, 2003). However, symbols of healing are not just explicit, like the statue at Lourdes, but can also be more subtle, such as the symbolic familiarity of the home space for comfort (Caspari et al., 2011; Gesler, 1996). As James (2019) and Alaazi et al., research (2015) explored, the symbolic needs of home emerge from a socio-cultural perspective; a position often overlooked when discussing the symbolic environment in TL (Bell et al., 2018). Therefore, creating a therapeutic environment for the participants of this project was about creating a home which symbolised comfort, safety, and self-expression, rather than just a symbol of healthcare. For the participants, symbolism of healing was present in the cues which represented a symptom responsive environment, captured the balance between isolation and connection, enabled self-expression, and captured their version of a healing home beyond ME/CFS.

Comfort and safety were symbolically present in physical objects such as a bed, technology for connection to others, and having simplified and easy to access spaces for when they did have energy. Comfort and safety were also symbolically embedded in spaces where emotions could be expressed, where they could be authentic in their experiences with ME/CFS.

This was mostly present in symbols that reflected hope for navigating the cycle of difficult to good days, e.g. inspirational sayings, a buddha statue, a bible, and visuals of nature. Comfort and safety were further symbolised in the maintenance of familiarity around the home, so that the home represented a place of normalcy and self-expression rather than a place of healthcare or caution. Prioritising rest, as a management tool, was symbolically present in having spaces that were responsive to symptoms, spaces which were quiet, isolated, had assisting technology such as scheduled lights, and organisation to reduce cognitive load. Escapism was captured symbolically for ME/CFS through connections to things outside the home without leaving home e.g. spaces of retreat, social adjustments, access to nature, and enrichment of their environment. Escapism was also captured in the tension between needing to have spaces of isolation for coping with ME/CFS, but also in how being homebound creates a more isolating existence. Nature held symbols of connection, tranquility, peace, and symbols connecting to their journey with ME/CFS, such as Oleander's bandaged plant.

Collectively, these symbols capture an essence of healing to the participants because it encapsulates their relationship to their home as a site for their version of healing. The ways in which they enriched and adapted their environments meant that their home could operate not as a symbol of healthcare and caution, but one of joy, participation, and self-expression. In creating their own symbols of healing around the home they were able to create environments that did not make them feel trapped by their illness but instead brought them outside of their illness. Their home symbolised elements of control over their (uncontrollable) illness, in their ongoing adaptations, and as Taheri et al., (2021) expressed, having control over one's environment and health is valuable to the therapeutic experience. The symbols became metaphors for things beyond their illness, beyond their symptoms, and acted as reminders of who they are in the world outside of managing their ME/CFS. Their symbols were barely about the offering of specific healing or treatment practices, but simply in an offering to be themselves beyond their illness.

6.5 Contemporary Use of the TL Framework

The TL framework is used to better understand landscapes, spaces, or environments that provide positive healing experiences; most commonly in curative form (Gesler, 2007). But as Williams (2007) asserts there is much more flexibility in the application of the TL framework, especially in examining spaces where health outcomes are compromised or complicated. One landscape where this has been considered is that of the home as it is intertwined with experiences of the everyday and is a site used by unwell, disabled, or terminal people who do not have a cure available to them. The findings from this research provide a valuable contribution to the expansion of the TL concept which has been lacking a consideration of spaces wrapped up in everyday life (DeVerteuil & Andrews 2007). This research demonstrates a use of the framework in everyday spaces, used relationally and responsive to the person/s using a space and their specific healing desires, to bring forth their meaning-making experiences that create the layers of a TL (Conradson, 2005; Rathman, 2021).

This research demonstrated the strength in the TL framework as a relational analytic tool through utilising the first-person narrative of people with ME/CFS and how they have created and experienced their version of a TL. In marrying methodological tools which prioritise experiential insight of phenomena with the TL framework, this research was able to bring forth meaningful (therapeutic or healing) experiences and behaviours occurring with the home in relation to ME/CFS. The understanding of health outcomes in this context was not in cure, but in symptom management and relief, self-expression, and life beyond illness. Such ideas of non-curative healing in the home were also explored with the TL framework in Allen et al., (2017), Donovan & Williams (2007), Karasaki et al., (2017), Nagib and Williams, (2018), and Williams, (2002). My research, alongside others, shows how the TL can be applied in settings that are not just curative or host positive healing, but can be in settings that offer other understandings of healing.

6.6 Better Understanding and Healthcare Implications

People with ME/CFS continue to report dissatisfaction with healthcare services (Melby & Nair, 2024). As an under researched and misunderstood illness, with a hard-to-reach population, research into this illness needs to continue to prioritise patient stories and shape their care plan around individualised needs (Culver, 2021; Hsu, 2024; IOM, 2015; NICE, 2021). This research adds to the growing body of literature imperative to better understand ME/CFS experiences; most notably for those who are predominantly homebound, but do not identify as very severe.

These findings support one of the key recommended approaches to managing this illness: pacing and individualising one's PEM management plan (NICE, 2021; Sanal-Hayes et al., 2023). It is suggested that a focus on PEM management increases satisfaction with healthcare providers (Marjon et al., 2023). These findings demonstrate ways in which people have adapted their environments to enhance their ability to pace their activities, limit their symptom impact, reduce their PEM, and recover safely while in PEM. Healthcare providers can utilise these findings and the TL framework, alongside tools from Te Whare Tapa Whā, to consider how PEM can be managed at home (detailed in Table 4). It is well-evidenced that the psychological experience of an environment impacts physiological outcomes, as explored in Maggie's centre (Frisone, 2024). This is knowledge which healthcare providers can take into practice when discussing management strategies with their patients; prioritised by symptoms of highest impact.

Table 4

Knowledge for Healthcare Providers Informed by a TL Approach

TL Category / Pillar	Considerations
Impact of the built environment - *Tinana* (physical)	Creating sites for rest, incorporating technology, and creating ease-of-access systems to prioritise rest, navigating PEM triggers and recovery, and limiting physical and cognitive exertion.
Impact of the natural environment - *Hinengaro* (mental)	Creating access to elements of nature to limit physical exertion in accessing the outdoors. Psychological benefits in connecting with nature and creating an expansive sense of space to reduce feeling trapped.
Impact of the social environment - *Whanau* (family)	Navigating guests, encouraging connection with family, friends, and wider community, while also creating safe places of isolation. Benefits in maintaining social well-being while minimising symptom impact and balancing the need for isolation for emotional expression.
Impact of the symbolic environment - *Wairua* (spiritual)	Creating a home-space that feels comfortable, safe, and enriching by introducing symbols of healing, care, and connection, or spiritual tools. Supporting psychological and spiritual well-being as a holistic tool and encouraging engagement with spiritual well-being.

Of specific relevance to clinical psychology practice is processing the emotional spectrum of living with ME/CFS, as this could be a beneficial consideration alongside CBT treatment, as anxiety can impact one's ability to manage their illness (Wright et al., 2021).

Additionally, technology was a valuable tool in health management. Tools used for symptom relief include massage chairs and heat packs; tools for health monitoring include heart rate trackers; and tools for well-being are items such as iPads, mobile phones, or gaming devices as they provide low-energy entertainment, connections to others, and access to spiritual resources. Many of these tools are commonly discussed within the ME/CFS community, as we continue to be a resource for one another, but they would be valuable for healthcare professionals to consider when providing support for symptom management and health tracking. However, technology has a financial cost, and many people with ME/CFS are not in full-time employment there are implications for funding sources.

6.7 Implications for Further Research: Developments and Limitations

There are many exciting ideas for further research which come from this project. Further investigation into the role of the home as healing would always be welcomed for those who are homebound; especially those who are very severe as they remain an under-researched group in ME/CFS research (Montoya et al., 2021). It is a valuable addition to any research on managing chronic illness at home to prioritise the patient perspective (Anderson & Bury, 2024).

In recruiting for this project, some members of the Facebook page shared that their home felt like a prison. While it was intentional to invite positive experiences, it would be valuable to investigate challenging experiences of ME/CFS in the home to understand how the home could be a harmful or non-therapeutic environment. This could remain within TL research, through the expansion of compromised spaces referred to by Williams (2007).

Culture is incredibly influential to one’s experience of health and the home (Hadjiyanni, 2019), and it could be valuable to explore how differing cultural values in the home aid in ME/CFS management. Of relevance to Aotearoa, further research could investigate experiences of home with ME/CFS from Māori or other cultures, as Indigenous cultural values are valuable to the creation of a therapeutic home (James, 2019). This would be a welcomed and valuable addition to the research for the context of Aotearoa, as the TL framework maps on nicely to the Māori model of health, Te Whare Tapa Whā, and would aid in the development of the framework's cross-cultural relevance (Williams, 2007).

As most of the participants of this project were homeowners they held an element of control over their environment: they could more easily carry out repairs and renovations and would have held more ontological security which comes with being a homeowner. It would be valuable to conduct similar research with a population of people with ME/CFS who are exclusively renters, as their experience of home could be vastly different. Further research could continue to explore the role of the therapeutic home when living with ME/CFS for different age groups, genders, level of severity, length of illness, and parents with ME/CFS.

6.8 Implications for the ME/CFS Community and Exhibiting the Paintings

It is hoped that this research provides positive stories of living with ME/CFS and can provide hope alongside ideas of things which others with ME/CFS can adopt in their homes. I have adopted some of these, such as using an Alexa next to the bed for meditative soundtracks, a Fitbit for tracking my heartrate, ensuring supportive rest spaces in shared areas, and continuing to personalise my home for my symptoms and joy for my space.

During the project it was decided to utilise the paintings for a public exhibition at the Pop-Up Gallery space at Square Edge Community Arts, Palmerston North, during August 2025, as a means of disseminating the research findings in a community setting. An application was made to ANZMES for funding to support this exhibition. This mode of research dissemination provides a rare opportunity to encourage a kōrero/conversation with the public about the experiences of the home when living with ME/CFS. The exhibition will be supported by resources on ME/CFS to aid in the community educational experience.

CONCLUSION

In answer to the research question, the experience of home as therapeutic when living with ME/CFS has been about creating an environment that works for you, not against you. The adaptations these participants have made to their homes to foster a TL has meant they can enjoy many health-enhancing activities (when symptoms permit) within the safety of their home. Their homes are environments which do not disable them or result in a life led by caution and not letting the ME/CFS strip away all that is valuable and achievable in their lives. With sites of rest, easier systems, symbols of joy, access to nature, and enriching their environments, their homes contain a source of healing not as a cure but in alleviating challenges and living a life beyond ME/CFS. The TL framework has allowed an insight into how the interactions with these adaptations have created meaning between person and place in relation to their health experience and the therapeutic outcome.

REFERENCES

Abshire, M. A., Bidwell, J. T., Pavlovic, N., DeGroot, L., Mammos, D., Larsen, L., Bautista, S., & Davidson, P. M. (2021). A picture is worth a thousand words: Exploring the roles of caregivers and the home environment of ventricular assist device patients. *European Journal of Cardiovascular Nursing*, *20*(8), 782-791. https://doi.org/10.1093/eurjcn/zvab043

Action for ME. (2025). *What does ME feel like?* https://www.actionforme.org.uk/get-information/what-is-me/what-does-me-feel-like/

Alaazi, D. A., Masuda, J. R., Evans, J., & Distasio, J. (2015). Therapeutic landscapes of home: Exploring Indigenous peoples' experiences of a Housing First intervention in Winnipeg. *Social Science & Medicine*, *147*, 30–37. https://doi.org/10.1016/j.socscimed.2015.10.057

Allen, F., Cain, R., & Meyer, C. (2019). How people with dementia and their carers adapt their Homes. A qualitative study. *Dementia*, *18(3),* 1199–1215. 10.1177/1471301217712294

Anderson, R., & Bury, M. (2024). *Living with chronic illness: The experience of patients and their families*. Routledge.

Andrews, G. J., & Holmes, D. (2007). Gay Bathhouses: The transgression of health in therapeutic places. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 221–232). Routledge.

Applebaum, M. (2012). Phenomenological psychological research as science. *Journal of Phenomenological Psychology*, *43*(1), 36–72. https://doi.org/10.1163/156916212x632952

Associated New Zealand ME Society. (2025). *What is ME?* https://anzmes.org.nz/what-is-me/

Avellaneda A., Pérez A., Izquierdo, M., Arruti, M., Barbado, F. J., de la Cruz Labrado, J., Díaz-Delgado, R., Gutiérrez, E., Palacín, C., Rivera, J., & Ramón, J. R. (2009). Chronic fatigue syndrome: Aetiology, diagnosis and treatment. *BMC Psychiatry, 9* (Suppl 1)*,* S1. https://doi.org/10.1186/1471-244X-9-S1-S1

Azevedo, A. (2020). A new theoretical framework for therapeutic landscapes: Coastal (blue), forest (green), spiritual "power spots" (gold) and wilderness (dark/white). *Journal of Spatial and Organisational Dynamics*, *VIII(1)*, 29–51. https://doaj.org/article/b1cdc2bf94bd4d43a34636be4f4a6778

Banham, R. (2020). Emotion, vulnerability, ontology: Oerationalising 'ontological security' for qualitative environmental sociology. *Environmental Sociology*, *6*(2), 132–142. https://doi.org/10.1080/23251042.2020.1717098

Bateman, L., Bested, A. C., Bonilla, H. F., Chheda, B. V., Chu, L., Curtin, J. M., Dempsey, T. T., Dimmock, M. E., Dowell, T. G., Felsenstein, D., Kaufman, D. L., Klimas, N. G., Komaroff, A. L., Lapp, C. W., Levine, S. M., Montoya, J. G., Natelson, B. H., Peterson, D. L., Podell, R. N., … Yellman, B. P. (2021). Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials of diagnosis and management. *Mayo Clinic Proceedings, 96*(11), 2861–2878. https://doi.org/10.1016/j.mayocp.2021.07.004

Baxter, H., Speight, N., & Weir, W. (2021). Life-threatening malnutrition in very severe ME/CFS. *Healthcare, 9*(4), 459. https://doi.org/10.3390/healthcare9040459

Bell, S. L., Foley, R., Houghton, F., Maddrell, A., & Williams, A. M. (2018). From therapeutic landscapes to healthy spaces, places and practices: A scoping review. *Social Science & Medicine, 196*, 123–130. https://doi.org/10.1016/j.socscimed.2017.11.035

Bien, T. (2006). *Mindful therapy: A guide for therapists and helping professionals*. Wisdom Publications.

Boulazreg, S., & Rokach, A. (2020). The lonely, isolating, and alienating implications of myalgic encephalomyelitis/chronic fatigue syndrome. *Healthcare, 8*(4), 413. https://doi.org/10.3390/healthcare8040413

Braun, V., & Clarke, V. (2024). Reporting guidelines for qualitative research: a values-based approach. *Qualitative Research in Psychology*, 1–40. https://doi.org/10.1080/14780887.2024.2382244

Bridgman, R. (1999). The street gives and the street takes: Designing housing for the chronically homeless. In Williams, A. (Ed.), *Therapeutic landscapes: The dynamic between place and wellness* (pp. 153–169). University Press of America.

Brinkmann, S. (2017). *Philosophies of qualitative research*. Oxford University Press.

Briones-Vozmediano, E., Öhman, A., Goicolea, I., & Vives-Cases, C. (2017). “The complaining women”: Health professionals’ perceptions on patients with fibromyalgia in Spain. *Disability and Rehabilitation*, *40*(14), 1679–1685. https://doi.org/10.1080/09638288.2017.1306759

Brown, C., & Johnson, A. (2021). *Where will we live in the future? Tā tātou kainga e noho ana ki hea ā te wā heke mai: Research into the unmet housing needs of people with disabilities, their family and whānau*. https://disabilityconnect.org.nz/wp-content/uploads/where-will-we-live-in-the-future.pdf

Brown, N. (2018). Exploring the lived experience of fibromyalgia using creative data collection methods. *Cogent Social Sciences, 4*(1), 1447759. https://doi.org/10.1080/23311886.2018.1447759

Brown, N. (2022). “It is …, it stands for …, it shows …”: Arts-based representations in data generation and analysis. In Hinsliff-Smith, K., McGarry, J., & Ali, P. (Eds.), *Arts based health care research: A multidisciplinary perspective.* (pp. 15–29). Springer. https://doi.org/10.1007/978-3-030-94423-0_2

Burani, K., & Nelson, B. D. (2020). Gender differences in anxiety: The mediating role of sensitivity to unpredictable threat. *International Journal of Psychophysiology, 153*, 127–134. https://doi.org/10.1016/j.ijpsycho.2020.05.001

Cairns, R., & Hotopf, M. (2005). A systematic review describing the prognosis of chronic fatigue syndrome. Occupational Medicine, 55(1), 20–31. https://doi.org/10.1093/occmed/kqi013

Cambridge Dictionary. (n.d.a). Healing. In *Cambridge English Dictionary*. Retrieved December 12, 2024, from https://dictionary.cambridge.org/dictionary/english/healing

Cambridge Dictionary. (n.d.b). Therapeutic. In *Cambridge English Dictionary*. Retrieved December 12, 2024, from https://dictionary.cambridge.org/dictionary/english/therapeutic

Came, H., Baker, M., & McCreanor, T. (2021). Addressing structural racism through constitutional transformation and decolonization: Insights for the New Zealand health sector. *Journal of Bioethical Inquiry, 18*(1), 59–70. DOI: 10.1007/s11673-020-10077-w

Caspari, S., Eriksson, K., & Nåden, D. (2011). The importance of aesthetic surroundings: A study interviewing experts within different aesthetic fields. *Scandinavian Journal of Caring Sciences, 25(1)*, 134–142. https://doi.org/10.1111/j.1471-6712.2010.00803.x

Chu, L., Valencia, I. J., Garvert, D. W., & Montoya, J. G. (2019). Onset patterns and course of myalgic encephalomyelitis/chronic fatigue syndrome. *Frontiers in Pediatrics, 7*, 12. https://doi.org/10.3389/fped.2019.00012

Clague-Baker, N., Dickinson, K., Bull, M., Leslie, K., & Hilliard, N. (2024). An international survey of experiences and attitudes towards pacing using a heart rate monitor for people with ME / CFS. *Physiotherapy, 123*, e223–e224. https://doi.org/10.1016/j.physio.2024.04.280

Clayton, E. W. (2015). Beyond myalgic encephalomyelitis/chronic fatigue syndrome: An IOM report on redefining an illness. *JAMA, 313*(11), 1101–1102. https://doi.org/10.1001/jama.2015.1346

Collins, D., & Kearns, R. (2007). Ambiguous landscapes: Sun, risk and recreation on New Zealand beaches. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 15–33). Routledge.

Collins, Peter. (2007). The construction of place as aesthetic-therapeutic. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 349 – 366). Routledge.

Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, & Institute of Medicine. (2015). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. National Academies Press (US).

Complex Chronic Illness Support. (2023a). *ME/CFS & long COVID support in New Zealand*. Ministry of Health. https://tatou.health.govt.nz/the-future-of-the-health-system/me-cfs-long-covid-support-in-new-zealand

Complex Chronic Illness Support. (2023b). *Press release: World ME day 2023.* CCI Support. https://ccisupport.org.nz/media/press-release-world-me-day-2023/

Conradson, D. (2005). Landscape, care and the relational self: Therapeutic encounters in rural England. *Health & Place, 11(4)*, 337–348. https://doi.org/10.1016/j.healthplace.2005.02.004

Conradson, D. (2007). Experiential economy of stillness: Places of retreat in contemporary Britain. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 33–48). Routledge.

Conroy, K., Bhatia, S., Islam, M., & Jason, L. A. (2021). Homebound versus bedridden status among those with myalgic encephalomyelitis/chronic fatigue syndrome. *Healthcare, 9(*2), 106. https://doi.org/10.3390/healthcare9020106

Cortes Rivera, M., Mastronardi, C., Silva-Aldana, C. T., Arcos-Burgos, M., & Lidbury, B. A. (2019). Myalgic encephalomyelitis/chronic fatigue syndrome: A comprehensive review. *Diagnostics*, *9*(3), 91. https://doi.org/10.3390/diagnostics9030091

Corbin, J. M., & Strauss, A. L. (1988). *Unending work and care: Managing chronic illness at home*. Jossey-Bass Publishers.

Cox, D. L., & Findley, L. J. (2000). Severe and very severe patients with chronic fatigue syndrome. *Journal of chronic fatigue syndrome, 7*(3), 33–47. https://doi.org/10.1300/j092v07n03_04

Crawford, R. (2006). Health as a meaningful social practice. *Health, 10(4),* 401–420. https://doi.org/10.1177/1363459306067310

Culver, A. (2022). *Information regarding myalgic encephalomyelitis/chronic fatigue syndrome.* https://www.health.govt.nz/information-releases/information-regarding-myalgic-encephalomyelitischronic-fatigue-syndrome

Curtis, S., Gesler, W., Fabian, K., Francis, S., & Priebe, S. (2007). Therapeutic landscapes in hospital design: A qualitative assessment by staff and service users of the design of a new mental health inpatient unit. *Environment and Planning C: Government and Policy, 25(4),* 591-610. https://doi.org/10.1068/c1312r

Daly, A. (2016). *Merleau-Ponty and the ethics of intersubjectivity*. Palgrave Macmillan UK. https://link.springer.com/book/10.1057/978-1-137-52744-8

Darwin Holmes, A. G. (2020). Researcher positionality - A consideration of its influence and place in qualitative research - A new researcher guide. *Shanlax International Journal of Education, 8*(4), 1-10. https://doi.org/10.34293/education.v8i4.3232

Delaney, M. E. (2020). *Nature is nurture: Counseling and the natural world*. Oxford University Press. https://ebookcentral.proquest.com/lib/massey/reader.action?docID=6185238

Despres, C. (1991). The meaning of home: A literature review and directions for future research and theoretical development. *Journal of Architectural and Planning Researcher, 8(2)*, 96–115. http://www.jstor.org/stable/43029026

Devendorf, A. R., Jackson, C. T., Sunnquist, M., & A Jason, L. (2019). Defining and measuring recovery from myalgic encephalomyelitis and chronic fatigue syndrome: The physician perspective. *Disability and Rehabilitation, 41*(2), 158–165. https://doi.org/10.1080/09638288.2017.1383518

DeVerteuil, G., & Andrews G. J. (2007). Surviving profoundly unhealthy places: The ambivalent, fragile and absent therapeutic landscapes of the Soviet Gulag. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 273–287). Routledge.

Dibley, L., Dickerson, S., Duffy, M., & Vandermause, R. (2020). *Doing hermeneutic phenomenological research: A practical guide*. SAGE Publications. https://doi.org/10.4135/9781529799583

Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health, 22*(7), 851–867. https://doi.org/10.1080/14768320600976224

Dickson, A., Knussen, C., & Flowers, P. (2008). ‘That was my old life; it’s almost like a past-life now’: Identity crisis, loss and adjustment amongst people living with chronic fatigue syndrome. *Psychology & Health, 23*(4), 459–476. https://doi.org/10.1080/08870440701757393

Dinu Roman Szabo, M., Dumitras, A., Mircea, D., Doroftei, D., Sestras, P., Boscaiu, M., Brzuszek, R. F., & Sestras, A. F. (2023). Touch, feel, heal. The use of hospital green spaces and landscape as sensory-therapeutic gardens: A case study in a university clinic. *Frontiers in Psychology, 14*. https://doi.org/10.3389/fpsyg.2023.1201030

Donovan, R., & Williams, A. (2007). Home as therapeutic landscape: Family caregivers providing palliative care at home. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 199–218). Routledge.

Doughty, K., Hu, H., & Smit, J. (2023). Therapeutic landscapes during the COVID-19 pandemic: Increased and intensified interactions with nature. *Social and Cultural Geography, 24*(3–4), 661-679–679. https://doi.org/10.1080/14649365.2022.2052168

Doyle, D., Jeffrey, D., & Doyle, D. (2000). *Palliative care in the home* (2nd ed.). Oxford University Press. https://academic.oup.com/book/10683

Durie, M. (1998). *Whaiora. Māori health development* (2nd ed.). Oxford University Press.

Dutton, M. A., Dahlgren, S., Martinez, M., & Mete, M. (2023). The holistic healing arts retreat: An intensive, experiential intervention for survivors of interpersonal trauma. *Psychological Trauma: Theory, Research, Practice, and Policy*, *15*(5), 727–737. https://doi.org/10.1037/tra0001178

Dyck, I., Kontos, P., Angus, J., & McKeever, P. (2005). The home as a site for long-term care: Meanings and management of bodies and spaces. *Health & Place, 11(2)*, 173–185. https://doi.org/10.1016/j.healthplace.2004.06.001

Eaton-Fitch, N., Johnston, S. C., Zalewski, P., Staines, D., & Marshall-Gradisnik, S. (2020). Health-related quality of life in patients with myalgic encephalomyelitis/chronic fatigue syndrome: An Australian cross-sectional study. *Quality of Life Research, 29*(6), 1521–1531. https://doi.org/10.1007/s11136-019-02411-6

Eatough, V., & Smith, J. (2017). Interpretative phenomenological analysis. In C. Willig & W. Stainton Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 193-211). Sage.

Espeso, C. S. (2022). From safe places to therapeutic landscapes: The role of the home in panic disorder recovery. *Well-being, Space and Society*, *3,* 100108. https://doi.org/10.1016/j.wss.2022.100108

Falk Hvidberg, M., Brinth, L. S., Olesen, A. V., Petersen, K. D., & Ehlers, L. (2015). The health-related quality of life for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *PloS One, 10*(7), e0132421. https://doi.org/10.1371/journal.pone.0132421

Fall, E. A., Chen, Y., Lin, J. S., Issa, A., Brimmer, D. J., Bateman, L., Lapp, C. W., Podell, R. N., Natelson, B. H., Kogelnik, A. M., Klimas, N. G., Peterson, D. L., Unger, E. R., & MCAM Study Group (2024). Chronic overlapping pain conditions in people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): A sample from the multi-site Clinical assessment of ME/CFS (MCAM) study. *BMC Neurology, 24*(1), 399. https://doi.org/10.1186/s12883-024-03872-0

Fish, B. (2023). Response art: A resource for practice and supervision, in person and online. *Journal of Applied Arts & Health, 14*(1), 73–84. https://doi.org/10.1386/jaah_00128_1

Foley, R., & Kistemann, T., (2015). Blue space geographies: enabling health in place. *Health & Place, 35*, 157–165. https://doi.org/10.1016/j.healthplace.2015.07.003

Frisone, C. (2024). *The therapeutic power of the Maggie's Centre: Experience, design and well-being, where architecture meets neuroscience.* Routledge. https://www.taylorfrancis.com/books/mono/10.4324/9781003244516/therapeutic-power-maggie-centre-caterina-frisone

Frost, N., & Bailey-Rodrigues, D. (2019). Quality in qualitative research. In C. Sullivan & M. A. Forrester (Eds.), *Doing qualitative research in psychology: A practical guide* (2nd ed., pp. 60–77). Sage.

Fuchs, T. (2024). The not-yet-conscious: Protentional consciousness and the emergence of the new. *Phenomenology & the Cognitive Sciences, 23*(4), 717–742. https://doi.org/10.1007/s11097-022-09869-9

Garg, A., & Dewan, A. (2022). *Manual of hospital planning and designing: For medical administrators, architects and planners*. Springer. https://doi.org/10.1007/978-981-16-8456-2

Geores, M., & Gesler, W. (1999). Compromised Space: Contests over the provision of a therapeutic environment for people with mental illness. In Williams, A. (Ed.). *Therapeutic landscapes: The dynamic between place and wellness* (pp. 99–121). University Press of America.

Geraghty, K. J., & Blease, C. (2016). Cognitive behavioural therapy in the treatment of chronic fatigue syndrome: A narrative review on efficacy and informed consent. *Journal of Health Psychology, 23*(1), 127-138. https://doi.org/10.1177/1359105316667798

Gesler, W. (1992). Therapeutic landscapes: Medical issues in light of the new cultural geography. *Social Science & Medicine, 34(7)*, 735–746. https://doi.org/10.1016/0277-9536(92)90360-3

Gesler, W. (2003) *Healing Places*. Rowman & Littlefield.

Gesler, W. (2018). Therapeutic landscapes. *The International Encyclopedia of Anthropology*, 1–9. https://doi.org/10.1002/9781118924396.wbiea1422

Gesler, W. M. (1993). Therapeutic landscapes: Theory and a case study of Epidauros, Greece. *Environment and Planning D, 11*(2), 171–89. https://doi.org/10.1068/d110171

Gesler, W. M. (1996). Lourdes: Healing in a place of pilgrimage. *Health and Place, 2*(2), 95–105. https://doi.org/10.1016/1353-8292(96)00004-4

Gesler, W., & Kearns, R. (2005). *Culture/Place/Health*. Routledge. https://doi.org/10.4324/9780203996317

Gesler, W., Bell, M., Curtis, S., Hubbard, P., & Francis, S. (2004). Therapy by design: Evaluating the UK hospital building program. *Health & Place*, *10*(2), 117–128. https://doi.org/10.1016/s1353-8292(03)00052-2

Giesbrecht, M., Crooks, V., & Morgan, J., (2016). Place, health, and diversity in Canada. In Giesbrecht, M.D., & Crooks, V.A. (Eds.). *Place, Health, and Diversity: Learning from the Canadian Experience* (pp. 1–13). Routledge. https://doi.org/10.4324/9781315600598

Giles-Vernick, T., Bainilago, L., Fofana, M., Bata, P., & Vray, M. (2016). Home care of children with diarrhea in Bangui's therapeutic landscape (Central African Republic). *Qualitative Health Research*, *26*(2), 164–175. https://doi.org/10.1177/1049732315570117

Glover, T., & Parry, D. (2009). A third place in the everyday lives of people living with cancer: Functions of Gilda's club of greater Toronto. *Health & Place, 15(1)*, 97–106. https://doi.org/10.1016/j.healthplace.2008.02.007

Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023). Diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome. *Mayo Clinic Proceedings, 98*(10), 1544–1551. https://doi.org/10.1016/j.mayocp.2023.07.032

Guzmán, V., Bustamante, G., Kobayashi, L., & Finlay, J. (2022). 'Going outside for fresh air, sunshine and walking': A qualitative analysis of US older adults' therapeutic landscapes during the COVID-19 pandemic. *Medical Sciences Forum, 4*(1), 34. https://doi.org/10.3390/ecerph-3-09088

Hadjiyanni, T. (2019). *The right to home: Exploring how space, culture, and identity intersect with disparities*. Springer Nature. https://link.springer.com/book/10.1057/978-1-137-59957-5

Haggard, L., & Hosking, S. (2003). *Healing the hospital environment: Design, management and maintenance of healthcare premises.* Taylor & Francis. https://doi.org/10.4324/9780203015780

Haney, E., Smith, M. E., McDonagh, M., Pappas, M., Daeges, M., Wasson, N., & Nelson, H. D., (2015). Diagnostic methods for myalgic encephalomyelitis/chronic fatigue syndrome: A systematic review for a national institutes of health pathways to prevention workshop. *Annals of Internal Medicine, 162*(12), 834-840.

Hannah, M. (2022). *Ministry will not reclassify chronic fatigue as disability*. Manawatu Standard, 4. https://research.ebsco.com/c/4egzpd/viewer/html/cuqq7ojmpr

Hanson, M. R. (2023). The viral origin of myalgic encephalomyelitis/chronic fatigue syndrome. *PLoS Pathogens, 19*(8), e1011523. https://doi.org/10.1371/journal.ppat.1011523

Hawkins, R. D., Hawkins, E. L., & Tip, L. (2021). "I can't give up when I have them to care for": People's experiences of pets and their mental health. *Anthrozoös*, *34*(4), 543–562. https://doi.org/10.1080/08927936.2021.1914434

Hermanowicz, J. C. (2002). The great interview: 25 strategies for studying people in bed. *Qualitative Sociology, 25*(4), 479–499. https://doi.org/10.1023/A:1021062932081

Hiscock, R., Kearns, A., MacIntyre, S., & Ellaway, A. (2001). Ontological security and psycho-social benefits from the home: Qualitative evidence on issues of tenure. *Housing, Theory and Society, 18*(1), 50–66. https://doi.org/10.1080/140360901750424761

Hopner, V., & Liu, J. H. (2021). Relational ethics and epistemology: The case for complementary first principles in psychology. *Theory & Psychology, 31*(2), 179–198. https://doi.org/10.1177/0959354320974103

Howden-Chapman, P. (2015). *Home truths: Confronting New Zealand's housing crisis*. Bridget Williams Books.

Hsu, V. J. (2024). The imperative of lived experience for ME/CFS and long COVID research: What to make of patient stories. *SSM Mental Health, 5*. https://doi.org/10.1016/j.ssmmh.2023.100291

Hudson, M., Milne, M., Reynolds, P., Russell, K., Smith, B., Pūtaiora Writing Group, & Health Research Council of New Zealand. (2010). *Te ara tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members.* Health Research Council of New Zealand on behalf of the Pūtaiora Writing Group. https://www.hrc.govt.nz/sites/default/files/2019-

06/Resource%20Library%20PDF%20-%20Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics_0.pdf

Hunt, J., Blease, C., & Geraghty, K. J. (2022). Long Covid at the crossroads: Comparisons and lessons from the treatment of patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Journal of Health Psychology, 27*(14), 3106–3120. https://doi.org/10.1177/13591053221084494

Institute of Medicine [IOM]. (2015). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. The National Academies Press. https://doi.org/10.17226/19012

Jacob, S.A. & Furgerson, S.P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report*, *17*(42). https://nsuworks.nova.edu/tqr/vol17/iss42/3/

James, B. (2019). *Home, space and place: A review of Māori and Indigenous literature contributing to dementia-friendly housing design.* Building Better Homes, Towns, and Cities Ko Ngā Wā Kainga Hei Whakamāhorahora. https://www.buildingbetter.nz/case-study/home-space-and-place-a-review-of-maori-and-Indigenous-literature-contributing-to-dementia-friendly-housing-design/index.html

Janicki, S. (2018). *[Dis]placed by illness: Lyme disease as a case for re-imagining everyday places to recognize invisible chronic illnesses* [Masters thesis]. University of Washington. https://digital.lib.washington.edu/researchworks/items/eeea31f4-8ffb-4084-937d-2edb6096c1b3

Jason, L. A., Brown, M., Brown, A., Evans, M., Flores, S., Grant-Holler, E., & Sunnquist, M. (2013). Energy conservation/envelope theory interventions to help patients with myalgic encephalomyelitis/chronic fatigue syndrome. *Fatigue: Biomedicine, Health & Behavior, 1*(1-2), 27–42. https://doi.org/10.1080/21641846.2012.733602

Johnson, M. L., Cotler, J., Terman, J. M., & Jason, L. A. (2022). Risk factors for suicide in chronic fatigue syndrome. *Death Studies, 46*(3), 738–744. https://doi.org/10.1080/07481187.2020.1776789

Karasaki, M., Warren, N., & Manderson, L. (2017). Orchestrating home. *Medicine Anthropology Theory, 4(1)*. https://doi.org/10.17157/mat.4.1.366

Khaleghimoghaddam, N. (2023). Understanding the interplay of light, color, and interior design in healthcare spaces. *Journal of Design for Resilience in Architecture and Planning*, *4*(2), 219–231. https://doi.org/10.47818/DRArch.2023.v4i2094

King, N. (2019). Research ethics in qualitative research. In Sullivan, C & Forrester, M. (Eds.). *Doing qualitative research in psychology: A practical guide* (pp. 35–60). Sage.

King, N. & Hugh-Jones, S. (2019). The interview in qualitative research. In Sullivan, C & Forrester, M. (Eds.). *Doing qualitative research in psychology: A practical guide* (pp. 121–145). Sage.

Kingdon, C., Lowe, A., Shepherd, C., & Nacul, L. (2022). What primary care practitioners need to know about the new NICE Guideline for myalgic encephalomyelitis/chronic fatigue syndrome in adults. *Healthcare, 10*(12), (2227-9032). https://doi.org/10.3390/healthcare10122438

Knapp, A. (2020). *Client perceptions of the therapy room*: *Effects of homely therapeutic landscapes* [Doctoral dissertation, Antioch University]. OhioLink. http://rave.ohiolink.edu/etdc/view?acc_num=antioch1597606861565978

Knight, C. (2020). *Nature and well-being in Aotearoa New Zealand: Exploring the connection*. Totara Press.

Komaroff, A. L., & Lipkin, W. I. (2023). ME/CFS and long COVID share similar symptoms and biological abnormalities: Road map to the literature. *Frontiers in Medicine*, *10*. https://doi.org/10.3389/fmed.2023.1187163

Krabbe, S. H., Bjorbækmo, W. S., Mengshoel, A. M., Sveen, U., & Groven, K. S. (2024). A suffering body, hidden away from others: The experience of being long-term bedridden with severe myalgic encephalomyelitis/chronic fatigue syndrome in childhood and adolescence. *Nursing Inquiry, 31*(3), 1–11. https://doi.org/10.1111/nin.12625

Krabbe, S. H., Mengshoel, A. M., Schrøder Bjorbækmo, W., Sveen, U., & Groven, K. S. (2023). Bodies in lockdown: Young women's narratives of falling severely ill with ME/CFS during childhood and adolescence. *Health Care for Women International, 44*(9), 1155–1177. https://doi.org/10.1080/07399332.2022.2043862

Krasner, J. (2010). *Home bodies: Tactile experience in domestic space*. The Ohio State University Press. https://doi.org/10.2307/j.ctv16qk3fb

Lacerda, E. M., Geraghty, K., Kingdon, C. C., Palla, L., & Nacul, L. (2019). A logistic regression analysis of risk factors in ME/CFS pathogenesis. *BMC Neurology, 19*(1). https://doi.org/10.1186/s12883-019-1468-2

Larkin, M., Shaw, R., & Flowers, P. (2018). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology, 16(*2), 182–198. https://doi.org/10.1080/14780887.2018.1540655

Larsen, H. G., & Adu, P. (2021). *The theoretical framework in phenomenological research: development and application*. Routledge. https://doi.org/10.4324/9781003084259

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2*(3), 21–35. https://doi.org/10.1177/160940690300200303

Leaño, C. (2021). How can we turn to the healing power of nature? *Health Progress, 102*(4), 45–49. https://www.chausa.org/publications/health-progress/archive/article/fall-2021/how-can-we-turn-to-the-healing-power-of-nature

Leavy, P. (2020). *Method meets art: Arts-based research practice* (3rd ed.). The Guilford Press. https://ebookcentral.proquest.com/lib/Massey/detail.action?docID=6268652

Lim, E. J., Ahn, Y. C., Jang, E. S., Lee, S. W., Lee, S. H., & Son, C. G. (2020). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *Journal of Translational Medicine, 18*(1), 100. https://doi.org/10.1186/s12967-020-02269-0

Loder, A. (2020). *Small-scale urban greening: Creating places of health, creativity, and ecological sustainability*. Routledge. https://doi.org/10.4324/9781315642857

Lyons, A. C. & Chamberlain, K. (2006). *Health psychology: A critical introduction.* Cambridge University Press. https://ebookcentral.proquest.com/lib/massey/detail.action?docID=254981

Maas genannt Bermpohl, F., Kucharczyk-Bodenburg, A.-C., & Martin, A. (2024). Efficacy and acceptance of cognitive behavioral therapy in adults with chronic fatigue syndrome: meta-analysis. *International Journal of Behavioral Medicine, 31*(6), 895–910. https://doi.org/10.1007/s12529-023-10254-2

Maiocchi, M. M., & Shafieyoun, Z. (2022). *Emotional design and the healthcare environment.* Springer Nature. https://link.springer.com/book/10.1007/978-3-030-99846-2

Mallett, S. (2004). Understanding home: A critical review of the literature. *The Sociological Review, 52(1)*, 62–89. https://doi.org/10.1111/j.1467-954x.2004.00442.x

Marcus, C., & Sachs, N. (2013). *Therapeutic landscapes: An evidence-based approach to designing healing gardens and restorative outdoor spaces.* John Wiley & Sons. https://download.e-bookshelf.de/download/0003/9957/37/L-G-0003995737-0002509446.pdf

Marjon E. A. Wormgoor, & Sanne C. Rodenburg. (2023). Focus on post-exertional malaise when approaching ME/CFS in specialist healthcare improves satisfaction and reduces deterioration. *Frontiers in Neurology, 14*. https://doi.org/10.3389/fneur.2023.1247698

Marks, D. F. (2022). The rise and fall of the psychosomatic approach to medically unexplained symptoms, myalgic encephalomyelitis and chronic fatigue syndrome. Arch. *Epidemiol. Public Health Res, 1*, 97–144. https://doi.org/10.33140/AEPHR.01.02.06

Marsh, P., & Williams, A. (2023). *Cultivated therapeutic landscapes: Gardening for prevention, restoration, and equity*. Taylor & Francis. https://doi.org/10.4324/9781003355731

Martin, J., & Sugarman, J. (2001). Interpreting human kinds. Beginnings of a hermeneutic psychology. *Theory and Psychology, 11*, 193–207. ttps://doi.org/10.1177/0959354301112003

Massey University. (2017). *Code of ethical conduct for research, teaching, and evaluations involving human participants*. https://www.massey.ac.nz/research/ethics/human-ethics/

Matheson, J. L. (2015). The voice transcription technique: Use of voice recognition software to transcribe digital interview data in qualitative research. Qualitative Report, 12(4), 547–560. https://doi.org/10.46743/2160-3715/2007.1611

McLean, C. P., Asnaani, A., Litz, B. T., & Hofmann, S. G. (2011). Gender differences in anxiety disorders: Prevalence, course of illness, comorbidity and burden of illness. *Journal of psychiatric research, 45*(8), 1027–1035. https://doi.org/10.1016/j.jpsychires.2011.03.006

McLean, C.P., & Anderson, E.R. (2009). Brave men and timid women? A review of the gender differences in fear and anxiety. *Clinical Psychology Review, 29*, 496–505. 10.1016/j.cpr.2009.05.003

McQuoid, J. (2017). Finding joy in poor health: The leisure-scapes of chronic illness. *Social Science & Medicine*, *183*, 88–96. https://doi.org/10.1016/j.socscimed.2017.04.044

ME Support. (2023). *What is ME/CFS?* https://www.mesupport.org.nz/about-me-cfs

Melby, L., & Nair, R. das. (2024). “We have no services for you... so you have to make the best out of it”: A qualitative study of myalgic encephalomyelitis/chronic fatigue syndrome patients’ dissatisfaction with healthcare services. *Health Expectations, 27*(1), 1–12. https://doi.org/10.1111/hex.13900

Mirin, A. A., Dimmock, M. E., & Jason, L. A. (2022). Updated ME/CFS prevalence estimates reflecting post-COVID increases and associated economic costs and funding implications. Fatigue: Biomedicine, *Health & Behavior, 10*(2), 83-93. https://doi.org/10.1080/21641846.2022.2062169

Montoya, J., Dowell, T., Mooney, A., Dimmock, M., & Chu, L. (2021). Caring for the patient with severe or very sever myalgic encephalomyelitis/chronic fatigue syndrome. *Healthcare, 9*(10), 1331. https://doi.org/10.3390/healthcare9101331

Moore, A., Carter, B., Hunt, A., & Sheikh, K. (2013). 'I am closer to this place'—Space, place and notions of home in lived experiences of hospice day care. *Health & Place, 19,* 151–158. https://doi.org/10.1016/j.healthplace.2012.11.002

Moss-Morris, R., Deary, V., & Castell, B., (2013). Chronic fatigue syndrome. *Handbook of Clinical Neurology, 110*, 303–314. https://doi.org/10.1016/b978-0-444-52901-5.00025-3

Nagib, W., & Williams, A. (2018). Creating "therapeutic landscapes" at home: The experiences of families of children with autism. *Health & Place, 52*, 46–54. https://doi.org/10.1016/j.healthplace.2018.05.001

NICE. (2021, October 29). *Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: Diagnosis and Management*. www.nice.org.uk/guidance/ng206

Noor, N., Urits, I., Degueure, A., Rando, L., Kata, V., Cornett, E. M., Kaye, A. D., Imani, F., Narimani-Zamanabadi, M., Varrassi, G., & Viswanath, O. (2021). A comprehensive update of the current understanding of chronic fatigue syndrome. *Anesthesiology and Pain Medicine, 11*(3), 1–10. https://doi.org/10.5812/aapm.113629

O'connor, K., Sunnquist, M., Nicholson, L., Jason, L. A., Newton, J. L., & Strand, E. B. (2019). Energy envelope maintenance among patients with myalgic encephalomyelitis and chronic fatigue syndrome: Implications of limited energy reserves. *Chronic illness, 15*(1), 51–60. https://doi.org/10.1177/1742395317746470

Oliver, D. G., Serovich, J. M., & Mason, T. L. (2005). Constraints and opportunities with interview transcription: Towards reflection in qualitative research. *Social Forces, 84*(2), 1273–1289. https://doi.org/10.1353/sof.2006.0023

Olson, K., Zimka, O., & Stein, E. (2015). The nature of fatigue in chronic fatigue syndrome. *Qualitative Health Research, 25*(10) 1410–1422. https://doi.org/10.1177/1049732315573954

Orji, N., Campbell, J. A., Wills, K., Hensher, M., Palmer, A. J., Rogerson, M., Kelly, R., & De Graaff, B. (2022). Prevalence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in Australian primary care patients: Only part of the story? *BMC Public Health, 22*(1). https://doi.org/10.1186/s12889-022-13929-9

Orr, N., Abbott, R., Bethel, A., Paviour, S., Whear, R., Garside, R., & Coon, J. T. (2023). What are the effects of animals on the health and wellbeing of residents in care homes? A systematic review of the qualitative and quantitative evidence. *BMC Geriatrics, 23*(1). https://doi.org/10.1186/s12877-023-03834-0

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report, 13*(4), 695–705. https://doi.org/10.46743/2160-3715/2008.1579

Packer, J. (1985) Hermeneutic inquiry in the study of human conduct. *American Psychologist, 40*(10), 1081–1093. https://doi.org/10.1037/0003-066x.40.10.1081

Palacios, N., Molsberry, S., Fitzgerald, K. C., & Komaroff, A. L. (2023). Different risk factors distinguish myalgic encephalomyelitis/chronic fatigue syndrome from severe fatigue. *Scientific Reports, 13*(1), 2469. https://doi.org/10.1038/s41598-023-29329-x

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health, 42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology, 7*(2), 99–121. https://doi.org/10.1080/14780880802513194

Patel, M., Lewando Hundt, G., & Slowther, A. (2023). End-of-life care at home as a therapeutic landscape within a compassionate communities approach. *Progress in Palliative Care, 31(6)*, 366–371. https://doi.org/10.1080/09699260.2023.2256176

Payne, S. R., Mackrill, J., Cain, R., Strelitz, J., & Gate, L. (2015). Developing interior design briefs for health-care and well-being centres through public participation. *Architectural*

Engineering and Design Management, *11*(4), 264–279. https://doi.org/10.1080/17452007.2014.923288

Pendergrast, T., Brown, A., Sunnquist, M., Jantke, R., Newton, J. L., Strand, E. B., & Jason, L. A. (2016). homebound versus non-homebound patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Chronic Illness, 12*(4), 292–307. https://doi.org/10.1177/1742395316644770

Pereira, A. T., Cabaços, C., Araújo, A., Amaral, A. P., Carvalho, F., & Macedo, A. (2022). COVID-19 psychological impact: The role of perfectionism. *Personality & Individual Differences,* 184, 111160. https://doi.org/10.1016/j.paid.2021.111160

Pitt, H. (2014). Therapeutic experiences of community gardens: Putting flow in its place. *Health & Place*, *27*, 84-91. https://doi.org/10.1016/j.healthplace.2014.02.006

Rathmann, J. (2021) *Therapeutic landscapes: An interdisciplinary perspective on landscape and health*. Springer Nature. https://link.springer.com/book/10.1007/978-3-658-33848-0

Relph, E. (1976). *Place and Placelessness*. Pion.

Reyes, A. T., Serafica, R., Kawi, J., Fudolig, M., Sy, F., Leyva, E. W. A., & Evangelista, L. S. (2023). Using the socioecological model to explore barriers to health care provision in underserved communities in the Philippines: Qualitative Study. *Asian Pacific Island Nursing Journal*, *7*(1), 1–10. https://doi.org/10.2196/45669

Sanal-Hayes, N. E. M., Mclaughlin, M., Hayes, L. D., Mair, J. L., Ormerod, J., Carless, D., Hilliard, N., Meach, R., Ingram, J., & Sculthorpe, N. F. (2023). A scoping review of 'Pacing' for management of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): Lessons learned for the long COVID pandemic. *Journal of Translational Medicine, 21*(720), 1–22. https://doi.org/10.1186/s12967-023-04587-5

Schuh, A., & Immich, G. (Eds.) (2022). *Forest therapy: The potential of the forest for your health.* Springer. https://doi.org/10.1007/978-3-662-64280-1

Sehmbi, T., Wearden, A., Peters, S., & Dienes, K. (2024). 'The world was going through what we go through everyday': The experiences of women with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) living with their partners during the COVID-19 lockdown in the United Kingdom. *British Journal of Health Psychology, 29*(3), 629-643. https://doi.org/10.1111/bjhp.12717

Shostak, S. (2017). *Food systems and health*. Emerald Group Publishing. https://bookstore.emerald.com/food-systems-and-health-hb-9781786350923.html

Singh, A. P. (2006). *Compendia of the world's medicinal flora*. CRC Press. https://doi.org/10.1201/b11006

Sirotiak, Z. (2023). My experience with ME/CFS and implications: A personal narrative. *Work, 74(*4), 1253–1259. https://doi.org/10.3233/WOR-220487

Smith, J. A. (2019). Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis. *Qualitative Research in Psychology, 16*(2), 166–181. https:doi.org/10.1080/14780887.2018.1540648.

Smith, J., & Eatough, V. (2012). Interpretative phenomenological analysis. In G. Breakwell, J Smith & D. Wright (Eds.), *Research methods in psychology* (4th ed., pp. 439–459). Sage.

Smith, N., Georgiou, M., Chastin, S., Foley, R., & Tieges, Z. (2022). Urban blue spaces as therapeutic landscapes: "A slice of nature in the city." *International Journal of Environmental Research and Public Health*, *19*(22), 15018. https://doi.org/10.3390/ijerph192215018

Søvde, B. E., Sandvoll, A. M., Natvik, E., & Drageset, J. (2021). In the borderland of the body: How home-dwelling older people experience frailty. *Scandinavian Journal of Caring Sciences, 36(1)*, 255-264. https://doi.org/10.1111/scs.12984

Spandler, H., & Allen, M. (2018). Contesting the psychiatric framing of ME/CFS. *Social Theory & Health, 16*(2), 127–141. https://doi.org/10.1057/s41285-017-0047-0

Sperling, J., & Decker, J. (2007). The therapeutic landscapes of the Kaqchikel of San Lucas Tolimán, Guatemala. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 233–254). Routledge.

Springer-Sullivan, C. (2005). The resurrection of "female hysteria" in present-day ERISA disability law. *Journal of Gender, Law & Justice*, *20*(1), 67–74. https://doi.org/10.15779/Z387659F03

Staats, K., Grov, E. K., Husebø, B. S., & Tranvåg, O. (2020). Dignity and loss of dignity: Experiences of older women living with incurable cancer at home. *Health Care for Women International*, *41*(9), 1036–1058. https://doi.org/10.1080/07399332.2020.1797035

Sternberg, E. (2009) *Healing spaces: The science of place and well-being*. Belknap Press.

Strassheim, V., Newton, J. L., & Collins, T. (2021). Experiences of living with severe chronic fatigue syndrome/myalgic encephalomyelitis. *Healthcare, 9*(2). https://doi.org/10.3390/healthcare9020168

Suddick, K. M., Cross, V., Vuoskoski, P., Galvin, K. T., & Stew, G. (2020). The work of hermeneutic phenomenology. *International Journal of Qualitative Methods, 19*, 1–14. https://doi.org/10.1177/1609406920947600

Sweetman, E., Kleffmann, T., Edgar, C., de Lange, M., Vallings, R., & Tate, W. (2020). A SWATH-MS analysis of myalgic encephalomyelitis/chronic fatigue syndrome peripheral blood mononuclear cell proteomes reveals mitochondrial dysfunction. *Journal of Translational Medicine, 18*(1), 365. https://doi.org/10.1186/s12967-020-02533-3

Taheri, S., Ghasemi Sichani, M., & Shabani, A. (2021). Evaluating the literature of therapeutic landscapes with an emphasis on the search for the dimensions of health: A systematic review. *Social Science & Medicine*, *275*, 113820. https://doi.org/10.1016/j.socscimed.2021.113820

Tate, W. P. (2023). *ME and Long Covid's 'missing thousands' still await support.* Otago Daily Times. https://natlib.govt.nz/records/52521724?search%5Bpath%5D=items&search%5Btext%5D=%22ME+and+Long+Covid%E2%80%99s+%E2%80%98missing+thousands%E2%80%99+still+await+support%22

Tate, W. P., Walker, M. O. M., Peppercorn, K., Blair, A. L. H., & Edgar, C. D. (2023). Towards a better understanding of the complexities of myalgic encephalomyelitis/chronic fatigue syndrome and Long COVID. *International Journal of Molecular Sciences, 24(*6), Article 6. https://doi.org/10.3390/ijms24065124

Telfar-Barnard, L., Bennett, J., Robinson, A., Hailes, A., Ombler, J., & Howden-Chapman, P. (2019). Evidence base for a housing warrant of fitness. *SAGE Open Medicine, 7*. https://doi.org/10.1177/2050312119843028

Torkelson, C., & Marienau, C. (2022). *Beyond Menopause: New Pathways to Holistic Health*. CRC Press. https://doi.org/10.1201/9781003250968

Tuller, D., & Vink, M. (2023). Graded exercise therapy and cognitive behavior therapy do not improve employment outcomes in ME/CFS. *Work, 74*(4), 1235–1239. https://doi.org/10.3233/WOR-220569

Twisk, F. N. M., & Arnoldus, R. J. W. (2012). Graded exercise therapy (GET)/cognitive behavioural therapy (CBT) is often counterproductive in myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). *European Journal of Clinical Investigation, 42*(11), 1255–1256. https://doi.org/10.1111/j.1365-2362.2012.02718.x

Underhill, R., & Baillod, R. (2020). Myalgic encephalomyelitis/chronic fatigue syndrome: Organic disease or psychosomatic illness? A re-examination of the royal free epidemic of 1955. *Medicina, 57*(1), 12. https://doi.org/10.3390/medicina57010012

Valdez, A. R., Hancock, E. E., Adebayo, S., Kiernicki, D. J., Proskauer, D., Attewell, J. R., Bateman, L., DeMaria, A., Lapp, C. W., Rowe, P. C., & Proskauer, C. (2019). Estimating prevalence, demographics, and costs of ME/CFS using large scale medical claims data and machine learning. *Frontiers in Pediatrics, 6*, 412. https://doi.org/10.3389/fped.2018.00412

Valero, S., Sáez-Francàs, N., Calvo, N., Alegre, J., & Casas, M. (2013). The role of neuroticism, perfectionism and depression in chronic fatigue syndrome A structural equation modeling approach. *Comprehensive Psychiatry, 54*(7), 1061–1067. https://doi.org/10.1016/j.comppsych.2013.04.015

Vallings, R. (2022). 'The lightning process' and chronic fatigue syndrome/myalgic encephalomyelitis. *Journal of Primary Health Care, 14*(3), 283–284. https://doi.org/10.1071/hc22078

Vernon, S. D., Hartle, M., Sullivan, K., Bell, J., Abbaszadeh, S., Unutmaz, D., & Bateman, L. (2023). Post-exertional malaise among people with long COVID compared to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Work, 74*(4), 1179–1186. https://doi.org/10.3233/WOR-220581

Vesely-Flad, R. (2022). *Black Buddhists and the Black radical tradition: The practice of stillness in the movement for liberation*. New York University Press. https://doi.org/10.18574/nyu/9781479810482.001.0001

Vink, M., & Vink-Niese, A. (2022). The updated NICE guidance exposed the serious flaws in CBT and Graded Exercise Therapy trials for ME/CFS. *Healthcare*, *10*(5), 898. https://doi.org/10.3390/healthcare10050898

Vyas, J., Muirhead, N., Singh, R., Ephgrave, R., & Finlay, A. Y. (2022). Impact of myalgia encephalomyelitis/chronic fatigue syndrome (ME/CFS) on the quality of life of people with ME/CFS and their partners and family members: An online cross-sectional survey. *BMJ Open, 12(*5), e058128. https://doi.org/10.1136/bmjopen-2021-058128

Wang, Q., Coemans, S., Siegesmund, R., & Hannes, K. (2017). Arts-based methods in socially engaged research practice: A classification framework. *Art/Research International: A Transdisciplinary Journal, 2*(2), 5. https://doi.org/10.18432/r26g8p

White, P. D., Goldsmith, K., Johnson, A. L., Chalder, T., & Sharpe, M. (2013). Recovery from chronic fatigue syndrome after treatments given in the PACE trial. *Psychological Medicine, 43*(10), 2227–2235. doi:10.1017/S0033291713000020

Wiborg, J. F., van der Werf, S., Prins, J. B., & Bleijenberg, G. (2010). Being homebound with chronic fatigue syndrome: A multidimensional comparison with outpatients. *Psychiatry Research, 177*(1/2), 246–249. https://doi.org/10.1016/j.psychres.2010.02.010

Williams, A. (1999). Introduction: In A. Williams (Ed.), *Therapeutic Landscapes: The dynamic between place and wellness* (pp. 1–13). University Press of America.

Williams, A. (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine, 55(1)*, 141–154. https://doi.org/10.1016/s0277-9536(01)00209-x

Williams, A. (2007). Introduction: The continuing maturation of the therapeutic landscape concept. In A. Williams (Ed.), *Geographies of health: Therapeutic landscapes* (pp. 1–12). Routledge.

Willig, C. (2022). *Introducing qualitative research in psychology* (4th ed.). McGraw Hill Education, Open University Press. https://ebookcentral.proquest.com/lib/Massey/detail.action?docID=6801307#

Willis, J., Goad, P., & Logan, C. (2019). *Architecture and the modern hospital : Nosokomeion to Hygeia*. Routledge. https://doi.org/10.4324/978042943449

Winchester, M., & McGrath, J. (2020). Therapeutic landscapes. *Medicine Anthropology Theory*, *4*(1). https://doi.org/10.17157/mat.4.1.472

Wojcik, W., Armstrong, D., & Kanaan, R. (2011). Chronic fatigue syndrome: Labels, meanings and consequences. *Journal of Psychosomatic Research*, *70*(6), 500–504. https://doi.org/10.1016/j.jpsychores.2011.02.002

Wood, V., Gesler, W., Curtis, S, Spencer, I., Close, H., Mason, J., & Reilly, J. G. (2015). ‘Therapeutic landscapes’ and the importance of nostalgia, solastalgia, salvage and abandonment for psychiatric hospital design. *Health & Place*, *33*, 83–89. https://doi.org/10.1016/j.healthplace.2015.02.010

Wood, M. S., Halmer, N., Bertolli, J., Amsden, L. B., Nugent, J. R., Lin, J.-M. S., . . . Covid, S. (2024). Underdiagnosis of myalgic encephalomyelitis/chronic fatigue syndrome-like illness in a large integrated healthcare system — Kaiser Permanente Northern California, 2022-2023. *MedRxiv.* https://doi.org/10.1101/2024.12.04.24318508

World Health Organization (2025). *Constitution of the World Health Organization.* https://www.who.int/about/governance/constitution

Wright, A., Fisher, P. L., Baker, N., O’Rourke, L., & Cherry, M. G. (2021). Perfectionism, depression and anxiety in chronic fatigue syndrome: A systematic review. *Journal of Psychosomatic Research, 140*. https://doi.org/10.1016/j.jpsychores.2020.110322

Zahourek, R. P. (2012). Healing: Through the lens of intentionality. *Holistic Nursing Practice*, *26*(1), 6-21–21. https://doi.org/10.1097/HNP.0b013e31823bfe4c

Zličić, T., Korovljev, D., Šćepanović, T., & Milovanović, I. (2023). Effects of Graded Exercise Therapy and medical care on chronic fatigue syndrome. *Annales Kinesiologiae, 14*(2), 143–154. https://doi.org/10.35469/ak.2023.425

APPENDICES

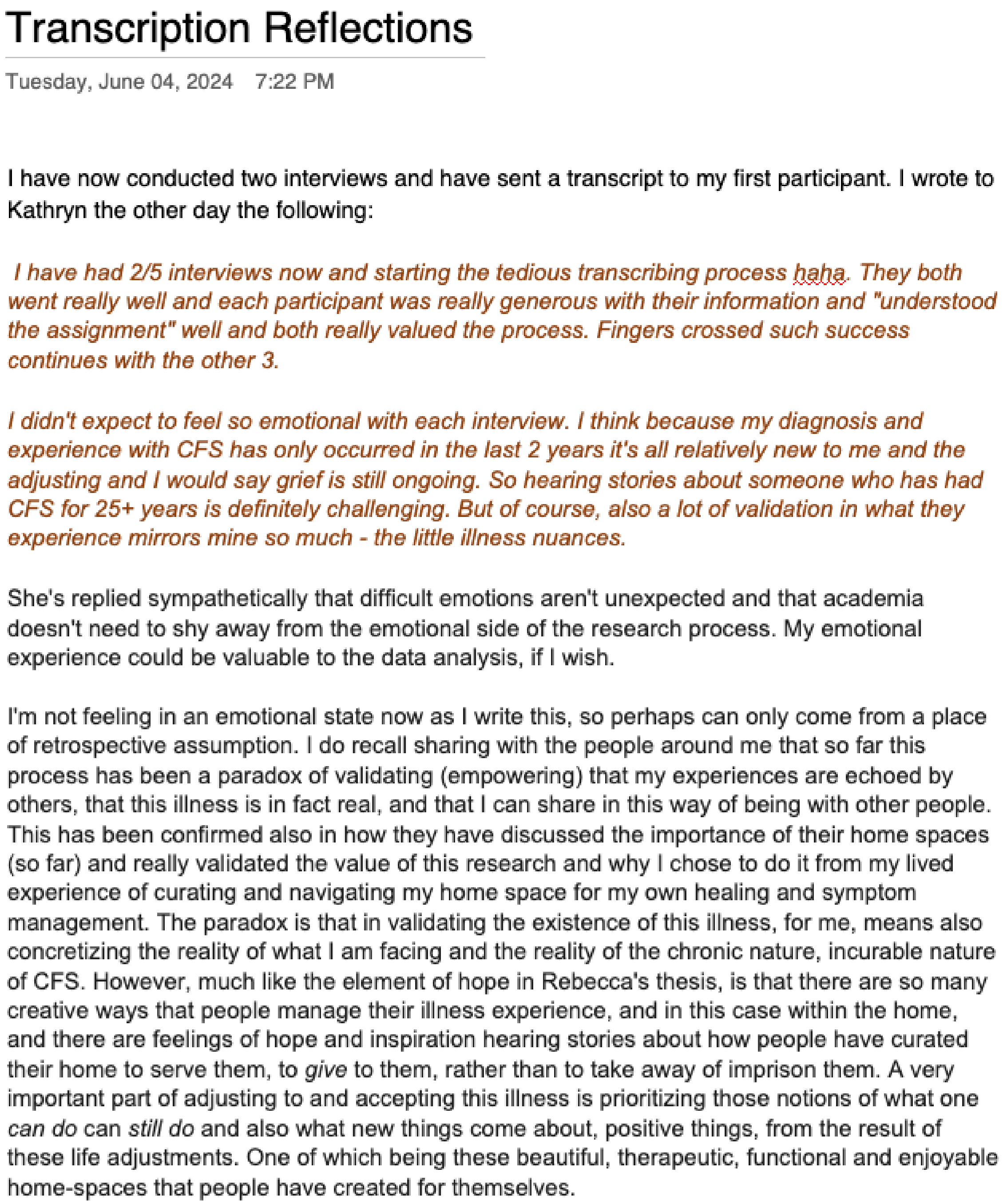
Appendix A: Artistic Inspiration for this Research

In addition to the phenomenological grounding of ABM, I would like to comment on some works of inspiration on my painting practice which inform this project.

Works by Edward Hopper (1882-1967), an American realist painter, captured what looks like stills from the private life: *Morning Sun, 1952* illustrates a female gazing out a window as she sits on a bed, arms wrapped around her knees, in a light pink slip; or *Sun in an Empty Room*, 1963, which captures an empty interior space with the sunlight squares cast again the walls from a window, much like that of *Morning Sun*. The magic of his paintings is that there is stillness and calmness, an experience noted as valuable in the therapeutic. His paintings hold emotional and sensory space for a viewer to project their experience onto; the experiences of what it feels like to be in moments of stillness.

Outside of my own painting practice, art has long depicted fatigue and illness. A favourite artist of mine, Botticelli, has depicted many relaxing figures: *Venus and Mars* ca.1483, has a male reclining in slumber while Venus relaxes awake alongside him, and Cherubs play at his side; or *Sleeping Venus* by Giorgione ca.1508, with a nude female in a slumber; or *Noon: Rest from Work* by Vincent Van Gogh, 1890, which depicts two figures in siesta on hay stacks. While there is significantly more meaning to these paintings than depictions of fatigue or relaxing, they are connected by themes of rest or slumber, the idyllic state of dreaming or taking a break. They hold a sense of peace or joy in them. Comparatively, some paintings capture fatigue through the illustration of exhaustion or pain, such as paintings which depict Jesus Christ in anguish. Exhaustion is illustrated in other works through figures who have their heads in their hands, like Vincent Van Gogh’s portrait *At Eternity’s Gate, 1890* or figures slumped over tables, collapsed, or in a state of disarray.

Appendix B: OneNote Reflective Entry



Transcription Reflections

Tuesday, June 04, 2024 7:22 PM

I have now conducted two interviews and have sent a transcript to my first participant. I wrote to Kathryn the other day the following:

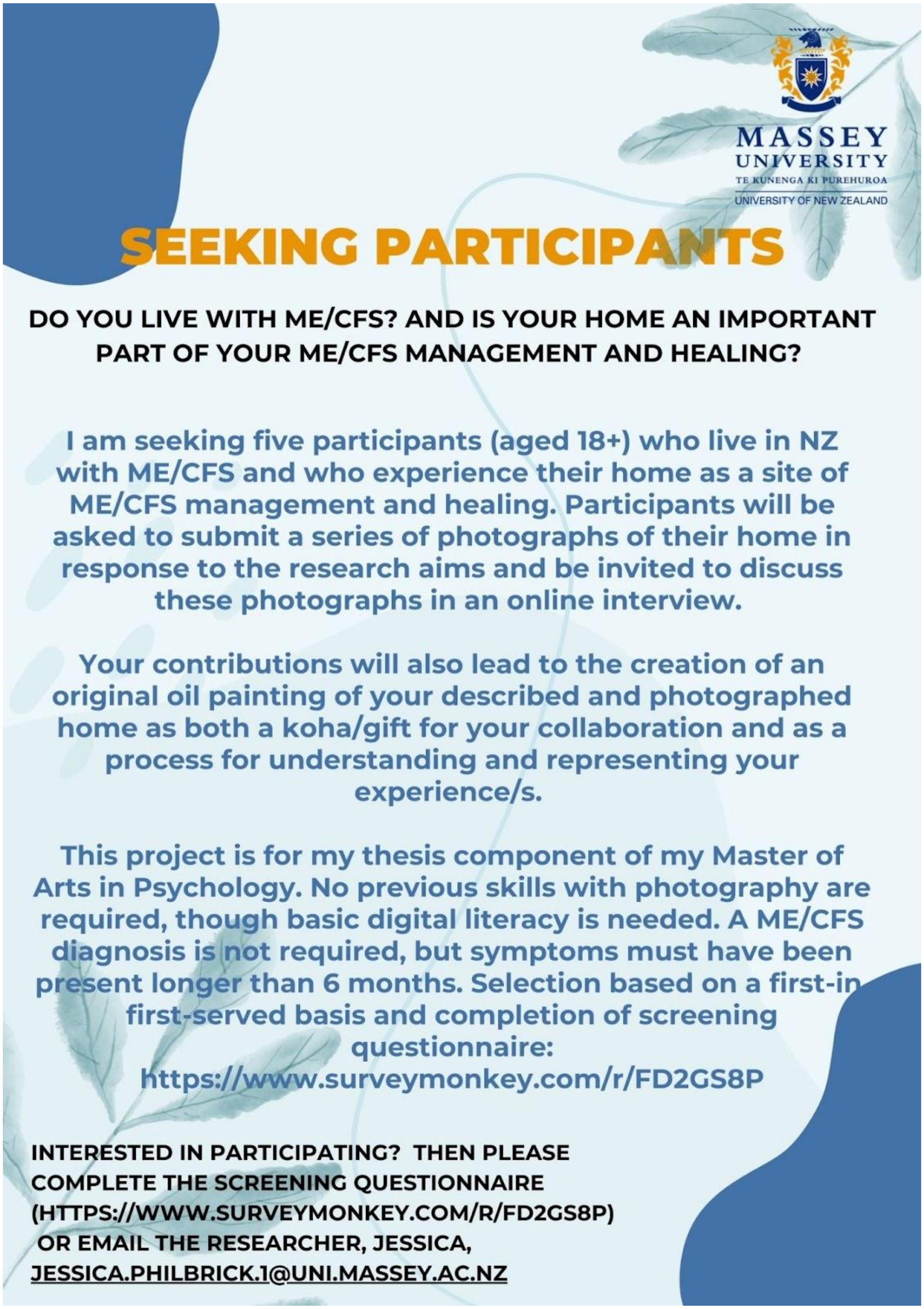
I have had 2/5 interviews now and starting the tedious transcribing process haha. They both went really well and each participant was really generous with their information and "understood the assignment" well and both really valued the process. Fingers crossed such success continues with the other 3.

I didn't expect to feel so emotional with each interview. I think because my diagnosis and experience with CFS has only occurred in the last 2 years it's all relatively new to me and the adjusting and I would say grief is still ongoing. So hearing stories about someone who has had CFS for 25+ years is definitely challenging. But of course, also a lot of validation in what they experience mirrors mine so much - the little illness nuances.

She's replied sympathetically that difficult emotions aren't unexpected and that academia doesn't need to shy away from the emotional side of the research process. My emotional experience could be valuable to the data analysis, if I wish.

I'm not feeling in an emotional state now as I write this, so perhaps can only come from a place of retrospective assumption. I do recall sharing with the people around me that so far this process has been a paradox of validating (empowering) that my experiences are echoed by others, that this illness is in fact real, and that I can share in this way of being with other people. This has been confirmed also in how they have discussed the importance of their home spaces (so far) and really validated the value of this research and why I chose to do it from my lived experience of curating and navigating my home space for my own healing and symptom management. The paradox is that in validating the existence of this illness, for me, means also concretizing the reality of what I am facing and the reality of the chronic nature, incurable nature of CFS. However, much like the element of hope in Rebecca's thesis, is that there are so many creative ways that people manage their illness experience, and in this case within the home, and there are feelings of hope and inspiration hearing stories about how people have curated their home to serve them, to *give* to them, rather than to take away of imprison them. A very important part of adjusting to and accepting this illness is prioritizing those notions of what one *can do* can *still do* and also what new things come about, positive things, from the result of these life adjustments. One of which being these beautiful, therapeutic, functional and enjoyable home-spaces that people have created for themselves.

Appendix C: Recruitment Poster



MASSEY
UNIVERSITY
TE KUNENGA KI PUREHUROA
UNIVERSITY OF NEW ZEALAND

SEEKING PARTICIPANTS

DO YOU LIVE WITH ME/CFS? AND IS YOUR HOME AN IMPORTANT PART OF YOUR ME/CFS MANAGEMENT AND HEALING?

I am seeking five participants (aged 18+) who live in NZ with ME/CFS and who experience their home as a site of ME/CFS management and healing. Participants will be asked to submit a series of photographs of their home in response to the research aims and be invited to discuss these photographs in an online interview.

Your contributions will also lead to the creation of an original oil painting of your described and photographed home as both a koha/gift for your collaboration and as a process for understanding and representing your experience/s.

This project is for my thesis component of my Master of Arts in Psychology. No previous skills with photography are required, though basic digital literacy is needed. A ME/CFS diagnosis is not required, but symptoms must have been present longer than 6 months. Selection based on a first-in first-served basis and completion of screening questionnaire: https://www.surveymonkey.com/r/FD2GS8P

INTERESTED IN PARTICIPATING? THEN PLEASE COMPLETE THE SCREENING QUESTIONNAIRE (HTTPS://WWW.SURVEYMONKEY.COM/R/FD2GS8P) OR EMAIL THE RESEARCHER, JESSICA, JESSICA.PHILBRICK.1@UNI.MASSEY.AC.NZ

Appendix D: Screening Questionnaire

Massey University,

School of Psychology

contact@massey.ac.nz

PH: 0800 627 739

PARTICIPANT SCREENING QUESTIONNAIRES

Principle Investigator: Jessica Philbrick, Jessica.Philbrick.1@uni.massey.ac.nz

Supervisor: Kathryn McGuigan, k.mcguigan@massey.ac.nz

Interview study on:

How is the home experienced as therapeutic

when living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

Questionnaires will be submitted via Survey Monkey

Screening Questions: https://www.surveymonkey.com/r/FD2GS8P

1. Do you live with *Chronic Fatigue Syndrome/Myalgic Encephalomyelitis*? Y/N
2. Have you experienced symptoms for longer than 6 months? Y/N

3. Do you live in Aotearoa New Zealand? Y/N
4. Are you over 18 years of age? Y/N
5. Do you spend a lot of time at home due to *Chronic Fatigue Syndrome/Myalgic Encephalomyelitis*? Y/N
6. Is your home an important place for your *Chronic Fatigue Syndrome/Myalgic Encephalomyelitis* management and healing? Y/N
7. Will you be able to provide and upload four photographs of your home to be used during a Zoom interview? Y/N
8. Will you be able to participate in an interview that is 60-90 minutes in duration? *Or* will you be able to participate in an interview that is split into two sessions, 30-60 minutes in duration each? Y/N
9. Are you interested in participating in research aiming to explore your experiences of *Chronic Fatigue Syndrome/Myalgic Encephalomyelitis* management and healing in the home? Y/N
10. Please provide your email address so that the researcher, Jessica, can be in contact with you regarding the next steps.

Demographic Questionnaire: https://www.surveymonkey.com/r/BY3TGPR

1. Name (optional)
2. Age (optional)
3. Gender (optional)
4. Ethnicity (optional)
5. Living with *Chronic Fatigue Syndrome/Myalgic Encephalomyelitis*
6. Length of illness
7. Diagnosed or self-defined *Chronic Fatigue Syndrome/ME?*

8. Length since diagnosis
9. Living with another/different illness contributing to fatigue?
10. Living situation/Place identified as home: Renting, home owner, living alone, living with parents, living with partner, living with children etc. Tick all that apply
11. How much time do you spend at home?

Interview Needs: https://www.surveymonkey.com/r/W3MLSV3

12. Would you like a support person or person from your Whakapapa or Iwi present for your interview? If yes, please complete this section in your consent form
13. Would you like the interview split into two sessions?
14. Would you like the Māori responsive version of the interview schedule to be used?
15. Do you have any other health requirements for consideration during the interview process?
16. Do you have any other cultural requirements for consideration during the interview process?

Appendix E: Participant Information Sheet

Massey University,

School of Psychology

contact@massey.ac.nz

PH: 0800 627 739

PARTICIPANT INFORMATION FORM

Principle Investigator: Jessica Philbrick, Jessica.Philbrick.1@uni.massey.ac.nz

Supervisor: Kathryn McGuigan, k.mcguigan@massey.ac.nz

Interview study on:

How is the home experienced as therapeutic

when living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

Kia ora, talofa, Nǐ hǎo, and hello,

You are being invited to take part in a study on your experiences of your home (the domestic private space you live in) as therapeutic in relation to your chronic fatigue management and healing. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask me if there is anything you would like more information about.

If you haven't already, please complete the screening questionnaire to ensure your suitability for the project: https://www.surveymonkey.com/r/FD2GS8P

What is the purpose of the project?

The purpose behind this project is to better understand how you experience your home as therapeutic in relation to your CFS/ME. The interest in this project for me has come from my lived experience with CFS/ME and my resulting time at home. Many people with CFS/ME tend to spend a lot of time at home as a result of this illness, so it is important to understand more about how the home is experienced alongside CFS/ME.

What will be involved?

Participation Tasks and Timeline

Participation Sign Up
Read information sheet and confirm interest in participating.

1 Week

Pre-Interview and Consent
Organise non-obligation pre-interview to discuss project and interview needs. Complete consent.

1 Week

Photograph your home
Upload images to the OneDrive folder within two weeks of confirming your participation.

2 Weeks

Online Interview
60 - 90 minute Zoom interview to discuss home photographs and CFS/ME

2 Weeks

Transcript Review
Review your interview transcript to rectify, clarify or withdraw.

4 Weeks

Participation Complete
You will have 4 weeks from transcript review to withdraw from the project.

If you are interested in participating you will be invited for an **initial 15-30 minute Zoom meeting** to discuss your participation. This meeting is introductory, to cover research aims, ask questions, and discuss interview needs. It does not mean that you are then required to participate. If you wish to participate, you will be provided with further instructions and a digital consent form. You will receive a short questionnaire to complete (some “about you” details and interview needs) and be provided with a secure OneDrive link to upload photographs. Basic digital skills are needed to upload photographs and forms, though you can ask a friend/family member to assist you. You will be given **two weeks to photograph and submit images of your home**, instructions for photographs will be provided. But essentially, think about parts of your home which assist in your CFS/ME symptom management, healing and sense of well-being - the places or things which make you feel good. Following this, an **online interview (60–90 mins)** will be arranged, at a time that suits you. I will ask you questions about your experience with CFS/ME and how you experience your home therapeutically with specific questions on your submitted photographs.

The interview will be recorded as I will be required to transcribe the discussion for my assessment. You will be given an opportunity to **review your transcript within two weeks after your interview** to clarify any points, remedy any misunderstandings, or make the decision to withdraw all or parts of your data. A request to review your transcript will occur with email, you are able to respond via email or we can arrange for a follow-up Zoom meeting to discuss any points. This follow-up meeting may need to be recorded if you are providing additional data to your interview.

Outcome

Your interview and photo content will then be used to create a painting of your home as a gift for participating and a creative step for understanding your experience. I am a practising artist and it is a part of my practice that other people's homes inspire my work. If you consent, an image of the painting will be uploaded onto my artist website (visit website: https://www.j-philbrickartist.com/). You will have the right to decline this or to reach out to me at any date to remove the image from my website. No identifying information will be associated with the painting and no prints of the paintings will be made available. The file will be titled as "*Untitled Painting: Therapeutic Landscapes Project 2024*". The painting will be approximately 300x400mm and made from MDF board and oil paint. It will have backing support to be ready to hang wherever you like.

Do I have to take part?

Taking part in this research is entirely voluntary. If you decide to take part you will be given this information sheet to keep and be asked to sign a digital consent form. Even if you decide to take part, you can change your mind at any time and **withdraw from the study up until 4 weeks**

after your review of your interview transcript without giving a reason. After this date, the use of your interview content for my assessment will be underway and the painting would have been started. You will be reminded of your right to withdraw periodically during the process.

What are the possible advantages and disadvantages of taking part?

The aim is that sharing your story will contribute to valuable conversations and research on CFS/ME healing, recovery, illness management and treatment. This is important because of the stigma this illness has and the difficulty behind access to treatment resources. Your voice matters. You will receive an original oil painting of your described home as a koha/gift for participating, a gift that hopefully you can treasure and be reminded of the healing aspects of your home.

There are minimal risks associated with this study, and it is hoped that you enjoy taking part in sharing your story. Though please note that sometimes talking about health challenges can bring up uncomfortable or distressing emotions and thoughts. Increased fatigue can be a result of the interview process (post-exertional malaise); therefore it is vital that we create an interview plan that will best suit your health needs, e.g splitting the interview into two sessions or taking regular breaks.

If discomfort or distress occurs for you, I will ask if you want to stop the interview. I will utilise basic counselling language and empathy skills to assist you through difficult moments where suitable. If in the course of participating in this interview you think that you would like some additional support, then in the first instance please contact your personal support/s (friends or Whanau) or other national support services (see list below). It is advised that if you are currently experiencing significant fatigue from long conversations or emotionally charged conversations that you clarify your interview needs early or do not opt to participate in this research.

You are welcome to have a support person with you during the interview. Their identity and any verbal expressions will *not* contribute to the data collection. This will need to be arranged prior to the interview. If needed, an interview question list can be provided in advance if you wish to review them.

Will my taking part in this project be kept confidential?

All personal information relating to you (e.g., name, email address) will be kept confidential and in a password protected file stored on Massey University's network, OneDrive, which is a highly secure cloud system. This data will be backed up and protected against viruses and other attacks. This reliable system ensures that privacy and confidentiality is respected. Your consent forms will be stored for 5 years and accessible by myself and the research supervisor, Dr Kathryn McGuigan.

Due to the nature of transcribed information your confidentiality cannot be guaranteed. It is advised to *not* provide identifying information during the interview to ensure anonymity. However, if you say something that might hint at your identity (e.g., city you live in), then this information will be removed and not included for analysis. The research write up will use pseudonyms and thus your anonymity is further protected. The transcript that will be included in my assessment will be anonymised so that you cannot be identified in the research in any way.

Due to the nature of the images, providing photographs of your home may make you identifiable to those who can recognise your home. It is up to your discretion on which parts of your home that you photograph as the **photographs will be included in the thesis write up.** It is asked that images do not contain people (yourself or others) for privacy and protection. Other forms of identifying information in images will not be accepted (such as family pictures, home location, identifying documents). As you are uploading digital photo files, it is noted that there is metadata which can be linked to your identity. It is up to your discretion if you wish to remove this metadata.

Recordings and transcripts will only be viewed by myself (the researcher) and you (the corresponding participant).

Māori participation

The research will be responsive to Māori needs where appropriate. I will uphold the values of aroha and mana tangata. A version of the interview which includes Māori Tikanga such as karakia and use of (basic) Te Reo, is available. Please note that I, the researcher, am not fluent in Te Reo, but can understand commonly used Kupu, phrases, and Tikanga. The pre-meeting is an opportunity to build whakawhanaungatanga between us. You are also welcome to have a member of your Whanau or Iwi present with you during the interview. As above, their identity and contribution will *not* be included in your interview content for analysis, unless arranged otherwise for relevance to the project. A member of your Whakapapa is most welcome to read over this participant information sheet, consent form, and reach out for further details. If needed, a question list can be provided in advance if you wish to review them for cultural appropriateness or if you need support. Additionally, a final version of the research project can be provided for dissemination within your community if desired; and of course, a painting will be provided in which you can display at any site of your choosing.

Who has reviewed the project?

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/12. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz. Also by my supervisor, Dr Kathryn Guigan.

If you have cause for complaint before, during or after the interview, you are invited to contact the researcher and/or the research supervisor.

Contact for further information on the project

Jessica Philbrick: Jessica.Philbrick.1@uni.massey.ac.nz

Kathryn McGuigan: k.mcguigan@massey.ac.nz

If in the course of participating in the study you feel you would like to talk to somebody in a therapeutic way, the following services might be useful:

Students:

Massey University Counselling Services https://www.massey.ac.nz/student-life/services-and-support-for-students/counselling-services/

Massey University TalkCampusApp: https://www.students.talkcampus.io/massey-university

Māori Support at Massey https://www.massey.ac.nz/student-life/m%C4%81ori-at-massey/he-ringa-%C4%81whina-tauira-m%C4%81ori/te-rau-tauawhi/

Students and Non-students:

Free call or text 1737 any time for support from a trained counsellor

Anxiety Helpline 0800 269 4389 www.anxiety.org.nz

Depression Helpline 0800 111 757 Free Text 4202 www.depression.org.nz

Lifeline: 0800 543 354 or Free-Text 4357 www.lifeline.org.nz

Samaritans 0800 726 666 www.samaritans.org.nz

Hearing Impaired Assistance: www.nzrelay.co.nz

Rainbow Community Support OUTline 0800 688 5463 (6-9pm) https://outline.org.nz

Pacific Helpline 0800 652 535

Or visit www.findahelpline.com for other services

Appendix F: Consent Form

Massey University,

School of Psychology

contact@massey.ac.nz

PH: 0800 627 739

PARTICIPANT CONSENT FORM

Principle Investigator: Jessica Philbrick, Jessica.Philbrick.1@uni.massey.ac.nz

Supervisor: Kathryn McGuigan, k.mcguigan@massey.ac.nz

Interview study on:

How is the home experienced as therapeutic

when living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

This form is to ensure that I (participant) have read and understood the Participant Information Sheet. I have had the details of the study explained to me, any questions I 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 participating in the study until the time specified in the Information Sheet. I understand that if I do not consent to my interview content being used I have one month from the date of reviewing my transcript to redact the data. I understand that consent includes agreeing to have my anonymized data and provided photographs used in the researchers' project.

	Initial Showing Consent
I confirm that I have read and understood the information sheet for the project in which I have been asked to take part and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving any reason.	

I understand that I am free to withdraw my data without giving any reason until one month after reviewing my transcript.	
I understand that the interview will be recorded and that the audio file will be stored securely and only listened to by the investigator signed below.	
I understand that my responses will be anonymised in the interview transcript, and will be seen by markers / examiners of the assignment.	
I understand that all personal data about me will be kept confidential.	
I agree to take part in the above research project.	
I agree to have a photograph of my painting on the researcher’s artist website.	
I agree to have my submitted photographs used in the researcher’s final assessment	

I would like to receive a final copy of the research findings	

I, ………………………………………………………………………… (**Participant's** full name) hereby volunteer to participate in the above named study.

Signed (participant) ……..……..
Date………………………

Optional Support Person's full name:...

Signed (support person) …………...   Date………………………

I, …………………………………………………………………………… (**Investigator’s** full name) certify that the details of this procedure have been fully explained and described in writing to the person named above.

Signed (investigator)............................

Date……………………………………

Appendix G: Photograph Instructions

Massey University,

School of Psychology

contact@massey.ac.nz

PH: 0800 627 739

PARTICIPANT PHOTOGRAPH INSTRUCTION SHEET

Principle Investigator: Jessica Philbrick, Jessica.Philbrick.1@uni.massey.ac.nz

Supervisor: Kathryn McGuigan, k.mcguigan@massey.ac.nz

Interview study on:

How is the home experienced as therapeutic

when living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

You are being asked to take and submit a series of images of your home in response to the following four categories: natural, built, symbolic and social environment. It is important that in photographing each category that it is in relation to your ME/CFS management or healing experience/s. Essentially, think about parts of your home which assist in your ME/CFS symptom management, healing and sense of well-being - the places or things which make you feel good.

Instructive descriptions for each category are given below, though please do not feel obliged to photograph the exact examples provided. Be creative!

You can submit 1-3 photographs *per category*.

If you feel unsure on what the category requires of you, you are welcome to get in contact with me to discuss.

Natural Environment

Please photograph a place or item/s in your home which represents a connection with the natural environment as a place which is important to your ME/CFS management and healing (such as plants, water, gardens, something aesthetically pleasing/beautiful, or any naturally formed place or thing etc).

Built Environment

Please photograph a place or item/s in your home which represents the built environment that is important to your ME/CFS management and healing (such as the physical structure and design features of your home, furnishings, architecture “man-made” aspects etc).

Symbolic Environment

Please photograph a place or item/s in your home which represents your symbolic environment, which could include spaces or objects which hold symbolic meanings for your ME/CFS management and healing (such as something representative of your healing, something representing a ritual of healing, representative of any cultural or spiritual healing, or any other symbolic or metaphoric meaning).

Social Environment

Please photograph a place or item/s in your home which represents your social environment, which can include a representation of the relationships you have in the home in relation to your ME/CFS management and healing (such as a place where you interact with others, a place where someone assists your with your healing, a place that you share in healing activities with others etc).

Due to the nature of the images, providing photographs of your home may make you identifiable to those who can recognise your home. It is up to your discretion on which parts of your home that you photograph as the ***photographs will be included in the thesis write up.*** *It is asked that images do not contain people (yourself or others) for privacy and protection. Other forms of identifying information in images will not be accepted (such as family pictures, home location, identifying documents).*

Appendix H: Interview Schedule

Massey University, School of Psychology

contact@massey.ac.nz

PH: 0800 627 739

PARTICIPANT INTERVIEW SCHEDULE - ENGLISH VERSION

Principle Investigator: Jessica Philbrick, Jessica.Philbrick.1@uni.massey.ac.nz

Supervisor: Kathryn McGuigan, k.mcguigan@massey.ac.nz

Interview study on:

How is the home experienced as therapeutic when living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

Interview Schedule

Good morning/afternoon [name]. Thank you for volunteering to be a part of this research project, I am very appreciative of having you here. This project on therapeutic home spaces and chronic fatigue will contribute to my thesis for my Masters in Arts qualification.

Thank you for participating in the pre-meeting Zoom about this project. I trust that you have a good understanding of the project and your involvement, but I would like to open this conversation with a brief description, allow time for you to ask any questions, and then move onto the interview which includes your selected images. So the start of this is just going information we've already discussed.

I would like to remind you that your participation is *voluntary* and you have the right to stop the interview at any stage, not answer a question, and withdraw your contribution as outlined in your participant information sheet. This interview should take anywhere between 60 - 90 minutes, with pauses if required. If you wish to have your camera *off* for the interview you may do so.

Can you please verbally confirm that you have read your participant information sheet and your consent form [wait or reschedule if needed]. Thank you for also providing me with a copy of your signed consent form [if applicable].

Before commencing, do you have any further questions about your rights? [Allow time for questions and answers].

Thank you [name] for your questions and clarifications.

I will now give you a brief reminder about the aims of the research project and then we will move into the recorded portion of the interview.

As you are aware this research project aims at gaining insight into experiences of a therapeutic home-space in relation to your self-identified or diagnosed chronic fatigue. This style of interview, in which I ask you questions about the photos you have submitted, is designed to focus on your experiences with these particular places or things you have photographed. The aim is that the interview content will provide an understanding on not only what you engage with as therapeutic at home but also why you do so. This is to gather the essence of what this means for you in terms of your Me/CFS health management and experiences of home as healing, or not healing. This interview is participant-driven which means that I, as the researcher, will not be explicitly imparting my personal or researched opinions about therapeutic landscapes, healthcare at home, or Me/CFS experiences. In saying that, I do come from a background of living with chronic fatigue and related chronic illnesses and I have invested a lot time into making my home-space therapeutic, so there is a deeply personal reason behind carrying out this project and hopefully in knowing that I also experience this illness it will invite a level of trust as you share your experiences. But ultimately, I am here to engage in conversation *with you* and this is a discussion space for *your* experiences. I am excited by where this discussion could lead us and am therefore open to the many directions your responses can go in. You are in charge here.

Do you have any questions about the aims of the research? [Allows time for questions and answers.]

Great. Thank you [name] for that. Additional to the aims of the research your interview and your photographs will contribute to the creation of a painting of your space/s. As detailed in your information sheet it is a part of my practice that other people's homes are a great source of inspiration for my work. It is really important that the painting made for you is informed by you as much as possible. The process will of course involve my own creative interpretation as reflected in previous paintings I have created but ultimately the painting aims to capture your space and evoke a sensory experience of what that space means for you in terms of a healing environment.

Do you have any questions about the painting aspect of the research? [Allow time for questions and answers.]

Thank you for listening to the introduction of the research and clarifying that you understand what is involved and why. Do you still consent to participating in this project? [Await answer and proceed accordingly.]

For continuity, can I please ask if you prefer to identify with ME or CFS for this interview?

Do you need to take a pause before continuing? [Await answer and proceed accordingly.]

Right then, we will now move into the recorded portion of the interview in which I will ask you several questions related to the images you have submitted for discussion. I will start with a few general questions to get you thinking and talking about your ME/CFS generally and your home generally and then I will move into questions specific to your submitted images. *I will screen-share these images for us both to see* and if you would like me to type the question into the chat so that you can read it, do let me know. Again, you are welcome to skip a question or ask for clarification and I will probably have a few follow-up questions, in a conversation style. You can also ask to take a break at any stage or let me know if anything else arises for you. If you would like to have your camera *off* please do so now.

Are you ready to start? [Wait for answer]. Great! I will now press record. [Press record].

Okay, let's get started. As mentioned, I will start with a few warm-up questions and then move into questions more specific to your submitted images.

Introduction Questions

I am assuming you have chosen to do this interview at home. So I want to firstly touch base with how you are and where you are in your home for the context of the interview.

1. **Can you tell me a bit about where you have chosen to have this interview today? And perhaps why you've chosen this space?**

   [Interjection] Thank you for sharing that. I'm glad to hear that you have chosen a space that is comfortable for you to be in. I am interested to hear more about your personal experiences with CFS/ME in general and what it looks like in your life.

I'm going to open with a broad question but have some specific follow up questions also, unless you already cover them in your response.

2. **Can you tell me a bit about yourself and your experience of living with Me/CFS?**

   Prompts and follow-ups:

   Can you tell me about how long this has been going on for you?

   Can you tell me about how you describe your CFS/ME? For example, do you describe it as an illness or a disability?

   Can you tell me about how CFS/ME is integrated into your life? / How does CFS/ME show up in your life? (Physical, social, emotional, other…)

   Can you describe the symptoms you experience?

   Can you describe some of the ways you manage your symptoms / manage your healing?

   Can you tell me a bit about what you understand "healing" to be, in terms of your CFS?

   Offer a summary of thoughts to the participant to ensure understanding.

3. **Can you describe your living situation and environment?**

   Prompts and follow-ups:

   Can you tell me a bit about your housing setup? For example, do you flat with others, live at home, live with a partner etc?

   Can you describe the physical structure of your home? For example, is it a new build, a shared unit, has lots of windows, cleanliness, the colours, design features etc.

   What words would you use to describe your living environment?

   Offer a summary of thoughts to the participant to ensure understanding.

4. **Can you describe how your living environment impacts your CFS?**

   Prompts and follow-ups:

What does your home mean to you in terms of your CFS?

Can you tell me a bit about what it is *like* to live in this environment?

Can you tell me about your general approach to symptom management in the home?

Can you tell me about how much time you spend at home and why?

Are you normally home alone or do you share your home-time with others? How is that important to your CFS/ME management and healing?

Can you tell me about different parts of your living environment that are helpful or unhelpful to your health?

Offer a summary of thoughts to the participant to ensure understanding.

[Mirror participant's contribution to ensure correct understanding.] Thank you for sharing that information about your CFS/ME in general and more details about your living situation and environment. We are now going to move into talking about your specific images, one category at a time.

BUILT ENVIRONMENT

5. **Can you please describe what is in this picture/these pictures you photographed?**
6. **Can you describe why you chose to photograph these as a representation of the "built" environment of your home?**

Offer a summary of thoughts to the participant to ensure understanding

Can you describe the physical design features of your home? Such as lighting, ventilation, home security, furnishings

Can you describe how your current living environment provides a therapeutic place for you and your CFS? For example, can you talk about how or if your home provides a safe and secure environment, and how its physical features contribute to your CFS management?

(If applicable) Can you describe any physical modifications you've had to make in your home to accommodate for your illness?

7. **Can you please tell me about how you feel when you look at these pictures and the things in these images?**

Prompts and follow-up:

Can you describe some of the feelings associated with this place?

8. **Can you describe some of the things you do in this place/with these things that you have photographed?**

Prompts and follow-up:

Can you describe how it feels to do those activities in this place/with these things?

Can you describe some experiences you've had in this place/with these things?

Can you describe why these activity/ies are meaningful in terms of your symptom management and healing?

9. **Can you please tell me, how do you *feel* when you are in this space/with these things that you have photographed?** [Repeat for all images.]

Prompts and follow-up:

Can you describe which parts in this photo/in this place that are therapeutic or healing for you?

NATURAL ENVIRONMENT

10. Can you please describe what is in this picture/these pictures you photographed?

11. **Can you describe why you chose to photograph these as a representation of the "natural" environment of your home?**

Offer a summary of thoughts to the participant to ensure understanding

12. **Can you please tell me about how you feel when you look at these pictures and the things in these images?**

Prompts and follow-up:

Can you describe some of the feelings associated with this place?

13. **Can you describe some of the things you do in this place/with these things that you have photographed?**

Prompts and follow-up:

Can you tell me about what this natural environment means for your healing and symptom management?

Can you describe some of the associations you make with this natural environment?

Could be associated feelings, ideas, memories, meanings etc.

Can you describe how it feels to do those activities in this place/with these things?

Can you describe some experiences you've had in this place/with these things?

Can you describe why these activity/ies are meaningful in terms of your symptom management and healing?

14. **Can you please tell me, how do you *feel* when you are in this space/with these things that you have photographed?** [Repeat for all images.]

Prompts and follow-up:

Can you describe which parts in this photo/in this place that are therapeutic or healing for you?

As we have discussed two categories I just want to check in if you need a break? Otherwise another break will be offered after discussing the other two categories?

SOCIAL ENVIRONMENT

15. **Can you please describe what is in this picture/these pictures you photographed?**
16. **Can you describe why you chose to photograph these as a representation of the "social" environment of your home?**

    Offer a summary of thoughts to the participant to ensure understanding

    Can you describe who is involved with your care and support in your home? (If applicable to the image.)

    Can you describe some of the activities you do at home, alone or with someone, within the bounds of your CFS? (If applicable to the image.)
17. **Can you please tell me about how you feel when you look at these pictures and the things in these images?**

    Prompts and follow-up:

    Can you describe some of the feelings associated with this place?
18. **Can you describe some of the things you do in this place/with these things that you have photographed?**

    Prompts and follow-up:

    Can you describe how it feels to do those activities in this place/with these things?

    Can you describe some experiences you've had in this place/with these things?

    Can you describe why these activity/ies are meaningful in terms of your symptom management and healing?
19. **Can you please tell me, how do you *feel* when you are in this space/with these things that you have photographed?** [Repeat for all images.]

    Prompts and follow-up:

    Can you describe which parts in this photo/in this place that are therapeutic or healing for you?

20. **Can you please describe what is in this picture/these pictures you photographed?**

SYMBOLIC/SPIRITUAL ENVIRONMENT

21. **Can you please describe what is in this picture/these pictures you photographed?**
22. **Can you describe why you chose to photograph these as a representation of the "symbolic or spiritual" environment of your home?**

    Offer a summary of thoughts to the participant to ensure understanding
23. **Can you please tell me about how you feel when you look at these pictures and the things in these images?**

    Prompts and follow-up:

    Can you describe some of the feelings associated with this place?
24. **Can you describe some of the things you do in this place/with these things that you have photographed?**

    Prompts and follow-up:

    Can you describe some of the symbolic meanings in this photograph?

    Can you describe how these symbolic elements play a meaningful role in your CFS management?

    Can you describe any cultural or religious symbolic meaning/s in this image?

    Can you describe how it feels to do those activities in this place/with these things?

    Can you describe some experiences you've had in this place/with these things?

    Can you describe why these activity/ies are meaningful in terms of your symptom management and healing?
25. **Can you please tell me, how do you *feel* when you are in this space/with these things that you have photographed?** [Repeat for all images.]

    Prompts and follow-up:

Can you describe which parts in this photo/in this place that are therapeutic or healing for you?

[Mirror participant's contribution to ensure correct understanding.]

[Interjection]: We are nearing the end of the interview. I have some more questions to wrap up the portion relating to your home and the images you have provided and then you are welcome to add any additional thoughts or questions.

As we are at this stage of the interview, I would suggest that we take a short break. We will stay in the Zoom meeting but you are welcome to turn your camera off and mute your microphone and we will take a 10-15 minute break.

[Take a break if not requested/taken already].

26. **As we have now discussed your images by category, I'd like to ask you if any new thoughts or feelings emerged on how these images capture your experience of your home as a healing environment, or not, for you?**

    Prompts and follow-ups:

    [Question re-wording option]: Upon reflecting on your own experiences of engaging with these images, are there any new thoughts or current experiences of these images which relate to your experience of your home and the management of your fatigue symptoms?

    Did anything "come up" in the discussion of these images that was unexpected, or re-affirming, or something you simply hadn't thought about before?

    What felt valuable for you in discussing these spaces?

[Interjection]: Thank you for sharing that additional information. We've now finished officially discussing your submitted images and their relationship to your ME/CFS and healing in the home. As you are aware, a part of this project will involve turning your interview content into a painting. While much of this painting will be informed by the images and descriptions you have already provided, I'd also like to ask you some brief follow-up questions to ensure I have a shared understanding with you of your space in regard to what is important and the visual or physical features which may feature in the painting. This follow-up process can occur again when you are reviewing your transcript, so please do not worry about addressing all of this right now.

Would you like to have a pause before we continue with this section? [Await answer and proceed accordingly.]

27. **Are there any additional visual or physical features of your home that you feel are representative of your healing experience in your home that haven't been photographed or discussed?**

    Prompts and follow-ups:

    For example, is there a particular colour scheme in the house that feels healing for you?
    Or are there other parts of your home that offer healing features for you?
    Is there a part of your home that you have not photographed but would really like to be painted?
    [Reflect interview content to phrase questions. But could include: *This colour/room-scape/object/space has come up often in this interview, is this a meaningful colour to the experience of your home and healing?*]

[Mirror participant's contribution to ensure correct understanding.]

28. **Before we end the interview, is there anything else you want to discuss about your experience of your home as a healing environment for your Me/CFS that is not depicted in these pictures or you have not yet addressed?**

[Mirror participant's contribution to ensure correct understanding.]

[Interjection]: That concludes the official interview section. Thank you so much for sharing your experiences. As mentioned at the beginning of the interview, your consent, safety, health and enjoyment of this process are paramount to this project and I wish to check in with you on how you are feeling after sharing all of that information? [Respond accordingly.]

I wish to also check that you have felt okay with the information that you have shared and still consent to contributing?

[Follow up where required.] Thank you for sharing those additional points.

Closing

Thank you again for your time not only today but also leading up to the interview in providing the images that have been so incredibly valuable to this research and discussion. [Insert personal reflection on the appreciation of in the interview, e.g the participant’s vulnerability or revelation of thought].

As outlined in your participant information sheet, I will provide you with a transcript of this interview for you to review within two weeks from now. This will be your opportunity to amend, remove, or expand on any points of your contribution. The option to withdraw will also remain open at this point until four weeks after you have reviewed your transcript.

Do you have any further questions about the handling of your content, the transcript, or anything else? [Pause for answer.]

I will now stop the Zoom recording, afterwhich our time will be "off the record". We can continue to discuss things if you wish, though what we then share together will be outside of the research project unless stated otherwise. You are welcome to keep your camera off or turn it bak on [if off].

[Turn off recording.] Is there anything else you wish to discuss, off the record? [Pause for answer.] *[If the participant adds potentially valuable information, ask if they are willing to re-say this via recording, or ask if their responses can be added into their data with the researcher's discretion.]*

Thank you again for your time and personal contribution today. Is there something that you are going to do after this interview for self-care or rest?

I will be in touch regarding your transcript though if you have any questions or concerns in the meantime, please feel free to contact me via email.
Thank you so much. [End Zoom call.]

Appendix I: Authority to Release Form

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AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

Principle Investigator: Jessica Philbrick, Jessica.Philbrick.1@uni.massey.ac.nz

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Interview study on:

How is the home experienced as therapeutic

when living with Myalgic Encephalomyelitis?/Chronic Fatigue Syndrome?

I confirm that I have had the opportunity 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 reports and publications arising from the research.

Signature: ………………………………………………………… **Date:** ………………………

Full Name - printed ……………………………………………………………………………

Appendix J: Reflective Note on Artistic Challenge

I am grateful to these paintings for their challenges they proposed. As homes were not photographed from perspectives I'd typically photograph a space for the purpose of painting it, I definitely had to be imaginative on how spaces came together. It was not enough to just paint a rather abandoned interior space like I usually do, but it was in painting a fireplace, pictures on the wall, a dog, a bookshelf, soft toys, plants, and the objects which these people engage with in their everyday life.

Most paintings included two spaces from their living environment; but all the details and objects in each painting came from various areas of their home as they held symbolic importance to their story. The intention for marrying spaces into one was to illustrate that multiple sites in their home offer stories and valuable points to the research. All these details also come together in reflection of the TL categories by addressing the built environments (rooms chosen), natural environment (symbolic plants and access to nature), symbolic environment (objects which allude to greater meanings), and social environments (reference to relationships in/out of the home, especially with pets).