

EXPERIENCES, SYMPTOMS AND MANAGEMENT RELATED TO CHRONIC FATIGUE SYNDROME: A SMALL STUDY

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A research project Submitted in partial fulfilment of the requirements

for the degree Of Master of Applied Practice

Unitec, Institute of Technology, 2018

Declaration



Declaration

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This Thesis/Dissertation/Research Project **entitled:**

EXPERIENCES, SYMPTOMS AND MANAGEMENT RELATED TO CHRONIC FATIGUE
SYNDROME: A SMALL STUDY

is submitted in partial fulfilment for the requirements for the Unitec degree of
Master of applied practice (Health Science)

Principal Supervisor: Dr Hayo Reinders

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Candidate's declaration I

confirm that:

- This Thesis/Dissertation/Research Project represents my own work;
- The contribution of supervisors and others to this work was consistent with the Unitec Regulations and Policies.
- Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.

Research Ethics Committee Approval Number: 2018-1011

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Acknowledgment

I am most grateful to the research participants who gave generously their time to participate in this research. Without their participation this research would not have been possible.

I am sincerely grateful to my principal supervisor Dr Lisa Maurice-Takerei for her intellectual advice and supervision. Lisa, your support and confidence in me that I could complete this research will always be remembered. I appreciate your encouragement and guidance. Thank you.

Special thanks to my lovely husband Michael Chukwurah who supported me and encouraged me all through my study, particularly when I was at the edge of giving up. Thank you for the financial support, it would not have been possible without you.

I would like to acknowledge my children Joshua and Jordan who encouraged me with their lovely words, saying I am an inspiration to them. Thank you, my stars.

I am grateful to my father Benson Osawe, my mother Grace Osawe, and my brothers Nosa, Ame and Ozed for their encouragement and prayers. Thank you

I would like to acknowledge my mother-in-law Anne Dan Coke for her prayers. She continually told me how proud she was seeing me studying. Thank you

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Section 1

1. Introduction to thesis

Having worked as a nurse for 9 years, I have nursed patients either in their own homes or at the hospital. The need for a nurse to understand his or her patient's condition and to show empathy cannot be over emphasised. Solomon et al (2003) state developing an understanding of specific problems related to the experiences of people with CFS can help us to better understand and manage this illness and it will help position carers to provide improved care.

This project aims to understand the experience of the illness and its symptoms from a CFS sufferers' perspective. The aims of the project are to explore the experiences of group of people

living with CFS and their perception of the illness symptoms. It also aims to explore ways the symptoms are being managed.

Participants in this study were those who had been formally diagnosed with Chronic Fatigue Syndrome. It is their stories, experiences, understandings and knowledge that this study sought to document with a goal to increasing the understanding of the condition.

Three research questions guided this study:

- What are participants experience of living with CFS?
- What are peoples' perceptions of the symptoms associated with CFS?
- How do people manage the symptoms and experiences associated with CFS?

Undertaking this research in New Zealand could be used to improve healthcare services for CFS patients in Auckland and across other regions of New Zealand. This study could also create an awareness of the illness to the general public. It will be presented at nursing conferences in New Zealand.

Eight people diagnosed with CFS living in New Zealand were interviewed. The diagnoses, management and impact of the illness were of special consideration. Three research questions developed in this study explore CFS patients' perception, experience of living with CFS, and the management of the illness. A qualitative research methodology was selected for the purpose of this study, using thematic analysis, including the use of debategraphs. The semistructured interview technique was used for data collection. Codes and nodes derived from the research transcript were represented in graphs called debategraph.

This thesis is arranged in three main sections. Section 1 outlines the definition of CFS, other names for CFS, prevalence of CFS, causes, symptoms, diagnosis, treatment and management of CFS. Section 2 of the thesis contains a manuscript, which includes an abstract, literature review, methodology, methods, analysis, results, discussion and conclusion. In the literature review, other studies were examined for the purpose of comparing the studies with the findings from this research. The conclusion summarised the participants experiences of CFS. Section 3 includes references, appendices, and other material supplementary to the thesis.

2. Chronic Fatigue Syndrome

Friedberg et al (2012) state the term chronic fatigue symptom (CFS) or Myalgic Encephalomyelitis (ME) describe a complex physical illness that is characterized by debilitating fatigue, post-exertional malaise, pain, cognitive problems, sleep dysfunction and other immune, neurological and autonomic symptoms. Friedberg et al (2012), explain CFS/ME as a physical illness but also emphasise CFS association with secondary psychological symptoms. Chronic Fatigue Syndrome is defined by Solomon et al (2003) as a severe fatigue of at least six months duration that interferes substantially with occupational, educational, social, or personal activities. Highlighted by Solomon et al (2003) CFS is not alleviated by rest but accompanied by at least four of eight specific symptoms. The symptoms mentioned by Solomon (2003) includes severe post-exertional fatigue, significantly impaired memory or concentration, unrefreshing sleep, sore throat, tender lymph nodes, muscle pain, joint pain, and headaches. For the purpose of this study, CFS is operationally defined as a severe fatigue and pain that lasts for months. Vincent et al (2012) state the 1994 case definition includes a lengthy list of medical and psychiatric exclusions and comorbid conditions. Vincent et al (2012) further explained that the etiology and pathophysiology of chronic fatigue syndrome (CFS) remain poorly understood, and there are no tests, clinical signs, or physiological markers that are diagnostic for this condition. Vincent et al (2012) state the illness is diagnosed clinically, based on self-reported symptoms and clinical evaluation for medical and psychiatric conditions.

Below are the alternative titles for CFS that have been agreed by different countries. Friedberg et al (2012) state the term ME is more commonly used in Europe and Canada, while the term CFS is often used in Australia and United States of America (USA).

Table 1: Names of CFS

| UNITED KINGDOM | UNITED STATES OF AMERICA | NEW ZEALAND | AUSTRALIA |
|-----------------------------|---|-------------|---------------------------|
| Myalgic - Encephalomyelitis | Chronic fatigue and immune dysfunction syndrome | Tapanui flu | Chronic fatigue syndrome |
| Royal free disease | Chronic fatigue syndrome | | Myalgic Encephalomyelitis |
| Yuppie flu | Epidemic Neurasthenia | | |

| | | | |
|-----------------------------|-------------------------------|--|--|
| Post viral fatigue syndrome | Chronic fibromyalgia syndrome | | |
| | Immune dysfunction syndrome | | |

(Budd, 2013)

2.1. Prevalence of CFS

Bruce et al (2011) state Chronic Fatigue Syndrome is primarily an endemic disorder that occurs in both epidemic and sporadic forms. Bruce et al (2011) explain CFS as an illness that affects all racial/ethnic groups and epidemiological studies have indicated a wide range of prevalence from 75 to 2,600 per 100,000 in different care settings. Bruce et al (2011) points out that in a large sample of over 28,000 adults, 422 per 100,000 or 0.42% suffered from CFS. As stated by Bruce et al (2011) it is more prevalent in females (522 per 100,000) than in males. A female to male ratio of 3:1 was found by Dinos et al (2009). Hart & Grace (2000) highlighted the prevalence of CFS in New Zealand to be approximately 127 per 100,000. It was further explained by Hart & Grace (2000) that nearly three quarters of CFS patients in New Zealand are women of working age, with CFS symptoms causing them to have financial problems as a result of not being able to work. However, Carruthers & Van de Sande (2003) stated CFS affects all age groups including children.

As stated by Solomon and Reeves (2004) one consequence of the controversy surrounding the CFS diagnosis is that most cases of CFS go unrecognised. In other words, there are people in the society with CFS but have not been diagnosed with the illness. De Lourdes et al (2011) states the disease is poorly recognised by health, social professionals and the general public.

2.2. Causes of CFS

Some people believe CFS is caused by a combination of viruses, influenza, excessive vaccinations, drug side effects, environmental pollutants, mental factors, emotional factors and food additives. Friedberg et al (2012) point out that many patients state their illness began with an infectious-like illness.

Bruce et al (2011) clearly state that there is no conclusive evidence that pathogens are the cause of CFS and it is unclear whether pathogens play a direct causal role. Carruthers & Van de Sande (2003) state most patients enjoy a healthy active life style prior to the onset of CFS. However, Carruthers and Van de Sande (2003) stated that the elevated levels of a wide variety of intracellular pathogens suggest the dysfunction in the body's response to infection which plays a significant role. Carruthers & Van de Sande (2003) explain some possible causes of CFS such as infections and genetic predisposition that should be considered when more than one separated family member is afflicted. However, Carruthers & Van de Sande (2003) state the cause of CFS remains unknown, although in many cases, reported symptoms may be triggered by an infection or other prodromal events such as immunisation, anaesthetics, physical trauma, exposure to environmental pollutants, chemicals and heavy metals. Carruthers & Van de Sande (2003) explained that quite often a rapid deterioration of health can occur at the onset of CFS and at other times, a gradual deterioration of health could occur with no obvious cause. Recent research has suggested that the contributing factors to the illness, apart from infection and immunity, include cognitive factors such as sleep, metabolic and biochemical abnormalities (Bested and Marshall, 2015). Bested and Marshall (2015) state the immune system abnormalities in people with CFS are diverse and tend to wax and wane over the course of the illness. However, Bested and Marshall (2015) state a specific cause of CFS has not been found and there is no clinical diagnostic test. Johnson et al (2008) state there is some evidence that CFS is a stress-related disorder. Bruce et al (2011) argue that CFS is a severe systemic acquired illness that manifests symptoms predominantly based on neurological and endocrine dysfunction.

2.3. Symptoms of CFS

Budd (2013) points out that CFS patients do not have the same symptoms and it is rare to have two patients presenting with the same symptoms. Friedberg et al (2012) state the illness onset

may be characterised by flu-like symptoms and these symptoms can vary from mild to severe. Friedberg et al (2012) emphasised 25% of people with CFS are bedridden, housebound, or wheelchair dependent. The authors pointed out that as a result of the severity of the symptoms of the illness, many people with CFS do not work. Budd (2013) highlights the difficulty in knowing the severity of fatigue in CFS patients. Being unable to assess the severity of the fatigue could explain why there is a controversy around its diagnosis. Budd (2013) states many doctors refuse to believe that their chronically fatigued patients are physically ill and that they require pain relief, sleeping pill and anti-depressive medications to relieve symptoms. Brooks et al (2014) state people with CFS have reported experiencing disbelief and lack of empathy from both the medical community and the society more widely. However, Brooks et al (2014) points out that the condition has no clear biological marker or symptoms. Friedberg et al (2012) states factors that can worsen the symptoms of the illness include physical or mental overexertion, new infections, sleep deprivation, immunizations, distress and co-existing medical conditions.

2.4. Diagnosis of CFS

Chronic Fatigue Syndrome is a controversial condition because of the variation in the diagnostic tools (Budd, 2013). Friedberg et al (2012) point out that despite the substantial progress that has been made in understanding the underlying biology of CFS/ME, researchers, clinician-scientists and physicians do not have sufficient diagnostic test. The authors state with no validated diagnostic test for the illness, diagnosis is based on patient reported symptoms as described in many overlapping case definitions.

Fukuda et al (1994) explain the CFS diagnostic criteria published by the 1994 Centre for Disease Control. The inclusion criteria clearly emphasise the need to clinically evaluate people for unexplained, persistence or relapsing chronic fatigue lasting more than six months. The chronic fatigue must be new or definite onset, not the result of ongoing exertion, not substantially alleviated by rest, substantial reduction in previous levels of occupational, educational, social, or personal activities. The clinical evaluation should involve a clinical investigation of the person's history, physical and mental status, laboratory screening to include blood tests. The symptoms must concurrently present for more than six months. Symptoms were seen to include Sore throat, Tender cervical or axillary lymph nodes, muscles pain, multi

joint pain, unrefreshing sleep and post exertion malaise. To exclude the diagnosis of CFS, the patient must have an active unresolved or suspected disease that is likely to cause fatigue. Other exclusion criteria in the diagnostic tool include the exclusion of psychotic disorder, depression, and dementia.

As stated by Carruthers and Van de Sande (2003) a patient with CFS will meet the criteria for fatigue, post exertional malaise and/or fatigue, sleep dysfunction, pain, neurological or cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestations. However, Eidelman (2003) states that the 1994 Centre for Disease Control diagnosis criteria for CFS has remained controversial. De Lourdes et al (2011) stress that the diagnosis of CFS has been restricted to the use of clinical history and exclusion of other diseases because there are no specific symptoms and diagnostic tests. De Lourdes et al (2011) state that lack of knowledge and inadequate communication between patients and health professionals have often been the barriers to diagnosis and care. However, Balachander, Rao, Sarkar and Singh (2014) state most patients with CFS meet the criteria for depression or anxiety. Balachander et al (2014) explain depression has been found to be associated with CFS and there are certain similarities between CFS and depression. Balachander et al (2014) further explain that studies have suggested many psychiatric disorders are associated with CFS. Lawrie and Pelosi (1995) explain CFS is often not diagnosed or misdiagnosed as psychological morbidity or a psychiatric disorder. Balachander et al (2014) state the diagnosis of CFS is therefore based on exclusion of other medical disorders.

2.5. Treatment and management

Bested & Marshall (2015) state people must be empowered to take charge of their healthcare. Carruthers et al (2016) states patient should be taught ways of recognising early signs of symptoms and methods of preventing the condition worsening. Carruthers et al (2016) further explain the use of mindfulness, and exercise to relief the symptoms of CFS. He advised people should be aware of the activities or exercises that could impact on physical being.

2.5.1. Relieving the symptoms of CFS

Bruce et al (2011) explain people with CFS can become depressed or have other mental health issues. Bruce et al (2011) stress the need to provide CFS patients with antidepressant medications, which are sometimes helpful in managing CFS symptoms and also help in increasing the energy level and reducing anxiety and depression.

2.5.2. Cognitive Behaviour Therapy

Bilsen (2013) explains that cognitive behaviour therapy (CBT) is the application of learning principles to bring about change. Bilsen (2013) state CBT is the application of cognitive psychology principles and learning theory principles to problems of individual clients. According to Rimes and Wingrove (2011) CBT interventions typically address unhelpful thinking and behavioural patterns by teaching thought challenging techniques. Bilsen (2013) points out that the essential component of CBT is for the therapist to understand and make his/her patient understand that there is a link between their problems and their beliefs and behaviour. Bond and Dryden (2005) state CBT treatments are brief and time limited in nature. Bond and Dryden (2005) state many CBT treatments have led to significant clinical improvement and symptom reduction. Rimes & Wingrove (2011) points out that CBT aims to address particular thinking patterns, behaviours, and emotion regulation strategies that seem to affect or interact with physiological processes that contribute to CFS symptoms.

2.5.3. Exercise and related therapies

Carruthers & Van de Sande (2003) points out that people with CFS should be encouraged to use techniques and practices such as Yoga to improve balance while staying within their limits and not exercising beyond their capacity. Carruthers and Van de Sande (2003) explain studies have shown patients have different physiological responses to exercise, hence care must be

taken when prescribing its uptake. In other words, exercise must be individualised. Tidy (2016) states exercise therapy has been shown to moderately improve fatigue levels, work and social adjustment, anxiety, and post-exertional malaise. Tidy (2016) explains people with CFS may generally benefit and feel less fatigued following an exercise therapy. Tidy (2016) states there is currently no evidence suggesting that exercise therapy may worsen outcomes, in other words a positive effect has been seen with respect to sleep, physical function and self-perceived general health but no conclusive evidence for other outcomes such as pain, quality of life, anxiety or depression. Tidy (2016) states the effectiveness of exercise therapy seems to be similar to that of CBT.

2.5.4. Complementary and supplementary therapies

Nice (2007) state some people with CFS choose to use some of the complementary/supplementary therapies for symptom control, and find them helpful. Nice (2007) points out that there is insufficient evidence for the use of supplements such as vitamin B₁₂, vitamin C, co-enzyme Q10, magnesium or multivitamins and minerals for people with CFS, and therefore they should not be prescribed or recommended for treating the symptoms of CFS. However, Nice (2007) explains some people with CFS have reported finding these supplements helpful as a part of their self-management strategy for their symptoms.

Section 2: Manuscript

1. Abstract

This project aims to understand the experience of Chronic Fatigue Syndrome (CFS) and its symptoms from the perspective of people suffering from it. Developing an effective care pathway will require the participation of people experiencing the illness. The outcome of the research could be used as a basis for other researchers and practitioners developing care pathways for people with CFS. The outcome of this project may contribute to better healthcare for people with CFS.

The idea that a greater understanding of CFS will contribute to improved care is supported by literature. According to Solomon et al (2003) developing an understanding of specific problems related to the experiences of CFS will help a medical practitioner to both understand and

manage this illness. A study carried out by De Lourdes et al (2009) systematically reviewed the need for supporting, managing and maintaining social inclusion for people with CFS.

This research into CFS presents the result of 8 face-to-face semi structured interviews with 8 New Zealanders (7 women and 1 man). The participants were recruited from Auckland and Hamilton regions. None of them had recovered from CFS, they all still had CFS and had developed management plans for themselves. The research data were analysed using the debategraph and thematic analysis approach. The result of the analysis was an exploration of the experiences of CFS. Common themes were identified and discussed. Themes identified were compared with other studies highlighted in the literature review. The research participants were requesting for people in the society particularly healthcare practitioners to listen to them and believe their experience of the illness. Participants want to see people creating awareness of CFS in public places such as schools and magazines.

Aims of project:

- 1) To explore the experiences of a group of people living with chronic fatigue syndrome (CFS)
- 2) To investigate people with CFS perceptions of symptoms associated with CFS
- 3) To investigate how people manage their experiences of symptoms associated with CFS

Research Objectives:

- 1) To explore Patients, experience of diagnostic pathways, treatment, and management
- 2) To explore the lived experience of up to ten people with Chronic Fatigue Syndrome from the Auckland region
- 3) To explore Patients, experience of the impact of the illness on life

Research questions

- 1) What are peoples' experiences of living with CFS?
- 2) What are peoples' perceptions of the symptoms associated with CFS?
- 3) How do people manage the symptoms and experiences associated with CFS?

Keywords:

Chronic fatigue syndrome, experience, diagnosis, lifestyle before and after diagnosis, CFS management plans.

2. Introduction

Based on the existing studies on CFS, it is indicating that there is still a lack in understanding the illness and its diagnosis. Comprehensive research on the lived experience of the illness will

not only improve future research but it will assist those caring for the sufferers to provide better health service. Providing better health services could reduce the distress and frustrations of CFS patients.

As stated by Brooks et al (2014) Chronic Fatigue Syndrome (CFS) is equally known as Myalgic Encephalomyelitis which is a symptomatically defined condition that is primarily characterised by severe and persistent fatigue, often associated with substantial functional impairment. Steefel (2011) defines CFS as a chronic illness, a relapsing illness that demands attention and care. Steefel (2011) further describes CFS as an illness which the sufferer will not 'grow out of'. This means that the illness remains with the sufferer, it can be possibly managed but may not be eliminated. Hughes (2009) states the prognosis for people with CFS is generally considered to be poor and people could be affected for less than two years or remain ill for several decades. Steefel (2011) pointed out that a CFS sufferer is like an inflated balloon that develops a small pinprick and then slowly deflates physically, emotionally, spiritually and mentally, leaving the sufferer empty and wanting to sleep at all times. Hughes (2009) states that full recovery after CFS symptoms have persisted for more than five years is rare. Reid et al (2000), points out that adults rarely recover from it, with 20% to 50% showing some improvements and 6% recovering fully. Budd (2013) stressed that CFS has multiple interrelated causes that need to be treated before health is restored. Mooney (2012) points out that CFS is difficult to diagnose early. However, it was stated by Van Cauwenbergh et al (2012) that the illness is common.

Friedberg et al (2012) pointed out that 25 years ago no one had an idea of the underlying pathophysiology and biological abnormalities of the illness. The authors also state that some clinicians and scientist argued the illness was probably psychological, and others argued it was a fabrication. The argument was that patients were imagining symptoms and the frustrations of practising physicians at that time was that they had no knowledge or proven tools to use to assist people with CFS. Friedberg et al (2012) explain researches of the past 25 years have shown underlying biological abnormalities more in people with CFS. The authors state brain imagining has found abnormalities in both the grey and white matter of the brain. It was further explained by the authors that there is evidence that energy metabolism and mitochondrial function are impaired in many people with CFS.

Solomon et al (2003) state despite the disabling nature of CFS, little research has adequately addressed the impact of the syndrome on patients' daily activities and quality of life.

Researchers have conducted studies to find out people experience of the illness. In this section, some of the experiences of CFS by other authors/researchers will be discussed, similarities and differences will be highlighted.

3. Literature Review: Other studies

A qualitative study on CFS using a semi-structured interview instrument was conducted by Gotts, Newton, Elliss and Deary (2015). The participants had been diagnosed with CFS. The research data were analysed thematically to explore and describe patients' experience of sleep and its impact on their lives. The aim of the study was to explore the role of sleep in patients' experience of their illness. As stated by Gotts et al (2015) the role of sleep in CFS had been neglected by previous researchers.

Results of the study indicated that sleep was a key aspect of the illness experience and its management. Based on the interview that was conducted with the participants in Gotts et al (2015) study, sleep had an effect on their daytime functioning. Most of the participants said sleep either maintained or exacerbated their existing symptoms. All the participants had sleep disturbance, but the nature of the sleep varied from one participant to another, and the pattern

of their sleep changed over time. Some participants said they went to bed but were unable to sleep; others said they had disturbed sleep patterns, whereby they woke up several times at night. Other participants said they spent most of their time awake at night, while some said all they could do was to sleep. Caruthers et al (2016) study was similar to Gotts et al (2015) study. The study explained the relationship between CFS and sleep. This study state insufficient sleep is one of the factors that is considered during the diagnosis of CFS. When there is insufficient sleep without any other underlying illness, it may indicate the presence of CFS (Caruthers et al, 2016). Other participants in Gotts et al (2015) study felt very uncomfortable at night and woke up in pain. Some reported being hungry at night and unable to sleep, and some said they experienced body temperature fluctuations and could not sleep because of hot flushes. Caruthers et al (2016) study describe these frequent awakenings in people with CFS as loss of deeper phases of sleep. It could be explained that the loss of deeper phases of sleep leads to not feeling refreshed when awake. When comparing these two studies (Gotts et al, 2015 and Caruthers et al, 2016), they both examine sleep in CFS. Caruthers et al (2016) study support the reports of the participants in Gotts et al (2015) study. Most participants in Gotts et al (2015) study indicate they felt dreadful when awake. A participant in Gotts et al (2015) study described her body as having forgotten to wake up because she could sleep for days without having to get out of bed. Another similar study by Crowhurst (2015) explains the sleep disturbances in people with CFS. He states people with CFS could have insomnia and unable to sleep for a long time. Crowhurst (2015) points out that people with CFS may have altered sleep pattern, not sleeping until the early hours of the morning and sleeping into the afternoon. This author further explained that despite the difficulties getting to sleep, people with CFS may then experience difficulties waking up or may keep falling back into sleep.

The key disturbers of sleep that emerged from the participants in Gotts et al (2015) study were pain, mental alertness, vivid dreaming and temperature problems. Based on these studies, it appears the key disturbers of sleep are symptoms related to CFS. In Gott et al (2015) study, each participant had a unique experience of sleep. The researchers commented that despite the differing narratives regarding the role of sleep in CFS, all the participants had the same belief, that sleep was a vital process for health and well-being, which has had a direct bearing on the course and progression of their CFS. The participants also stated that the impact of disturbed sleep in CFS should also be considered for clinical and research work.

Another study, described its title as an old life that is almost like a past life, an identity crisis, loss and adjustment amongst people living with chronic fatigue syndrome (Dickson, Knussen

and Flowers, 2007). This study was conducted in the United Kingdom (UK). Fourteen people with CFS were interviewed. The interview focus was on the experience of living with CFS from the participants perspective. The participants reported an ongoing sense of personal loss characterised by diminishing personal control, and an inability to plan for the future, with subsequent feelings of failure and worthlessness. Participants reported that the illness shaped their experiences and controlled virtually every aspect of their lives. One of the statements from the patients they interviewed was that, CFS is a dictator, which dictates the sufferer's everyday life. Other comments include: the illness determines what you can and cannot do, it controls the body and mind and every part of the being. The participants perception of the illness was that it controlled every aspect of their lives.

The researchers in Dickson et al (2007) study confirmed that the themes presented in their study matched the reports of CFS by other authors. They said that participants described their inability to undertake a broad range of both physical and mental activities. Many of their participants described their experience as a loss of their old body and wanted to return to their pre CFS (old body). Their experience was likened to death because it left them numb and without feeling. They had lost every sense of their being, their mind and their bodies. They no longer knew who and what they were (identity crisis). For this study, the participants' experience of CFS was profoundly distressing for them. The researchers state that the participants had to learn to trust their new minds and bodies after periods of crises. The researchers suggest, there was a need for health psychology to play a role in the management of CFS because western society is struggling to respond to the increasing prevalence of chronic health conditions such as CFS. The researchers recommend further research be conducted on experience of loss, adjustment and coping with CFS, in order to tailor support to the needs of people living with the condition and to ultimately improve their overall quality of life. A study by Rutherford, Manning and Newton (2016) state many people with CFS have referred to CFS as an illness with difficulty in maintaining muscle activities due to lack of energy/fatigue. However, Rutherford et al (2016) explain that the precise mechanisms underlying the dysfunction in CFS people has not yet been fully elucidated. It could be argued that, the inability of being able to control muscular activities in CFS explains why the participants in Dickson et al (2007) study describe CFS as a dictator, an illness that takes over their bodies and leaving them with less control.

“People with severe ME cannot participate in social activities, cannot work, cannot volunteer for anything, cannot travel, cannot go to school, cannot do anything in this life, we are left to

exist, that is it” (Crowhurst, 2015, pp 13). Crowhurst (2015) describes the impact of CFS as an illness that destroys every normal event and celebration. He said it invades every part of life and awareness. The reports from Dickson et al (2007) participants is similar to Crowhurst (2015) explanation of the experience of the illness. One of Dickson et al (2007) participants described CFS as a dictator. Comparing the description of CFS as a dictator with Crowhurst (2015) explanation, CFS appears to be truly a dictator. It determines what is going on in your life. You are unable to carry out tasks you would like to do, unable to celebrate when you want to or participate in events you would love to participate in (Crowhurst, 2015). These studies highlight the impact of severe CFS/ME on people suffering from it. Friedberg et al (2012) states one in four patients can be disabled, confined to a chair or bed and rarely leave home. It further explained that these individuals are unable to attend regular office visits.

The expressed needs of people with CFS was studied by De Lourdes et al (2009). The study systematically reviewed the need for support in managing the illness and maintaining social inclusion expressed by people with CFS. The study data were personal stories, which expressed the needs of people with CFS. Data were also extracted from databases such as Amed, Cinahl, Embase, Assia and Central. The data extracted included the expressed needs of people with CFS living in the United Kingdom, the United States, Australia, the Netherlands, Canada, New Zealand, Sweden, and Norway.

The support needs as expressed by people with CFS included the need for people in the society, particularly the health care services to make sense of the symptoms and diagnosis. It also included the need for service providers to show respect and empathy. Positive attitudes and support from friends and families were requirements in the study. Availability of information on CFS and the development of strategies for maintaining or regaining social participation were suggested by the study. People with CFS in the study emphasis the need for recognition that CFS is a multi-faceted, disabling illness. Many reported that living with CFS was particularly hard when doctors disbelieved their illness. Disbelief and lack of empathy by health care providers emerged as common experiences. Many reported leaving the doctor’s office in tears knowing that they were very sick but having no way to convince others about the legitimacy of their illness. Basted and Marshall (2015) explain treatment and management begin with validation of the patient’s experience of CFS and acknowledgement that the patient’s illness exists. Having a diagnosis is the beginning of healing for many patients who have been told they were mentally unwell (Basted and Marshall, 2015). Balachander et al (2014) point out that

the initial management plan for CFS revolves around forming a therapeutic relationship with the CFS sufferers. Balachander et al (2014) explain Forming a therapeutic relationship includes acknowledging the symptoms are based on the diagnosis. Balachander et al. (2014) point out that various guidelines are available for the management of CFS, they all focus on a thorough history, meticulous physical examination, and a mental status examination. Bested and Marshall (2015) explain the goal of CFS treatment is to include improving current symptoms, functioning, and quality of life, preventing worsening symptoms, helping patients cope with the emotional impact and preventing the development of depression and potential suicide. Bested and Marshall (2015) explain the need for healthcare providers to support people with CFS and their families by building a therapeutic relationship with them in order to achieve set goals in their management plan

A similar study by McInnis, Matheson and Anisman (2013), emphasis women living with CFS have endured some challenges in their social lives such as unsupportive social interactions. McInnis et al (2013) study stress the need for the public and healthcare practitioners to be provided with some proper education on CFS because the illness has not been well known or received a widespread acceptance. Both studies De Lourdes et al, 2009 and McInnis et al, 2013 emphasis the need for health practitioners and the society to be provided with useful information about CFS. These studies have similar views about the lack of knowledge of the illness and the need for a better understanding of it. The studies believe the reaction people with CFS receive from the public, their families, friends and health practitioners is as a result of lack of knowledge of the illness.

The researchers in De Lourdes et al (2009) state one of the participants said she was told to put her make-up on and she would feel better. Some reported that they were treated as a nonperson. The participants expressed the importance of friends and families. One of the participants talked about a time when her husband asked why she was always sleeping even though the doctor had told her there was nothing wrong with her. According to the participant, this statement from her husband left her in disbelief and frustration. The study shows the lack of recognition of the needs of people with CFS and the poor support from the health and social systems. Due to the lack of health and social support, the socioeconomic status, daily lives, and social participation of people with CFS could have been compromised. McInnis et al (2013) study strongly suggest the need for the public to be enlightened on the subject (CFS).

Despite studies that have been carried out, researchers are still encouraging people to carry out further research in order to fully understand the illness. It is deemed necessary to carry out further research to ascertain if the experiences reported in past years are still the same in this present time. Such as people's experiences of living with CFS in Auckland, New Zealand considering the support they now have, their perceptions of the symptoms associated with CFS and the management of the symptom.

3.1. Economic cost of chronic fatigue syndrome

Bested and Marshall (2015) point out that there is a burden for patients and their caregivers, as well as healthcare systems. Bested and Marshall (2015) explain the unemployment rate among those with the disorder ranged from 35% to 69%. Hughes (2009) states the experience of CFS symptoms can affect the ability to perform chosen or necessary occupations either temporarily or permanently. Balachander et al (2014) point out the illness causes a significant impairment in daily functioning. Bested and Marshall (2015) state in a research study conducted in Canada, it was found that income losses of approximately \$20,000 annually occurred in households with CFS sufferers. Sabes-Faguera et al (2010) explain fatigue has been proven to affect the economic cost to societies due to its impact on employment.

However, Van Cauwenbergh et al (2012) explain most patients with CFS are unable to work full time. De Lourdes et al (2011) state up to 25% of people may at any one time become severely ill, as in being housebound or bedbound. Sabes-Faguera et al (2010) point out that in most cases, families and friends spend a considerable amount of time caring for their loved ones with CFS. Research in New Zealand shows that CFS can affect quality of life as seriously as Parkinson's Disease or Multiple Sclerosis (MECF, 2017). Taking this into consideration, it will not only lead to financial problems for people with CFS, but it will also have an impact on the economy (loss of income generated) of any country. Patients with CFS are often in need of a comprehensive rehabilitation programme that includes medical treatments, psychological support and occupational therapy to accommodate a successful return to work or to school (Van-Cauwenbergh et al, 2012). Rainbow et al (2012) suggest not to underestimate the burden and effect of CFS on healthcare and economy of a nation.

4. Introduction to Methodology

The chosen research methodology is qualitative research methodology. Flick (2008) states that research undertaken using a qualitative methodology is interested in the perspectives of the participants in everyday practices and knowledge. The focus of attention in this study is the experience of Chronic Fatigue Syndrome (CFS) in people, wherein the perspectives of the people suffering from CFS, in relation to the illness will be considered. Flick (2008) explains qualitative methodology as that which examines the perspectives of participants in research. Similarly, Thomas and Magilvy (2011) state the qualitative researchers typically collect a lot more information on one topic phenomena or experience to build further knowledge or to develop a more patient-focussed practice.

Brace (2013) stressed that the qualitative research approach is used in the exploration of behaviour, perspectives and experiences of the people studied. Similarly and in terms of methods, Goyal (2013) points out that qualitative research methods are typically used when focusing on a limited number of informants who are selected strategically so that their in-depth information will give optimal insight into an issue about which little is known. Eight participants were involved in this study, they were happy to share their experiences of CFS, these unique features of this study meet the criteria for a qualitative research. This study has limited number of participants, it examines the perspective of the participants concerning a topic and a large amount of data was collected from the participants during the interview sessions.

5. Research Method

Research data were collected using a semi structured interview process. Individual interviews (face to face) were conducted. The purpose for using interviews was to give the interviewees the opportunity to have an in-depth dialogue about their experiences of CFS. The semi structure interview was considered for this study because of their advantages. These advantages are stated below.

Interviews consisted of open ended questions to give participants the opportunity to fully discuss their experiences. Thibodeaux (2017) points out that the interviews are considered open-ended because the interviewer usually does not know what the content of the response will be. In my study, I was unaware of the possible responses of my participants. Open-ended questions were a prompt for my participants to discuss their experiences. Some of my participants spoke readily while others were more reticent. This type of interviewing allowed

for variations in individual responses. Thibodeaux (2017) stressed that semi structured interviews, using open ended questions usually focus on the participants thoughts, feelings, experiences, knowledge, skills, ideas and preferences. My participants expressed their feelings, experiences, preferences, knowledge and skills in relation to their illness (CFS). Gillham (2000) defined a research interview as a tool that is used to obtain information and understand issues relevant to the general aims and specific questions of a research project. Similarly, my study intends to use the outcomes of the interviews conducted to answer the research questions and to understand their relationships with the research aims.

Hannahbuss (1996) points out that if many interviews are carried out, the research can prove expensive in staff and time. He explains that they are often intensive and time-consuming and runs the risk of covering only a small and possibly unrepresentative sample of respondents. Hannahbuss (1996) states that respondents may try to deceive the researcher by hiding or misrepresenting things. He states, respondents may not want to talk when being recorded and may respond in idiosyncratic ways which makes comparison with other respondents difficult. This was true for some of my interviews, there were times the recordings were stopped for some reasons, given the poor health of some of my participants, other participants wanted the recordings stopped for few seconds because they did not want certain aspects of their conversations recorded. Hannahbuss (1996) further explained that with interviews, people are busy and may be suspicious, they may be widely dispersed geographically, and they may need to be approached through gatekeepers in organizations who may steer you towards unrepresentative respondents or even prevent you from seeing them. Some of my participants were a bit suspicious of my study, some spoke to me on the phone for more information and others emailed me. The sooner they heard from me, providing them with my research information, they were willing to participate. Other CFS people remained suspicious and would not participate. As mentioned in Hannahbuss (1996) I had to go through some stakeholders which Hannahbuss (1996) referred to as the gatekeepers to get to my participants. Some gatekeepers in my case were unhelpful and would not allow me to see their clients. Other gatekeepers were very helpful. 6 of my participants were recruited from a CFS group and two were from the general practitioners (GP). My participants were widely dispersed geographically across Auckland, and another city outside Auckland.

Studies have highlighted the advantages of a face to face interview. Gillham (2000) points out the richness and vividness of the data obtained from a face to face interview. He states face to face interviews are efficient if a small number of people are involved, if the people are

accessible, and if the questions are open ended because research aims only require insight and understanding. Remenyi (2011) states interview is an increasingly popular way of collecting data or evidence in the social sciences and it has a role to play in both qualitative and quantitative research. Remenyi (2011) explains an interview to be a very positive experience where the researcher and the informant engage in a two-way conversation about the topics in the interview schedule. He points out that useful data could be collected from a two-way conversation.

Participants in this study had the opportunity to have some questions explained to them when they asked for clarity. I was able to ask my participants, for more information when there was a need for it. Comparing a face to face interview with other method of data collection, Gillham (2011) states the response rate when using questionnaires is low when compared to face-to-face interviews. Gillham (2000), explains that people are far more willing to devote an hour and a half to an interview even if it is of no benefit to themselves than to give fifteen minutes to the completion of a questionnaire. He explains the various reasons for this, such as, people like the attention from an interview, they like to be listened to and they like their opinions being considered. Gillham (2000), consider these as human needs, which we all share. He states, the great strength of the interview is that, these human needs in a small way are fulfilled. Overall, participants in this study were extremely cooperative and wanted to support the study. They did so by providing further contact details and recommending readings and papers. Two of my participants referred me to a famous CFS doctor in Auckland that provides support to people with CFS. I contacted the doctor and in her kind gesture she sent me a magazine on CFS and promised to leave my research flyer in her practice for her clients.

Remenyi (2011) points out face-to-face interview improves the researcher's interview technique, thereby helping the researcher to obtaining richer data from subsequent informants. Remenyi (2011) states the researcher will also be able to fine tune the questions themselves. Remenyi (2011) also highlights the relevance of using interviews for small scale study because of its cost. This was a small-scale study, and the goals were well suited to using interviews as a method.

Gillham (2000) points out the advantages and disadvantages of conducting research interviews. He states face-to-face interviews are enormously time consuming. The cost of carrying out a face to face interview is high, it is not cost efficient. There is extra cost including setting up and travelling to and from the interview location. Gillham (2000) states the travelling time could be more than the actual time spent in interviewing. The advantage to using this method

however is the rich data that can be generated. Most of my interviews were about an hour, and three of the interviews were over an hour. Interview locations for most of my participants were in their houses because they were house bound and bedridden. However, two of the interviews were conducted in local libraries closer to participants houses.

All interviews were voice recorded and were transcribed with the assistance of a transcriber with whom a privacy agreement was in place. Remenyi, (2011) explains that the analysis of interviews is every bit as challenging as any numerical analysis. The analysis of my research data was time consuming, giving attention to every text that was in the transcript. In order to have a good overview of the relevant texts that were in the transcripts, the codes were grouped into nodes and then represented graphically using the debategraph.

5.1. Recruitment Process

The study was advertised on chronic fatigue syndrome support group online and in 2 general practitioner (GP) practices. Interested participants responded to the advertisement, to express their interest and ask for further information on the research. Participants information sheet and consent forms were emailed to the participants. People who took part in the study signed and returned their consent forms. Interview venue, dates and time were arranged with the participants.

Five of the participants were interviewed in their own homes and two were interviewed in a local library, one was interviewed by Skype. Skype was an option because she was severely bedridden at the time of the interview. The interview venues were chosen by the participants based on the options of venue that were available. They were given the choice of a library or their own homes. Each individual interview was intended to last for an hour. Three of the interviews lasted more than an hour because the participants had more to say about their experiences of CFS.

People diagnosed (self-diagnosed or GP-diagnosed) with CFS were potential candidates for this study. The participants in this study were diagnosed with CFS by their GPs or other health specialist.

Criteria for selection of participants (inclusion)

- Chronic fatigue syndrome must be diagnosed by a General Practitioner (GP) or a health specialist
- Must be an adult 18 and above

- Well enough (Mentally and physically) to participate in an interview, discussing symptoms and experiences of illness
- Must be registered with a GP or CFS support groups
- Participants can be a male or a female
- Must speak English language fluently

Exclusion criteria

People that have recovered from CFS could not participate in this study. Children were excluded from this study.

5.2.Data Collection

Data were collected from participants, using interview questions. Face to Face semi structured open ended interview process was used. The interview sessions were audio recorded to provide accurate data and to aid easy transcription of the interviewees words. Participants were advised prior to the interview their right to opt out of the study if they wished to do so. Participants current health was not affected as a result of the research data that were collected. All of my participants advised I could come back to them should I require further information.

5.3. Interview transcript

Remenyi (2011) defines a transcript as data required for the analytic part of the research. He points out the relevance of verifying the interview transcript. Remenyi (2011) states when the transcript has been fully written up it is sometimes thought to be appropriate that the informant read it so as to verify that the researcher has correctly understood the data which was supplied. The transcript for this study was completed shortly after all the interviews were conducted. Each interview transcript was sent to the participants for verification. Most of the participants replied quickly that they were happy with the content of their transcripts. However, one of the participants was too sick to respond to me immediately and was given a further two weeks to look at the transcript and respond.

The purpose of sending my participants the transcript was to ensure the transcript was their actual words and that I have heard the recordings correctly. Remenyi (2011) states the transcript process is a step the researcher takes before the researcher starts his/ her analysis of the data received. He emphasises the transcript process is a relatively straight forward process where the informant reads the transcript document and either states that it is a fair reflection of what was said or perhaps asks for a few small amendments to be made in order to improve the

understanding of the situation. Out of my 8 participants, only one participant requested I take out some areas she spoke to me in confidence. The content of the transcript was a full reflection of her words during the interview, but she was not comfortable with me including a particular area of the transcript in my research analysis.

Remenyi (2011) states it is a good practice sending the transcript to the interviewees because some researchers feel that it is an important aspect of due diligence on the part of the researcher. Before each interview session, I asked my participants if they were interested in reviewing the interview transcripts. They were all interested in reviewing the interview transcripts. When the transcripts were ready, as part of my due diligence, it was emailed to them.

5.4. Thematic Analysis

An exploratory approach to qualitative data analysis was a preferred choice of data analysis, using thematic analysis. Guest, MacQueen & Namey (2012) explain thematic analysis as that which identifies and describes implicit and explicit ideas within the data/themes.

Qualitative data was collected through an in-depth interview, using open ended questions. Key words, trends, themes and ideas were retrieved from the data collected from the participants. Guest et al (2012) describe research data as textual representation of a conversation. Guest et al (2012) define theme as a unit of meaning that is observed in a data by the reader.

The interview recordings which was the raw data were transcribed, all repeating words in the text were identified and a list of the repeating words were made. Repeating ideas and concepts were identified. The list of repeating words, ideas and concepts were carefully studied, the themes were chosen from the lists. Some of these themes were narratives such as sleeping. The themes were further studied to identify the relationship between them. Research questions were considered when establishing the relationship between the themes. Guest et al (2012) explained themes to be concepts that reoccurs across transcripts.

5.5. Coding of themes

Guest et al (2012) describe code as a component of a theme. Saldana, Leavy & Beretvas (2011) explain a code in a qualitative data analysis as a word or a short phrase. Some codes were identified in this research data to represent themes. The codes identified were studied to record their frequencies in the research data. The relationships between the codes were studied and discussed.

5.6.Ethical Considerations

Walker (2007) stresses the importance of assessing participants for signs of distress during the interview process. In the event that participation in the interview causes the interviewee emotional distress, the interviewees welfare would take priority over the research (Walker, 2007). In the event of a participant/participants being distressed during the interview, the plan was to stop the interview, and offer to remain with the participant. Offering basic emotional support such as attending, listening and empathising. Fortunately, in all of my research interviews none of my participants was distressed as a result of the interview. I had planned, should any of my participant become distressed, I would give them the opportunity to either continue or stop the interview and advise them to see their support group counsellor. The interviews were conducted during the day and times their support group counsellors were available and easily accessed. Participants were allowed to have a support person with them, one of my participants had her mum with her during the interview and another had his wife with him. The support person could either be a friend or a family member.

Should I become distressed as a result of the interview, I had the option of contacting my principal supervisor for support. I had the opportunity of using the employee assistance programme (EAP) available at work. EAP offers counselling sessions for work related issues and other issues that may affect work. I was dropped off at the participants houses and picked up after the interviews.

Participants will be anonymised in my research findings. Participants names will not be identified with the voice recordings and in the research report. Data will be stored on a password protected computer (presumably this will include the voice recordings which will be electronic). The data will be stored in my Personal Computer (only researcher will have access to it). The audio recording will be locked away in a locked cabinet in supervisor's office at Unitec. Consent forms will be kept in a locked cabinet in my supervisor's office at Unitec

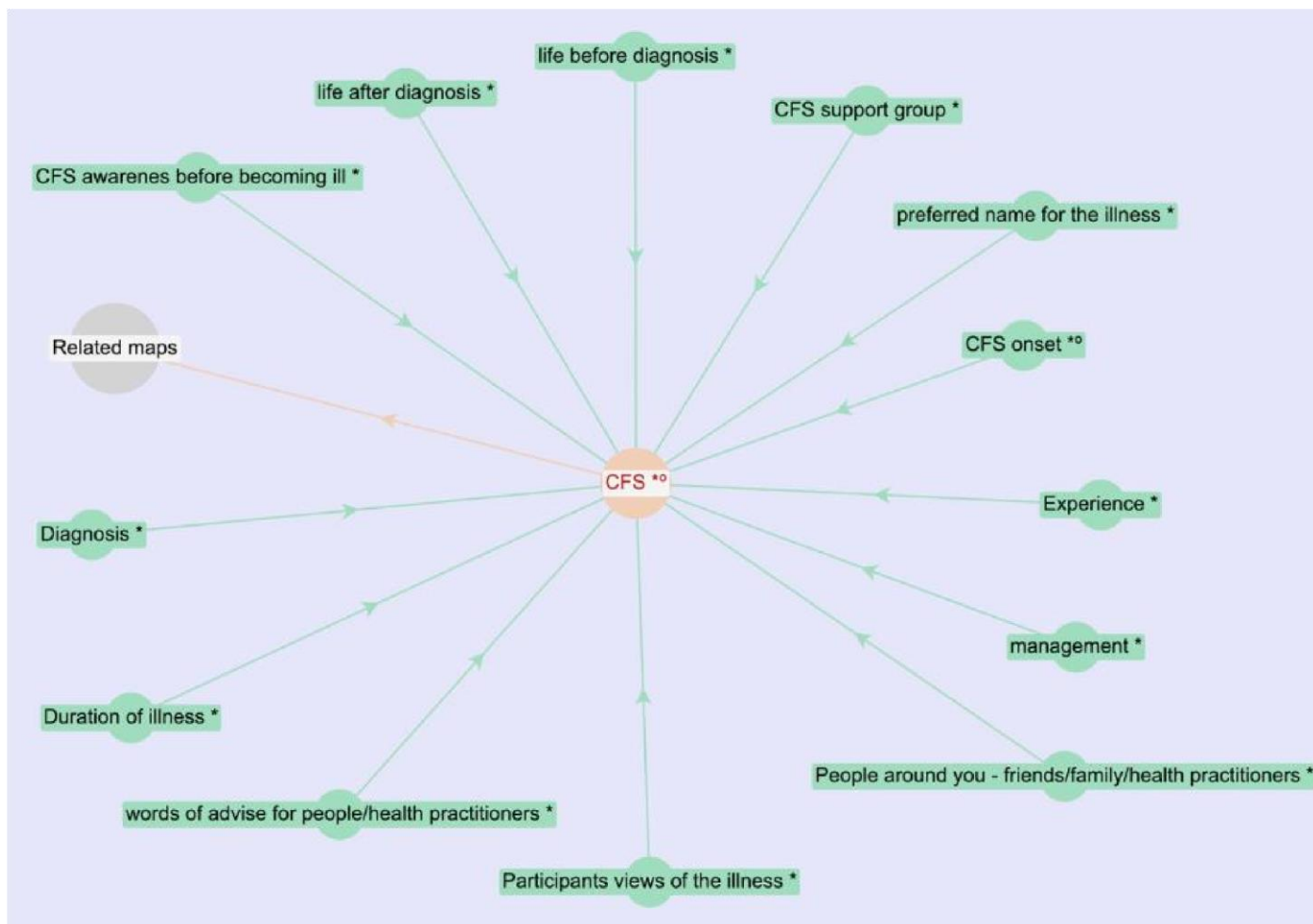
6. Data Analysis

Codes and Nodes

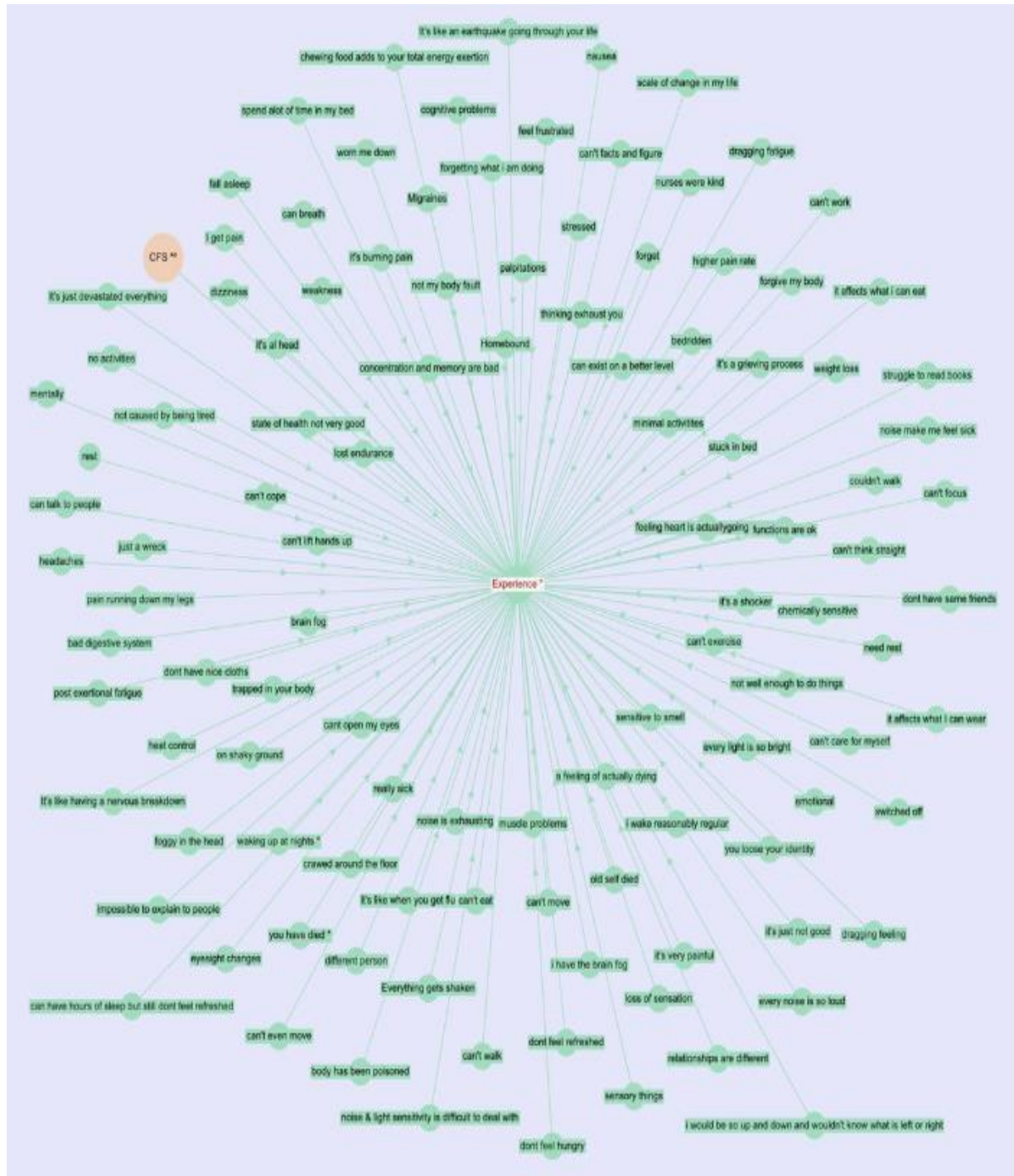
Codes and Nodes have been represented graphically using the debategraph as shown below. Parent Node: Chronic fatigue syndrome (CFS). The parent node was named CFS, being the topic of the study. The nodes in green colour attached to the parent node are headings for the

codes derived from research data. It was relevant to know how they were before their illness and how much impact the illness has made in their lives.

Figure 1: Nodes linked to parent node



The codes in the debategraph below were participants descriptions of their experiences of the illness - CFS



3 Management linked to codes

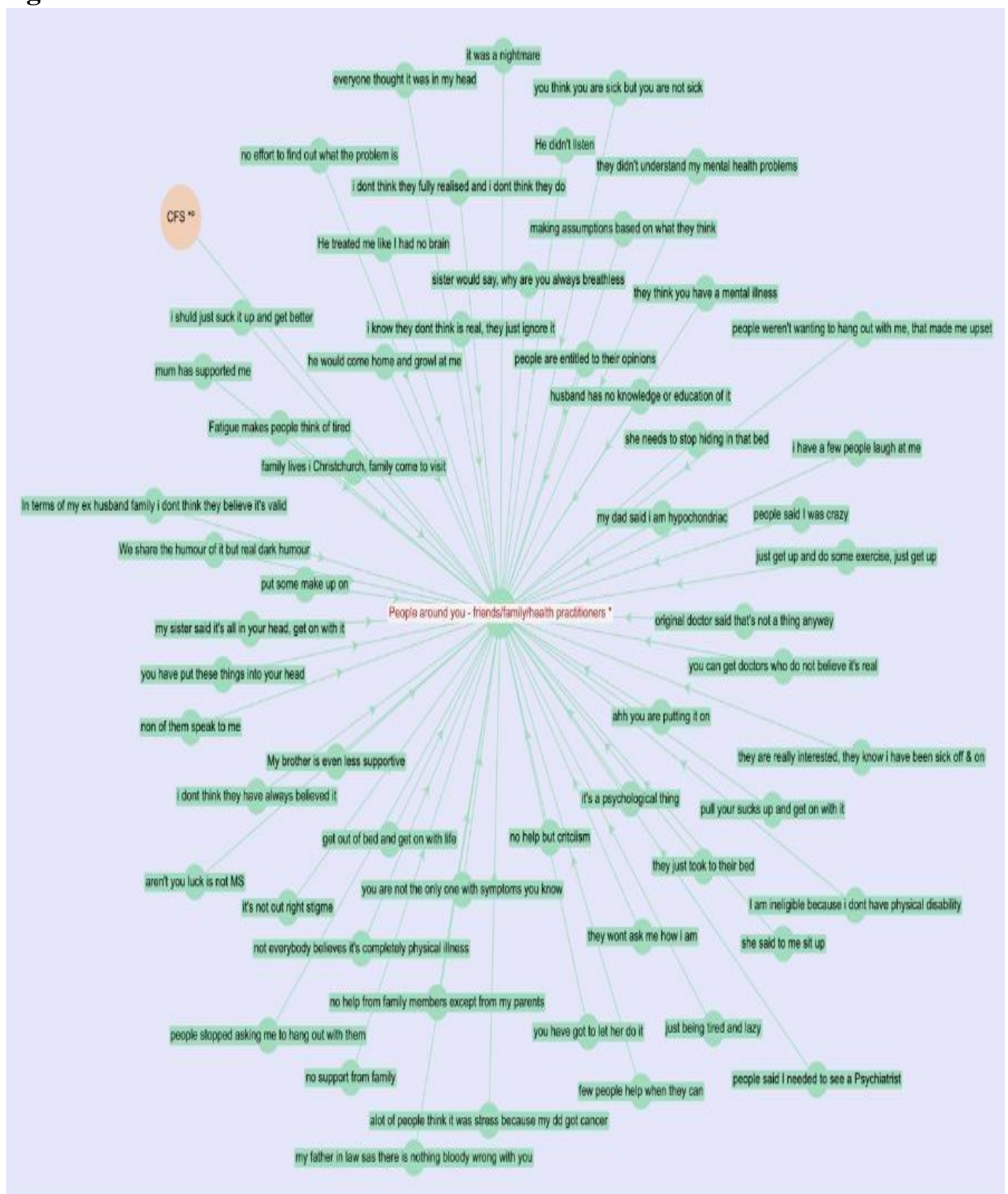
There were codes linked to this node. The codes were phrases the research participants used to describe their management plans (CFS).

The diagram is a radial network with 'management *' at the center. It features numerous nodes connected by lines, representing various aspects of chronic fatigue syndrome management. The nodes are organized into several clusters around the central hub:

- Medical Treatments and Medications:** Includes nodes for 'Ibuprofen', 'Acupuncture', 'supplements', 'get all the bits of electrolytes', 'Nortriptyline', 'low dose of antidepressant', 'Codeine doesn't help', 'Clonazepam', 'Tramadol', 'Magnesium', 'Powerade powder', 'Paleo meal, called fit me in', 'Naturopath', 'Panadol', 'vegetables, meat/protein', 'diet', 'praying', 'mum being able to help', 'daughter helps', 'Psychologist', 'able to sleep', 'slept for two weeks', 'support group', 'It takes the edge off but it does not fix it', 'go home and sleep', 'GP's see us on our good days', 'forgetting to eat/drink, slept for 2 weeks', 'I know now how to manage it', 'have treatment plan that is actually working', 'the relief for me was immediate', 'support is available but complicated', 'use muscle rub', 'no additional stress', 'can't pick a trigger', 'calmed everything down', 'dont do home visits anymore', 'thinking carefully about what i am doing', 'know where your line is', 'spend alot of time resting', 'sleeping pills', 'heat is quite effective', 'pain clinic', 'to help you sleep', 'it has to be 9 hours of sleep', 'government support', 'carer', 'cook and put stuff in the freezer', 'dont listen', 'CFS **'.
- Lifestyle and Social Support:** Includes nodes for 'friends make you feel so much better even on a bad day', 'bad days happen if i do too much', 'figuring out what's too much', 'know where your line is', 'spend alot of time resting', 'sleeping pills', 'heat is quite effective', 'pain clinic', 'to help you sleep', 'it has to be 9 hours of sleep', 'government support', 'carer', 'cook and put stuff in the freezer', 'dont listen', 'CFS **'.
- Other Notes:** Includes nodes for 'I know now how to manage it', 'have treatment plan that is actually working', 'the relief for me was immediate', 'support is available but complicated', 'use muscle rub', 'no additional stress', 'can't pick a trigger', 'calmed everything down', 'dont do home visits anymore', 'thinking carefully about what i am doing', 'know where your line is', 'spend alot of time resting', 'sleeping pills', 'heat is quite effective', 'pain clinic', 'to help you sleep', 'it has to be 9 hours of sleep', 'government support', 'carer', 'cook and put stuff in the freezer', 'dont listen', 'CFS **'.

The codes linked to node, contains phrases about what they thought other people around them perceived of their illness. Their experience of other people perceptions of their illness (CFS).

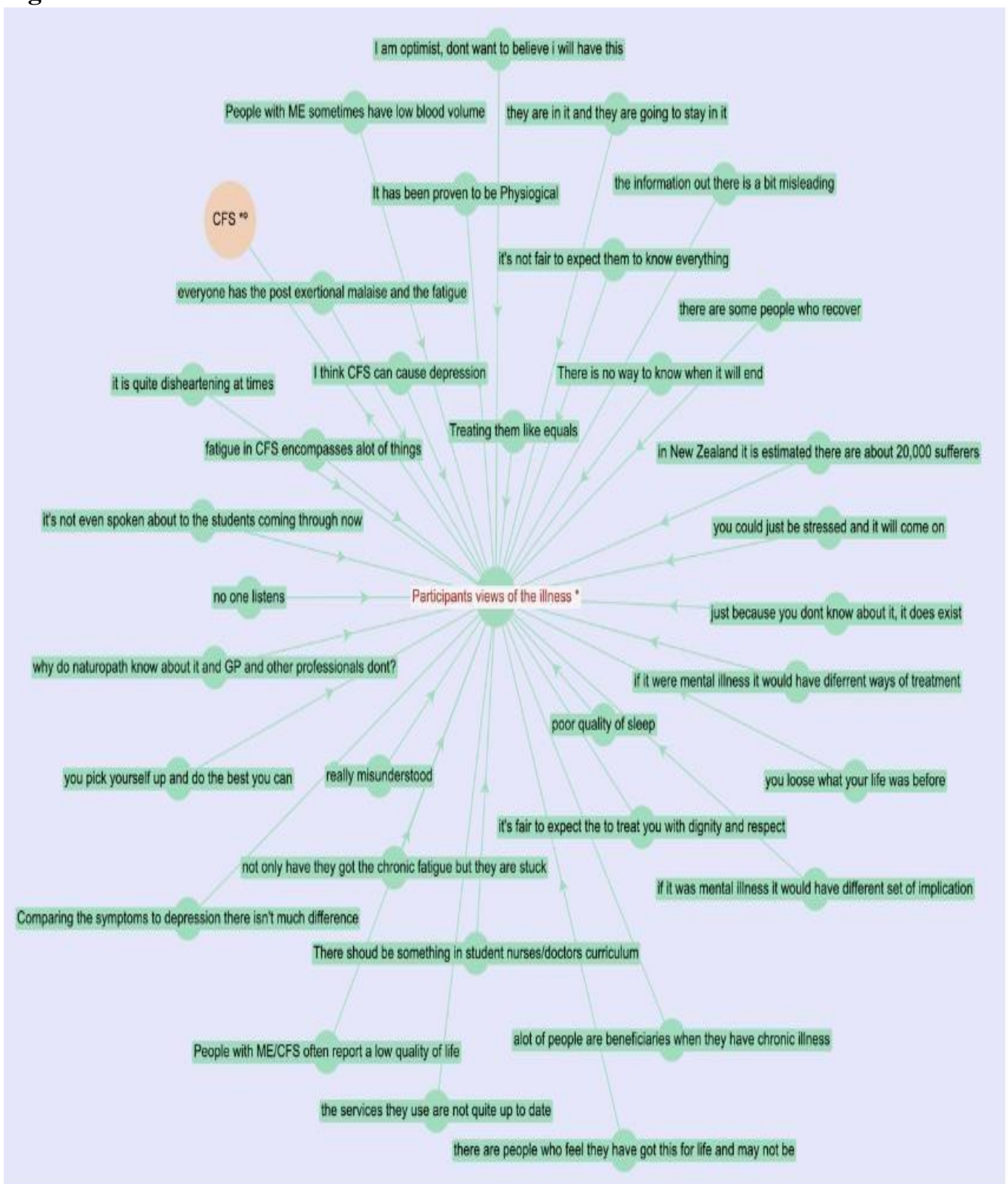
Figure -



5 participants views of the illness linked to codes

Codes with short descriptions of participants awareness of CFS.

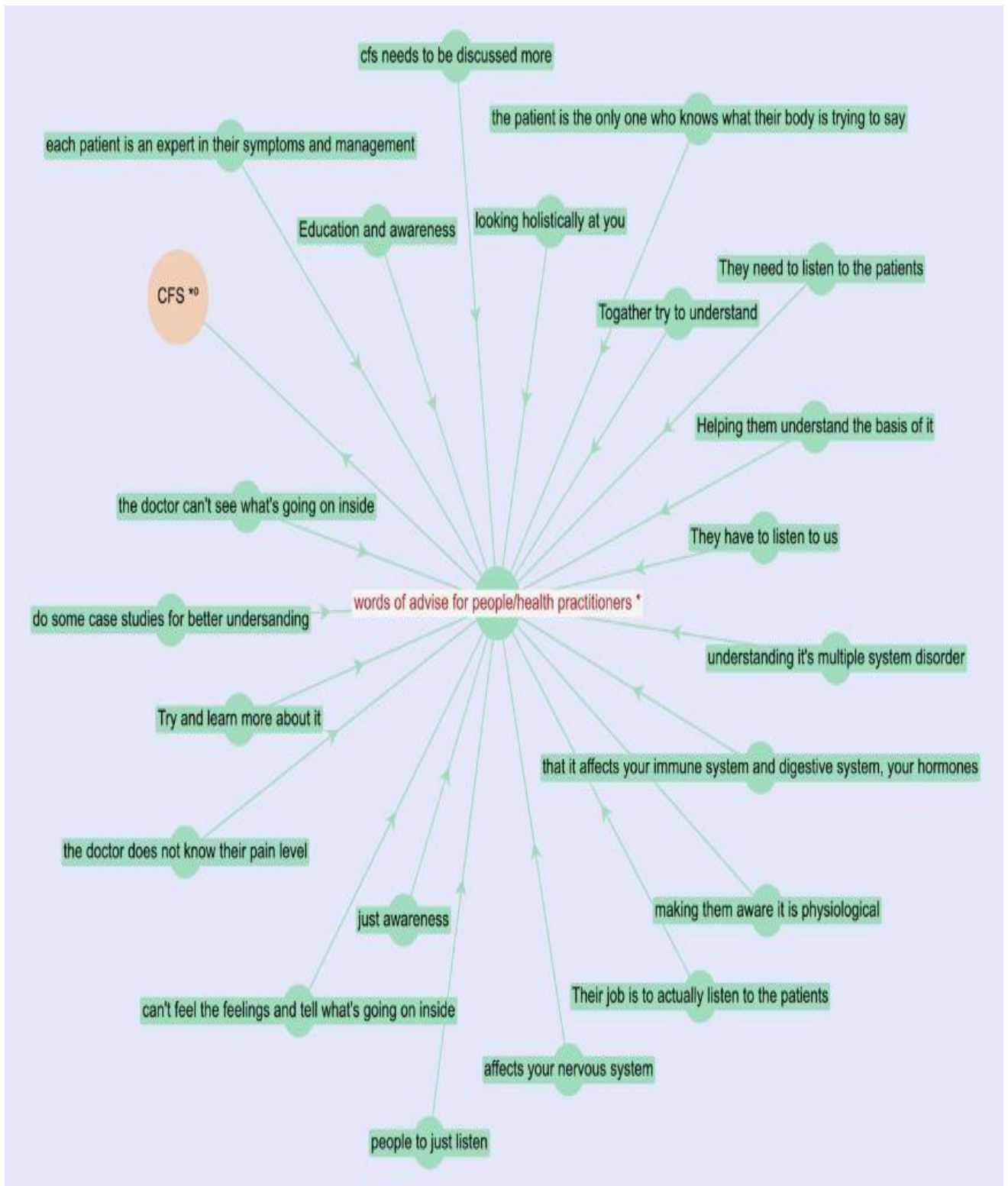
Figure : Node -



6: Node words of advice for people & health practitioners

Figure

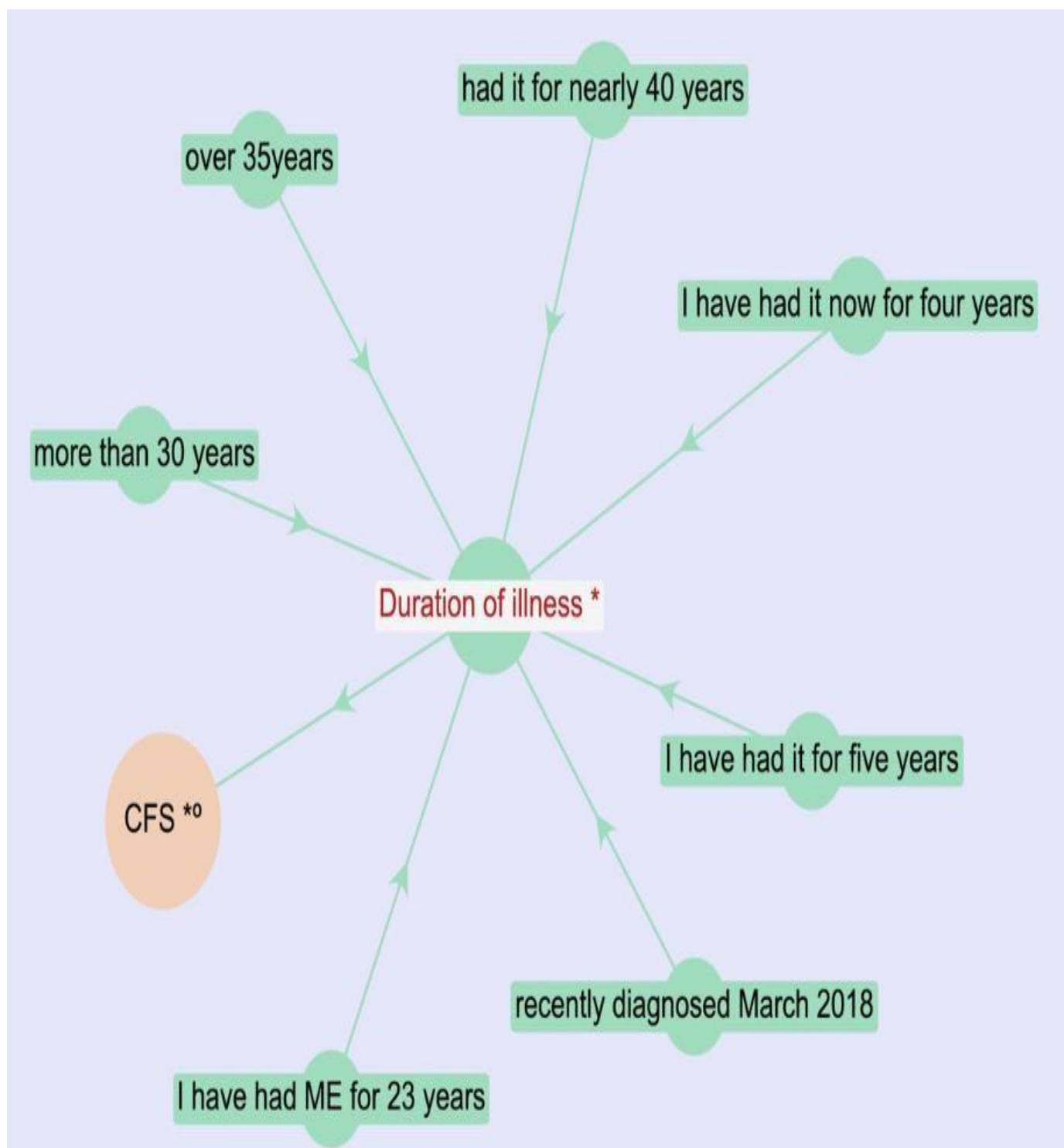
Codes containing what the participants expect of the public, people around them.



7 duration of illness (linked to codes)

Figure : Node -

Codes highlighting the length of time some participants have had CFS.



Codes describing participants experiences of their diagnosis

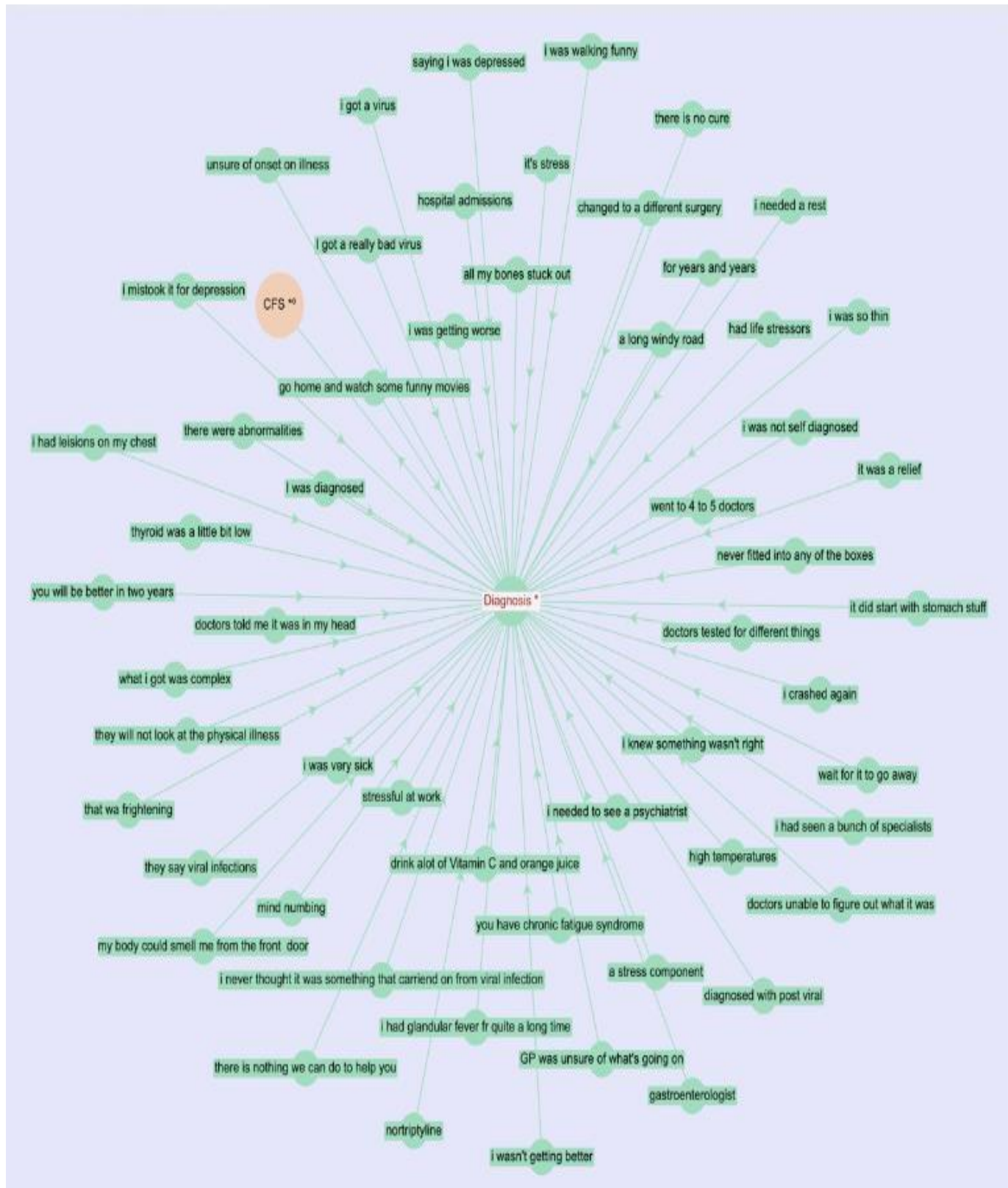
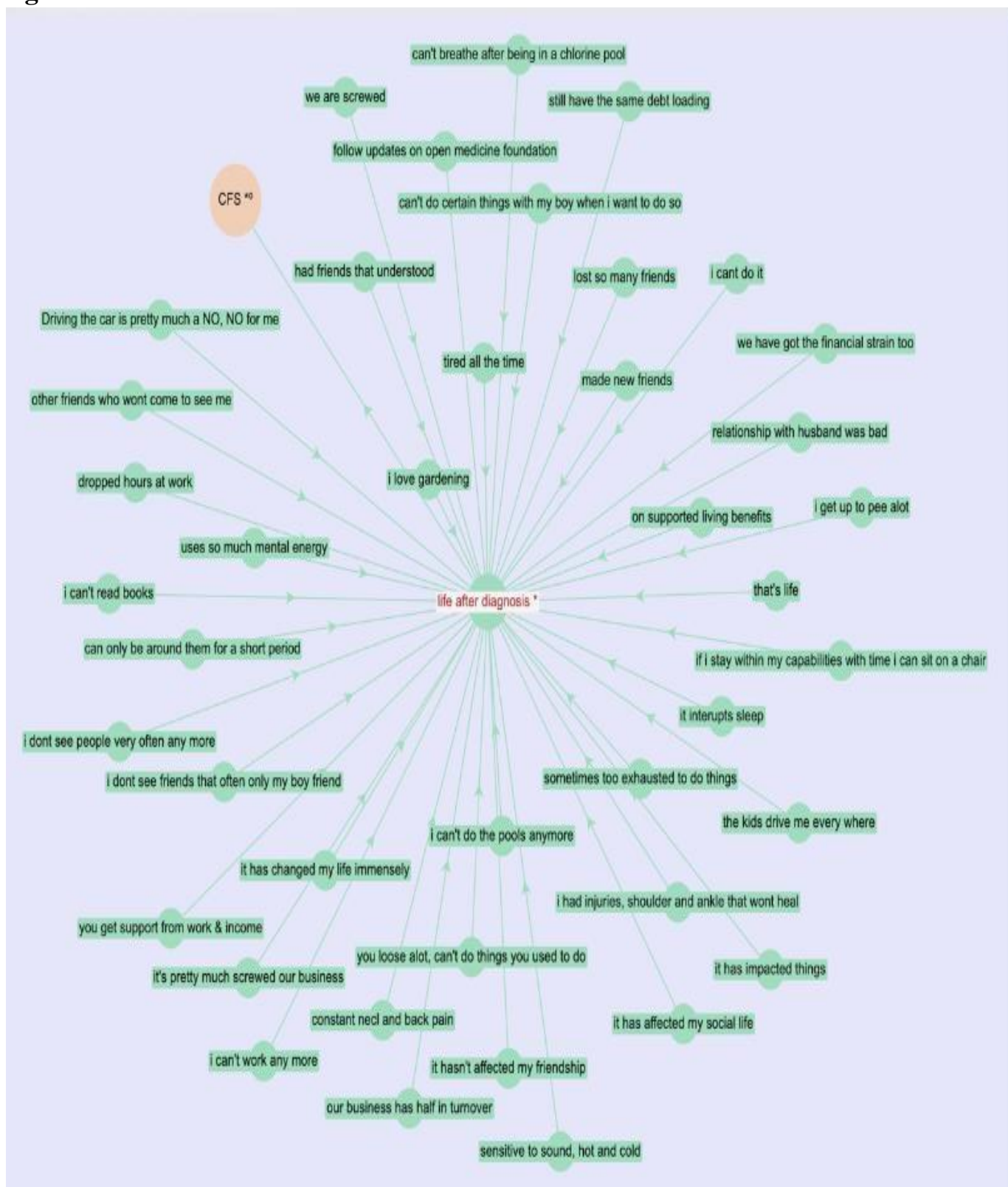


Figure : Node -

9 life after diagnosis (linked to codes)

Participants descriptions of their lives after receiving a diagnosis. Short phrases from participants

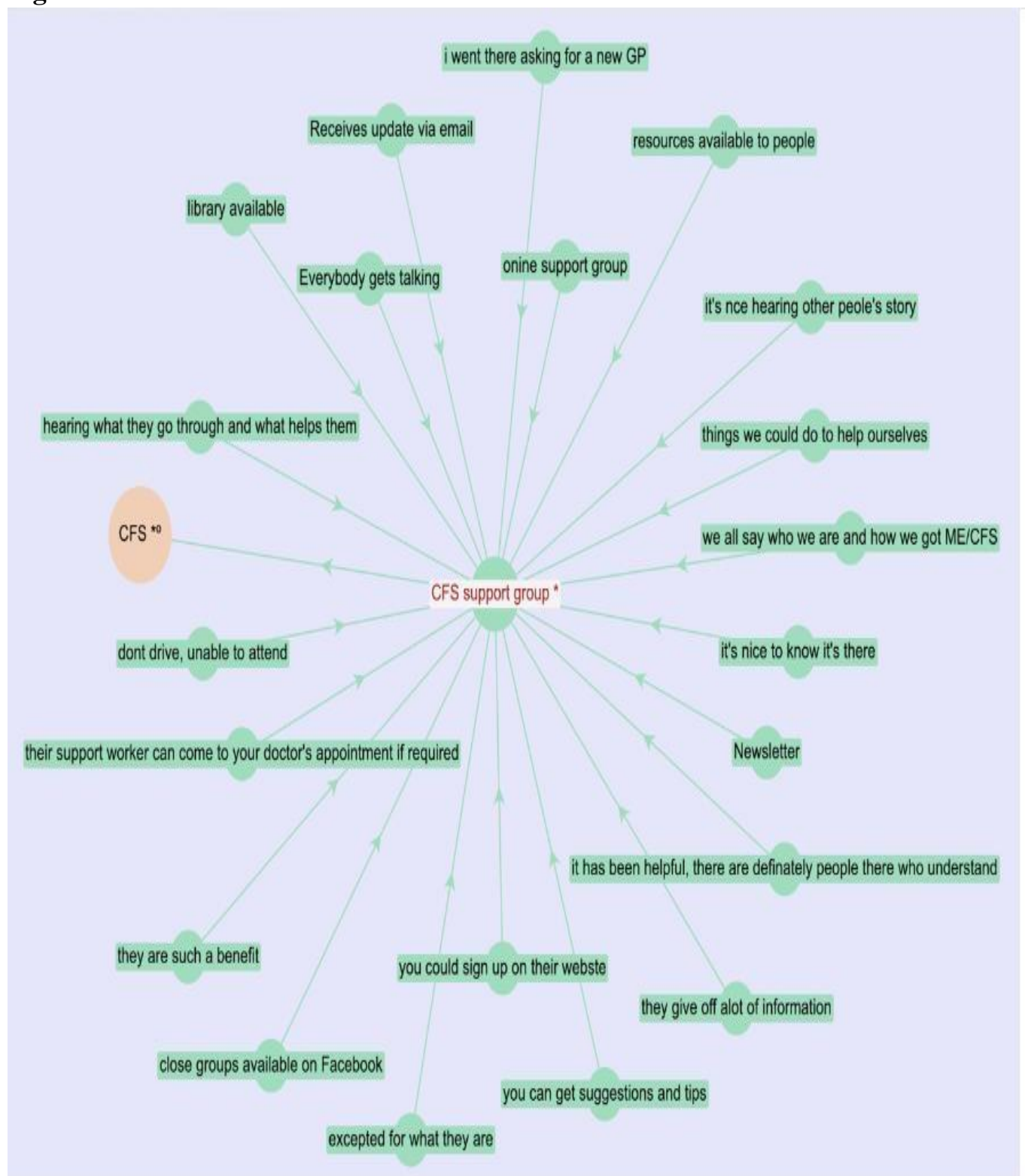
Figure : Node -



10 CFS support groups (linked to codes)

Participants experience of CFS support groups.

Figure : Node -

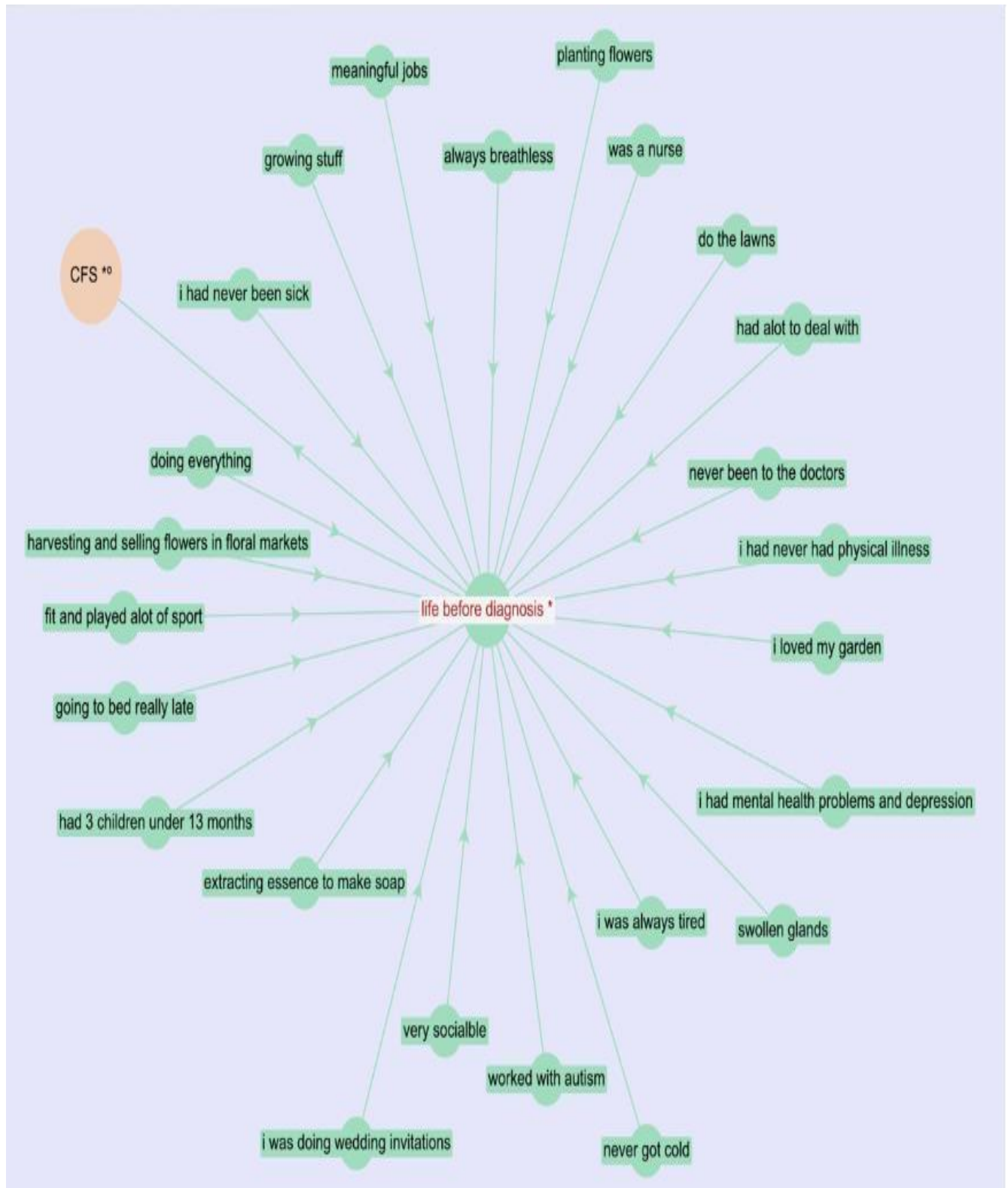


11 life before diagnosis (linked to codes)

Participants experience of life before diagnosis. Participants short phrases describing their experience.

11 life before diagnosis (linked to codes)

Participants experience of life before diagnosis. Participants short phrases describing their experience.



12 CFS awareness before becoming ill (Node is linked to codes)

Participants knowledge of CFS before becoming ill with CFS.

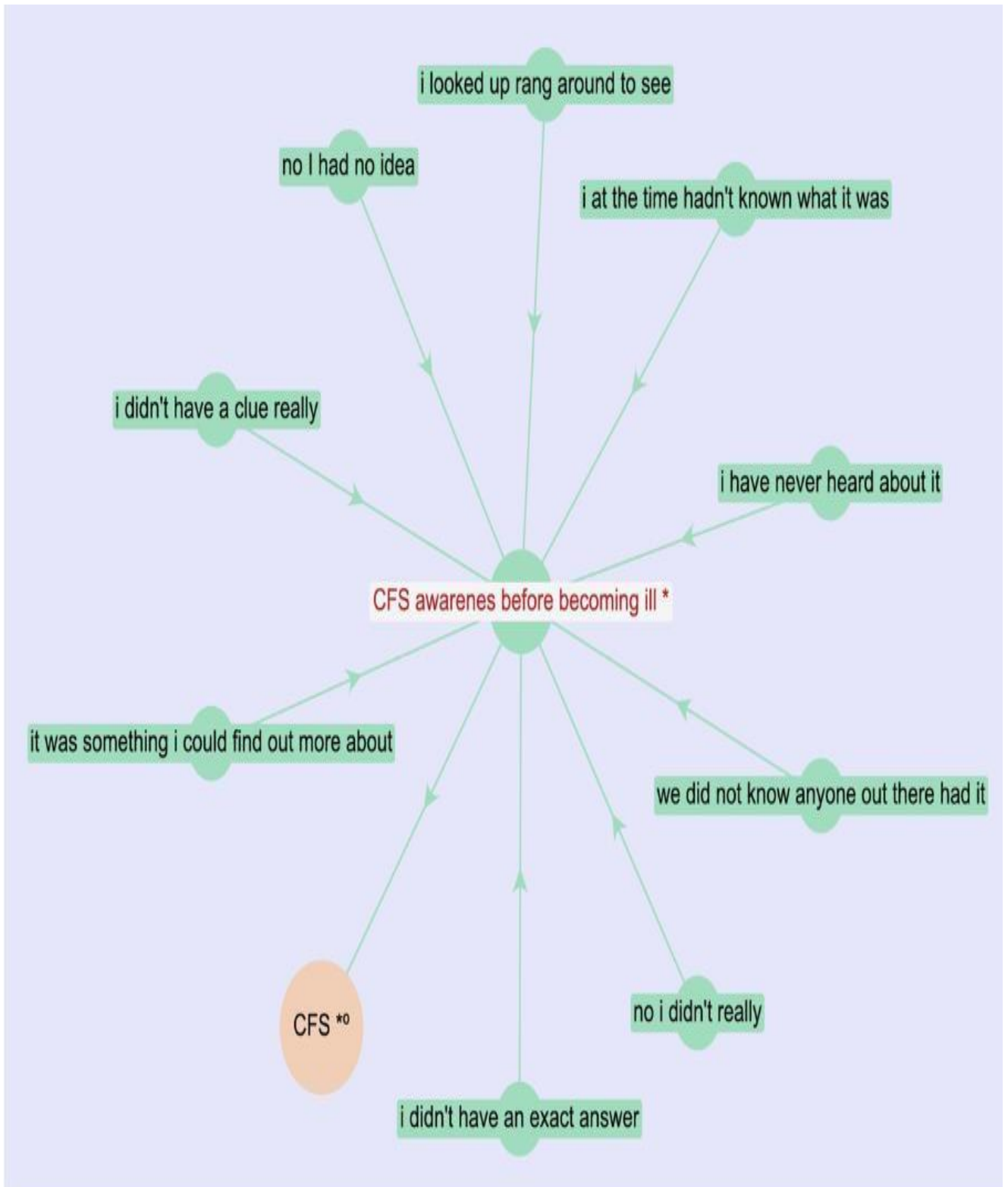
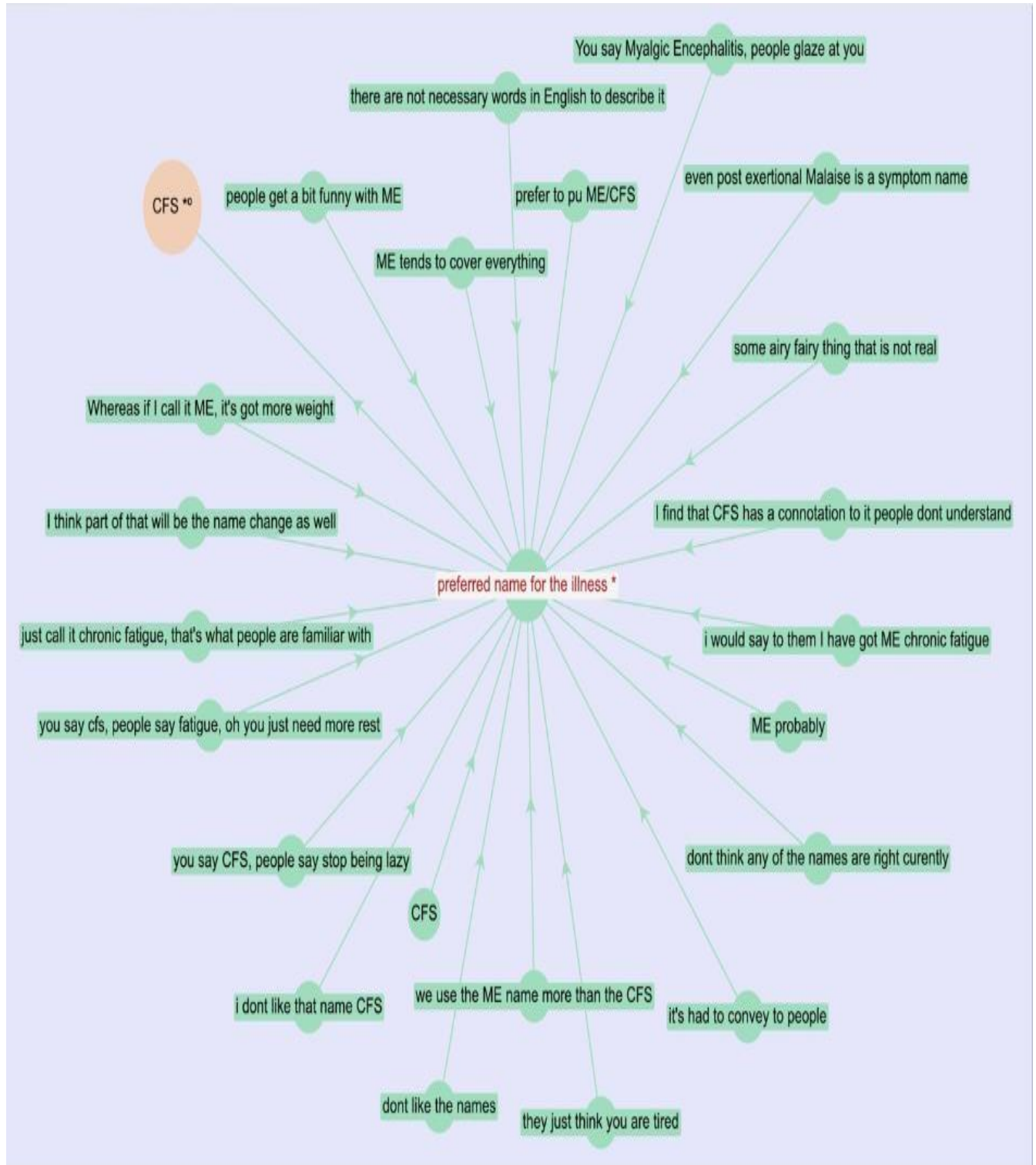


Figure : Node -

Figure 13: Node - Preferred name for CFS (node linked to codes)

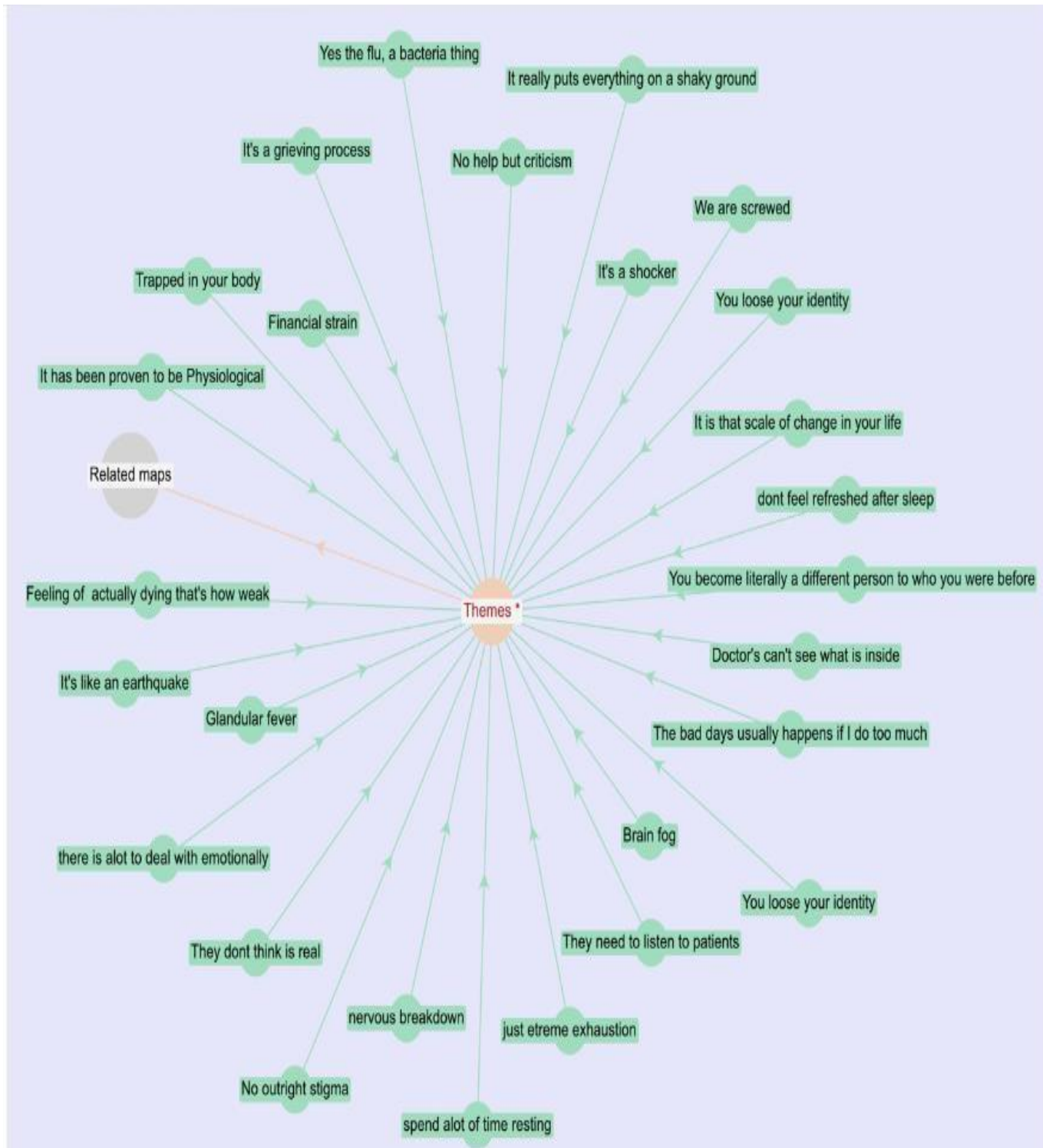
Participants experience of the name CFS, and their preferred names.



Themes:

These were common phrases used by participants. The occurrence of the phrases was high. Themes with higher occurrences were studied and discussed.

Figure 14: Themes



7. Results

Prominent themes were identified from the research data. This include:

The need to listen

The participants expressed the need for health care practitioners/carers to listen. Participants felt they were not being listened to by their doctors when they attempted to explain their illness. Participant W talked about one of her visits to the hospital, where she insisted her daughter went with her. In her conversation during the interview, she said she told her daughter “I’m not going on my own, they won’t listen to me”. Participant W referred to the rights of patients that have been violated so many times in relation to patients not being listened to. However, Participant W talked about her visit to a cardiologist who actually listened to her, she said the ability of the cardiology to listen to her made a lot of difference to her treatment. Participant W said, “it’s listening and believing what I tell them, not thinking I don’t know anything”. Participant M said, “I think one of the things is for people to just listen” Participant M said by doing this, you show respect to the person as well as giving them their dignity. Participant M believes people need to be listened to first before having some form of validation. Participant A, talked about health practitioners, she suggested “their job is to actually listen to the patient, find out what is going on, make an educated guess based on the available information that they have”.

The need for more education/awareness for health practitioners and the public

Participant JO, in his conversation during the interview emphasised on the need for doctors to have more knowledge of chronic fatigue syndrome (CFS). He believed more knowledge of the illness will make a huge difference in understanding and responding to the illness. Participant J expressed the need for a public awareness of the illness, such as having it in media and magazine. Participant J in her words said, “helping us as far as I can see is letting more people know about it”. Participant Ka said an awareness of the illness will be helpful. Participant A said, “there are a lot of doctors who don’t know a lot about it”. Participant A suggested CFS should be included in higher education curriculum.

It is real

They believe people, including their doctors do not believe the illness exist. Most of the participants said their doctors told them they were depressed and that the illness is in their imagination. As expressed by participant W “they kept telling me I was depressed, and I knew I wasn’t depressed”. Participant W said, most of her family members believed all of her symptoms were being imagined, however she said her parents believed her. Participant W said she was very sick physically, when she was told she had depression. At that point in time, participant W said her physical illness was not acknowledged. Participant A said her dad told her that it was “in her head”. Participant K expressed disappointment in her ex-husband family, she said “in terms of my ex family, I don’t think they believe it’s valid”. Participant K recalled the number of times she was referred to the psychiatrist by her doctors because they did not believe she had other illness but thought it was a mental illness. “Participant K expressed her disbelief in her friends and extended family members. In her statement, she said “but I know that they don’t think it’s real, so they just ignore it”. She said her friends and extend family members would call her on her phone to speak to her and would not ask her of her state of health but would rather ignore it throughout their conversation. Participant SO, said she believes her family never believed her. In her statement, she said, “I don’t feel they have always believed me”. Participant A explained that people with CFS get treated as if they have come up with ideas of the presenting symptoms. According to participant A, “people get treated like, oh you are just making it up or you are over exaggerating”. Participant M said, “just because you don’t know about it, doesn’t mean to say it does not exist”. Participants impression of people around them was that, people do not believe the illness exists, people are of the opinion that CFS sufferers are either depressed or imagining symptoms.

Experience of CFS in relation to diagnosis

Some of the participants said they had glandular fever at some stage in their lives but unable to ascertain if that was the cause of their CFS. Participant JO did not have glandular fever at any time in his life, however he had influenza. Participant JO said after being treated for influenza, he continually had headaches and weakness, and following the constant headaches and weakness, he was diagnosed with CFS. Participant K had glandular fever which progressed into CFS. Participant M had influenza at the age of 60 and became very sick and unable to return to work. Participant Ka had influenza when she was 20 years of age and got better soon after. Later in her life, over a period of 5 years she encountered significant life stressors. According to participant Ka, “I was having some really stressful stuff happening at work and

after that I went downhill”. Participant Ka, said she never got better, she got weaker and was diagnosed of CFS.

Two of my participants said they did not have influenza, but they experienced some life challenges that appeared to have been stressful. Participant W, separated from her first husband after having two children, got married to her second husband and had 3 children within 13 months. she had to look after the toddlers alone when her husband was away at work. Participant W said it was extremely difficult for her to stay at home to look after the children. Participant W said she was always very tired and unable to move her body. Participant W was initially diagnosed of post viral infection and following this she was diagnosed of CFS. At a particular time in participant J’s life she had a bad marriage and at the same time had a job that was very stressful. During this period, she said she would have muscle pain, weakness and sore throat for months. Participant J said her tonsils were surgically removed with no improvement to her weakness but soon after her tonsils were removed, she was diagnosed with CFS.

One of the participants (participant SO) had stomach upset which she referred to as gastrointestinal (GI) problems. Participant SO said she never had influenza or glandular fever prior to her diagnosis. Participant SO had GI for a significant length of time and was referred to a Gastroenterologist. The Gastroenterologist diagnosed her CFS.

Participants said they experienced delays in their diagnosis. They visited different doctors and were referred to specialists before arriving at a diagnosis. Participant SO, said “my GP never diagnosed it, I have seen a bunch of specialists”. Participant K said “I went to different doctors to ask them to test for different things”. However, one of my participants said she was diagnosed of CFS after a little delay and did not have to visit many doctors. Her GP diagnosed her illness. Participant K said she was diagnosed of CFS by her General Practitioner (GP) 6 months after she had glandular fever. Participant W expressed her frustrations before arriving at a diagnosis, she said she had hospital admissions numerous times before arriving at a diagnosis. Most of the participants expressed their frustrations before arriving at a diagnosis. Participant W said, “I went to 4 or 5 doctors”. Participant SO, was referred to two specialists before her diagnosis. Her GP did not give her a diagnosis after so many visits but one of the two specialists she was referred to diagnosed her of CFS. Participant M visited her doctor couple of times after she became ill, but she was diagnosed of CFS 6 months later.

Experience of CFS in relation to depression

Six of the participants were told they had depression and were treated for depression.

According to participant W “they kept telling me I had depression and I knew I wasn’t depressed”. Participant W said despite it was obvious she had physical illness that were proven with some tests carried out at the hospital, the doctors at the hospital thought she had depression. According to participant K, “I mistook it for depression actually, I thought that maybe I was just really depressed and that was the reason why I felt that way”. However, participant K said her doctor said it was definitely not CFS. She said the time of her diagnosis was “quite a confusing time”. Participant M was diagnosed of mental health illness and was treated for it and then she was diagnosed of CFS. Participant A received a diagnosis for depression and then CFS.

Experience of chronic fatigue syndrome in relation to Physical health

The participants all believe their illness affected their physical wellbeing. Participant A described her experience as “that dragging fatigue where you can’t even move sometimes”. She further explained in her own words “when you get this, especially as it gets more severe, it has a higher impact of what you can do”. According to Participant W, “I get Migraines from working on the internet if I do too much”. Participant W said despite the impact of her illness on her physical wellbeing, her doctors did not believe her illness affected her physical wellbeing. “but they still wouldn’t look at it as a physical illness” (Participant W). Participant A said, “it’s very physical”. Participant M expressed her physical experience as “pain running down my legs all the time”. She described the pain as a burning pain. Participant JO said, “Most of mine is pain”. According to participant M, “three years ago I could walk properly, now I can’t walk properly”. Participant K explained her physical experience of the illness as “I’m trying to lift my legs to get up the stairs, but I just can’t”. The participants strongly believe CFS impacts on the ability to carry out most physical activities. Participant K said the exhaustion she has experienced from her illness cannot be described.

Experience of chronic fatigue syndrome in relation to Light and Noise

Some of my participants said it was difficult for them to deal with light, they preferred to stay in an environment with dim light or no light. Participant W said, “Noise and light sensitivity is hard to deal with”. She said, “noise is exhausting and makes me feel sick”. Participant K described her experience as “wanting to be in the dark, I couldn’t stand light”. She said she avoided the light and had to live in the basement of her house.

Experience of chronic fatigue syndrome in relation to cognitive ability

The participants talked about their cognitive ability. According to participant Ka, “I get the brain fog, I just can’t think straight”. According to participant Ka “I walk into a room and I forget what I am doing”. Participant K described her cognitive experience in these words “I can’t think about what I’m doing, and I get frustrated at myself and people get frustrated at me”. The participants also expressed their frustration of being forgetful. Participant SO said “I’m always forgetting things”. She explained that her ability not to retain information made it extremely difficult for her to read books or watched movies. “I was forgetting to eat and forgetting to drink, nobody was reminding me” (Participant W). Participant JO had to refrain from legal responsibilities in his private business. He has been unable to think sensibly. Participant JO gave an example of his cognitive ability in his words “I have written an email and think it’s all good, but it didn’t make any sense, the words didn’t even flow together, that side of it is a bit frustrating”. For participant JO, he described CFS as an illness that affects the head in particular, he said “it’s all head”.

Experience of chronic fatigue syndrome in relation to emotions and Social activities The participants emotional expression of the illness was frustration. Not being able to think or do the activities they loved to do. According to participant A “it’s affected my social life because I am too exhausted to do things”. She explained she can only socialise with her friends and family only for few minutes. According to participant A “I get frustrated and irritable”. She explained, she gets frustrated when not being able to follow stories people are telling her because they involved some mental activities. According to Participant M, “CFS has changed my life immensely”. One of the participants had been bedridden for 20 months as a result of CFS. Another participant was house bound, she could only go long distances with her mother in a car. At the time of the interview participant JO, had stopped driving. “Driving the car is pretty much a no, no for me” (Participant JO). For these participants their social life had been compromised due to the illness.

Financial impact

Majority of the participants said having CFS has affected their financial status. “our business has halved in turnover” (Participant JO). Participant JO has been unable to assist his wife to run their business and due to his inability to assist his wife to run their business they had financial debt and have been struggling financially. Participant SO has not been able to work. “I can’t work anymore” (Participant SO). Amongst my participants, only one of them was still

working, Participant K, was able to work 8 hours shift a day and then return home to rest for the day.

The participants that were not working had some financial support from the government. They said the financial support received was not enough to cover other aspects of their lives such as having extra clothes or paying the bills. “I am a sole parent, so I get sole parent support and then the disability support on top of that it doesn’t meet expenses that you have” (Participant Ka). “I am only on a benefit” (Participant M). Participant W had a carer who came to her house to care for her because she was bedridden. “Government support, carer caring – 20hours per week” (Participant W).

Experience of chronic fatigue syndrome in relation to CFS management

Participants experience of managing their illness was similar. They all knew when to stop doing activities to rest. The participants said CFS management was understanding your body and knowing your limits particularly when talking and doing house chores. “I have a rest day because I am feeling a bit lower than usual in energy levels” (Participant A). “After a while you will get to know yourself and you will know where your line is” (Participant M). “I have learned to manage my illness, I guess, when I feel the symptoms coming on when I feel like I am starting to get a bit sick and tired and weak, especially if I am on early shift in the morning, I start to go home and sleep after I have finished work” (Participant K). Some of the participants were on medications to relief them of pain.

All the participants had problems having a good sleep. Some had to take medication to sleep. Sleeping and feeling refreshed afterwards was their biggest challenge. They all said, they never felt refreshed after sleep. Although they spend most of their time sleeping, it made no difference in terms of feeling refreshed after having hours of sleep. “couldn’t sleep, and I couldn’t eat” (participant W). Participant W had sleeping medication prescribed for her to help her sleep. “I’m on sleeping pills to try and help with that” (Participant JO). “I don’t really feel refreshed, I can have nine hours of sleep and I still don’t feel great when I get up in the morning” (participant Ka). In this study, only one of the participants (participant A) was able to give a reason why she could not have a decent sleep. She said, she wakes up several times at night to use the toilet. The participants who complained of fluctuating body temperature, light and noise did not indicate if that affected their sleep.

Some of the participants had close relatives caring for them. Participant A had her mother caring for her, she was house bound. Participant W had her husband caring for her with the assistance of a carer. Participant K had help from her mother when required. Participant K could still go to work but there were days she had fatigue and unable to work. Participant M's daughter was her helper.

Most of the participants have once been prescribed sedative pills to help them manage their sleep issue. However as of the time of the interview, some of them had come off their sedative pills. The sedative pills were prescribed at that point of their lives when they needed it to help them sleep well. "I am on sleeping pill to try and help" (participant JO). Participant W had a sedative medication prescribed for her when she most needed it. She said the sleeping pill was effective as she was able to sleep. "I was able to sleep" (Participant W). Some of the participants had been on anti-depressant because they were initially diagnosed of depression and other said they were prescribed anti-depressant to help them sleep. "I have been on antidepressant for five years" (participant Ka).

Some of the participants took pain relief medication to manage pain or headaches. Participant JO had Tramadol prescribed for him because of constant headaches. Participant K experienced a lot of headaches. In her own words she described her experience as "headaches, really bad headaches".

Other participants, like participant A, used special ointment for her muscular pain. "I use the muscle rub" (Participant A). Participant M was referred to the pain clinic to help manage her pain. "I take Ibuprofen when I get headaches" (participant K).

Participant Ka managed her CFS using diet and supplements alongside other treatments. "I think with the supplements that I'm taking and the diet, no carbohydrates, no sugar, no fruits, no dairy, pretty much vegetables and meat and protein and that is definitely helping (Participant Ka). Participant Ka said the supplements she is on contains a lot of amino acids. Participant A was having a particular drink to boost her energy level. She called the drink "Powerade". "I have that powerade powder that you can buy from the super market and I just make up some of that, you get all the bits of electrolytes that you need" (participant A). "We changed my diet and I am on a whole lot of supplements (participant M). Three of the participants (A, JO & K) said they took magnesium supplement to help with muscular pain. "I have magnesium now

before I go to bed” (participant K). Participant JO said he was on Co enzyme Q10. Participants K, A and M found the supplements helpful.

Participant A said she did some exercises to help manage her CFS but her experience was not good and she had to refrain from it. “I went to do an exercise programme, my experience was not pleasant, I’m not making any additional effort to get exercise” (participant A).

All the participants made effort to rest during the day as part of their management plan. “I spend a lot of time resting” (participant A). “When I feel like I am starting to get a bit sick and tired and weak, especially if I am on early shift in the morning, I start to go home and sleep after I have finished work” (participant K). Resting during the day appeared to be one of the participants coping skill, particularly participants Ka and K.

Loss of Identity

The participants had personal phrases to describe the CFS. These phrases included, loss of identity (participant M), being screwed (participant JO), like an earthquake going through your life, everything get shaken, rocked and changed (participant W), trapped in your own body (Participant A), scale of change in your life, becoming literally a different person to whom you were before (participant A), a grieving process (participant A), Your old self is dead, you have died (participant A), It’s a shocker (Participant M), I feel like my body has been poisoned (Participant M), you feel kind of poisoned in a way (participant M). A feeling of actually dying, on shaky ground, just a wreck, devastated everything, lost endurance, stressed (participant W). Participants used these phrases to describe how much control CFS has over their lives. Their explanation of these phrases was that CFS literally takes control over your life, unable to live life the way you would normally do and unable to plan for the future. Participants said the symptoms experienced virtually controlled their bodies.

8. Discussion

The results from this study have been carefully considered and discussed. Similarities and differences between the study results and literature review were discussed.

Participants perception of people around them:

Participants talked about their experience of not being listened to by some health practitioners and other people within their families, including friends. As previously mentioned in the literature review, De Lourde et al (2011) state the lack of knowledge and inadequate

communication between patients and health professionals have often been the barriers to diagnosis and care. It could be argued that communication includes the ability to listen to others. In this study, participants were requesting people listen to them first, before offering care or treatment. They also want people to believe the illness and its symptoms are real. The participants were of the opinion that better care and treatment will be offered to them if people believed the illness exist and affects the physical health. The participants in de Lourde Drachler et al (2011) study reported that living with CFS was hard, particularly when doctors disbelieved their illness. Disbelief and lack of empathy by health care providers emerged as common experiences in De Lourdes et al (2009) study. In De Lourde et al (2011) study, many reported leaving doctors rooms in tears knowing that they were very sick but having no way to convince others about the legitimacy of their illness.

In this study, participants also commented on their perception of health practitioners level of awareness of CFS. Participants recommended more education on CFS for health practitioners and the general public. De Lourde et al (2011) study, indicated that there was lack of knowledge on CFS amongst the health professionals. McInnis et al (2013) study stress the need for the public and healthcare practitioners to be provided with some proper education on CFS because the illness has not been well known or received a widespread acceptance.

Participants frustrations:

Participants in this study expressed their frustrations with CFS. This was highlighted in the result of the study. The participants said they have lost their identity, no longer who they used to be because they were unable to do the activities they would normally do. As stated in Dickson et al (2007) study, the participants in their described CFS as a dictator. It was referred to as a dictator because it was believed it dictated its sufferers' everyday lives. This means the illness controls the sufferers, the sufferers have no control over it. Dickson et al (2007) state that the illness determines what you can and cannot do, it controls the body and mind and every part of the being. The participants perception of the illness in Dickson et al (2007) study was that it controls every aspect of life. Many of the participants in Dickson et al (2007) study described their experience as a loss of their old body and wanted to return to their old body which they referred to as pre CFS. Their experience was likened to death because it left them numb and without feeling. They had lost every sense of their being, their mind and their bodies. They no longer knew who and what they were (identity crisis). The words Dickson et al (2007) study participants used to describe CFS were very similar to that used in this study. Common words

that were used in this study were, loss of identity, identity crisis, loss of old body and death. It could be argued that the description of the illness by the sufferers indicates the extent of the damage they believe the illness causes. Dickson (2007) study participants reported an ongoing sense of personal loss characterised by diminishing personal control, and inability to plan for the future, with subsequent feelings of failure and worthlessness. This probably explains why the participants in Dickson (2007) study referred to CFS as a dictator.

Participants experience of diagnosis:

The participants experience of being diagnosed of CFS was a major theme that emerged. Most of the participants said their diagnosis took quite a long time. Some of them had to change their general practitioners several times, seeking for a diagnosis based on their symptoms. However, the participants said they were relieved when they finally arrived at a diagnosis. De Lourdes et al (2009) emphasised how the participants in their study perceived having a diagnosis. They state the participants perceived it was crucial having a diagnosis. De Lourdes et al (2009) state the search for a diagnosis in both adult and young people could take a long time. They further explain the diagnosis of CFS could take more than 10 years of consulting with health professionals without being taken seriously. One of the participants in this study said she was referred to a gastroenterologist, who later diagnosed her of CFS. As stated by Fukuda et al (1994) CFS is characterised by gastrointestinal symptoms. This probably explains why a gastroenterologist was able to give her a diagnosis and not her GP. Reflecting on the interviews with the research participants in this study, it appears they all had delays in their diagnosis. Friedberg et al (2012) point out that despite the substantial progress that has been made in understanding the underlying biology of CFS/ME, researchers, clinician-scientists and physicians still do not have enough accurate diagnostic test. Friedberg et al (2012) study explains the reason for the delay in diagnosis. They state it could be lack of sufficient diagnostic tool.

Some of the participants in this study were diagnosed with mental health illnesses such as depression, and bipolar. One of the participants was diagnosed with a bipolar disorder. Another participant said it was suggested to her that she had depression, but she disapproved of it because she knew she did not have depression. Balachander et al (2014)) state most patients with CFS meet the criteria for depression or anxiety. Balachander et al (2014) explain depression has been found to be associated with CFS and there are certain similarities between CFS and depression. Balachander et al (2014) further explain that studies have suggested many psychiatric disorders are associated with CFS. In other words, Balachander et al (2014) point

out that there have been studies to show the link between mental health illness and CFS and these studies have found a link between CFS and depression and suggest Psychiatric illness could also be associated with CFS. However, another study by Lawrie and Pelosi (1995) explain that CFS is often not diagnosed or misdiagnosed as psychological morbidity or a psychiatric disorder. In my opinion, based on these studies, there are still controversies around CFS diagnosis. Some studies are suggesting a link between psychiatric illness and CFS and other studies are suggesting CFS has been misdiagnosed as a psychiatric illness in some cases.

Effects of CFS on cognitive ability:

Participants in this study talked about their cognitive ability to retain information. Most of the participants said they are unable to remember information, and due to the inability to remember information, they had to stop working. Participant JO was an example, he stopped working due to his inability to think sensibly. Fukuda et al (1994) study points out that CFS could result in people having neurocognitive disturbances.

Physical inability to perform certain tasks:

Participants described their inability to carry out some tasks at home because of the pain and physical weakness they experience most days. The participants said they experience a lot of pain and severe fatigue. One of the participants said he experiences bad migraines that does not respond to his prescribed medications. Rutherford, Manning & Newton (2016) state many people with CFS have referred to CFS as an illness with difficulty in maintaining muscle activities due to lack of energy/fatigue. Van Cauwenbergh (2012) points out that CFS is a condition characterised by extreme fatigue that is not resolved with rest. The participants in Dickson et al (2007) study described their inability to undertake a broad range of both physical and mental activities.

Bruce et al (2011) stress the need to provide CFS patients with antidepressant medications, which are sometimes helpful in managing CFS symptoms and to increase the energy level and reduce anxiety and depression. Some of the participants in this study were on different types medications. One of them found the anti-depressant medication very helpful. She said she only took it for a short period of time and at the time she was prescribed the anti depressant, she was able to sleep well. Others had pain relief prescribed to them to help with body aches and migraine. Fukuda et al (2008) state CFS is a debilitating disorder that is characterised by headache, muscle and joint aches, and sleep impairments. Nice (2007) states there is insufficient evidence for the use of supplements such as vitamin B₁₂, vitamin C, co-enzyme

Q10, magnesium or multivitamins and minerals for people with CFS, and therefore they should not be prescribed or recommended for treating the symptoms of CFS. Joustra et al (2017) state CFS patients use nutritional supplements while it is unclear whether deficiencies in vitamins and minerals contribute to their symptoms. In Joustra (2017) study little evidence was found to support vitamins and minerals deficiencies playing a role in the pathophysiology of CFS.

Participants in this study also experienced poor sleep at nights. They said they never felt refreshed after so many hours of sleep. Similarly, in Gotts et al (2015) study all the participants had sleep disturbance. The participants in Gott et al (2015) study said they felt dreadful when awake from sleep. However, the participants in this study felt unrefreshed when awake. Gotts et al (2015) study indicated that the participants in their study had reasons not to sleep well because of their experience of fluctuating body temperature.

Social life:

All the participants in this study said CFS had an impact on their social lives. They are unable to socialise as they would like to with friends and families. Some of the participants could not socialise due to the impact of the illness on their wellbeing. "People with severe ME cannot participate in social activities, cannot work, cannot volunteer for anything, cannot travel, cannot go to school, cannot do anything in this life" (Crowhurst, 2015, pp 13). Crowhurst (2015) describes the impact of CFS as an illness that destroys every normal event and celebration.

Employment:

The participants ability to work was affected by CFS. Only one of the participants in this study could work as a full-time worker. The rest of the participants could not work because they were not physically well enough to work. Hughes (2009) study explains the experience of CFS symptoms, it states the illness can affect the ability to perform chosen or necessary occupations either temporarily or permanently. Bested and Marshall (2015) explain the unemployment rate among those with the disorder ranged from 35% to 69%. Bested & Marshall (2015) study also indicates that some people with CFS can work. Participants that were unable to work in this study received some financial support from the government. Sabes-Faguera et al (2010) study explain fatigue has been proven to affect the economic cost to societies due to its impact on employment.

In terms of managing CFS, Sabes-Faguera et al (2010) state in most cases, families and friends spend a considerable amount of time caring for their loved ones with CFS. Sabes-Faguera et al (2010) study support the participants reports of having their family members caring for them

when unable to care for themselves. Most of the participants had close family members to assist them at home. One of the participants had a carer (non family member) to assist her everyday of the week with her daily activities.

9. Limitations of the study

There were people from other parts of New Zealand that were interested in the study and wanted to participate. However, they were resident outside Auckland, and it was impossible to visit them and have them interviewed. The research was a small study and not many participants were required. The initial plan was to interview 10 people diagnosed with CFS.

People with CFS living in Auckland were interested when the research was advertised. Some of them were unsure if to participate and could not be persuaded to participate. Others were unable to participate within the time frame given due to other commitments they had.

Two of the participants edited their transcripts and would not allow some of the information provided to be disclosed in this thesis.

10. Conclusion

The participants were unable to establish the cause of their illness. However, one of the participants wondered if her illness (CFS) was caused by glandular fever and another participant was unsure if her CFS was stress related. Based on this study, the cause of CFS is still uncertain, none of the participants was able to explain the cause of their illness. Their experience with the diagnosis was frustrating, being ill for several months with no diagnosis. Participants acknowledged the lack of awareness of CFS by people around them. Their desire is to see people creating an awareness of chronic fatigue syndrome in the community. The participants believe the more people learn about the illness the more they accept them and understand their symptoms. The participants expressed their frustrations with some friends and family members who do not understand their symptoms or believe CFS exists. The voice of the participants is for people in the communities to be aware of CFS. They believe an awareness of CFS will help people to believe their symptoms and become more helpful. It could be argued, that an awareness of CFS be raised in the communities like other illnesses such as diabetes and cardiovascular disease. People in the community need to be aware of CFS symptoms, not until this research was conducted it was unknown to the researcher that CFS can badly affect your physical body and make people bed ridden or house bound. An understanding of CFS from the perception of CFS patients may become helpful to health care providers when managing the illness.

Most of the participants were unable to engage in social activities because of the symptoms they experienced from CFS. Their inability to socialise with friends and family was frustrating. In this study it was evident that CFS could affect people's social life, which appears to be the most important aspect of the human life.

Some of them acknowledged being discriminated against because of their illness, particularly from their acquaintances, general practitioners (GP), families and friends. However, a few of the participants did not feel they have been discriminated against or stigmatised. Those that felt they were discriminated at believe this was due to lack of awareness of CFS in the communities.

They could manage their symptoms themselves, they all knew when to stop an activity and rest or have some medications to relief their symptoms. One of the participants strength was the ability to take charge of their illness. They all knew how to care for themselves, they had their own individual management plans. They put together their management plans with little or no help from their health providers. This was very interesting and good to know because from past experience with patients they would not attempt to create their own management plans, their management plans would be put together by their health care providers. Participants in this study were very good in understanding their illness and creating care plans to relief symptoms.

One common attribute among the participants was their willingness to share their experience. They greatly supported this study with materials on CFS and encouraged the researcher to complete and publish the study. The participants generously gave their time to this research, which was very helpful.

Section 3

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2. Appendix

Proposed Timeline Of Completion

| Research activities | Completion date or period of activities (the order below is not necessarily chronological) |
|--|---|
| Submission of ethics application | 7 th April 2018 |
| Collection and generation of data | 25 th June 2018 |
| Completion of literature review chapter | 30 th August 2018 |
| Completion of methodology and methods chapter | 20 th September 2018 |
| Analysis of data | 15 th October 2018 |
| Presentation of findings | 30 th October 2018 |
| Discussion of findings | 5 th November 2018 |
| Conclusion, recommendations and implications | 7 th November 2018 |
| Completion of full manuscript draft for supervisors (Please allow approximately 2 weeks for feedback and up to another 2 weeks after that for your final edits). | 12 th November 2018 |
| Submission of completed thesis to the Postgraduate Office for examination (three soft-bound copies and one e-version) | 17 th December 2018 |

2.2. Individual Participant Information sheet

My name is Winifred Chukwurah, I am currently enrolled in Master of Applied Practice at Unitec, New Zealand. I seek your support in meeting the requirement of a research for a thesis course which forms a substantial part of this degree.

Research Topic: Experiences, symptoms, and management related to chronic fatigue syndrome: A small study The aims of this research are:

To explore the experiences of a group of people living with chronic fatigue syndrome (CFS)

To investigate people with CFS perceptions of symptoms associated with CFS

To investigate how people manage their experiences of symptoms associated with CFS

Criteria for participants selection:

General Practitioner (GP) diagnosed CFS

Must be an adult 18 and above

Well enough (Mentally and physically) to participate in an interview discussing symptoms and experiences of your illness

I request your participation in the following ways:

To be interviewed. The interview is intended to last for an hour. During the interview, you will be asked some questions in relation to your experience of CFS. You do not have to respond to all the questions. You may stop the interview at any time. With your consent, the interview will be audio taped and transcribed by me.

The identity of the participants will remain confidential to the researcher. Information will not be linked to you in anyway except you choose to have it linked to you.

You can bring a support person to the interview session.

You may consider whether to take part in this study over the next few days, if you agree to take part by first contacting me (the researcher), we will arrange a date and venue for the interview to take place. This will be a date that is convenient for you.

Your GP or support groups will not be informed if you have chosen to participate or not to participate. Neither you or your GP practice/support group will be identified in the final thesis. Copies of the transcripts will be sent to you to edit or to add information. You will not be able to withdraw your information two weeks after reviewing your interview transcript. The findings of the research will be published and presented in various nursing forums.

You will not incur any expenses as a result of your participation in the study. The interview will be conducted at a venue convenient for you. This could, for instance, be your home or a local library closest to your house.

Please indicate if you need a Kaupapa Maori support. This can be arranged prior to conducting the research interview with you. For further information please contact me.

I hope that you find this invitation to be of interest. If you have any queries about this research, please do not hesitate to contact me.

Contact details:

Winifred Chukwurah

Phone number: 02108208425 Email:

winifredchukwurah@yahoo.com

Supervisors:

Dr Lisa Maurice-Takerei

Email: lmauricetakerei@unitec.ac.nz

Professor Hayo Reinders

Email: hreinders@unitec.ac.nz

UREC REGISTRATION NUMBER: 2018-1011

This study has been approved by the UNITEC Research Ethics Committee from 23rd April 2018 to 23rd April 2019. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 8154321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

2.3. Participants Consent form



Research Topic: Experiences, symptoms, and management related to chronic fatigue syndrome: A small study

Start date: 23rd April 2018

Finish date: 23rd April 2019

I have had the research explained to me and I have read and understood the information sheet given to me.

I understand that I don't have to be part of this research, should I choose not to participate in this research, I may withdraw at any time prior to the data analysis.

I understand that my identity will be kept confidential and none of the information I have provided will be able to be linked to me. I also understand that all the information that I give will be stored securely.

The only persons who will know what I have said will be the researcher and her supervisors.

I understand that my discussion with the researcher will be audio recorded and transcribed. The researcher will do the transcription.

I understand that I can see the findings of this research.

I have had time to consider everything and I give my consent to be a part of this project.

I wish to receive a summary of the results, Yes/No (Delete as appropriate) If yes please provide an address for the summary to be mailed/emailed to you:

.....
.....

I require Kaupapa Maori support, Yes/No

Please sign and return consent form using the email address below:

winifredchukwurah@yahoo.com

Participant Name:

Participant Signature: *Date:*

2.4. Interview Questions for Participants

Icebreakers:

- Researcher will exchange greetings with the participant and thank participant for his /her time to be interviewed
- Is this your first time being a participant in a research?
- What attracted you to participate in this research?

Introductory points; Researcher will briefly summarise the participant information sheet that had been given to participants in order to reiterate the essence of the study

1. How would you describe your current state of health?
2. How do you prefer to refer to your illness?
3. How did you arrive at a diagnosis of CFS?
4. How did you feel when you received your diagnosis?
5. What was your experience of the diagnosis?
6. Did you know about CFS before you became ill?
7. How long were you sick before you were diagnosed?

8. Did you hear of CFS before your diagnosis?
9. What do you believe caused your CFS?
10. Have you done any research on the illness? If yes, was the research useful?
11. How has CFS impacted on your life: Financially, Physically, Emotionally, Cognitively, socially, work, family, Status?
12. Have you experienced any stigma or discrimination due to your illness?
13. How have you described your illness to health practitioners?
14. Have you connected with CFS support groups? Please tell me about this experience.
15. Apart from your GP have you contacted other professionals for help?
16. What other health professionals have you had to contact about your CFS?
17. Were these professionals useful?
18. Has your CFS changed your relationship with your friends, family, colleague or other significant people? If yes, how?
19. What do you think would improve health professionals approach? What have they done well? What could they do better?
20. How have you experienced the fatigue in particular?
21. Have you expressed the fatigue to a health practitioner? How did you do this? What was their response?

Closing the interview: Researcher will thank participant for participating in the interview and ask him/her if there are questions to be asked. Participants will be reminded of the opportunity to read the transcripts if they wish to do so.

2.5. Flyer

To be displayed at the GP practice & CFS support groups



VOLUNTEERS NEEDED FOR A RESEARCH PROJECT ON CHRONIC FATIGUE SYNDROME

To participate in a research project to assess volunteers experience of chronic fatigue syndrome. As a participant in this research, your support will be required to answer a few questions on chronic fatigue syndrome for about an hour. Your participation will be strictly confidential. The research findings will be available at your request. If you are interested or for further information, please register your interest by calling/texting the number below:

**021 082 084 25 Or (09) 4426950 Thank
you!**

**This study has been reviewed and approved by Unitec Research & Ethics committee,
Unitec Institute of Technology, New Zealand**

2.6. Research Proposal Approval

26 February 2018

Winifred Chukwurah

Dear Winifred

Thank you for submitting your research proposal 'Chronic Fatigue Syndrome: Analysis of up to 10, Auckland, New Zealand people living with Chronic Fatigue Syndrome.'

The Postgraduate Research Proposal Committee has considered and approved your proposal, subject to you completing amendments to the Principal Supervisor's satisfaction.

Please note there are some suggestions for your consideration which are also included in the attached sheet. Please talk these over with your supervisors.

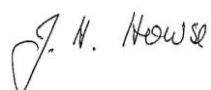
Your principal supervisor is Lisa Maurice-Takerei and your associate supervisor is Julia Hollis

Please be aware that ethical approval may be required for your research once you have finalised your proposal. To determine the need for ethics application and approval, we recommend that you read the Guidelines for Ethical Approval in the *Research* folder on the Moodle site *Postgraduate Students Resources*, to identify any ethical issues that may arise. Discussion with your supervisor or the ethics committee (email: ethics@unitec.ac.nz) may also assist in this decision process. This will help determine the need, or otherwise, for a full application for ethical approval. Ethics applications and accompanying documents should be submitted as email attachments to the above address.

Please contact us if you have any questions, or if we can assist you in your research, by calling extension number 7376 or emailing to jking@unitec.ac.nz.

We wish you every success in completing your research project.

Yours sincerely,



Jo Howse

Chair

Postgraduate Research Proposal Committee

cc: Principal Supervisor:

Associate Supervisor:

Academic Leader:

Head of Practice Pathway:

Committee Administrator: Judith King

Postgraduate Academic Administrator: Cynthia Almeida

Research Administrator: Asher Lewis

2.7.Ethics Approval Letter



Dear Winifred Chukwurah,

Your file number for this application: **2018-1011**

Title: *Experiences, symptoms, and management related to chronic fatigue syndrome: A small study*

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and has been approved for the following period:

Start date: 23rd April 2018

Finish date: 23rd April 2019

Please note that:

1. The above dates must be referred to on the information AND consent forms given to all participants.
2. You must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.

You may now commence your research according to the protocols approved by UREC. We wish you every success with your project.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'N. Adams'.

Nigel Adams
Deputy Chair, UREC

cc: Asher Lewis

2.8. Interview Transcript

August 4th 2018

Researcher: Interviewer

Participant: J.O

Venue: Library

Interviewer:

Today is the 4th and I am here with J.O at Albany library and will be conducting a research interview, to last about an hour. Thank you, JO, for giving me this opportunity to interview you. We will start with the first question. How would you describe your current state of health?

J.O

Not the flashest. Concentration is an issue. I haven't been driving for the past two years because it takes too much concentration. I repeat myself a lot, or I ask the same question over and over again, or she asks the same question over and over again and I just don't recall.

Interviewer:

Did you know about CFS before you were diagnosed with CFS?

J.O

No, when I first got sick a couple of people I knew talked about it. But that was a good year or so before they diagnosed it as what they thought it was.

Interviewer:

Did you diagnose yourself or was it a GP?

J.O

I initially saw a GP, and they ruled it out right from the start. So, we spent over a year with a lot of other tests and scans and cameras and various other things until there was a surgery that opened up in Pokeno where we live. So, to support the local guys we moved our medical files there and the Doctor there was L. We and he says, why do you want to start from the start again, because we have done most things and found nothing. And he referred us to Dr R. So, she was a lovely lady, and just straight away she said it's, there is no other option but it's CFS. So that was March of this year. So yeah, we have been learning a few techniques from her.

Interviewer:

Do you still see her?

J.O

We have seen her again as a follow up a few months afterward, to make sure the medication she put us on was doing what it was meant to do and things like that.

Interviewer:

Did she give you enough information, or are you still searching for information on your own?

J.O

A bit of both. We actually found Wendy Mathews on the Auckland MECFS page. She's absolutely lovely. Never met her, never met anybody off that page, but just very helpful. And it shows that as much as it's a shit thing to be dealing with, I do have it a lot better than a lot of the other people on that page. I haven't been bedridden or anything like that. I haven't been able to travel very far and things like that, and shakes and sweats in the early stages but I have found a way of managing those things now, and coping with them a bit better.

Interviewer:

How did you feel when you were diagnosed? Were you relieved? What kind of feeling did you get?

J.O

For me, nothing. Just another day. When you are going to the doctors, and it's talking to yourself as well, it's been life for the last couple of years so it just becomes normal, even though it's not who I used to be. But for me it's just my days now. For my wife, she's definitely noticed, well she is carrying the workload now, to be fair. The kids, having to drive me everywhere. Whether it's for my medical things, and we are still running a business. We are quite lucky we have good staff who are trying to hold that together for us. Demelza still does the accounts.

Interviewer:

So, you have your own business?

J.O

For how much longer, time will tell. It's pretty much screwed our business. It's got half the turnover it used to have, and things like that. That's life. We will just keep talking to people, and every day is just another day, make the best of it if you can. But yeah, it's just one of those things.

Interviewer:

And what do you think caused it?

J.O

Well I was crook at the start, in January '16. I got a flu like sickness and for the many years that we had been together prior to that, I didn't even get the flu. I'm from down in Southland and it was tee-shirt and shorts all year around. In winter. Never got a cold, never been to the doctor unless it was for a medical for a driver's licence. For nearly 20 years. So, to get a flu was a bit of an, oh ok. And I tolerated it for two months, and then it was March that I went to the doctor and April got chucked into Middlemore. So that's where it sort of came from then. And just, there have been various other, but I just never fitted into any of the boxes, your symptoms suited a lot of things but not enough to call it something else. Bloods were always fine, just never bounced back after getting that viral infection.

Interviewer:

You did mention some aspect of it impacting on your financial situation?

J.O

We are screwed.

Interviewer:

And physically? Are you able to do some things at home?

J.O

Yeah. She keeps telling me not to. I want to but the problem is that I don't slow myself. I go and do it and then I am buggered afterwards, where she is trying to tell me to stop because she knows I am going to be shit later on. Even just simple things like mowing the lawns takes three goes at it and it's only the size of a postage stamp. Normal house subdivision size, it's not a big lawn. But yeah, physically, that's when one of the doctors first started for more tests before I got diagnosed with ME was, this one here was only 6 months or less, and the Indian doctor was, I couldn't even hold onto her because my arms were so sore and I was losing sensation in my hands, and that's when he pushed for – we have to start digging on this if you can't even hold your new-born kid! The sensation, you just lost sensation, like you didn't know whether to hold them or not. Or the strength just wasn't there.

Interviewer:

What about your social life? Your friends?

J.O

Nil. Well they are all down south. We are in touch with them via phones and stuff like that. When we first moved up here we got a motorbike, and guys are always wanting to go up on a ride but I just physically, the bike is in the shed and I should really sell it but I don't want to. But yeah, wee short rides, I have gone on a couple of them. But you just have to pace yourself and I'm really not up to it at the moment. So, our life sort of revolves around the team at work, trying to keep them going, which they are good at. And Dee has an Auntie and Uncle here on the shore, just around the corner from here. And Dee's cousin, their boy was into rugby and so we try to make a trip to watch him play rugby. And that was sort of our outing once a week or once a fortnight was to come and say hi to them and get out of the house instead of having cabin fever.

Interviewer:

Cognitively, has it affected you? The way you think, or forgetting things?

J.O

I'm always forgetting things, even those things, I didn't even read them, the consent form. It just goes around and round and doesn't make sense. And even with work, with legal contracts and things like that, I have had to step back. And in the better days when we had a much better turnover I was just getting the lawyer to read over it and tell me what I need to know. Is it good, do I sign it? Which costs you, but when you are getting something that is like, 50 or 60 pages long, I wasn't anywhere near doing it. It's a wee bit better now, they usually just write

emails and put them on my signature. At the start I was trying to do it. I remember the team having a laugh, taking bets on what I was trying to say. Like, I have written an email and think it's all good but it didn't make any sense. The words didn't even flow together. They just thought it was a joke. So that side of it is a bit frustrating.

Interviewer:

Have you experienced any form of stigma? From your staff or anybody around? Do you feel stigmatised in any way?

J.O

Not from the staff because I pay them. They are pretty good. The older generation are a bit, because I am from, I'm old-school, like pull your socks up and get on with it. That is what annoys me about this. You just can't.

J.O's wife:

Which is also why we use the ME name more than the CFS. For the simple fact that when people hear chronic fatigue they have that stigma of, oh you are just being tired and lazy. Just get up and do some exercise, get up! And it's like, actually it doesn't help.

J.O

In the early days, the catalyst was, we have an ensuite in the house we are in and I would be puffed and sweating just from going to the ensuite. And it's like, well that is only five yards away! But I think a lot of the stigma just comes from, that it's not really public yet, and for a lot of the doctors, our original doctor said, no that's not a thing anyway! When we asked about chronic fatigue, because a mate said about it, because he has had it. She said, you don't have that.

J.O's wife:

And that was it, and so another year down the track, oh yeah you do have it. We could have done something earlier!

JO

Yeah, we could have planned a bit further ahead. But that's life isn't it. it's not really taught, and from a couple of things I have picked up on the ME page, it's not even spoken about to the students coming through now, for them to even have the option to look at or understand. I'm only 38, I should have a hell of a lot of life left. And I want to enjoy time with my kids. So, at this stage we are pacing ourselves so I can spend time with the kids.

Interviewer:

Is there any treatment you are currently receiving? Any treatment recommended, like pills?

J.O

No, I'm basically on QK10 and Magnesium. Most of my medication is pain related, so I'm on Tramadol and things like that.

Interviewer:

Are they helpful?

J.O

Yeah, they take the edge off. Last month I had been sent to the chronic pain clinic at the Manukau super clinic. Because I had been on Tramadol and codeine and a few others for just over two years, they said, oh we better stop these because you can start getting rebound headaches from them. So, the last month was an interesting month. I went through the whole cold sweats, cold turkey the whole lot. But as far as the pain, it got worse.

Interviewer:

Where exactly is the pain?

J.O

It's all head. My eyes are, it's what I call from the agricultural side, welders flash. If you do some welding and don't wear the goggles you get like a gritty conjunctivitis in your eyes. So that's why I wear the dark glasses all the time. Which is annoying. So mainly in the front of the head, which is really bad. It starts to push down the back of the skull to the top of the neck. So, the tramadol and stuff, I keep taking that. It takes the edge off but it doesn't fix it. So, I've still got blurry eyes and a few things. And just get disorientated. Most of mine is pain, my sleep is all up the whack.

Interviewer:

And how regularly does it happen? Is it daily?

J.O

Yeah, it's every day.

Interviewer:

And when you take the pain relief, does it just subside? Does it go away?

J.O

No, it doesn't take it away. It takes the edge away. I have even tripled what the doctor has written on the pill thing and it hasn't made any difference, whether I take the dose or I triple it.

Interviewer:

When you sleep, and you wake up?

J.O

Yeah, I wouldn't say they are the reasons I wake up

Interviewer:

Do you feel refreshed?

J.O

No. Last night I would have been in bed for a good 12 or 13 hours. I didn't sleep all the way through, I was waking maybe 5 or 6 times in the night. But definitely not refreshed when I get up. So, I'm on sleeping pills to try and help with that. I think it's nortriptyline they have got me on now. Sometimes if I don't take that I can go to bed at nine or ten o'clock and still be awake at two or three in the morning. I don't switch off.

Interviewer:

And do the doctors, and do you feel that the virus is still there?

J.O

I don't feel any effects of that, like I haven't got the cold. Well I've just had a cold but I don't think the viral infection is there anymore. I don't think there is any effects of that. But it's definitely left the headaches and the eyes and the fatigue there.

Interviewer:

Do you feel pains in your limbs?

J.O

If I have started to push myself then yes.

Interviewer:

Do you know your limits?

J.O

No, I'm still finding them I guess. I guess I'm lucky because my wife is with me all the time to help me when I do crash. We had a staff meeting on Tuesday, once a week they have a catch up, old jobs new jobs. I fell asleep in the meeting. So, they were sitting there chatting away, thinking it was a great joke and at the end of it they gave me a brief of what had been discussed. Cool, awesome. And that's why we have actually had to employ another guy to do what I should be doing in the business, because you can't be talking to clients and falling asleep! You can't talk facts and figures, because ours is an international business so we do shipping containers and air freight all around the world. You can't give them wrong information, you have got to be on your game as well.

Interviewer:

Do you sleep all night or just some hours?

J.O

Just some hours. I wake reasonably regularly. Last night I actually pulled up about 8 o'clock and went to bed. And I saw 2 o'clock and a bit after 3 and then 4 and then 5. And then the kids started about half past six. So, morning hours are quite broken, but I can usually get a few hours before midnight. You just don't feel like you have improved anything by going to bed. You are still tired, you are still foggy in the head.

Interviewer:

So, do you go to work every day?

J.O

Once a week. We are on the phone and emails all the time.

Interviewer:

You work from home?

J.O

Yeah, we have taken a computer home, because its cloud based. I can do it all from my phone here. Because my wife does all the accounts and stuff, my computer is linked in. Yeah, it's still there and it's still working but I don't class myself as an active participant. When things turn to shit, the buck stops with me, and I step in and help my staff, I'm very lucky that the staff we have now come on knowing that I am not fully active in the business. And they have still accepted the challenge of coming on and being autonomous and self-starters. So, I am very privileged on that front.

Interviewer:

And your wife seems to be very supportive as well?

J.O

Yeah, I'm very lucky. And to be fair, those two kids, we wouldn't have had them if we hadn't come to Auckland. Because they are fertility babies, so we wouldn't have done that if we hadn't have come up here either. So, coming here and getting sick hasn't been all bad. So, I'm hanging onto that, the positive out of that. And as much as I have read other peoples posts on Facebook, they are all quite depressive. And it's like well, and don't get me wrong I have my moments of emotions getting a hold of me and everything else, then I think, great, I have got a wife and a kid who wants to give me a cuddle. You have got to try to keep telling yourself that tomorrow is another day, there will be something else.

Interviewer:

it's good when you have a supportive family, am I right?

J.O

And I suppose I am lucky that, because driving the car is pretty much a no no for me, a motorbike in traffic is a bit easier for me for concentration levels. Because you can filter between the cars and you don't have to worry about them changing lanes in the same way. But we are pretty much together 24/7. If my wife sees me struggling, she just steps in and tells me to bugger off and she carries on, even if she, if her tension levels are high with the kids screaming. So, it's a big ask but I'm lucky because she's there all the time. Some other people with this mightn't have people there all the time, so they don't have the distraction or the support as much, that I am lucky enough to have.

Interviewer:

So apart from Dr R, which other doctors do you have? Do you have any other health professional that you visit? Like nurses?

J.O

Well I've got the health clinic, which is the one that has started up. And we have found that Dr L We is the guy, that started it up. He's been very good. He's the one who got us the referral into Dr R to start with. He was like, well it's been going on for so long, now we need to go back to the start and see if it's something that has been ruled out. So that's how we got down this track. Through the **pain clinic**. There were three that I have just been through with the chronic pain, to try and balance out the pain relief. Because they have ruled out Codeine. **Codeine doesn't help**, I am lacking in an enzyme that, Codeine needs a certain enzyme to break it down to become Morphine in your system. And I am one of those people who does not have that enzyme. So, I can take Codeine like it's nothing. I have taken ten times what they have told me to take and I just cruise on, no effect. So yeah there was that, and there is two more, and please remind me to ask my wife before we leave. Obviously, people with this do have pain related in the joints and for me they will be like phantom things. **I'll be sitting there and all of a sudden, I will have like pins and needles in my arm. And it's like, why?** For me being a really logical, old school type person. I'm a country boy through and through. It doesn't make sense and that's probably the hardest thing about it. **I can't pick a trigger. It obviously comes on more when you have pushed yourself, and things like that.** Hence, we have taken a very quiet morning so I can try and talk to you now. But yeah, no logic behind a lot of the things that happen now. And I suppose I have switched off. It's just life, you have to deal with it. I'm sort of, of the thing that there is no point whinging, no one listens. You pick yourself up and do the best you can.

Interviewer:

It seems you have good support from health professionals. What do you think would improve the way health professionals provide their services to people with CFS?

J.O

Well there are a few things, **I think just education**. It's the same as, I heard the other day that it's not that long ago that MS only got approved to be a proper acknowledged disease, and things like that. And people have suffered from that for so long! So, the same thing with this ME and CFS, there are a lot of doctors like Dr R that are doing some very hard work. And I have already asked if there is somebody coming on. Dr R, is the only one in New Zealand. And I don't like putting an age on a lady, but she would have to be pushing into her 70's.

Interviewer:

Quite elderly?

J.O

Is there someone coming on, to be an understudy type person. There's just so much knowledge and it would be a shame to lose it but there's a thing like education for that, and the other thing is what we are going through at the moment, is also things like WINZ and the IRD, **our business has halved in turnover, we still have the same debt loading.** So, we have got the financial strain too. Because the medical side, not all of it, we have tried, before being told what this was, we had gone down the Kinesiology route and a few things like that, because the normal doctor stuff wasn't working, it's like, we have got to try twigging this. But yeah, the first starting point is exactly people like you doing what you are doing. **To try and learn about it. Surprising.** And I'm fairly thick skinned. Like I say, my father in law says, **there's nothing bloody wrong**

with you. I'm thick skinned, I'll take that with a grain of salt, it's like oh well, go for a walk in my shoes and see how you go for a day. But yeah there are probably a lot of people who probably don't come out and say, this is what I have got, because they would get the looks or the judgement.

We have had the doctors go down, well not the lazy track but they asked me questions on depression and things like that. My main concern is stress. It's not depression, it's stress. And that all flows from me not being an active participant in the business. How do you pay rent, food and provide for my kids? That's the stigma and people are entitled to their opinions. If they want to call me a lazy prick then fine. If you are going to be a mate then you don't. You get in and support, that's what friends do. I have had a few people laugh at me, but no skin off my nose. But we have a very select, tight few that help when they can. Most people who have that type of view are people who have had things in their own life, where it is only through support that it has kept them going and they appreciate that they have got to give back as well, to help people. But it all starts with education and after education will come the funding and the rest of it, that's what I see. And I asked the questions when you first posted on the page there, you came up not long after I had got on that page, and I went to a few of the others and said, look I'm happy to talk but I know what Facebook is like (no offence) but there is a whole lot of crap on there too. And I just asked the other team members there, I said, well if you guys see this as something that is positive and going to help then I'm happy to partake. But I don't want to jump in boots and all, look at me and stuff it up for other people. But it all came back, they had sussed you out and realised it was there, and I was like, cool.

Interviewer:

My intention is to do some publishing if possible from the result of the research.

J.O. It's good, because you never know who would read it.

My wife got the PACE leaflet from Dr R, you have only got so much energy and if you over spend today you will be in negative later on. But, at the end of the day, publish it and if it sows the seed and questions come back from one or two other nurses, or year one year two doctors and if they do similar to you and they pick it for another one or two. It's got to start somewhere!

Interviewer:

Well you have done so well. One last question. The fatigue you mentioned, do you experience it every day or some days?

J.O

I would say every day, but some days are definitely worse than others. And I usually judge mine by the pain or the headaches. You know that you have overdone what you are meant to be doing.

Interviewer:

Thank you so much John. I think we have come to the end of the interview. I will send you the transcript, just for you to go through it.

J.O

Yeh that would be great.

Interviewer:

I am hoping to complete my research thesis by December 2018.

J.O

Everything that you do is a step, as far as I am concerned. This information is where it's got to start.

August 30, 2018

Participant: SO

Researcher: Interviewer

Interviewer:

Thank you, SO, for giving me the opportunity to interview you. Today is the 30th of August 2018. Thanks for coming to the library.

How would you describe your current state of health?

S.O:

Pretty sick. I can't work. Well enough to look after myself but not well enough to do things.

Interviewer:

So how would you prefer for people to refer to your illness?

S.O:

I just call it Chronic Fatigue, because that's what people are familiar with.

Interviewer:

How did you arrive at a diagnosis?

S.O:

After a lot of testing, I got it from, I saw Dr R. She diagnosed it and I got another diagnosis from an endocrinologist as well. My GP never diagnosed it, I have seen a bunch of specialists. The one that probably first brought it up was a gastroenterologist.

Interviewer:

Were you having stomach upsets?

S.O:

Yes, I was having that first. It came on slowly, I was having that before the fatigue came on.

Interviewer:

Did you have any flu symptoms?

S.O:

No, it never started with a virus, well it never started with any virus that I knew of.

Interviewer:

How did you feel when you received the diagnosis? Had you heard of Chronic Fatigue Syndrome before? Or was the diagnosis the first-time hearing of Chronic Fatigue Syndrome?

S.O:

Well it was kind of suggested for a while before it was definitely, it was like, maybe it's Chronic Fatigue, have you heard of Chronic Fatigue? But we are not sure if that's it yet because we are still looking for other stuff.

Interviewer:

How did you feel?

S.O:

When I started to know more about it, it got scarier and scarier. Because it's like, you don't get better! It's something that people say, there is nothing you can do. Scary.

Interviewer:

Did you read about it? Did you go and do research? Look into it and what is treatment?

S.O: Yes.

Interviewer:

Prior to then, you didn't know anything about CFS? did you?

S.O:

I might have vaguely heard about it but not really, no.

Interviewer:

So how long were you sick before you arrived at a diagnosis?

S.O:

Over six months maybe. Because I didn't get sick immediately, I kind of slowly got worse and worse over the six months. Maybe like a few months after that I got the diagnosis. I can't remember exactly.

Interviewer:

What do you believe caused your CFS?

S.O:

I'm not quite sure, but it did start with the stomach stuff. And I still have that.

Interviewer:

Any medication for that, or diet controlled?

S.O:

I have a diet, but it only keeps it under control. It hasn't made it go away. A lot of people thought that it was stress, because I got sick when my dad got cancer, so I had a lot of people suggesting that. But it didn't really make sense to me, just because of all the physical symptoms, the gut thing that happened first and all that.

Interviewer:

So how has it impacted your life? I know you have talked about this a little bit, so how has it impacted on your life? Your social life, your finance, everything!

S.O:

I can't work anymore.

Interviewer:

You used to work?

S.O:

Yes. And I don't see people very often anymore. I can't read books because I can't really concentrate.

Interviewer:

You can't focus?

S.O:

Not for long enough to, maybe I would read through the page, get lost and forget what happened on the last few pages. It was too much of a struggle to read a book it's not really worth it anymore. I can't exercise as well. I used to cycle.

Interviewer:

And what about emotionally?

S.O:

It was rough, it was scary. But I feel a lot better about it now.

Interviewer:

And what about your family? Do you get any support from your family?

S.O

I live with my mum.

Interviewer:

What about your friends? **S.O:**

Yeah, I don't see friends that often, I just basically see my boyfriend.

Interviewer:

He is still with you.

S.O:

Yes, but we don't live together. I do go and stay with him and stuff.

Interviewer:

Cognitively, you said you can't focus when you read books?

S.O:

Yes, and even when it gets really bad it's hard to even focus on things like movies. Like follow what is going on. But usually that is ok. It sometimes gets too hard to watch a movie or I don't have the focus to get immersed in the story and really be able to enjoy it because I can't focus on it.

Interviewer:

And financially, how has it impacted on you?

S.O:

Yeah, I have got the benefit. So, it's ok.

Interviewer:

And do you feel you have been discriminated against or stigmatised because of your illness - CFS? In some way or another?

S.O:

Well, not so bad. It's just that not everyone believes that it's a completely physical illness. They think maybe you have a mental illness. And I don't agree at all. It's not that people don't think I'm sick, it's just that they think I have some of mental illness. It's like, if it was a mental illness it would have a whole different set of implications and ways of treating it. And that's why the suggestion of mental illness feels like a big mistake. Because it would be going down the wrong path of treating it and dealing with it

Interviewer:

Were you ever prescribed antidepressant?

S.O:

No, well I have been offered it as well but I said no thanks.

Interviewer:

So, what does it actually do to you? Apart from the stomach upsets, do you feel weak?

S.O:

It's sort of like, I have lost endurance for any type of activity. So, it happened slowly, I used to cycle and I just felt like when I went out cycling I would reach exhaustion earlier and earlier. Faster and faster. And I also just worked less and less and less over those months.

Interviewer:

And the exhaustion, how long does it last? Is it for hours or days when you get exhausted?

S.O:

Pretty much the next day. But it feels really bad, you feel kind of poisoned in a way. Just sick all over.

Interviewer:

Have there been situations where you just have to stay indoors? Or you are just in bed and don't want to get up?

S.O:

I have only had a couple of days like that, where I have stayed in bed pretty much the whole day. It's pretty bad.

Interviewer:

And how is your appetite? Do you eat well?

S.O:

I don't feel very hungry. The thing is, I had some weight loss and I wasn't eating any differently or anything. So, I still don't know why I lost the weight. And when I started changing my diet I put some weight on again but then after a while it came off again. But lately I have put a little bit on, but I am still underweight. It might be the gut thing, I don't know.

Interviewer:

What kind of treatment are you on? After diagnosis. Did you use pain relief? Do you have pain?

S.O:

At the beginning when it had more stomach symptoms, stomach pain, they gave me tramadol for that and it worked really well. And I would also use it for the poisoned feeling that I would get, and I would get headaches as well and I would use it every day. I still use it every day but a lot less now

Interviewer:

How long have you used it for now?

S.O:

Maybe about two years.

Interviewer: every
day?

S.O:

Yes. The most I had was 4 a day. The 50mg ones.

Interviewer:

So that's about 200mg per day. And now you just take one?

S.O:

One, sometimes two a day. It's come down and down and down. Six months ago, it was maybe two a day. The thing is, what it also does for me, which people say is kind of unusual, is that it has a stimulant effect. For a while, if I felt I was just stuck on the couch for the rest of the evening, if I took the tramadol I would be able to get up and do a few things. Even if it was just getting up and making myself dinner. I think it's beneficial like that, but not everybody likes me being on it for so long. Like my GP wants me to get off.

Interviewer:

Have you connected with any CFS support groups?

S.O:

Yeah, I did recently. I went there asking for a new GP actually. That was a couple of months ago and I haven't actually sorted that out yet.

Interviewer:

So, with the support groups, do you find it helpful?

S.O:

I only went that one time. But yeah, they had a lot of information.

Interviewer:

Are you with them on Facebook?

S.O:

No, because I am not on Facebook. But they said you could sign up on their website, and after I did that I got an email from this support worker. Asking if I needed anything, and she offers to, she can come to your WINZ appointments or even your doctor's appointments if you need a support person. And she is paid, I think she does part time work. So, I never needed that but it was quite nice.

Interviewer:

Apart from your GP, do you see any other health professionals for help?

S.O:

I see a Gastroenterologist quite regularly. That's about it.

Interviewer:

And do you find GP and Gastroenterologist helpful?

S.O:

I guess so.

Interviewer:

And you have mentioned that your CFS has changed your relationship with your friends? What about family? Do you still have the same relationship with your family?

S.O:

I don't feel like they have always believed it.

Interviewer:

But your mum believes you, to some extent?

S.O:

It's been a little difficult. It's impossible to show people. You can't prove it in any way because you are just talking about your symptoms. There is nothing you could do to make it obvious. They just have to basically just believe you. That's all you have. So, it's either I am telling the truth or I am lying.

Interviewer:

What do you think would improve health professionals approach to CFS?

S.O:

Some of them. Like, some just didn't know very much about it. There is also lots of different recommendations on treatment. Some people say this and some people say that. Some people think antidepressants would help and some people don't.

Interviewer:

And what would you recommend, for these health professionals that you feel don't have that knowledge? What would be your recommendation? To help present and future patients?

S.O:

A lot of the doctor seem to take the view that it is at least partly a mental health thing. Except the information out there is a little bit misleading. Like have you heard about the whole Pace trial and all that stuff? Like, they are still health authorities who recommend the whole Cognitive Behavioural Therapy and all that stuff, even though it is in the process of being discredited. I have still had, like one of my doctors looked at, have you heard of Up to Date? It's some service that she looked up. It's supposed to be the most recent research about all the different illnesses. She looked it up on there. She was like, oh yeah. And I was like, no no that's old news!

I mean the services they use are not quite up to date. Maybe I am talking about something that is happening currently that is still in the process of happening. So maybe it's a bit too early.

Interviewer:

I think we have actually come to the end of this interview, but I just want to ask you one more question. Because you are not in any support group. Do you have any friends at all who has similar illness?

S.O:

I also go on internet forums about it, which is where I probably learned the most about it, on the internet. So that was probably the most important, the most helpful thing.

Interviewer:

So how often do you visit your GP?

S.O:

I have had to go at least every three months for the WINZ purposes.

Interviewer:

How long have you had CFS for? A year? Two?

SO:

Maybe two and a half.

Interviewer:

And you only see your GP when there is a need to see your GP?

S.O:

Yeah.

Interviewer:

And the gastro specialist, you see him/her often?

S.O:

Yes, probably every three months.

Interviewer:

The GP?

S.O:

Probably the same.

Interviewer:

Thank you so much for this opportunity, I will send you the transcript if requested on your consent form.

02 July, 2018

Participant: M

Interviewer: Researcher

Interviewer:

Thank you so much M. M will be sharing her experience of CFS with me, she will be answering a couple of questions. Today is Monday the second of July 2018. We will start with the first question. How would you describe your current state of health?

M:

My current state of health at the moment I would say is not very good. What I have got is CRPS on top of chronic fatigue. And CRPS is unfortunately progressive. So, it has already progressed to my lungs, my bladder and my legs. It's a pain syndrome. Nerve pain syndrome. So that pretty much tells you, I still do quite a bit in terms of, at the moment I am mentoring two girls through WINZ, two girls who have got a disability, through WINZ to get into work bridge. I do that personally because that is what my life work was before. I do all that sort of stuff, I work with the intellectually handicapped. So, my current health, well the prognosis is not good and it's progressive, but I just try. I love gardening, and I have got like these special things. Gardening is special and helping people. I have always got to have somebody to help. Somebody I am seeing falling through the cracks. So, I have got these two girls. And already one of them has got a work experience for three weeks at the Warehouse. And she started today. And I was thinking about her, she has got to work from eight until five thirty and she has never done that before in her life! But yeah, so while the things that I used to do like running and jogging and swimming and all those things. I can't do the pools anymore because the chlorine causes me, I just can't breathe for about two weeks after I have been in the chlorine pool. It's just no good.

Interviewer:

So how do you refer to your illness? What words would you use?

M:

I would say to someone asking me who was in the know, I would say to them I have got ME Chronic Fatigue, but on top of that and because of that I have Chronic Regional Pain Syndrome. And my doctor said to me, it's just really unfair that it has happened. He said it's rare, it's just one of those things. And it's partly, this year I have had two knee replacements. And I had them done when I was 50 because I literally ran my knees into nothing because I exercised all the time to keep my bipolar under control. And what has happened with the CRPS is, well the Chronic Fatigue has worn me down in many many ways and then the CRPPs have come along. And it's a pain disease and you actually, your brain starts malfunctioning and it's saying that these are wounds so it is sending out pain signals and unfortunately nerve signals. So, I have actually got pain running down my legs all the time. Hot, it's a burning pain like you have got a torch. You probably saw that Paediatrician in the theatre, so that's what it feels like for me. It's there, I can feel the electricity but I can't feel the pain because I am all doped up on medicine. It's the only way I can live.

Interviewer:

So how did you arrive at a diagnosis of Chronic Fatigue Syndrome? Who diagnosed you?

M:

Well I was very very lucky. Because I had never been sick, I had never had a physical illness. Only as a child, the normal things. And when I got to 60 I got the flu. And I had never had the flu before, and I was really sick. And then I tried going back to work and I would end up not being able to breathe. I would end up in A and E and end up on the nebuliser. In the end it was just ridiculous. I ended up going back to the doctor four times, because I got a huge infection in my chest. So, after I had four times going back to her, which she called viral fatigue, then six months had passed and she said not to go to work anymore. She said, you have ME Chronic Fatigue. And she was a young doctor, she was I think a part Maori lady, a young doctor. Young, slim, really nice but she knew her stuff. And she pulled out the primer that every doctor in New Zealand got but most didn't read. But mine did, and she said I know all about this. And then she sent me off to have tests for everything, because it's a bit of a worry what is happening in your brain, what is happening in your body. And I was walking funny so they didn't know if I had MS or a brain tumour or what. Or a tumour on my back. So, I went through the neurologist. They put me through all the tests and everything. And as it happened, nothing showed up. And it's a black joke, it's real irony. The neurologist on my last visit said to me, yes, I will agree with your doctor that you have ME Chronic Fatigue Syndrome. And he said, aren't you lucky it's not MS! I didn't say anything to him but I went home and I thought about it. Because when you see what is written, I know MS patients can be very very bad, because I have nursed them. But if and when Chronic Fatigue gets known and people understand the level that it gets to, it actually has a higher pain rate and more symptoms. And I don't think sickness is a competition but because we are so desperate in our way to be seen as patients and seen as something to validate. Because it's scary! For me, I was so lucky. And when my doctor left, she said would you like to go to doctor D? And I wasn't sure but I knew my mother in law had been going to him and I knew he was a nice doctor. And so, he was brilliant too, he is absolutely brilliant. He knows all about it and he lives with his mother who has got Fibromyalgia. And also, he's gone on to do more things. He has specialised. He does operations there. He has got a good broad mind. So, I fell into some very good hands. And I still go to Doctor D. And he said, did I want to go to the pain clinic, he referred me to the pain clinic. I got the letter but I won't go because I know they can't do anything more for me than what my own doctor who cares about what happens to me. I have built up a relationship with him and he understands the difficulties that I have with the bipolar which makes me want to go a thousand miles an hour, and the chronic fatigue and the CRPS where I have just got to literally rest and look after my body. So, this is the thing too. I have just got to say, I have been so so lucky, but the stories you will hear from other people are terrible. But for me, my sister came from Britain and she was visiting other people and she just stayed one half day and night and the next half day, and then she got picked up and went to the airport. And within that time, she slept on the sofa, she said who got up and had a shower at three o'clock in the morning? And I said to her, because she doesn't really know what is wrong with me, she doesn't accept it. And I said, well I did, I had to put my feet in a bucket of Radox or Magnesium to stop the pain. She didn't say anything, conversation ended. And then later on, because I didn't go back to bed, I just lay in my chair. She turned around to me and said, what are you doing? She said, sit up! You are not the only one with symptoms you know!

It was so painful. It just hurts to hell! My foster family, because I have been in lots of different families, but my foster family, none of them, well they didn't even understand my mental health problems because they didn't come from where we came from. If you go into a family, if you have lived with abuse and you get fostered into a family who have a totally different mindset,

they say to you, you are not “name” anymore you are now “..name”. They think that’s good and, in some ways, it is good. But you lose your identity, you don’t know who you are. So that kind of gives a bit of background to me and why I have coped so well, because I have built up a lot of resilience over my young days. But not everybody has that. But I’m not saying that they give in, because man they don’t. And nearly everyone that I have met, they are all intelligent, they are all class A type personalities.

Interviewer:

So, when you received your diagnosis, did you receive any counselling sessions or given information. How did you feel?

M:

No, I didn’t get any counselling. Because I was very lucky too, my friends from school, they all came and helped me. We have kept up for 50 years, going for coffee and things. So, I had help from them.

Winifred:

when you were told you had Chronic Fatigue syndrome, did you seek for information about the illness?

M:

I didn’t have a clue really. What I did was, I looked up, rang around to see, is there a group for this? I think I rang the Western Leader. And they had an ad in the paper. Because up until then I had just been doing my best, with the help from my doctor.

Interviewer:

And you didn’t know anything about it before that time?

M:

No. In a way, I did to some degree because my best friend, her daughter has Chronic Fatigue. But they live in Tauranga. And I never even gave it much thought, again I was probably one of the people who, not that I would disbelieve it but it just didn’t really come into my arena. So, what was the question again?

Interviewer:

Did you know about CFS?

M:

No, I didn’t really. Only my friend saying her daughter has chronic fatigue.

Interviewer:

And what would you say probably caused the Chronic Fatigue Syndrome? Would you by any chance know what? Apart from the flu.

M:

Yeah, the flu, the bacterial thing. But since I have read more, it's like, I have had a perfect storm in terms of a lot of trauma in my young days. Different families, a marriage that had, I could tell you but who is going to be listening to that, just you?

Interviewer:

Just my supervisors, myself and possibly my transcriber if I decide to use one. I have signed a confidentiality agreement form, my transcriber will also sign one if I use any.

M:

I stayed in a marriage that was pretty bad, because of the life I had, I thought this was what you had to do no matter what.

Once I knew, because I have always been a leader. So, once I knew what I had, I searched out the group and they had a support group here and I started going to the support group. And then I obviously came home. Because I have been learning stuff all my life by myself. So, I started researching it, and I got into all sorts of things! I researched it with proper, with the best material I could find. And part of the reason I did that is because I was involved with three, Tauranga's group, their online support group, our online support group and another closed group.

Interviewer:

Were they helpful?

M:

On Facebook, we have got closed groups on Facebook, and so they are such a benefit! Because everyone posts on it, and they ask for help with any information they need. How to go through WINZ, they get to know each other, they meet together. There are three support groups in Auckland and they meet once a month.

Interviewer:

Do you go?

M:

Yes. I wasn't long in being in the support group when the lady who had been running it, she had a big, what we call a crash. And she said to me, I can't do this anymore, can you take over? And that was it, I was left. And she just gave me everything. And so, I took over the group!

Interviewer:

And so, what do you do in the group? Do you just share knowledge?

M:

Well we have morphed into different things, depends on where we are all at. We have done all sorts of things. We have done times where we have had learning sessions. And because, especially if we have got a lot of new people, we make sure that they get to know everything that they need to know, and the people who have been in the group before talk about what's happened for them. We are pretty much the same as any support group. We all say who we are and how we got ME Chronic Fatigue. And everybody gets talking. And when Y was doing it, she was working through a programme, of basically the different symptoms and things, and

the things that we could do to help ourselves. And when you would talk to everyone in the group, someone would say, well I use this for my breathing or I use the magnesium. So, they give off a lot of information. And the other thing that is the most important, is that when these new people come into the group, they cannot believe that these people all understand! It is written all over their face, and that is what they say. What a relief! They just can't believe it, that there is this group that just totally accepts them for what they are. Because, this is how I look at it, this is my practical mind. People obviously know you well, and they know that for a certain period in your life you have worked. You have worked really hard, you have helped lots of people, you have done lots of things. You were at a good point in your life. I had my grandchildren, I was slim, everything was chugging along. Taking the grandchildren out to all sorts of things, because they were teenagers. And then suddenly bang, I get the flu. And then I am absolutely wiped out. And the one that was in the paper today was, he was a CEO and he got Chronic Fatigue and he was getting funding I think, he was getting some disability money. This was in either England or America. It was around the insurance/disability money. And they sneaked around and took photos of him doing this or that and then they stopped his money. So, he went, he took them to court. And you know what, he won. Actually, I can flick it over to you. He won, and he got a hell of a lot of money. We can't sue in this country so... I lose a lot of the fragments of what I am saying. So that is just amazing. So that judge must have known about it, or know somebody. And also, a lot of the researchers, the doctors and scientists and researchers are saying, once they get the bio-marker, and get the sub-groups sorted out as well, there is going to be a lot of doctors who have to apologise to their patients.

I was just going to say about the CEO, logic says to me, why would a man who has got a CEO job, doing well, then he got glandular fever. And he got struck down with it, and then as a result of it he got Chronic Fatigue. And he just couldn't go back to work. If people didn't believe him, you would think that logically this is a man who has worked his way up, why would he put himself in this debilitating situation! With people who don't even care for you! With family who don't even believe you. Who don't even want anything to do with you. You can't go out. And they don't understand, they just think you are pulling the wool over them. What sort of logic is that!

Interviewer:

That makes sense, right?

M:

I use my logic, and my logic would look at the context of the person and their life. And this would be for other things too, because I have worked in the community all my life. But basically, if you just put that logic to it, what is the pay off? There is no payoff, absolutely no payoff! So that answers that question!

Interviewer:

It does! In fact, you have shared some of this, how has Chronic Fatigue impacted on your life? Financially, physically, emotionally, cognitively, socially? Work, Family, status? How has it impacted on your life?

M:

I'll just be very brief, can you just read them out one at a time because I can't cope with the whole lot.

Interviewer:

Ok, how has it impacted on your life.

M:

First of all, it was the last straw in my marriage. After 42 years, because my husband didn't believe me either.

Interviewer:

Financially?

M:

A huge amount, because I am only on a benefit. And I planned to work until I was 70. Because when you separate, they get half.

Interviewer:

Physically?

M:

It's impacted enormously, because I was always exercising, I was totally out there running, swimming, walking biking. So literally, it's the orstatic (sp?) intolerance, and some people say, well go for a walk, do this do that. But I only have to garden for a little while and I pay for it for the next two days. I just do not have the energy and the pain in my legs, my breathing, just everything, I am just a wreck for two or three days. So, if you want to know how it has impacted in my life, it has changed my life immensely. And I have had to deal with that in terms of mentally, emotionally and physically. And also, you have to, within that physical which I have now put into the spiritual, I can forgive these people because that's all you can do. Because if you want to move on in your life you have to. And unfortunately, a lot of people, they are still very angry, and they have stayed angry for years and I don't think it helps. But then if you can't find the way out, it's hard isn't it? And it depends on how high your fall. That CEO, his fall is enormous. But for me, because I couldn't do the kinds of jobs that I had got, then had to pull out after two years, because I had mental health problems and depression, so I had to decide, to say to myself, well I can't do that but I am going to be the best aid there is. And I worked in the hospitals, I worked in mental health, I worked with autistic, you name it. IHC for nine years. My whole life has been working, but it has been more of a vocation than a job. Because I started at 25, \$2.53 an hour, and at the end I was 60 when I was put off work, about 60 and a half, I was on the grand total of \$15.25!

Interviewer:

Socially, it looks like you still do your social activities with your support groups?

M: I don't go to the support group now because, like with the CRPS, which has got it's really got worse. Like three years ago I could walk properly, now I can't walk properly. If I go to the mall, because that's my exercise. If I have to stand in a queue I can sit on my walker.

Interviewer:

What about family? Do they support you?

M:

No. Not to start with at all. Nobody, zilch. My daughter, I was able to speak with her, and she's a very clever girl. She's in health and safety in the corporate side of a business. So, she has got a lot of brains. And she could see after a period of time, and now that she has been living here she can really see what it is. And I have got her total support. And she said, when I was all full of pain and anger and despair, she just kept saying to me, live in the love mum. Because my son and his wife and Taylor. Taylor is 23 now. I took her everywhere when she was young, but when they cut me off, that was five years ago. I was the only one not invited to her 18th birthday party, I didn't get to go to her 21st, none of them speak to me, nothing. I'm telling you this that it's these things that bring you down right to the bottom. And you have to think to yourself, you have to work through it in your head. You did all this stuff but you have to tell yourself, what did you do it for? And then you have to say to yourself, you did it because you wanted to. And you did it without conditions. And so, you can't go and put conditions on it now. It has to be, you did it because you wanted to. And I am trying to find the right words but I can't. You know what I mean though? I did it because it was just part of my inner self. I just love helping people and looking after people. Unconditionally is the word. You have to understand and say to yourself, you did it and you did it unconditionally. So, you can't go around having expectations. Because you gave it unconditionally. And a lot of people can't get to that point you see. And some people's lives are very very sad and they are stuck mentally, physically and emotionally. So not only have they got all their chronic fatigue, but they are stuck. And that's what you hear at the group, and you try and share some of these things. It's very painful.

Interviewer:

Have you been experiencing any stigma or discrimination with regards to your illness? I mean do you feel stigmatised or discriminated against?

M:

I haven't. The funny thing is, my family more than anything! Isn't that strange? And I think when you talk to other people, that's what they will say too. They will have other things, because I think my story is so cut and dry, because everything went perfect for me. But other people have had terrible times. Like the doctor just, I mean most of them are on my Facebook page and they will talk to me on messenger, and some of them are just crying, because they shop doctors because of disbelief, and some doctors even get to the point of absolutely growling at them. And sometimes, well there is one girl and she actually got into a shouting match with her doctor. And she is just in despair! Because, she has just only a little while gone and asked for disability money, and because she was actually doing the markets selling very beautiful things that she made, and she has tried everything to get well. And it has cost her a lot of money. So now she is in bed most of the day and she has got all this money she has got to pay and she doesn't know how she is going to pay it. So, you will hear some horrible stories. Some people just get to the lowest of the low, and they will be living in houses where you will just see all the grass growing around and nobody is attending to it and they are just there by themselves. And nobody believes them and no family visits them. It's a shocking story, absolutely shocking! Because I have bipolar and I have this over sociability, even though I am medicated, I have this push and the need to still get out there. But there are a lot of people, and I know it. They just can't! I mean look at me, this morning just from doing this little bit of housework, and knowing that you were coming, I'm showing a lot of signs!

Interviewer:

Apart from your GP, do you have any specialists that you see?

M:

No, I don't. My doctor asked me and referred me to the specialist, to the pain clinic. But because I, I am the sort of person who has to know somebody really well and feel emotionally connected. And I just did not want to start all over again with the pain clinic. So, I just wanted to stay with my doctor, on that personal level. I mean, gosh that surgery where I have been going! For instance, when I was having my lung troubles, my doctor, the lady doctor always lifted my shirt. And she saw, she said, there is something on your back I am not very happy about. And so, she asked me to see doctor D, and it was cancer. It was a big melanoma! And he took it out for me, he did the surgery on it. But if she hadn't seen that! Because a lot of doctors, they just put it on your shirt, they don't actually do the whole thing. I wouldn't have known, and people die of melanomas! So yeah, so anyway, as I was saying, there are other things that he has helped me with. So, I feel very warm and happy and healthy going to him.

Interviewer:

What do you think would improve health professionals' approach to CFS patients?

M:

I think one of the things is for people to just listen. That is the first thing. And even if they don't understand, give respect to that person. Give them their dignity. Just because you don't know about it, doesn't mean to say it doesn't exist! And so that is the first thing. And for doctors even to say, I can see you are unwell, I can hear you are unwell but I don't know what it is. And maybe together try to understand. But one of the first things that people need is to be listened to and then have some validation. And some point of moving forward. And if the doctor says, hang on I will look it up, or if the person with ME can say I can bring some information in. But you just get disbelief! And partly that's due to the way our medical system is now. It's a very Silo. It's not integrated the way, when an integrative doctor looks at you, they look holistically at you. Because all of the systems work together. But for people who don't understand these things, they will go along and say, I have got this pain. They won't even know how to describe their pain. Is it an achy pain, is it a bone pain, is it a nerve pain? These are all the things that people get tripped up on by doctors. They just don't know. They may have never had a pain like that before so how do they know? So, I think the biggest thing for doctors is to listen and believe and try to find a way forward. And either the doctor learning more about it or allowing the patient the dignity to bring in some information.

Interviewer:

Beautiful. I know you have talked about some days you are really tired. How have you experienced the fatigue in particular?

M:

Well some days, emotional things get to me more. Like talking today, probably tomorrow or the next day I will probably have to have a day in bed. But that's fine, it's worthy. I go to the garden and do that. I do it because it gives me something that I need inside myself. I think to myself, well it's worth it. So, you make decisions for those things.

Interviewer:

So, when you are so tired and you are in bed, do you get help? Who helps you with your dinner?

M:

No, I still, my daughter helps sometimes. But mostly, I mean it sounds ridiculous but I have crawled around on the floor. And it you ask, a lot of people do it. They have to crawl to get what they want because they can't stand up because they feel like they are going to fall over. We do all sorts of things, I tell you!

It's a shocker. And if you have, not with this, but other times when I have been doing too much I actually feel like my body has been poisoned. And you will hear that a lot as well, you have got this terrible nauseating feeling in your stomach and you can't even lift your arm above your head. You are just like a rag doll. You just have to crawl out here if you want to sit on your chair.

Interviewer:

How do you get some energy?

M:

Some people it takes days and weeks! I'm quite lucky it only takes me days. But some people if they overdo it, we call it pacing. You will read it all in that book. Pacing. After a while you will get to know yourself and you will know where your line is. And so, everyone is different though. And that's the other thing,

You see with me, like the doctor said, with the bipolar I don't want to stop. Nobody can tell me to stop, I just refuse to stop. I won't listen to anybody so I just carry on. And then, even though Annemarie might yell out Mum! You have been out there for two hours, come inside. And I will say, oh alright, and just proceed on. You try being bipolar as well as this! It's a strange mix my lot! But also, I have always had a very positive attitude and I laugh easily. It's always been like that for me. So, it's not something in my personality that just happens to work well with all of this. Because I can show up with a happy face and I actually feel happiness.

Interviewer:

Well thank you so much! And for the book, thank you so much! People have been so good to me, they have giving me so much information and I'm so grateful!

M:

You know why? Because we are so grateful. We are so grateful. And "W" actually, because "W" and I actually keep in contact on Facebook. We either call each other or we message each other. And she was just telling me the other day that she has managed to get up and sit in a chair now by the window. And that is utterly amazing!

Interviewer:

Amazing. She told me about that, that she sits there now.

M:

And you saw her that day! And she tells me, she tells everyone Mrs M saved my life. Isn't that amazing. And I say, oh Mrs W come on! And she says, Mrs M you did! You saved my life. Mrs W gave me also, Dr R details, is her doctor. She is the specialist. So, like, I talked to Dr R and I said to her, what is going to happen if we can't get Mrs W to do A, B and C? And she said, well she will die. And I said to Rosalind Hill, you need to go in and tell her that she will die, if she doesn't do A, B and C. And from that day when Rosalind Hill told her, because what happens is you are kicking into anorexia by the time you are 35 kilos. So that was the other person that I rang. Wendy gave me permission to ring the psychologist that she knows, and he knows Wendy very well. And he didn't know that she was so ill. And so, I talked to him quite a bit. And he said, it sounds as though she's got anorexic at the same time. So, he rang a colleague and later on he rang me back and we worked out some of the things that were happening then. Things that seemed, to somebody who is not sick, like washing your hands all the time, what is the word when you do all these things all the time? It's a psychiatric word. Compulsive disorder! And so that comes along with the anorexia. So what people don't understand is that you have got chronic fatigue, but if you keep going down and down, you come under other conditions. And that's the same if you are growing old. It's hard to know, so you have to have a good understanding, and you have to have really good knowledge. Because ok, working for IHC for ten years, a lot of people had dual diagnoses, triple diagnoses. I have got a triple diagnosis! So that's how I learned about all of those things. I learned on the job. And I also did in the end, and I did it and I was so proud of myself, I did a diploma at Auckland Teachers Training College. Teaching people with disabilities. So finally, I got my piece of paper.

Interviewer:

Thank you, M.

Interview Transcript:

Participant: A

Interviewer: Researcher Interviewer:

Hi, this is A and we are starting the recording for the research interviews 21st of July 2018. Thank you, A, for giving me the opportunity to ask you the research questions. My first question is, how would you describe your current state of health?

A:

Well apart from having MECFS I'm healthy. I don't have any other conditions, technically. I might have fibro but that's really hard to know because it overlaps. And you can't get in to see Rheumatology if you've got Fibro because the waiting list, at least in the Waikato is so long that if you get referred to them for that then they will just say no. Because they can't help you even if they do believe you have it. And then, just other stuff from before when I had ME I had depression and anxiety, but that would probably be what I would consider a lifelong thing. It's not like I got sick and then I got really depressed about it, it was prior to it. So, I take antidepressants for that. And then I also have asthma, but it's not really a thing. Like, it's the exercise induced asthma. Which I don't do now because of ME! Best kind of Asthma to have if you have ME!

Interviewer:

So how would you prefer people to refer to your illness?

A:

I don't know. I don't think that any of the names that currently are around are right for it. Because they don't know what causes it yet. But Myalgic Encephalitis, you say that and people's eyes glaze over. You say ME and they don't even know what you are talking about. Plus, let me be honest, when you type that into Google, it's just like ME. It could be anything, it could be me. CFS has a stigma. You say Chronic Fatigue Syndrome and people say, Fatigue, oh you just need more rest. Stop being lazy. And we share the kind of humour of it, it's like real dark humour. People coming up and saying, oh I've been really tired too.

Interviewer:

Do you know why?

A:

Yes, there is like an assumption made. And it might come in a different form each time, but the word fatigue makes people think of tired. But it's that dragging fatigue where you can't even move sometimes. But the post exertional malaise is more significant than the fatigue. Which is another reason I don't like that name. So, it's like, impossible to explain to people who have never had it. It's like when you get the flu and there is that really dragging feeling. It's not caused by being tired, like your body does it to you. To make you rest. And I think, like the theory is that it makes you rest because our body is telling us to slow down and fight whatever it is that is going on. But it means like any exertion, like even something as simple as chewing food adds to your total level of exertion for how much your body can tolerate. For a normal person, chewing and blinking and walking and all that stuff, they don't even think

about it as that because it's just regular. But when you get this, especially as it gets more severe, it has a higher impact of what you can do. And things like thinking, your brain uses something like a fifth of your energy, in total use for your day. So even if you think too hard it can exhaust you. It's hard to convey to people sometimes, and I don't think those names do that. The other thing is, even Post Exertional Malaise is a symptom name. I get that these are doctors writing this, but if you were to say that to people they would be like, what's that? I listen to the words and I'm like, oh ok but a lot of people don't have a vocabulary like mine and you say that to them and their eyes glaze over. It's the same thing, they don't want to put in the effort to find out or they make an assumption based on what they think it is.

Interviewer:

How did you arrive at a diagnosis?

A:

I was lucky enough to be going to a doctor who suggested I might have Chronic Fatigue Syndrome, when we went for all the tests and they came back normal. I'm really fortunate that the doctor I had suggested that, because a lot of people have problems where they are told that they are hypochondriacs or they are mis-diagnosed. They have to go to multiple doctors to get someone who knows what they are talking about. And even when you do get the diagnosis, sometimes you can get doctors who don't believe it's real and won't treat it because it's a psychological thing.

Interviewer:

Are you saying your doctor believed you?

A:

Well it wasn't so much that she believed in me, it was just that she knew of it so she suggested it to me.

Interviewer:

Was she aware of the illness?

A: But she didn't put it on my file once she suggested that I had it. So, I didn't realise that and when I went to a different doctor when I was at uni, she was the one who actually put the diagnosis on file. But I am really stubborn, so if I had actually encountered a doctor who had said to me, no that's bullshit. I'm not going to treat that, I would have just gone and got another doctor. I don't like doctors that ignore established science. To me that seems like you are not doing your job and you are not good at what you are doing. Why should I pay you money and risk my health?

Interviewer:

How did you feel when the doctor told you had CFS, or she suspects you have CFS?

A:

A combination. I didn't know a lot about it so I looked it up. And it was combination of relief for having a reason why I felt like I did but then disappointment because there is no specific duration. There are some people who recover. There are some people who are diagnosed who

probably have something else who recover. Then there are people who never recover, or don't recover for a very long time. There is no way to know when it will end. I suspect that because of not having a diagnostic test, just using criteria that in the past hasn't been very specific means that some of the predictions about how long it might last might not be that accurate. Most of the people who I have met in the support group and through events and stuff who have it, have had it for a very long time. And I think if they find a diagnostic test they will start to discover that most of the people of it for short durations either have a specific form of it or have been diagnosed incorrectly. But I've had it now for four years. I had, not the sudden onset kind. So, it's hard to know exactly when I got it. I mean, I have suspicions that it wasn't even when I started getting sick that I initially had that problem. When I was 20 I moved out of my grandmothers to live with some friends. And that day I went from feeling fine in the morning, feeling a little bit weird and then by the evening I had to crawl to the toilet. Which sounds exactly like the descriptions of some people's sudden onset. But then the next day I was fine. And every other 24-hour illness that I have ever heard of has been gastro. So, I don't to this day know if it is CFS related or what. But once I started hearing stories about people's sudden onset, it's like, well that sounds really familiar! Just not when I started getting the permanent problems. And then I think maybe what happened is whatever it was that triggered it might not have been enough to properly end up sick. But then something later on must have impacted on it and I ended up with it. That's my theory, there's no way to know. **Interviewer:**

it wasn't as if you were terribly sick before you got a diagnosis?

A:

Well I actually thought I had low iron to begin with. Because I had had it in high school then it had gone away, which is actually kind of common. Because it kind of felt like that exhaustion that you are never not exhausted.

Interviewer::

Were you exhausted being anaemic?

A: Because if you have low iron, it's not getting enough oxygen and stuff around your body, and that tends to make you exhausted. So, I thought it might be that. Because I did a type of drumming called Tikal drumming. Which I don't need to explain but it's very physical. And I was getting to the point where I couldn't lift my arms all the way up, I could only lift them part way up. They wouldn't go any further. And I was working at Whitcoulls and I was stocking out and getting exhausted – doing things that were regular for me. So, I went to the doctor and I was like, can you please check my iron? And it was fine so she did a whole bunch of other things, and then she said, I think you might have Chronic Fatigue Syndrome. And I was like, ok. I don't think she gave me any information about it, I just think I went and found it out myself. But then the next doctor that I saw was a lot better. She was at the university, at the student health centre. And I actually could go and see her for free, so that was good. And then she officially put it into my records, because the other one hadn't. And she did a whole lot more tests and redid those tests as well. So basically, I have had all the tests a couple of times, to say yes everything is normal and we didn't miss it the first time. And the doctor I am with currently, she is better as well. When I went to see Roselyn Vellings, she made some recommendations and I took them to my doctor, who was like, yep we'll do those. So, we did the B12 shots.

Interviewer:

Was that helpful?

A:

No. It is for a lot of people so it was worth trying. Like my auntie said, we can try it and if it doesn't work we are not any worse off. But if we try it and it's successful then that's something. But also, if we try it and it doesn't work then we know it doesn't work, and that's something that we can remember going forward.

Interviewer:

Was yours associated with pain? Did you have pain?

A:

I do get pain, it's got worse recently I think because of the Fibro stuff. But again, that is a speculation until I get a diagnosis. I would call it an educated speculation though. I know a lot about it because there are a lot of people within the MECFS community with Fibro. My best friend actually has Fibromyalgia. So, based on my discussions with her, it's probable that I do. Mostly it was joint pain, just inflammatory maybe.

Interviewer:

So, anti-inflammatory, do they give you any relief? Are they helpful?

A:

I don't actually take anti-inflammatories. Non-steroidal anti-inflammatories cause me stomach problems. I discovered that well before I was sick. It just messes with my stomach and I end up vomiting and stomach pain and diarrhoea. It's not fun. Found that out at work, so had to go home. My doctor did say that if we really need to we can try Lo-sec, something like that as well. But, I don't know, I'm hesitant to take a medication that will counter the side effect of another medication. Because you get to the point where you are taking this medication so you can take this medication. Which is something my best friend has to consider because she has a lot more stuff going on than me. Like she has heart stuff, so one of the things she would have to take for something she has to take.

At the moment I can manage.

Interviewer:

well if you can manage without it **A:**

A little bit of pain relief and a wheat bag, and I have the muscle rubs and things. So, they seem to help. I do get muscle problems from bad posture and stuff. I use the muscle rub on them and it helps.

I find heat is quite effective for me. Cold just doesn't really help. I think it would help if it was like, bruise related, because it would stop the swelling and all that kind of pain. But the heat is good because it helps with the inflammation, but it also helps to override the pain signal by giving it another signal to send, if that makes any sense?

Interviewer:

You said you have done some research on CFS?

A:

Yeah, I tend to follow what is happening on the Open Medicine Foundation. They are a nonprofit, organised by a lady who I think has a son or daughter with it, and a doctor called Doctor Ron Davis from Stanford University. He has a son who is severely ill with it, like one of the more severely ill ones I have ever seen. And because he wants his son not to die, he is trying to find out what caused it and how to treat it. So, he's one of the foremost medical researchers, he's turned his focus into MSCFS, which is actually helping a lot of people, in terms of giving them something to hope for. He recently got funding from the NIH over in America for five years, 500,000 a year or something. I can't remember exact figures, but that's amazing, because he has tried a couple of times and been rejected. Clearly, he has got something that they want to see more of. One of the things that's cool is, he created something called a nanosat, it's a tiny little chip. You can put a drop of blood into it and run tests on the electrical implements. So, say you put something into the blood and the blood reacts to it, it's going to change the electrical implements. So, he actually, the stuff that they have been working on have led to improvements in rejections for organs. He posts video updates, which is how I know this.

Interviewer:

What's his name?

A:

R. D. If you go on the open medicine foundation site, they have all that information about him and all the other medical researchers they work with. Because there are a team of them now. And they go to conferences and things now and talk to people, to medical researchers all around the world. Another place that is doing good work is G University. They think they might be close to a diagnostic test. So, like a blood test that you could just go down and get. That would be a big thing! Because then you would have a physical way to prove, for Americans for example, for your medical insurance. But even just here in New Zealand, for like WI, and the MOH. Yes, I do have this thing and I do need help with it.

Interviewer:

CFS support group? How helpful is it for you?

A:

It's nice to know it's there. And Tracy, the client services co-ordinator from MS Waikato, she is very supportive and very helpful. But because we don't know what it is, a lot of the things we are focussed on are like managing your pacing and managing your nutrition and all of that stuff. And you get to a point where it is no longer much use. Because you can only do so much. But that's not the fault of the support group.

Interviewer:

management skills?

A:

Yeah, and part of me is that I'm a little bit stubborn, I don't want to be all, going to meditation. It might help people but I'm just not the kind of person who wants to do that. If I could be shown scientific evidence I might be, but that's just how my brain works.

Interviewer: :

People are different.

A:

Exactly. And that's why I think things work for some people and some for others. The other thing I like about it though is that she makes resources available to people, so there are books and DVD's that they have. They have a library of them. And so, you can borrow them to learn more about it. I mean, with the internet I am able to learn a lot, but especially for the older ones, where this is not necessarily their first method of research, it's quite good. I did notice that a lot more people at the support group were my age or older. It didn't seem like young ones wanted to come and talk. And I haven't been there many times because I don't drive. And it's difficult because it's on the other side of town and mum usually has a volunteer job in the morning. But at the same time, I do receive updates via email, and she sends out a newsletter so that people who can't make it to the support group can still find out the information.

Interviewer:

How has it impacted in your life? Financially, socially **A:**

I'm on a supported living benefit. I was working full time at Whitcoulls. I had to drop down my hours, which eventually lead to dropping them down more and more and then I had to stop. Initially I tried dropping down my hours and going back to study, to try and get a job in a field where I could sit down and it wasn't so physical. But that's when I realised how hard it can be cognitively. I just couldn't keep up with the amount of information that you have to absorb at the rate that you have to absorb it. And then also doing the assignments, I can't guarantee that I am going to have enough 'good' days to meet the deadline. So, I stopped doing that. Yeah so, I was working, I think it was around 26 hours. My boss was really accommodating, because I had been there for a while and I think I had a bit of a reputation with her as being reliable and hardworking. Feels like I'm bragging, but it's what she tells me! So, she tried to accommodate me but it got to the point where I was showing up late, regularly enough that it made me feel bad, as well as making them feel like they have to talk to me about it. And I'm always very aware of how, like you want to stay in your job and there are things and you can't really control them but at the same time, they have a business to run. Like, it's not their fault I'm sick either. And it was really messing with my mental health to try and maintain that number of hours, and be that tired and exhausted and feel that awful. So, my mental health improved significantly when I stopped working. Because I wasn't stressing about trying to get there, about being late and then making them have to talk to me about it, stuff like that.

Interviewer:

You talked about the stigma related with CFS. Do you see yourself stigmatised? Has it had an impact on your friendships or social life?

A:

I'm not the sort of person who had a huge selection of friends to begin with. Like I'm a little bit socially different. Like I'm blunt and a lot of things that mean I don't make a lot of casual friendships. So, the friends that I do have, have always been very close. I can only think of one friend who hasn't been my friend since I started getting MSCFS and I'm not even sure if that was the reason why. She ended up in a different city with a corporate job, so it could just be difference. But the other friends that I have, it's their character rather than, because I think some of it depends on what kind of friends you have. Mine are the kind of people who stick by you even when stuff is going crazy. And I have made some friends since I have had it. They have only known me this way.

Interviewer:

Has it really affected your friendships or social life?

A:

It hasn't affected my friendships. It has affected my social life, because sometimes I'm too exhausted to do things, and if we do things they have to be specific things. Like I've got friends who go hiking, and if I were well I would go with them. But because I am not we do board games and movies and things like that. So, it changes what you can do with people. And it depends. Those people are so comfortable to be around that it's not stressful, doesn't use a lot of mental energy to be around them. So, I can hang out with them more. But then there are other people where you feel you are on all the time, and I can only be around them for a very short period of time. And this is going to sound terrible, but my dad is one of them. He tells long rambling stories where you have to follow along to be able to understand the point. And it uses so much mental energy that I just get frustrated and irritable and exhausted. And I have to be careful not to be a raging bitch.

Interviewer:

Do you have good days and bad days with the illness?

A:

I am better at figuring out what too much is now, than I was at the beginning. And when I was working, that was always too much. And so, when I was not working I was in bed. Like it was one or the other, there was no time for anything else. Since I have stopped working, and my mental health improved then, the bad days usually happen if I do too much. Nowadays, if I go out for a day or do a thing, like I volunteer every Thursday at the library doing computer mentoring, because I needed to get out of the house. I was going mad – literally because I have mental health issues. And so, even after the two hours I have to go home for a rest. And the next day is a bit of a rest day too. It's not, I'm so dead that I couldn't get up and do something, its if I have a rest day because I am feeling a bit lower than usual in energy levels, it doesn't hit me as hard. I went to do an exercise programme run by Wintec. I can't remember what it's

called, something clinic, Biokinetic clinic that's it! Because my doctor had said other people with it, with CFS had found some benefit. Unfortunately, my experience was not pleasant. Initially the person who contacted me was an English as a second language speaker who didn't take the time to make sure that she was communicating well. So, she sent me these emails, and before I could respond to them she would send me a text, and when she would text it would be this long text and then another long text and then another long text. And when you have this, you can't process this one before another one comes. And she rang me too initially, and because of her accent and how fast she was talking, I couldn't understand. And I only just got enough information to understand she was calling from Wintec. Because she said something about the clinic but she didn't use the word Wintec. So, I was like, I don't know what you are talking about! And eventually I had to complain about her because the contact that I was receiving was just overwhelming but also very poor quality of communication. And then the person they gave me after that was just really lovely. She was a good person with the communication, she was understanding. But they don't have anything specific. Like they have an exercise programme where you do a test at the beginning to see what your level of function is, and then they figure out something for you afterwards. That test is just standard. They didn't have an altered one for people with MSCFS so they wouldn't overdo it. So, I spent two weeks in bed after that. So, I get up and I go to the toilet and I have meals, but it stops me from doing pretty much everything else and it makes me sleep most of the time. So then afterwards I went to two appointments to do some exercise, because the whole idea is to improve your physical fitness I guess. But it's the other side of town, even further across town than going to the support group is. And mum has to drive me, and she has to wait there for half an hour or an hour or however long the appointment is, so she doesn't have to drive across town four times. And I just got to the point where I was just like, I'm not getting anything out of this significant enough to justify it. The other thing is, I've read stuff about people who do pacing, and graded exercise therapy and stuff. And I'm sure there are people with mild forms, where graded exercise might be useful, but in my case, it feels like people are pushing me to be fit because that's their understanding of things, and not taking into account the fact that fitness involves exertion which is basically what my body can't tolerate. So, at the moment I am not completely inactive, but I spend a lot of time resting. Most of my activity is walking around the house, or I walk to the dairy or I walk around the supermarket. I'm not making any additional effort to get exercise because I don't feel like my body is ready for that. It doesn't need the additional stress of recovering from that.

Interviewer:

And do you get support from family? I know you mentioned earlier that your mum supports you.

A:

Mum is supportive. Dad is mostly supportive but I don't think he understands very well. I explain it to him but I think, part of who he is just not comprehending it that well. But for the most part he is pretty supportive. My brother is even less supportive. He's very active and he's got this opinion that everybody should be fit. He likes to think that he would pay attention to scientific evidence if you gave it to him but he only reads the bits that support his arguments. So, we just don't talk about it now. Unless it's something like, when I moved in I said, I can't lift things. Actually, it was, will you be able to lift them because it will just be me and you. And I was like, no why don't you ask Terry if he's free (Terry is his best friend.) And he can earn himself a free box of booze and we don't have to have an argument!

Interviewer:

So apart from your GP, have you contacted other professionals for help?

A:

Apart from my GP, not really. Apart from Roz.

Interviewer:

Did you used to go to her?

A:

No, I went to her the one time. It was like an hour-long appointment, you tell them your history and I think some stuff has been sent along ahead of time. I know you fill out a form for her to look at. And then talk to her about the onset and the things you are doing to manage it, the things that you have tried. And she mentions things like B12 and she told me I should try Melatonin and gave me a prescription, but it's not funded. And I was a little sceptical.

Interviewer:

And do you pay to see her?

A:

Yeah it was two hundred and something dollars. There was a discount for people with a community services card. Just for that one off. Because it's like a specialty, you sit down for a whole hour. I think if you go to see her regularly, it's just like a normal GP visit. And there was another suggestion or two, but I didn't find much benefit from Co-enzyme Q10, which was something she suggested. By much I mean I didn't notice any difference. But then, how do you notice? It's a vitamin supplement, so if it's building up it's happening gradually. But there was no significant difference so I stopped, because I didn't want to spend money on something that isn't helping me when I have such a limited income. And the other one I was taking is Magnesium. I had been taking that already though because I had muscle cramps in my leg that were the worst I have ever had. It was so intense that my leg was sore for a couple of days afterwards. I was just like, Magnesium! Where is the Magnesium! I'm not taking it at the moment because I am lazy about getting another one, I probably will pick it up again.

I found that one useful, I looked up which versions were most useful for which things.

People with ME sometimes have low blood volume, and I would suspect that's common for me too, because I have had problems with low blood pressure before. By problems, I mean I can feel when it's happening. I have that Powerade powder that you can buy from the supermarket and I just make up some of that. And then I will have something to eat with it, because then you get all the bits of electrolytes that you need.

Interviewer:

How much energy?

A:

It's less about the energy and more to avoid the low blood pressure. Stops me from shaking. It boosts my blood volume and then helps boost the electrolytes so everything turns back from not being trembly and yuck feeling.

Interviewer:

It's quite interesting because you have people with different symptoms, I suppose?

A:

I think it's because the human body is so complex. That's why like antidepressant medication is like educated guesswork, because everybody's brain chemistry is different. Like it all has a fundamental building block that is the same but your neuro chemistry will be determined by your experiences and the way your brain forms and environmental factors. So, it's impossible to have one thing that works perfectly for everyone.

Interviewer:

It's quite interesting, because when you look through all the illnesses, they have specific symptoms for them.

A:

Whatever it is that is going crazy is affecting so many different parts of the body, but it doesn't do it at the same severity for every person. So, someone might have the same kind of, when they determine the level from the blood tests, the same level of ME as I do, but it will be more GI focussed. Or maybe someone will have pain. I think that the main thing that everybody has, is the post exertional malaise and the fatigue. And poor quality of sleep is another one. I think even the people who take melatonin and practice sleep hygiene and stuff, it improves their quality of sleep but it's still not at the same level as it was before they got sick. And obviously, when you have better sleep you are going to have a bit more energy and feel a bit better, which is great. And I'm glad that that works for some people, but I'm pretty sure it's not like a fix.

Interviewer:

And does it affect your sleep?

A:

I have irritable bladder, so I get up to pee a lot, which can interrupt your sleep. I'm really light sensitive and sensitive to sound and hot and cold. And I have the thermal dysregulation, so I get hot and cold really easy and I have to wear lots of layers. So that if I get a bit warm I can take some layers off rather than taking a big jumper off and I'm immediately cold and have to put it back on. If I get too cold it's really hard to warm back up, so I have to get a hot water bottle or a wheat pack or something to give my body something to heat it, to help it get going again. Which is a little bit scary, when it happened! I try not to get that cold now. And if I get really hot it's really hard to cool back down. In summer time I spend all my time laying flat on the bed, trying to move as little as possible with the fan on full, trying to stay cool. And then if that didn't work I would get into a cool shower. I find summer the worst because I just can't get a regular temperature. Like with the heater in winter you can heat the room at roughly

a constant temperature. So even if it's cold outside I can stay sort of, with a little bit of fluctuation, in a comfortable area. And you can add blankets, hot water bottles, wheat packs. But in summer it's just that much harder. One thing I did find is I really enjoyed the salt water, the buoyancy from the ocean. My friends took me to the beach a couple of years ago, and when I was in the water I was like, I feel great! But then you have to get out. And the gravity reasserts itself and you are like, ahhhhhhh! And then of course they picked a beach with a steep hill, and that was an additional not fun after getting out of the water. Next time I am going to make them take me somewhere flat. Just go in the water and then go back to the car. I like the beach, the beach was fun but I think, with all things where I leave the house I have to factor in how much energy it's going to take, how much I am going to have to recover from it afterwards. And that's even going to the supermarket and going and doing my volunteering. I have to be aware that it's going to have a bit of an impact on me. Occasionally you forget, and you are like, oh I'm going to go and do this thing after this other thing. And then you are like, oh crap yeah. Got to remember that!

Interviewer:

And when you are out taking your walk, do you suddenly know when to stop, and say I need to stop now?

A: It's more, I know from past experience that if I do this thing I can manage it, but if I do another thing afterward it will be too much. So often you can put yourself – that exercise test is a perfect example. There were some exercises where I was thinking, that's going to screw me over because of what they were. Like the one where you stand up and sit down as many times as you can within 30seconds. I was like, this is going to fuck me over because of the amount of heart involvement. And anything that makes me raise my arms above my head usually will have an effect as well. Because my arms being so close to my heart I guess. But there were other things where it was like, I wouldn't know I was overdoing it until the next day or the day after. Because sometimes I don't know until the second day. And then you just feel like death and you are like, I don't want to move!

Interviewer:

Ok yes. Well we are gradually getting to the end of the questions now. It has not changed your relationship with your friends... Right, this is good. What do you think would improve health professionals' approach?

A:

Education and awareness. There are a lot of doctors who don't know a lot about it. I think the other thing would be, making it something that is included so all new medical practitioners are taught about it. Because eventually, just by the virtue of the old ones dying out and the new ones taking their place, everyone will know about it. But the other thing would be, making them aware that it is physiological, and I think part of that would be the name change as well. There are some people where there is a stigma attached, even if they are medical professionals. Because they have been around for so long. For them, the entire time they have known CFS it has been psychological. And now that it has been proven to be physiological, they are all like, for all this time it has been psychological, so why would it suddenly be different, kind of thing. But I do think some of it is the fact that health professionals are human beings, with all the relevant biases and stubbornness, and not necessarily being good at telling scientific things

from opinions. I can't really say for certain, because I have had really good experiences, or at least not bad ones (that would probably be a better way to put it.) **Interviewer:**

Currently, what could they do better. Now. Apart from studying and being aware of what it is, how can they improve on their approach towards CFS?

A:

I think one of the things that should be done, that would help people with MECFS, is actually something that should apply to everyone. The current medical approach is to act like people don't know what they are talking about, because they have studied for so many years they are like, I know this, you shouldn't look on Google, you shouldn't do this, you shouldn't so that. It should be collaborative, maybe you could put it. The patient is the only one who knows what their body is trying to say. The doc doesn't know their pain level unless they can tell them. The doctor can't see what's going on inside, can't feel the feelings and tell what signals the nerves are sending. They have to interact to the patient to know that. And they also need to be aware that you can't always solve every problem. That's not their job. It's not to be miracle problem solvers, their job is to actually listen to the patient, find out what is going on, make an educated guess based on the available information that they have. And I think a lot of doctors forget that that is basically what their job is. Educated guessing. I think a lot of regular people forget that too. They think that their doctors should know everything. I have come to the realisation that it's not fair to expect them to know everything but it is fair to expect them to treat you with dignity and respect. And to make every available effort that they have to find out what's going on, without treating you like, like some people get treated like, oh you are just making it up or you are over exaggerating it. Which tends to be the kind of thing that happens because a lot of the medical industry is still older males and they have a misogynistic thing from society. They are not necessarily doing it on purpose but it's that women are emotional. It was actually interesting to read an article where they did a study on the difference in treatment between men and women who presented with abdominal pain. Men would often be given pain meds and be seen to and taken seriously, women would get left longer before they were seen, and told, kind of brushed off a little more. One lady was lucky she didn't die because she actually had ovarian torsion. And the doc was just kind of flippant. I can't remember how it got picked up in the end, but she sat there for like hours before they did anything about it. And they didn't really give her any pain relief or anything like that. I think one of the other things that needs to be kind of stressed, is yes men and women have differences but doctors need to consider that everybody's pain is as valid as everybody else's. Sure, this person might be reporting a small amount of pain but you don't know what their pain tolerance is. So, this person might have a high pain threshold and a low level of pain, where this person might have a low level of pain and a low pain threshold. It's relative, and no person should be suffering. So regardless of how much pain they are in, if they are in pain you should be taking that into consideration. And one of the other things is, don't treat people like they are out to get you. With all this opioid abuse stuff going on, a lot of people who have to take opioids for their pain management suddenly find that if they have to go to a different doctor, they are treated like they are drug seekers. Some MECFS people, if they have to go to hospital because their pain becomes overwhelming, or Fibromyalgia, they get treated like they are drug seekers without anyone taking they time to check if they actually need anything. And most of the time, they don't even want opioids. They are not asking for opiates. They are just asking for someone to help manage their pain. It could be Panadol, if that was effective.

There is a specific reason sometimes for asking for a specific medication.

Interviewer:

I mean, you would probably know the medication that works for you, especially when you have had the illness for a very long time.

A:

I also know the ones that don't work for me.

if you have any kind of chronic health condition, you probably know more than the doctor that you are seeing, if they are a new doctor. Even if they have more medical knowledge, you know more about YOUR health problems. And you may have tried 50 different types of medications and know the exact one that you need. But if you say that, they act like, who is this uppity person who thinks they know what they are doing? But it's a bad reaction to have. If someone suggests something to you, talk to them about it! I have a good dialogue with my doctor so I can suggest things like that. She doesn't even get grouchy for going on Google because she knows I look at the evidence, rather than going, oh god I have cancer! Like some people. I will look and I'll be like, ok I have looked at these places and the research suggests that in this situation you could try this. And when I said, Roz Vellings has suggested that I take

B12. Because there is a good reason for what I am saying to her, she doesn't say. Oh, you don't know what you are talking about, I'm a doctor, kind of thing. And she will try it. If she has any concerns, she will voice them and then we will discuss them. Which I think is how every doctor should treat every patient. So, I think it is something that would benefit MECFS.

Interviewer:

So, having that therapeutic relationship with your patients? That collaborative?

A:

Yeah. Treating them like equals, rather than the almighty doctor. And you are just trying to do your job and help this person. And it ties in with that thing if they can't help you then they don't want to know. There are some doctors who, if they can't figure out what you have or they can't treat it then they are not interested in having you as a patient. Or they are more flippant, or they regard what you say a little less. Or they treat you like hypochondriacs. There are a lot of doctors that do that. That said, probably the majority don't, but it's hard to find doctors like that, like how are you supposed to find a doctor like that, when every person is individual. A lot of people have a lot of difficulty finding doctors, and so I'm actually part of this Facebook group, for Fibro and CFS sufferers in New Zealand. And they have a list of Doctors that are not horrible. It's a closed group, so it is limited to people who have the illnesses. And there are rules regarding what you can and can't share and promote and whatnot. Because the other thing is, people with this become emotionally vulnerable. Which I think is something that is a little under recognised. When you have been told constantly, it's all in your head or it's not as bad as you say it is, you should just get out and do something, go get a job, you are a dole bludger. Because a lot of people are beneficiaries when they have a chronic illness. You get to the point where some of it starts getting internalised. And you also get desperate for a cure, for a magical fix. So, people try everything. And so, when people share something that they haven't thought out properly, these people might be desperate enough to try it, and a lot of those people with those 'cures,' they are just preying on people. Like they have just got this random thing that doesn't really work and they are trying to charge people

for it. Like, I have been told that thyme tea would cure me magically. I'm like, yep pretty sure it won't. Fairly sure if it did there would be this sudden patient, oh my gosh you have to try this, I'm fixed! And it would be repeated so many times I couldn't ignore it. If it was a cure, that's what would happen. It might work for a person, or some people. I feel like it's too complex for something as simple as tea. It's just people with emotional vulnerability don't have that kind of distance to go, yeah but that is ridiculous, why would I try that. Because they are desperate. They are desperate to be returned to normality because the situation they are in is so awful. People with MECFS often report a really low quality of life. And I seem well put together and that I am doing really well, and I am, compared to some situations like when I was in my previous flat it was way worse than it is now. But at the same time, I am predominantly housebound, I can't work at all. Even if I could get a part time job, there are none that offer a few hours and that are within my limitations. Even the volunteering, I have to think very carefully about what it is that I am doing and how much it is that I am doing. It effects what I can eat, it effects what I wear. Like I have sensitivities with my skin, so tight clothing makes me itch really badly. And because of the temperature fluctuations with my body temperature, I can't wear certain fabrics. So, I basically live in a specific type of track pants, and tee shirts, with a shirt and a zip up hoody. Or layers. And then, you get to the point where it's really difficult. And at times, when I have felt like I needed to go to an event, what am I going to wear? I don't have nice clothes – partly because of not being able to afford them from being a beneficiary. But also, at the same time I am a bit different from other people and I'm like, fuck it I'll go wearing what I have got on and if they have a problem with it, too bad. But it depends on the situation. Sometimes it's a good excuse not to go. Sorry I don't have anything to wear, but secretly I don't want to go.

Interviewer:

How have you experienced the fatigue in particular?

A:

That's a difficult question. It depends what you are referring to. Fatigue as in how well I've slept or fatigue as in exhaustion, or fatigue as in post exertional malaise? It encompasses a lot of things. I think it depends on how well I have managed my illness. If I have paced myself well, I usually am not exhausted but that makes me seem like I've got nothing going on. Really it just means that like, I have paced myself well and I am getting at least a reasonable amount of sleep and I'm resting. I have an alright baseline, where I can just sit and play games and I'm not feeling like death, but at the same time that still limits me from doing regular activities that other people are doing, working and whatnot. And if I haven't paced myself and I'm exhausted then everything kind of gets dragged into it, along with it. And I can be over tired without being fully exhausted and I can have some post exertional malaise and not be completely exhausted, although that doesn't often happen. But most of the time it's either I feel alright because I have managed everything or I have overdone it. There's just kind of a lot of middle ground.

Interviewer:

Someone described CFS as an earthquake. How would you describe yours?

A:

I don't know. I can understand why they could relate it to a natural disaster. Because it's that scale of change in your life. I am lucky that I am mostly homebound rather than bedridden. I spend a lot of time in my bed resting but I don't have to stay there. It's not like I can't get out of it. I feel like this is about as bad as it can get without it really ruining everything. Like I am still able to leave my house. But I can see why it can be described as an earthquake, because it really does put everything on shaky ground. It's that scale, like it's massive. You become literally a different person to who you were before. And you have to grieve. It's not always talked about a lot, which is one of the things I appreciate about the Facebook group, they do mention it and they talk about it with people. There is this grieving process because someone has died. You have died, your old self is dead. You don't have the same friends some of the time, you lose contact with family members some of the time. And even if you still have them, the relationships are different. And for me, I couldn't work, I couldn't do my drumming anymore, I couldn't do anything physical. And I don't outwardly look like some sort of gym junkie, like fit, but I enjoyed doing things that involved moving around and being active. Often dancing and drumming. And so, to be unable to do them, you feel kind of trapped in your body. I have to spend a lot of time reminding myself that it's not my body's fault that it's like this, and forgive my body. You can actually do bad things to yourself. Say people who have got an injury, they have to not hate their limb to make it heal properly. So, I am always aware that I should just keep in mind to not punish my body for something that it can't control. It's so hard to find words! Because it's still being researched and words are being made, there are not necessarily words in the English language to describe it.

Interviewer:

I have no regrets doing this research, to be honest with you.

A:

I would be completely glad and grateful if you did, because in New Zealand it is estimated there are about 20,000 sufferers. Just in New Zealand, with a population of around four million people. From my experience, and bearing in mind that the Facebook group isn't huge, that a lot of them struggle in some fashion. Whether it be socially or financially. And I feel like there is this kind of void in the medical support services, where people like me are not covered. Like I actually applied for home help but I have been told that I am ineligible because I don't have a physical disability. Meanwhile, I can't take care of myself on my own. Before I moved in with mum, I was eating really badly because it had to be microwaved, easily cookable for me. Or I ate things that didn't need any cooking. So basically, junk food. I was prediabetic. I am not pre-diabetic now, but that's because I switched to sugar free fizzy drink. And I tried to cut out the excessive amounts of sugar. But yeah, the kind of nutrition I got, I got no fresh food, no vegetables. Not a lot of meat unless it was in the microwave meal. It just wasn't a well-balanced diet. And like, you get referred to nutritionists and they tell you, this is good nutrition and you are like, ok well I have these limitations. Can you tell me how I am going to do that within this? But they don't offer you that.

Interviewer:

They only tell you what to do, but how do you do that?

A:

And those are all the free options. I was told about someone who might be good, who was good for another chronic illness sufferer, but it was \$75 for a skype consultation. Because she lives in Nelson, so it's not like she was going to travel. But it's good she does offer Skype ones. But private medical fees are beyond any beneficiary. I can't afford that, and I can't afford to go. I want to see an Osteopath, and I know one that is within my price range sometimes. But then, I have a friend with Fibro, and if she wasn't working, she couldn't afford to go to physio. And since she has hypermobility, if she didn't go to physio she would be dislocating things all the time. And I mean, she dislocated both her shoulders doing something as simple as lifting the washing out of the washing machine. And even though she has Fibro, that's the same story as a lot of people who have CFS, because they also have Fibro or because the CFS is different. Or just because they don't have the support they need to get the medical help that would improve things for them. So, I realise that the government has a limited budget for medical stuff, but I also think that part of the problem is the definitions of disability don't include chronic illness. And instead of creating a separate definition for chronic illness or including the two together, they have just ignored it. So, at the moment, living with mum, who has arthritis in her spine, we can manage our chores between the two of us. With probably a little less regularity than we should, but we are not living in filth. When I was living with my flatmates, part of the reason why I couldn't stay there was because they didn't clean and I couldn't. So, the kitchen was disgusting in my previous place. It got to the point where I was taking rage photos so I could show people, to prove to people that I wasn't overexaggerating how bad it was. And the other thing is that, people with chronic illnesses, you get the same amount of money as everyone else, right? Which is fair enough I guess, but the costs of living aren't the same. You have got Doctor's fees, and they are not just one-off fees, they are regular fees. I get mine covered by WINZ. But they pay for once every two and a half months, and instead of putting git on the payment card once every two months, I get like, four dollars a week. And at that point I was so stressed out and struggling to afford to eat, that that four dollars a week went on my food bill instead. Like I would make a way to get to the Doctors, but usually that would be not paying a bill that week and pushing it off. Or finding something else that I didn't have to pay for so I could afford to pay for the doctors that week. Because I couldn't just put it aside each week. Often the weeks were so stretched out that I, like I have only just been able to afford to buy new clothes, because I was so broke when I was living in the flat that I couldn't afford new clothes. I was wearing the same ones over and over until they wore out. And then I was wearing them again. Because this is a housing New Zealand property, so even with the loss of accommodation supplement and moving in with mum, I actually still have more money in my pocket than I did before. And it's not like I am rolling in dough, like the image of beneficiaries who don't do anything. It's enough to buy a few more clothes, start paying off my debt a little faster. Because you get in debt really fast when that happens because you have no buffer. My dog needed to be put down, and the reason why I'm not drowning in debt from it is because my friend sneakily snuck up to the counter and paid for it. He's amazing, like when she needed surgery a year before that, I made like a go fund me style things, and he just walked up to my house and handed me the money that I had asked for on the thing. And without Waikato animal outreach trust I couldn't have managed that either. But yeah, he just handed it to me in cash. And he just dropped by and did that. He didn't come over and hang out and go, oh by the way... He just handed me money and was like, see you later. And he was gone, and I was like, thank you! He was really helpful in looking after my dog too, because I had her before I got sick. And she was a rescue and she was quite old by the time I got sick. And so, it was really difficult to try and rehome her, nobody wants an old dog, they want puppies. And I think I would have been really emotionally damaged by getting

rid of her too. Because there were a lot of times, especially when I was in my previous flat, where the circumstances were so overwhelming and shit was going so badly that my depression got really bad. And the only thing keeping me going was being able to cry on my dog. So, she was my shoulder. I had a big dog, by the way. I didn't crush my little dog by crying on her. And she was put down five or six months ago. Because she got old.

Interviewer:

How old was she?

A:

Fourteen! Which for a big dog is like, decrepit old! But she was fine apart from a tumour that was, well the surgery she had the year before was to remove a mammary tumour. And then it came back, and it was growing really fast and it was just draining her life. And she was getting old and I didn't want to put her through surgery just to have it come back again. And there was a probability of it being cancer but I couldn't afford the test of the tumour. Because the surgery itself is like, ridiculous. But then you have got a couple of hundred dollars more just to test the thing! So, I didn't test it because I didn't have the dosh, and when it came back I was like, I need to make a decision and my decision is, I don't want to torture my dog with endless surgeries. She is old and probably has a limited life span anyway. So, I decided to make her life as good as possible and when it became obvious that it was affecting her quality of life, I took her and we did the one last day where she got to do all these awesome things. She had a cheese burger. I was like, I don't really have to worry that there is onion in it, because she is going to sleep in an hour. And then she had my friend and me there while she went to sleep. And he would take her on these adventures because I couldn't walk her, she was too big and too energetic. So, he would take her on these adventures. He would pull up in his car and she would get super excited, I always knew it was him as opposed to someone else. Because she would lose her shit. So, she would get in his car, they would drive off somewhere and they would go for a big walk, like a nature walk or something. She would get to play with other dogs, she would get tired out, and on the way home he would buy like a Krensky sausage or something and then split it with her. So, she would get spoilt in every possible way when she would go on these adventures with him.

Interviewer:

Interesting. Well thank you so much Anthea, you have answered every question! How old are you?

A:

I'm 30. I will be 31 in September.

Interviewer:

You don't even look 30! I was thinking, 23 or 24.

A:

Yeah, I get between five or ten years younger than I am. I think it's because I'm just fortunate but also because I have never smoked, don't drink much. Well I don't drink anything now because it has a negative effect on me.

Participant: W

Interviewer: Researcher

Venue: Skype

Date: 11/7/2018 **Interviewer:**

Hi W, how are you?

W:

I'm going good, can you hear me ok?

Interviewer:

I can hear you very well. I have got my recorder on because I am going to be transcribing. So, I need to have the recorder on. Is that alright with you?

W:

Absolutely, that is fine.

Interviewer:

How is your morning going?

W:

It's going well, I have been able to do some work on the computer. I have to manage it because I get migraines from working on the internet if I do too much, so I have to do a little bit and then rest. And some days I can do more and some days I think I am better off not to do anything on there today because it will set the migraines off, and the dizziness etc.

Interviewer:

Oh ok, well we will just crack on so I don't take too much of your time. I am going to be asking you a couple of questions, it may take up to an hour. First question is, how would you describe your current state of health?

W:

That's actually a really tricky one. As long as I do nothing I am ok. I can breathe, my functions are ok. As long as I do nothing. I might get heart palpitations and things like that, and I have problems with heat control and I can't actually tell if I am hot or cold. Those sorts of things. Sensory things. But as long as I do nothing I can still talk to people. I can't walk or do anything like that but I can exist on a better level.

Interviewer:

What do you mean when you say, you can't walk?

W:

I'm bed bound 24 hours. I have been for the last 21 months. But this is my third lot of being bed bound through relapse. I have had ME for 23 years. And the first time I was really sick I was in bed for two years, the second time I was in bed for seven years and this time I have been in bed for 20 months so far.

Interviewer:

Oh! Okay.

how old are you?

W:

I'm 62. I got ME when I was 39.

Interviewer:

How do you prefer to refer to your illness? Do you like people to refer to it as ME or CFS?

W:

ME probably, but when I write it, if I am writing documents I prefer to put in ME/CFS. Because some people get a bit funny about the ME, they just want the brain problems, and they get a little bit fussy about that. So that tends to cover everything.

Interviewer:

So how did you arrive at a diagnosis? Were you diagnosed or self-diagnosed?

W:

No, I wasn't self-diagnosed. I went to probably four or five doctors and I wasn't getting any better, I was getting worse. And the couple of hospital admissions I had, they just sent me away saying I was depressed, despite the fact that there were abnormalities. My thyroid was a little bit low, and there were other abnormalities there. Like I was having Rieger's etc but they basically took me and put me on oxygen, which really helped. And told me that the only problem that I had was that I was hyperventilating and I needed to learn how to breathe. And sent me to a breathing clinic, and the only way that helped me was the same way it helped me out when I had all my children. You do the breathing and concentrate on it and not on your symptoms. So that was helpful only in so much as that. But that took too much out of me and made me worse, going to all those appointments. So, I crashed again and they said I needed to see a psychiatrist. So, I went to see the psychiatrist and he put me on tablets that I reacted really badly to. And they shrank one of my kidneys a third and I was very very sick. But they still wouldn't look at it as a physical illness. They kept telling me I was depressed. And I knew I wasn't depressed, despite the fact that, I had been a nurse, and despite the fact that my situation was horrible and I was very sick, and that was frightening, I actually still had plans and hopes for the future and I was trying to get ahead. I wasn't depressed. But they said to me, you have got five children at home and your husband travels so you are basically a solo mother for all that time. So, from that they decided that I must be depressed!

Interviewer:

That is very difficult. knowing you are a nurse. You knew you are not depressed?

W:

Absolutely, so the second time I went into hospital I went under a specialist diagnostician and he was very good. I was in there for ten days and they ran every test they could think of. And they came back and they said, we have looked at everything, you have Chronic Fatigue Syndrome. There is no cure, there is nothing we can do to help you. You will be better in two years. So, go home and watch some funny movies and drink lots of vitamin C and orange juice and wait for it to go away. And that was actually really terrible because at that stage I didn't know how to get through the next five minutes, and to think that I was going to be like that for two years was actually mind numbing! And of course, it wasn't like that. And they didn't offer any support or medication, nothing! So, it was, the nurses were good, I was on an IV there and they did put me in a room on my own eventually, which was great. Because you know, noise and light sensitivity is hard to deal with. So, the nurses were actually quite kind in how they treated me. They saw it as a physical problem and were good.

Interviewer:

Did you know about CFS before you were diagnosed?

Did you know about it at all?

W:

No, I had never heard about it.

Interviewer:

Was it explained to you?

W:

Not really, no. They basically said, this is what you have got. This is how long it will take to get well. Go home and basically just do this. And the good thing was they didn't tell me to exercise my way out of it.

Interviewer:

Winifred:

There was no medication, nothing?

W:

Nothing. And so, we had to get in, because my husband was travelling, and he was really hesitant to get anyone in but my sister actually found a nanny for us and got her in. And it meant that I could rest while she looked after the children. And then, because I still wasn't getting well, because they diagnosed me with Post Viral, but still nobody does anything or tells you what it is. And then somebody said, there is a doctor who specialises in ME. Go and see her. And so, I did, it was Roz. And she said, yes you do have ME and what we will do is put you on a very low dose antidepressant. And I said, I'm not depressed. And she said, I know but this will help you to sleep, because we are not giving you the dose we are giving to a person who is depressed. It's just a tiny dose and it will help. And it might have been Nortriptyline or something, I can't remember. And I was on that, and

then I went onto some other different ones down the track because I found I would start reacting to them after a while so I would have to come off them. And then at one stage I had a very bad reaction. I was reacting to everything and I was on medications you couldn't just stop. And Roz was very good, she came to see me at home and I said, I just don't want to take anything, my body is just so unstable. It feels like chemical soup and I don't want to put anything in it because I just feel its going to go absolutely wired, more than it is now. I couldn't sleep and I couldn't eat. So, I was very very sick. And she said to me, look, you are a nurse, I have got a list of things that could be good for you, that could work in this situation. Have a look at them, is there anything there that would help you? The funny thing is, when I first got sick I said to my doctor, I think the thing that will help me is Valium, I just feel like my whole system needs something to calm the whole system down. And that's what it feels like, everything is on high alert. It's all too much, it needs something to calm it down. Of course, they said no, it's addictive we won't give it to you. But years later, probably about ten years later I was looking down the list and I saw clonazepam. And I said to Roz, how about we try that one? And she said, yes that would be good, lets try to get you two halves in today. And honestly, the relief for me was immediate. It suddenly calmed everything down I was able to sleep! And I actually went onto four halves a day. And it's only 0.5mg tabs. So, I was taking two of those. So, a milligram divided into four doses every four hours. And I just slept. I slept for probably two weeks. I was forgetting to eat and forgetting to drink and nobody was reminding me, but I needed to sleep. My body needed to sleep. And it just needed to calm down. And I thought, well it's no good sleeping this much, so I reduced it to three halves a day. Quite simply just by stopping taking one of the halves. Which made me a little bit more alert but my body was still calmed down. So then last year I managed to reduce down to two halves a day, and then I had another bad reaction two years ago and was starting not to be able to take the clonazepam, so I thought ok, sometimes I can take little amounts of something and get them in that way. So, I divided the halves into quarters and took a quarter every four hours. So, I was still on the two halves, 0.5mg's but I would just take a quarter every four hours. And that is working for me.

Interviewer:

That's brilliant. So how long were you sick for before you were eventually diagnosed? How long, was it years?

W:

That's a really hard one, because there are so many levels that I look at now. When I was about ten years old I got a virus that people thought was Glandular fever but it wasn't. And the doctor said, I'm pretty sure you have Glandular fever but the tests have come back negative. And I was quite sick, high temperatures and things. And I had always been a kid, even as a baby, I walked early and as soon as I was awake I would disappear out of the house, they would have to go and find me. I would be down the beach or I would be somewhere. I was always doing stuff. And even growing up I was like that. At seven or eight years old I was always up before the rest of the house, I would be out doing things outside. But after I had that, I didn't ever have the same energy again. They wanted me to train with a team they trained for the swimming sports, because I was a good swimmer. Same with gymnastics. But I just didn't have the stamina. But I kept going, I was ok. Just not the same stamina. And then when I was on my own, I had a first marriage that broke up and I came back to New Zealand with my two children, and I was working very hard. I got back nursing, I bought my own home, I was doing the lawns, I was doing everything. And I had a couple of instances where I woke up and just nothing would move in my body, just nothing. And I would say to the kids, you have to ring my mum and dad and get them to come up because nothing will actually work, I can't move. And that would last perhaps half a day and then I would be all right. Get up, go back

nursing. And so, I carried that on until I met my now husband, and then I had the children. I was always tired, I had three children under 13 months, because I had twins. Older boys from my first marriage and then we had a little boy and then thirteen months later we had twins. So, it was very very busy and I didn't have any help. And I was always tired. And I was up through the nights because they didn't sleep. So, I just remember that always tired feeling, and I would be breathless. And my sister would say to me, why are you so breathless when you get to the phone? And I would say, I don't know, I'm just always breathless. And so, then the little ones got to school, they were six years old and I got a flu. One of the twins got it at the same time and she came right and I didn't. I felt very sick, I started to not be able to eat certain foods, I had no energy, any kind of walk up a hill and my legs, I just had to stop, I couldn't get up there! I remember doing a parent race at the school, I was running and my legs felt like slow motion. And all the other parents were way down the track and finished and I was still trying to run. So that flu I think was the real start at that stage. And I was having shaking that would go on for hours, and I had lesions that would appear on my chest. I had these open lesions that were very much like you would see in chicken pox after the top had burst. And they were flat and they were just over my chest. They weren't painful. So, it wasn't like shingles or anything. And my eyes just streamed this green liquid. And my body, you could smell me from the front door, whatever was coming out of my body. It would stain my sheets. I felt starving. The only time I didn't feel like I was starving was when I was eating, so I think I wasn't absorbing anything. Because I was eating these huge meals and I looked like something that had walked out of a concentration camp. All my bones stuck out, I was that thin. And I was in bed, I couldn't talk to anyone, I couldn't have the lights. I couldn't see the children, I couldn't stand noise. Like being stuck in my body. I couldn't even turn over in bed. I ate with my hands because I knew I would just need to get the food in and then I would rest. And then I would have to try and get then energy to use the pan. Everything I had to do was in slow motion. I just kept feeling like my body was breaking down. It was a horrible feeling, like all the energy dropped out of it. Like I was actually dying. It was like everything was shutting down inside me and the only way I could get any energy back was to stay perfectly still with my eyes closed and my arms by my sides. For hours and days at a time.

Interviewer:

From my conversation with you so far, it's like you have done quite a lot of research on CFS?

W:

I have, but it's only been more recently because when I was sick we didn't have access to the internet and those sorts of things. Nor to support groups, we didn't know anyone else out there that had it. So, we were very much on our own. And after my experience in hospitals and with some of the medical people I have met, I thought you know what, I have got so little energy, I am worse when I go and see somebody and I don't get any help. I'm worse when I come out of hospital. I actually can't even go there. If I die in my bed I die in my bed but I think I have got a better chance here. So, I fell out from any kind of medical supervision for quite a long time. Got my repeats and things but it wasn't until I actually got a little bit better and we got the internet, and my other twin and I both got a flu again and I relapsed back and got back in bed again. And she ended up with CFS, and she was 13. She's 30 now and she's in her bedroom. She has times when she is a bit better and times where she is not so good. She can't go out, she can't go walking around the place or anything. So, sorry to get back to the original question, because she was really not able to socialise or meet anybody, when I was a little bit better I started a support group of my own. Mostly so that she could meet other young people. And we got so many people come, it was just fantastic. And then we all started sharing our information on what had helped and what hadn't, and then I was so upset, because I had a lady who I used to talk to on the phone, who had been put in touch with me, who had CFS, and she lived on her own and never married. She was a very intelligent lady, she was a

school teacher, very skilled in mathematics and things like that. And she was struggling, she was suicidal. And they said, how about we put you in touch with Wendy? And we just talked every day. She was in bed, I was in bed, we had the time. She kept saying to me, I have got pain, I've got pain! And I said, have you talked to your doctor about the pain? And she said, yes but because I have got CFS they don't take any notice of my symptoms. They think it's all in my head, they are not taking me seriously. And she said, they are trying to get me off, because she was on either Valium or Clonazepam and she said, they are trying to get me off that. But she said, I need it because I have sleep Apnoea. She had Meningitis when she was in New Guinea as a missionary, and she had developed sleep apnoea. And that was the only thing she said helped her not to have the sleep apnoea. And she was finding the same as me, they helped her. And then she was starting to fall, and I think that she, big long story around that that I can tell you another time, but the long and the short of it, I kept saying to her, Rosemary if you have got pain, there is a reason you have got pain and do investigate it! They should at least be doing an x-ray. So eventually they put her Waitax for West and Rehab. Well she had one day of Rehab and she was just resting there, but no xray again. She came home and the pain kept getting worse. And this is a person who has had three previous cancer scares. So, what would you think of! I mean, we are not doctors, we are just nurses but what would you think!

Interviewer:

She's got it again!

W:

Absolutely! And it's in her bones! So anyway, I didn't like to say that to her, so I said you just need to get an x-ray. So, she was in so much pain they put her into Auckland hospital, and we would ring every day, we would still keep in contact. And she said, I'm so happy, they have got me on pain relief! And it's really helping. And I said, I'm so pleased but have they taken an x-ray? No! And I said, well we really need to know what that is before you come home. And we both had faith, so I said I'm going to pray that they find out what it is before you come home. So, we prayed that. And that night she had a fall, and her femur went straight up through her pelvis into her abdomen. Because all the pelvic bone had been eaten out with cancer. Now she was probably dead in about four weeks or six weeks. Really bad. And this is what we are up against, this is what we are fighting.

Interviewer:

People need to know about this! Don't they?

W:

And I have been in contact with so many people with the support group. I walk through the Psych wards with them, I walk through the hospitals with them.

It's because they don't see us at our worst. They see us on a good day when we have managed to struggle into the surgery, because they don't do home visits anymore. And people have gone to six doctors trying to get a diagnosis so they look at these people who have gone to all these doctors and think, oh well they are just doctor hopping or shopping. And unless they know about CFS, I was so fortunate. Two maybe three years ago I got a really bad tummy flu. I ended up in Auckland hospital because I went into Atrial fibrillation because the chemicals got out of balance. And I went down to A and E and said, please put a saline drip up because I don't want to go to hospital. If we can just get my electrolytes ok I might be ok. And my pulse rate when I went to hospital was 140, when I got to

A and E. And it was shooting up to 250. Between 140 and 250. So, I said to them, look I just do not want to go to hospital. Please let's just try this. And they said, ok. So, I had been there a few hours and they said, this isn't settling down, you really need to go into hospital. I said ok. But my daughter was with me and so I said, Sarah you have got to come with me. I'm not going on my own, they won't listen to me. So, she did, she came with me. Fortunately, they put me straight into intensive care or cardiac care unit or somewhere, and put me on the monitors and things. But that was a completely different story because I had a disease and they knew how to deal with it. Protocol is in place, this is what you do when you get this. So, they said to me, your potassium levels are really low, we will give you some potassium to drink. And I said no I don't think I will tolerate that. They said, we can give it to you to drink or we can give it to you IV. It will probably work quicker just drinking it. I said, do the IV, for some funny reason I am always better on IV stuff than stuff that has to go through my digestive tract. So, I said, pop it in my IV. So, they did that and I was still vomiting. And they said, we are going to have to give you something for that. And I said, well it's obviously not going to stop, I'm not good on medications. They said, we will give you Maxillan. And I said, I only need tiny amounts of medication to work. Because of my system with ME is so touchy that very little amounts will work in my system. You don't have to give me what you would give an 18 stone man. I am not even 5ft2 and I am very very slim, probably on the skinny side. I don't need all that. And the nurse said, no the doctor has prescribed you ten milligrams so I'll give you the ten milligrams. And I said, I don't know how I am going to tolerate the ten milligrams! And she said, I have to give you that because that's what you have been prescribed. Now you and I know she could have rung the doctor and changed it. And just said, look can we just try her on 2.5 and if it doesn't stop then I can give her the rest. But she didn't do it. So, she gave me the whole amount and oh god, I could feel how sick I felt, and it shot my pulse rate even higher. So anyway, the long and the short of it was that I was there all night. In the morning it finally sorted itself out and we came home. But they said, we'll put you on beta blockers and we would like you to start taking a bit of aspirin every day and that will sort you out. So, I went back to Roz and said, what do you think about this? And she said, I don't think Beta blockers would be good for you. So, she is the ME doctor and she knows me. And she said, I don't think they would be good for you. And I said, ok. And she said, go and see a cardiologist. So, I found this guy called Patrick Kay, and I thought, this is going to be interesting. And when I got there he had had a lecturer at Otago University that had a wife with ME. And he had absolutely drummed into the students about ME, He knew about it! And he said Wendy, you are not at a huge risk for a clot, but the risk is there. And I said, look I just have to take my chances, I can't take all this stuff I just can't. And he was so good about it. He said, I understand. And honestly, the difference between going to see somebody like that, who I could actually talk with, who listened and who realised I have lived with this for a long time and probably knew my body quite well. And just let me be a person! And you look at all those, the rights of patients. Well I just read those and I thought, they get violated so many times with ME. All the time. And where do you go if they do?

Interviewer:

That's right. Nowhere else to go. How has the CFS impacted on your life? You know, financially, physically, emotionally it has. Cognitively, socially, work, family and your status. How has it influenced you? Your relationship with your family? Your work? You probably stopped work?

W:

Yeah. It's just devastated everything. It's like an earthquake going through your life. Everything gets shaken and rocked and changed. My siblings went to a doctor. Sorry, I forgot to tell you the end of that story, which was, I was so upset after this lady died that I went and saw my MP. I said,

this isn't right. I'm seeing this happening to people, it's wrong. And he said yes, if you get a petition together I will take it to parliament. So, I got the petition together and Anne Smess, who was a national body, saw that I was doing it. And they said to me, it might be better if you had an organisation behind it. And she invited me onto the committee and I have been there ever since. And the petition went to parliament and with help from everybody I got five and a half signatures on it. And Roz and I went and talked to the health sect committee. But they still came back with cognitive behavioural therapy and GT. You can actually go and read it, it's on the parliamentary website. Just look for CFS petition, Wendy Matthews. So, you can see their response. But that's how I got to know a lot more, to meet more people and learn about CFS. And then the support groups were the same. And then a few of us started up ME Auckland support group, made that into an incorporated society. And we all learned more that way. So, for me it has been word of mouth I have learned. Sometimes you don't want to look on the internet because you actually can't cope with what you are reading, it's too scary. And it's better for me when I am really really sick not to read that stuff. So that it's just, how do I deal with today, how do I get through today?

Interviewer:

When did you stop working as a nurse?

W:

I stopped working as a nurse just before I got married. I just thought, I need to have a break. One of my boys was starting school and I thought, I am just going to have three months with him before he starts school. And of course, then I didn't go back nursing again because four months after I got married I was expecting and then four months after I had that baby I was expecting twins! I didn't ever get back to my nursing, but I have nursed people in my house here with ME, so in that way I have been able to do that. But I started doing things from home, like I started making cards. I do art, I started doing a postgrad in medical illustrating. Because one of the doctors, when I was nursing saw my books and said, you should be doing this. And I had the opportunity then to work with the medical illustrator at the hospital. But I ended up going and living in Australia, so I didn't pursue that. But I always loved art. So being stuck in bed I just started drawing again. And so, I started making greeting cards and then I sold those designs to a card company and made some money that way. And then I like writing, so I researched jellyfish for a year and I had some photos I had taken of them all stranded on the beach. And the school journals actually ended up publishing the article for me and that made some money. And then they reprinted it and that made some more money. And then, what else have I done, then two years ago I thought, right we live on ten acres, I'm going to put in, I love growing stuff, I love my garden. I had two thirds of an acre howed, and then using an easy way, I had figured out an easy way to do it, I planted it out in flowers and I was harvesting and selling for the floral market. I had buyers, but then I had a lot of one product left over and I would make it into a soap. And in the process to extract the essence to make the soap, I got some of that essence on me and it actually was too strong. And it actually put my body into relapse again and my body started reacting to everything again. And that's why I'm back in bed. But I was never well those times, I was always exhausted. I went into the greeting, doing wedding invitations and I got into the corporate world doing invitations. I have tried every which way to get out there, to use every skill I have got. But I get stopped every time I start getting somewhere. I relapse.

Interviewer:

When you had your support group, Was that a social gathering for you?

W:

Yes.

Interviewer:

Since you stopped that, do you still socialise with siblings, family, friends? What is your social life like? What has been the impact on your social life?

W:

It was huge, when I first got it everyone thought it was in my head. And my sister went and talked to her doctor who said that he didn't tell people if they had MECFS because they just took to their beds! So, this doctor wouldn't even give them the diagnosis. So, my sister said, it's all in your head, you have to get along with it. I remember I had my 40th birthday in bed. I was really sick. And an aunt came to see me, she was so angry with me, she just stood and looked down at the bed and she wouldn't even talk to me. And then she said to me, you could have at least put some makeup on and made an effort for your birthday! And then she went out and she saw my husband, and she said, are you going to tell her or am I, that she needs to stop hiding in that bed. Get out of bed and get on with life! And this was, so no help came from any of the family except my parents when I was very sick. I went there and stayed there for three months and they looked after me. And we just had a nanny at home looking after the children. But even then, my sisters were ringing my parents and saying, you have got to make her do this, you have got to make her do that! And it was a nightmare for them. Because not only were they trying to look after me, they were getting no help but all this criticism. And I had the same with...

Interviewer:

Was your husband supportive?

W:

He was in a very difficult position because he didn't have information, he didn't have education so he didn't know if I was, and he is having people saying I was crazy and he just needed to get me to a psychiatrist. And he would see how sick I was, he saw all the brown stuff that was on my sheets that was coming out of my body. He would carry me every couple of months and put me in the bath, and bath me and carry me back, and I was just skin and bones. He saw all that, so he was just so conflicted. So, he would come home and growl at me because of what they were saying. And then he would feel bad. So, it was like that. And I just lost so many friends and it was very hard for him and I. Our relationship was very very hard. We have been married 33 years now. We survived it, but he is till, even this last time when I was reacting to everything and I was terrified. Nothing was safe anymore and the anxiety that came from that was huge. I didn't know if I could eat my food, if he got cross at me I wouldn't sleep all night. It was a dreadful time, it was a scary time. And a friend of mine who had actually been in the support group, she rang me and she said, you sound terrible, I'm coming to see you. And she came over and she said, I'm going home to pack my bags and I'm coming back to look after you. And it was only because of her, and she said to my husband, I go home on a Friday and your wife is settled because I have kept her like that for the week. And if I come back on the Monday and she is a mess then we are right back to square one. So, he thinks he can do everything and he can't because he doesn't realise the deep level of our need.

Interviewer:

So, have you experienced any stigma? Or discrimination?

W:

By what people have said, by what I have experienced, and I suppose just remarks that I have heard back that have been said. I remember going to an optometrist and I said, I can't have that stuff in my eyes. And I was in a wheelchair and he just treated me like I had no brain and bullied me, and said it's not going to hurt you and just put it in. I guess those things. And even now, I have got my friends that understand, but have other friends who won't come and see me.

Interviewer:

I heard you talk about praying. Are you a Christian?

W:

Absolutely, it's the only thing that gets me through.

A month ago I had a sore that hadn't healed and I had been putting salt water on it to help it heal and to stop it itching. And I looked down one night and it had gone red and it had gone under my arm, and I had this rash going down my body and I thought, oh gosh I have got cellulitis. And I said to my husband, I think I am going to have to go to the A and E but I'm not sure what I am going to do because I can't take anything they can give me, I can only take one antibiotic and I have to start that really slow, and I can't take any antihistamines that they are going to want to give me. I can't do that stuff! I don't know what I am going to do. And he said, lets just leave it and see what you are like in the morning. And I said, I can't leave this, this is too bad, I can't leave it. So, I called my daughter in, and said to my husband, we are going to have to pray. And we prayed, and when I got back a minute and a half later, the redness had gone, my rash had gone. The whole thing had gone completely in about an hour. And that's the way, like I hurt my shoulder probably ten months ago. And I was in so much pain because I can't even take Panadol, and I had just been kind of praying my way through it. I rang another couple I know and I said, please can you just pray for my shoulder. And they just prayed for my shoulder, and the majority of the pain went and it actually started to heal. It's been healing. He is our everything.

I had to go to the hospital, it was amazing, I had this incredible peace and I just knew that at that time it was the medical profession that had to do something. And I knew I would be ok and that He was looking after me. Everybody else was more worried about it than I was.

Interviewer:

Are you still in any support groups?

W:

Well it's funny, sort of yes and no. Because I had to cancel my support group here because I couldn't run it anymore and nobody else was well enough to pick it up. So, I don't run that anymore and I resigned from being on the board of ME Auckland. But I still moderate their Facebook page.

Interviewer:

Do you still keep in touch with Doctor R? Do you still communicate with her?

W:

Yeah, so it's like, I still moderate that and because I am a moderator I get a lot of support by reading what they are doing and being able to help them a little on their journey. And I think my daughter and I, we support ourselves a lot. I had to get a new carer in when I crashed, and the government is

going to need 20 hours, and my daughter 14 hours a week, which is fantastic. But I couldn't handle the carers they sent through Geneva, because we don't fit in their boxes. They send them for 20 hours but I might only have different times where I can do anything. So, what we did is we advertised and we got our own carer in. And the nursing agency paid her, and she looks after "S" and I. But because she looks after us privately, she actually stays with us and she lives in and we pay her for the extra hours. And she goes home in the weekends. So that is working really well, but in saying that, when she first came she did not get this at all. She used to get so angry with us, but she has been with us over a year now and she has learned.

Interviewer:

Are there days where you can't get out of bed?

W:

No. I can't have a shower, I can't do any of that but I find that as I rest and if I stay within my capabilities, it takes months but, and I said to her about four months ago, I am going to try and sit on that chair while you make the bed today. She said really? I said yeah, just bring the chair over and, because I can't take the weight on my feet, I said I'll see if I can just transfer myself into the chair, which I did! I sat there while she made the bed, and probably about two weeks ago I said, I'm going to, oh that's right it was my twins 30th birthdays. So, I organised the family to help out and have a party here, and I said I am going to try and get to the lounge room for your parties. I just rested and rested and rested, did nothing, less than usual. And I thought, I am going to get down there for the day! And I did. I was able to go and lie down in a lounge. My son and my husband picked me off the chair and put me there, and I rested there and was able to enjoy everything for a couple of hours. And then I came back. And then two weeks ago I said to my carer, put my wheelchair outside on the deck and put a chair by my bed. I'm going to try to go from the chair and then onto the wheelchair. And then you can just push me around the deck so I see what is happening. Outside the house and everything. And she did that, and I got myself back, but I needed help to get back into the bed. And then about a week ago I thought, well I will take my buzzer with me in case I get stuck, but I just have to get myself onto that chair so I can look out my door, and then I am going to try and get myself back into bed. So, I didn't go on the deck, I just hopped myself into the wheelchair by my bed, looked out the door for a bit and then, because my bad arm was getting better, tried to get myself back into bed. It's progress! And I have brought myself a chair for the shower, because I find I have to do all this stuff by myself, my family wouldn't get me a chair, they wouldn't do that

stuff. So, I have had to go out and find all this stuff myself. So, I got a shower chair and that's sitting in the shower waiting until I feel ready. So, we are not unmotivated people!

Interviewer:

What do you think would improve health professionals' approach? What would help us look after CFS people better?

W:

They have to listen to us. We go in and they have either no idea or a pre-conceived idea of what it is, and it isn't. They need to listen to the patient, because each patient really is an expert in their symptoms and their management. Especially if they have had it for a while. If they are very new they are going to the doctor and they are wanting some help. And it's sad because they go there and they get none. But the ANSPES? (inaudible sorry) has sent out doctors' primers to every doctor in New Zealand on CFS, but most of them obviously haven't bothered to read it!

Interviewer:

So, the main problem with CFS is it fatigue and pain?

W:

No, it's a lot of things. When you say fatigue, yes, it's fatigue but it's not like just being tired fatigue, it's like the fatigue that comes when your body has just run out of everything. It's like if you have never practiced for a marathon and you ran ten miles, your body would be really in strife after that. It would be stressed, it would be struggling. That's the sort of fatigue we are talking about. And for me, I am quite chemically sensitive and sensitive to smells. So, if I go into a hospital, the smells, the cleaning products and things like that can make me feel quite sick. Noise makes me feel sick, the noise is exhausting. It's like having a nervous system that is turned up full bore. Every noise is too loud, every light is too bright.

Interviewer:

When you expressed this fatigue to the doctors, what was their response like?

W:

Well for me personally, my example would be trying to talk to them about the injection, they wouldn't modify it. Last time I went to A and E, about 20 months or so ago, the doctor said, do you have any management plan? Because he didn't know about CFS. And I said yes, not written by my doctor specifically, but if you can put a litre of normal saline up for me, it really really helps me. And he said no, let me check your ketones first to see if you are dehydrated, and he said, if you are dehydrated I'll put one up but otherwise no. And so, I did a urine thing and then they discovered all this blood in the urine, and he said, do you have a urinary tract infection? And I said, no I haven't, I have had them in the past. And I know when I get them because I immediately start bleeding, they go straight to my kidneys. And it's very obvious to me, I am in a lot of pain and I need to go all the time. And I know I haven't got one, the blood has been coming and going for some months. And he said, the antibiotics he put me on for the sore mouth, that will clear up your urinary tract thing. And I said, well are you going to send a spec off? To make sure I've got a urinary tract, because they have sent specs off before and I don't have one. And I said, I don't know where the blood is coming from. And there was no follow up to see if it had been cleared or not. So, he didn't listen. A long time ago I was really sick, I had got to Dr Vellings, I saw a locum, obviously a new doctor and he said I think you need to go to hospital. And I said no I have got a better idea. Put me down to A and E and get them to give me a litre of fluid and I will be fine. And he said we do have this thing where we can put you there, we can do that. So, they send me to A and E and gave me a litre of fluid, and I was fine and I was able to go home. So, you see it's listening! And believing what I tell them! Not thinking that I don't know anything! I have got a friend who is a doctor, he has the same trouble! I thought they would listen to one of their own but they don't!

Interviewer:

It's more about awareness. Right?

W:

Absolutely, and the other thing is you see really, (inaudible two words) select committee, Paul Hutchinson was my MP, which was really great. He's a doctor. And the problem is that the New Zealand medical profession follow the NICE guidelines. And the NICE guidelines haven't been reviewed for so long! And their recommendation is, well it is under a neurological illness. It's not under psych, it's under neurological. And when you look up under the classifications and they

recommend graded exercise therapy and cognitive behavioural therapy, but even they say, not for the very ill. And they only say that because of the Pace trials that I sent you the link for. Which all the patients are fighting. It's even been held up as how not to do a study! These people are still fighting because they have got too much prestige to lose, in the UK. In the Lancet as well, because they printed it. But the NICE guidelines took the recommendation of that and that is what our government uses. So, when I took the petition I said, this doesn't work for us! And they came back recommending specialist treatment, CBT and GET. And I said to Paul Hutchinson, I said why did you do that! And he said, well Wendy, these are very learned people, more learned than you. They know these things and they have decided that is best. I said, your patients call it and they walk with their feet. If they can't talk to you, they vote with their feet. What you will find is that they won't say anything to you if you are not listening. They will not come back and they will go to an alternative medical practitioner or they will fall out from under medical care! And he went really really quiet because he knows exactly what happens.

Interviewer:

Thank you so much Wendy, I hope I haven't exhausted you! How are you feeling?

W:

I'm fine. Because I am so passionate about it I could talk about it for ages. So, if I haven't answered any questions just tell me what I haven't answered. Anything that you need to know.

Interviewer:

You have really given me so much answers! If there are things that I need to know after the transcribing I will definitely get in touch again, if that is okay with you.

Wendy:

That's okay.

Interview Transcript:

Participant: J

Interviewer: Researcher

24th June, 2018

Interviewer:

Thanks J for giving me the opportunity to interview you for my research work, we are starting our recording now. I will be asking you a few questions. And today's date is the 24th of June 2018. So, starting our questions now. My first question is, how would you describe your current state of health? How do you feel now?

J:

I would say average but it probably does to other things other than the fatigue syndrome. Because although I have got that it has been harder to cope with what I have had to go through recently.

Interviewer:

And how do you prefer to refer to your illness? Would you prefer people to refer to your illness?
How you feel?

J:

Well they don't really understand and I get very tired, but apart from that I don't elaborate much because, as I say people don't understand unless they have had something to do with it.

Interviewer:

When you say, have something to do with it, with regard to, a doctor having something to do with you?

J:

No, I need to say that, can I give a bit of my history? When I was eight years old I had glandular fever for months. Very seriously, and I had a lot of serious childhood illnesses. And then I was suffering tiredness, sore throats. And when I was about 30-40, it was probably partly I had had a bad marriage and then I had a job where I worked hard. And then I had all the muscle pains, the tiredness and strep throat for months and months and months, and all the other symptoms. And they took my tonsils out but that didn't really help. They never identified the culture on the tonsil. And my doctor diagnosed me with ME. And I have kept going, at that time I was on my own, so I could manage myself. Manage myself taking pain killers. And I still take pain killers. So, anyway, then things weren't too bad. Then I remarried but five years ago my husband got sick. And I had him at home for three years which was very stressful, until I couldn't cope anymore. He was then in care for two years, and now it's only about seven months since he died. So, what with the fatigue syndrome, or ME, and then the stress I have been under for five years, it's hard to separate all of the symptoms. And lately I have been taking more pain killers again. And so, it's hard it's because I have got ME that it's harder to counteract the stress, and it's hard to split my present state from my ME sort of symptoms, to stress. And they all intermingle. As I say, I have only just begun to be able to start writing again, because of the shakes and that. And then my age comes into it. So, it's hard to separate.

Interviewer:

How old are you Janice?

J:

I'm 77.

Interviewer:

Oh wow! You don't look that, you look like someone who is in their 60s.

J:

So that's why my doctor says to me, stop complaining! Because you are doing quite well for your age!

Interviewer:

Well you look very well!

J:

And that's part of it, because you look well! So that they don't understand how you feel. So that gives you a bit of background. How I feel varies from day to day.

Interviewer:

When you first received your first diagnosis, how did you feel? Did you suspect you were going to have that diagnosis? How did it hit you when you were told you had it?

J:

By that time, I had been through so much. The pain, all sorts of different muscle pain, kept going with Digesic to make it easier. But then there were the headaches, there is just so many different...

Interviewer:

Did you feel relief that you finally had a diagnosis?

J:

Yes. Yes, it is a relief. Not that you sort of understand. But then I joined the ME society, I went to, and then you try to find things that are going to help you, because nobody knows what is going to help you. I have taken B12 injections for years and then I stop and then I'm back on them. And I take all my vitamins and try and rest. I ended up going to Dr Tizard for 12 months, who treats people with symptoms like that. And they say its toxic poisoning from sprays and things like that. And I met up with other people who were in a similar situation. And then I ended up, I went to all sorts of natural people, even ended up with a Psychiatrist. Went through a lot, because people would suggest different things, but you just really have to work through it. But you forget. You just have to move on.

Interviewer:

So how do you feel about chronic fatigue syndrome or ME, how did you feel about it before? Did you know anything else about the symptoms before you actually experienced it?

J:

No, because I had been ill most of my childhood, and from the bad glandular fever when I was eight, I went from a bright child to an introvert. And because of my home circumstances (a very possessive mother) I never really came right until I left home when I was 21. And then I had some good years. But even then, I would be going to the doctor for my B12, and my system has never really recovered from that initial glandular fever. If I get overtired or stressed or something, it sort of comes back. And I have looked up things on the net, and there are quite a lot of people like me, who put things on the net. Who have had glandular fever and it never really leaves. So, the fact that it was given another name, but even then, there is no remedy. You have got to work it out yourself. I'm lucky that I have been able to keep taking pain killers, otherwise I wouldn't be able to

Interviewer:

What sort of painkillers do you take? Paracetamol?

J:

I get prescribed Paracode now, and I have them with Nurofen. They are not serious painkillers.

Interviewer:

Do they help?

J:

Yes. It's the muscle, but I don't know how other people describe it.

Interviewer:

Yours is more muscular pain?

J:

But also, it hurts in your head. You can't think properly, you can't function properly in your brain. And that leaves that. Don't ask me technically or anything. You can be sitting there and think, oh I feel awful and you just take a couple of pain killers and then you can start thinking properly again.

Interviewer:

Does this happen every day?

J:

No, not every day. But it happened more when I was a bit younger and I was trying to keep going all the time. But I was much better on analgesia before they withdrew them. But I try not to take them too often and I write down when I take them. Just so I, I had got down to two a day.

Interviewer:

How long were you sick for before you got a diagnosis? Was it a very long time?

J:

Yeah it would have been three years or more. Well they didn't understand it then, Dr Donaldson, who diagnosed me, he was very good to me. Even sent me to Auckland Hospital to have Physio on my muscles. And that was the worst thing ever! With the muscles, they can't take any pressure. When I was a child we used to go to Taupo a lot, and go on the really hot baths. And I used to be a mess when I came out of them, even as a child. And I have later learned that it's the pressure on your body. It's like sometimes when you are lying in bed, sometimes you just can't lie there anymore because your body doesn't want any pressure. Same with your clothes. I remember one lady telling me it's like you want to wrap your body in cotton wool. But you just learn to live with it.

Interviewer:

And what do you think caused the illness?

J:

Well I would probably go back to glandular fever, to the immunity from childhood diseases. Because I was sick for months. And it's just who I am and it's just how I have grown up.

Interviewer:

And have you done quite a lot of research on the illness?

J:

Yeah, that was in 79, that was something I filled in for something. Middlemore hospital, department of Rheumatology. That's interesting. And then I joined the ME society, and I'm still in touch with

one of the ladies. And then I have googled it. Someone said to me, you can't get recurring Glandular fever. And I thought, that's a load of... And then I printed off a whole lot of stuff. If you go into Living with recurring Glandular fever, you get heaps of stuff on Google.

Interviewer:

You have done quite a lot of research on Google?

J:

Well I'll tell you why I do it. You are trying to understand yourself while you don't feel right. And you just wonder why it can't be explained.

Interviewer:

How has CFS impacted on your life? Financially? What is the impact? Financially, physically, cognitively, socially or towards your family?

J:

Well I have no children of my own.

Interviewer:

Because of this?

J:

Subconsciously, or if it was because of my upbringing, or my makeup. The first person that I married I knew instinctively that I didn't want to have children with him. It wasn't the right person. And then I was on my own for a long time, which suited me because I could cope better on my own. And then I met a friend and I knew him for 20 years and we married in 2001. That's "OW" who died recently. And his daughter got cancer. So, it's been ten years of my life really! But going back to my childhood, I have got one sister who is five years older than me. And I said to her a while ago, how do you remember me when we were growing up? She said, oh you were just always sick. And our childhood wasn't that good, but it was what it was. And I'm lucky I have been strong enough to learn from my mistakes and I have just done the best I can with who I am. I have never had a lot of money.

Interviewer:

Because you couldn't work?

J:

No, I manage quite, I have always kept working. I always pushed myself to get up and go out. And even for the last two years when Owen was in care because I had worked a lot, I still each day I would go to the home where he was and I would do his washing. Because that kept me going. If I could get up and get out. And even now, I might have the odd day at home where I don't go anywhere but otherwise I might go to the mall or I might meet someone for coffee. But then I get tired. I'll come home and read my book and watch television or something.

Interviewer:

When you were younger and you had to go to work, were there days where you couldn't go to work because you were too ill?

J:

I kept on going.

Interviewer:

Even when you didn't feel well? Even when the pain was there? You went to work?

J:

I kept myself going. I know a lot of people can't get out of bed. But I have just pushed myself. Also, because I just don't like being in bed a lot. Occasionally I will think, oh it's nice in bed this morning and other morning I will think, oh I need to get up. Probably I haven't had a choice. When you are on your own, you have got to have the money.

Interviewer:

And do you feel any different when you are with your friends or your family? Or do you feel the same as them? Do you wonder, why do I have this pain?

J:

No, I've just lived with it all my life. I have got some wonderful cousins, families that knew about my background so they have adopted me into their families.

Interviewer:

And they have accepted you the way you are?

J:

Yeah, well they don't see me any different. I take my pain killers and away I go!

Interviewer:

Wow! And it's good that the painkillers are actually effective.

J:

I mean there are days. And sometimes I will actually only last, I'll go out and lately three hours is my maximum and I will have to come home. Three hours out would be about maximum. The tiredness is creeping in a lot more now.

Interviewer:

Have you ever experienced any stigma or any discrimination? And how can you describe your illness to health practitioners? It's very difficult describing it to a doctor.

J:

Fortunately, I have been going to the same one for a very long time! If I have to go to somebody else, well generally they just look at my history and give me my pain killers. The other medication I take is not major, but I do take quite a few vitamins.

Interviewer:

The doctors don't doubt what you are telling them, or think it's all in your head?

J:

Well I think they used to.

Interviewer:

Not anymore?

J:

Well I've been going to Dr Gentry for so long now. That's why I was saying, I wasn't 100% sure if he even understood. There is nothing in the tests to diagnose you, you see.

Interviewer:

Did they do any test? Using the symptoms you presented to diagnose?

J:

Well testing wasn't in there.

Interviewer:

Is there a diagnosis criteria?

J:

Well I'm a bit of a mixed bag. I have a lot of problems with my throat, and that was my weakness 37 years ago, was my throat. And my throat's gone now, it's basically softish foods and stuff like that. And Dr Gentry did send me for an endoscopy. And that was clear, and then the specialist sent me for a barium swallow, which was clear. So, it's just me! Ice cream is nice. But what is happening, with my age and one thing or another. A lot of people get at my age, digestive problems and things like that.

Interviewer:

Are you in any support groups? Do you go to support groups?

J:

For years I did. I was one of the original people who joined the ME society, in goodness knows when. And I was part of that. And a lot of them did all sorts of diets and stuff like that.

Interviewer:

So, you are no longer in the group?

J:

No.

Interviewer:

Was there any reason why you left?

J:

Well, that's nearly 40 years ago. It sort of, disintegrated for a while. I don't know whether it's there now or not.

Interviewer:

I think they have CFS groups on the North Shore.

J:

I have a lovely dear lady, she must be 90 this year! We have kept in touch. She was part of it. There is nothing anyone can really do to help. I have just got to do my thing. People think I isolate myself but I'm content on my own. Probably because I don't have to worry. It was different with Owen, we got on well until he got sick. But now, I am probably a bit selfish in some ways but that is probably how I am. I have to do things when I want to do them and how I want to do them. And that's probably how I cope better, I mean I interact when I feel like it.

Interviewer:

When you were in the support group years ago. Was it helpful? Did you have friends?

J:

It was helpful. It was more people against spray. It was actually that. The group was against toxins Against TAG it was called. And it was people who were going to Dr Tizard. They were forming groups to oppose spraying around schools and around roads. It was more that. It all seemed to tie up but nobody could really put their finger on just what was going on. I'm probably complicating you now!

Interviewer:

Oh no I'm fine! Apart from your GP, do you have any other professionals that you talk to? Like a nurse or anyone else?

J:

We have got a nurse in the village. I go down once a month at the moment and she gives me my B12 injection.

Interviewer:

The only person you speak about your CFS is your GP?

J:

Yes

Interviewer:

And your doctor has been helpful, hasn't he?

J:

Yes. Because he is such a gentle soul. And he has got a knack that, I relate him to when you are watching a crime thing. And just as the detective is just going out the door they say, oh I just want to ask you one more thing. And doctor will say, oh well, because I got overweight and my doctor said, oh you really need to get the weight off or else you will have a heart attack. And up until then I hadn't been able to. But I did, and at that time I lost 17kg I think. And also, for my muscles and

joints. And there was something else I said, I know the other day, I am trying to push myself driving. I want to drive myself to Thames in a couple of weeks. And the family is against it you see. And as I was going he said, you do that drive, keep pushing yourself! He just gently says something occasionally and it gets in your head. But as I say, I don't really know what he thinks. He prescribes me what I need, but nothing is ever showing up in my blood tests. He just checks my cholesterol and things like that.

Interviewer:

Has CFS changed your relationship with your family, has it changed your relationship with your friends and what do you think would improve health professional's approach to the treatment of CFS?

J:

I think there should be more out there in the media. In some form or another, so people out there read about people like us. So that not just, we can't spread the word because we don't understand. Do you know what I am trying to say? If people with these chronic illnesses are somehow portrayed occasionally in magazines, like all these other illnesses that you see cropping up. So that the average people read them, because helping us, as far as I can see is letting more people know about it, that haven't got it.

Interviewer:

That makes sense.

J:

They say, oh but you look fine. This is the other thing, people look well! Because there is nothing apart from support groups. But I am not big on groups of any sort, so it's probably my fault. I don't know, I was on my own a lot as a child and lived on my own a lot. But I managed to buy and sell the odd house. I'm sort of, quite capable just to do my thing. And I guess I'm quite lucky like that. The strength that I have had to grow myself, and I had to support myself and I just never really gave in. I try not to. But I have been good to people and they have been good to me and it goes around in circles.

Interviewer:

So apart from using painkillers for pain, how do you manage your fatigue?

J:

Piece of chocolate!

Interviewer:

Does chocolate help?

J:

Yes! And it's not necessarily sugar, and even in the car I will have it, or biscuits. It's probably like being diabetic.

Interviewer:

Just to have something sweet to manage fatigue?

J:

Yeah it just does something. Probably relaxes you as much as anything. I don't know what it really does. But yesterday in the car I made sure I had some biscuits and a couple of favourites or something. And water. You just have to learn, when I am going somewhere that I have something with me that I can just take. Even when I am just looking at shops or something, or I know its time to come home. Because another thing I get is like a wall in my brain. And if I do more, sometimes you keep going, you go out in the garden and you keep going instead of stopping. And then I'm really down for quite a while. But that's just between me and the walls. Take my painkillers and then I just sit and read or stare at the television,

Interviewer:

So, when you say a wall in your brain, when you see the wall, does that mean you need to stop now?

J:

Yeah. Your energy is just gone, it's hard to explain but it's, that's the only way I can explain it. It's just the way I'm feeling in my head. And I think. Oh, I can't go any further at the moment. I don't know, it all sounds a bit weird to me. Some people probably think I'm nutty.

Interviewer:

Have you ever told your doctor about feeling tired? The fatigue? Or do you just manage it?

J:

I just manage it. My doctor can't do anything. Nobody can do anything. There is no real cure because we are all different. What I find frustrating is, live with this and when you live in a village and there are a lot of mature people and they get this and they get shingles. They get this and that and they have a hip replacement or a knee replacement. But they come right, but I don't because it's chronic. I've got a friend who says, oh are you all right today, are you feeling better? Do you want to do this, this, this or this? She expects,

Interviewer:

Is it really hard to explain to people?

J:

There was a big article written, I think she wrote a book but it was all too much. Someone has done some research on it, and interviewed people. And decided that people like me, it comes from some trauma in the past. And I don't know, maybe it has. But the symptoms are real, they are not imaginary symptoms. Because a lot of people think they are imaginary symptoms, like neurotic sorts of things.

Interviewer:

How did you feel when you were referred to the Psychiatrist?

J:

Yeah sort of. I can't remember all the places I went to. I went to Doctor T for a year, and he just said he couldn't do anymore. And then I went to some other strange person. I think it was just, with the group of people I was with, people were doing these things. But it was all weird, all of these things. I went to a psychic, she told me I had a grey halo. Actually, what she said kind of made sense at that

stage. My mother and I had problems with my childhood, and then I got this bad marriage. And she said, until my mother died and my first husband died, I wouldn't be free. Which was partly true. You have to do what you can do yourself. We can't rely on other people to do it for us. You can't go to the doctor with a medical situation. I sort of, over the years have said something to Dr G, but how much he understands I am not sure. But he had understood me the past five years, with my husband being sick, and the stress I have been under. And that has affected my nerves, but I'm coming right. I can nearly right my name again.

Interviewer:

Well thank you so much Janice, I think you have answered all of my questions. And if there is anything you want to add to it, please feel free to do so.

J:

It will be interesting to see the outcome. I think subconsciously, it has just made me feel better. That there are other people out there who feel like I do. Even though I'm not actually interacting with them, apart from my dear friend Jill. And I'm well enough to my friends most of the time, I get by. And I get by because I've got my lovely little villa here, and even though my dear husband died. He was stressed, I was stressed. Five years was a long time of stress on top of everything. But no, I have joined a garden group and someone is trying to teach me how to play Ma Jong, I don't know how successful that will be. That was one thing I found interesting, the second time I went to Ma jong, and they were getting a bit serious and I had to concentrate, I thought oops, careful here. So, the next time I took some chocolates with me!

13th July 2018

Participant: **Ka**

Researcher: **Interviewer**

Interviewer:

Today is the 13th of July, I am interviewing Ka. Thank you, Ka, for giving me this opportunity to interview you on my CFS research. It will probably take about 40 minutes to an hour.

How would you describe your current state of health?

Ka:

My current state of health is good. I do get tired at times but that is just a result of work. But overall, I am in good health. I am not sick, I don't have any flu symptoms or anything like that. So, I feel very well at the moment.

Interviewer:

How do you prefer to refer to your illness? Do you prefer to refer to it as CFS or ME? How do you prefer it to be referred to?

Ka:

CFS.

Interviewer:

How did you feel when you received the diagnosis, and how did you arrive at the diagnosis of CFS?

Ka:

I had glandular fever, and from glandular fever it sort of carried on to CFS. I saw the doctor a while after I had glandular fever, maybe six months after I had it. And that's when I was diagnosed.

Interviewer:

That's when the doctor diagnosed you? How old were you then?

Ka:

Fifteen.

Interviewer:

You were quite young! How bad was your illness then?

Ka:

Very bad. I mistook it for depression actually. I thought that maybe I was just really depressed and that was the reason why I felt that way. I also felt that maybe it was still carrying on from glandular fever, but the doctor had already said that no it was definitely CFS. So, it was quite a confusing time for me.

Interviewer:

Obviously a very hard time. Did it impact on your school?

Ka:

Yes. I took quite a lot of time off school just before my pre-exams. My mock exams before my NCEA exams at the end of the year. And none of my friends knew what was happening because I didn't even have the energy to call them or text them to say listen, this is what is going on with me. Don't worry about me I'm ok. So, I pretty much just blocked everything out of my life. It was hard. And then I just got enough effort to come to school for my mock exams. I rested enough and found enough energy to come to school for my exams, but only just.

Interviewer:

Before then did you know about CFS?

Ka:

No, I had no idea.

Interviewer:

That was the first time you had heard about it? When the doctor told you, you had CFS, did he explain the illness to you? did he give you information?

Ka:

Yes, he did. And he told me what happens sometimes after you have glandular fever. And how it can lead to CFS if you are not getting well fast enough or you are not resting enough. If you are not taking care of yourself enough. And that's how it can lead to that syndrome. But after that I remember I had a friend at school who also had glandular fever before me. And I didn't realise but my mum told me that after I had come out and said this is what the doctor has said, she actually said that my friend had the same thing. But I think she had it a lot worse than me because she took a lot of time off school. Like more than half the year I would say.

Interviewer:

Is the doctor, still your GP?

Ka:

No. I have changed, just because I moved. Our whole family moved to a different doctor.

Interviewer:

So, what was your experience of the diagnosis? When you got your diagnosis, what was your experience? Did you feel relief?

Ka:

Yes, in some ways I felt relief that I knew what was happening to myself, because obviously I had no idea what was happening. So, because they told me it was CFS I could rule out depression and everything else, and that it wasn't glandular fever anymore.

Interviewer:

So, it was you who thought it was depression?

Kn:

Yes, I myself thought it was. Because I didn't want to get out of bed. Any little thing, talking to people. Walking down the road, I would have to just rest. I could never get enough rest. I would sleep for so long.

Interviewer:

So, you were feeling very weak?

Ka:

Yes, very very weak. Headaches, feeling weak. It was terrible.

Interviewer:

So how long were you sick for? Before they diagnosed it? I think you mentioned about six months or so.

Ka:

Yes. So, I had glandular fever for quite a long time. I'm not sure but it was quite a few months. I would say maybe 4 months, and I was very very sick. And then went to see the doctor, then six months, then CFS.

Interviewer:

So, what do you think caused the CFS? What do you believe led to CFS?

Ka:

Well when I was fifteen I was very sociable. I was going out with my friends a lot till late at night. My mum seems to think that because I was sick, you know when you have the flu and you just want to go out with your friends and you are like, oh nah I'm fine. That was me. With swollen glands I would keep going out and going to school and staying up late, going to bed really late. And mum just said, you know what, I think this is what has happened. You didn't get enough sleep and your body is in overdrive now. You really need to take care of yourself. So now I can't express it enough for people to rest when they need a rest. Before they get sick.

Interviewer:

So, have you made enquiries about the illness?

Ka:

Yes, after I was diagnosed I did a bit of research. Some of the symptoms that came up in the research that I typed in on Google didn't relate to me. I felt like that wasn't me. Because there are a lot, and I felt like some of them just were not me.

Interviewer:

So, what were your symptoms?

Ka:

Just headaches, really bad headaches. Weakness. Pure weakness and every time I would sleep it was almost as if I didn't sleep at all. Like I would wake up and I would be like, man! I would sleep but I didn't, at the same time. Because I would wake up feeling so uugghh. Gluggy and just headaches. And when I got stressed as well, that's when I felt it a bit more. When I was at school and studying or studying for exams. Then I would be like, oh man I need to stop, I need to rest because I am seriously going to just collapse. I'm just going to pass out.

Interviewer:

So now that you are working, how do you feel?

Ka:

Now I'm working, I'm ok now. I have learned to manage my illness I guess. There are times where I am not doing anything whatsoever, and I have been to the specialist about this and they say the same thing, that it is carrying on from CFS. I will collapse in the middle of

anything. I could be doing anything, I could even be sitting down and I will just collapse. Pale, cold sweats and I will collapse. And this has happened to me when I am sleeping as well. I get up feeling really weak. I get up, I go to the bathroom and then collapse. It has happened twice.

Interviewer:

So, at these times did you have people at home?

Ka:

Yes. Both times I have had people around me. Usually I will wake my mum up and be like, mum this is happening to me. And she has seen me in that state so many times. At times I feel like I am actually dying, like that is how weak I feel. I feel like maybe my heart is going to stop, because I can't even move. I can't even lift an arm.

Interviewer:

Has there been ever a time where you just can't even get out of bed at all?

Ka:

Yeah.

Interviewer:

You are just too weak, you can't move your hands?

Ka:

Yes, couldn't get out of bed, can't move my arms. Even if I do get up I can't even open my eyes. And I'm trying to lift my legs to get up the stairs but I just can't.

Interviewer:

What about your appetite?

Ka:

Really bad. Can't eat as well.

Interviewer:

You don't feel like eating?

Ka:

That's why I thought it was depression. I just thought, maybe I'm just, I've just had enough of life. Maybe I just don't have any drive whatsoever. Maybe something is wrong. I never thought of it as something that had carried on from a viral infection.

Interviewer:

For you now, how do you feel it has impacted on your finance, physical, emotions and cognitive, that's thinking. When you have the symptoms, does it affect your thinking ability?

Ka:

Yes. Because I don't have the same drive, when I do have my symptoms. All I can think about is pretty much sitting on the ground, sleeping or just not doing anything at all.

Interviewer:

And that probably impacted on your social life too?

Ka:

Heavily. Because all my friends just realise, I would keep saying to them, I would make plans but I was one of those friends who would make plans and then cancel my plans because I was really not feeling ok. And when your friends do that, I know if my friends were to do that to me I would feel like, is there something wrong with our friendship? Are we ok? So, people stopped asking me to hang out with them because they knew I would just cancel at the last minute, and all that kind of stuff. But I don't think they fully realised, and they probably still don't. They probably don't even realise that that's exactly what happens.

Interviewer:

Do you still have them as friends now?

Ka:

Yes. Still have them as friends, but because obviously I am working and they are working, we try to find time here and there to hang out, but it's not how it was at school. Which is good, you know. There is not so much pressure. Like we can when we can. And I think that if we were to sit down and talk about it, then they would be a bit more understanding. But I just never got the chance to be like, oh this is what is going on.

Interviewer:

So, for you now, you don't think it has impacted on your social life?

Ka:

Now? Not so much now. Because what happens is when I feel the symptoms coming on and when I feel like I am starting to get a bit sick and tired and weak, especially if I am on early shift in the morning, I start to go home and sleep after I have finished work. I will sleep for two hours and then I will get up and have dinner. Go out with my friends. And so, it gives me those two hours, those extra two hours that I might not have to sleep later on. If I miss out on sleep or if I can't sleep, at least I have got that nap there to save me. Because I feel like if I don't then I will just crash and burn. And I have noticed now with myself, I can't work more than six days. If I work a seventh day, especially a morning shift, I physically can't.

Interviewer:

What about late shift?

Ka:

Late shift is fine. I am fully ok during late shift. But I sleep for a long period. Like ten until about ten, pretty much. Ten o'clock at night until ten o'clock in the morning. And I wake up and I'm feeling ok. Sometimes I feel great, sometimes I feel ok.

Interviewer:

So, does your manager know this? So they can help with putting you in the best of... **Ka:**
No.

Interviewer:

You didn't bother?

Ka:

No, just because I know now how to manage it. If it was getting to the point where I was doing so many morning shifts, then I would have to be like, ok I can't really do this.

Interviewer:

Ok. So, you have a mixture of morning and afternoon.

Ka:

It's good. It's so much better.

Interviewer:

What about your emotions? Does it affect your emotions?

Ka:

Yes, because it makes me feel frustrated because when I sort of felt like I was losing friends and that people weren't wanting to hang out with me, that made me feel upset. In the end, I didn't realise but your friends actually make you feel so much better, even on a bad day. Just being around people. I felt like, when that started to go away, I only really had myself and my family when they were around, to cheer me up and be like, hey it's alright.

Interviewer:

Did your family believe in you?

Ka:

Yeah, of course.

Interviewer:

So, they supported you?

Ka:

In a way though, my dad did say, oh you are a hypochondriac. You have put these things into your head and you think that you are sick but you are not sick. To this day he sort of says stuff like that. But my mum, she has supported me throughout, so that has been nice. And she is the one who has really pushed me. You need to rest, when you have time to rest you

need to have a rest. So, it's been good like that. But my dad will always be like, ahh no you are putting it on!

Interviewer:

And, do you think it has affected your status in any way?

Ka:

Status in terms of?

Interviewer:

Personality?

Ka:

Not really. No, I've still maintained, well I have still always been the same bubbly person I have always been. So, in terms of that, no. But when I do start to get tired and feel like I am getting sick I do start to get snappy sometimes and a bit more grouchy. But that is when you know that I haven't had enough sleep or I'm just fed up with how I am feeling.

Interviewer:

So now when you have your sleep, it does help?

Ka:

Yes, it helps me heaps. As I was saying, I can't do seven straight days of six o'clock starts.

Interviewer:

Sure!

Ka:

It's stress. Even though you have from two thirty onward to rest. But it's like, it's not only six, you have to think about the time you have to wake up before then to get ready. So, it's hard.

Interviewer:

Exactly. So, you have to be up maybe 5am! Have you experienced any stigma or discrimination due to your illness?

Ka:

No. If you are talking about work wise, I have never mentioned this part of me to work because I feel like I don't need to. And I have learned to manage it. But if it was more recent and I was feeling sicker, obviously I would say something. But in terms of being discriminated, no.

Interviewer:

So have you ever been to other health practitioners about your illness apart from your GP?

Ka:

Just my GP

Interviewer:

What about the focus group? Are you connected to any chronic fatigue focus groups? Have you joined any of their groups?

Ka:

No, I didn't because I felt that it was very much that I had to sort out what suits me and my routine. And its nice hearing other people's stories and what they go through and what helps them, but at the same time it is very much a journey that only yourself can manage because you are the only one who knows your daily routine. And your work and your work schedule. So, I was ok.

Interviewer:

You were ok with just your GP and not to be part of the CFS group?

What do you think would improve health practitioners approach to CF, because from the way you have been speaking it feels like your GP has been very supportive.

Ka:

Yes

Interviewer:

So, during that time you felt so weak, and even when you feel weak now, does he prescribe any medication to help you sleep?

Ka:

No. They didn't give me any medication. Only because I was getting a large amount of sleep. It was the fact that when I would wake up I would not feel refreshed.

Interviewer:

So, what about the headaches? What do you do about headaches?

Ka:

Just Brufen. I didn't feel like it was heavy painkillers. At one point though I was getting panadene. But nothing heavier than that.

Interviewer:

So, when you take brufen now, it just sorts itself out?

Ka:

Yes, it just sorts itself out. When I take Brufen when I get the headaches, it's usually when I am just about to go to sleep. It's not usually in the day. So, I usually take Brufen or Panadol, and I have Magnesium now before I go to bed. For anxiety and all that. It seems to be good.

I just take one of those, take my Panadol or Brufen if I have a headache, and the Magnesium sorts itself out and makes me feel sleepy anyway.

Interviewer:

Which Magnesium? Is it the one you dissolve in the water or the capsule?

Ka:

The capsule. I was taking, they must have been 200mg tabs. But they were for sleeping so you take two of those at night. They were alright but at the moment I am taking just one 400, and this one you are supposed to be able to take it at any time of day. But I have never taken it in the morning because I don't trust that I won't get sleepy. So, I have just been taking it before I sleep.

Interviewer:

So, what do you think would help health professionals' approach?

Ka:

I think that CFS needs to be discussed more, especially with people who do have the viral infections. Because people need to know what will happen if they don't rest or they don't take care of their bodies. Because it can be anything you know, you could just be stressed and it will come on. So, I think if people knew more about this syndrome, and people were aware about it and the symptoms, people could manage it more. Man, I thought it was depression, that's really bad. You start doing things, obviously I was going out with my friends because I thought, maybe it's depression, I need to be around people. But no, it was the opposite, I needed a rest!

Interviewer:

So, you feel that CFS can happen to anyone, if you stretch yourself beyond what your body can take? Or it could be a viral infection.

Ka:

Yeah so true.

Interviewer:

They still name it as a syndrome.

Ka: And they don't know the causes for it either. The same thing my doctor said to me, oh we don't know what could have caused it. They say viral infections, and they were talking about how I had glandular fever just a little bit before.

Interviewer:

And you feel awareness would help?

Ka:

Yeah, well and truly. I just think people need to be more aware to the syndrome because at the moment they are so blinded.

It's so exhausting, you can't even describe it. It's like, when I was so sick with it and I wasn't managing myself properly, when you are tired, sluggish, it's like oh whatever get out of the bed! But it's not to the point where you can't even literally lift a limb. And that is when you know it's different. And when you have to manage it, that's when you know it's different. When you have to manage yourself just so you can get out of bed! That's when you know it's serious.

Interviewer:

How are you managing yours now?

Ka:

Honestly, I think work is really saving me at the moment. Obviously with the 6am, that's not helping, but the fact that that is split by the pm shift as well. I think, if I was to do the job just with the 6am shifts I would stay sick and I would have no way of managing it. And I think if I didn't have the opportunity for sleep, that's another thing. I would just get sick, I would get so sick.

Interviewer:

So, you are literally managing yours by having enough sleep and you take your magnesium to help you and you take your Panadol or Ibuprofen when you have a headache. And you have a job that has a mixture of morning and afternoon shifts to suit you. And the eight-hour shift doesn't bother you?

Ka:

No. It's not the eight hours, it's just the waking up early is the biggest part. Because for me, I have to get a certain number of hours of sleep. It has to be at least nine hours of sleep. Because I feel like if I get anything less than that I'm going to really struggle. And this is where I think, how would I even last in a hospital situation where it's like night shift and its pm shift and its morning shift. I would be so up and down and I wouldn't know what is left and right.

Interviewer:

Because your shifts are such a mixture, I can see why you are happy where you are. Because the hospital is actually a mix of night shift.

Ka:

Yes, I know, and sometimes you just never even get a break. At least with the prison, I know I have my set breaks, my two breaks during the day, so thank goodness.

It's been good. There has only been two days where I have had to go home because I am really really tired. And I can't work, I just switch off. I can't think about what I'm doing, and I get frustrated at myself and people get frustrated at me. And then I'm saying, I just need rest. But then, so does everyone else?

Just awareness, make people really know their routine, their work schedule and what they do after work, so they can manage. Really figure out how much time they have before they start

feeling like crap, and then how much sleep they need to feel great or even feel good. The minimal amount of sleep that they need as well. That's what you need to keep an eye on, because if you go anything below that, that's when it is getting dangerous.

Interviewer:

You just found a way of managing it yourself?

Ka:

Yes. My mum said the same thing. You just need to learn to manage yourself and you need to know what suits you and what feels right for you and your schedule. Around work. I don't go out nearly as much, just because when I come home from work, if I am doing 6 until 2.30 I obviously sleep. And then after sleeping I get up and make dinner. So that doesn't leave me a very good amount of time to spend with friends and stuff like that. So, I try to leave that to my days off, but on my days off I am recovering from my working week. So, it's like you are trying to make up for the day before and the day before and the day before.

Interviewer:

Do you do a routine visits to the GP?

Ka:

Not really. Because I have learned to manage it, but if it was to get bad again with my work then I would definitely go and be like, listen something is not working for me. I either need to take medication for it or we have to discuss a plan. But like as you said, even GP's know very little.

When I was really sick I wasn't eating, and that's something obviously you need to be keeping track of. I wasn't even drinking water and that is something you really have to watch out for.

When I was really sick with it when I was 15, it was summer at the time I was really sick. And my house has two stories and at the bottom story and at the bottom, I wouldn't call it a basement but it was like a garage into a living room. So, we cleaned it all out and it looks very nice, but it's still very cool down there compared to the top storey. And I was sleeping down there. I wasn't sleeping in my room upstairs because I found everything so hot. I wanted to be in the cold. I wanted to be in the dark, I couldn't stand light. Anytime anyone opened any curtains I was like, no close the curtains I just want to lie here in the cold and in the dark.

Interviewer:

It must have felt so strange to you.

Ka:

Yeah. But then when you think of it, people who are depressed, they don't want to be around people! They don't want to be in light places! I thought, oh man is this what it has come down to! I don't know where it had come from, this depression.

Because when I had a look at the symptoms years ago about what it was, on Google and Mayo clinic and all that stuff, they said that migraine symptoms, when you look at light you have a pounding headache. For me that was like, that's not right. Yes, I wanted to be in the

dark but it didn't mean that bright lights would give me a massive headache. There are so many symptoms and when you compare them to depression, most of them. And it's like, hey that's not much different. Yeah there honestly needs to be more awareness around it.

Interviewer:

Do you know anybody who has CFS?

Ka:

Yes, that girl I was telling you about, the girl who also went to my school. She had glandular fever before me, but her mum is good friends with my mum. That's why I knew she had it. And I think for her it's the same thing. It's still ongoing but she's learned to manage it now. But she had more than half a year off. We stopped being friends, we had a big fall out. But yeah, we are fine now but we don't chat away or anything. But I have said hi to her and talked and stuff like that. But man, she was so sick, and even first year of university, hardly went to any of her lectures just did them all at home in the dark. She just couldn't be in a lecture room with the lights.

Interviewer:

You know, I have no regrets doing this research. Just talking to people gives me more understanding of the illness. Thank you so much Kathryn for your time. You have done so well, I am so grateful!

25 July 2018

Researcher: **Interviewer**

Participant: K

Interviewer:

Thank you, K. This is my sixth interview, and today is the 25th of July. We will just start our interview now with the first question. And thank you very much for giving me this opportunity. How would you describe your current state of health?

K:

Average, and fluctuating. Today has been a good day, and it's actually been really nice because I have been able to get up and get out of the house and get a few things done in the house. However, on Monday I pretty much slept all day after I took my little one to daycare. I slept, had some lunch, slept and then went and got him. So, it fluctuates.

Interviewer:

Does the sleep help you?

K:

It does a bit, but I don't really feel refreshed. I can have nine, ten hours of sleep and I still don't feel great when I get up in the morning. But sometimes I can have nine hours of sleep and get up in the morning and feel reasonably ok, like this morning.

Interviewer:

Do you have headaches, when you get up?

K:

Yes, most of the time I have headaches.

Researcher:

And do you feel weak?

K:

Yeah. And I have the brain fog, I just can't think straight. The days where I sleep during the day, I walk into a room and I forget what I am doing. I think about something else and I walk into a room and forget. I think, I just have to lie down. And then I fall asleep, and that's as much as I can get done that day.

Interviewer:

How do you prefer people refer to your illness?

K:

I have started to call it ME more than chronic fatigue, because I find that chronic fatigue has a connotation to it that people don't understand and they just think you are tired and it's just some airy-fairy thing that is not real. And I have experienced that first hand with people that I know. Not understanding and thinking that I should just suck it up and get better. Whereas if I call it ME and talk about the systems that it effects in your body, then it feels like it's got more weight to it.

Interviewer:

And how did you arrive at a diagnosis?

K:

A long windy road! We are not sure if I have had this for three or four years or if I have had this for 20 years. When I was 20 I got a really bad virus. The doctors couldn't figure out what it was, I was in bed for three weeks unable to move. And I slowly recovered but my heath, I had dietary issues and bowel issues and headaches and a whole lot of problems. For years and years. And then I got a bit better at the end of my 20's, started getting back a bit into sport. And went overseas and travelled, and the whole time I knew something wasn't right but I didn't know what it was. And I thought it was just me because all the doctors that I went to told me it was in my head. And then over the last five years I have had some really significant life stressors. And last year I played the world masters for water polo, which was something I have wanted to do for ages and it was in New Zealand. And I kind of knew that it probably wasn't a good idea but it was one of those opportunities that I wanted to take up. At the time I was having some really stressful stuff happening at work, and after that I went downhill and started investigating myself to what could be going on. And went to different doctors to ask them to test for certain things. And then my GP said she didn't know what was going on, so someone recommended I change to the wholistic medical centre. And I changed to them, and that's when the GP looked at everything that was happening and diagnosed it then. So, whether it had been going on since I had that virus in my 20's, or if I had glandular fever five years ago. We don't know.

Interviewer:

So, from the time it was diagnosed till now, how many years is it?

K:

That was last year. And then I dropped my hours at work in February to 20 hours a week, thinking that that might help and I could manage it but actually I wasn't really managing at all. And then I had to stop completely in May.

Interviewer:

What kind of symptoms do you get with CFS?

K:

Brain fog. Headaches, just extreme exhaustion. I can be feeling ok and go out to do something, and within five minutes feel really tired and have to come back home and lie

down. I can't remember things, I have to write lists. My concentration and my memory are really bad. My eyesight changes. I can put contacts in and they won't make any

difference. So, I am wearing my glasses most of the time because my eyes just can't tolerate contacts. And they get really sore so I can't look at a screen for very long, otherwise I just have to close my eyes, which causes tension headaches. And I have had really bad digestive problems. The doctor I went to sent a stool sample to Australia, that showed I had a really bad imbalance of bad bacteria in my gut. So, we changed my diet and I'm on a whole lot of supplements for that. And I also, there is another thing I thought of and now it's gone out of my brain, and today is a good day! I got injuries that just won't heal. So, I injured a shoulder and an ankle last year, and they just won't heal. And I've got constant neck and back pain as well.

Interviewer:

How did you feel when you were diagnosed?

K:

I guess relieved in a sense that A, somebody believed me. Somebody understood. And that there was something that I could research, even though we didn't have an exact answer or a pill that you can take. It was something that I could find out more about.

Interviewer:

Was it your first time hearing of CFS?

K:

Yeah, a naturopath had mentioned it to me a year or so before that. Because I had gone to one because I was tired all the time. And he said that he thought I had chronic fatigue but he didn't say anything more. Just the one comment. And I at the time hadn't known what it was and I thought he meant I was just really really tired. Whereas if he at the time had said, this is what chronic fatigue is and this is how it effects your systems and this is what you can and can't do and this is what you should and shouldn't do, I think I would have looked at things differently from then. But I didn't and I just put it off as me being tired. But I'm quite driven and good at pushing myself. So, it was probably also me wanting to go, oh that's probably just me being tired, and push myself more. Which is what kind of got me into the state of being this bad. But I have kind of got a treatment plan that is definitely helping.

Interviewer:

You came up with the treatment plan?

K:

No, the naturopath and the doctor, and I am seeing a psychologist as well. Because there is a lot of, mentally it's really hard. Because you lose a lot. All the things that you used to do in life. The sports you used to play and the things you used to do. And the social things that you used to do. You lose a lot. So, there is a lot to deal with emotionally. I had a lot to deal with, just from everything I had been through for the last five years. So, there is definitely an emotional component to it. So, seeing a psychologist has been really helpful. And also,

helpful to know what baby steps are, to take the recovery. Because I am the type of person who when I feel better will do a lot, and then I will go downhill again. So, having someone to help you go, well actually, this is how much you are allowed to do, which is actually only a small amount. And even though you feel good, it's still all you are allowed. That kind of gives you some boundaries to understand it.

Interviewer:

So, what do you believe caused your illness? Do you believe it was probably the viral infection you had in your 20's?

K:

Yeah. In the research I have done it also says there is a genetic component. And then a stress component. And I know I have the stress component and the viral. Also, speaking to my mum, she thinks she had it when she was in her 40's. Not as bad but she was also a housewife, well she wasn't working. She had three kids and things were very different now to what they were then. She went through a period of time where she was really exhausted all the time. So, there could be a genetic component to it. So, I am not discounting that but it's hard to say yes or no.

Interviewer:

How old are you now?

K:

I'm 41

Interviewer:

So, you have done a whole lot of research on CFS haven't you?

K:

Yes.

Interviewer:

And when the doctor diagnosed you, did he give you any information about the illness? Was he helpful?

K:

He was. Yes, he was really helpful. I think initially he thought there was more of an emotional component to it because of this stuff that I had been through in the last five years, that there actually is. I think he has over time realised the physical element of what was going on. Especially when we looked at the gut stuff and found what was going on with my gut. They have also done some other tests which actually cost quite a lot of money but have been really helpful. So, they did a 24-hour urine test that looked at all my hormones. And it was interesting because they had previously done a blood test of my cortisol that showed it was a little bit low, but my previous doctor had looked at it and gone, oh it's a little bit low but it's fine. Whereas the urine test showed that my cortisol level was flatline all through the

day. So, it didn't actually go up like it's meant to. So, I just had no cortisol during the day, which will affect your fatigue and stuff. So, I am really happy that my mum has been able to help me out with some of the costs, the medical costs. So, I could get those tests done. But when I think about other people who may not have the means to do that, because the GP's originally just dismissed that cortisol. There was nothing wrong with it. But when you actually do a comprehensive test you can find out so much more. And ATP production in the mitochondria. So, they have supplemented me with things like that. And I think with the supplements that I am taking and the diet, because I am doing the no carbohydrates, no sugar, no fruit, no dairy. Pretty much vegetables and meat and protein. And that is definitely helping.

Interviewer:

No carbohydrates at all?

K:

No.

Interviewer:

How long have you been doing this?

K:

Four months. I didn't think I could do it for a start.

Interviewer:

I couldn't imagine doing that!

Ka:

I was the carbohydrate queen before this!

Interviewer:

And you are ok?

K:

Yes. I have got used to it. It was a challenge initially but I have got used to it. And I kind of, well there are some carbohydrate things that I miss that I would go back to but there are some that I probably just wouldn't bother anymore because I just got so used to this, and it's healthy. And I kind of need to give my system everything that I can at the moment, if I am going to recover properly from this. So, I figure that if it's for a short amount of time then it's worth it. So, the supplements I am taking have got lots of amino acids in them and things like that. And I have also just started taking a mushroom extract.

Interviewer:

Which mushroom?

K:

From some research I found from the US. From listening to broadcasts.

Interviewer:

So, your research is actually helping you?

K:

It is, yes. And I find that listening to podcasts is easier. I can't read things. I just can't take it in or concentrate that long. But I can listen to podcasts because I can close my eyes and just listen. Which is really helpful because in the times that I can't do anything else I listen to podcasts. And sometimes watch Netflix.

Interviewer:

It's good to find a way of helping yourself. You talked about, not going to work. How has CFS impacted on your life financially?

K:

Huge. Because work and income you can get support, and I am a sole parent so I get sole parent support and then the disability support on top of that. But it doesn't meet expenses that you have. And I was talking to a friend this morning, I'm not spending anything extra, medical and supplements and food are the only things I spend on, unless I have to get something for my little boy. That and your rent and your childcare and those sorts of things?

Interviewer:

How old is your little boy?

K:

He's four and a half. He's awesome. He keeps me going actually. He tires me out but he keeps me going. So, I have 50/50 custody with his dad. So, the days I don't have him I rest and then I have the energy when I do have him. Ye so financially it is very difficult, and it has taken a few months but I think I have finally worked out what I am entitled to with Work and Income. And their system is so complex. You can get one thing here and another thing here and then IRD can give you a family tax credit. The support is kind of there but it's so complicated.

Interviewer:

Nice, you are getting the support you need **K:**

Yeah and that is amazing, because I can imagine that in some countries that you can't. There is nothing like that.

Interviewer:

Nothing like that at all.

K:

We are very lucky.

Interviewer:

Very lucky.

K:

I have often wondered, with Work and Income. If only some of the people who are on Work and Income could get some money to pay for some of the tests that I have had done that might help their chronic fatigue and recover and get back into work. But it's just not known about enough.

Interviewer:

Yes **K:**

Yeah. So, I used to be really fit and play lots of sport. And I have had to stop all of that. I have started just in the last few weeks doing some yoga at home, but that's about as much as I can manage. And it's really slow stretching type yoga. And only a few times a week. But it's also impacted things like how I do things with my little boy. Some activities I just can't manage to do with him. I wanted to take him to the zoo ages ago because we had some free passes and I had to keep putting it off because I just didn't have the energy to walk around the zoo with him. And so, there is certain things that I just can't do with him, which is really hard for me because I want to be able to do things like that.

Interviewer:

So how do you cope, like when there are days when like you don't have the energy for cooking.

K:

So, I try when I do feel well to cook and then put stuff in the freezer. But also, there are paleo meals called Fit me in, and they deliver meals and they are all really healthy. So, on the occasion, I don't do it all the time, but sometimes I will order meals for the week and then I will know that for that week I don't have to worry about it. And for lunches I cook stuff, like some split peas and then I chuck a whole lot of spinach in there and make soup. Just things that are quick and easy like that. Crock pot.

Interviewer:

You seem to have a good way of managing yourself with your meals.

Emotionally, has it impacted on your life?

K:

Yeah. It'd really hard to be at home a lot without interaction with people. And I am an achiever, and to actually not be out there achieving things and doing things. I have just started doing little arts and crafts things at home because then I feel like I am actually doing something. And my jobs have always been meaningful jobs where I have been trying to make a difference to people and communities. So, it's really hard to not be doing that. And

it's also difficult to not be able to spend time with friends. If they are going out and doing dinners. There are so many times where I would have loved to go out for dinner with people and I have just had to say no I can't do it.

Interviewer:

Has it affected your friendships with them?

K:

No. Luckily my friends that I have got have been amazing, and really supportive. There are probably a few that don't understand it, and I kind of look at it and think, that's kind of their problem. If they are not willing to try and understand it.

Interviewer:

So, do you keep in touch with those ones?

K:

Not so much. I don't have the energy, actually. I have got a certain amount of energy to use and I really need to use it wisely. So, I have to use it on people who are supportive.

Interviewer:

Do they come and visit?

K:

Some friends do. My family all live in Christchurch, so I don't have any family up here. But my mum comes up occasionally and my brother comes up for work. So he comes around for dinner, which is nice.

Interviewer:

Are you ok in Auckland?

K:

Yeah. I have too many friends here and my little boy's dad is here. I don't want to take him away from his dad.

Interviewer:

Have you experienced any stigma or discrimination?

K:

From doctors, yeah. In terms of originally just not knowing what was going on and not being able to diagnose it. Not understanding it. And I think there are acquaintances, in terms of my ex's family. I don't think they believe it's valid. There are members of his family.

Interviewer:

Was that what broke up your relationship?

K:

No. What broke up our relationship is one of the things that broke me, about four years ago. But they sort of just ignore it. So, it's not outright stigma but I know that they don't think it's real so they just ignore it. So, they will send me messages and they won't ask me how I am. Or they will ask me and I'll say, I'm not doing so well or I'm improving and they will just ignore it.

Interviewer:

Really?

K:

Yeah. It can be and I guess I have just learned. When I was in my 20's and I was really sick, I learned who my true friends were then. And I guess I learned that if people are like that then there is just no point putting the energy in.

Interviewer:

And you are still with this GP who diagnosed you?

K:

Yes.

Interviewer:

Do you have any other health professionals?

K:

Yeah so, I'm seeing the GP. And the naturopath and the psychologist. And actually, they are all at the same centre. And what is amazing about that is that they all talk to each other. I had obviously given them my approval for that. Which is good because they have three different minds of training, areas, and they can all talk to each other and say what about this? And I have found that to be really beneficial. And I was for a while seeing an acupuncturist, who just had a baby. Which was helpful too. And occasionally I will see an osteopath, because my neck and back get quite bad. She also works on my stomach sometimes, and other things too.

Interviewer:

You are paying for this, aren't you?

K:

Yes. I did injure my neck and back so I have got some sessions through ACC, but you still have to pay on top. But it was actually my osteopath last year who picked it up, and said, I think you should talk to your doctor about it. She thought that I had adrenal fatigue. And she gave me a book to read, and she said, I think you should read this to see if it resonates with you. And it really did, and that's when I went to a different GP and said, I have done this research. And that's when they diagnosed me. So, it was actually my osteopath who picked it up initially.

Interviewer:

Have you connected with any CFS support groups? Do you attend any support groups?

K:

Not physically, but I have just been on the Facebook one. And I have had the support worker come and chat to me. And she was awesome. Just to give me some tips and tricks and suggestions on how to manage it.

Interviewer:

Is there any reason why you are not part of any support groups, apart from the Facebook one?

K:

I just haven't really physically got there I guess. Getting somewhere physically is harder than being online and I have only noticed one session that has been booked out west, and there's one on the shore here. The north shore is a bit far to go and I wasn't quite sure what would happen at that group and what it would be like. And what I would get out of it.

Interviewer:

So, the Facebook one has been helpful?

K:

Yes and no. It has been helpful in that there are definitely people out there who understand. And you can get suggestions and tips. There is also an element of, people who feel like they have got this for life and may not be, and this is the impression I get so I may be really wrong, may not be doing everything that they can to recover. Like, they are in it and they are going to stay in it. And that is quite disheartening at times. And I am an optimist and I don't want to believe that I am going to have this, I may have it for life and have to manage it, but I want to be at a stage where I can be back at work and doing more things with my little boy, and living a better life than being at home.

Interviewer:

Have you heard, when people say, it's something of the mind. It's in the head? It's not real. How do you feel when people say that to people with CFS?

K:

Really misunderstood.

Interviewer:

It's kind of similar with depression, and then later people are diagnosed with CFS and they say, no this is not depression. What's your understanding of this?

K:

Yeah. And I have been on antidepressants actually for five years. And I was on them when I was in my 20's. And when I think about it, then I don't think it was depression, I think it was CFS. And it's an interesting conversation because I think CFS can cause depression, because you lose what your life was as it was before. And that is really hard emotionally. So, I think it is very hard for someone to make a comment and say, you have depression instead of CFS because one might be causing the other. And also understanding, what is tiredness vs what is CFS, tiredness from depression or tiredness from CFS.

Interviewer:

Do you feel diagnostic criteria are the same?

K:

Yes, it seems like that. Unless they have purposely gone out of their way to look at things differently and train or understand stuff that is not just that narrow way of thinking. I think of the number of medical professionals I went to in my 20's, who literally sent me to a psychiatrist.

Interviewer:

It's quite interesting!

K:

I remember saying to mum, why won't anybody listen to me? This is not in my head, this is how I feel. And then I think I got to the stage where I got myself better and I thought that maybe the things that were going on were in my head and maybe this was just me. But now that I have been diagnosed, I look back and I think, this is what was going on during that time.

Interviewer:

Are there more people looking into CFS?

K:

Not a lot. On the Facebook group I have subtly made a few suggestions or put posts out there from the research that I have done. And often you will get a rebuttal type response back. Saying, oh but this won't do this. I actually contacted the New Zealand ME, chronic fatigue organisation, because there is an Osteopath in England who has developed something called the Perrin (spelling?) technique. He works to try and get your brain and your cerebral spinal fluid flowing the right way. He had a chronic fatigue patient years ago and noticed that the spinal fluid wasn't flowing right using cranial osteopathy. And then started to study it and did a research project on it. And it's one thing that has helped more chronic fatigue patients than any other. And he trains people all over the world, and he has trained a few people in Australia but no one in New Zealand. And my osteopath said she would be trained, and she is doing what she knows of cranial technique on me at the moment, to see if it makes a difference. And I contacted them to see about advocacy work and to see if they could advocate for him to come over. And they said that they can't advocate for anything that is not 100% researched, and stuff.

It was disappointing, it was really disappointing because it was pretty much a flat-out no. And if that is going to be the way people look at it then we are never going to get there.

Poor little old New Zealand is still an island. I know we have got lots of awesome things happening and a great healthcare system in general compared to some countries, but we are a little old island.

So, there are things like that that I have found. I feel like some people are kind of stuck in what they are going through. And maybe they have tried lots of things and they haven't worked so they have kind of given up on trying more? I don't know.

Interviewer:

So, with your family. Has it changed your relationship with them? Do they believe you? Your siblings, your parents?

K:

So, my dad passed away five years ago. But my mum had been amazing, really helpful. And my brothers have been a lot better actually. I think it took a lot for them to understand it, I sent them a lot of things that they could read. And they were really interested and they know that I have been sick on and off for a long time. So, I think it probably makes sense to them now. When they have seen what I went through when I was in my 20's.

Interviewer:

And the fatigue? How have you experienced it? How much. How bad is it on a daily basis?

K:

So, it varies, I have been lucky that I can get out of bed most days. There are some days where I get up, I get out of bed, I take my little one to day-care and I come home and I get straight back into bed. And I'll be there for the morning and I'll get up and have lunch and then I will lie on the couch and watch some tv or listen to something for the afternoon. And then go and pick him up. And then there are days like today where I have had the energy to go out and get some groceries and then do some things at home and not have a sleep. And I have tried to track it, I have tried to know what is the difference between today and yesterday where I slept and the day before when I slept all day. And it's so hard to know. So, I am lucky that I haven't got as bad that I am in bed all the time. I don't want to get there. But before, when I was working, there were days where I would come home from work, after working just five hours in a day and feel like I could just pull over on the side of the road and just lie down and go to sleep. And it took everything I could just to get home. And I would just go to bed. So now that I am not working I think that I am managing things just a little bit better. But the fluctuation is challenging because it makes planning things hard and I have to say to people, well I will plan this but if I have to pull out then I will pull out.

Interviewer:

We are close to finishing the interview, just rounding up. So, with the health professionals, what do you think would improve health professionals' approach to caring for people with CFS?

K: I think understanding that chronic fatigue is ME, and that it's a multiple system disorder in terms of that it affects your immune system and your digestive system and your hormones and your nervous system. And having them understand the basis of it, and potentially some case studies of people. So that all GP's know.

Interviewer:

That would probably help **K:**

Because you can explain something, but obviously the case studies are helpful. But also, with the case studies alone, doctors may still get the oh no it's all in their head thing. But if you show the systems that it effects and how it effects those, I think that can affect their understanding.

Interviewer:

And do you think they need more awareness out there?

K:

Definitely. Especially with medical professionals.

Interviewer:

So how do you think we can get there? To create this awareness?

K:

I think there needs to be something in the curriculum for nurses and doctors and any medical professionals. Naturopaths know about it. So why do naturopaths know about it but GP's and other mainstream medical professionals not?

Interviewer:

Unsure **K:**

And there are probably other conditions out there too that they don't know about. But this is one that really really impacts the person who has it because of what it effects.

Interviewer:

It's appears serious!

K:

Absolutely. So, I think definitely getting it in the training, but then for the GP's and everybody that is out there. I mean, all the GP's are linked to another body getting that information through them. The research project that I mentioned, when we were chatting at the beginning, I produced a booklet in an infographic style because I knew that the people we

were waiting to read this would probably not pick up a written report. But we wanted people to understand the perspectives of these young people and how the system failed them and that sort of thing. So, we did it in a visual way. And I think, if there could be something that could be produced like that for doctors and nurses who are already in the profession, to understand chronic fatigue. And it's actually, because that is something I have actually done as a job, it is something, I'm interested to know if when I get better, there is something I could do in that space. I would be interested in it.

Interviewer:

It's quite good.

K:

You can look it up if online if you want to. Knowing someone cares. It will kind of give you an idea of what I am talking about with the infographic. It's a PDF online. Because I think there is so much information out there about everything and we should be knowing this and knowing this. And if you can make it easily digestible for people.

Researcher:

I have been looking into documents and things like that online, and there are heaps of researchers. More in America, and the UK. Very little from New Zealand.

K:

There is someone in Otago doing a study. A doctor down there, because his daughter has got chronic fatigue and that is the reason why he started to do a study on it. But other than that,

K:

Have you interviewed doctor R?

Interviewer:

I have heard about her from most of my participants. I have written to her. I sent an email last week.

K:

I am reading her book at the moment. And it's very good actually.

Interviewer:

You have not met her, have you?

K:

No, I haven't.

Interviewer:

I have written to her, I would like to talk to her, because she is providing treatment to people with CFS. It would be nice to meet her.

K:

Even if you can get hold of the book it could be helpful.

Interviewer:

I saw her books online.

We have come to the end of our interview, thank you Kate for your time, I appreciate it **K:**

You are welcome.

2.9. Confidentiality Agreement for transcriber



Research Title: Experiences, symptoms and management related to chronic fatigue syndrome: A small study

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Signature: J. Allen

Date: 108 8/2018

UREC REGISTRATION NUMBER: 2018-1011

This study has been approved by the UNIT EC Research Ethics Committee from 23rd April 2018 to 23rd April 2019. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.



Institute of Technology

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EXPERIENCES, SYMPTOMS AND MANAGEMENT RELATED TO CHRONIC
FATIGUE SYNDROME: A SMALL STUDY

Practice Pathway:Cisc 9090.....

Degree:Masters in Applied Practice.....

Year of presentation:2019.....

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