



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

Research Commons

<http://researchcommons.waikato.ac.nz/>

## Research Commons at the University of Waikato

### Copyright Statement:

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

The thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of the thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from the thesis.

**Unpredictable, Incurable, Unemployable?**  
**A Collection of Constructed Narratives**  
**Exploring the Experiences of People with Chronic Conditions**  
**in Relation to Finding and Keeping Work**

A thesis

submitted in fulfillment

of the requirements for the degree of

**Master of Social Sciences**

at

**At the University of Waikato**

by

**Lynley Uerata**



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

**2011**

## **ABSTRACT**

People with chronic conditions have a health problem that is characterised by longevity, permanence, incurability and unpredictability of symptoms. They face significant challenges in gaining and maintaining employment, and are often seen as unemployable. As Chapter One shows, previous research on this topic tends to focus on selected aspects of their experiences. There is little literature which examines the employment issues of people with chronic conditions in a way that pays attention to the everyday life context.

The main research questions addressed in this thesis are: What are the subjective experiences of people with chronic conditions in the context of finding and keeping paid employment? What are the meanings they ascribe to those experiences? How do they interact with and operate within the micro-structures of the family, friends, the medical system and government agencies? What is the role of societal norms, values and dominant ideologies?

Chapter Two describes how this research draws on a “critical interpretivist” perspective and qualitative methodology to (re)present four people’s own stories in their own words in order to explore the subjective experiences of people with chronic conditions within the context of work and broader social structures. Two in-depth, semi-structured interviews were undertaken with these four participants, designed to capture their subjective experiences and enable the researcher to retell their stories. Their stories form the heart of the thesis in Chapter Three. In Chapter Four, each narrative is summarised to highlight the employment issues faced by each participant, and answers are provided to the research questions.

People with chronic conditions contend with a complex reality. These complexities stem from the fact that they are permanent, incurable and their symptoms unpredictable. And, because there lacks policies or political mechanisms that acknowledge the complex realities they face, they contend with these by themselves and with the people who are willing to assist them. In some circumstances, they are eminently employable.

## **ACKNOWLEDGEMENTS**

As I think about the process of completing this research, many words come to mind: eventful, painful, enduring, tears and joy. To those who helped me through, whether by offering words of support, stirring my mind, sharing your experiences or growling me when I became complacent, I am very thankful.

Thanks to the organisations - University of Waikato, The Faculty of Social Sciences and Waikato Tainui Te Kauhanganui Incorporated - that supported this research either through scholarships or grants.

Special thanks go to the research participants who shared their stories with me.

To my supervisor, John Paterson, thank you for helping me to write up my research in a way that I am proud to hand back to the people whose stories I gathered, analysed and wrote about. You have helped me to be a better researcher and writer. For this, I am very grateful.

## TABLE OF CONTENTS

<b>Abstract</b> .....	ii
<b>Acknowledgements</b> .....	iii
<b>Chapter One: Introduction and Literature Review</b> .....	1
The Three Sets of Research Questions .....	2
Literature Review .....	4
Definition of Chronic Conditions .....	5
Social Construction of Illness .....	9
Employment and Chronic Conditions .....	14
Other Actors and Structures .....	22
<b>Chapter Two: Methodology</b> .....	33
Qualitative Research .....	35
Method of Information Collection .....	37
Structure of the Interviews .....	38
Narratives .....	44
Principles Used in the Construction of Narratives .....	45
Reality Resists Analysis: Some Reflections on the Tensions ....	46
and Challenges Faced During the Construction of the Narratives	
Thematic Analysis .....	48
<b>Chapter Three: Narratives</b> .....	50
Pauline: Introduction .....	50

Pauline’s Story .....	51
Susan: Introduction .....	69
Susan’s Story .....	70
Pearl: Introduction .....	89
Pearl’s Story .....	91
Tony: Introduction .....	108
Tony’s Story .....	109
<b>Chapter Four: Conclusion</b> .....	126
Summaries .....	126
Pauline .....	126
Susan .....	128
Pearl .....	130
Tony .....	131
The Lived Experience of People with Chronic Conditions .....	133
The Employment Experience of People With Chronic Conditions .....	136
People with Chronic Conditions, Social Norms and Ideologies .....	139
Methodological Limitations and Strengths, and Further Research .....	140
Unpredictable, Incurable, Unemployable? The Complexity of .....	142
Chronic Conditions and Employment	
<b>References</b> .....	145
<b>Appendices</b> .....	161
Interview Guide .....	161

## **Chapter One**

### **INTRODUCTION AND LITERATURE REVIEW**

The research topic that this project seeks to investigate is the ‘lived experience’ of people with chronic conditions in relation to finding and keeping paid employment, and the social, cultural, economic and political factors that influence their experiences. A chronic condition is understood to be any illness, injury, disease, disorder or disability that is long-term, permanent, unpredictable and incurable in nature. The details of the definition are discussed below (see pages 5-9).

I became interested in this area of research when the health of a personal friend deteriorated to the point where he could no longer work. When the benefit became his only source of income, I wondered how he sustained his medical regime and how he felt about being a dad with limited financial means. My friend’s experience of having multiple chronic conditions made me aware that there are some issues that people with chronic conditions face that are unique. A sense of unease stirred inside me because, as an ‘able-bodied’ person, the realities he had to contend with seemed traumatic and fraught with difficulties. When my friend was given a terminal diagnosis, the research topic was cemented.

Close to this time the National government of New Zealand signalled their “unrelenting focus on getting beneficiaries into employment” and their intention to tighten the conditions under which people could gain invalid and sickness benefits (Key, 2008, para. 1). Because this action will make life even more difficult for people who are affected by chronic illness, it provided more motivation to pursue this research.

After sharing my research aspirations into the field of chronic illness and employment issues with friends, I began to learn more about some of the political, social and economic contexts within which this group of workers exist. I discovered there were no formal structures and mechanisms to assist people with chronic conditions in the areas of health, welfare and employment. I learned that the disclosure of illness clause in the employment

application process often lead to this group of people not gaining employment. My sense of unease was reinforced because there seemed to be a disconnect between what I perceived and understood about my friends experience of having multiple chronic conditions and the things the government said about people who are sick and who benefit from welfare. During these conversations I also came to know about more personal accounts of friends living and working with chronic conditions of which I was not previously aware. This led me to want to hear people's stories.

### **The Three Sets of Research Questions**

The following are the three sets of research questions addressed in this thesis:

- What are the subjective experiences of people who live with a chronic condition? What the meanings they ascribe to those experiences? How do they interact with and operate within the micro-structures of the family, friends, the medical system and government agencies?
- What are the subjective experiences of people with chronic conditions in the context of paid employment? How does having a chronic condition colour their experience of finding and keeping paid work?
- How do people with chronic conditions interact with and respond to societal norms, values and dominant ideologies that may be difficult for them to conform to given the nature of their chronic condition?

By drawing on a “critical interpretivist” perspective (explained below, page 36-37), it is my hope that this research will make their voices heard through (re)presenting their own stories in their own words. This will be achieved by trying to understand the perspective of the participants affected by chronic illness by paying attention to their subjective experience of the world of work as well as broader social, cultural, economic and political structures. By catching a glimpse into how these structures impinge on and support these people, it is my hope to gain an understanding of how services can be redesigned to better suit the needs of participants and others like them. I hold

the view that to make meaningful policy for people who experience chronic conditions, we must first listen to them.

This research project is of value in a number of ways. First, by providing a space for the previously unheard voices of people with chronic conditions to be heard, shared and recorded, this project will contribute to understanding better the realities of this diverse group of people. The completed thesis will be made available online by the University of Waikato. This will make it accessible to a wide range of people who might be interested in it.

Second, the thesis will be valuable by making those in the political arena aware of the experiences of people with chronic conditions and their employment issues. This may encourage the development and implementation of political mechanisms to enable this diverse group of people to be more successfully engaged in meaningful employment. While I am concerned about how the findings from this project might inform policy, however, before this can be done, it is important for this group of people to be heard. Though this thesis does not develop recommendations for policy, it is my intention to disseminate the thesis to relevant government agencies, such as Health Research Council of New Zealand, The National Advisory Committee on Health and Disability [NACHD], The Ministry of Social Development, Work and Income New Zealand [WINZ] and The Ministry of Health.

Third, this study adopts the approach taken by Falkenstern, Loeb, Gueldner, Penrod and Poon (2005)<sup>1</sup> who argued that understanding the impact of chronic illness on an individual's daily life is critical to delivering health care that meets the health needs of those affected, regardless of the setting. For those working in the field of health and illness, the narratives contained in this study can provide valuable insight into the myriad of struggles, and employment issues faced by this diverse group of people. It is essential for health and illness professionals to understand these experiences because they reveal patient needs and the areas in which they need help. It is my intention to disseminate the thesis through health providers.

---

<sup>1</sup> This thesis follows the referencing style of the American Psychological Association.

This thesis is divided into four main sections. In Chapter One, the literature review, though not an exhaustive one, contextualises the research topic and provides an overview of the central themes of this study. The literature reviewed here comprises a mix of international and national articles, books, and other relevant documents. The international literature provides the broader context while the national literature provides more detailed insights into the particularities of the New Zealand experience.

Chapter Two outlines the methodologies used in this study. The central theme of this research relates to discovering and capturing the subjective experiences of people with chronic conditions in the employment context. To this end, qualitative methodologies have been central to the collection and analysis of empirical material. Here I outline the inductive logic of this study and justify the use of the narrative approach to (re)presenting the empirical material.

The stories of the research participants form the centrepiece of this thesis. In Chapter Three, the stories stand by themselves as representing subjective experiences of people living and working with chronic conditions. Each story is preceded by an introduction which provides demographic information about each participant, cues the reader into sensitive issues and outlines how the participants and the researcher felt about different parts of the research process.

The final section winds up the thesis. In Chapter Four, each narrative is summarised and themes are drawn from the four stories to highlight their employment experiences and personal circumstances. The three sets of research questions are then answered in the light of the narratives and summaries and compared to existing literature. Comments are also made about the strengths and limitations of the methodology used in this thesis and further research possibilities are suggested.

## **Literature Review**

This literature review is organised into three parts. The first part canvasses the issues identified in the literature surrounding the definition of the term ‘chronic condition’. The different elements relating to the term are isolated

and discussed in detail to reflect the multiplicity and fluidity of meaning that can be ascribed to this term. The second part of the literature review covers the social forces that influence the social construction of illness as well as social understandings of health, illness and healing. The third section covers the literature on the employment experiences of people with chronic conditions as well as other actors and structures that influence this group of people.

### ***Definition of Chronic Conditions***

‘Chronic condition’ is a term laden with meaning (Sidell, 1997). While there is a broad consensus around the general elements relating to the term, I did not find a definition that included all its elements. This occurred simply because different points of view highlight different elements of the definition. It is also difficult to define because, as Perrin, Newacheck, Pless, Drotar, Gortmaker, Leventhal, Perrin, Stein, Walker and Weitzman (1993) pointed out, elements of chronic conditions overlap with other kinds of ill health.

Lee and Chan (2005) claimed that a chronic condition refers to a “spectrum of illnesses, injuries or diseases caused by the dysfunction of various human biological systems” (pp. 359-360). Other authors, such as Hymovich and Hagopian (1992), Vickers (1995) and Sidell (1997), held the view that a chronic condition is one that interferes with the person's physical, emotional, psychological, ability to make judgements, learning limitation, learning disability and/or social functioning. While some of the impacts to the emotional, physical and psychological functioning of an individual can be a symptom of chronic illness, Ware (1992) pointed out that they can also be an outcome of being chronically ill.

A range of descriptive terms are used in the literature when discussing chronic conditions, such as ‘condition’, ‘illness’, ‘disability’, ‘disorder’ and ‘disease’. Perrin et al. (1993) advocated the use of the term ‘condition’ for a number of reasons. First, they argued the terms ‘illness’, ‘disability’, ‘disorder’ and ‘disease’ carry connotations of deficiency and negativity. They believed the term ‘condition’ has a more neutral connotation. Second, these authors pointed out that some forms of ‘disability’, such as spina bifida, are not

considered to fall under the term 'illness'. Perrin et al. (1993) asserted that the term 'condition' can act as an umbrella term for the various forms of ill health. In light of this, I have generally used the term "chronic condition" in this thesis. However, I have also incorporated other terms or descriptors, such as "chronically ill" or "chronic illness", that were used in existing literature or by the participants.

Chronic conditions were often compared to the definitions of acute, terminal and life-threatening illness in order to distinguish how they are different and similar. These discussions allude to the fluidity of meanings that are attributed to the different forms of ill health. One of the issues identified by Finseth (2009) about having exclusive categories for different forms of ill health is that they can move across categories. Leukemia, for example, is considered to be a chronic condition, however, if an individual relapses it can become a life-threatening condition (Finseth, 2009). Further, acute illnesses are conditions are considered to be the opposite of chronic conditions in the sense that their onset is sudden and are usually short-term (Perrin et al., 1993). However, Perrin et al. (1993) highlighted that some acute illnesses, such as headaches and migraines, can be recurring and therefore can fall under the banner of chronicity.

There were four elements identified in the literature that make up the definition of a chronic condition. The first and most commonly articulated element was the long-term and permanent nature of chronic conditions. According to Perrin et al. (1993) and Sidell (1997), this is the main distinguishing feature of a chronic condition compared to other kinds of ill health. However, Perrin et al. (1993) argued that while the criterion of time is the main distinguishing feature of a chronic condition, it is also problematic for three main reasons. First, because the onset of the condition may be sudden or gradual, when the condition began can be unknown (Perrin et al., 1993; Pollin, 1994; Bury, 2005). Second, a number of authors pointed out that some forms of cancer and heart disease, for example, can exist within the body without any manifestations of symptoms and therefore diagnosis may occur after initial symptoms (Perrin et al., 1993; Pollin, 1994; Bury, 2005).

Third, as previously mentioned, some conditions that are not chronic can reoccur (Perrin et al., 1993).

While most authors highlighted the long term and/or permanent nature of chronic conditions (Bury, 1991; Sidell, 1997; Beatty & Joffe, 2006; Varekamp, Heutink, Landman, Koning, Vries & van Dijk, 2009), there was some disagreement around the minimum length of time one needs to be ill for it to count as chronic. Some sources suggested a state of ill health can be considered chronic if it persists for three months or more (Perrin et al., 1993; NACHD, 2005; Finseth, 2009). Vickers (1994, 1995 & 1997) considered an illness to be chronic only if its duration exceeded six months.

The second theme related to the incurable nature of chronic conditions. The long-term nature of chronic conditions is inextricably linked to the fact that they cannot be cured by conventional or alternative interventions (Bury, 1991; Sidell, 1997; Miller, 2000; Falkenstern et al., 2005) and that they do not follow linear patterns of illness (warning signs - illness - treatment - recuperation - recovery) (Parsons, 1951; Pollin, 1984; Vickers, 1995; Sidell, 1997; Beatty & Joffe, 2006; Varekamp et al., 2009). Kinzel (1993) and Sidell (1997) pointed out that despite how vigorously diagnosis or treatment is pursued, the person affected by chronic illness will be left with a residual, usually progressive, condition. As such, chronic conditions require complex monitoring and maintenance that involve coordinated inputs from a wide range of alternative and conventional health practices, processes and professionals (Sidell, 1997; Unwin, Epping Jordan, Bonita, Ackland, Choi & Puska, 2004; Lee & Chan, 2005; Nolte & McKee, 2008). According to Anderson (1991), Sidell (1997) and Lee and Chan (2005), the focus of these processes is to minimise the impact of the condition on the body and to prolong life. This is achieved primarily through monitoring and controlling symptoms (Sidell, 1997; Lee & Chan, 2005) and adhering to treatment regimes (Falkenstern et al., 2005; Miskelly, 2006).

The third theme pertained to the typology of chronic illnesses. Wellard (1998) identified four key features in the typology of a chronic condition. These are:

- “‘onset’ the rate at which the disease occurs;
- ‘course’ of the disease categorised as either progressive, constant or relapsing/episodic;
- ‘outcome’ on life span; and
- the ‘degree of incapacitation’” (p. 50).

As mentioned, while there are key ‘stages’ to the typology of a chronic condition, many authors added that chronic conditions do not follow ‘normal,’ predictable or linear patterns of illness (Parsons, 1951; Pollin, 1984; Vickers, 1995; Sidell, 1997; Beatty & Joffe, 2006; Varekamp et al., 2009). Bury (2005) highlighted the unfolding, emergent character when describing how chronic conditions pass through different stages. Donoghue and Siegel (1992) emphasised that people who experience chronic conditions live with a “baseline of illness that is broken up by periods of remission” (p. 5). Wellard (1998) added that chronic conditions are “marked by medical crises” (p. 50).

The fourth theme related to the nature of symptoms. The symptoms that people experience are much like the unpredictable typology of chronic conditions. Symptoms can be seen or unseen (Seccombe, 1995; Vickers 1995) and vary day to day (Beatty & Joffe, 2006; Varekamp et al., 2009). Sidell (1997), quoting Pollin (1994), also pointed out that a chronic condition can be “incapacitating or not; may have a sudden or a gradual onset; it may be fatal, potentially life-shortening, or of no consequence to one's life span; and it may be progressive or unchanging” (p. 7).

Some definitions implied or set a threshold in terms of the degree of severity of the condition (Pollin 1984; Radley, 1989; Wellard, 1998). However, as Pollin (1994) and Sidell (1997) pointed out some chronic conditions can be incapacitating, such as MS, and others may not be severe enough to cause impairment, such as sinusitis. The severity of chronic conditions, even those with the same condition, can also vary from person to person (Boot et al., 2008). Further, as Bury (2005) argued, how might severity be measured and compared?

It seems then that the term ‘chronic condition’ invokes ideas around longevity, permanence, unpredictability typology and symptom management. In light of the points made above the operational definition for this research project focuses on people who have experienced a chronic condition for a number of years and whose severity of illness is or has been significant but some form of paid employment is possible.

### *Social Construction of Illness*

The three sets of research questions provoked me to examine how the term ‘chronic condition’, within the scope of this thesis, is socially constructed. Wellard (1998) asserted that research of a sociological nature into the field of chronic conditions should apply a critical lens to the social forces that influence our understanding of health, illness and healing. She also highlighted the importance of understanding the politics of being a person in the absence of full health in a world of health centred people. The literature canvasses a number of key social forces that are relevant here – political forces, the health system, the biomedical model and the notion of the ‘ideal’ person. These are discussed below, however, it must be noted that it is not a complete list.

A number of authors argued that social understandings of health, illness and healing as well as the health system need to be understood in relation to the broader political and economic framework (Engels, 1963; Navarro, 1979; Senior & Viveash, 1997; Annandale, 2008). In terms of socially constructed ideas around health, illness and healing, Miskelly (2006) asserted that the role of the state should not be overlooked or underestimated because the government both regulates the health sector and funds the majority of public health services. Given the above, she continued that the government has the power to define terms such as ‘health’ and ‘illness’, determine ‘acceptable’ health providers and control access to the health system.

Because of the increasing prevalence of chronic conditions (Sidell, 1997; Phillips & Stuifbergen, 2006; Nolte & McKee, 2008; Novotny, 2008; Pomerleau, Knai & McKee, 2008), the economic and social consequences (World Health Organisation [WHO], 2005; Suhrcke, Fahey & McKee, 2008)

and its use of health care resources (Sidell, 1997; WHO, 2005; Suhrcke, Fahey & McKee, 2008), national and international organisations, such as the WHO, recast chronic conditions as a “burden ... confronting health systems” (Nolte & McKee, 2008, p. 1; Novotny, 2008; Pomerleau et al., 2008; Suhrcke et al., 2008).

From a political perspective, further motivation for recasting chronic conditions as a burden relates to the fact that “being ill means both not being able to work” (Radley 1988, p. 87; Virtanen, 1994; Vickers, 2001), and those who do not work are able to access assistance in the form of subsidies and welfare from government services (Beynon & Tucker, 2006).

According to Navarro (1979) and Senior and Viveash (1997), the health system, which evolved during industrialisation, was designed to ensure that sick workers were made fit for work in order to continue making profit for employers. Maintaining control over health means that workers could stay at work longer, less people were taking time off and people were able to return to work quickly after illness (Senior & Viveash, 1997). To this end, Navarro (1979) and Senior and Viveash (1997) argued that the health system is an ideological state apparatus exercising control over those who are defined as ill, those who can be defined as ill and what symptoms can be defined as an illness. While the health system assisted workers towards a state of health that enabled them to work, Navarro (1979) and Senior and Viveash (1997) asserted that employers benefitted from a healthy workforce.

According to Wellard (1998) and Miskelly (2006), the biomedical model<sup>2</sup> is central to socially accepted understandings of health, illness and wellbeing because it is dominant within western societies<sup>3</sup>. Foucault (1977) argued that, when the biomedical model became attached to the state, its practitioners were given the “power to label bodies as deviant or normal, hygienic or

---

<sup>2</sup> According to Giddens (2001), the ‘biomedical model’ is a set of principles that underpin Western health systems and practices. The biomedical model, which treats the body like a machine, “defines forms of illness objectively and asserts that the body can be restored to its proper working order through using scientifically-based treatment” (p. 684).

<sup>3</sup> See Senior and Viveash (1997) for an explanation of how the biomedical model became the dominate model for understanding health, illness and wellbeing.

unhygienic or requiring control” (as cited in Miskelly, 2006, p. 96; Lupton, 1994). Because this labelling serves as a mechanism for state surveillance, many authors argued that this renders the health system as a site of surveillance and social control (Foucault; 1977; White, 1999; Lupton, 2000; Miskelly, 2006)<sup>4</sup>. According to Turner (1988) and Miskelly (2006), the use of state surveillance is related to the expansion of individual rights and the need to control access to scarce resources. Rose (1996) noted that, as a result of the above, more and more of everyday life has become medicalised and the state and the health system were given the power to “conduct the conduct of others” (p. 3).

The biomedical model explains ‘symptoms’ as a consequence of ‘illness’ which may have a psychological or pathological basis (Weston & Brown, 1989; Perrin et al., 1993; Senior & Viveash, 1997; Bury, 2005; Miskelly, 2006). By promoting the view that illness is a biological, and therefore an individual, issue rather than a social issue or an outcome of structural inequality, it becomes easy to see why national governments would align with the biomedical model (Senior & Viveash, 1997). Within the biomedical model, Navarro (1979), Senior and Viveash (1997) and Annandale (2008) claimed, governments are not seen as contributing to ill health, nor responsible for improving the economic and material circumstances and it facilitates ideological control over the way people understand health issues. To this end, doctors become agents of the state and act in the interests of private enterprise (Senior & Viveash, 1997; Annandale, 2008).

The orientation of the biomedical model, which treats the body like a machine, is to find the “‘fault’ of an illness within the individual” and to cope with these ‘disturbances’ to the ‘health’ of an individual” with ‘illness’ (Senior & Viveash, 1997, p. 23; Parsons, 1951; Bury, 2005; Miskelly, 2006). Overseen by medical practitioners, the person affected by ‘illness’ engages in ‘treatment’ or ‘therapy’ which aim to restore them to ‘health’ or ‘normality’ (Parsons, 1951, p. 429). According to Radley and Green (1989), the

---

<sup>4</sup> For more on state surveillance, see Lupton (1994), White (1999) and Miskelly (2006).

biomedical approach to research is experimental. These authors described how these experiments use 'normal' populations (healthy persons) as control groups to contrast those in a 'normal' state of health to those who are 'diseased', 'disabled' or 'ill'. Embedded within these assumptions is the idea that 'health' and 'illness' are separate entities in which people transition from a state of 'health' to one of 'illness' (Radley & Green, 1989), and that 'disability', 'disease', 'illness' and 'injury' are under human control (Vickers, 2001; Garland-Thomson, 2002; Miskelly, 2006; O'Connell, 2009).

Kelly and Field (1996) claimed that the meanings attributed to health and illness are designed to "constrain and organise expectations about behaviour" (p. 246). These authors explained that the "central prerequisite for the development of the human being is the control of the physical body and its capacities" (p. 244). Control over the physical body "provides a sense of control and constancy of the embodied self and the ability to plan and predict future actions" (p. 244).

Phenomenological perspectives asserted that modern society operates around the notion of the 'ideal' person (Gething, 1984; Vickers, 1995; Senior & Viveash, 1997). Brown (1995), Senior and Viveash (1997) and O'Connell (2009) argued that the 'ideal' person is clean, youthful, 'able-bodied' and without disease. Within this way of viewing health and illness, the body's normal and natural state is viewed as being 'healthy' (Coward, 1989; Sharma, 1992; Fulder, 1996; Heelas, 1996; Vickers, 2001; Miskelly, 2006). Charmaz (1983) added that being 'normal' becomes "the symbol of a valued self" (p. 169). In light of the above, a number of authors argued that people develop a discomfort towards illness and disability and become increasingly fearful about being sick or disabled (Wang, 1992; Kelly & Field, 1996; Vickers, 2001). Kelly and Field (1996) suggest that this "becomes clear when the body 'lets us down'" (p. 246). As a means to both avoid invasions to the body and to maintain a level of good health, people are encouraged by the government and the health industry to engage in what Shilling (1993) and Miskelly (2006) described as individual surveillance and regulation. These involve monitoring both one's physical appearance and what goes in the body, such as grooming, exercise, maintaining a healthy diet, taking steps to reduce stress, controlling

alcohol consumption and not consuming cigarettes and drugs (Radley & Green, 1989; Shilling, 1993; Miskelly, 2006; O'Connell, 2009). This has been described by many as 'the body project' (Shilling, 1993; Brumberg, 1997; Miskelly, 2006).

Miskelly (2006) argued that individual surveillance and regulation reflect neoliberal and individualistic ideologies in that individuals are required to monitor their own health so they do not "succumb to illness, or injury through negligent or careless behaviour" (p. 112)<sup>5</sup>. Vickers (2001) suggested that it reflects a view in the modern Western world that "illness and disability can and should be overcome with sheer guts and determination or, at least, the lashings of positive thought" (p. 7). Senior and Viveash (1997) suggested that individual surveillance and regulation illustrate how the state both draws attention "towards the problems of individual lifestyle" and "away from the social system" (p. 316).

Against the 'ideal' body, the body in the absence of full health is seen as breaking normal social and cultural conventions, and is rendered as 'other', 'deficient', 'ungovernable' and 'shamelessly immoral' (Kleinman, 1988; Susman, 1994; Vickers, 1995; Wellard, 1998; Garland-Thomson, 2002; O'Connell, 2009). Within this view, illness is not seen as an "integral part of one's embodiment" or "way of relating to the world" (Garland-Thomson, 2002, p. 1568; O'Connell, 2009) and "fault is located in the body of the disabled person, rather than in the society that excludes them" (O'Connell, 2009, p. 155).

According to Kerson (1985) and Sidell (1997), the term 'chronic' is laden with negative connotations. This is reflected in that people with chronic conditions are described not as "chronically happy or healthy but as chronically depressed or ill" (Kerson, 1985, p. 1; Sidell, 1997). "Labelled by the disease they experience and the treatments they use people with chronic conditions are set apart from others" and become subject to the stigma that is attached to physical deformity (Wellard, 1998, p. 51; Brown, 1995; Vickers,

---

<sup>5</sup> For more on neoliberalism and individualism and how they have influenced health systems, practices and processes, see Miskelly (2006).

1995 & 2001). To this end, many authors noted that this labeling acts as a means of ostracising deviants and alludes to what is ugly, feared or inhuman (Gething, 1984; La Bier, 1986; Kleinman, 1988; Vickers, 1995).

### ***Employment and Chronic Conditions***

In advanced western nations, modern organisations operate within a competitive capitalist context (Landau & Chisholm, 1995; Rees, 1995; Vickers, 1999 & 2001)<sup>6</sup>. Landau and Chisholm (1995) and Vickers (1999 & 2001) noted that one of the ways organisations seek to be competitive is to operate under the notion of efficiency in production processes, also known as a ‘lean’ organisation. The doctrine of efficiency, which is controlled and administered through managerialism (Landau & Chisholm, 1995; Vickers, 1999 & 2001), both serve as a mechanism for setting standards for performance and for establishing sanctions to enforce those standards (Vickers, 1999). In this context, the role of managers, who are required to focus on outputs rather than the process of work or workers, seek to complete ever-increasing levels of productivity with a minimal number of workers, machines and units (Denhardt, 1981; Hughes, 1994; Vickers, 1999 & 2001; Allen & Carlson, 2003).

Underpinning western notions of workplace success is the “need for fully functioning individuals to provide utility to organisations” (Vickers, 2001, p. 18). As a result, “any level of illness that takes a person below optimal capacity” can be viewed as a problem by management because they inhibit

---

<sup>6</sup> While this literature review has a narrowed scope, it must be noted that I am aware of literature on chronic illness that goes beyond this focus – chronic illness, identity and change (Charmaz, 1983, 1991 & 1997; Anderson, 1991; Kelly & Field, 1996), subjective understandings of the genesis of chronic illness (Williams, 1984), experiencing chronic conditions (Ironside, Scheckel, Wessels, Bailey, Powers & Seeley, 2003; Pierret, 2003; van Staa, Jedeloo, Latour & Trappenburg, 2009), experience of loss and chronic sorrow (Sidell, 1997; Ahlstrom, 2005), stigma and chronic illness (Wang, 1992; Susman, 1994; Joachim & Acorn, 1999), the economic and social consequences of chronic illness (Stenbeck & Hjern, 2007; Jeon, Essue, Jan, Wells & Whitworth, 2009), transitions, coping strategies and adjustment to illness (Pollin, 1984; Radley & Green, 1987; Radley, 1989; Miller, 2000; Kralik, 2002; Loeb, Penrod, Falkenstern, Gueldner & Poon, 2003), stressors in chronic illness (Hymovich & Hagopian, 1992), the meanings people attribute to ‘feeling healthy’ within illness or disability (Lindsey, 1996), illness and maternity (Twork, Wirtz, Schipper, Klewer, Bergmann & Kugler, 2007), the experiences of parents in maintaining employment who have a child with a chronic illness (George, Vickers, Wilkes & Barton, 2008), barriers to managing chronic illness in urban Kenya (Porter, Chuma & Molyneux, 2009), and the experiences of rural women in relation to managing chronic illness (Sullivan, Weinert & Cudney, 2003).

the process of efficiency (Parsons, 1951, p. 430; Vickers, 1999 & 2000). Many authors argued that these workers tend to be marginalised (Parsons, 1951; Vickers, 1999 & 2001; Peterson, Pere, Sheehan & Surgenor, 2006) and workers without limitations are seen as a “premium commodity” (Vickers, 2001, p. 27; Turner, 1988; Virtanen, 1994; Lublin, 2004).

Madden (2004) noted that ill-health has a significant effect on labour market participation in a myriad of ways. One’s capacity to be employed is directly related to the functional and cognitive limitations imposed by the condition and the pain experienced by those affected (Beatty, Blanco, Wilbanks, Paul & Hames, 1995; Camilleri, Jessop, Davis, Jessop & Hall, 1995; Bombardier & Buchwald, 1996; Gordon, Stoelb & Chiriboga, 1997; Baanders, Rijken & Peters, 2002; Beynon & Tucker, 2006). According to Beynon and Tucker (2006), these factors combine to reduce the number of hours and type of work they are able to do. Given the situation outlined above, it is difficult for people with chronic conditions to find employment (Yelin, 1986; Tagalakis, Amsel & Fichten, 1988; Virtanen, 1994; Baanders et al., 2002; Beynon & Tucker, 2006; Boot, Heijmans, van der Gulden & Rijken, 2008) that fits their interests (Yelin, 1986; Tagalakis, Amsel & Fichten, 1988; Boot et al., 2008) and is appropriate to their health needs (Beynon & Tucker, 2006). While the reality they face in regard to their health determines their capacity to gain work, several authors noted that other factors, such as demographic characteristics, education, work experience and economic incentives, influence their employability as well (Baldwin & Johnson, 2001; Beynon & Tucker, 2006). In an overview of literature on the participation rates of people with disabilities in the labour market, Baanders et al. (2002) found rates were lower among women, people over the age of 45, those with low education levels and those with serious physical disabilities. Beynon and Tucker (2006) discovered that people who are chronically ill were more likely to be employed in temporary or part-time jobs or be self-employed.

In a questionnaire-based research project investigating the experiences of discrimination of 785 people with mental illness, Peterson et al. (2006) found that many people did not apply for jobs due to fear of discrimination. This was particularly so for people who had been out of the workforce for

extended periods (Beynon & Tucker, 2006). Concern that work might aggravate their condition was also a barrier to entering the workforce (Beynon & Tucker, 2006).

The Privacy Act 1993, which seeks to address the access, collection and storage of personal information, requires people to disclose health conditions that may or may not affect their ability or capacity to work to potential or existing employers (Deeks & Rasmussen, 2002). While this legislation is designed to ensure the safety of people within the workplace, embedded within it is the assertion that employers have a right to know about the health status of potential and existing employees that may be of consequence to the organisation (Allen & Carlson, 2003). To this end, it is for the benefit of employers and enables the protection of business assets (Dyck & Jongbloed, 2000; Allen & Carlson, 2003).

The disclosure of illness has been described by Vickers (1995), Dyck and Jongbloed (2000) and Allen and Carlson (2003) as a 'dilemma' for people with chronic conditions. This is because they have to weigh the decision to disclose or conceal their health status to management and colleagues within the workplace, against perceived outcomes (Vickers, 1995; Dyck & Jongbloed, 2000; Allen & Carlson, 2003). They then have to decide who, where, when and how much to tell (Goffman, 1963; Vickers, 1999). To avoid this, Allen and Carlson (2003) discovered people affected by chronic conditions would often opt for self-employment or seek employment through people who were familiar with their disability.

One of the main problems for people with chronic conditions when they are seeking employment is the perceptions of employers (Vickers, 1995 & 2001; Baanders et al., 2002), particularly for those returning to work after extended sick leave (Allen & Carlson, 2003). This is because chronic illness is frequently misunderstood by managers, particularly those without personal experience and because there is a common perception that 'illness', 'disease' or 'disability' reduces work performance, increases absences (Kleinman, 1988; Vickers, 2001; Lublin, 2004; Beatty & Joffe, 2006). Because the labels associated with chronic illness and the therapies used can become a

“metaphor for characteristics attributed to the person” (Greene, 2000, p. 124), disclosure means having to deal with the stigma attached to ‘illness’ in general, and the stigma attached to their ‘illness’ in particular (Vickers, 1999; Dyck & Jongbloed, 2000; Allen & Carlson, 2003). On top of this, the complex needs of people with chronic conditions can require the organisation to provide different forms of workplace support, such as flexible working conditions or special equipment (Seccombe, 1995; Jakobsen, 2001). As a result, managers, who determine who gets employed under what conditions (Krieger, 2010), often chose not to recruit or promote people with chronic conditions (Tagalakakis et al., 1988; Virtanen, 1994; Seccombe, 1995; Vickers, 2001; Allen & Carlson, 2003; Madden, 2004; Beatty & Joffe, 2006; Peterson, et al., 2006), even when they were evaluated more positively than ‘able-bodied’ applicants (Tagalakakis et al., 1988).

Those who chose to disclose their condition were aware it might be viewed as a problem to potential and existing employers (Tagalakakis et al., 1988; Gaze, 1991; Vickers, 2001; Allen & Carlson, 2003; Lublin, 2004; Boot et al., 2008) and might reduce their chances of getting a job (Tagalakakis et al., 1988; Gaze, 1991; Vickers, 2001; Allen & Carlson, 2003; Lublin, 2004; Boot et al., 2008). In order to mitigate and/or circumvent the real or perceived risks of disclosure, people affected by chronic illness deployed a number of strategies. First, people affected by chronic conditions emphasised their abilities, skills and experience (Tagalakakis et al., 1988; Vickers, 2001; Allen & Carlson, 2003; Lublin, 2004). This was the most common strategy found in the literature. This was often coupled with an explanation of how they coped with everyday symptoms and/or acute episodes as a means to emphasise relative control over the unpredictability of the condition (Tagalakakis et al., 1988; Lublin, 2004). Second, participants were adamant about not wanting to be pitied or given special treatment and that work tasks would be completed when they were well enough to do so (Lublin, 2004). Both strategies were attempts to alleviate employer concerns about their performance and capabilities, and to portray themselves as a reliable employee and a secure investment (Tagalakakis et al., 1988; Vickers, 2001; Allen & Carlson, 2003; Lublin, 2004). To obtain employment, Tagalakakis et al. (1988) claimed people with chronic conditions

needed to both possess the required skills and abilities as well as impress management to obtain employment or promotion in comparison to applicants without long-term chronic conditions.

In their qualitative study titled, *To conceal or disclose a disabling condition? A dilemma of employment transition*, Allen and Carlson (2003) found that physical limitations and/or disabilities beyond the control of the individual were favourably regarded by employers when acknowledged in the interview setting. Many authors added that disclosure often lead to the “verification of disability status required for receipt of disability benefits” (Allen & Carlson, 2003, p. 20; Dyck & Jongbloed, 2000; Lublin, 2004). That is, employers and colleagues were more tolerant and understanding when they needed sick leave, unexplained absences or performed below workplace standards (Seccombe, 1995; Dyck & Jongbloed, 2000; Vickers, 2001; Allen & Carlson, 2003; Lublin, 2004).

When people who live with chronic conditions perceived or expected to be penalised for being chronically ill or when they felt employers would not care or be prepared to listen to the reality of their illness, they were less likely to disclose their illness (Dyck & Jongbloed, 2000; Vickers, 2001). This was particularly so for those with incapacitating or potentially incapacitating kinds of chronic conditions (Vickers, 2001) and people with limited financial security (Dyck & Jongbloed, 2000). Dyck and Jongbloed (2000) and Vickers (2001) also found that those with visible symptoms, if possible, would hide them as a means to pass as ‘normal’. Other sources found that many often keep silent about their condition until they successfully gained employment (Vickers, 1999 & 2001; Allen & Carlson, 2003; Lublin, 2004).

The literature revealed that many concealed their illness from employers and colleagues. A number of motivating factors were identified. These included: to preserve one’s self-concept (Dodier, 1985; Fitzgerald & Paterson, 1995; Allen & Carlson, 2003); to retain control over and/or mitigate the impacts, whether real or perceived, on their social and occupational identity (Dodier, 1985; Fitzgerald & Paterson, 1995; Vickers, 1995 & 2001; Dyck & Jongbloed, 2000; Allen & Carlson, 2003; Beatty & Joffe, 2006); to control the

way in which others perceived them and their abilities (Fitzgerald & Paterson, 1995; Vickers, 1995; Dyck & Jongbloed, 2000; Allen & Carlson, 2003; Beatty & Joffe, 2006); to avoid or control negative labour market outcomes (Dyck & Jongbloed, 2000; Greene, 2000; Vickers, 2001; Allen & Carlson, 2003; Madden, 2004); to avoid stigma, patronising responses from others or discrimination (Fitzgerald & Paterson, 1995; Vickers, 1995 & 2001; Dyck & Jongbloed, 2000; Greene, 2000; Allen & Carlson, 2003); and to respond to the fear of discrimination (Vickers, 1995 & 2001).

However, those who chose to conceal their illness had to face a number of negative outcomes. They risked being perceived or labelled as ‘lazy’, ‘incompetent’, or ‘deviant’ when they did not complete their work duties or when they took time off (Seccombe, 1995; Vickers, 2001; Beatty & Joffe, 2006), and they risked being accused of dishonesty when others found out about their illness (Tagalakakis et al., 1988; Vickers, 1995 & 1997; Lublin, 2004). According to Goffman (1963), they deprived themselves of being affirmed in their experience of illness and of receiving comfort in discovering there are others who care and may provide help when needed. Vickers (2001) also found that concealment could potentially threaten their safety if they were to relapse in the work context. Without detailed information about how to respond to a health crisis, others within the workplace would not be able to assist (Vickers, 2001).

When people with chronic conditions were successful in gaining employment, a number of authors noted they often get entry level, unskilled and/or low earning positions (Klimoski & Donahue, 1997, p. 110; Vickers, 2001). The limitations imposed on a person with chronic conditions can lead to reduced hours or loss of employment (Whitehead, 2009), which, in turn, has a negative effect on earning capacity (Radley & Green, 1987; Radley, 1989; Perrin et al., 1993; Vickers, 1995; Madden, 2004). On the one hand, several authors noted that poor health and treatment regimes may directly affect their work performance (Charmaz, 1983; Brown, 1995; Seccombe, 1995; Madden, 2004; Falkenstern et al., 2005; Varekamp, Verbeek & van Dijk, 2006) as well as the desire to work (Jakobsen, 2001; Hirth, Chernew, Turenne, Pauly, Orzol, & Held, 2003). On the other hand, Radley (1989) noted that people

who are chronically sick can feel “bound within a work ethic that they can not satisfy” (p. 245).

According to Vickers (2001), people have chronic conditions do not “fit comfortably or neatly into capitalist structures” (p. 17). Vickers (1999 & 2001), who described chronic illness as a neglected workplace issue, asserted that modern organisations and the nature of work can be intolerant of illness in a number of ways. First, work systems tend to operate within the “notion of zero tolerance”, and are often “impersonal, inflexible and apply to all regardless of individual capacity” (Vickers, 2001, p. 27; Landau & Chisholm, 1995). Second, normative modes of completing work tasks, such as constant activity, speed, predictable scheduling (Vickers, 2001; Beatty & Joffe, 2006), continuity (Charmaz, 1983; Jakobsen, 2001) and deadlines can be problematic for people with chronic conditions to adhere to. Third, Vickers (1995) argued technology is designed with the assumption it will be operated by an ‘able-bodied’ person. Fourth, workers are encouraged not to be sick or to take time off and are often discriminated against when they do (Vickers, 1999; Madden, 2004).

Kleinman (1988) and Vickers (1995 & 2001) noted that once people with chronic conditions gain employment, managers without knowledge or experience of chronic illness can be ambivalent to the challenges they face. Kleinman (1988) claimed that the response from employers can range from “gross inattention to embarrassing over concern” (p. 168). Ware (1992), whose qualitative study investigated the suffering experiences of people with chronic fatigue syndrome, found that managers and colleagues trivialised their symptoms. Ware explained that this occurred because “everyone from time to time endures aches and pains, sore throat, feelings of depression, and fatigue, such complaints can be construed as minor... consequences of everyday living” rather than as symptoms of serious chronic illness (p. 350). Participants in her study repeatedly complained of being disbelieved or not taken seriously because they did not appear sick, were not pale, visibly disabled and could function normally. Vickers (2001) found that visible symptoms were “demonstrably discomforting” to some colleagues (p. 7).

Others felt marginalised by colleagues who were judgemental, treated them differently and were reluctant to associate with them (Peterson et al., 2006).

The uncertain nature of chronic conditions pose unique challenges for those diagnosed (Sidell, 1997). Falkenstern et al. (2003) revealed that, as a means to cope with all that is involved in paid employment, people with chronic illness deployed a number of coping strategies. These strategies were designed to mediate and/or control the effects of the condition to enable them to cope with and function at work. According to Lazarus and Folkman (1984) noted that coping strategies are emotion and problem-based. People who are affected by chronic conditions put pressure on themselves to convey a picture of normality to conceal their illness and to preserve their occupational identity (Goffman, 1963; Kleinman, 1988; Ware, 1992; Wellard, 1998; Dyck & Jongbloed, 2000; Vickers, 2001). They also felt expectations from management and other colleagues to appear 'capable' or 'normal' (Kleinman, 1988; Ware, 1992; Wellard, 1998; Dyck & Jongbloed, 2000).

Vickers (1999) found that, for the most part, individual coping mechanisms were deployed at work. Both Jakobsen (2001) and Madden (2008) suggested this occurred out of the absence of or limited policies and mechanisms to make it easier for workers with chronic conditions to care for their health at work. These authors also claimed that organisations often do not have adequate facilities to assist people with chronic conditions in the work context, such as wheelchair facilities, ramps, and access to special equipment. Madden (2008) viewed this as a form of discrimination. Though I did not see it in the literature, in New Zealand employers are not required by legislation to offer people with chronic conditions any form of workplace support.

There are a number of factors influencing one's ability to function in and maintain paid work. According to Baanders et al. (2002) and Beynon and Tucker (2006), these include disease duration, the episodic nature and frequency of symptoms, pain, fatigue and functional disabilities. Dyck and Jongbloed (2000) found that one's capacity to maintain paid employment increased when they had job flexibility, reduced hours, the ability to take time off and supportive employers and colleagues. Beyond the functional

limitations experienced by people with chronic conditions, Varekamp et al. (2006) identified the multiple factors as integral to maintaining employment, such as attitudes and beliefs, job and organisational characteristics, social support in the workplace and macro-economic factors. Dyck and Jongbloed (2000) also discovered that forms of workplace support were offered most when the workers had specialised skills that made them difficult to replace or had proven themselves as a valuable employee. Eakin and MacEachen (1998) and Beynon and Tucker (2006) found that work worsened their condition.

Considering the typology of chronic conditions and the impacts of the condition outlined above on one's experience of work, people with chronic conditions follow different work trajectories than non-disabled persons (Tagalakis et al., 1988). This is because they have a tendency to move in and out of the labour market when they are well and not well. Many authors noted that when the onset of chronic illness occurs early in one's career, it stifled career advancement (Vickers, 1995; Allen & Carlson, 2003; Beatty & Joffe, 2006).

### ***Other Actors and Structures***

A number of authors noted that being chronically ill placed enormous stress on the psychological, familial, social, vocational and economic aspects of a person's life (Curtin & Lubkin, 1990; Sidell, 1997; Vickers, 1997 & 2001; Brooks, 2003; Lee & Chan, 2005). As such, people affected by chronic illness were forced to restructure their daily life, self-concept, relationships and lifestyle (Radley & Green, 1987; Radley, 1989; Anderson, 1991; Sidell, 1997; Kralik, 2002). Anderson (1991) noted that this restructuring was influenced primarily by the severity of the condition and the effectiveness of treatment regimes as well as the mediating circumstances of everyday life, such as employment, transport and financial resources. The following section reviews the roles of the family, the health system, legislation regarding rights and discrimination, and the government-funded welfare system in mediating and structuring individual's lives and abilities to cope with chronic conditions and employment.

Pierret (2003) asserted that “the family undoubtedly represents the first line of affective and material support” (p. 11). The reduced capacities of those affected by chronic conditions necessitated a shift in the way roles and responsibilities were divided among family members and recasting them as caregivers (Hymovich & Hagopian, 1992; Perrin et al., 1993; Faison, Faria & Frank, 1999; Hwang, Chang, Alejandro, Osenenko, Davis, Cogswell, Srinivas & Kasimis, 2003; Pierret, 2003; Slattum & Johnson, 2004; Falkenstern et al., 2005; Whitehead, 2009). Others authors added that those with chronic conditions had to constantly negotiate and renegotiate domestic relationships and roles to match their changing limitations (Radley & Green, 1987; Perrin et al., 1993; Jakobsen, 2001; Vickers, 2001; Whitehead, 2009). According to Whitehead (2009), the capacity and ability of the family to cope with the challenges they face is strengthened by flexible work arrangements, maintenance of relationships and access to financial resources.

While family is a main source of support and can enable people with chronic conditions to be employed (Dyck & Longbloed, 2000), it can also be a source of angst and conflict (Peterson et al., 2006). The changes to family roles and responsibilities as well as additional caring roles and responsibilities can confuse relationships between parents and children, strain or enhance intimate relationships (Murphy, 2000; Whitehead, 2009) and leads to lost status in the home of the person affected by illness (Radley, 1989). Those who received care from friends and family felt guilty for needing help (Charmaz, 1983; Radley & Green, 1987) and felt indebted to those who helped them (Radley & Green, 1987).

People with chronic conditions are able to access and use elements of the health system - conventional, complementary and alternative practices and practitioners - as well as community services to assist in the maintenance of their condition and their overall wellbeing (Perrin et al., 1993; Wellard, 1998; Lee & Chan, 2005; Miskelly, 2006)<sup>7</sup>. The structure of the New Zealand health system and the broader social and political context within which it lies is

---

<sup>7</sup> For a further discussion on the terms surrounding orthodox, alternative and complementary medicine, see Miskelly (2006) and the Ministerial Advisory Committee on Complementary and Alternative Health [MACCAH] (2002 & 2004).

beyond the scope of this thesis. A comprehensive review of the historical developments and the structure of the New Zealand health system is provided by Davis and Dew (2005) and Miskelly (2009).

In relation to issues around diagnosis, what people who experience chronic symptoms appear to want is for health practitioners to attribute meaning to their symptoms, clear up the ambiguity of symptoms through a diagnosis and explanation (Parsons, 1951; Goffman, 1963; Senior & Viveash, 1998; Miskelly, 2006). However, the process of determining an accurate diagnosis and explaining symptoms can be difficult for two main reasons. First, Ware (1993) and Bury (2005) explained that some chronic conditions have complex pathologies and overlap with other types of illness which make it difficult for health practitioners to definitively diagnose. Second, Bury (2005) noted that there may not be a symptom that can act as a definitive marker. Similarly, Ware (1992) added that chronic conditions. Patients, who as the consumers of healthcare are encouraged to evaluate the medical advice offered by health practitioners, also resisted and challenged the knowledge and advice of health practitioners (Senior & Viveash, 1997). When this occurred, the patient and practitioner often entered into a process of negotiation which, in turn, resulted in the development, extension of and changes in medical knowledge (Senior & Viveash, 1997). When conventional doctors offered a diagnosis that later proved to be wrong or incomplete, Miskelly (2006) found that patients were very unforgiving. Though, participants in her study did not report the same dissatisfaction when unconventional doctors were not able to make an accurate diagnosis or later if treatment was unsuccessful (Miskelly, 2006).

When forming a diagnosis proved elusive, patients often felt a sense of betrayal, sought a second opinion from other conventional practitioners (Ware, 1992), turned to complementary and alternative health care providers or devised their own ways of managing their symptoms (Ware, 1992; Senior & Viveash, 1997; Falkenstern et al., 2005). Patients often engaged in self-diagnosis because they viewed themselves as experts in knowing their own bodies and, through their own experiences of illness and talking with friends and family about their symptoms, formed their own explanatory models for their illness (Miskelly, 2005 & 2006; Boot et al., 2008). It is not clear from

the literature, however, whether self-diagnosis occurred before or after accessing medical practitioners. According to Miskelly (2005 & 2006), when patients felt confident about diagnosing their own illness, they would choose a health practitioner or type of treatment that embodied how they wanted to deal with their illness.

In relation to issues around treatment, Miskelly (2006) found that some forms of treatment were too expensive for people to access which narrowed patient choice around healing options. She explained that this particularly true for individuals from lower socio-economic backgrounds and therefore were “more likely to opt, whether they wanted to or not, for a consultation with an orthodox practitioner” because they were able to “secure a government patient subsidy” (p. 116).

Beyond the financial capacities of the person seeking healthcare, the factors that influenced the choices people made about the elements of the conventional, complementary and alternative practices they use are contested. Miskelly (2006) argued that people chose types of medical treatments that were aligned with their beliefs about health and illness, their beliefs about intervention methods, the “levels of responsibility they want to contend with” and the experiences of people they know (p. 72). Hirth et al. (2003) held the view that treatment choices were related to whether they wanted to stay employed and also the nature of their employment<sup>8</sup>. They also found that the choice of medical treatments or changes in available treatments over time can mediate the effects of health on employment participation, wages, earnings and hours.

As previously mentioned, because of the progressive and incurable nature of chronic health conditions, the focus of treatment regimes in the biomedical approach is to minimise the impact of the condition on the body (Wellard, 1998; Falkenstern et al., 2005) and to prolong life (Anderson, 1991). Wellard (1998) claimed that because the biomedical model is designed to “reverse the course of illness and restore the patient to a ‘normal’ state of health to affect a

---

<sup>8</sup> See Currie and Madrian (1999) for a review of the interactions between the healing options and the labour market.

‘cure’”, it “fails to acknowledge a reality beyond the physical body of chronically ill people for whom cure is not attainable” (p. 49-50; Anderson, 1991). Cooper (1990) added this obscures the “care and dependency needs” of those with chronic health conditions (p. 20). And, though I did not see it in the literature, participants in this study made me aware that some types of chronic conditions do not have treatment plans or only experimental treatment plans.

The best way to achieve optimal outcomes for the patient was contested. Nolte and McKee (2008) suggested that inputs from a wide range of alternative and conventional health practices, processes and professionals need to be coordinated and “embedded within a system that promotes patient empowerment” (p. 1). Though they do not describe how and by whom it would be coordinated, nor define what they meant by empowerment, Varekamp et al. (2009) stated that an empowered patient is one who, after increasing their knowledge and skills, “define their own treatment goals and take responsibility for their medical regime” (p. 398)<sup>9</sup>. To this end, Miskelly (2006) asserted, “information is seen as the key to enabling patient autonomy and informed choice” (p. 106). Other authors, such as Falkenstern et al. (2005), argued that understanding the impact of chronic illness on the daily lives of those affected is critical to delivering individualised health care that meets their needs regardless of context. Whitehead (2009), whose research investigated the coping strategies of families affected by chronic illness, asserted that healthcare providers and treatment regimes need to consider the needs of the individual as well as the needs of the family. This is because family members, who she described as a unit of care, can be responsible for administering and/or monitoring the treatment regimes of the person affected by chronic illness.

There is a large body of literature documenting the limitations of western medical systems and practices. Dudgeon (1992), Vickers (1995), Senior and Viveash (1997) and Miskelly (2006) noted that the tools of conventional health systems, such as medicine and surgery, can be invasive, dehumanising, damaging and cause suffering. This is because they can be employed in a

---

<sup>9</sup> For more about how responsibility is attributed in health and illness, see Miskelly (2006).

manner that is not sympathetic to the psychological, psychosocial, emotional and spiritual concerns of the patient (Dudgeon, 1992; Vickers, 1995). According to Miskelly (2006), other factors contributing to increasing scepticism include:

concern about the increasing use of technology; invasive procedures; long hospital/specialist waiting lists; the lack of time given to patients during consultations at primary and secondary levels; disillusionment with orthodox medicine's ability to treat chronic conditions; plus the desire for a patient-centered approach as opposed to a doctor-centered one which often invokes ideas about medical paternalism and lack of patient autonomy (p. 185).

Furnham and Forey (1994) and Miskelly (2006) found that if patients were dissatisfied with conventional health practices, they did not always seek alternative or complementary interventions.

Patient discontent with the approach and limitations of the biomedical model is related to the increased use of complementary and alternative therapies (Furnham & Forey, 1994; White, 2000; Dew & Kirkman, 2002; Miskelly, 2006). The reasons patients include the benevolence of healing options, individualised treatment regimes, promotion of self-care and self-healing, the appeal of holistic therapies (Miskelly, 2006) and it offers them an active, rather than a passive, role in the healing process (Brooks, 1998; Miskelly, 2006).

The power of employers and managers can be offset, or enhanced, by unions and legislation<sup>10</sup>. One of the roles of government is to regulate the relationship between employers, unions and workers through legislation and other political mechanisms (Deeks & Rasmussen, 2002)<sup>11</sup>. The Employment Relations Act 2000 and its successive amendments establish the rules under which work and workplace relationships should be conducted. Other work-

---

<sup>10</sup> There was no literature relating to the way and extent to which unions can support people with chronic conditions.

<sup>11</sup> The Equal Employment Opportunity Unit was disestablished under the National Government in 2009.

related statutes, such as Health and Safety in Employment Act 1992 and The Privacy Act 1993, and more general statutes, such as The New Zealand Bill of Rights Act 1990, The Human Rights Act 1993 (overseen by the Human Rights Commission [HRC]), The New Zealand Public Health and Disability Act 2000 for physical and intellectual disabilities, Accident Compensation Corporation [ACC] for repetitive strain injury and stress caused by work are also relevant here. While these political mechanisms exist to support those involved in work, there are no specific policies that are designed for workers with chronic conditions.

In New Zealand two pieces of legislation are designed to promote and protect the basic rights and freedoms of people (HRC, 2008; Ministry of Justice [MoJ], n.d.)<sup>12</sup>. The New Zealand Bill of Rights Act 1990, in accordance with the Universal Declaration of Human Rights and the International Convention on Civil and Political Rights, set out to affirm, protect and promote human rights and fundamental freedoms, such as freedom of thought, the right to natural justice and the right to freedom from discrimination (HRC, 2008; MoJ, n.d.). These pieces of legislation seek to redress forms of disadvantage that are systemic, occur in the public sphere and cause harm. Basser and Jones (2002) asserted that this is achieved this by “locating the barriers to inclusion in the social fabric and structures of society” rather than in the individual (p. 262, as cited in O’Connell, 2009). The Human Rights Act 1993 makes it unlawful to discriminate against someone on the basis of sex, marital status, religious belief, ethical belief, colour, race, ethnic or national origins, disability, age, political opinion, employment status, family status or sexual orientation (HRC, 2008) in the following areas:

- “government or public sector activities
- employment
- access to education
- access to public places, vehicles and facilities
- provision of goods and services

---

<sup>12</sup> Comparatively, Australia has a more robust anti-discrimination framework that exists at state and federal level. For more information on this framework, see O’Connell (2009).

- provision of land, housing and accommodation
- industrial and professional associations, qualifying bodies and vocational training bodies; and
- partnerships” (MoJ, n.d., para. 6).

Peterson et al. (2006) explained that the nature of discrimination can be either direct or indirect<sup>13</sup>, however, it might not always be unlawful. Several sources explain that discrimination occurs when an individual is treated unfairly from another individual in the same or similar circumstances (Peterson et al., 2006; HRC, 2008; MoJ, n.d.). While legislation is in place to stop some forms of discrimination, Vickers (1995 & 2001) noted that legislation cannot change peoples’ perceptions. And this has implications as noted for the employment experiences of people who have chronic conditions.

O’Connell (2009) asserted that discrimination occurs most in the workplace. This view is supported by Peterson et al. (2006) who found that 34% of respondents with mental illness had been discriminated against while applying for a job and 31% reported that they had been discriminated against within a job. These findings are supported by Brown (1995), Vickers (1999 & 2001) and Madden (2004) who found that people with chronic conditions were more likely not to be offered employment and were more vulnerable to being made redundant than workers without chronic conditions.

Decisions not to hire, promote or fire people with chronic conditions are often made without regard to “social and ethical considerations” and without regard to evidence that people with chronic conditions can perform to workplace standards (Vickers, 1999, p. 124; Adams & Balfour, 1998; Allen & Carlson, 2003). Vickers (1995) added that employers use creative means to circumvent anti-discrimination laws, such as providing other reasons why they choose not to employ, promote or fire people affected by chronic illness. Other authors, noted that because these decisions are supported by the ideologies of

---

<sup>13</sup> “*Indirect discrimination* occurs when a law, rule or practice that appears to treat everyone in the same way, disproportionately disadvantages a person or group of persons because of special characteristics” (MoJ, n.d., para 6). Indirect discrimination is unlawful under the Human Rights Act 1993, “unless the person whose action or policy is done for ‘good’ reason” (MoJ, n.d., para. 7).

capitalism, individualism and rationalism, they are “packaged as ‘normal’ and ‘appropriate’” (Vickers, 1999, p. 124; Adams & Balfour, 1998). According to Vickers (2001), these decisions both negate the notion of social support and reflect the capitalist view that illness is a “bothersome human inadequacy detracting from the efficient processes of organisational life” (p. 28).

Baanders et al. (2002) noted that there are always a number of people with chronic conditions for whom any form of work is not feasible. In New Zealand, people who are unable to work for health or disability related reasons can access the sickness or invalids benefit for financial support (Peterson et al., 2006). In Australia, Vickers (1995) found that a government pension was the primary source of income for 45% of disabled people. When applying for a welfare benefit in New Zealand, people with mental illness felt they were made to feel like a bludger, were accused of feigning their illness and their symptoms trivialised (Peterson et al., 2006). When working part-time, they felt pressure to increase their hours to maintain their financial security and also in response to pressure from employers (Beynon & Tucker, 2006). In many cases, this was unsustainable because it “jeopardised their health” (Beynon & Tucker, 2006, p. 87; Eakin & MacEachen, 1998). The majority of Beynon and Tucker’s (2006) participants felt the financial benefit from engaging in full-time work was “marginal and some were either worse off or, once abatements were taken into account, working for only two to three dollars an hour” (p. 87).

In recent times, the welfare system has been targetted by the National government as an avenue through which government expenditure and welfare dependency can be decreased, and employment increased (Key, 2008; Wright, 2010; Bennett, 2011). As of May 2011, sickness and invalid beneficiaries who were assessed by a designated doctor as capable of sustaining 15 to 29 hours of employment per week are obligated to actively seek employment, be involved in work-related training or accept any offer of employment (Key, 2008; Wright, 2010; Bennett, 2011). These legislative reforms require beneficiaries to provide medical certificates four weeks and eight weeks after receiving the benefit, every 13 weeks to prove eligibility, and to undertake a compulsory review after receiving a benefit for more than 12 months (Wright,

2010; Bennett, 2011). It also requires beneficiaries to attend a budget advisory service (Key, 2008). Wright (2010) also noted that sickness and invalids benefits also lapse after one year, to which recipients must re-apply (Wright, 2010).

Those who do not fulfil their obligations under the new provisions will face a three-strike penalty and will not be eligible for further benefit advances (Key, 2008; Wright, 2010; Bennett, 2011). First, their benefit will be cut by 50% (Wright, 2010; Bennett, 2011). Second, their benefit will be suspended. Third, the benefit will be cancelled (Key, 2008; Wright, 2010; Bennett, 2011).

The sickness benefit, Bennett (2011) explained, is “designed to support people while they get well and get back to work” (para. 5). The National government argued that “long-term welfare dependency locks people into a life of limited income and limited choices” (para. 4), and that “paid work is the route to independence and well-being for most people” (para. 4). Bennett (2011) also argued that, because long-term unemployment makes it more difficult to return to work, the government needs people on benefits to return to work sooner. Key (2008) also claimed that paid employment is the “best way to reduce child poverty” (para. 4).

Critics argued that this legislative change is draconian, ideologically driven and lacked evidentiary support (Turei, 2010; Wright, 2010). Many authors claimed that embedded within this legislative change is a ‘work-first’ approach that is designed to move people from the benefit to employment (Turei, 2010; Wright, 2010). It also embodied the ideal that “any paid work, however menial and at whatever conditions and pay rates, is better than no paid work” (Turei, 2010, para. 8).

Turei (2010), who described people on sickness and invalids benefits as one of New Zealand’s most vulnerable groups, expressed concern those who are employed would receive casual and/or temporary work. She believed that the stress involved in looking for work and the threat of sanctions will cause on-going stress for this group of people. She also added that it may intensify

housing and food insecurity as well as the gap between the wealthy and the poor.

## **Chapter Two**

### **METHODOLOGY**

The three sets of research questions set out in Chapter One relate to discovering the subjective experiences of people affected by chronic conditions in employment. As mentioned, my interest in this topic arose when I became aware of the complexities experienced by a friend living and working with multiple chronic conditions. At the beginning of this research it became clear that gaining an understanding of the employment experiences of people with chronic conditions would require a qualitative approach.

Varekamp et al. (2006) noted that few studies on chronic illness and employment are qualitative and conducted from the perspective of those affected. Some qualitative studies have collected information from large numbers of research participants with a specific condition. Dyck and Jongbloed (2000), for example, examined the employment issues faced by 54 women with MS in paid employment in Canada. Informed by the socio-political model and feminist scholarship, Dyck and Jongbloed (2000) used a mixed method approach to examine the gender, identity and policy issues experienced by women with MS. This study engaged women in either full-time work or part-time work and those who were unemployed. The mixed method approach necessitated two phases to the research. In the first phase, in-depth, semi-structured interviews were conducted with each participant. In the second phase, a questionnaire informed by the themes derived from the first phase, was sent to 864 women. 553 questionnaires were returned. In this questionnaire women were asked to identify social, familial and work-related factors that enabled participants to maintain some form of paid employment.

Varekamp et al. (2009) gathered information from a large number of research participants with varied chronic conditions. Varekamp et al. used a qualitative approach to document the experiences of 64 people with varied chronic diseases who participated in a vocational rehabilitation training programme designed around the principles of empowerment. The aim of this study, which specifically sought participants who had work-related problems as a result of

their chronic condition, was to encourage participants to develop their own solutions to their workplace issues.

To study the subjective experiences of people with chronic conditions within the scope of this thesis means that fewer participants can be included. For instance, Vickers' (2001) Phd thesis titled, *Work and unseen chronic illness: Silent voices*, arose from her own experience of living and working with a chronic condition and her concerns about people with varied unseen chronic illnesses and what they endure in their working life. The empirical material was collected through two focussed, in-depth interviews with each of the ten participants. Written both from a social justice as well as an insider's perspective, Vickers used a Heideggerian hermeneutical phenomenological approach to explore the "psychic and social reality" of people with unseen chronic illness, as well as how they interpreted and responded to their experiences (p. 29).

Using a phenomenological approach, Jakobsen (2001) explored the experiences of 13 people with varied chronic diseases who, after a period of sick leave, returned to a previous job. The main focus of the study was to examine how participants responded to the changes in their employment status, the strategies deployed by participants in the process of re-employment and its impacts on their identity. The study also looked at how people retained a sense of identity and health through employment. The information, like all but one of the studies reviewed here, was obtained through in-depth interviews.

For reasons set out in the next section, I adopted a qualitative research approach to examine individuals' experiences of chronic conditions and employment issues in the context of their everyday lives. On the one hand, I wanted to explore the experiences of a group of workers who are often marginalised or excluded from paid employment. On the other hand, I wanted to highlight situations where people with chronic conditions are fully engaged in the workplace. A proposal was developed to undertake in-depth interviews

with four people with chronic conditions<sup>14</sup>. This gained ethical approval from the University of Waikato Faculty of Arts and Social Sciences Human Research Ethics Committee.

### **Qualitative Research**

This research draws on the qualitative approach to explore the subjective experiences of people with chronic conditions within the context of employment. Two in-depth, semi-structured interviews with each participant produced transcripts which were used to construct narratives aimed to capture the subjective experiences of the interviewee and to reconstruct the events of their experiences around finding and keeping work.

“Qualitative research is fundamentally not a mechanical or technical process” (Taylor & Bogdan, 1998, p. 97) but rather a process of finding out about people - their stories, experiences and perspectives - “as it is expressed in their own words” (Minichiello, Aroni, Timewell & Alexander, 1990, p. 19; Faraday & Plummer, 1997; Sarantakos, 1998; Taylor & Bogdan, 1998). Sarantakos (1998) noted that the qualitative method of inquiry recognises human beings as complex and views the social world as a product of human creation. The purpose of qualitative research, then, according to Sarantakos (1993), is to explore, understand and explain social life and to describe it as it is experienced by the participants. By getting close to the participants and becoming immersed in the details of empirical material to discover important themes, the researcher can learn about how “people make sense of the world,” the social and context determined meanings that people attribute to things within their lives and how they understand their role or place within it (Sarantakos, 1998, p. 48; Patton, 1990; Bryman, 2004; Crang & Cook, 2007). Several authors add that qualitative research gives “attention to process and change” by viewing the world as a constantly as well as “places findings in a social, historical and temporal context” (Patton, 1990, p. 47; Sarantakos, 1998; Bryman, 2004).

---

<sup>14</sup> At the time of the interviews Tony was terminally ill. Despite ‘transitioning’ into this category of ill health, it did not remove the fact that he was still ‘chronically’ ill.

This research uses an inductive approach to understanding. The inductive approach, according to Sarantakos (1998) and Bryman (2004), is a strategy for the process analysis where the findings emerge from and are drawn out to develop themes from the empirical material. I choose to take this approach because it allowed me to do justice to the complexity of participants' experiences and meanings and not impose my own preconceptions on them.

I come to this research out of my sense of injustice at how people I knew with chronic conditions struggled to find meaningful employment. I take a critical stance towards people, structures and policies that fail to support the needs of such people. But I also sought through this research project to understand more about the subjective experience of individuals whose lives are mediated and shaped by structures and forces outside of their control.

The overviews of philosophical perspectives in social science often refer to three main groupings: positivism, interpretivism, and critical perspectives (mainly Marxist and feminist but also, in the New Zealand context, some forms of Maori research), sometimes adding post-modernism (for example, Lincoln & Guba 1985; Johnson, 1989; Sarantakos, 1998; Neuman, 2006; Gray, 2009). My desire for social justice and my acknowledgement of the significance of social structures pushes me towards the critical group of perspectives. But my decision to focus on individuals' experiences of chronic conditions and to let them speak for themselves to a significant degree aligns me with interpretivist perspectives. In a sense, I am adopting a "critical interpretivist" stance, viewing the representation of individuals' everyday experiences as indirect yet powerful way to discern the operation of structures and forces in their lives. Some of the few social researchers to refer to "critical interpretivism" as such are Sugden and Tomlinson (1999) and Gratton and Jones (2010) both in sports studies, Levinson (2001) in education, and Doolin and McLeod (2005) in information systems research. They all refer to its mix of ideals and concerns taken from both the critical and interpretivist camps. They all advocate the use of qualitative methods for critical purposes, not in a structuralist way but in a way that values and validates individual lives and experiences. In broad terms, then, my aim is critical, my sensitivities are interpretivist, and my methodology is qualitative.

My critical interests have led to the choice of topic, as reflected in the formulation of my sets of research questions (the reference to interaction with the medical system and government agencies and the impact of dominant values and ideologies), and to some of the questions I raised in my interviews (for example, Themes Seven on “Broader Structures” - see Appendix). These interests also lie behind the issues of structure and power discussed in the Conclusion. My interpretivist sensitivities have led primarily to the adoption of a qualitative methodological approach with its emphasis on understanding the meaning of things to individuals in the context of their everyday lives.

### **Method of Information Collection**

This project developed out of my experience of a friend living and working with a chronic condition. This friend was happy to be involved in the research project that resulted. The three other interviewees were recruited through known contacts. Two in-depth, semi-structured interviews with each participant were designed to capture the subjective experiences of the interviewee and reconstruct events that the researcher was not a participant in (Sarantakos, 1998). All the interviews were digitally audio-recorded by the researcher.

Crang and Cook (2007) assert the subjects and sites of qualitative research are intimately related. They continue that people’s identities or parts of their identities “are immersed in and between the spaces and places of their lives” (p. 63). All participants were given the opportunity to determine where and when the interviews were undertaken. Three participants opted to conduct their interviews in their homes at a time negotiated with the researcher. These participants then took on the role of creating a comfortable interview space for me as well as themselves. One participant, who lived at the beach, created an interview space with comfortable deck chairs outside on a concreted area. The other participants chose to sit comfortably in lazy-boys in the lounge. This enabled participants to make reference to objects within their homes, determine and/or create an interview space and tend to domestic responsibilities during interview breaks (Crang & Cook, 2007). One participant asked for the interviews to be undertaken at the University of

Waikato at a time determined by them and a location organised by the researcher. I tried to arrange a comfortable office space for the participant who asked for the interviews to be conducted at the university. She chose to sit by the window.

Leibrich (1993) Taylor and Bogdan (1998) and Lightfoot (2011) asserted that an important role of the researcher is to create a space in which the participant can talk without restraint or where the participant feels like the information, thoughts and feelings will be well received. There are many ways in which I tried to achieve this during the interview process, such as, I allowed the interviewee to determine where and when the interview would take place; I allowed the research participant to determine the flow of conversation; I took a genuine interest in and was not non-judgemental of their perspectives, opinions and experiences; and I listened until the participant indicated to me that I could ask another question. Approaching the participants in this way also enabled me to respectfully prompt the participants to consider and reflect on their ideas and beliefs, and further, their contradictions, illogical conclusions and exaggerations (Taylor & Bogdan, 1998).

These interviews are however not relaxed everyday conversations between friends or acquaintances. The formalities, such as the audio recording of the conversation, taking notes during the interview and that the information will be used for a pre-determined purpose defined by the researcher, are associated with the research process and means that the interview becomes a constructed, rather than a naturally occurring, conversation. It creates a situation where the interviewer and interviewee are mindful of what they do and what they say.

### ***Structure of the Interviews***

Prior to commencing the interviews, each participant was asked to complete a form designed to collect demographic information, such as age, ethnicity, marital status and number of children, as well as contact information. Also, the interviewer took the participants through the process of informed consent and they were given an opportunity to ask questions of the researcher. Upon request, the interview guide was sent to the participants prior to the interviews. All the participants were happy to be audio-recorded.

The interview guide had two parts (see Appendix 1). In the first part of each interview I asked an open-ended question about their chronic condition and how it had influenced their experience of employment. I used this interview technique for a number of reasons. First, it situates the interviewee in the dominant role (Crang & Cook, 2007; Davies, 2008). Second, summarising the literature, Wengraf (2000) suggests it enables the interviewee to “tell their story in their own way, beginning wherever they like, for as long as they like” (p. 141; Leibrich, 1993; Hollway & Jefferson, 2000; Crang & Cook, 2007; Davies, 2008; Lightfoot, 2011). At the same time, it gave me insight into their pre-conceived ideas and feelings about the research topic and the interview process, and the type of person they wanted to convey themselves as (Rapley, 2001; Rubin & Rubin, 2005). Third, though related to the second, I felt it was important for the research participants to decide what was important and relevant rather than attempting to fit their stories into boxes that I had decided, or existing literature had determined as important and relevant (Leibrich, 1993; Hollway & Jefferson, 2000; Rubin & Rubin, 2005; Crang & Cook, 2007). This is supported by Murray and Holmes (1994) who argue that this way of asking questions provides “a window [into] the very structure of individuals’ representations... [Such] stories allow researchers... to see the interrelations of structural linkages that individuals perceive among positive and negative attributes and experiences” (p. 660; Jones, 2003; Davies, 2008). Fourth, Crang and Cook (2007) add that it reveals “the ways in which people make sense of the world and the events around them, and render them ‘true’ in their own terms, that is most revealing about how their lives are embroiled in larger social, cultural, economic and political processes” (p. 14; Mills, 1959; Davies, 2008).

During the first part of the interview, the participants spoke without interruption. I did not prompt the interviewees or make suggestions about what to talk about. When the participant indicated that they were finished - whether by a nod or verbal cue - I would either prompt them to elaborate on a point they had already made or move on to the second part of the interview.

Susan was the only participant to respond with a narrative to my initial open-ended question - what is your chronic condition and how has it influenced

your employment? This narrative, which took 72 minutes and ended with the words, “So yeah, quite a long story but there it goes”, detailed how her injury occurred, and the various ways in which and how she felt about the impacts her injury had on her working and private life. Both interviews with this participant took a total of six hours. The other three participants separated out both sides to the double barrelled question and treated them as two separate questions. The information shared in their summarised answers was neutral, factual and seemed rehearsed. Perhaps they chose to respond in this way because they knew structured questions would follow and were more comfortable with that interview format, or perhaps this reflects their preconceived notions about how the interviews would play out. In other words, these participants needed to be prompted to explore issues, and, it is important to note, until asked directly, they did not reveal to any great depth how they felt about living and working with a chronic condition.

In the second part of the interview, I prompted the interviewee, using questions that were more closed in character, to think about their experiences in relation to specific issues in which I was interested. I asked these questions if the interviewee had not mentioned these issues in the first part of the interview. These questions evolved from other research in the same field and reflected my own interests and what I thought was relevant to understanding their experiences and views. Some questions were more factual, such as – what medication do you take? What elements of the health system have you experienced? Other questions sought an opinion on a particular topic, such as – what do you think about the health system? How would you summarise the support provided by the government for people with chronic health conditions? This adds depth to and checks the issues that I thought were important that the interviewee may have overlooked. Leibrich (1993) argues that this approach to collecting information frames and limits the originality of the participants’ responses. These limits however were overcome by the open-ended questions in the first part of the interview.

During this phase of the research, the researcher followed the direction of the conversation as determined by the participant (Sarantakos, 1993). This was achieved by using the interview guide in flexible and adaptive ways, which

Rubin and Rubin (2005) term responsive interviewing. The length of the interviews was determined by how much the participant wanted to speak about the different topic areas.

To close the interview, I asked a series of questions that were designed to get the participant to talk about things that gave them joy, such as, what things do you really enjoy about your job? What are the things you do to relax? What do you consider to be the two greatest achievements in your life to date? The last question - do you have anything to add that we have not covered? - was designed to see if there were any themes or questions that we had not touched on. Three of the four participants felt that we had explored all the important terrain and mentioned congratulations for the thorough interview guide. One participant commented that “from a chronically ill person’s point of view, I think you’ve asked the right questions”. Two participants took the opportunity to add a few more thoughts. One participant added more comments around the unpredictable nature of the condition and how the transition between different stages of the condition impacted on his abilities and capacities with regard to work, his self-perception, his attitude towards his condition and his thoughts in regard to the future. Another participant reiterated the impacts of her condition on her self-perception as well as her employment, such as reduced employment choices, missed opportunities for promotion, her perception of the way in which colleagues and school management perceive her and the response of school management towards her requests for tools to enable her to cope.

Follow-up questions and questions not answered in the interviews were emailed to the participant to complete in their own time. The email responses were brief and to the point. The transcriptions, and draft and final versions of the stories were given to the participants to comment on each respective document and, importantly, to check that I have understood them and have reflected their story accurately.

At the conclusion of the interviews, one participant expressed concern about the way in which she might have portrayed herself in the interviews. Two participants gave me a hug. All the participants offered kind words and

encouragement in relation to beginning the next phase of the research. Three participants reiterated several times after the last interview to make contact at anytime for further questioning and clarification. One participant removed the swear words and, what she termed, “bad slang” from her transcript. This participant, while noting the frequency with which she would change the direction of the conversation, also made a comment around how she resisted making the transcripts grammatically correct. Another participant really enjoyed reading his transcripts and mentioned that he laughed often.

Prior to the interviews, two people expressed concern that either they did not have much or anything interesting to say. When the participants expressed these concerns, I encouraged them that their stories were worth telling. Taylor and Bogdan (1998) suggest that people are not always aware of what they know until they are questioned. They continue that the process of asking questions and probing for more information, understanding or meaning, the interviewees are encouraged to think and talk about things that they have not articulated before. I suspect that the participants who believed they did not have an interesting story or much to say may have surprised themselves by the length of the interviews. When I asked participants if they wanted to stop the interview, they would often say that they were happy to continue.

At times, the way in which the participants spoke seemed rehearsed for a particular audience or a story told many times to different audiences. Perhaps it may have reflected their preconceived notions about how the interviews would go as well as what and how they would say things. Perhaps it was a reflection of the skills acquired through other experiences. Or perhaps, this was a result of the formality brought to the interview by the audio recorder. Other times, the participants addressed me specifically. This was particularly so when they were trying to get an important point across or when they needed someone to agree with their perception of different situations. There were also times when it was clear they used the interviews to understand how they perceived and felt about different experiences.

Prior to the interviews, I became aware of and was concerned about how I might respond if participants were to get upset while revealing sensitive or

personal details about their life (Rubin & Rubin, 2005). After consulting my supervisor, I decided I would acknowledge the emotional impact by allowing the participant time to compose themselves and by allowing them to decide if they wanted to pause or stop the interview until they were ready to resume. Two of the participants became distressed while revealing sensitive information to me. One of these participants became distressed a number of times. Both participants spoke through their distress. It felt strange when they would apologise for being distressed about something that I had asked them to talk about. After the first instance of distress, I found myself wanting to avoid questions that I felt were difficult or would distress the interviewee. However, I deliberately proceeded with the questions because of their importance to the research.

Using the words of Leibrich (1993), the most difficult task as the researcher was to understand the world of the participant on their terms - "how they understood it, how they describe it, how they make sense of change within their life" - rather than my own (p. 20). Duneier (1999) believes that when a researcher is writing about people who occupy race and class position different from his or her own, "the inner meanings and logics embedded in language that is distinctive to those positions can be easily misunderstood and misrepresented if not accurately reproduced" (p. 13; Davies, 2008). This principle also applies to age, gender, race and other demarcations (Rubin & Rubin, 2005). Early in the research process I became aware that without a chronic condition of my own the meaning embedded in the language of the participants may be misunderstood. The only point of reference I could draw parallels between the participants, however weak, were self-inflicted injuries, broken bones and surgery as well as associated periods of disempowerment and recovery. As already mentioned, to ensure that I understood and reflected their story accurately, the transcriptions, and draft and final versions of the stories were given to the participants to comment on each respective document. However, this research assumes that language can convey aspects of experiences and views that are worth hearing.

## **Narratives**

Story... is an ancient and altogether human method. The human being alone among the creatures on the earth is a storytelling animal: sees the present rising out of a past, heading into a future: perceives reality in narrative form (Novak, 1975, p. 175).

Once the interview material was transcribed, it was evident that to understand the issues faced by participant in the context of work, you also had to understand how they felt when diagnosed, how they felt about their condition, their experience of the health system, their experience of other government services, how the condition influenced their relationships and other personal circumstances. To locate the employment experiences within the broader context of their lives and because I wanted to show the relationships between these mediating factors, I decided to adopt a narrative approach.

Once the interview material was transcribed, it was also evident that the participants presented themselves through stories and that those stories were deeply personal (Davies, 2008). According to Barthes (1966) “there does not exist, and never has existed, a people without narratives” (p. 14; Polkinghorne, 1988). Polkington (1988) noted that the narrative form has a central place in human life and is the “primary form by which human experience is made meaningful” (p. 1). Polkinghorne also noted that self-identity is generated through the narrative of the self. These reasons reinforced the decision to use the narrative method for (re)presenting the interview material. The stories of the people studied to be the centrepiece of this study and take up most of the thesis.

The narrative method seeks to obtain and record a detailed, biographical account of the participants’ life or an aspect of their life (Sarantakos, 1993). Biographical methods through interpretive procedures enable the researcher to analyse the “connections between events and between events and contexts” (Bryman, 2004, p. 314) as well as relate the “personal and the social” (Chamberlayne, Bornat & Wengraf, 2000, p. 2). Many authors, such as Coffey and Atkinson (1996) and Bryman (2004), argued that narrative should be viewed in terms of the functions it serves for the storyteller.

The role of the researcher, as Jones (2003) noted, shifts from active listener during the interview process to the “weaver of tales... or a narrator of narrations” in the writing up of the stories (p. 61; Bryman, 2004). Narrative writing, which Clifford (1986) described as “something made or fashioned”, aims to generate an understanding of the participants’ perceptions of particular life experiences through the (re)organising and (re)construction of a series of stories to create another narrative (p. 6; Davies, 2008).

### ***Principles Used in the Construction of the Narratives***

My approach to the construction of participants’ narratives follows closely the way that Lightfoot (2011) approached the interviews with 11 people who had “come out” in the Anglican Church in New Zealand. For each of the participants, I took the two transcripts (primary material) and some secondary material and turned them into narratives. There were four steps to the construction of each narrative. Step one required the researcher to read the two transcripts and secondary material of each participant in order to identify and understand their chronic condition or conditions, their employment issues, and other challenges the participant deemed as significant. Step two involved deciding what to include and exclude each individual story from the primary and secondary material. This step involved fleshing out what was important for the reader to understand about the subjective experience of each participant in relation to living and working with one or more chronic conditions as well as the issues and challenges they faced, how they felt about, understood and coped with them.

Step three involved the chronological sequencing the events as narrated by the interviewee (Jones, 2003). To distinguish the voice of the researcher from the voice of the participants, an italicised text has been used for the researcher’s voice (Davies, 2008). To distinguish secondary material from the researchers’ voice and the primary material, a different font has been used. Step four involved ‘tightening up’ each individual story to make it flow without losing the essence and the messiness of the stories. It must be noted that this is an iterative, rather than, a linear process so it took four months to produce the four stories that form the centrepiece of the thesis (Bryman, 2004; Crang &

Cook, 2005). Analysis is a complex process of reading, re-reading, referring to literature, writing, re-writing and discussion, in order to come to realise and portray the nature and complexity of the interview material (Crang & Cook, 2005).

Prior to each story, I have written an introduction (Lightfoot, 2011). It is designed to introduce each participant to the reader by placing them in context, providing information such as age, marital status, number of children, class and other identifiers, and by offering a glimpse into the personality of the interview subject (Lightfoot, 2011). The introduction also cues the reader into sensitive issues, how the participants felt about different parts of the research process and some of my reflections on the interview process.

Different textual devices, such as interpretive commentary and keying the reader in to non-verbal behaviour, have been utilised to frame and add depth to the narratives as well as provide additional information to the reader (Davies, 2008). The symbol, ‘...’, indicates breaks between and the fusion of different extracts taken from different parts of the primary and secondary material.

### ***Reality Resists Analysis: Some Reflections on the Tensions and Challenges Faced During the Construction of Narratives***

My job in this research was to make sense of the subjective experiences of people with chronic conditions and to then bundle it up and retell it. When it comes to doing research, there is a constant push and pull between wanting to be a good researcher but also wanting treat their information and their stories as sacred. This battle is best summed up by Davies (2008): “How the researcher was to be present in the text? How do I ensure the integrity and meaning embedded within and behind the words was present in the stories, without imposing my own narrative form during their construction?” (p. 23). During the construction of each narrative, I experienced some tensions and challenges which are discussed below. When story elements collide and tensions occurred, chronology formed the overriding logic for the narratives.

The first tension I experienced related to language and meaning. Because I wanted to (re)present the stories of the participants I felt restricted to their language and the way that they have expressed their stories. However, at times, I had to ‘smooth over’ their words for the purpose of maintaining the chronological order and flow of the stories as well as the meaning embedded in the words. In other words, I treated the meanings embedded in words, rather than the words, as sacred. Where possible, I used the same kinds of words used by the participant in other parts of the interviews. Thus, I have edited the words of the participants, though without imposing my own, in a way that preserves the meanings embedded within the words (Davies, 2008).

The second tension pertained to decontextualisation. I wanted the (re)presentation of each participant’s stories to reflect how and the sequence in which the participant talked about their issues and challenges in relation to living and working with a chronic condition (Jones, 2003). However, in the same breath participants would reflect on years of events and emotions, and skip across the past, present and the future very quickly and often without finishing sentences. This way of talking about their issues indicates a link in relation to either how they feel about the different issues, how they understand them, the proximity of events, the time in which they occurred, the significance they have in the context of their lives and/or the impact the issues have had on their lives. I tried to allow the relationships between themes to structure the text as much as possible. However, while I have, at times, separated the issues and presented them in isolation for the purpose of telling a linear narrative, I acknowledge that the issues overlap, interrelate and are influenced by each other in complex ways (Crang & Cook, 2007). Further, it must be noted that within the context of people’s lives, they are not that separable.

Another tension related to how, over both interviews, the participants often talked about the same issues in different ways, would emphasise different things and used different points of reference to show how they understood the different issues they faced. I would then have to make decisions around which extract fit best into the structure of the story or added depth to the stories.

One participant allowed me to use information from stories she had written 15 years prior. While she agreed for those stories to be used, she also wanted the (re)presentation of her story in this thesis to reflect her at the time of the research. This meant that I had to be careful about the way in which I used the information provided. Thus, the information extracted from those stories was primarily for chronological purposes.

In general, when a researcher chooses to include and exclude empirical material, decisions are made about what is relevant and important and therefore what is irrelevant and unimportant. But this is an unavoidable tension as well. To ensure that I accurately re-presented their subjective experience of living and working with a chronic condition, each participant was asked to check their narratives. When the researcher and the participant wanted different things, the researcher went with what the participants wanted.

### **Thematic Analysis**

Thematic analysis takes place with I answer the three sets of research questions in the Conclusion. Boyatis (1998) described thematic analysis as “a way of seeing”, as well as a way of organising and presenting empirical material (p. 1). Individual pieces of collected empirical material are compared for the purpose of deriving themes and relationships between themes. A theme is a pattern found in the empirical material that organises and describes aspects of a phenomenon. Themes, which can be identified at manifest or latent levels, can be generated from the empirical material or from theory or existing research. Bryman (2004) suggested this type of analysis assists the researcher to interpret and analyse what research participants have to say. Coffey and Atkinson (1996) viewed thematic analysis as a way of relating collected material to the researchers’ ideas about the material.

After qualitative information is gathered and the process of thematic analysis is applied, the researcher leverages a process of coding to categorise, identify and label patterns, similarities and differences in the collected material (Huberman & Miles, 1994; Coffey & Atkinson, 1996; Boyatis, 1998; Hollway & Jefferson, 2000; Marks & Yardley, 2004). These themes that are

formed as a result of this process are informed by the empirical material itself, the findings of prior research, the principles that underpin the research and the questions the research seeks to answer (Huberman & Miles, 1994; Coffey & Atkinson, 1996; Boyatis, 1998; Hollway & Jefferson, 2000; Marks & Yardley, 2004). Many authors add that this process also enables the researcher to make sense of phenomena or aspects of phenomena, to construct perceptions of reality (Huberman & Miles, 1994; Hollway & Jefferson, 2000; Marks & Yardley, 2004), examine differences along the lines of gender, class, or other groupings as well as confirm and challenge existing literature (Boyatis, 1998; Marks & Yardley, 2004). It must be noted that thematic analysis is a cyclical, as opposed to a linear, process. Analysis is a complex process of reading, re-reading, referring to the literature, writing, re-writing and discussion in order to come to realise and portray the nature and complexity of participants' realities.

The next chapter and the Conclusion contain the constructed narratives of my four interviewees and summaries of their employment experiences and personal circumstances. It is here that I also return to the three sets of research questions and discuss how the narratives provide answers to those questions. In this section, the themes derived during the process of analysis are discussed with reference to existing literature. Given the large number of themes that were derived from the empirical material, I was very selective about which themes to include, and therefore exclude.

## Chapter Three

### NARRATIVES

#### Pauline: Introduction

“It makes me interesting. It gives you a whole other depth... It’s never taken away my voice.”

Pauline came to know about my research through a mutual friend and contacted me by email. Without any further information, she was eager to be involved in the research as a participant. At the bottom of the email it read, “Big Hugs from a real woman who is fabulous at 40!!” In that email, Pauline informed me of her condition, Systemic Lupus Erythematosus, and that she had experienced two major flares during the course of her illness.

Pauline, who currently resides with her mother, requested that I meet her before the interviews commenced. Early in our conversation, Pauline asked me why I wanted to do a research project on the employment issues of people with chronic conditions and then proceeded to tell a summarised version of her story.

Pauline sent me stories she had written about her experience of having a chronic condition. Her stories reveal how she feels about her chronic condition and how it impacts her life and thus feature in my writing up of her story below. As mentioned, the stories Pauline wrote assume a different font in her narrative. After an initial reading of the transcriptions, Pauline asked if she could use them to write more stories. She said, “I see it as a creative writing opportunity.”

One of Pauline’s ongoing challenges is to managing her energy levels and fatigue. Thus she wanted to treat the interviews like an exercise. She monitored her energy levels during the interview. She would indicate to me when she was starting to get tired and how much more time she “would be good for.” I made sure that I assisted her by frequently checking in with her about her how she was doing and how much longer she would like to continue.

Sometimes Pauline uses unusual words or uses words in creative ways. I have retained these to give a sense of how she expresses herself. Pauline described herself as a ‘creative accountant’ and has worked in this profession for 21 years. She currently has two part-time jobs. She is doing project based work for a farm improvement company as well as doing two to three hours a week of administrative work for the small business of a close friend.

When I asked why she agreed to be involved in the research, she replied:

“Ummmm... I suppose because it’s an honour and privilege to be able to share your story and I was struck by how much of a poignant question you are asking - What are the impacts of a chronic condition on a person’s work life? It’s such a real and ongoing challenge to find a sense of balance, work satisfaction and feeling of contribution when you have to come to terms with physical challenges. Given my experience of this firsthand and currently being in the thick of my limitations, I was very touched that someone wanted to understand the issue and research it. So best of luck, Lynley. I look forward to reading the results.”

### **PAULINE’S STORY**

My family had just returned to New Zealand after living in England for a year when... I developed a butterfly rash on my face. A dermatologist took blood tests and determined it was Systemic Lupus Erythematosus, or Lupus for short. I was diagnosed when I was nine. I know a lot of people go through painstaking years of strange symptoms not knowing what it is. I was lucky to have that determined quite quickly. I remember the regular six monthly visits to the specialist at Waikato hospital. He was a world class expert on Lupus. He has since died... Mum said it was like her child was diagnosed with a cancer because you don’t know anything about it and suddenly there’s this big thing that your child has got. My Mum sourced out information and support groups and that was good for her. She went through a process of “what is this thing called Lupus?”

Lupus is an autoimmune condition that during a lifetime can come in and out of remission and different levels of activity. It’s a connective tissue disease

and a form of Rheumatoid Arthritis. It can affect multiple systems and organs in your body including blood, skin and joints. Also, any part of your body can become inflamed. Basically, my immune system is busy attacking me, instead of attacking bugs.

I have a quandary of symptoms. The rash continues to be one of my major symptoms from the condition. Fatigue is huge now. I've experienced unexplained, severe fevers with no obvious or known infection. My skin on my hands is completely thinned out. I have a level of Reynaud's which is a lack of circulation in the fingers so the skin is very fragile. I'm a singer and I play the guitar, but for the last couple years I haven't been able to play my guitar because of my fingers. I was never fanatical about my guitar but it enabled me to sing the songs that I'd written, and now I can't sing the songs that I've written. The thing about Lupus is something will come up, you tell the doctor and then find out it's another aspect of Lupus. I've been through depression as a result of Lupus. They say depression can be a symptom of Lupus, but I also think that it was a result of the stuff I was dealing with in relation to the condition and the affect it had in my life. I go through stages where it's hard to walk which is caused by inflammation points in my feet. I forget the different symptoms because they are varied. Fatigue and my skin rashes would be the heavy duty stuff at the moment.

I remember the impacts to me as a child. One of the symptoms of Lupus is you're allergic to the sun. That's a really big feature, especially if you've got rashes as a symptom. My grandmother wanted to buy me an umbrella for play time at school. For a ten year old to have an umbrella, I wasn't gonna have a bar of that. I remember when I was 12, having to wear a hat in the playground and getting teased and bullied by a girl. Those are the big things I remember as a child.

I was living independently at 19. I went to Auckland and went flatting. I was then in charge of my own health and my Mum would say that that was the beginning of the demise of me and the build up to a major flare at 23. She would say that because... aside from a full-time job and studying part-time to finish my diploma, I had a whole other world that began after five o'clock... I

was right into my sports at that time. I used to do dragon boating, touch rugby, swimming and outrigger. I was untouchable and thriving on it all... I became quite a fitness freak. I was going at it full-throttle. Exercise was wonderful. There is a question around whether that is good or bad for me, the fact that I go full throttle on it. The comment has always been that I'm a go getter and I operate at 110%. My friends say, "You do more than a person without any chronic condition." It's the way I am. I've got to do this, got to do that, this is on, that is on... I'm very boom, boom, boom.

*Up until the age of 22, Pauline had only experienced some of the symptoms associated with Lupus, such as rashes on her face, forearms and hands, joint pain and arthritic pain. In her stories Pauline describes laughing and crying with her Nana during a period of severe arthritic pain, saying she knew what it was like to be 80. At the age of 22 Pauline started to plan an overseas experience with six friends to London. A story written by Pauline described the period leading up to their departure.*

It was the stressful and exciting 12-month build up to my first overseas experience that became my demise. I was very excited about leaving and stubbornly continued to ignore signs of rash on my face. They began as brown birthmarks on my forehead and, over that year, became red and fiery. There is one small blessing in suddenly being given a 'mask' to wear. For the first time in 13 years, I had a visual aide to explain my illness. In the past, if I wasn't feeling well I would try to explain 'Lupus', but no one ever had anything to see. It's very natural for people to need something to look at. It gives them immediate understanding that something's really wrong, and you get an instant supportive 'buy in'.

I was determined to leave New Zealand alongside my six friends on our planned departure date. My condition had never before got the better of my plans and I wasn't about to let it start now. I learnt a lot about myself during those first few weeks in London. I learnt that I liked a sense of security and a sense of knowing what I was going to do next. The freedom of no job and no home would be heaven to some but for me the combination of coping with an active chronic condition and London's grey smoggy face was a match made in hell. London may have a population of millions but

you can feel very alone. It took all my remaining healthy energy to fight the urge to hop on a plane home.

I was on a phone call home one night, telling a friend how London was affecting me when she asked:

“Have you bought a guitar yet?”

“No not yet. I will when I get settled.”

“But it will be too late then, go and buy one now and write some music.”

Seeing some logic in her encouragement, I went and bought a guitar. Connecting with my music was the trigger point to open the floodgate to all the feelings of control I was doing so well to dam up. The biggest of those was pride.

*The following is a story about how Pauline feels about music.*

My life is celebrated with music. My music has always been a big part of my world. The term “Creative Accountant” certainly applies when your brain works in perfect balance between the left and the right. I wouldn’t have it any other way, although I still prefer to elaborate on the musical career when people ask what I do. Each year there seems to be some new phase to the opportunity music gives me. My love of performing in front of people has never left me. No matter how scary the mask got, the voice was always in perfect pitch. When I get up on stage to sing I sometimes close my eyes to the images of the song’s lyrics. If the balance is right I can give myself goosebumps all over my body. That’s when it’s magic! That’s when you know you’re in the best place you can be! The very essence of who you are and what you have to say will never change in times of struggle and challenge.

I applied for jobs while I was there and was getting opportunities for interviews but I didn’t like London. I didn’t like the smog and the concept of having to travel a couple of hours on the tube to work didn’t enthrall me... At 23, the butterfly rash really came back in full force. My face was a red, hot

fireball and I had a bright red rash over all the sun exposed parts of my hands and forearms. I also lost a lot of hair during that time... I had to come home.

*The following is a story written by Pauline about when her hair, which she described as a badge of honour, declined.*

Accepting I had nothing to be vain about anymore was the easy part. There was no professional intervention, no coercing or counseling to get me back 'out there'. At times it gets the better of me but never for long.

Soon after I got a wig, a good friend insisted on a 'girls' night out to which she encouraged me to wear my wig. I was weary of this concept right from the beginning but with her support I decided it was a safe social opportunity to take it for a test drive. We had a great night and I received some good comments from friends who found it easy to ignore the obvious change in my appearance. For brief moments during the night I lost myself in the fantasy that someone who did not know me could be fooled into being attracted to this 'normal' looking young woman. But it was my very own reality check that finally brought me to the decision of not wanting to wear the wig again. If you haven't already figured it out let me explain it to you.

I was 23 at the time, 'girls' nights out usually involve some sort of anticipation in dancing around the opposite sex, literally and from across the room. Now that part's fine and innocent enough, but what if during such an occasion, whilst under the disguise of said wig, I was to actually like someone and worse still what if they liked me? At some point in the future the wig must be removed and the 'real' me be presented. I couldn't see how I could reconcile that fairly, for me, or any unsuspecting male. So this young single 23 year old thought it better to stay bald and single than hopeful and embarrassed!

I remember when my hair first became long and strong enough to have a perm once again. My boss at the time, who had employed me in a state of balding disarray; came into my office the morning after I had been to the hairdresser. He couldn't hide his surprise and compliments at the change in my appearance. It was like he was seeing me for the first time as feminine woman. Like I was actually pretty! His reaction was great and I remember it to this day.

These days the remains of the physical devastation are faint and represent no more of a scar than a freckle or a hormonal discoloration. I notice now, that in explaining Lupus to people my hand automatically and involuntarily points to my face in referral. I assume they must be able to see the scars just as they were in the peak of their fury. It is my future challenge to let go of that explanation 'crutch' and stop lifting my hand to my face. My face doesn't have to tell my story anymore.

*Pauline drew on her attitude as a way of coping with the vicissitudes of symptoms.*

There is no room for vanity with this condition. I'm supposed to wear a hat, have sun tan lotion on and cover up. I've got to wear good walking shoes so you can't get nice shoes. You can't do this and you can't do that. There's so much that you can't be vain about. You don't have the luxury. If you get yourself all worked up about it then you wouldn't function in society, it could be the demise of you. For me, I can't care even about one spot on my face because I've got to focus on getting on with it. These days my friends don't notice the rash because once I open my mouth the personality comes out and the rash takes a back seat. Now and again I think twice. I've got a bit of hair loss and some nice and exciting bald patches. I see myself in the mirror and I think, "Oh my god, you look terrible." It's sort of like a reminder. My theory is that if what I see in the mirror is okay for me then that sets my spirit up for how I'm feeling that day... I often say, "Today is a good day, this is a good week." You just deal with each thing one at a time, that's all you can do. So you just celebrate the fact that you are in a good space right there, and then you dig in deep and deal with it when the crappy stuff starts to happen.

*The onset of her first major flare provided some motivation for Pauline to seek out a support group for the first time. Pauline hoped to learn more about Lupus and gain some positive tools to help her create and/or retain a sense of normalcy in her life. In a story she wrote about her experience of the support group, she recalls noticing that she was the youngest at the meeting and the only one with visible symptoms. She continued:*

I said, "I'm going swimming" and they said, "Oh but doesn't the chlorine affect your skin?" I said, "No. Even if it did, I wouldn't care because I feel strong and powerful when I'm in the pool and I love it." "But shouldn't you be worried about having good skin so you can meet a man who will look after you in your old age with Lupus?" I thought, "If that's the attitude, then I don't have to go there"... I certainly don't need a man to look after me with Lupus. I do a very fine job of that myself... Because of that experience, I haven't chosen or felt the need to go back to one. These days, I would probably be a really good person to start a support group because there isn't one in Hamilton and I would frame it in a different way. But I haven't really got the energy.

*Since the interviews, Pauline has organised the Hamilton Gathering of Lupus Patients. Pauline deliberately did not use the label 'support group' and asserted that the gatherings are not designed to be a "soap box" for the people who attend. Rather the purpose of the gatherings is to make connections with other people who face similar circumstances. In an email conversation she made some further comments: "The women were all very relieved to meet each other and we are all very dynamic young women getting on with living our lives whilst dealing with a whole bunch of challenges every day. Meeting people that 'understand' what you're going through in the smallest of ways certainly gives you a lift." She also suggested that being able to organise these gatherings reflected improvements in her health.*

*After a premature return from her overseas experience, Pauline was told by her doctors not to work for three months. Pauline admitted that she lasted only two months. In the following extracts Pauline describes her thoughts around her experience of returning to work.*

Other than stopping work for a couple months and coming back from my overseas experience as a result of not being well, my first major flare didn't have a major impact. It changed the course of my plan of my life at that time but at least I could come back into work and then spend the next ten years coming back into full remission as a result of that... Sure I'd had a major flare and sure I hadn't been working for two months but I was pretty naive at that point and thought that certainly that wasn't going to stop me. I was ready to

go back to work and so off I did... And bless my bosses' cotton socks, I interviewed looking like something the cat had dragged in with this red and fiery face. But the rash was the only hindrance at that point. I was lucky. They chose me because I'd had four years good experience. So I got a full-time job at the hospital as a management accountant.

At 32, I went across to Melbourne. For a while, the chronic condition didn't feature. I used to quote myself as being disgustingly healthy... The position I held there was also referred to as a management accountant... It was a maternity contract for ten months. They liked me and, when the maternity contract finished, they made the position permanent. I had a bit more seniority there. I was managing staff and that was okay.

*However, two years after arriving in Melbourne Pauline started to struggle with fatigue.*

I used to take my blow up lillo bed into the office and have a sleep at lunchtime. I used to have a 'V' drink everyday to get through the afternoon because I don't drink coffee. Then, of course, I would come home and have a sleep straight away after work. That was me trying to fight my way through maintaining a full-time permanent role. They had a 48-52 week leave programme where people could sort of buy an extra four weeks leave and you could use it when you wanted. I took it off for health reasons. I spread it over six months and I used to have one day off a fortnight. It became a stepping stone to formally deciding to reduce down to four days a week. That was one of the first workplace support options I took up.

*At the age of 35, Pauline entered into what she considered as her second major flare up.*

I worked in Melbourne for three years full-time but, for the last six months, I was in effect part-time. I was very sick at that point. I had moved up to a whole new level of drugs that I hadn't had to experience before. Eventually I had to give in to the reality of my health situation and I went on sick leave without pay, with the thinking that I would eventually go back. But, of course, things got worse and there was no chance of me going back to live and work

in Melbourne on my own. I loved the big bustling city - I thrived on it and I certainly rose to the occasion -but it took a level of unconscious stress to live that life. It's a different type of stress when you are living with bigger populations and major public transport systems. I didn't have a car. Life just takes a little bit more of an effort. The question is – does the stress involved in living on my own overseas in a big city and doing the 110 things that I like to do, then become my demise to have to come home again because of my illness?

*For the second time, Pauline was forced to return home to New Zealand as a result of her condition. Pauline has not returned to full-time employment and has been living in a supportive environment with her Mother.*

Being on a sickness benefit full-time is fraught with stigma. Oh the joy of queuing up at the ol' work and income and explaining to someone, who looks at you and thinks you are totally physically capable, that you need to go on the sickness benefit. You experience a bit of prejudice, or you perceive that you do anyway. They try to be very professional but I feel like I've got to look sicker than I do because, apart from the rashes, people can't physically see the signs of my condition. I worked part-time and I used to ring up and declare the money that I was earning on top of the sickness benefit. They would make that tone, as if to say, "Gosh you're on a high hourly rate." I was coming from an accounting background so the work I was doing was giving me a high rate. So you experience prejudice as if it was only low socio-economic people that would ever need to be on a benefit... Then there are everybody's perceptions, or your assumption of their perceptions, about why you are not working.

The money you get from the sickness benefit is dissolved up very bloody quickly and you end up using some of your savings, so you watch your savings diminish. Then there is the huge long-term worry because you realise that your earning capacity and your ability to save long-term has reduced so much. It is a bit scary really. You can't think about it on a day to day basis. It's too overwhelming.

The role I first went back into was an accountant role for a smallish company. That was, supposedly, 25 hours a week. There was a lot of pressure with that position because it was sole charge. It was all a bit much because I had only just returned to work and I had autonomy over the finances of the entire business and the staff. There was too much accountability for me. Stress and Lupus don't mix so well. It was a full-time role and I gave them that feedback. After I left, they recruited a full-time person... I didn't work at all for the next year.

Now, being 40, I've had Lupus for 30 odd years... I'm back living at home in Hamilton with my mother... I think Hamilton is good for me. It's a low stress town to live in traffic wise, all those things... I've never been married, never had children. I often think about how my life would be without Lupus in any sense. It feels quite foreign to me now, the concept of not having it in any sense... If my condition were to disappear, in theory I should not miss it at all. But after 30 years, it becomes part of you. It takes time to grieve what you lose when the condition gets serious so I imagine it would also take time to realise that I don't have to compensate for it and explain it anymore, to myself or anyone else... To a degree, it makes me interesting and it gives me a whole other depth in regard to the challenges that have been put in front of me.

You realise that you are different in the sense that I've had all this exposure and experience of the medical system and doctors. They are all a big part of my life. I'm very positive about the health system. When you need it and when you've got a chronic condition like this and you are drawing on the health systems services a lot, it's excellent. I get wonderful support from the Waikato Hospital Rheumatology Clinic which I'm attached to. They make sure I've got access to all the services I need, such as occupational therapy, podiatry and dental services. I see the podiatrist because my feet and toe nails are subject to infection and blisters. I can't rave about it enough really. When the system needs to kick in, it kicks in.

I'm on a swag of ugly drugs. The drugs are helping maintain my certain level of quality of life, although I'm always on a mission to reduce the drugs. I'm starting to experience the long-term side effects of long-term drug use. I take

blood pressure medication because one of the drugs I was on increased my blood pressure. I've had surgery to remove cataracts in both eyes because of the steroids. Long-term steroid use is never a good thing for your body. Your bones become prone to osteoporosis. I get a bone density test every couple of years and so far it's been good. Getting cataracts was an eye opener. When someone is considering going on steroids, the doctors say, "These are all the side effects that you could be exposed to." Now I've got to that stage where I realise that these sorts of things do start to happen to you... If a new drug is being introduced and they are suggesting I go on it, I will source information from websites and other patients' stories.

So the girls at the pharmacy know me well. I'll see them once a month to get my different medications. They ring me up and ask, "Where are you at this month Pauline with your medication? What levels do you want?" I have my drugs put into a blister pack to make life easy because I'm stuffed if I'm gonna have ten bottles sitting on the kitchen bench. That's a wonderful service. They are very good because I am very demanding. They know me and they know that I know my body and the impacts of these drugs. So I'm allowed to change my steroids at the rate that I choose to change them because I have such a relationship with my specialist. There are some drugs that I won't play with without consultation. It's important when you've got a condition like this that you have a good relationship with your pharmacist because you are there so much, you are demanding and they know that you know what you are talking about. And even at your GP [general practitioner] clinic and the nurse there. It's got to be a fluid relationship. I know how to work with the system as far as getting the results of my blood tests, what I'm entitled to, what I'm not entitled to and all those sorts of things.

*At this point in the interview, I asked Pauline why she had relative control over her medication.*

I'd say 15 years ago. It's always been there to a degree. I've become more and more confident and independent about it and the doctors are confident to work with me like that because they don't have the answers. There's no perfect rule book on how to treat and manage Lupus. It's a mystery to them a

lot of the time so it's probably a great gift to them that I am astute and can help be a partner in my treatment plan. I will often think to myself, "Gosh. How do people cope if they are too sick, haven't got their wits about them, or if they are not that way inclined or organised to manage their own medication?"

Over a period of 30 years, I've experienced two major flares, one at 23 and one from 35 to 40. I still consider myself to be in a flare because of the level of drugs that I'm on, the symptoms that I'm experiencing and the fact that I see my doctor far too much [Pauline laughed]. Life is good if you don't see your specialist for a couple of years or once a year... I've gone through this really severe patch in the last five years and I now have a new found understanding of the power of the condition... I am aware I have been forced to 'live' my disease. It defines so much more of the framework of my life these days... I think when people ask me how I am, they are really asking me because they know the ups and downs of the last five years. I can't get away from that at the moment because it influences my lifestyle so much. In the past, my lifestyle was pretty much the same as other people in the sense that I worked full-time, I would come home and I'd go to the supermarket. But now, my lifestyle is so much more different due to this condition that it gives a point of reference for people all the bloody time. One could get annoyed at the fact that it's become such a big topic of conversation of late... It becomes a boring conversation after a while. It's too overwhelming. I'd rather talk about music or some other interesting thing.

*At the time of the interviews, Pauline worked part-time in a management accounting position in an organisation she had previously worked for. She also worked in an administrative capacity two to three hours a week for a friend who has a small human resources consultancy business. This work is undertaken at home via the internet.*

I was patting myself on the back even this morning... I'm blessed that they came to me with project work. I said, "Yes, I'm available but under these conditions." The condition had to be totally out on the table. I told them that I hadn't worked for a year and a half, that my confidence completely went into

the gutter because I hadn't been working, that I could now only work part-time... and that I may need to have time off for different medical appointments or treatments... My knowledge of the organisation, and my skills and experience helped to outweigh the fact that I could only do 20 hours a week... We came to an agreement together... So I'm managing my time totally independently. To me, that's just amazing really and I'm very, very lucky to have that at this stage. I'm lucky in the sense that it is with an organisation who knows me and who knows the value that I can give. They also fully know my situation with the condition. So it's a win win situation. I feel like I'm adding value to them and they are certainly giving me a great opportunity to be able to do that. It is an all encompassing workplace support because they are providing me with an employment opportunity that marries up with the limitations I have.

In the last two years the condition has been so active, so my work colleagues are much more aware of what I live with, than they ever have been before. It provides an explanation of why I'm only working shorter hours and my strange comings and goings.

*Pauline's job was not a permanent position and was due to end three months after the interviews.*

If I'm starting to feel a bit blue about the fact that my job could be coming to an end, it's good for me to talk about how I'm feeling about that. I know that it's important to process that myself, as far as how does that feel, and what does that mean. I have learnt to frame it in a different way and look at it as an opportunity to have some time off and refocus the energy into other activities, such as exercise, that could help my health overall.

*In a conversation after the interviews took place, Pauline mentioned that her employer extended her contract. In the following extracts, she elaborates on the impacts her chronic condition has had on her employment and career choices.*

Part of me is aware that for the benefit of my overall health, I shouldn't be working at all. At the moment, I don't have the capacity to do much physical

activity. I'm very inactive and it's putting me at risk of all sorts of exciting things like cardiovascular risk and blood pressure problems. I'm not giving myself the best chance to reach a level of remission. If I was to give up work for six months and really give my body an opportunity to get the exercise it needs, it may enable to get to a real state of remission. That then may enable me to work even more than 20 hours a week. That's the catch 22 and the ongoing, vicious cycle of how to manage it.

One of my ongoing challenges is to take time out and give 'me' a break. You have to get good at doing this when you're dealing with a stress-induced condition, more important when you personally have a tendency to over-do it... Fatigue is the biggest hindrance for me as far as working goes. It's about conserving energy for the next thing... I talk about managing the spoons and I only have so many spoons of energy in a day... In my working life, I've always worked very hard and I produce at quite a fast rate. That probably doesn't help my stress levels but you know it's just the way I am. It would be nice to be able to have the energy to be able to give so much more of you, of your skills and experience to the organisation. I think I'm passed that feeling of guilty for leaving work at one o'clock.

When opportunities for permanent roles come up through my organisation, I think, "Yeah. I would like to apply for that." But I can't commit to all that's involved in a permanent role... In the last five years I haven't been in permanent full-time employment and, for a period of that time, I haven't been able to work at all.

To me, it's a success that I can work 20 hours at the moment, not that I really have a choice these days. I don't have the physical capacity to do much more than that. But I suppose one could push themselves and that could really do some damage... Even though I only work part-time, for me that's full-time because it means I'm managing my condition, my medical regime, my energy levels on a full-time basis and fitting in normal errands. It all takes effort which makes it feel like full-time work... To have a condition like this, it's a lot of work. It's like me thinking to myself as I wrote in my diary this morning, "I've got to have a blood test on Monday before I see my specialist

the next Monday so that he's got the results so that we can have a decent conversation." There is a lot of coordination and management going on which is another reason why it becomes exhausting. Then the concept of full-time work [becomes difficult] when you are managing all these issues you've got going on.

If my current job does come to an end, and if I really want to work, I know can only work under my limitations, and it is bloody hard work to find that work. The concern for me about where to next and how I might replace those 20 hours, is pretty scary stuff... I thought I was lucky that I'd developed a career that didn't require me to be out in the sun. If I was then to think about what other jobs I could do, that is really scary because I can't do anything outside, I can't do anything that requires me to stand up. I used to think about if I had to be a checkout operator at Pak 'n' Save, they sit and they stand. I used to really worry about that and dealing with my symptoms, especially the fatigue. I used to feel I was completely unemployable and there's always the risk of that thinking again.

My condition has affected me in the sense that now I can't formally apply for a job. If I was to go into an organisation and stand up with a contingent of applicants, the potential employer is going to look at me and go, "She has this condition." You have got to tick a box... I have to legally declare that I have a condition so I feel I have to then declare that I may need time off and it could come with some parameters. Will I be discriminated against based on those limitations? If they've got a person with the same skills and experience up against me and I come with those limitations then they are naturally going to choose the other person... In the past, my condition hasn't been an issue, but now I've got to admit that it affects my life. I feel a lot less marketable these days. That's the only sadness for me, is that you lose confidence in your abilities. There's no way you are going to stand up against other fit and healthy people who are offering to work 20 hours a week and can commit fully to an organisation.

It's affected how high a level of ambition I could have in my career. I got over the aspiration to be a manager of a big team of people because I can't

cope with that level of stress. I don't apply for those jobs. For me, the seniority of my job is the autonomy in my job as a management accountant. I don't have that ambition anymore.

When the disease is non-active and it's not causing you dramas, it is pretty uneventful... But when it starts affecting your ability and capacity to work, it then reduces your income level which then reduces your quality of life or perceived quality of life in financial terms. It's a bit of a bugger. It's quite a grieving process when you first realise that you can't do what you used to do. The biggest thing is the grieving process of letting go of what you used to do and the assumption you're ever gonna be able to do that again or earn that kind of money again... It took me two good years to get over the grief of losing my 'normal' life... and to come to terms with the grief of actually formally resigning... I also used to own a home and I sold it... Aside from the grief and the financial loss, you lose the social interaction and the reason to get up in the morning and that sense of structure and the chit chat that goes on at morning teas... I buy into the idea that people should work hard and be productive and so, of course, that perception takes a toll when you physically can't be productive. You waste energy working through the grief and letting go of what you 'should' be doing and of course worrying about what people think.

So that becomes the ultimate day dream really is whether I can get back to that level of independence [Pauline gets upset]. I could probably deal with the work thing but that's the annoying feature about whether that will ever become real again. I call it "the state of the nation." My current "state of the nation" feels very, to a degree, abnormal. I accept that it's my "state of the nation", it's my story, it's my quality of life but it's different to other peoples. My friends are very supportive but you just realise you are a bit different in that regard... It's feeling further and further and further a distance idea that I could get back to full-time work and to full remission. Maybe that will happen. I don't know.

When you've lost your capacity to work it is pretty damn scary. You don't have your health, so you can't actually get that money in. As a single person,

it's even scarier again... Given my state of health for the last five years I have needed someone to be in my corner. That has been my mother both emotionally and financially. I still pay my way week to week but I do think I would find it difficult, financially, to live on my own. Besides the fact that I couldn't afford to financially, I couldn't afford to emotionally as well. I think I need someone around me that's aware of me... If I didn't have the infrastructure of being able to lean on my Mum then I am not sure how I would cope. I worry about my future when my Mother passes away and I will have to reassess how I will manage being responsible for myself. I would have to lean on someone in some context. I don't know. It's scary.

In the last five years, I've been connected to the Lupus Trust of NZ. It is just a small body of people who have an association with each other. They put a newsletter out and have a seminar once a year... They asked me to speak at the annual seminar about the International Congress of Lupus that I've just been to. So now it's me giving the information back. I'm gonna talk about my experience at the patient programme there. I will talk about my impressions, the other patients I met and some of the new drug regimes that they are excited about, none of them indicating a cure. One of my impressions was a lot of them don't work. Their doctors will tell them that their job is to exercise and rest and they talk about the importance of exercise. And that there are other things that you need to be doing to ensure that you stay healthy so that you don't put yourself at risk of more extreme symptoms and things.

After going to this congress and seeing people in wheelchairs and seeing people that are 95% blind and seeing people that are dealing with some heavy duty shit, I realise that there are still other depths I can go to with regard to my condition. God forbid, my kidneys could get more seriously involved and, god forbid, I could need a kidney transplant and, god forbid, I could have a heart attack. I've learnt that women my age 35-45 with Lupus are 50% more likely to have a heart attack. So that's a whole new awareness for me, new information for me and it makes me realise that I now need to get really serious about my cardiovascular risk.

One could say that going to an international congress was the ultimate of information gathering. That's the other thing, if anything I'm always happy to give information. I'd rather people ask me about my condition than assume I've got eczema or something like that because the rash is not itchy, dry and scaly. If anything, I think it would be awful to have eczema. I can deal with having Lupus but I wouldn't like that [Pauline laughed].

## **Susan: Introduction**

“Schools just don’t allow for people to be disabled. Isn’t that ridiculous?” ...  
“If I knew then what I know now, I would have gone on ACC and stayed off work.”

Susan, who is 52 and has two adult children, has been a secondary school teacher for 28 years. She has worked at two schools during the course of her injury and is currently a full-time math teacher at a private secondary school in the Bay of Plenty.

Susan’s injury is a mystery. After many years of self-research and consulting both conventional and unconventional health professionals, Susan believes her injury, which she sustained in August 2005, has two parts to it. It is believed she has chronic regional pain syndrome as well as an oedema in the navicular bone of her foot. An oedema is an abnormal build up and retention of fluid [swelling] in one or more cavities of the body (Encyclopaedia Britannica, n.d.). Susan is the only known person in New Zealand to have this condition.

When I arrived at her house to carry out the interviews, Susan immediately drew my attention to a folder containing all her health related documents, information and correspondence she had had with various health professionals and government agencies. The folder was thick and organised.

Susan responded to my initial open-ended question - What is your chronic condition and how has it influenced your employment? - with a 72 minute story of how her injury occurred and the various ways in which her injury impacted on her private and working life. In particular, Susan spoke at length about how she navigated social politics at work, her experience of the health system and the difficulties she experienced trying to manage her condition and treatment regime as well as full-time employment. She did not disclose the name of her condition until asked directly in the 97th minute of the interview. Both interviews took three hours.

Susan was the only participant in this study to frequently experienced forms of discrimination, alienation and ostracization from colleagues within the workplace. This formed a major part of the reconstruction of her illness narrative. As a result, her way of (re)telling and (re)constructing the events of the past, present and her thoughts around the future were qualitatively different to those of the other participants. Susan found it difficult to read her transcriptions and narrative. She said, “It is still a bit horrible and long and hard to deal with.”

Susan explains her reasons for agreeing to be involved in the research.

“Because I hope it can help anyone else to know that negative outcomes can happen to people like me who have a high level of education, are proactive and can be assertive about their health. I was completely undermined and helpless when I landed in depression as a result of pain and unrealistic expectations from my workplace. I had always been a high achiever. Plus, I can be anonymous [Susan smiled].”

### **SUSAN’S STORY**

I had an injury at eight am in August, 2005. I was going up the stairs to my classroom and I got a sharp stabbing pain in my foot. After I hopped and stumbled to my classroom, my foot seemed to get a bit better. I got up to answer a question and I swore. I’ve never sworn at school before. The entire class went silent. They were shocked and so was I. It was like somebody had taken a machete and chopped it through my foot.

I went over to the school medical centre and they said, “I’m sorry, the doctors can’t see you. The doctors are here to treat students, not staff.” They did offer to take me back in a wheelchair but it seemed pointless because I had to go up stairs. They gave me some panadol and sent me back to my room. I told the students that I couldn’t really teach them but they could come to me for help. They were really understanding about that and carried on with their work. I would have gone home right then but I had a trainee teacher. The school would have left him alone with my classes and I had some badly behaved classes.

The next day, I stayed home and couldn't even get a cup of tea. I had to hop places. It was miserable because the house was cold and I couldn't light the fire or look after it. I couldn't get around on the crutches because every time I used them my neck felt really bad... That day I went to the medical centre and had x-rays but they couldn't explain it. My foot was swelled up like a balloon and quite painful to touch in certain spots. They put it in an open cast to make the swelling go down.

I returned in two weeks and they still couldn't explain it. At that point, they sent me off to my first orthopaedic specialist. He wasn't sure what was in there but wanted to open it up and see. But that was going to involve 15 weeks of recovery and I thought that was a long-time and I didn't want to be off work. Little did I know [said with sarcasm].

During the summer holidays, I did all the things the doctors told me to do. I rested, had my foot up, put ice packs on it, took anti-inflammatories and my foot still wasn't better. During that time, I also had an MRI [Magnetic Resonance Imaging] and a cat scan and they found nothing. I was starting to get worried... I shifted orthopaedic specialists to get a further opinion. He did some further investigating but when he couldn't find anything, he told me there was nothing wrong, that I needed to get it stronger and there was nothing more he could do.

I had done everything I knew to sustain what I had as a life prior to the injury but I couldn't cope. I was spiralling down because I was in pain and not sleeping. And I didn't feel like I could find help from anywhere else because I had been through the experts. I was still seeing my osteopath who was concerned but didn't really want to jump in. I went to the orthotics lab at the hospital where they tried to make me an orthotic and that didn't work. By March [seven months later], I'd crashed. When you are going through physical pain and it doesn't seem like anything is wrong, people think you are a head case. I was trying to act like I wasn't having any pain because I didn't feel like there was a right to have any pain. Why do you have pain when there is nothing wrong? [Said with insistence].

I went back to the general practitioner and she gave me nurofen... without advice or caution. I used it constantly and damaged my stomach lining... Now that's not good in a classroom because you can't be burping and carrying on [Susan laughed]. So I was trying to take Mylanta and other bits and pieces to calm it down. The GP put me down to have a gastroscopy and colonoscopy which, of course, when you get on the waiting system took three years. I've avoided nurofen since then. I try not to take other pain medication just in case it has the same consequences. I must have taken more than the recommended dose but I was desperate. It seemed to be the one thing that stopped the pain and I was trying to get to sleep. I was a bit ignorant about how to take my medication correctly because I've never really taken stuff before. The pain, I think, makes you more susceptible to taking whatever drugs are handy. I used to keep packets of the stuff beside the bed. By 2006, I had to alter my lifestyle and not teach so much so that I could recover.

*In a conversation after the interviews, Susan mentioned that the damage to her stomach lining was still an issue for her and that she was experimenting with some new medication to help her with this issue.*

Prior to school starting in 2006, I spoke to my head of department [HOD] and said, "I would like a room downstairs." He agreed to look into it. I didn't realise how bad my injury would be going back to work full-time. When I went back to school, I found I was still in an upstairs room and I also had a low ability maths class of 36. That class usually ran at 20 students max because those students are slightly special needs and have behaviour problems as well. I was well-known for coping well with those students but I was no longer coping with my life, let alone with special needs students in quantities of 36 [Susan laughed]. I went back to my HOD and said, "I really need that downstairs room and can we do something about this class of 36?"... He said, "We are going to have to see how you go with that class" which means, "We can't do anything about that now. I've made a decision. Live with it"... I remember coming home sobbing. Later on, he denied I'd asked for a downstairs room. I just felt betrayed because I desperately needed it.

I coped until March 2006 but I was exhausted beyond belief. I found myself sobbing on my friend. I'm so grateful I never did that in front of the students. Students are still at that age where if you smile at a male colleague, they believe you are having an affair. It's all shortland street to them. You want to keep some sort of semblance. She said, "Go home. This needs to get sorted out without you." My husband came and got me. On the way home, I got a phone message saying that the class of 36 would be split but I was beyond it by then. I decided to have two weeks off on stress leave. When I went back to work, I knew I couldn't go back to full on work so they put me on light duties. I was angry that my injury had been made so much worse by the way the school had treated me.

I went about applying for my next job very nervously. I've never really had to apply for a job. They were always offered to me and then suddenly I was dicey about even applying for one... During the application process, I went and met with the school management and I mentioned that I had a foot injury. I had to say to them, which was incredibly embarrassing, that I was having difficulty at my school and that I wasn't confident of some of the references I might get by phone. I had got a couple of people on side who were aware of the difficulties I was having and I used them as references. I just couldn't risk it.

In July 2006, ACC got involved. Once they knew I was on light duties, they wanted me to get some help from medical professionals. That was good because I needed some support from the psychologist desperately by then. I was just feeling like the world was against me and I didn't want to do anything... I knew I had to get out of that school. I was dead scared of losing my job and ACC because I wanted to shift schools. And when you've got a terrible reputation, you can't always shift schools because they don't want you... I still wanted to work because we had children going to university, extra money was going towards my medical regime and we have a couple of rental properties. We wouldn't have survived financially had I been off work.

ACC brought in an occupational therapist who was completely useless. She told me that my students could carry my stuff from place to place but students

are in a hurry to get from class to class. Even the ones that really, really liked me would have found that irksome. You can ruin your relationships with students and it's all about the relationships when you are working in a school because you are dealing with people all time. She also suggested that I move around the room on a chair with wheels. She suggested that I wait till everybody was in their classrooms before I moved from class to class to avoid the blockage of students in the corridors. It would have been impractical as I would arrive ten minutes late to every class... My husband cracked up laughing when I told him what she suggested and so did other staff members... It's one of the best jokes I can tell.

*The occupational therapist visited Susan during the school holidays to assist with her work-related issues. At that time, Susan insisted her suggestions were inappropriate and asked the occupational therapist to return when the school holidays had ended. When the occupational therapist visited a second time during normal school hours, she admitted her previous suggestions were not going to assist Susan.*

After ACC got involved, the school finally let me have a downstairs room that no one else wanted. I didn't care at that stage, at least it was downstairs and I could get to it relatively quickly. It was a storage room but I fixed it up. Another colleague that was bringing shelving in for me was told by the HOD not to do so. He then said to the HOD, "Well, you tell her because I don't think that's fair." The HOD stood back then. I ended up getting that support. You just love those people when you are in need and they come to your aid.

Other department members were ready to go into battle. I felt like I had divided the staff because some were just so angry about what they see happening to you... I did have some people on side but they weren't people of power... I feel guilty that my husband can't look at some of these people in the same way because of the threats and unpleasantness they created for me. And yet he needs to deal cooperatively in a team with them. It takes a lot for him to do that. He has to keep that hidden.

In the last term of 2006, the school management came to me and said, “Right, you are on light duties so we want you to be a relief teacher. You can be in this classroom, that classroom and do all sorts of things.” And I said, “I can’t do that. I’m not mobile. I need the classes to come to me.” And they went, “No. I think you are just going to have to do it”... Some people would have just said, “No” but I didn’t have that luxury because I was injured and couldn’t make a fuss.

Close to that time, one of the science teachers broke her leg and, because I didn’t want to be a relief teacher, they told me I could take up her science class. I’m a maths teacher. I hadn’t taught science. I asked the science department if they had any teaching resources so I could pick it up and teach it. They didn’t have anything. That would involve hours of preparation at night and I was so tired, I couldn’t do it... The school management chose me because they thought it would be the simplest solution for them and maybe they drink with these other people so they don’t want to upset that private relationship. So that makes me a difficult customer because I’m a bit more resistant.

I contacted an organisation that could provide me with support because I was in an incredibly vulnerable position. But that didn’t turn out to be useful. By then [November 2006] I had announced that I was leaving and going to another school in the following year. One of the deputy principals said, “Do you want me to ring them and tell them you are being difficult?”

*Susan made some general comments about her experience of working at her first school.*

My first school was a tough environment and there were difficult social politics... They did give me a mobility park that was almost as far away as the other parks to my room. Other than that, I did not receive any other form of workplace support or any consideration unless it was begrudgingly. I was expected to be incredibly grateful for anything I got... I felt like I had to get mean to get what I needed. I did not want to be going to the PPTA to get them

worked up over things. It's not the kind of waves I want to create in the workplace but I had too.

A lot of colleagues were horrified that I wasn't made second in charge because they knew my talents and skills. Though, I couldn't take another thing on my plate and I was more miserable than they knew. You put on a brave front when you are at school.

I still suspect that there was an element of trying to drive me out because I was being asked to do stuff that was beyond me... It was almost constructive dismissal... The principal made it very hard for me to do my job. I think that's why he saw it completely red because he's previously had a constructive dismissal suit against him. I also know that, at that stage, I was slightly toxic because I was so miserable. But I was still good in the classroom. I was discriminated against by certain people. It was very blatant and mean... I had to move schools to get away from that.

If that hadn't happened, I probably would have stayed there because I loved teaching those students. Students would arrive in my class and be happy to be there. You can't buy that.

When I went to my second school in 2007, I hoped I would be better. However, every time you start in a new school, you are treated like a new teacher. The students have no respect for you and you have to earn it... Also the HOD, who subsequently left, said I would have my own room and it would be close to the staffroom but it didn't happen. It was very difficult because they put me in 14 different rooms.

In 2007 I had a pretty miserable year. I was taking medication and taking days off. But it was becoming more often because my foot would be very so... I got to a stage where I didn't really want to be here anymore. Prior to any of this, I would have never thought that I could have thought like that ever... I had already given up any sense of trying to act cool and taken a wheelie bag to school to carry around my teaching resources. The students found it funny. But there are limits, I fought against taking tablets and then you just decide that the consequences are not worth it.

I told my HOD that I was stressed and under pressure and the foot was still a problem. I asked whether it would be possible to have one room for one of my classes I taught and the kind man reluctantly let me have it... He decided he would be mobile. That made a huge difference to managing the behaviour of my students because I was prepared a lot better... I felt like I owed my dues though and paid him off with chocolate, a bottle of wine and other things. I was that desperate to be in a room.

Then there was a situation where I wasn't timetabled to be in the computer room but I needed it for an assessment. I approached the assistant principal and he suggested that my one class be split between three rooms and I would walk between all three rooms to check on the students. The HOD had already asked the computer teachers if I could have some time in the computer room and one female teacher, who was giving me a hard time, said, "No." The students tend to know when they aren't getting a fair deal and complained. The deputy principal came to me to ask me what happened. I told him I wasn't happy with the solution provided by the assistant principal. In a later conversation, the assistant principal denied that it was his idea to have split classes. He got his knickers in a knot about that and circulated a nasty email. He hadn't just targeted me so I don't need to take it quite so personally. But I was upset because he made out that I had been extremely difficult... In the end, I decided I would teach the computer class at eight am.

*While Susan taught her classes in the computer room, the assistant principal decided to use her normal teaching room to teach his classes. Once Susan completed the computer assessment, the assistant principal decided he wanted to keep her room, which meant Susan had to teach in multiple rooms again.*

In 2008 I went back to the specialist and they decided to give me another MRI. They widened the scope a bit and picked up a problem on the edge of my foot. They didn't tell me what the problem was but he said he was afraid this bone would disintegrate if I was walking or weight bearing for any length of time... He also thought it may have been caused by walking a lot... I felt relief because they'd finally found something and I had a chance that they could try and fix it. It felt like a long battle. I also felt satisfied that I had been

proved right and that I wasn't making it up just to be difficult. They discovered that I have an oedema in the navicular and that was three years after the initial injury. We then tried to get a second opinion in Auckland at another orthopaedic specialist, just to see if he could clarify issues. He basically put it down to chronic regional pain syndrome as the primary issue and the oedema in the navicular as a secondary issue. But no one could tell me why I got it. It's quite unsatisfying because I like to know how things happen so I can avoid them [Susan smiled].

Normally, people with chronic regional pain syndrome have got nothing structurally wrong, they've just got pain because your brain misinterprets it. My way of thinking of it, and I'm not sure it's accurate, but it's like people who get hayfever. There is nothing really wrong with them but their body reacts to something. My body reacts to this foot. The nerves, the specialists believe, are set up to be hypersensitive and things that shouldn't cause pain, cause pain. My theory is that when you tolerate pain so much, it builds up to a point where it is trying to make you realise something is not right so it just keeps upping the pain until it can't switch off. I also have a structural problem in that the navicular won't heal. The two issues are slightly unrelated, one gets dealt with by the gabapentin and the other one is something that I just need to be careful about. So there's a mixture of trying to get fit and work past the pain but then not over doing things because I could upset the structural part. The medical professionals are all confused and so am I. The specialist said I am a medical mystery and that is not reassuring. I'd rather have a label, even a bad label. I also don't know if it was something that was inherent when I was a child that was always set to go wrong or if it came from the accident I had in my early twenties where I broke it in three places.

After that appointment, I asked the assistant principal if I could have a room so I didn't have to walk so much. He didn't appreciate that. I felt devastated. Eventually, we ended up in the principal's office to discuss it... I took my husband in because it's too easy to breakdown and that's not what they are looking for as a teacher. My husband is useless [Susan laughed]. He is far too kind and thinks of their perspective and doesn't always put across my point of view... The principal said to me, "You are not doing any sporting or

extracurricular stuff so you need to contribute in some way.” I mean standing up was my extracurricular at that point because I still had this problem. The assistant principal said I was a burden to the school because I wasn’t able to be mobile, that I was difficult and I didn’t have a great relationship with certain staff members. I was quite negative then because I was very much in pain. The amount of reserves, the strength and drugs I would have needed to be chipper and bubbly about that sort of stuff would have been huge.

I was so tired of hearing I was being difficult. I was managing as best I could and trying to say, “This is the limit for me” without being heard. So I said to the principal, “My specialist is saying I need to take some time off, maybe I should do that now?” He agreed but thought I would be back the week after on crutches. I said to them, “If you want me to rest, I have to be at home.” I really liked the students but I couldn’t do it. I wouldn’t do justice to myself.

*In 2008, Susan took a term off work. During this time she attended a second rehabilitation programme paid for by ACC and a pilates course to gain strength.*

A person who I would have counted as a friend and thought I was a really good teacher said, “Maybe you shouldn’t be teaching if you need time off.” Needing time off was just a big no. It was tolerated rather than approved of and not even tolerated in some cases.

I went into plaster and that was the first time I’d been out of pain for two and a half years. It was wonderful. But when I came out of plaster, I don’t know whether the pain was worse or whether I had just got used to not having the pain, but it was just intolerable. It was not a good way to be in a staffroom or classroom or at home. I hadn’t taken anything for the pain. The pain nurse at the hospital suggested he write to my doctor and try some different drugs to deal with it. So we tried a few different medications and then finally hit on Gabapentin. Within about four days, I could walk without being stabbed and then it became a little further and a little further. I kept touching wood because I couldn’t believe that the pain had gone... I have a love, hate

relationship with medication. I hate taking it but I love that it takes away the pain.

The beginning of 2009 was a bit like a high. I'd done a little bit of a brain turn around because I'd started listening to *The Secret*, that positive stuff. I had a brilliant year because the assistant principal went on study leave. That's when the female colleague who had given me a hard time, came to value that I was being a help rather than a hindrance. They must have been feeding off each other. The tantrums, the tension and the animosity stopped. Other colleagues, who had been firm associates and drinking buddies of the assistant principal, realised I wasn't a problem because we had a smooth year.

*Susan made some general comments about her experience of working at her second school.*

I think I have worked pretty hard to be valued at my second school. But every time there is a new change of management it puts that under threat because it's not something that is written in stone. It just tends to be something that you get in response to being there.

I was discriminated against in that I lost a promotion at my second school. They wanted a second in charge and I pretty much do that role but it went to another male teacher because he was taking sport. I was quite shocked because I didn't think it could actually happen. Other colleagues in the department wanted me to get that job because they knew I would do a good job, I have the experience and I've put a lot of resources into the school. I didn't get that promotion because I'm not taking sport, I had taken time off and they saw me as a burden.

Some colleagues picked up on what was going on and they would come to me to say they think it was unfair and unjust. It's nice to be acknowledged, but it's hard for me to hear people say that sometimes because I don't want to be worked up about it. They want me to get upset and thump desks and I can't do that. I feel like there are a certain number of cards I can play and I have to pick my battles. So getting upset about something that I probably can't change [is not worth it].

*In the following extracts, Susan summarises how she feels about working as a teacher while dealing with a chronic injury.*

Schools just don't allow for people to be disabled. Isn't that ridiculous? I think they move heaven and earth to make sure that students with disabilities have the best possible outcome. They don't do anything for teachers, quite the reverse. Like I said, I hobbled across to the medical facility and they said they didn't treat staff. They've since changed that policy but that's the kind of policy you get in schools.

I'm quite angry that schools can get away with this sort of stuff and don't have a human resources person in there. Considering we are dealing with people all the time and over 100 people work in a school, a human resources person might be useful. I don't know. I would like to experience one because the occupational therapists, that are good, see it from the perspective of their client in terms of what they can and can't do... If I know I'm going to need to ask for something specific, I will try and see if an occupational therapist can come in because the second they are in the room, the school take it more seriously. They are fantastic because they say, "That's an unrealistic expectation for somebody in Susan's position." And I think, "Thank you" [said with feeling].

*In a casual conversation with Susan and her husband after the second interview, we discussed the need for and the role a human resource manager would have in schools. They informed me that, currently, it is assumed that the principal is to play a human resources role within schools. However, they contended that, because principals have a large workload and lack a neutral position, they are not suitable for such a role.*

The trouble is school management and the timetabler have control over my destiny. Schools are like a small business. It is totally dependent on the whim of the person above you as to what you get. If you get a top class that is working hard, then you don't need to very much teaching. You just keep them stimulated and life is sweet as. If you have bottom level classes where all the kids want to do is argue, they've probably had a bad time at home, and they

are not feeling great about themselves and would like to share that. It's an awful lot of work just to get some harmony. You don't have an even job every day. Now who decides what jobs you get? The people above you... School management and the timetabler often give themselves the nice classes.

People who have power are the ones that I had difficulty with. They resent having to deal with the frailties of people. Also, the principal is not in the classroom anymore and have forgotten the pressure of being in constant demand and don't understand it. Parents expect you to be perfect. It's very stressful... Teaching is full on. It is like playing a rugby match every period... One of the principals I had was one of those people who believed in suffering for sufferings sake. As a religious aspect, he sort of felt that you needed to be walking on stumps before [incomplete sentence] and to continue was a valuable contribution. My belief these days is, that is stupid. If the car flicks on the warning light, would it be best to get it fixed then or wait till it's a burning heap on the side of the road?

A lot of stuff that happened was not helpful rather than actual discrimination. It's just the way that things run in a school. People are not aware of what limitations you have and they don't want to be aware of it. Some people do not want to have someone with any disability in the workplace... So there's an awful lot of, "Oh you can't do such and such," which is like a negative press... I sometimes have to approach people very cap in hand to say that I can't do certain things. It's quite difficult... On top of that, it can make for a hostile environment when I have to ask for stuff because there are limited resources anyway.

I feel very judged by people who have nothing wrong with them. They think you might be a malingerer. I feel like people dismiss me out of hand in the same way that people with disabilities can be dismissed out of hand. Often my husband said it was my fault because I look like I'm okay, but I'm faking it... If I knew then what I know now, I would have gone on ACC and stayed off work.

*Susan spoke at length about managing full-time work and her medical regime at school.*

Schools and the medical system do not fit each other. Both are busy places and think you will accommodate them. I tried but I could not make those two things mesh... One day, I had to cancel an appointment for an infusion. I was promised it would be in the holidays so I didn't have to take any time off work. I was trying my hardest to look like a responsible and reliable teacher who was not going to be difficult. The hospital rings and tells me I need to go in for an infusion during teaching. I told them the notice was too short. The secretary at the orthopaedic specialists told me off. I was amazed how quickly I went back to a negative head space. I was completely vulnerable. I sobbed and sobbed because I just couldn't believe that my trying to fit in and not be difficult with the school meant that I looked like I was being difficult with the medical profession. One does not understand the other. Also, if you cancel an appointment, it can be six weeks till you get another appointment and a lot of stuff can happen in six weeks.

I had to run off to about four medical appointments a week after school for about six weeks. Often the department would call an impromptu meeting. I would say, "I can't" and they would respond with a grumpy tone. If my ailment had been a growth on my head they probably would have understood but because it was an injured foot that I was trying not to limp on, it was very much a roll the eyes and moaning situation... If I have an appointment with the specialist or at the hospital, I take a day off now because you can wait for three hours in the waiting room and you cannot be late back to school because they can get tetchy.

The health system is open between 8am, if you are lucky, and 4.30pm and I start work at 7.45am and I don't get home till 5.30pm. Whenever you ring them you get an answer phone telling you they will call you back. I can't sit in this room waiting for a phone call back when I'm at school. If you are working, you really are disadvantaged because they can't access you and you can't access them. I've played phone ping pong with so many medical people. They promise stuff and then you never hear back from them.

*Susan spoke at length about the challenge of maintaining the private and public realms of her life.*

When I was first injured and in a lot of pain, I was so incredibly tired. I didn't realise that until I was out of pain. I couldn't focus, particularly when I wasn't sleeping. It was a supreme effort to be teaching and there was so much to focus on, like juggling between the physio, acupuncture, homeopath, specialist, pain clinic people, general doctor and my children.

My children went through the worst times with me. Just before they left home, I was at my lowest and most needy. I look back on that now with huge regret because often at home I would be sitting on the couch with my foot up and resting. I didn't have a life. I had teaching and nothing else and sometimes it was fairly miserable... My husband has pretty much taken over the grocery shopping, the washing and just about everything. A lot of the domestic work I have slowly taken back, but I can tell when I'm reaching my limits both in tiredness and in achiness and it just means tools down and rest. At home, I can do that. At school, I bluff it out... I forget the burden that I am on my family. Thankfully they don't remind me every day. In fact they are helpful and understanding but I don't want to use up too much good will. A lot of marriages break up when this sort of thing happens to one of them so I'm lucky in a lot of ways.

*In the extracts below, Susan talks about the impacts of her condition on her employment choices.*

The one thing you lose is your potential because there are caps put on it. I get regarded as less valuable because I can't be mobile or do extracurricular stuff. I get regarded as a liability because I need a room base and some specialist equipment. I don't have the aspiration that I used to have... I no longer look for positions of responsibility or promotions. I had to give that one up. Prior to my injury, they were generally being offered to me and I can do that work. But having the title and pay means it is expected and I'm much happier not doing it. It frustrates me that my husband is still thinking of moving on up and I can't. But I have let that go.

My husband and I want to teach overseas. We were going to teach overseas but it does not look like it will be possible because I cannot rely on this dodgy foot. I would be a new teacher and it would be asking too much of me so it's better not to try. I'm really worried about the fact that I'm getting older and things might happen that might prevent us going later and they don't really want to employ you if you are 70. We aimed at that well before this injury. Teachers get paid much better overseas so it was part of our retirement plan. We teach in a highly sort after area but I'm a limitation.

I have a lack of certainty. What happens if it happens again? I wouldn't stay teaching even though I get so much value out of it. I don't know many jobs where you get stopped in the middle of a shopping mall by a student saying, "Thank you so much. I passed my exams because of your help." I still get positive feedback from my first school... I couldn't work at any of the other schools in the area because, as a campus, they are too big and I would have to walk too far. And I don't know if I can do that... At the moment, I'm coping with full-time teaching. I'd love to be much more full at it but I don't have the energy.

*In the following extracts, Susan describes how she feels about her injury and the impacts it has had.*

My injury does dominate my life. I don't have much joy and fun outside of school because I'm often exhausted from being at school... It is intrusive. It takes over. It's the elephant in the room. It's constantly there. It's in the back of my mind when I'm asked to do something or an opportunity pops up... I have to think twice. Instead of having that freedom of being able to say, "Yeah let's do that" because I don't know how I'm going to be on that day. I'm not fun to know when I'm in pain. It brings out the grouchy... I look at everything from a perspective of the limitation – can I do that or can't I? ... It's heartbreaking. I feel like I've lost so much... I'm hugely more fearful because I'm just aware of how vulnerable we all are. I'm not quite as empowered as I used to be, in fact totally disempowered and sometimes, disenfranchised.

*In the following extracts, Susan summarises how she feels about the various forms of government support she has received for her injury.*

Government assistance is hard to come by and short lived. It's really good when you are getting it but... you have to go through so much to get it... and then it's over. They often have six week programmes, but how is that meant to deal with a three year long problem?... I noticed they only really get serious about offering you anything if you have to give up work. That's disappointing because I sometimes feel like they think that you are asking for more than what you need and maybe they are used to people doing that. For me, it was the other way around. I would ask for assistance when I couldn't bare it anymore and then you've got a three month wait... I'm sure other people must have had that experience because often when you are legitimately ill, you can't tell. I felt that from ACC. They think you are malingering until they meet you.

I get the strong feeling, and I have be warned by medical people, that they are trying to look very hard for how injuries can be hereditary and how they can get out of it so I keep a documentation. Other people, who I've spoken to with injuries, do it too. It's like having a common relationship, you have an instant bond with people who have their own chronic injuries. You swap stories and they say, "For goodness sake, keep track of your interactions with your employer and with ACC." So I'm suspicious of them.

I think medical professionals are great but they have limitations. They are just people and they can't always help. It's annoying when they have access to things but don't mention it. It's like they need a tick box sheet. But I think it's also timing, I wasn't really ready to hear it before that. I kept thinking it would get better.

I love my general practitioner. She didn't know what was going on but she tried her hardest to get me some solutions. Gabapentin is quite new so I don't know if it was around when I was first injured. I do trust her even though she knew about the Gabapentin and didn't offer that. She waited for the directions from the orthopaedic specialist. She was caring and concerned. She phones

me at night when she knows I am available. I feel like she's gone the extra mile... I know that my orthopaedic specialist is wonderful because everyone in the country tells me so. But he is busy and, if he can't get in there with a scalpel and fix it, he is frustrated. I had to break down in his office for him to realise how important this is for me... You need somebody who is a holistic carer because the orthopaedic specialist was not interested in what my injury was doing to my head space until I burst into tears in his office.

Health professionals don't seem to talk to each other... I kept getting shifted to other carers. Every time you go to somebody else, they haven't read your notes, you have to repeat the whole story again and again, and as you have just heard, it's a really long story. It feels like Murphy's law that that particular doctor has left now so I've got another one or that particular nurse is no longer here and so I've got another one and ok. I feel like if I'm new with somebody and they think I'm exaggerating and I'm not.

*Below, Susan summarises her experience of and relationship with medication.*

I'm a chemist so I kind of know what I need to ask the pharmacists. That is possibly why I'm a little bit more reluctant to take medication as well because everything has consequences. So, generally, they understand that I'm not stupid and they will give me what I need... You are only supposed to get two weeks of medication at a time but I pretend I'm going overseas because my limited mobility makes it hard for me to get there. So they give me four weeks of medication.

Medication is one of those things where you just try everything until something works and it's hard to have faith in stuff that doesn't work. It can't be predicted to work. I really, really need it to work. I want to be able to rely on it. When I went on the gabapentin, that was a major, significant change around. So the pain clinic guy that suggested it, I trust more than any other medical professional... He said there's even a better pain medication that I could take but I would have to pay for it. Well I would pay for anything. Things start to look cheap once you've been in pain for a while. I mean these shoes retail at \$260. I won't wait for a sale. I wear them every day and that's

cheap and, again, I can only do that because I'm working. If I wasn't working, I couldn't afford the injury related stuff that I need.

*Up until the end of 2008, Susan had relied on conventional practices and medicine. The lack of positive outcomes prompted her to seek out alternative practices to help with her injury.*

I have since got a naturopath... and I have discovered that acupuncture was brilliant for me... I hadn't tried these alternative methods before because I was waiting for the conventional medicine to do its stuff... I got feeling back in the top of my foot for the first time in three years when I had one needle. It sent this huge jolt threw my body. It was like an electric shock. I nearly kicked the person doing the acupuncture and I couldn't stop hiccupping and burping after that [Susan laughed]. It was like this huge tension relief. Later on that day, I could feel my foot. It had been tingly. The pain can build up to a point where I can feel it getting tense and tight and acupuncture can just relax everything again. It's weird but it can make me see better. I have no idea why but everything gets brighter and clearer and easier to see. Strange. I can feel when they hit the right spot. It feels like when somebody is pushing on a tight muscle.

I am champing at the bit to be able to go walking again. I'm thinking I'm going to try that once it gets more into spring because I will have a go and see if it works and if it doesn't cause me major side effects I'm going to do that. The thought of being able to go walking again makes me hopeful but I'm dead scared it will be taken away... Now that I'm out of pain much more there is a lot of fear that it will come back but, more than that, I think it's the medications which they say I'll get used to. They are still upping my dosage. So, fingers crossed [Susan smiled].

## **Pearl: Introduction**

“Endometriosis and MS are just things that I live with.”

Pearl, who is a 40 years old woman, lives with her partner and daughter in a rental property close the beach. Pearl comes from a white, middle class family in the eastern suburbs of Auckland. Pearl, who is shy and has only recently undertaken tertiary study in psychology and social policy, sees herself as the black sheep within a family who all have tertiary qualifications.

Pearl came to know about my research through a mutual friend. She contacted me by email to say that she would be interested in participating in the research. In the email, she told me she had been diagnosed with MS at the end of 2009. Pearl recalled, during the interviews, that she experienced MS symptoms many years earlier. MS is a disease of the central nervous system (MedlinePlus, n.d.; The National Institute of Neurological Disorders and Stroke [NINDS], n.d.). The disease damages the myelin sheath which encases the nerves and enables the transmission of nerve signals throughout the nervous system (NINDS, n.d.). When the myelin becomes damaged, it slows down or blocks the messages transmitted through the nervous system causing impaired functioning or altered sensations, such as muscular weakness, difficulties with coordination, numbness or memory loss (MedlinePlus, n.d.). The term ‘multiple’ is used in the label because this disease affects a number of locations in the central nervous system and because relapses and remissions that characterise this disease are reoccurring (MedlinePlus, n.d.; NINDS, n.d.). People who are affected by MS are not able to predict when attacks will occur, how long they will last or how severe they will be (MedlinePlus, n.d.).

In her late teens Pearl was also diagnosed with endometriosis. While the cause of this disease is unknown, it is a problem that affects the uterus (The National Women’s Health Information Center [NWHC], n.d.). This disease occurs when the tissue that lines the uterus, called endometrium, grows in cavities of the body outside the uterus (MedlinePlus, n.d.). This condition can cause pain, infertility and very heavy periods (MedlinePlus, n.d.; NWHC, n.d.).

Pearl, who offered to have the interviews at her home, created an interview space on a concreted area out in the sun. She wore subtly applied makeup and took frequent breaks to check on her daughter and to have a cigarette. Prior to the first interview, Pearl expressed concern that she would not be able to provide the kind of information that was relevant to the research because she had not sought employment since her MS diagnosis. I reiterated that the purpose of the interview was to find out about her and to give her the opportunity to voice her experiences in relation to the three sets of research questions. We engaged in a conversation where I assured her about the significance of her concerns about seeking employment and her preconceived notions and thoughts around what it might mean to manage a chronic condition while in paid employment in the future. In this conversation, however, she also revealed she had lived and worked with endometriosis since her late teens.

Given the recency of her MS diagnosis, Pearl has not had time to understand how she feels about it. This was a strong theme in the first interview and was manifested through contradictions, emotion and tears. Prior to commencing the second interview, Pearl expressed concern about this and provided an explanation of the cause of those manifestations. She elaborates:

“It’s so early in my diagnosis that I’m still really processing this stuff. It’s not something I’ve really lived with for a long time. When I look back on our previous interview, there were things that I was talking about, and hence the inconsistencies in what I was saying, because I don’t know. I haven’t processed so much stuff. I haven’t talked about it. When you left, I was horrified. It sounded like I was in a hopeless situation and I don’t think that at all.”

When asked, Pearl explained why she agreed to participate in the research.

“Oh that’s a double edged word [Pearl laughed]. I have an interest in certain types of research. I think it’s a valid way of finding out about the reality of things. I’m a student and you’re a student. I’m interested in your research and I can look at your questions, see how you’ve devised it and the process that

you have gone through. I feel privileged to pass on that information. When I had an MRI [Magnetic Resonance Imaging] scan, I asked them if I could take the pictures home because I am studying. They said I had a really good attitude and that's just who I am. I'm interested. I am able to step outside of myself and observe. But I'm fascinated and that's why I agreed to do research with you. And plus, I thought, "Well Cheryl (mutual friend) thinks you are cool so [why not?]" [Pearl laughed].

Pearl summarises how she felt after reading the transcriptions.

"It was weird to see my ramblings in black and white, but hopefully you can pull some good stuff when you do your analysis. It's an awful lot of work isn't it? I'm really looking forward to seeing your finished masterpiece. It's very inspiring to see research in action so it's great to be part of the process. Anything I can do to help, let me know. Keep in touch."

### **PEARL'S STORY**

I think I developed endometriosis in my late teens. One day I was in severe pain to the point where my flatmate at the time called an ambulance. I had grown cysts on my ovaries. My blood pressure had dropped considerably. There was this build up of blood, it formed a ball and had got bigger and bigger. It had got to the size of a grapefruit and it went splat. That was a nightmare because the doctors told me I had an ectopic pregnancy. Unless I was the virgin Mary, there was no way I would have been pregnant. That was really insulting because they thought I was lying. I've had a dreadful experience with the medical profession. The specialist came in and told me off because all I had was a bad period and they couldn't believe that I had been admitted to hospital.

The doctors did a scan and saw that my entire insides were awash with this stuff. They did a laparoscopic surgery and pulled out huge amounts of crap. The doctors apologised and said that the scans didn't reveal the extent of the disease. At that stage, the specialist came in and said, in a very brusque way, "Well, essentially your reproductive organs are chewing gum and you won't ever be able to have children" and walked out the door. I lay there in shock.

The nurse came and held my hand and was pretty horrified at the way I had been delivered the news.

I was diagnosed with severe endometriosis at the age of 20... That diagnosis was a relief because a lot of people with endometriosis are told they are just having bad periods and to suck it up. So at least I had a name. We are talking two weeks out of four where I was incapacitated and you feel like you are making it up. I thought I was going insane and that I just had a very low pain threshold.

I lost my faith in the medical profession at that time because the only practical thing they could see to do was to give me a full hysterectomy. At 20 years old, I said, “No.” They then said, “Well if you’re not going to do what we tell you too [incomplete sentence]. You’ve lost an ovary, the other one isn’t functioning due to endometriosis, you will never have children so why do you need all the bits? If we get rid of them, then you won’t have endometriosis.”

The doctors put me on medication which I wasn’t comfortable with and to counter my discomfort they then put me on anti-depressants. So pills for the pain, pills for the depression. It was rubbish. I could go and get pain relief, if I needed it. I had pethadene on tap, if I wanted it. I did that for a while and then I decided that I didn’t like conventional drugs. I didn’t like what they did, so I withdrew from the conventional medical system. I decided to try to manage my condition naturally. The internet wasn’t even available in those days but I just did my own research. I developed a system of knowing my body. I’m a huge fan of supplements. There were the odd things that I went on, like cider vinegar, green tea, calcium and magnesium. I managed that illness.

*Pearl also had three or four surgeries throughout her twenties to remove endometrial tissue. At the time of her diagnosis, Pearl was working in an administrative role in a drug and alcohol rehabilitation centre. She recalled the impacts of her condition on her work.*

My endometriosis was worse in the early days of my diagnosis... I remember times when I was at work and I was in a pain bubble. I would wonder, “I must look like I’m about to die but nobody is saying anything. What’s going on?”

Usually, that sort of pain resulted in me having to vomit and go home. When I was in pain, besides pain relief, I'd use breathing techniques. They are quite good for the pain. They were the same breathing techniques I use when I'm at the dentist or I'm fearful. If nothing else, it provides a really good distraction. I tried lots of different exercises.

I didn't talk about it a lot because, for the most part, the rehab centre was an all male environment... I would never have asked for any sort of special concession or consideration because I had an illness. In fact, I saw my illness as having nothing to do with my work environment. Looking back on it, I see that I would have been entitled to ask for a chair that didn't hurt my back. I was a bit too scared to say anything and they didn't know until something came on. There was never any time, after they knew that I had endometriosis, that they said, "What are your needs? What can we do for you?"... It's funny, when you mention to male employers that you've got any sort of gynaecological problems, they will pull away and say, "I don't need to know anymore. That's fine. You take as much time as you like" [Pearl laughed]. They didn't really want to go there, as long as I was getting my work done.

I was good at my job. I don't think my condition really interfered with the quality of my work when I was there, but it certainly meant that I needed to take time off to rest and to go into hospital and that was noted. At times I would have to race up to the doctor to get some pain relief. I don't think I ever felt discriminated against for having a condition... I don't think it was ever really acknowledged that I had a physical condition. It was more of an eye rolling, like when someone phones up and they've got a hangover. It seemed to be more like an excuse. But I don't think anybody ever said, "Hey, this has got to stop."

*Pearl owned her own store in Mangere from 1996 to 1998. When asked to summarise what it was like to be self employed over an email conversation, she explained her experience of self-employment in relation to its advantages and disadvantages.*

Being self-employed came with pros and cons. On the one hand, not having to explain why you're not feeling well to a boss is a bonus. However, with your own small business, you have to be there or at least be able to fill in any gaps left by the few staff I had. I remember, at the time, finding the whole process to be very empowering and my illness played no real part in my participatory role. I was fortunate that the business was in Auckland, where all my immediate family were and they would drop everything to help me out if I asked. Asking, however, is not in my nature [:].

My experience of being self-employed was mostly positive. In spite of the hours involved, and not to mention the paperwork [written with exclamation], setting the standards to ensure that not only I was comfortable in my own working environment, but that others were too, had huge merits. I really enjoyed that relative freedom when comparing it to years of working for bosses, some of which were great about my illness and others, not so much.

I then studied horticulture and went on to work in garden centres for years. I lifted bags of compost and bags of potting mix day in, day out for people who often looked a hell of a lot stronger than I did. There was never any concession for lifting. I was shocked and horrified at the treatment there. From a disabilities point of view, the employer wouldn't have cared. They didn't care about their workers. Due to endometriosis, I have a lot of back issues. I probably did my damage to my back through just needing to get the job done.

I also worked on a hydroponics farm and drove tractors, lifted blocks and scampered about... My boss was a slave driver. It didn't matter what was wrong with you. You went to work, you ran around, you sharpened your knives and cut the lettuce up. It was a factory. I ended up with ailments from the damp, cold and working outside without being provided with any protection. To him, my condition was nonsense. You were there to do your job... You don't want to ask for help in that sort of an environment, so I think I damaged my back quite a bit. I probably would have anyway whether I had an illness or not because I'll be damned if I'm going to be defeated by

anything. I did do a lot of physical work and a lot of physical labour. I also ended up with ailments from the damp, the cold and working outside without being provided with any protection... I left that job. I had a screaming match with him because I wasn't used to being treated without dignity and respect.

*Though Pearl did not obtain every job she applied for, she did not experience difficulty gaining employment. Pearl made some general comments around managing her chronic condition in the work environment.*

Endometriosis was something that I just quietly coped with. I didn't talk much about it to anybody. It was as private as any illness can be until it affects anything you do in the public realm... I would tell employers and work colleagues if I wanted to get them to leave me alone [Pearl laughed]. I would give some kind of medical explanation of what endometriosis was, usually after I'd had a fairly acute attack. I think I could, in medical terms, give a pretty good explanation of why it was happening and kept it fairly neutral. I never talked about how it affected me.

I found that it was predominantly women that I worked with. That was a bit of a double edged sword when you have endometriosis and you talk to other women who experience no problems. I would say to someone, "I've got a really bad headache" and they would be like, "Well I haven't, so what's your problem?" There was not a lot of understanding around it, but you also run amongst women who suffer in silence themselves. I see everything as a tennis match, if you throw that ball out and if you get one back, you'll hit one back. If I talked about it a little bit to people it often opened a way for people to talk about their own health issues. I never talked about the fact that I couldn't have children.

Let's face it, there are not many employers out there whose main objective is not to make a big buck. There is not a great deal of emphasis, that I have seen, on fair treatment for employees whether it's to do with a disability or looking after their children or a death in the family. It's all a bit of a pain in the arse to them and it just means lost revenue.

When I look back on it, there were a couple of jobs that I did leave, not specifically because I had an illness, but it certainly didn't help that I had to take time off. I didn't lose jobs over it. I think there were times when I chose to leave because it all got a bit overwhelming and I didn't like being sick but that wasn't the only reason I left. I always managed around my work. I was always good at what I did. I was an asset.

*General comments around how Pearl felt about having endometriosis.*

Since my late teens I have dealt, in one way or another, with physical illness. It's a funny one because it's not just a physical illness. I had a huge component of PMT [Premenstrual Tension Syndrome]... As the years have gone on, it has become less problematic for me physically, but emotionally I think it's still the same... I experience extreme mood swings that often are just strong depression. It saddens me that I don't trust my emotions. I almost dismiss my own feelings now. I run a real risk of suppressing emotions, of living in denial and not making the right decisions... The endometriosis altered the entire course of my life in a way that I expected it to be. The news that I couldn't have children through endometriosis changed, I believe, the direction of how my life was going to be. I never was one of those people that thought marriage, children, picket fence. I never ruled out the children bit. I thought the world was insane and why would I bring another child into this crazy mess? That's how I was in my twenties.

I moved to Tauranga ten years ago and I believe that journey was a big part of my healing from my endometriosis. I started yoga, I started visualisation, used natural therapies, I was eating well and had healings. I became well. I'd become well enough to conceive. To get pregnant at 34, my daughter (now five years old) was an absolute miracle. It proved to me that I had done the absolute right thing in spite of what the doctors told me.

I was diagnosed with MS at the end of 2009. I had symptoms over the years but I thought that they were part of being old or living life [Pearl laughed]. I used to do a lot of walking... I quite clearly remember going for walks and getting electric shocks, tingling and numbness up my body. I experienced

these for some time but I thought my back was out and I'm not too good at going to the doctor [Pearl laughed]... Chronic fatigue is another symptom of MS but I don't know any women who aren't tired so I didn't feel I could moan about it.

I went to an osteopath and they said, "I think you had better go to the hospital." When I went into hospital, the complete right side of my body was no longer feeling things. It was like having bands around that whole side of my body and, as a result, I wasn't walking properly. They did a lumbar puncture and a scan. They found lots of white spots and lesions throughout my brain. I have quite extensive brain damage. I had no idea that it would be MS. I vaguely knew what it was... My specialist said, "This is what you've got. It's pretty random. It's a fascinating disease. If you get little niggly symptoms, go and see your GP. I don't want to know. I just want to know about the big stuff." They also said my MS was relapsing. There wasn't a lot of compassion. They put me on a course of steroids in the hospital and, after a week, it hadn't improved the condition.

I was absolutely devastated with my MS diagnosis. I was devastated that I may have to go down a spiralling path of ill health and have days in bed. I felt completely and utterly alone. I had to be in hospital. I'd never been away from my daughter. I did feel grief and loss with this diagnosis [long pause], a loss of health I suppose [long pause]. When you are told you have got something that can't be cured, it is not terribly hopeful... You are just left with a wait and see kind of approach. You get philosophical when you have no choice [Pearl laughed]... When things happen to you, you reinterpret your life, you accept it, cope and get on. You reinterpret yourself in relation to those things and change your life... If there was more that I could do, I would. There is a multitude of experimental medications out there, some work for some people, some don't... Now that I have not relapsed to any great extent, I am very hopeful. I am still positive about the fact that it could be worse. I don't have the galloping MS. Some people are diagnosed and they never get better. It's just something that I live with... I kind of feel like disease of the week. Amongst having endometriosis and MS, I have had a very interesting life and so many bizarre things have happened to me. I sound like the walking

wounded [Pearl laughed]. I get a bit embarrassed about it, just the way that my life turned out. I didn't expect this. So at the level of health - MS and endometriosis - they are as big as some of my other problems.

I do suffer from a form of depression around MS. I feel a little bit alienated. It's hard for me to separate out how I am emotionally, especially now that I've had this flippin' IUD [Intra Uterine Device] removed (*under the advice of a Family Planning Clinic and medical specialists, Pearl had a IUD surgically inserted in order to prevent her endometriosis symptoms*).

Intuitively I knew it wasn't a good thing to do but I was dealing with very heavy periods and pain. It had been four years since the birth of my daughter and the endometriosis started coming back. One year later the onset on my MS came on. When I got the tingling, numbness and then the eventual lack of function on my right hand side, I decided it was the IUD that had caused it. I again googled and found out that people have had nightmare experiences with this IUD. I got it removed after my MS diagnosis. It was helpful for my endometriosis symptoms but, in my mind, it was also an artificial body within my body that had become ill and I needed to remove it. Now I'm dealing with the endometriosis again [Pearl laughed], but what do you do?

I talked to the women in the hospital. I was a lot younger than them. It was a bit like being a little girl in boarding school. I saw a lot and I'm really grateful to have that experience. When I had my low times - lying with a drip in my arm and tears coursing down my face - these women would come and hold my hand. I would learn their stories and they would learn mine. I think that there are so many stories to be told of people who are lying in hospital beds. Initially, I wanted to be in a room on my own and I didn't want to be surrounded by old, dying women... But in the end, bizarrely, I had a lot of gratitude. I was lying in a ward with a woman who had inoperable brain cancer, a woman opposite from me died. At that stage, I was like, "Well, all I've got is MS and I'm ok." I realised it wasn't a terminal illness and that's what I did say to my family who were devastated.

As crappy as it was, I rested. I read that people often get ill because they are burnt out and I hadn't had a rest for a long time. Amongst the sadness and the

illness, I actually quite enjoyed lying in a hospital bed, I had a dvd player and I watched girly crap for hours. It was the first time that I could do that and I recognise that I'm allowed to do those things without needing to justify it.

When I left the hospital, the neurologists' parting shot was, "Do you want anti-depressants?" I said, "No" and he said, "You are going to want them. Every single patient I've had need anti-depressants." I thought, "Really? So you are just setting me up for that." When I returned to the hospital, he offered me some more. That's actually been the story of my medical life, all they do is offer me anti-depressants. I am not a disbeliever in anti-depressants. I have seen people's lives saved through medication. But I don't think that's the right thing for me.

*A few months after the last interview, Pearl started to experience panic attacks and deep depression. She went to the doctor where she "admitted defeat" and asked for anti-depressants. At that appointment, Pearl became aware of six free counselling sessions with a grief counsellor she was entitled to under the Mental Health Act 1992. Pearl found the sessions to be "a good start but does not make things okay".*

When they did a lumbar puncture they removed the cerebral spinal fluid from the brain and it affected me badly. I couldn't stand up. I was in a lot of pain. I didn't get regular pain control which I needed. They sent me home with a whole lot of panadol and told me to drink coffee and coke because I had severe headaches [Pearl laughed bitterly].

I went home with no real information. I was pretty pissed off with the hospital because I didn't leave with so much as a brochure. I wasn't given anything about Multiple Sclerosis New Zealand [MSNZ]. Nothing. I was just told to go home... So I started good ol' google [Pearl laughed]. Being a student and aware of research, there's a lot of information out there that is unsubstantiated. I went to look at things like the Cochrane Collaboration that amalgamates lots of research.

I found out that particular course of treatment - an intravenous dose of steroids for five days consecutively - is only effective if it's for a first time

attack. My brain showed that it wasn't a first time attack. I don't understand why they did that. The consequences of being on the steroids were horrific. I was a mess. I was crying. I was raging. I couldn't work out what emotions were real. My symptoms hadn't been fixed. I still had a numb side. My walking was compromised. I was heartbroken for my daughter. I think it was the pregosone. I had to remove myself because I was just so angry. Once the steroids dissipated, I was left with the knowledge that I had a disease. I think that's the hard part with MS, there's no correlation with what part of your body it's going to effect. In the first month or so I would wake up and do a scan of my body to make sure everything was functioning. I became a different person. I, at that stage, thought I never wanted to go on steroids again.

Once I realised that was going to be better I could see a way that I could manage this disease... I'm not medicated. There is not much medical intervention for MS because it's such a random illness. I try and manage this illness, as much as I can, down a holistic path... I come from a family who believe that our bodies can be fixed or healed through the right nutrients, the right supplements and the right attitude. Mum had breast cancer and refused chemo. She's been in remission for many years. I had that model for me where you work out intuitively what works for you.

I looked for natural therapies, exercise, vitamins and diet. There's an MS diet. I got out a load of books from the library. I read a lot of autobiographies of women who had MS. I read and read and read. I'd go to bed with a pile of books on MS. Then one day I thought, "Read them but don't take them to bed with you." I decided that I could research it without it consuming me... I got angry. I'd read too much about it. I know that one in four women suffer from it. It's a modern day disease. I was interested in that we never used to have it and what's going on. Is it the hormones in the food that we are eating? I was making my own connections about why I have it... I don't want to be defined by my illness. I was going to have times when I was well and times when I was not.

There was some resistance from my partner on some of the things I decided I wanted to try. I suppose for a long time now he's rubbished some of the stuff I've been interested in anyway. He always calls it your self-help books and always does those quotation marks and so it's a bit patronising really.

I've lost my faith a little bit in my spiritual side and I don't know what to do about that. I used to meditate every day. I had [short pause] extreme faith. In matters of spirit, I was very convinced. I had my own philosophy and that it worked for me. I read a lot on the Tao and I saw lives changed through it and believed that the way of the Tao was the way for me to find peace in my life and it worked. Instead of being challenged and continuing with that, I think I threw it out the window. I got to a point where I thought, "Bring it on. Bring it on. I've had so much shit in my life. There was no point anymore." So I abandoned my spirituality. I am desperate to reconnect with that and do those things, even just connecting with my breath. I believed in the life force of the breath and the healing and cleansing of the breath. And whenever I wanted to heal I just breathed and I think I have lost that. I am hopeful that I will regain it.

*Pearl summarised the reactions of friends and family to her MS diagnosis.*

There's a mixture. I used to be very close with my sister. When I delivered the news she was on holiday with her family in the Gold Coast. I texted her and said, "Hey, I'm in hospital, a bit of bad news, it looks like I've got MS." It ruined her holiday [Pearl laughed]. I was in trouble for that [Pearl laughed]. Her response was hurtful but sort of understandable. In my defence, I didn't realise what my diagnosis really meant. I was lying in hospital with drips coming out of me and I didn't think it was that serious. She was upset that I couldn't wait until she got back from her holiday and she told me off about that. I was a little bit pissed off that she couldn't come to see me when she got home. I needed her. We gloss over that. I think she's in denial about it. She didn't really want to know. I don't know why.

I don't have family here in Tauranga. I wish I did [Pearl gets upset]... My father is an amazing man. I am his little girl. He is extremely supportive. He

did a bit of research too and he sends me emails on new books that come out. I think Mum and Dad predicted worst case scenario for me because all they had experienced with MS were people in wheelchairs, who were incapacitated and who appeared to be a burden on their family. I know I would never be a burden upon them, however ill I got... It was a difficult situation for them. My parents came and stayed but my partner wasn't very receptive to them just hanging around while I was in hospital. There were all sorts of dynamics going on. He was quite relieved when they went home. I don't really talk about it. They don't really talk about it. I think that I'm close to my family but I think that's the reason that I live here. There is a lot of unsaid stuff and I need people that I can talk to about real things and who are not going to stop the conversation when it gets a little bit too difficult for them. I have a family who are notorious for denial and that's where they are at. But it is ok. I know they love me and I love them and we all manage in our own way... Dealing with the family, the worry of the family, was really difficult.

Friends have been a lot more supportive by offering to look after my daughter when I needed some space... I also have friends who are afraid so I don't really talk about it a lot with them and that's hard. It's hard to know. Occasionally, they'll ask how I am. But they have also watched me be positive and carry on with my life. It's quite isolating but it doesn't have to be. I could involve myself more, I suppose, with other people.

I've talked to my daughter about MS. She calls it my 'numbness' and laughs about when mum couldn't feel that I had shoes on. It's not that we've downplayed to her, but how do you tell a five year old about MS? I've talked about the connections in the brain. One of my dearest friends has a mental illness and we've talked about his illness, so she knows about that unseeable stuff that can go on with people... My biggest concern is how it affects her. My fear is that she is an only child and there will be times when she's isolated and emotionally neglected because I'm so wound up in myself and what I'm experiencing in my illness. I'm concerned that that is going to be harmful to her. I think we are doing alright. I think she is well provided for.

I have a partner here. I think he's as supportive as he can be but I think he's got a lot of denial around my disease. It is understandable. We almost have a competition - if I'm tired, he is twice as tired [Pearl laughed], if my back is sore, his is twice as sore. And that's hard... because I don't feel validated... I don't know what to do about that... The biggest stress in my life right now is managing my relationship in a peaceful way. It's quite exhausting. I'm a bit stuck in the role of making it all ok for everybody else.

*In the following extracts, Pearl summarises how she felt about having MS.*

There are times when I feel like I've got a time bomb ticking within my body – tick, tick, tick, tick. When's it going to go off? I try to be respectful in the way that I talk and think about my body but I think I'm pretty pissed off with it. I'm quite a controlling person. I'm very organised. I don't like to think that I'll be half way through writing an assignment or half way through doing anything and have to come home because I'm too tired. I don't like the unpredictability of the condition but I'm very accepting around it as well... I think the hardest thing is the fatigue that comes with MS. I feel a little bit childish saying, "I really am tired. I need to go and have a nap." I don't rest enough... If you are in excruciating pain, you've got this very genuine reason for not being able to do what you need to do but fatigue sounds so vague and a bit pathetic.

When I'm in pain, it's quite a dominant part of my life. I think women juggle really well. I can be experiencing symptoms or fear or pain but I can still come to the party and still be pleasant and do what I have to do. I can put on a really good face... On the other hand, when you don't appear to be ill and your insides are destroying you, there's an element of fear that people think you are making it up. With my MS, I worry that people think I'm making it up. That's nobody's fault.

It doesn't rule my life. I don't see it as the biggest thing in my life at all. Some days go by and I don't think or talk about it. I did initially of course. It is still quite early for me with this diagnosis. It's not who I am. It has actually been a big wake up call for me in lots of ways to become the woman I always wanted

to be. It has given me more motivation to do stuff rather than less. I don't identify as "Hi I'm Pearl. I've got MS." If it comes up and it's appropriate or I'm not well, it may be a good explanation to give people. I think it would be different if it was physically visible. It would be quite difficult to be seen as somebody who talked funny or walked funny. I've lost hearing in one ear and knowing that I could be suddenly rendered disabled [is difficult] but I haven't had any noticeable things happen. I'm in remission and I suppose that is as good as it's going to get.

I have not met anyone with MS. I am avoiding support groups like the plague right now. I'm just not ready to walk into some drafty hall to see what the future could be [Pearl became upset]. I don't want to go and confront people who were desperately struggling and kind of go, "I'm ok, for now." I don't want to do that but I'll need the support. I don't know. I'm not in limbo. I'm pretty exhausted... I went on the website for MSNZ. I had been observing the facebook comments for a while but I didn't say anything because I didn't want my facebook friends to know. I did a private communication because I wanted to know something. I said that I had been recently diagnosed. A woman from MSNZ got in touch with me straight away. She said, "Do you want to sign up to our Knowledge is Power course?" I said, "Yes" and within a few days it was on the doorstep. That was pretty cool so I joined facebook MSNZ... I was interested in the social networking side of people with MS.

*A few months after the interviews, through other parents at her daughter's school, Pearl met two women with MS. She described making connections with these women as "a great experience". This is because one of these women, who had lived with MS for eight years, gave Pearl hope. Pearl believed that the other woman, who had MS only a few months, gained hope from seeing Pearl live as a fully functioning individual.*

When I was first diagnosed, I wanted to go back to uni full-time. There was this bullishness in me that said I had to do everything as quickly as possible in case my body wouldn't allow me to do it. I was devastated when I knew I had to drop a paper and I would have to slow my eventual readmission into the workforce. At that stage, I thought it was a timing thing. If I could finish and

complete everything before I lost my cognitive abilities [incomplete sentence]. Being in a wheelchair is pretty devastating but that didn't hurt me as much as the idea that, cognitively, I'd be damaged. Blindness, loss of hearing and loss of the senses are also really big concerns. The fear of losing my cognitive abilities gets to me at times as well as trying to manage the illness and worrying about the future.

When the university asked if I had any disabilities, I was like, "No." In my mind, it was nobody else's business and it wasn't affecting my studies. Not disclosing my MS at uni penalised me when it did affect my studies. I thought, "Man I should have said something" [Pearl laughed]. Now I have to go through the whole rigmarole again and go see the doctor and get a medical certificate. People would say, "Why didn't you say anything?" It's really obvious why you don't say anything. You don't want to be known as that person who has to take time off work or is different from anybody else. You don't want to be cast in that light. I didn't want everyone to get the violins out and feel sorry for me. Compassion is nice but I don't want to have allowances made either.

It has been fairly easy disclosing to some people. To some people, it's inevitable, like if I've had symptoms or days where things haven't gone well. But we are dealing with people who are smart so it makes all the difference. I get supported. If things weren't going well, I would go straight to disability support services and they would help me. And, unlike WINZ and the hospital, they sent me information about things that I could access, things that I needed to do and my rights.

I did three counselling sessions. She was great. She was the first person that I truly opened up to about what I was going through. I think I qualify for three more sessions and I think I should do it. I'm pretty messy but I'm not very good at revealing that. I have high stress levels. It is my belief that what kicked off this disease was stress and I'm not sure how to manage that stress still. The counsellor started to look at strategies for me... I have just decided to get on. I did ok in my last two papers and that was really important to me.

I know the university environment is vastly different from an employment environment but that's been a good place to dip my toe in the water and see how my condition is responded to. I know that they have good mechanisms and they have disability support services which have been fantastic. So it's kind of like a little playground before I get to the work environment.

*Pearl has not sought employment since she was diagnosed with MS. She has not thought about but is concerned about how she might deal with her symptoms, particularly the fatigue, if she returns to work. In an email conversation around what it was like to be self-employed and live with endometriosis, Pearl recalled, "Actually while writing this I see that being my own employer is still a very attractive proposition for me, but I gotta get through uni first [ :) ]."*

My degree and my future career options changed with my diagnosis. I changed my major because I realised that employability might be difficult for me. So it's more the psychology of it - the idea of working with MS and managing the condition at work - rather than me having difficulty applying for work just yet... I feel quite fortunate that I have the opportunity, at my age, to go to university and then potentially use the skills that I learn there to earn money. I would love to get a job that paid really well... We really are left at the mercy of our own incomes which, when you've got a chronic illness, sometimes doesn't amount to much.

I have fears that I will be fully functioning one day and then not fully functioning the next day. Those fears are all-encompassing. That fear is an everyday thing for me, regardless of what I'm doing. I have fears that I will turn up in the school yard and be incapacitated. So I think that the fear around working is as large as all the other things that go on in my life, apart from the fact work gets me the money. I have real fears of not being able to provide adequately. I'm hopeful that, if I don't lose some of my cognitive abilities, that I could make money with my brain, even if my body is not functioning so well... I have fear around how things are going to pan out in the workplace. I do withdraw quite a bit from social activities so I'm presuming I will probably withdraw emotionally from connecting people in a work

environment when I'm not feeling well. That's what I do now. I don't know how to make that better.

I have had concerns about whether I would be employable and whether I would find somewhere that is flexible enough if I have a relapse... When I first got this diagnosis, I thought, "Who is going to employ somebody with a double whammy of health issues, with the possible ramifications if I may not be able to carry out tasks effectively?" I think about how that could be a bit of a nuisance to an employer. [Long pause] There would be a question over whether my work would be compromised or not and it's a fairly legitimate concern. It's a big question mark for me as much as even being able to complete my degree is a question mark... I don't think they would take the risk. In previous jobs, I overheard why my employers didn't employ people or why some employees lost their jobs. The employer felt that they were too risky for a wide range of reasons... Also, I think people with disabilities aren't gonna ask some people for concessions because they know that there is no point.

There is the dilemma with potential employers around whether I would fully disclose that I have MS. I think it would depend on how I was at the time and what sort of job it was. If I felt that it would be something that I would be discriminated against then I probably shouldn't be working in that environment anyway... In the fields of work that I want to look in, hopefully they will have a philosophy or a mission statement that will be inclusive of me. I don't know if my chronic conditions will be a problem. I hope not... I would like to think that I would have an employer who would employ me on the quality of my testimony or the recommendations or my degree. In my more positive days it doesn't really concern me, in my darker days, I wonder whether I will ever get legitimate employment again.

## **Tony: Introduction**

“Sick of being sick.”

Tony’s experience inspired this research. Tony, who is 49 and has multiple chronic conditions, likes to joke that he is 29, six foot five and bullet proof. He lives in a small two bedroom state house in Hamilton. Tony, who is of Māori descent, has five children and two grandchildren which he describes as his biggest achievements.

Tony and I worked together in the food distribution industry from 2004 to 2006. At that stage, I was unaware he had multiple chronic conditions. When he did not turn up to work, I thought he was ‘skiving off’. When he did not work at the same rate as I did, I thought he was ‘slacking off’. When he had to rest because his joints would seize up - which I discovered during the interviews was caused by gout - we joked that he needed to ‘harden up’. I watched him struggle to carry out physical tasks at work and thought perhaps that he was just unhealthy. Nevertheless, I enjoyed our playful banter and hearing his stories.

I came to know about Tony’s chronic condition when he was admitted to hospital in 2007. I was not given specific or detailed information about the extent of his illness, however, I was informed, though not by Tony, of the terminal nature of his illness. Tony’s experience of having a chronic condition, particularly when his health deteriorated to the point where he could no longer work, made me aware that there are some issues that people with chronic conditions face that are unique. This was reinforced when he received a terminal diagnosis. It was then that I felt it was important to capture his story before he passed away. When I approached Tony with the idea of conducting research on a project inspired by him where he would be a participant, he warned me that his life was not interesting enough. One of the main reasons Tony agreed to be involved in the research was because he wanted to help me.

It was only during the interviews that I came to know the type, nature and extent of his illnesses. Tony was initially diagnosed with cardiomyopathy in

1996. He later developed other chronic conditions, such as congestive heart failure, diabetes, gout as well as thyroid and kidney problems.

During the interviews which were conducted in his home, Tony would stare off into the distance as he thought about and told his story. When he felt he had made his point, the look of concentration in his face would fade, he would look at me and nod which indicated he was ready for the next question. At times, the way in which Tony spoke seemed rehearsed for or a story told many times to a particular audience. Perhaps it may have reflected his preconceived notions about how the interviews would go as well as what and how he would say things or perhaps it was a reflection of the skills acquired through the type of work he has been involved in. Other times, he addressed me specifically, particularly when old work stories were recalled. There were also times when it was clear he used the interviews to understand how he perceived and felt about his experiences. During the interviews, which both took two and a half hours, Tony needed to take frequent toilet breaks because of the rapidly produced fluid caused by the diuretics. When I arrived at his house to conduct the second interview, Tony said to me, "You're lucky. I nearly went back into hospital." Five months after the interviews, Tony passed away.

### **TONY'S STORY**

*Tony recalled when he first experienced symptoms.*

It was in 1996, so 14 years ago... I lived a busy life. I was a part-time soldier. I was working full-time in the prison service. I was active in civil defence, emergency search and rescue and a volunteer fireman... I was feeling really good, very fit, and was playing representative rugby. It was after a game of rugby when I felt really tired. I just wanted to go home and lie down. Had I been allowed, I probably would have gone to sleep. That was not like me after a game of rugby back in the day, I was always ready to party [Tony laughed]. That was the first tell tale sign. And at work, I started to feel fatigue. I knew something was wrong then.

A trip to the doctor sounded alarms that I needed to go and see a cardiologist. I had to wait nearly eight months to get in to see one. The deterioration was quite slow, but noticeable during that time. The cardiologist told me I had cardiomyopathy. He explained what that was and it answered a lot of questions as to why I was feeling so fatigued and tired. The heart was doing a lot of extra work.

My heart condition has two parts to it. One is cardiomyopathy which is the weakening of walls of the heart. The other part of it is congestive heart failure. So, hand in hand together, the heart isn't pumping the fluid out of the lungs and out of itself properly. So what happens is, I actually drown in my own fluids. To offset that, I take a lot of diuretics which help take away all that fluid and, of course, we are manipulating the heart... with a pacemaker and a defibrillator... so that it beats stronger and is able to pump out more of the fluid.

*At this point in the interview, I asked Tony whether he altered his lifestyle after his diagnosis. He replied:*

No. I stepped it up actually. I didn't have time to be sick and I figured that if I kept myself busy it would go away. No, to be honest, I kept myself busy so I didn't have to think about it. That would be more accurate... I was given a pamphlet and that was it. I read it once and threw it away... Accepting the diagnosis was hard for me because I was so active and fit. So hearing news that I had a heart condition didn't go down too well. I've got to admit, I ignored it for about five years [Tony laughed]. I just carried on, six foot five and bullet proof, until I fell over properly [Tony laughed].

I was a real arsehole to my cardiologist. I didn't turn up for her clinics because I thought I was such a superman [Tony laughed]... I acknowledged that to her today. I was under a different cardiologist who left, and when given a choice about who I wanted to take over my case, I chose my very first cardiologist. Upon my arrival, she looked at me and frowned and I said, "Hang on doctor. I know I owe you an apology for all those years I mucked you around." And she goes, "Alright Tony, I'll take you back on but the

minute you stuff me around, that's it." "Alright boss. Understood." So straight away we were on equal grounding and I was prepared to help her in every way that I should have been. And in hindsight, had I listened to her then, I mightn't be in as much trouble as I am today. But I don't think so.

The condition was uneventful for a while. Then one day we were out on a search and rescue mission in the bush at the back of Te Awamutu and I had to stop and get my breath. I actually needed to sit out of the group, take a knee, and really suck it in. I thought, "Oh this isn't good. Something is not right here" because normally I would run around those places.

I was the Unit Commander of the Emergency Response in the internal response unit at Waikeria Prison. We were called up to Poremoremo Prison in Auckland because the inmates were rioting up there and had taken over the jail. I took 20 prison officers up and we got caught in a bad, bad situation. We got trapped between two fires in one of the wings up there because the inmates had set fire to the foam mattresses. We fought our way out but the damage from the smoke inhalation had got to all of us. Seven of those fullas [fellows] have died since because of it.

*Immediately after the riot, Tony spent a number of months in the hospital. ACC covered his medical bills during this time.*

That event sped the process up for me. It sparked the heart and it started acting all funny. I was having a lot of heart failure... I deteriorated really quickly from there in the sense that I became symptomatic again, only the symptoms were a lot stronger and lasted a lot longer. To begin with, shortness of breath was a big thing. I felt like I had a cold all the time. I thought maybe I was just asthmatic or something like that. I started looking for things other than heart failure [Tony laughed]. But as I deteriorated, it became very obvious what was wrong, so I had no real option really... I wasn't on any medication up until the riot. After the riot, I had to go on medication.

It went from an illness to a chronic illness. That change over was quite a big step. And I was just really angry and annoyed at myself because I had allowed it to go that far. It's very frustrating. It's not a nice label either, chronic

illness. The acceptance of the name itself was hard. When things go wrong and things keep going wrong and other things keep happening, you think, “Oh man.” It’s a hard thing to accept even sometimes today. I keep believing there is a way out of it.

*Other symptoms Tony experienced at this point were fatigue, sore joints and gout. When prompted to talk about medication in the interview, Tony handed me a Health Waikato pamphlet that identified the medication he was required to consume, when and how to consume it, how long he needed to take it, what to do if he missed a dose, possible side effects and other substances that might affect its purpose. In the following extracts, Tony talks about medication and his medical regime.*

My medical regime is quite stringent and it requires me to be on time with things. If I’m a bit late, I will feel it. It can ruin the rest of the day. So I’ve got to be really, really responsible and take control of the management of my own drugs... I have a set routine in the morning which I meticulously carry out. Meticulously [Tony laughed]. It’s a routine that I got myself into and it appears to be the best way to do it. It’s just a way of remembering what drugs I’m taking. I have two series of drugs to take in the morning. The second one really knocks me around so they influence a lot of how my day goes. My lunchtime medication helps to stabilise me so I don’t feel sick and disorientated. At night I take blood thinners so it is easier to pump around the body, as well as anti-nausea pills. We set them up in those times because they are most effective at those times and they sort of set each other up to help me get through the day... I’ve got to take my blood and sugar levels four times a day for the diabetes and take insulin at night... I have to weigh myself everyday so that my weight doesn’t fluctuate too much. If I put on more than two kilos then I’ve got an overload of fluid. If I lose two kilos too quickly, I’ve got a problem the other way. So I’ve got to maintain a balanced weight... So it’s quite a lot spread over in the day.

The drugs are hard because I just feel like fricken throwing them out the window. Sorry. I think I do a pretty good job of it. Sometimes I get a little bit lazy and hoha [a Māori term which means, among other things, fed up with]

with the drugs... I take a heck of a lot of drugs. I never have been comfortable with it but you resign yourself to the fact that you need them.

*At this point in the interview, Tony talked about how he got to know his medication.*

The ward at the hospital has a procedure where the patient is responsible for checking their medication. A lot of people just take their pills and swallow, but I would tip it out and make sure I go through the pills and know what I am taking. At first, I upset a couple of the nurses. But they helped me with it after a while. They would tip it out and I'd rattle them off. That way we are helping each other. They became quite used to me doing that and then they started doing it with everybody else. It only takes a couple of minutes. I think it's important to know what you are taking, what it does and the side effects. It also meant that I was able to differentiate between a side effect or a completely new symptom... I know them all - the colours, the different shapes - and that's just through being on so many... I know enough about my medications to ask questions. Any changes that are made, I can understand why and if I don't think they are a good idea, then I can say, "No I don't want to do that."

*Tony admitted not taking his medication at different times during the course of his illness. I asked him what the outcomes were.*

I got sick very quick [Tony laughed]. The doctors would wonder why and I would say [Tony sheepishly raised his hand and laughed], "I know why". They said, "Have you been taking these?" "No." "Well there you go." I dig my heels in. I don't like taking some of the pills because I don't like the effect. But I've got to keep taking them.

*Without prompting, Tony described a significant side effect of consuming medication.*

The medication I take to help the heart has reacted in other ways and now I have to take other medications to stop those from happening. I used to get chronic gout which is caused by the diuretics. It means that I have to go on

another medication to help with the gout and prevent the gout attacks... I was hospitalised a lot for gout problems. Normally, gout attacks one joint and probably a big toe in most people. But it would affect all my joints and it was just impossible to move. I couldn't do anything. It is a horrible, horrible disease. I don't know which is worse – the heart condition or the gout? Thankfully, I haven't had any gout attacks for a while. Touch wood. From the gout problem, I got a thyroid problem. So I have to take medication for the thyroid problem... The thyroid problem played a major role in my first heart attack. It was thyroid induced. And other diuretics have stuffed up my kidney function so the kidneys start producing more stuff than they should, so I have to take medications for that too. For my heart condition, I only need to take about half a dozen pills but because of the side effects from the heart medication, I'm up to about 37 a day.

*During the interview, Tony spoke at length about and emphasised the impacts of the condition and medication on his life.*

As I came to the realisation that I had to stop doing different things, I would sit down and have a cry about it [Tony laughed]. I was a keen hunter. Rugby. Anything physical. It was really, really hard. It even got to the stage where going to watch my son play rugby was a real effort. I did it, but I used to pay for it afterwards. It was really hard letting things go and, unless I'm a hundred percent, it's something I wouldn't even have a go at doing. I think I'm a bit annoyed because I was cut down a bit before my time. I think I had another few years left in me, [Tony laughed] especially with competitive sport. So it was very depressing and a very frustrating time. I had a lifestyle that was very much get up and go. Slowly, one by one, I had to give it all up. I was a keen tennis player. I loved squash. I loved golf. I miss them all terribly [Tony laughed]. I miss the feeling of getting out and testing yourself [Tony laughed] to see how superman you are [Tony laughed].

I was so outgoing before and I would always have something to do. I lost my confidence a bit. Before I was quite open and used to look forward to meeting and talking to do different people. I'm a bit closed off now and I like just

moving in circles of people that I know. I feel safe. I don't need to explain my position. They know what's wrong with me and can talk to me normally.

Now I try to get out as often as I can. There is a weekly trip to the hospital. Either my sister or my kids' mum takes me to do the shopping. I try to visit Merve [a friend of Tony] once a week. I try to go to the RSA [The Royal New Zealand Returned and Services' Association] once a week just to stay in touch with everyone there. Then I just love jumping in the car and going for a ride anywhere. People call around to see me and I say, "Where are you going? I'll come for a ride." You get cabin fever sitting in this place sometimes. Sometimes I need to be home and other times I can't stand the place.

I don't do a lot of things because I don't know how I'm going to do with it. There are times when my mind wants to do things, but I know all my body wants to do is lie down [Tony laughed] and rest. Once I've rested, I'm alright but if I carry on I'll be paying for it forever. So I've just got to listen to the body and do what it's telling me. If I feel ok, I will. If I don't, I don't worry about it. I'll do it another day [Tony laughed]... It limits you. If you want to go out or something like that because you've got to do timing around when you have your medication and stuff like that... That is why I can't really afford to go away, or if I go away, I've got to take a whole bag full of stuff with me [Tony laughed]... And quite often I have to take a jar of pills with me so that I can go somewhere.

*I asked whether he would take the jar of pills to the pub. He laughed: "Yeah. I wash them down with a beer." Tony continued:*

Travelling is a big thing. I missed out on a funeral because it was too far away. It hurts sometimes when I can't go and do the things that I'm passionate about, especially these local Māori and council issues. There are a lot of things there that I don't agree with and I am either not well enough to attend, or not independent enough to get to those things. It will brass you off a bit.

I started to spend a bit more time in hospital. I had had four or five trips to the hospital from the period after the riot till I finished work at the prison service

in 1999. I left because I was very unstable and we were still trying to find out what was going on and a lot of it was damage from the smoke and what it was doing to the heart condition.

*When Tony left the prison service he was no longer covered by ACC.*

By mid 2000, I had got my health up to a reasonable standard and the doctors gave me clearance to go back to work... That process of getting yourself fit again is really stressful. For me, I knew I was close. I just had to prove that I could manage my condition with the medication and get a bit fitter. It was like a race for me. I'm glad that I thought about it that way because it gave me that incentive to hurry up and get better or as well as I could. But that didn't happen once or twice, I was downgraded five times and I fought my way back.

I got a job as a security officer at Waikato Polytechnic... That was where I met Merve [Tony laughed]... We did a lot of looking after cash, opening the institution in the morning, lock down patrols, and patrolling during the night. It was a good job. It was good fun, especially with Merve because we used to get the lock down done quite early and then play table tennis, go to the gym or have a band practice in one of the studio blocks.

I thought I was working through my condition and medication there. I was learning how to deal with the symptoms through the help of medications and just getting to know what the body was going through... I used to go to work with a pocket full of drugs [Tony laughed]. There were some that I had to take at specific times and there were some that I could take to help counteract different symptoms. I used to get hot all the time and sweat. That was uncomfortable and so I had pills... and took a towel for that... I often felt like I was in space [Tony laughed] so I used to take some pills to bring me back to earth or just to stabilise me a bit. I took my medication discretely and would try to hide it away from everyone.

What really beat me down from there was struggling with the shift work. We were working mainly night shifts, afternoons, and a couple of day shifts, but I was struggling in those hours... and there was a lot of walking around...

Within the first year, I was downgraded again because, medically, I wasn't stable enough. I got written off. The doctors said, "You're not fit for work." So that was the second time I had been forced, by my condition, to stop work.

*Later in the interview, Tony revealed that losing employment for the second time and further physical decline due to the condition prompted him to begin the process of "getting serious" about his condition. Tony retrieved information from the cardiology unit at Waikato hospital.*

When I had been put off work for a second time, that was when I thought, "I need to do my homework" [Tony laughed]. I started looking at this condition a bit more seriously. I found out more about cardiomyopathy. I had got congestive heart failure by then too. The availability of information was there all the time, all I had to do was ask. Slowly losing my ability to do the physical side of things was a big thing. I thought I could still do all those things and it meant I had to find out quickly how I go about doing this. How do I fix it? Is it fixable? How do I get out of this? [Tony laughed] The more I found, the more I read, the more I didn't like what I was reading [Tony laughed]. It was telling me that I would no longer be able to do physical things and that I needed to change my lifestyle. I didn't like hearing that to begin with... I used to spend a lot of time in hospital. I would grab pamphlets and one nurse I used to 'q and a' all the time. She would sit down and tell me a bit more. I've got to know my situation quite well. It pays to ask. The different health professionals are very knowledgeable.

It can lead to other mental problems too. I went through a bout of depression there. It can really get you down being chronically sick but I imagine that it would apply to anyone that is chronically ill. It's quite depressing not being able to do the things that you use to be able to do or are used to being or doing. Believe it or not you're not even aware of it. You sink into the depression and you don't know what's going on, you can't sleep and you can't eat and you're always frustrated all the time. And so that was a big step in getting help and coming to terms with being clinically depressed because it's a form of mental illness. No one likes to hear that [long pause]. How's that for a spanner in the works aye? [Tony laughed].

I fought back and got myself up to a level ground again and was allowed to return to work... I became a teacher [Tony laughed]. I taught an open security course, which Mervyn and I had developed, at the polytech with the objective of getting people into employment in security. It was mainly preparation and we had classes full of youngsters. I was teaching nine unit standards and it was manageable.

I had a good rapport with everyone. They all had good things to say about the way I worked and how professional I was in handling situations. That was a plus for me and it sort of counteracted the times when I needed to go home because of my condition. It sort of levelled it out. I only went home if I really felt like I needed to and if I wasn't well. They were very understanding and supportive. I am very lucky... Merve and I were studying at the same time so we were doing quite a few things. But the politics of teaching at the polytechnic didn't suit us. So we left there and mucked around for a bit.

I went up to the university to sign up for a course and I saw a job advertised for a Disabilities Liaison Officer. I applied for it and got it. It was a much better job. It was only 20 hours a week... and the doctors agreed that that would be manageable... Then another position came up internally, so I asked for them to combine the two. They did, so I became full-time. It was the Māori liaison side of it so my title was Disabilities Māori Liaison Officer. It was a neat job too. There was no physical element. It was more mentally involved, preparing things, meetings, working with people and I had the capacity to work from home so it was right down my alley.

I got out and had to work with students and I spent a lot of time liaising with schools and other Māori liaison officers who promote disability awareness and the disability service... Communicating to students with disabilities, that I had a disability of my own, made them feel at ease. They would feel more comfortable sitting around me knowing that we weren't that different after all... My colleagues would make sure that I was comfortable and they took the time out to sit with me to make sure I was feeling alright. One of my giveaways when I was feeling crock was, I would get big black eyes. They

would look at me and say, “Oh you don’t look right. Go home.” They were really, really good.

I was my own entity there. There was no one like me within the whole country so I was the hallmark [Tony laughed]. I was doing very well there for two years. Then things started to deteriorate... My condition has really taken its toll over a ten year period. At that point, the cardiologist said, “Forget about work. You are not going to be able to maintain any work at all.” That was in 2004, and that’s about the time I started working in food distribution [Tony laughed]. I started to drive Merve’s truck. I was pretty sick during that stage too. I slowly deteriorated from there, even worse.

I was a bit hesitant with the physical work. I thought, “I’ll just take it easy here a bit” [Tony laughed]. When I first started dragging those bread stacks, I thought, “Oh well there’s only one way to try it.” Once I got used to the feel of it, it was alright. There were times where I had to stop and have a bit of a rest [Tony laughed]. Sometimes it was easy to forget that I had a heart condition but it always reminded me. It sort of made me hesitant and I lacked a bit of confidence because you’re not sure of how you are going to be, whether it is going to affect you or not or in what way or whether you are going to set something major off like a heart attack [Tony laughed].

When I went to renew my driver’s licence, I had to get a medical so I went to see my doctor. He looked at me and he said, “Are you driving?” And I went, “Yeah.” He said, “You shouldn’t even be driving a skateboard man.” [Tony laughed]... The medication I was on didn’t allow me to drive. I don’t drive today. It’s too dangerous. I miss it and I miss the independence... When I was in the army, I got every licence I could... They were going to be my backstop for retirement. I always figured that one day those licences were going to help me and I was going to need those licences. So that was the plan to get all those and when I lost my licence, it was terrible. I keep thinking about whether I will be allegeable to get it back again. The likelihood is not until I get a new heart and come off some of this medication.

*Since losing his licence, Tony has applied for one position as an Occupational Health and Safety officer.*

I quite enjoyed the occupational health and safety side of the security course I taught at the polytech. What really fancied me was getting in and doing the assessments, evaluating what the potential dangers and risks are and putting in preventative measures. That was the reason I applied for that job but I knew I wasn't going to get it. I swallowed those feelings aye. I wanted to see how I would do. I got shortlisted right till the end and then when they asked me, "Do you have any health conditions?" I just walked out. I knew I had done well right up until that health part. They didn't make much of it at the time but I knew it was enough to knock me back and consequently I didn't get the job. But you don't mind when you know you are not expecting it aye. It's not so hard.

I haven't worked since I lost my licence and... I haven't bothered applying for work because I've been too sick. I guess that was the year when I finally surrendered to it. I said, "Well maybe I need to concentrate on getting myself as best as I can because there is no point in struggling on and thinking you can work when you can't" [Tony laughed]. I had to give up that bullet proof feeling of mine... I've spent probably three of the last six years in hospital [long pause] off and on [long pause]. I've had three surgeries on the heart putting the stents in. I've had a pacemaker and a defibulator put in and have spent a lot of time getting use to drugs... I've definitely struggled in the last six years.

*Tony made some general comments around managing her chronic condition in the work environment.*

It was quite difficult sometimes because I would have some good days and I would have some real bad days too. My conditions did require a bit of sitting down and trying to decide whether I should go home or work through it. There were times when I was too bad to go to work. I would end up in hospital a lot so I became a bit vulnerable to things like colds and flus. Basically, when I was sick, I was very sick... Resting was a big thing. If I

rested well then I would have no significant problems with my symptoms at work... Often, I was able to work right through till my days off and on my days off I would be absolutely buggered [Tony laughed]. All I did was sleep and recover.

I was very careful and cunning and I knew not to bite off more than I could chew... I managed my day around what I thought was manageable, not what I thought people wanted me to manage. I think you've got to work within your means... I know my capabilities and I'm not capable of very much. I wouldn't put myself in that situation now where I couldn't do the job... Thankfully, I had understanding employers who gave me the time to do what I needed. I think the work that I did in between the good and the bad times was enough for them to warrant keeping me on. They never made me feel that my condition would threaten the job or incapable of doing the job.

But I would inevitably fall over because of my health. If we had more control over the condition it would have not been a problem and I would probably still be working today but it has just got too bad. I retired due to ill health, not because I was incapable... I only had to finish work when my condition got too bad and I wasn't any use to anybody by staying on. It wasn't helping me health wise and it wasn't helping my employer. But when I fought my way back to good health they were happy to take me back on again.

*After his terminal diagnosis, Tony commenced some part-time extra-mural study. At the time of the interviews, Tony hoped to return to some form of employment in the future. As mentioned, he was certain previous employers will re-employ him. With regard to seeking employment in organisations he has not previously worked for, Tony was concerned that he may face discrimination.*

If I could work, I would be out there in a flash. When I am able to work again, I will be out there in a flash. I would like to think I would still be in a teaching role or at the university. I know they would have me back there if I was well enough. So when I get a new heart, I will be knocking on the door again... I'd

love to earn a decent wage and contribute more to the kids. That would be normal for me.

There have been a couple of times when I've been in hospital when I thought I was gonna go [Tony laughed]. I was really quite calm. I'd had a bad run where I was shocked about four times in a row. I felt terrible and when the nurse told me that there was a danger that I could die, the relief was sensational [Tony laughed]. It was like, "Oh yay. I don't have to go through this crap anymore." I actually died, a few times. They brought me back and they asked me if I wanted to be resuscitated again next time. I choose for them not to resuscitate me and then it happened again but they resuscitated me [Tony laughed].

*Tony was nicknamed 'miracle boy' by the doctors and nurses at Waikato hospital because he survived many crisis points when they predicted he would pass away. Tony, who felt he was well looked after and spoilt by the medical staff, had his own room at Waikato hospital. This is a reflection of the nature of his condition and the rapport he had with medical staff. Tony recalled the reactions of his friends and family to his decision not to be resuscitated.*

Merve got angry [Tony laughed]. He stormed out [Tony laughed]. My sisters knew where I was coming from. Believe it or not, it's a nice place to be. And to be brought back again for what? To have to go through it all again. And, as I say, it's been 20 or 30 times that my defibulator has saved me and I'm sick for a long time afterwards because it takes me a long time to recover. We didn't tell everyone. We just told my sisters, Merve and my immediate family. My oldest boy and girl didn't take it too well but they respected my wishes.

My sister used to do all my talking for me. I find it difficult talking about myself and my sister would explain to everyone what was going on. That was a lot easier for me, otherwise I would be repeating myself a thousand times [Tony laughed]. You begin to feel like a scratched record after a while.

In September 2009, the specialists sent me home. They didn't give me long at all. They had done all they could. My heart was going into funny rhythms all

the time and the doctors couldn't predict what was going to happen. They thought perhaps one time I was going to go into it and not come out of it. It is July 2010 now and I'm still here [Tony laughed]. I don't know what they are keeping me around for [Tony laughed].

*During this time, it was decided that one of Tony's sisters would stay with him to be his caregiver so he would not be alone when he passed. Tony also went under the care of Hospice Waikato. At this point in the interview, Tony referenced an emergency cord which, when triggered, alerts the ambulance service. Tony recalled the reactions of friends and family to his terminal diagnosis.*

My children were very stand offish to begin with. When they understood what's wrong with me and what could happen, they could be very understanding and got the idea really quick. For the two youngest ones, because I can make it sound funny, it sort of makes it easier for them. My sisters took my terminal diagnosis harder than I did. My mates were all a bit stand-offish. I guess it's not the easiest thing to be around a person who is terminally ill. What do you say? [Tony laughed] I don't know. What do you say? [Tony laughed]. I guess being close to my army mates, their initial reaction was, "Oh good, another hangi" [Tony laughed] or, "Could I have this? Can I have that?" [Tony laughed] I just loved that. I could only laugh. We always look at each other and they go, "You're still here aye bro?" "Yeah, still here brother."

When they told me to go home, there was an inner peace with me because at least I knew where I was at. It meant that I was not chronically ill anymore where I'm gonna be sick regardless but there was going to be a point where I was gonna be relieved of this illness. That was quite a comfort. Being chronically ill means that you've always got to be on top of something, always got to have your medications right, always got to be on time with this, on time with that, do this, do that. Being terminal means that you do it but, I think, with a more calming sense about you. It's quite strange.

*By November 2009 Tony had developed diabetes. Tony described how he felt about having multiple chronic conditions.*

Being chronically sick, to me, is a sentence. It's something you have to try and live with but it can be very restricting. If you take away a person's ability to work and fend for himself, the capacity to provide for himself and to go and enjoy life, those are three big things to take away from any person. Being chronically ill, coming from a person who was active, it is a sentence because it doesn't give you a hell of a lot more to do. And I haven't got the patience to sit around and do jigsaw puzzles or paint or knit [Tony laughed]... Being chronically ill suggests to me that you are sick all the time. You feel like disaster all the time [Tony laughed]... It's funny to explain but you feel like you are living on borrowed time, and you're grateful for the borrowed time, but then it's no use living like that if you want to have a normal life.

In my mind, I'm still active. I think that has been one of my main problems throughout. In my mind, I've always felt like I could do things. Of course, I'd go and do things and end up falling over and in hospital again. I know people look at it differently. I've always felt like I could dig my way out it somehow... I've been to some conferences where people thrive on being chronically ill, almost to the point that they are bragging about it. I can't see it that way... It's quite a [short pause] closed shop for me. I wanted to be that way. I didn't really want to talk about my problems with anyone else... Other patients you know they are blah blah blah. All they want to do is talk about themselves. So I wasn't really interested in finding out, in hospital anyway, about other people's conditions. It was enough to know we were all in the same boat [Tony laughed].

I think another important thing is the different stages you go through. You have constructive and destructive times, you have times when you are full of hope and it turns into despair and you find yourself back on the bottom of the pile. Those situations change quite frequently. From week to week I could be feeling really good and then hit a slump or hit a wall or something and feel really depressed and uptight again. There are some frustrating ebbs, lows and highs there. It's like a big wave sometimes and the longer it flattens out the

easier it is getting... I went from a point where I was able to work then unable and then I was disabled and then incapable. It is like it's stripping you piece by piece and you lose one and then the other and you get to the bottom and there's nowhere else I can go from there.

I'm on the invalid person's benefit [Tony laughed]. I'm an invalid person [Tony laughed]. I hate that name. It's terrible. Invalid's beneficiary. I qualify for a disability allowance [Long pause]. It's a struggle being on it. You don't get very much [long pause] but it's enough to keep me in my home, look after my kids and I'm still alive so [Tony laughed]... The government pay a subsidy on all my drugs. While I was working, the drugs a month were costing me \$390. So that's basically where all my wages were going when I was working. Now that I'm on the invalid's benefit, I pay for the first 21 items per year and the rest is all subsidised which is a huge saving... I don't think there is much more the government can do to improve my situation.

I've come such a long way though mate, I tell you. In September they gave me a month and that is almost a year ago. Last September I felt like I only had a month [Tony laughed]. I felt like crap. End of story. [Short pause] because I've been doing so well, Hospice Care have discharged me from their books. I no longer see them so that's a victory in itself and a very good one.

I could have a chance of returning to some sort of normalcy in my life where work would be a factor. I'm still only young. I've still got 20 years of work in me, easy... If I can get down to 100 kilos then the doctors are gonna to look at giving me another heart. It's not going to happen overnight but my diet is gonna help me get my weight down. That's the ultimate goal anyway and then I'm then I can throw all these drugs away [Tony laughed]... I'd also get the pacemaker and defibulator taken out and I would be more independent.... I've given myself a year to be ready now that I've been given the option. So while being chronically ill was a sentence before, given this option, I can see the out now. So maybe it's just a stage in my life that I need to go through. I still don't know what the lesson is yet. I think there's a few in there aye? [Tony laughed].

## Chapter Four

### CONCLUSION

People's narratives stand by themselves as representing subjective experiences of people living and working with chronic conditions. However, it is also appropriate to draw out some of the key themes that the stories reflect about people with chronic conditions and their employment experiences. There are two ways this will be done. First, each narrative will be summarised in order to highlight the employment issues faced by each participant in the context of their chronic condition and personal circumstances. Second, the three sets of research questions will be revisited and answered in the light of the narratives.

#### Summaries

##### *Pauline*

Pauline, who is now 41, was diagnosed with Systemic Lupus Erythematosus at the age of nine. Given that 31 years has lapsed since she received this diagnosis, Pauline has come to see her condition as a part of her identity, embodiment and something that adds depth to her personality. It has also influenced how she sees the world, how she approaches other people (with lots of empathy and compassion) and her attitude toward life. When I asked her what it would be like if her condition disappeared, she struggled with the idea of not having it.

Pauline has worked as an accountant in varying positions of seniority for 21 years in New Zealand and Australia. Work provides her a number of important values - it gives her structure, the capacity to be independent, the capacity to socialise, to do the things she likes, and, for a time, the capacity to live and work overseas. What struck me during the interviews was how the rhythm of work - constant and fast-paced – is in tune with the rhythm of her personality. Work also serves as an outlet for her skills and abilities.

Pauline always willingly told her employers of the name, nature and the impacts of her condition on her ability and capacity to work during the application process. Pauline emphasised that her employers were always very

understanding of her condition and had received a number of forms of workplace support, both formal and informal, throughout her work history.

Pauline's current employment provides numerous forms of workplace support because it "matches her limitations" and she is able to tend to her health needs when required. The nature of this work, however, is contractual and short-term which means she does not have the security that comes with a full-time, permanent position. At the time of the interviews, the end of her work contract was approaching. Pauline spoke a lot about her concerns around losing her income and of seeking employment in an open labour market against 'able-bodied' applicants. Fortunately, after the interviews were conducted her current employer extended her contract indefinitely. Pauline supplements this work with some stable, though limited employment for the business of a personal friend.

There have been a number of impacts on her current and future employment choices. Pauline's condition has progressed to a stage where she cannot cope with the pressure that is involved in permanent, full-time employment. At the time of the interviews, Pauline felt able to work up to 20 hours per week. In terms of her overall health and wellbeing, she was aware that "it would be better for her health not to work". Pauline can no longer aspire to positions of seniority because she cannot cope with the stress of managing the work of others as well as an active chronic condition. When applying for employment in organisations she has not previously worked, Pauline emphasised her concerns around finding work that matches the stage and limitations of her condition as well as being discriminated against on the basis of her health status.

Pauline has experienced two major flares in her condition. Despite effort to cope with and maintain full-time employment, both of these flares have forced her to discontinue work on a temporary basis as well as return home to New Zealand to live with and be partially cared for by her mother. She also had to sell her home. In particular, Pauline misses the independence that comes with full-time work and living overseas. She wonders whether she will be able to return to full-time work, enjoy a level of financial independence

and be able to look after her condition without the help of her mother or another person. Pauline is concerned about replacing the support provided by her mother when she passes.

### *Susan*

Susan's condition is a mystery. It is believed she has chronic regional pain syndrome as well as an oedema in the navicular bone of her foot. Susan, who is a hard working high achiever, sees her injury as an intrusion on her health, lifestyle, aspirations and potential. At the time of the interviews, she felt "completely disenfranchised" by her injury.

For Susan, gaining an explanation and diagnosis took years talking to different conventional and unconventional practitioners, including four surgeons, an osteopath, a naturopath and foot mechanics, as well as self-research. What she wanted from her health practitioners was an accurate diagnosis, advice about how to cure or deal with her injury and for information to be conveyed in a way she could understand. After many inaccurate diagnoses and because she believed they were guessing, Susan formulated her own explanation of her injury.

Susan has a community of health professionals, both conventional and alternative, to assist in the maintenance of her injury and wellbeing. Susan emphasised the difficulties faced in relation to managing the public and private parts of her life as well as her medical regime. In particular, Susan stressed the incompatibilities between the health system and full-time work.

To be able to tend to the needs of her injury and maintain full-time employment, she had to negotiate and re-negotiate domestic relationships and roles in her family life. Susan was often unable to assist in the completion of domestic tasks due to stress and the fragile nature of her injury. For this, she feels guilt.

Susan has worked as a secondary school teacher in a number of high schools across the Bay of Plenty for 28 years. Work reinforces her sense of self-

worth, she enjoys interacting with students, it enables her to sustain her lifestyle and meet the costs of her treatment regime.

Susan has worked in two schools since the onset of her injury in 2005. At both schools, she approached school and departmental management on several occasions to ask for forms of workplace support to enable her to carry out her normal work roles or to ease her load. However, in a context of limited resources and staff, Susan received very few, informal and often temporary mechanisms to cope with full-time employment and her chronic injury, unless assisted by an independent body, such as ACC or an occupational therapist. Susan quickly became aware that school management and colleagues did not want to listen to the issues she experienced in relation to her injury.

Susan, who felt judged and targeted by school management and some colleagues, described both schools as hostile environments. In order to deflect and/or temper this hostility, Susan deployed fronting and passing behaviour so she would not appear to be causing difficulties to other colleagues and school management. Other coping mechanisms deployed by Susan were primarily designed to minimise her walking, the pain and manage her energy levels.

Due to the unwillingness of school and departmental management to accommodate her limitations, Susan's injury was exacerbated and she experienced considerable stress and depression. To this end, she sought to and successfully gained employment at another school. Because she was concerned about the comments colleagues at her first school may have made about her to the prospective employer, she forewarned the second school during the application process. Susan specifically sought out a private school because it had a smaller campus and they offered her a classroom near the staffroom.

Susan is begrudging of the limitations imposed on her by her condition. With regard to employment, her chronic injury has had many impacts on her current and future employment choices. Susan feels that she cannot apply for

or take on positions of seniority. Due to issues with mobility, she cannot work in schools that have a large campus and requires her own classroom which is not viewed favourably by some colleagues and school management. Susan and her husband have also stalled plans to teach overseas because she is concerned about whether her condition would flare up again.

### *Pearl*

Pearl was diagnosed with endometriosis in her late teens and with MS at the end of 2009. After many ‘dreadful’ experiences of both the practices and practitioners of the mainstream health system in relation to endometriosis, Pearl decided to manage it through a holistic regime and developed a system of “knowing her body”. After a similarly dreadful experience with the mainstream health system during initial treatment for MS, Pearl decided to leverage the systems she had developed to deal with endometriosis to cope with the physical impacts of MS. While Pearl had learnt to deal with the physical impacts of both diseases, she continued to struggle with the emotional impacts. In particular, Pearl had difficulty trusting how she perceived and felt about things within her world. Pearl commented, “I just don’t know what’s real anymore”.

Pearl worked primarily in administration and horticulture with endometriosis and had recently undertaken tertiary level study when she was diagnosed with MS. Pearl, who would not willingly disclose her condition to her employers or her colleagues during the recruitment process, would disclose and talk about her condition to colleagues when she needed time off, after an acute attack and when she believed other colleagues had their own health issues which she suspected they wanted to talk about. While her male employers did not want to know about her “female” health issues, her employers were willing to allow her to take time off when she required. Though Pearl took time off occasionally, she felt that her condition did not impinge on her contribution to the workplace. Pearl did not lose employment due to endometriosis, however, there were times when she opted to leave jobs for a number of reasons. The issues she faced around her health while working was one of these reasons.

Pearl had particular difficulty dealing with and negotiating the responses of friends, family and partner to her MS diagnosis. To this end, she deployed fronting and passing behaviour and became “stuck in the role of making it okay” for friends and family. Pearl is most concerned about the impacts her condition might have on her daughter.

While Pearl begrudgingly accepts the current parameters that come with her illnesses, she is still coming to terms with and is very concerned about the future limitations she may face due to MS. She is particularly concerned about the potential loss of her cognitive abilities. At the time of her MS diagnosis, Pearl had started tertiary study in the subjects of psychology and social policy. In the light of realising the current and potential limitations of her condition, Pearl reduced her workload, was forced to rethink and change her current course of study and thus future career options. Pearl has not sought employment since her diagnosis.

Pearl is concerned about her employability and about the idea of seeking employment in the future. The idea of working with an unpredictable, uncontrollable chronic condition and her concern about whether an employer would be willing to accommodate her health needs is one she has not been able to reconcile. Pearl was also concerned that future potential employers might question her skills, abilities and capacity to reliably and continually produce at work.

### ***Tony***

Tony was diagnosed with cardiomyopathy in 1996. Prior to and at the time of this diagnosis, Tony was a very active and outgoing person. He had many physically demanding jobs and was involved in competitive sports. Tony loved to challenge himself and to extend his abilities and capabilities in these areas of his life.

Tony went through different phases in regard to his attitude towards his condition. Because a potentially incapacitating heart condition did not match his occupational identity and self-image at the time of his diagnosis, Tony denied the existence of the condition and did not alter his lifestyle until it

progressed to an active stage. Since the event that triggered that progression, the condition and its symptoms became more and more difficult to manage, particularly while in full-time employment. Tony, who drew parallels between living with a chronic condition and a prison sentence, had an army of only conventional medical professionals assisting in the maintenance of his health and wellbeing. Relationships with and information gained through conversations with medical professionals, enabled Tony to understand and then “get serious” about his chronic condition.

When his condition deteriorated to the point where he was forced to stop working and acknowledge the impacts it would have on his life, he slowly but begrudgingly accepted it. At the time of the interviews, Tony described himself as a “closed shop” and commented that he missed the independence that comes with being ‘able-bodied’. Further, he missed the choices, sense of normalcy and financial independence that he had when working full-time.

His employment history is characterised by getting fit for work, trying to maintain a form of employment for a period of time and then being forced out of work due to acute or gradual deteriorations in his condition. Work, particularly physical work, exacerbated his condition and advanced it to a more active and serious stage. As his health deteriorated the nature of his positions and jobs involved less physical tasks as well as working with people with disabilities. An interesting point to note here is the progression of the jobs he obtained matched the progression, and, in particular, the limitations of his condition. Tony repeatedly emphasised that he was lucky to have had supportive employers and colleagues. When Tony was unable to renew his licence in 2004 due to the high amount of the medication he was taking, he did not return to any form of employment. He did, however, engage in part-time study. Tony applied for one job since 2004 but did not obtain it.

Tony hoped to, once again, become well enough to return to some form of employment. Due to his reputation and performance, he was certain that previous employers would re-employ him. In relation to seeking employment in organisations he had not previously worked for, Tony was aware he may have faced discrimination on the basis of his health status. Until he received a

new heart and his medication intake reduced significantly, Tony was not eligible to return to work or renew his driver's licence. The latter may have been a significant barrier to obtaining employment. In December 2009, Tony passed away.

### **The Lived Experience of People with Chronic Conditions**

The first set of research questions outlined in the introduction is: What are the subjective experiences of people who live with a chronic condition? What are the meanings they ascribe to those experiences? How do they interact with and operate within the micro-structures of family, friends, the health system and government agencies?

The participants went through different phases in relation to their attitudes towards their condition. Each participant had to come to terms with the incurable, unpredictable nature of chronic conditions and were begrudging of the limitations it imposed on them. While participants may have come to terms with the current limitations of the condition, they were all concerned about limitations that they might have to deal with in the future. Pearl commented, "I think the fear of it [the future impact of the condition] gets to me at times, trying to manage the illness as well as worrying about the future." Those who were diagnosed with a chronic condition in their adult life missed the independence and freedom that comes with being 'able-bodied'. In effect, they had to learn how to live with a long-term, unpredictable condition.

Not one of the participants in this study belonged to or regularly attended a support group. Pearl commented, "I am kind of avoiding that [support groups] like the plague right now. I'm just not ready to walk into some drafty hall to see what the future could be." While Pearl was not prepared to attend a support group at the time of the interviews, she was aware that she needed to access some form of support. She decided to join MSNZ on facebook where she observed online discussions and communicated anonymously with a MSNZ representative. After the interviews, Pearl was introduced to two women with the same condition. These women have become a source of support. Pauline, who had a bad experience at a support group when she was younger, started a gathering of people with the same condition as her.

Participants described themselves as the decision makers around the various health practitioners they chose to advise them about how to manage their illness. Tony and Pauline, who drew primarily on the conventional health system, saw themselves as working in partnership with the health practitioners that helped them. Pauline, who controlled how much medication she would take, would consult her doctor before changing the dosage of some her medication. Pearl, who only accessed the conventional health system after acute episodes and whose condition did not have a treatment regime, developed her own way of managing her condition.

All of the participants described the management of their treatment regime as a full-time job and the management of symptoms as an on-going, daily struggle. Those who accessed elements of the health system as part of their treatment regime emphasised the importance of having good relationships with health practitioners. Pauline mentioned, “It’s important when you’ve got a condition like this that you have a good relationship [with people in the health system] because you are there so much, you are demanding and then they know you know what you are talking about.” It seemed that having a good relationship with health practitioners also enabled participants to get what they needed more promptly.

Susan, the only participant in permanent, full-time work, stressed the barriers she faced when trying to access the health system. She pointed out, “If you are working you really are disadvantaged” because health practitioners work during the same hours of the day. This barrier restricted access to the health system and seemed to create other barriers that she had to contend with, such as contacting and receiving health practitioners during work hours, the lack of a private phone at work and completing her own work while having to take time off for consultations or treatment.

Participants in this study seemed to want health practitioners to make sense of their symptoms, to diagnose them accurately, to explain their illness without expert or technical language and offer treatment options that worked. This applied to both conventional and unconventional practitioners. This finding affirms those of Parsons (1951), Goffman (1963), Senior and Viveash (1998)

and Miskelly (2006). When participants were not satisfied, they would engage in their own research around their condition and healing options, ask their practitioners for different treatment options and/or consult other conventional or unconventional practitioners. This finding is supported by Miskelly (2006). She also noted her participants often continued therapies when they did not work, a finding of this research as well.

The participants in this study were ambivalent about medication. The often high cost of medication posed a financial burden. Also, while they were aware that medication would give them relative control over their symptoms and would assist them in mediating the impacts of their symptoms, they were uncomfortable about the short-term and long-term consequences of consuming medication. Pauline commented, “The drugs are helping maintain my level of quality of life, although I’m always on a mission to reduce the drugs. I’m starting to experience the long-term side effects of long-term drug use.” Susan pointed out, “I have a love-hate relationship [with medication]. I hate taking it but I love that it takes away the pain.” Participants who consumed medication wanted the medication to bring about the outcomes they promised. Susan pointed out, “I really, really need it to work. I want to be able to rely on it.”

“The welfare system is a necessity for us”, Tony commented. People who are chronically ill move in and out of the labour market and they have reduced capacity to earn. Participants who accessed the welfare system were questioned by their case workers about the existence of their condition because they did not have visible symptoms or appeared to function normally. Pauline commented, “I feel like I’ve got to look sicker because they can’t physically see the signs of it.” These experiences mirror the experiences of people with mental illness whose case workers accused them of feigning their illness, trivialised their symptoms and made them feel like a ‘dole bludger’ (Peterson et al., 2006). Participants also talked about the struggle of transitioning to from a wage to welfare as well as maintaining their medical regime while on a benefit.

It seems further changes to welfare provision introduced in May 2011 might exacerbate the experiences of people with chronic conditions. If those on the sickness benefit are deemed able to cope with work are obligated to accept employment. However, this reform makes no indication that the work will be sensitive to the type, nature and stage of their condition.

The participants were dissatisfied with the limited and short-term nature of assistance they received from ACC. Susan mentioned, “They often have six week [rehabilitation] programmes, but how is that meant to deal with a three year problem?” Participants also noticed that ACC tried to find ways to get out of offering assistance and only became serious about offering assistance when their condition might force them to discontinue work.

### **The Employment Experience of People with Chronic Conditions**

The second set of research questions outlined in the introduction is: What are the subjective experiences of people with chronic conditions in the context of paid employment? How does having a chronic condition colour their experience of finding and keeping paid work?

After coming to realise the impacts of the condition on their current and future employment possibilities, all the participants internalised those limitations and reduced their employment aspirations to suit. Further, because of the progressive nature of chronic conditions, these aspirations continually shift with the condition. For all of the participants in this study there was a difference between what they hoped to achieve and what they were able to achieve within the context of work.

People with chronic conditions are unique in the sense that, on top of factors that influence recruitment and promotion processes, such as age, gender, previous experience, level of education and so on, they need to seek employment that is in tune with the nature and stage of their condition. Beynon and Tucker (2006) found that the reduced capacities of those with chronic conditions affect the number of hours and type of work they are able to do. Several other studies found that one’s capacity to be employed is directly related to the functional and cognitive limitations imposed by the

condition (Baanders, Rijken & Peters, 2002; Beatty, Blanco, Wilbanks, Paul & Hames, 1995; Beynon & Tucker, 2006; Bombardier & Buchwald, 1996; Camilleri, Jessop, Davis, Jessop & Hall, 1995; Gordon, Stoelb & Chiriboga, 1997). What became apparent from this study is that the nature and stage of the condition determines what is possible for people with chronic conditions in terms of the kinds of study, jobs or careers they can aspire to, how much they can work and the types of tasks they can physically carry out and cope with. These factors narrow the employment choices of this group of workers to particular jobs, positions and sectors of the labour market.

All the participants were aware of and concerned that they may face some form of discrimination in the future when applying for employment. This was particularly so when in competition with 'able-bodied' applicants, when applying for work in organisations they had not previously worked and for those returning to work after being out of the workforce for a long time. This mirrors the findings of Vickers (1995 & 2001) and Allen and Carlson (2003). The concern revolved around how prospective employers might perceive the impacts of their condition on their work performance. Pauline commented, "They are going to look at me and go, "She has this condition." You've got to tick a box, you know. So I feel a lot less marketable these days. There's no way you are going to stand up against other fit and healthy people who can commit fully to an organisation."

The limitations experienced by people with chronic conditions can be mediated by how willing employers were to accommodate the condition-related needs of the participants. None of the organisations that the participants worked for had a policy around disability, injury or illness. Workplace support mechanisms offered to those who disclosed their illness were mostly informal, limited, short-term and attached to individuals. These mechanisms only existed as long as those individuals worked in the organisation or department or as long as they are willing to offer them. Despite this, participants stated that, for the most part, employers were understanding of their condition and the impacts it had on their contribution to the workplace. However, even in organisations that are willing to

accommodate the limitations of people who are chronically ill, the nature of the work itself can still be intolerant of chronic conditions.

Paid work is a difficult terrain for people with chronic conditions to negotiate. This is because the agenda and the rules of work - work tasks, deadlines, the pace of work and so on - are set by something or someone else. When participants were employed in forms of work that were not in line with the limitations of the condition and/or when participants sought to defy the limitations of their condition within the context of work, their symptoms would be exacerbated and/or the condition would progress to a more active stage. If their condition was already active, the condition would incapacitate them.

While none of the participants reported difficulties getting work, all participants experienced considerable difficulty maintaining work. This is supported by (Dyck & Jongbloed, 2000; Baanders et al., 2002; Beynon & Tucker, 2006; Varekamp et al., 2006). To maintain employment, participants needed to create ways of coping with long-term illness as well as the vicissitudes of everyday life. When participants were involved in employment, they engaged a core of transferable coping strategies and mechanisms. Additional strategies and mechanisms were developed when new or unusual issues arose. When their condition worsened, participants had to deploy more coping mechanisms. The strategies and mechanisms deployed by participants were their way of both enabling them to complete daily work tasks and to retain employment.

All of the participants have been forced by their condition to discontinue work on a temporary or permanent basis. At the time of the interviews, Susan was the only participant involved in permanent, full-time work and another participant was at a stage where it was beneficial for their health not to work. Pauline commented, "If I was to give up work for six months, it may enable to keep me more fuller into remission which then may enable me to work even more. But that's the catch 22 and the ongoing, vicious cycle of how to manage it." Two participants left an organisation and sought employment

elsewhere because their employer and some colleagues were not willing to accommodate their needs, nor provide meaningful support.

At the time of the interviews, the two participants not involved in any form of paid employment faced significant barriers in their desire to return to work. Tony required a new heart and a significant improvement in his overall wellbeing. Tony commented, “I know my capabilities and I’m not capable of very much.” Pearl faced some strong psychological battles. She commented, “In my darker days I wonder whether I will ever get legitimate employment again. I do have times when I think, ‘Who’s gonna want to employ me?’”

All the participants who were not able to engage in permanent, full-time work missed the values that come with permanent, full-time employment. These values included, but are not excluded to, the capacity to contribute financially to their families, the capacity to pay for different aspects of their treatment regime, the means to save for retirement, the means to own a home or pay for rent and/or the means to. Participants struggled to support themselves without financial support from a family member, government subsidies and/or welfare. Tony commented, “It’s a struggle being on it. You don’t get very much.”

### **People with Chronic Conditions, Social Norms and Ideologies**

The third set of research questions outlined in the introduction is: How do people with chronic conditions interact with and respond to societal norms, values and dominant ideologies that may be difficult for them to conform to given the nature of their chronic condition?

The participants in this study held firmly to the belief that all people should work hard. All of the participants wanted to be able to give more of their skills, abilities and experience to the organisations they worked for. This confirms the findings of Radley (1989) who said that people who are chronically ill as “bound within a work ethic that they could not satisfy” (p. 245). The participants who had to reduce their hours of work or were not able to sustain any form of work talked about how they had to come to terms with societal perceptions associated with those who are unable to work. Pauline

commented, “I buy into that idea [that people should work hard and be productive] so of course that perception takes a toll when you physically can’t be productive. You waste energy working through the grief and letting go of what you ‘should’ be doing and of course worrying about what people think.”

The participants in this study wished to live as independently as possible. At different times in the past, all of the participants required some form of care or support as a result of hospitalisation, incapacitation or because they could not do things for themselves. They were uncomfortable with the idea of needing help and saw themselves as burdening those they leaned on. These feelings were tempered somewhat by the realisation that care and support was something they really needed.

The participants who were parents were aware that they were not able to provide financially for their children. They sought to be a good parent by being supportive and caring in other ways, such as being supportive with their homework, their health and happiness. Tony mentioned, “We are on a very, very tight budget. I think if I can provide a breakfast, some lunch and a hot meal for them at night, I’m doing well. I spoil them every chance I get when I’ve got spare money.” Both Tony and Pearl were very concerned about the impacts of their condition on their children. Pearl commented, “My biggest concern is how it [my condition] affects her [my daughter]. My fear is that she is an only child and there will be times when she’s isolated and emotionally neglected because I’m so wound up in myself and what I’m experiencing in my illness.”

### **Methodological Limitations and Strengths, and Further Research**

My study is distinctly limited by its size and scope. Only the narratives of four people who experience chronic conditions are presented. However, because their stories are (re)presented in full, readers get an understanding of the lives of these individuals who experience chronic illness and the issues they face in the context of employment. An expansion of this study could include a large-scale research project incorporating a wider range of people with different kinds of chronic conditions.

One of the participants in this study owned a small business during the course of her chronic condition. While Pearl felt empowered and enjoyed the relative freedom of being her own boss, she was required to be at work all the time and had to organise cover for staff when they required time off. While there is an ample amount of research around the experiences of workers who have chronic conditions, the experiences of managers and those who own organisations who are affected by chronic conditions is under-researched. Further research on this group would fill a gap currently untapped, particularly in relation to how they cope with their role as manager or owner, what enables them to carry out or maintain their positions of seniority and work tasks, what kinds of people they employ (whether they employ people with or without health issues) and their reasoning for employing or not employing them.

Another area requiring further investigation are the views of the government, employers and workers around where responsibility lies when people with chronic conditions are involved in employment. As mentioned, though forms of workplace support can be negotiated between workers and employers, in New Zealand employers are not statutorily required to provide support for workers with chronic conditions. None of the employers of my participants had a policy around chronic illness and the forms of workplace support were mostly informal. While some participants in this study asserted their employers should provide them with support, whether it be in the form of adequate facilities, special equipment or flexible working arrangements, other participants did not expect to receive workplace support but grateful were when they did. This raises the following questions: How does each group perceive their responsibilities or where do they believe responsibilities lie? What factors influence how people view responsibility and how it should be attributed? What expectations do workers with chronic conditions have of their employers with regard to support, and do they mirror the views of employers and the government? How do the views of these groups reflect dominant neoliberal, individualistic values?

## **Unpredictable, Incurable, Unemployable? The Complexity of Chronic Conditions and Employment**

This is a qualitative account of the subjective experiences of people with chronic conditions within the context of work and broader social structures. It deals with a small, diverse group of people at a particular point in time. The intention of this study is to make their voices heard through (re)presenting their own stories in their own words. The reader is able to listen to these accounts and to think about the lives that are revealed. It is firmly located within present-day New Zealand and sheds more light on an area that is under-researched.

Though the participants in this study were in different stages of their condition, their stories reveal both similarity and complexity. I have found that people with chronic conditions were forced to negotiate and renegotiate social, familial and collegial relationships. They were also confronted by social structures which did not facilitate the working lives they wanted to lead, and by social norms and ideologies whose standards and ideals they could not meet. However, participants were also able to work within these social structures to create positive outcomes.

Despite obvious and considerable differences in the types of employment engaged in by the participants, important commonalities exist in the employment experiences of this small, diverse group. The issues faced by participants and their capacity to engage in work were related primarily to the nature and stage of their chronic condition. What is possible within the context of employment - the kinds of jobs they can have, the kinds of tasks they can carry out, and the level of seniority they can hold - was determined not by their aspirations, nor by the kind of worker they wanted to be, nor the career they wanted to pursue. It was determined rather by the parameters of the condition, and by issues surrounding medication and treatment regimes, what an employer was willing to accommodate, how they dealt with their personal circumstances and how they coped with relationships with other people. They have learned to accept significant differences between what they aspired to achieve and what they are able to achieve.

These complexities experienced in the workplace seemed to stem from the fact that their conditions are incurable and their symptoms unpredictable. This seemed to create difficulties in all areas relating to finding and keeping work. To gain work in the labour market with an incurable and unpredictable condition, competing against 'able-bodied' workers who do not have limitations, people who are chronically ill sought employment through people they knew and sought employment in organisations they had previously worked for. If these kinds of options were not available to them, either they did not seek employment or had low expectations about whether they would be successful in their pursuit of employment. While it may have been better for their health and wellbeing not to work, at times they either very strongly desired or acutely needed to obtain the values, satisfactions and rewards that work can offer.

Work can be a place where people with chronic conditions struggle to manage their condition and have to negotiate and renegotiate several areas of their life to sustain work. It can also provide a sense of structure, a sense of normality, a source of self-worth, a space for meaningful interaction and independence.

I strongly agree with Vickers (2001) who asserted that people who have chronic conditions do not "fit comfortably or neatly into capitalist structures" (p. 17). Vickers (2001) also asserted, and again I strongly agree, that modern organisations can be intolerant of illness because it is viewed as a "bothersome human inadequacy detracting from the efficient processes of organisational life" (p. 28). Because of the incurable, unpredictable nature of chronic conditions and the limitations they impose on one's capacity to perform at work, people who are chronically ill can easily be viewed by employers as unemployable. Some employers and managers did not want to deal with the frailties of people and did not feel a sense of responsibility to assist them.

Those employers and managers who are willing to listen and be creative with solutions to assist them in employment, value the knowledge, skills and empathy that people with chronic conditions acquire as a consequence of their condition.

Pauline and Susan have both been successful in maintaining employment. Though this has come at a personal cost because of the things they have to do, they gain many benefits from being able to work and from being able to bring about outcomes their employers value. Both Pauline and Susan have achieved this through their unrelenting determination to overcome the difficulties they face. But it was also achieved through support provided by family, friends and health professionals and because their employers were committed to helping them. As Pauline put it:

“They are providing me with an employment opportunity that marries up with the limitations I have... So it’s a win win situation. I feel like I’m adding value to them and they are certainly giving me a great opportunity to be able to do that.”

Unpredictable, incurable, but employable.

## REFERENCES

- Adams, G. B., & Balfour, D. L. (1998). *Unmasking administrative evil*. London, England: Sage.
- Ahlstrom, G. (2005). Experiences of loss and chronic sorrow in persons with severe chronic illness. *Journal of Clinical Nursing, 16*(3a), 76-83. doi: 10.1111/j.1365-2702.2006.01580.x
- Allen, S., & Carlson, G. (2003). To conceal or disclose a disabling condition? A dilemma of employment transition. *Journal of Vocational Rehabilitation, 19*(1), 19-30. Retrieved from EBSCO database.
- Anderson, J. M. (1991). Immigrant women speak of chronic illness: The social construction of the devalued self. *Journal of Advanced Nursing, 16*(6), 710-717. doi: 10.1111/j.1365-2648.1991.tb01729.x
- Annandale, E. (2008). The political economy of health and healthcare. In S. Earle & G. Letherby (Eds.), *The sociology of healthcare: A reader for health professionals* (pp. 3-12). Basingstoke, England: Palgrave MacMillan Press.
- Baanders, A. N., Rijken, P. M., & Peters, L. (2002). Labour participation of the chronically ill. *European Journal of Public Health, 12*(2), 124-130. Retrieved from ABI/INFORM Global database.
- Baldwin, M., & Johnson, W. G. (2001). *Dispelling the myths about work disability*. Washington D.C., Washington: National Academy of Social Insurance.
- Barthes, R. (1966). *Introduction to the structural analysis of the narrative*. Birmingham, England: Centre for Contemporary Cultural Studies.
- Beatty, J. E., & Joffe, R. (2006). An overlooked dimension of diversity: The career effects of chronic illness. *Organizational Dynamics, 35*(2), 182-195. doi: 10.1016/j.orgdyn.2006.03.006
- Beatty, W. W., Blanco, C. R., Wilbanks, S. L., Paul, R. H., & Hames, K. A. (1995). Demographic, clinical and cognitive characteristics of multiple sclerosis patients who continue to work. *Journal of Neurologic Rehabilitation, 9*(3), 167-173. Retrieved from Academic OneFile database.
- Bennett, P. (2011). *Next phase of future focus kicks in*. Retrieved from

<http://www.national.org.nz/Article.aspx?articleId=35845>

- Beynon, P., & Tucker, S. (2006). Ill health, disability, benefit and work: A summary of recent research. *Social Policy Journal of New Zealand*, 29, 78-101. Retrieved from <http://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj29/ill-health-disability-benefit-and-work-29-pages78-101.html>
- Bombardier, C. H., & Buchwald, D. (1996). Chronic fatigue, chronic fatigue syndrome and fibromyalgia: Disability and health care use. *Medical Care*, 34(9), 924-930. Retrieved from JSTOR database.
- Boot, C. R. L., Heijmans, M., van der Gulden, J. W. J., & Rijken, M. (2008). The role of illness perceptions in labor participation of the chronically ill. *International Archives of Occupational & Environmental Health*, 82(1), 13-20. doi: 10.1007/s00420-007-0298-5
- Boyatis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA; Sage.
- Brooks, M. V. (2003). Health-related hardiness and chronic illness: A synthesis of current research. *Nursing Forum*, 38(3), 11-20. Retrieved from Academic OneFile database.
- Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health & Social Behavior*, 35, 34-52. Retrieved from JSTOR database.
- Brumberg, J. J. (1997). *The body project: An intimate history of American girls*. New York, NY: Random House.
- Bryman, A. (2004). *Social research methods* (2nd ed.). Oxford, UK: Oxford University Press.
- Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness*, 13(4), 451-468. Retrieved from EBSCO database.
- Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health and Illness*, 23, 263-285. Retrieved from EBSCO database.
- Bury, M. (2005). *Health and Illness*. Cambridge, MA: Polity Press.
- Camilleri, J. P., Jessop, A. M., Davis, S., Jessop, J. D., & Hall, M. (1995). A

- survey of factors affecting the capacity to work in patients with rheumatoid arthritis in South Wales. *Clinical Rehabilitation*, 9(3), 250-253. Retrieved from EBSCO database.
- van Campen, C., & Cardol, M. (2009). When work and satisfaction with life do not go hand in hand: Health barriers and personal resources in the participation of people with chronic physical disabilities. *Social Science & Medicine*, 69(1), 56-60. doi: 10.1016/j.socscimed.2009.04.014
- van Campen, C., & Iedema, J. (2007). Are persons with physical disabilities who participate in society healthier and happier? Structural equation modelling of objective participation and subjective well-being. *Quality of Life Research*, 16(4), 635–645. Retrieved from EBSCO database.
- Chamberlayne, P., Bornat, J., & Wengraf, T. (2000). *The turn to biographical methods in social science: Comparative issues and examples*. London, England: Routledge.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5(2), 168-195. Retrieved from EBSCO database.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1997). Identity dilemmas of chronically ill men. In A. Strauss & J. M. Corbin (Eds.), *Grounded theory in practice* (pp. 35-62). Thousand Oaks, CA: Sage.
- Cooper, M. C. (1990). Chronic illness and nursing's ethical challenge. *Holistic Nursing Practice*, 5(1), 10-16.
- Coward, R. (1989). *The whole truth: The myth of alternative medicine*. London, England: Faber.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary strategies*. Thousand Oaks, CA: Sage.
- Crang, M., & Cook, I. (2007). *Doing ethnographies*. London, England: Sage.
- Curtin, M., & Lubkin, I. (1990). What is chronicity? In I. M. Lubkin (Ed.), *Chronic Illness: Impact and intervention* (pp. 2-20). Boston, MA: Jones.
- Davies, C. A. (2008). *Reflexive ethnography* (2nd ed.). London, England: Routledge.
- Davis, P., & Dew, K. (2005). *Health and society in New Zealand*. Auckland,

- New Zealand: Oxford University Press.
- Deeks, J., & Rasmussen, E. (2002). *Employment relations in New Zealand*. Auckland, New Zealand: Pearson Education.
- Denhardt, R. D. (1981). *In the shadow of the organisation*. Lawrence, Kansas: Regent Press of Kansas.
- Dew, K., & Kirkman, A. (2002). *Sociology of health in New Zealand*. Auckland, New Zealand: Oxford University Press.
- Dodier, N. (1985). Social use of illness at the workplace: Sick leave and moral evaluation. *Social Science & Medicine*, 20(2), 123-128. Retrieved from ScienceDirect Journals database.
- Donoghue, P. J., & Siegel, M. E. (1992). *Sick and tired of feeling sick and tired: Living with invisible chronic illness*. New York, NY: Norton.
- Doolin, B., & McLeod, L. (2005). Towards critical interpretivism in IS research. In D. Howcroft & E. M. Trauth (Eds.), *Handbook of critical information systems research: Theory and application* (pp. 244-271). Cheltenham, England: Edward.
- Dudgeon, D. (1992). Quality of life: A bridge between the biomedical and illness models of medicine and nursing? *Journal of Palliative Care*, 8(3), 14-17. Retrieved from ProQuest 5000 International database.
- Duneier, M. (1999). *Sidewalk*. New York, NY: Farrar.
- Dyck, I., & Jongbloed, L. (2000). Women with multiple sclerosis and employment issues: A focus on social and institutional environments, *Canadian Journal of Occupational Therapy*, 67(5), 337-346. Retrieved from ProQuest 5000 International database.
- Eakin, J. K., & MacEachen, E. (1998). Health and the social relations of work: A study of the health-related experiences of employees in small workplaces. *Sociology of Health & Illness*, 20(6), 896-914. Retrieved from EBSCO database.
- Encyclopedia Britannica. (n.d.). *Edema*. Retrieved from <http://www.britannica.com/EBchecked/topic/178972/edema>
- Engels, F. (1993 [1945]). *The condition of the working class in England*. Oxford, UK : Oxford University Press.
- Faison, K. J., Faria, S. H., & Frank, D. (1999). Caregivers of chronically ill

- elderly: Perceived burden. *Journal of Community Health Nursing*, 16(4), 243–253. Retrieved from JSTOR database.
- Falkenstern, S. K., Loeb, S. J., Gueldner, S. H., Penrod, J., & Poon, L. W. (2005). Healthcare providers' perspectives: Estimating the impact of chronicity. *Journal of the American Academy of Nurse Practitioners*, 17(5), 194-199. Retrieved from ProQuest 5000 International database.
- Faraday, A., & Plummer, K. (1997). Doing life histories. *The Sociological Review*, 27(4), 773-798. doi: 10.1111/j.1467-954X.1979.tb00360.x
- Finseth, C. (2009). *What is chronic illness? A definition and explanation of chronic disease*. Retrieved from the General Medicine website: [http://chronicillness.suite101.com/article.cfm/what\\_is\\_chronic\\_illness](http://chronicillness.suite101.com/article.cfm/what_is_chronic_illness)
- Fitzgerald, M. H., & Paterson, K. A. (1995). The hidden disability dilemma for the preservation of self. *Journal of Occupational Science: Australia*, 2(1), 13–21.
- Foucault, M. (1977). *Discipline and punish: The birth of the prison*. New York, NY: Vintage.
- Fraser, T. M. (1992). *Fitness for work: The role of physical demands analysis and physical capacity assessment*. London, England: Taylor.
- Fulder, S. (1996). *The handbook of alternative and complementary medicine*. (3rd ed.). Oxford, UK: Oxford University Press.
- Furnham, A., & Forey, J. (1994). The attitudes, behaviours and beliefs of patients of conventional vs complementary (alternative) medicine. *Journal of Clinical Psychology*, 50(3), 458-469. Retrieved from EBSCO database.
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *National Women's Studies Association Journal*, 14(3), 1–32.
- Gaze, H. (1991). More than meets the eye: Hidden disabilities. *Nursing Times*, 87, 49-51.
- George, A., Vickers, M. H., Wilkes, L., & Barton, B. (2008). Working and caring for a child with chronic illness: Challenges in maintaining employment. *Employee Responsibilities & Rights Journal*, 20(3), 165-176. Retrieved from ProQuest 5000 International database.
- Gething, L. (1984). Cumberland's strategy for changing attitudes. *Australian Disability Review*, 1, 44-52.

- Giddens, A. (2001). *Sociology* (4th ed.). Cambridge, UK: Polity Press.
- Glaser, B. G., & Strauss, A. L. (1999). *The discovery of grounded theory: Strategies for qualitative research*. New Jersey, US: Aldine de Gruyter.
- Goffman, E. (1963). *Stigma*. London, England: Penguin.
- Goffman, E. (1971). *The presentation of self in everyday life*. Harmondsworth, England: Penguin.
- Gordon, P. A., Stoelb, M., & Chiriboga, J. (1996). The vocational implication of two common rheumatic diseases. *Journal of Rehabilitation*, 63(1), 15-19. Retrieved from Academic OneFile database.
- Gray, D. E. (2009). *Doing research in the real world* (2nd ed.). London, England: Sage.
- Gratton, C., & Jones, I. (2010). *Research methods for sports studies* (2nd ed.). New York, NY: Routledge.
- Greene, K. (2000). *Disclosure of chronic illness varies by topic and target: The role of stigma and boundaries in willingness to disclose*. Mahwah, NJ: Lawrence.
- Hebl, M., & Kleck, E. (2002). Acknowledging one's stigma in the interview setting: Effective strategy or liability? *Journal of Applied Social Psychology*, 32(2), 223–249. doi: 10.1111/j.1559-1816.2002.tb00214.x
- Hirth, R. A., Chernew, M. E., Turenne, M. N., Pauly, M. V., Orzol, S. M., & Held, P. J. (2003). Chronic illness, treatment choice and workforce participation. *International Journal of Health Care Finance & Economics*, 3(2), 167-181. Retrieved from JSTOR database.
- Hollway, W., & Jefferson, T. (2000). *Doing qualitative research differently: Free association, narrative and the interview method*. London, England: Sage.
- Huberman, M. A., & Miles, M. B. (1994). *Qualitative data analysis* (2nd ed.). Thousand Oaks, CA: Sage.
- Hughes, O. E. (1994). *Public management and administration*. Basingstoke, England: MacMillan Press.
- Human Rights Commission. (2008). *Human Rights Act 1993*. Retrieved from <http://www.hrc.co.nz/human-rights-environment/human-rights-legislation/human-rights-act/>
- Hwang, S. S., Chang, V. T., Alejandro, Y., Osenenko, P., Davis, C.,

- Cogswell, J., Srinivas, S., & Kasimis, B. (2003). Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs Medical Centre. *Palliative and Supportive Care, 1*(4), 319–329. Retrieved from ProQuest 5000 International database.
- Hymovich, D. P., & Hagopian, G. A. (1992). *Chronic illness in children and adults: A psychosocial approach*. Philadelphia, Pennsylvania: Saunders.
- Ironside, P. M., Scheckel, M., Wessels, C., Bailey, M. E., Powers, S., & Seeley, D. K. (2003). Experiencing chronic illness: Cocreating new understandings. *Qualitative Health Research, 13*(2), 171-183. doi: 10.1177/1049732302239597
- Jakobsen, K. (2001). Employment and the reconstruction of self. A model of space for maintenance of identity by occupation. *Scandinavian Journal of Occupational Therapy, 8*(1), 40-48. doi: 10.1080/110381201300078500
- Jeon, Y., Essue, B., Jan, S., Wells, R., & Whitworth, J. A. (2009). Economic hardship associated with managing chronic illness: A qualitative inquiry. *BioMed Central Health Services Research, 9*, 1-11. doi: 10.1186/1472-6963-9-182
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243-248. Retrieved from Blackwell Science database.
- Johnson, D. P. (1989). *Sociological theory*. New York, NY: Wiley.
- Jones, K. (2003). The turn to a narrative knowing of persons: One method explored. *Nursing Times Research, 8*(60), 60-71. doi: 10.1177/136140960300800109
- Jones, K. (2004). Mission drift in qualitative research, or moving toward a systematic review of qualitative studies, moving back to a more systematic narrative review. *The Qualitative Review, 9*(1), 95-112.
- Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health & Illness, 18*(2), 241-257. Retrieved from EBSCO database.
- Kerson, T. S. (1985). *Understanding chronic illness*. New York, NY: Free Press.
- Key, J. (2008). *National focuses on work in benefits policy*. Retrieved

- from <http://www.national.org.nz/Article.aspx?articleId=28355>
- Kinzel, T. (1993). Key psychosocial aspects in the medical management of chronic illness. In J. A. Toner, L. M. Tepper & B. Greenfield (Eds.), *Long-term care: Management, scope and practical issues* (pp. 123-129). Philadelphia, Pennsylvania: Charles Press.
- Kleinman, A. (1988). *Illness narratives: Suffering, healing and the human condition*. New York, NY: Basic Books.
- Klimoski, R., & Donahue, L. (1997). HR strategies for integrating individuals with disabilities in the workplace. *Human Resource Management Review*, 7(1), 109-138. Retrieved from Business Source Premier database.
- Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2), 146-154. Retrieved from Blackwell Science database.
- Krieger, N. (2010). Workers are people too: Societal aspects of occupational health disparities – An ecosocial perspective. *American Journal of Industrial Medicine*, 53(2), 104-115. doi: 10.1002/ajim.20759
- La Bier, D. (1986). *Modern madness: The emotional fallout of success*. Sydney, Australia: MacMillan Press.
- Landau, M., & Chisholm, D. (1995). The arrogance of optimism: Notes on failure avoidance management. *Journal of Contingencies and Crisis Management*, 3(2), 67-80. Retrieved from Blackwell Publishing database.
- Lazarus, R. S., & Folkman, S. (1984). *Stress appraisal and coping*. New York, NY: Springer.
- Leibrich, J. (1993). *Straight to the point: Angles on giving up crime*. Dunedin, New Zealand: University of Otago Press.
- Levinson, B. A. (2001). *We are all equal: Student culture and identity at a Mexican secondary school, 1988-1998*. Durham, NC: Duke University Press.
- Lightfoot, L. (2011). *Outspoken: Coming out in the Anglican Church of Aotearoa New Zealand*. Dunedin, New Zealand: Otago University Press.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Thousand Oaks, CA: Sage.

- Lindsey, E. (1996). Health within illness: Experiences of chronically ill/disabled people. *Journal of Advanced Nursing*, 24(3), 465-472. Retrieved from Blackwell Publishing database.
- Loeb, S. J., Penrod, J., Falkenstern, S., Gueldner, S. H., & Poon, L. W. (2003). Supporting older adults living with multiple chronic conditions. *Western Journal of Nursing Research*, 25(1), 8–29. Retrieved from SAGE Premier database.
- Lublin, J. S. (2004, January 13). Should job hunters reveal chronic illness? The pros and cons. *Wall Street Journal*. Retrieved from <http://online.wsj.com/article/SB10739498076300700.html>
- Lunt, N. (2006). Sickness and invalid's benefits: New developments and continuing challenges. *Social Policy Journal of New Zealand*, 27, 77-99. Retrieved from Academic OneFile database.
- Lupton, D. (1994). *Medicine as culture*. London: Sage.
- Lupton, D. (2000). The social construction of medicine and the body. In A. Albrecht, R. Fitzpatrick & S. Scrimshaw (Eds.), *The handbook of social studies in health and medicine* (pp. 50-63). London, England: Sage.
- Madden, D. (2004). Labour market discrimination on the basis of health: An application to UK data. *Applied Economics*, 36(5), 421-442. doi: 10.1080/00036840410001682133
- Marks, D., & Yardley, L. (2004). *Research methods for clinical and health psychologists*. London, England: Sage.
- MedlinePlus. (n.d.). *Trusted health information for you*. Retrieved from the National Library of Medicine website: <http://www.nlm.nih.gov>
- Miller, J. F. (2000). *Coping with chronic illness: Overcoming powerlessness* (3rd ed.). Philadelphia, Pennsylvania: Davis.
- Mills, C. W. (1959). *The sociological imagination*. London, England: Oxford University Press.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1990). *In-depth interviewing: Researching people*. Melbourne, Australia: Longman.
- Ministerial Advisory Committee on Complementary and Alternative Health. (2002). *Terminology in complementary and alternative health*. Retrieved from the Ministry of Health website: <http://www.newhealth.govt.nz/maccah/terminology.htm>

- Ministerial Advisory Committee on Complementary and Alternative Health. (2004). *Complementary and alternative health care in New Zealand: Advice to the Minister of Health from the Ministerial Advisory Committee on Complementary and Alternative Health*. Retrieved from Ministry of Health website:  
[www.newhealth.govt.nz/maccah/publications.htm](http://www.newhealth.govt.nz/maccah/publications.htm)
- Ministry of Justice. (n.d.). *Ministry of Justice: Tāhū o te ture*. Retrieved from <http://www.justice.govt.nz>
- Miskelly, P. A. (2005). Lost in translation: Understanding expertise in medical And healing encounters. *Sites*, 2(1), 68-93. Retrieved from EBSCO database.
- Miskelly, P. A. (2006). *Healing pluralism and responsibility: An anthropological study of patient and practitioner beliefs*. University of Waikato, Hamilton, New Zealand.
- Munir, F., Leka, S., & Griffiths, A. (2005). Dealing with self-management of chronic illness at work: Predictors for self-disclosure. *Social Science & Medicine*, 60, 1397-1407. doi:10.1016/j.socscimed.2004.07.012
- Munir, F., Randall, R., Yarker, J., & Neilsen, K. (2009). The influence of employer support on employee management of chronic health conditions at work. *Journal of Occupational Rehabilitation*, 19(4), 333-344. doi: 10.1007/s10926-009-9199-7
- Murphy, B. (2000). Role reversal, role conflict and role relinquishment: The impacts of women of caring for an ageing parent. *Health Sharing Women*, 10(4), 6-9.
- Murray, S. L., & Holmes, J. G. (1994). Storytelling in close relationships: The construction of confidence. *Personality & Social Psychology Bulletin*, 20(6), 650-663. Retrieved from Academic OneFile database.
- National Advisory Committee on Health and Disability. (2005). *Meeting the needs of people with chronic conditions*. Retrieved from [http://www.nhc.health.govt.nz/moh.nsf/pagescm/666/\\$File/meeting-needs-chronic-conditions-feb07.pdf](http://www.nhc.health.govt.nz/moh.nsf/pagescm/666/$File/meeting-needs-chronic-conditions-feb07.pdf)
- National Institute of Neurological Disorders and Stroke. (n.d.). *NINDS*

- multiple sclerosis information page*. Retrieved from [http://www.ninds.nih.gov/disorders/multiple\\_sclerosis/multiple\\_sclerosis.htm](http://www.ninds.nih.gov/disorders/multiple_sclerosis/multiple_sclerosis.htm)
- National Women's Health Information Center. (n.d.). *What is endometriosis?* Retrieved from <http://womenshealth.gov/faq/endometriosis.cfm>
- Navarro, V. (1979). *Medicine under capitalism*. London, England: Croom Helm.
- Neuman, W. L. (2006). *Social research methods: Qualitative and quantitative approaches* (6th ed.). Boston, Massachusetts: Pearson.
- Nolte, E., & McKee, M. (2008). Caring for people with chronic conditions: An introduction. In E. Nolte & M. McKee (Eds.), *Caring for people with chronic conditions: A health system perspective* (pp. 1-14). Maidenhead, England: Open University Press.
- Novak, M. (1975). "Story" and experience. In J. B. Wiggins (Ed.), *Religion as Story* (pp. 175-178). New York, NY: University Press of America.
- Novotny, T. E. (2008). Preventing chronic disease: Everybody's business. In E. Nolte & M. McKee (Eds.), *Caring for people with chronic conditions: A health system perspective* (pp. 92-115). Maidenhead, England: Open University Press.
- O'Connell, K. (2009). The clean and proper body: Genetics, stigma and disability discrimination laws. *Australian Journal of Human Rights*, 14(2), 139-162.
- Parsons, T. (1951). *The social system*. London, England: Routledge.
- Patton, M. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.
- Perrin, E. C., Newacheck, P., Pless, B., Drotar, D., Gortmaker, S. L., Leventhal, J., ... Weitzman, M. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics*, 91(4), 787-793. Retrieved from EBSCO database.
- Phillips, L. J., & Stuifbergen, A. K. (2006). Predicting continued employment in persons with multiple sclerosis. *Journal of Rehabilitation*, 72(1), 35-43. Retrieved from Academic One File database.
- Pierret, J. (2003). The illness experience: State of knowledge and perspectives

- for research. *Sociology of Health & Illness*, 25(3), 4-22. Retrieved from EBSCO database.
- Plummer, K. (1983). *Documents of life: An introduction to the problems and literature of a humanistic method*. London, England: Allen.
- Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Pollin, I. (1994). *Taking charge: Overcoming the challenge of long-term illness*. New York, NY: Random House.
- Pomerleau, J., Knai, C., & McKee, E. (2008). The burden of chronic disease in Europe. In E. Nolte & M. McKee (Eds.), *Caring for people with chronic conditions: A health system perspective* (pp. 15-42). Maidenhead, England: Open University Press.
- Porter, T., Chuma, J., & Molyneux, C. (2009). Barriers to managing chronic illness among urban households in coastal Kenya. *Journal of International Development*, 21(2), 271-290. doi: 10.1002/jid.1552
- Radley, A. (1989). Style, discourse and constraint in adjustment to chronic illness. *Sociology of Health & Illness*, 11(3), 230-252. Retrieved from EBSCO database.
- Radley, A., & Green, R. (1987). Illness as adjustment: A methodology and conceptual framework. *Sociology of Health & Illness*, 9(2), 179-207. Retrieved from EBSCO database.
- Rapley, T. J. (2001). The art(fulness) of open-ended interviewing: Some considerations on analysing interviews. *Qualitative Research*, 1(3), 303-323. doi: 10.1177/146879410100100303
- Rees, S. (1995). The fraud and the fiction. In S. Rees, & G. Rodley (Eds.), *The human costs of managerialism: Advocating the recovery of humanity* (pp. 15-27). Sydney, Australia: Pluto Press Australia.
- Reissman, C. K. (2005). Narrative analysis. In N. Kelly, C. Horrocks, K. Milnes, B. Roberts, & D. Robinson (Eds.), *Narrative, memory & everyday life* (pp. 1-7). Huddersfield, UK: University of Huddersfield.
- Rountree, K., & Laing, T. (1996). *Writing by degrees: A practical guide to writing theses and research papers*. Auckland, New Zealand: Longman.
- Rubin, H., & Rubin, I. (2005). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.

- Sarantakos, S. (1993). *Social research*. South Melbourne, Australia: MacMillan Press.
- Sarantakos, S. (1998). *Social research* (2nd ed.). South Yarra, Australia: MacMillan Press.
- Seccombe, J. (1995). Asthma or angina, migraine or multiple sclerosis: Working with chronic illness. *People & Performance*, 3(4), 32-36.
- Senior, M., & Viveash, B. (1997). *Health and Illness*. Basingstoke, England: MacMillan Press.
- Sharma, U. (1992). *Complementary medicine today: Patients and practitioners*. London, England: Routledge.
- Shilling, C. (1993). *The body and social theory*. London, England: Sage.
- Sidell, N. (1997). Adult adjustment to chronic illness: A review of the literature. *Health & Social Work*, 22(1), 5-11. Retrieved from ProQuest 5000 International database.
- Slattum, P. W., & Johnson, M. A. (2004). Caregiver burden in Alzheimer's Disease. *Consultant Pharmacy*, 19(4), 352-362.
- van Staa, A., Jedeloo, S., Latour, J. M., & Trappenburg, M. J. (2009). Exciting but exhausting: Experiences with participatory research with chronically ill adolescents. *Health Expectations*, 13(1), 95-107. doi: 10.1111/j.1369-7625.2009.00574.x
- Stenbeck, M., & Hjern, A. (2007). Social consequences of illness. *International Journal of Social Welfare*, 16, 105-126. doi: 10.1111/j.1468-2397.2007.00518.x
- Stokes, F. (1997). Using the Delphi technique in planning a research project on the occupational therapists role in enabling people to make vocational choices following illness or injury. *British Journal of Occupational Therapy*, 60(6), 263-267. Retrieved from Academic Onefile database.
- Stroupe, K. T., Kinney, E. D., & Kniesner, T. J. J. (2001). Chronic illness and health insurance-related job lock. *Journal of Policy Analysis & Management*, 20(3), 525-544. Retrieved from JSTOR database.
- Suhrcke, M., Fahey, D. K., & McKee, M. (2008). Economic aspects of chronic and chronic disease management. In E. Nolte & M. McKee (Eds.), *Caring for people with chronic conditions: A health system perspective* (pp. 43-63). Maidenhead, England: Open University Press.

- Sullivan, T., Weinert, C., & Cudney, S. (2003). Management of chronic illness: Voices of rural women. *Journal of Advanced Nursing*, 44(6), 566-574. Retrieved from Blackwell Publishing database.
- Susman, J. (1994). Disability, stigma and deviance. *Social Science & Medicine*, 38(1), 15-22. Retrieved from ScienceDirect Journals database.
- Tagalakis, V., Amsel, R., & Fichten, C. S. (1988). Job interview strategies for people with a visible disability. *Journal of Applied Social Psychology*, 18(6), 520-532. doi: 10.1111/j.1559-1816.1988.tb00033.x
- Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative methods: A guidebook and resource* (3rd ed.). New York, NY: John Wiley.
- Turei, M. (2010). *Beneficiary-bashing bill back in Parliament, and worse than ever*. Retrieved from <http://blog.greens.org.nz/2010/07/31/beneficiary-bashing-bill-back-in-parliament-and-worse-than-ever/>
- Turner, B. (1988). Individualism, capitalism and the dominant culture: A note on the debate. *The Australian and New Zealand Journal of Sociology*, 24(1), 47-64. doi:10.1177/144078338802400103
- Twook, S., Wirtz, M., Schipper, S., Klewer, J., Bergmann, A., & Kugler, J. (2007). Chronical illness and maternity: Life conditions, quality of life and coping in women with multiple sclerosis. *Quality of Life Research*, 16(10), 1587-1594. doi: 10.1007/s11136-007-9268-3
- Unwin, N., Epping Jordan, J., Bonita, R., Ackland, M., Choi, B. C. K., & Puska, P. (2004). Rethinking the terms non-communicable disease and chronic disease. *Journal of Epidemiology & Community Health*, 58, 801-803. Retrieved from JSTOR database.
- Varekamp, I., Verbeek, J. H. A. M., & van Dijk, F. J. H. (2006). How can we help employees with chronic diseases to stay at work? A review of interventions aimed at job retention and based on an empowerment perspective. *International Archives on Occupational Environment Health*, 80(2), 87-97. doi: 10.1007/s00420-006-0112-9
- Varekamp, I., Heutink, A., Landman, S., Koning, C. E. M., de Vries, G., & van Dijk, F. J. H. (2009). Facilitating empowerment in employees with chronic disease: Qualitative analysis of the process of change. *Journal of*

- Occupational Rehabilitation*, 19(4), 398-408. Retrieved from ProQuest 5000 International database.
- Vickers, M. H. (1995). Chronic illness: An organisational perspective long overdue. *Policy, Organisation & Society*, 10, 166-140. Retrieved from Australian Public Affairs database.
- Vickers, M. H. (1997). Life at work with 'invisible' chronic illness: The 'unseen', unspoken, unrecognized dilemma of disclosure. *Journal of Workplace Learning*, 9(7), 240-252. Retrieved from ProQuest 5000 International database.
- Vickers, M. H. (1999). Sick organizations, rabid managerialism: Work-life narratives from people with in visible chronic illness. *Public Voices*, (4)1, 59-82.
- Vickers, M. H. (2001). *Work and unseen chronic illness: Silent voices*. London, England: Routledge.
- Virtanen, P. (1994). An 'epidemic of good health' in the workplace. *Sociology of Health & Illness*, 16(3), 394-401. Retrieved from EBSCO database.
- Waitzkin, H. (1978). A Marxist view of medical care. *Annals of International Medicine*, 89(2), 264-278.
- Wang, C. (1992). Culture, meaning and disability: Injury prevention campaigns and the production of stigma. *Social Science & Medicine*, 35(9), 1093-1102. Retrieved from ScienceDirect Journals database.
- Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, 6(4), 347-361. Retrieved from ProQuest 5000 International database.
- Wellard, S. (1998). Constructions of chronic illness. *International Journal of Nursing Studies*, 35(1), 49-55. Retrieved from ScienceDirect Journals database.
- Wengraf, T. (2000). Uncovering the general from within the particular: From contingencies to typologies in the understanding of cases. In P. Chamberlayne, J. Bornat & T. Wengraf (Eds.), *The turn to biographical methods in social science: Comparative issues and examples* (pp. 140-164). London, England: Routledge.
- Weston, W. W., & Brown, J. B. (1989). The importance of patients' beliefs.

- In M. Stewart & D. Roter (Eds), *Communicating with medical patients* (pp. 77-85). Newbury Park, CA: Sage.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175-200. Retrieved from EBSCO database.
- White, P. (2000). What can general practice learn from complementary medicine? *British Journal of General Practice*, 50(459), 821-823. Retrieved from Academic OneFile database.
- Whitehead, L. (2009). *Living with chronic illness: Support for family members who live with heart failure*. Retrieved from <http://www.familiescommission.govt.nz.ezproxy.waikato.ac.nz/sites/default/files/downloads/living-with-chronic-illness.pdf>
- World Health Organisation. (2005). Preventing chronic diseases. A vital investment: WHO Global Report. Geneva, Switzerland: Author.
- Wright, R. (2010). *John Key calls benefit shake up a 'kick in the pants'*. Retrieved from <http://www.3news.co.nz/John-Key-calls-benefit-shake-up-a-kick-in-the-pants/tabid/419/articleID/147741/Default.aspx>
- Yelin, E. (1986). The myth of malingering: Why individuals withdraw from work in the presence of illness. *The Milbank Quarterly*, 64(4), 622-649. Retrieved from EBSCO database.

## APPENDICES

### INTERVIEW GUIDE

In the first part of the interview, I will ask you a very general question which lets you tell your story in your own way. I have then prepared a list of questions about the specific issues I am interested in, and I will check these to see if I need to ask you about something you haven't mentioned.

#### **Theme One – Your Story**

1. Tell me what's going on in your life at the moment.
2. Tell me about your [chronic condition] and how it has [influenced, affected] your employment.
3. Tell me about how your condition has [influenced, affected] your employment.

#### **Theme Two – Condition-Related Information and the Health System**

In this part of the interview we will talk about information relating to your condition.

1. What is your chronic condition?
2. What are the various symptoms that you have experienced since the onset of your illness?
3. When did you first experience symptoms?
4. When was it diagnosed?
  - a. Tell me about when you got your diagnosis.
  - b. What were your thoughts around your diagnosis or the diagnostic process?
  - c. Prompt - If they haven't given a time-frame for these events - Can you give me an idea of the time-frame?
  - d. What kinds of emotions did you experience at that time? Fear, relief, sadness?
5. What are the symptoms that you experience on a daily basis?
6. What are you currently doing for your condition? How do you manage your health?
7. How hard is it to have a chronic condition?
8. Can you tell me about a time when your condition was really bad?
9. Let's talk about the health system for a minute.

- a. The term ‘the health system’ is used in the media a lot, on TV, online and in the newspaper. What do you think they are referring to?
  - b. What elements of the health system
    - i. Have you experienced?
    - ii. Have tried to help you?
    - iii. Have been involved with you and your condition?
  - c. What do you think about it?
  - d. How helpful has it been?
10. What things do you use to look after your health?
- a. Do you have a doctor? Pharmacist?
  - b. How often do you visit the doctor? Pharmacist? Hospitals?
  - c. What kind of a relationship do you have with the doctor? Pharmacist? Hospitals? – Trying to find out about the nature of those relationships.
    - i. What kind of a patient are you?
  - d. What medication do you take?
    - i. You mentioned that you took [medication] Do you take anything else?
  - e. Do you feel in charge of your medical help?
11. Do you use alternative therapies?
- a. If so, what alternative methods or therapies have you looked at?
  - b. And what do you think of them?

### **Theme Three – Attitudes Towards and Experience of Chronic Conditions**

In this part of the interview I want to talk to you about your attitudes toward and experience of your condition.

1. What is it like to have a chronic illness?
  - a. *Prompt? - People use lots of words to describe their experience of their chronic condition and how it effects their lives (disruptive, fractured, unpredictable, traumatic, vulnerable, fragile etc), how would you describe yours? What words would you use?*
2. How do you feel about or what are your thoughts around the unpredictable nature of your chronic condition?
3. How do you feel about having no or limited control over the ebbs and flows of your chronic condition?

### ***Relationships***

In this part of the interview I would like to talk to you about how having a chronic condition has affected your relationships with friends and family.

1. How do people (friends, family) respond to your chronic condition?
2. Who are the people that you talk to about your illness? (Friends, family, support people, support groups?)
  - a. What things do you feel comfortable telling people?
  - b. What does it mean for you to be able to talk about it?
  - c. Is it hard for some people to hear about what you go through? (It is often hard for healthy people to hear what it is like to be sick)
3. What other people do you talk to about your condition? Or a similar condition?
4. If participants do not talk to anyone.
  - a. Are there things you would like to tell people?
    - i. If so, what kinds of things?
  - b. What does that mean for you not to talk about it? (Do you feel isolated?)
  - c. What do you think talking about it would do for you?
  - d. Why did you want to talk to me?

### ***Change***

In this part of the interview I would like to find out about how your condition has changed your life.

1. What things do you do in an average day?
2. How has having a chronic condition changed your life? How did your life change after the onset of your chronic condition?
3. Did you find you had to let some things go due to your condition? What did you have to let go of due to your chronic condition? And how did that make you feel?
  - a. *Prompt - Did you have to let go some dreams, goals or ambitions because your chronic condition limits your ability or capacity to fulfil them? If so, which ones? How do you feel about having to let go of or compromise on them?*
  - b. *How often do you leave the house? To the supermarket, socialising, sports, for dinner with friends and family?*



6. If suddenly your condition disappeared, how would you miss it?

### ***Normality***

1. People that have written about people with chronic conditions say that they do things to retain a sense of normality to counter the unpredictable nature of their condition.
  - a. How do you relate to that?
  - b. Do you do things to feel normal? Or to make life more normal?
    - i. If so, what kinds of things do you do?
  - c. What does normal mean to you?
2. Here's a different kind of question for you - if suddenly you had \$300,000 what would you do with it?

### ***Dependency***

Let's talk a bit about your condition and the care that you need.

1. What do you do when you can't care for yourself?
2. When you are not able to look after yourself, who looks after you?
3. What kind of care do you need?
4. How do you feel about needing care? Or needing to be taken care of?
5. Can you tell me about the last time you needed someone to take care of you?
  - a. How did you feel about that?
  - b. How common is that?

### **Theme Five – Sources of Information**

Now I would like to talk about how you go about getting information about your condition.

1. When you found out what condition you had, what type of information did you look for?
2. What type of information did next look for?
  - a. What else do you know about your condition?
3. How do you go about getting information about your condition?
4. Where/how do you get information about your condition?
  - a. Do you read about it? DRs? Other PwCC?
5. How much time do you spend getting information about your condition?
6. What kinds of information are not useful?
7. If they didn't look for information – why didn't/don't you look for information?

## **Theme Six – Chronic Conditions and Work**

Now I would like to talk to your condition and work.

1. Work History - Tell me about what kinds of jobs have you had and what positions you have held [since their diagnosis, or when they first experienced symptoms].
  - a. Check - Try to establish whether they were working when they were diagnosed or first experienced symptoms.
2. For each of the jobs since you got [your condition, name of condition];
  - a. Tell me about how you went about getting the job?
  - b. How hard was it to get the job?
  - c. What helped you to get the job?
  - d. What is it like to work and have a [your condition, name of condition]?
  - e. How did [your condition, name of condition] influence your experience of work?
  - f. What kinds of things/tasks were involved?
  - g. How did [your condition, name of condition] influence your ability or capacity to
    - i. Get to work on time?
    - ii. Carry out physical work tasks? Lifting things, carrying things
    - iii. Carry out mental work tasks?
    - iv. Concentrate? Focus
    - v. Be mobile? Walking
    - vi. Communicate with colleagues?
  - h. How hard was it to keep each job? What barriers did you face in relation to keeping each job?
  - i. What helped you to keep the job?
  - j. If relevant - how hard was it to get a promotion?
    - i. What barriers do/did you face in relation to getting a promotion?
  - k. How did you manage your condition at work? (Strategies, tools – did they have different strategies for different jobs because of the different nature of jobs)
  - l. What kinds of workplace support did you get for your condition?

- i. How hard was it to ask for sick leave?
    - ii. How hard was it to ask for time off to do health related stuff?
  - m. Did the organisation have any policy about illness or injury or disability or disease for its employees?
3. How do you think people with your condition or other chronic conditions are viewed by employers?
4. If relevant:
- a. Tell me about times when you applied for but didn't get a job.
    - i. Do you think that your condition had something to do with it? Did you feel that it was discriminatory?
  - b. Tell me about the last time you tried to find work.

### ***Disclosure***

Now I would like to talk with you about how you go about telling people about your condition. This topic can be a sensitive issue and there is the potential for some minor illegal things to arise. If such things do arise, I will respect my promise of confidentiality and not pass on identifiable information to any third parties without your consent. If I wish to refer to any minor illegal issues when I am writing up this research I will do it in such a way that people's identities will be kept anonymous.

1. Strategies of disclosure
  - a. What's your policy about telling other people about your condition at work?
  - b. Have you always had a policy?
  - c. Do you always stick to that policy?
  - d. What kinds of things do you [consider, think about] before telling someone about your condition? (thought process – fears about how people will receive them and their condition – perceived implications of disclosure – ambivalence).
2. If relevant – questions around the nature of disclosure.
  - a. Did anyone know about your condition?
  - b. How did they know about it?
  - c. Once you got a job how did you go about letting people know about your condition?

- i. Did you tell anyone about your condition?
- ii. Who did you tell?
- iii. When did you tell them?
- iv. How much did you tell them about your condition?
- v. Did things change when you told people about it? Did they treat you differently?

### ***Social Interaction***

1. How did your workplace and people within your workplace respond to your chronic condition?
2. What are your thoughts around how your chronic condition has influenced or influences your interaction with work colleagues?

### ***Discrimination and Marginalisation***

1. In the workplace, do you feel
  - a. Guilty about your abilities or contributions?
  - b. Inadequate?
  - c. Others judge you?

Let's talk more specifically about discrimination in the workplace.

2. What kinds of discrimination have you experienced at work?
  - a. If so, what are your thoughts around that experience?
  - b. How did those experiences make you feel?
3. Check - what do you mean by discrimination? What does discrimination mean to you? How do you know something is discriminatory? What does it look like?
  - a. Being ignored in the tearoom
  - b. Being left out of work tasks/projects/promotions
  - c. Being left out of other work-related events
4. How did you deal with that?
5. Do you think it might happen to you in the future?
6. The literature says that discrimination occurs most in the workplace – what are your thoughts about this statement?

### **Theme Seven- Broader Structures**

#### ***Ideology***

Now I would like to talk with you about how you interact with the ideas that society has about how people should behave.

1. Society has ideas about people should behave. One of these ideas is that people should work hard and be productive.
  - a. How much do you agree with that?
  - b. How hard a worker are you?
  - c. (If there is a disjunctive) how do you feel about that?
2. Another idea is that people should be independent.
  - a. How much do you agree with that?
  - b. How independent are you?
  - c. (If there is a disjunctive) how do you feel about that?
3. Another idea is that people should be responsible for themselves.
  - a. How much do you agree with that?
  - b. How responsible for yourself are you?
  - c. (If there is a disjunctive) how do you feel about that?
4. Another idea is that parents should provide for their children.
  - a. How much do you agree with that?
  - b. How able to provide are you?
  - c. (If there is a disjunctive) how do you feel about that?
5. Another idea is that people should be helpful and giving to others.
  - a. How much do you agree with that?
  - b. How helping and giving are you?
  - c. (If there is a disjunctive) how do you feel about that?
6. Another idea is that people should be active citizens.
  - a. How much do you agree with that?
  - b. How active a citizen are you?
  - c. (If there is a disjunctive) how do you feel about that?

***Government and the Welfare System***

Let's talk about the government and the welfare system.

1. What welfare assistance have you sought since the onset of your condition?
  - a. If yes, what are your thoughts around that experience?
  - b. How did it make you feel?
2. What ACC assistance have you sought since the onset of your condition?
  - a. If yes, what are your thoughts around that experience?
  - b. How did it make you feel?
3. Tell me about the last time you accessed welfare assistance.

4. How would you summarise the support provided by the government for people with your health condition?
  - a. How adequate do you think that is?
  - b. What is missing?
5. What kinds of things do you think the government should have? What kind of role do you think the government should have?
6. If relevant - what isn't the government doing that would be helpful for [people with your condition or other chronic conditions]?
7. How do you think people with your condition or other chronic conditions are viewed by
  - c. The government?
  - d. The welfare system?
  - e. By ACC?
8. Let's talk about Human Rights.
  - a. Are you aware of any anti-discrimination legislation that applies to you or a person in your situation?
    - i. If yes, what is it?
      1. Is it effective in helping you?
        - a. If yes, how does it help you?
        - b. If no, how could it be more effective?
      - ii. If no, is there a need for anti-discrimination legislation?
        1. If yes, what kind of laws should there be?
          - a. To achieve what?
        2. If no, why?
  - b. The Human Rights Commission says that it is a fundamental human right for people to have access to decent work.
    - i. Do you feel you are being accorded this right?
      1. If yes, how effective is this in assisting you?
      2. If no, how could it be given to you?
  - c. The Human Rights Commission says that everyone in NZ should have a right to equal pay for equal work.
    - i. Do you feel you are being accorded this right?
      1. If yes, how effective is this in assisting you?
      2. If no, how could it be given to you?

d. The Human Rights Commission says that everyone in NZ have a right not to be discriminated against.

i. Do you feel you are being accorded this right?

1. If yes, how effective is this in assisting you?

2. If no, how could it be given to you?

### ***Organisations and Activities***

1. What organisations concerning your condition do you support?
2. To what extent have you been involved in any campaigns or activities concerning your condition?

### **Ending**

1. What things do you really enjoy about your job?
2. What are the things you do to relax?
3. What are your hobbies?
4. What do you consider to be the two greatest achievements in your life to date?
5. The aim of these interviews is for me to understand how your chronic condition has affected your employment. Do you have anything to add that we have not covered?

Clarification: "What do you mean...?"

Amplification: "Tell me more about..."

Explanation: "Why?"

Significance: "How did you feel about...?"

Prompts - Verbal or non-verbal signals to show that I am following, and encourages participants to elaborate. These can include a nod, a smile, "hmmm", "oh really", "go on", "Yes?" or "I see".

Checks: Summaries to make sure that I have understood the interviewee.

Examples of these include: "If I were to summarise your experiences it would be...", "So what you are saying is..." or "When you say *they*, who are you referring to?"