



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.

**“The Being in some body: An Autoethnographic Account of  
*Being and Becoming-in-the-world with Multiple Sclerosis*”**

A thesis  
submitted in fulfilment  
of the requirements for the degree  
of

**Doctor of Philosophy**  
at  
**The University of Waikato**

by  
**CAROLINE ALLBON**



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

2013

## **PROLOGUE**

## Prologue: A Morphing of Being...

*October 1998. Having said goodbye to my family, I set off for another busy week at a newly formed Primary Health Care Organization (PHCO) located in the central city, not far from the main general hospital. I had been appointed to manage a new PHCO project: Respiratory Education. My brief was to deliver respiratory education for PHCO members within the designated geographical territory, and health education services to non-PHCO members, community health care centres, schools and some Non-Government Organisations (NGOs). The job was huge as was the geographical area that I had to cover. This was a dream job for me. There would be no more of the hospital shift work typical for nurses. I was getting out and about meeting many interesting people in different locations in a job that I loved.*

*Driving to work that morning I took notice of the beautiful leafy riverside landscape. There was not a cloud in the sky. Perhaps I had seen this beauty before – but not really noticed. I was feeling 'fine' and my world appeared to be 'fine' too. But the journey became memorable for quite some other reasons. When I arrived at my place of work, I parked the car in the designated car park. I took a quick look at the folder in my satchel to ensure that all tasks set in the diary could be attended to.*

*My office was located down the corridor, past the main boardroom, the Chief Executor's office and the kitchen. The Chief Executor Officer was my immediate boss and a medical doctor. I passed the kitchen area. My boss and several colleagues were there. They waved and greeted me. "How was your weekend?" I replied: "Fine"... Someone asked: "Do you want a coffee before the team meeting?" Not wanting to appear*

*distracted or off hand I replied: "No thanks! See you all soon". I didn't stop to engage in any more conversation. I could not! I was in sudden and extreme pain. I smiled whilst clutching my bag, trying not to grimace or cover my left eye with my hand. I just wanted to get to my office, shut the door, hang my jacket and bag on the door hook and sit down. This done, I clutched my head. My hands and fingers were tingling. What was going on? My head was aching. I had a throbbing-painful sensation in my left eye. It was now most uncomfortable to focus on things for long. The lights in my room, although not excessively bright, seemed to be causing my eyes some level of discomfort, a flickering sort of experience. I started to feel rather 'odd' as I sat down at my desk.*

*I use this word 'odd' quite intentionally because I could not figure out what was happening. I now experienced a combination of a dull headache, some pins and needles in my fingers, and severe pain in my left eye. I was quick to apply my trusted nursing skills to the situation with a thorough head to toe assessment in order to make some sense of this feeling, to find an explanation, to name a condition or even a preliminary diagnosis. I could not identify plausible reasons for this odd feeling.*

*I had left for work that morning believing that I was 'fine' - a fine and healthy woman. I returned back to my home that evening feeling somewhat 'less than fine'. I did not know then or even suspect that I had experienced the first symptoms of an acute attack of Multiple Sclerosis (MS). Life as I knew it would never be the same again. I would never be the same again. For me, as I reflect back on this day, it constituted a beginning on the one hand and an ending on the other. It was also to be the start of a new relationship with the medical profession and the pharmaceutical industry. I did not know that then.*

*I really did not envisage that this pain would last for long, or that it was too serious. I thought that it would soon pass. I had recently fielded a phone call from an NGO requesting an education session for their staff on asthma and use of asthma medications. I wanted to get to my office to look at the wall planner to see how my week was looking and how I could accommodate this request. I intended to update the wall planner so that my line manager and other colleagues could readily see where I would be at any time. I had much to do!*

*I was now late for the weekly staff meeting. There was a knock on my door. It was my boss. He asked me if I was all right. I said: "Well not really". I asked why he had not sent someone else to hurry me along. He said: "I saw you as you walked past the kitchen. I thought you didn't look yourself. You never hold your head down to cover your eyes." How perceptive of him! He did some very quick head to toe examinations and sent me home immediately. He advised that I should take some stronger migraine like medications and to ring him in a couple of hours. He offered to drive me home or ring my husband. I said I'd be fine to drive myself and would take the pills when I got home. I drove home, took the drugs and fell into sleep.*

*The simultaneous ringing of the house telephone and my mobile phone awakened me. "Gosh!" I thought, "I was meant to phone my husband and to ring my boss back. I did both right away. I felt ghastly and in so much pain. My boss said "You get yourself to the hospital! I'll phone your GP." My husband took me there. I now needed to undergo a whole lot of medical tests. I thought what is all this about? I did feel rather apprehensive, but not afraid. I felt for my husband who was also going through a whirlwind of emotions himself.*

*When it came time to hear the results from the many examinations and tests I had undergone, I could sense that things were not good. I schooled myself to keep my head clear in order to process all the information I was about to receive. The Specialist came in to the side room off the reception area where I was sitting. He said he had found significant inflammation in my left optic nerve, a symptom that can be indicative of Multiple Sclerosis. He was very careful to say that this illness is very difficult to diagnose. More tests for other parts of my body were needed to give a confirmed diagnosis. The results of these tests would be discussed with other neurological specialists, a method of peer review ensuring accuracy in clinical decisions.*

*Once I had undergone all the tests, the MRI, blood tests, neurological tests and ophthalmology testing and the results had been reviewed, I returned to the clinic and once again schooled myself to listen carefully. The Specialist looked at me and said: "I don't know how to say this..." I replied: "Just say it how it is please". He continued: "You have Multiple Sclerosis. Do you have any questions?" My reply was: "No, not today - but could you please telephone me tomorrow - thank you."*

*As a nurse I was aware that MS is a chronic degenerative illness. Previous nursing experiences of caring for people with MS evoked less than pleasant feelings about this illness. In my experience young individuals with the illness were typically placed in long-term geriatric wards for their short-term care. I could never appreciate then as well as I do now, why individuals at the prime of their life were afflicted by this illness, and more importantly, why they were nursed in this way.*

*Many feelings and thoughts now passed through my head and hands - this head that was aching, these hands that were numb. My grandmother came to mind. As I recollect - she too lived with a long-term illness - diabetes mellitus. We had been very close in life. My grandmother's native language was Arabic. She did not speak English or write in western script. To me her writing was a set of beautiful symbols. I was not taught how to read or write Arabic, so I could not communicate with her in the written Arabic form, nor could she communicate with me in English. We used symbols, hand gestures, and family translators. For some reason I now befriend some of my grandmother's explanations for making intuitive sense of difficult life situations.*

*My grandmother regularly made reference to her intuitive way of knowing as seeing with 'the third eye'. She once gave me a piece of jewellery modelled in the shape of an eye. It is blue and it was pinned inside the coat I wore as a child. It was intended to be obscure to the external eye. The person beholding it, she said, would be guided and protected. Such traditions may be considered a form of folklore or 'witchery-craft' by non-believers. To me she was indeed a very wise muse.*

*Years later, my grandmother still has a large presence in my life. To this day this 'third eye' guides and protects my life and the lives of my family. It is no longer pinned in the inside of the childhood coat I have long since outgrown. It is safely stored in her jewellery box that she left to me. I now reflect on her way of her being with challenging life experiences as her ethnographer's eye. It is in/with this way of knowing that I have learned how to move forward, in doing so acquainting a new self, as Carrie with MS.*



*I now see through the auto ethnographer's eye/I- the eye/self that notices, sees, and writes. I do so comfortably knowing that a shift of mind and thinking has been shaped by the influences on my life of this wise muse and of other gentle souls. By living in the moment it is with the new 'I' that writes about this un-invited change and social in-justice I came to face. I did not invite this illness nor do I feel this was a justified change in my life. However, this profound change did occur. It felt as though my personal compass located within my body, mind and soul had been re-set. I was now re-focusing on embodied change and experience.*

With the *eye/I* that writes/rights I am now focused more formally on social change and human action in and around everyday life as I experience it. From a search of the literature I was drawn to Heidegger's (1927) *Philosophy of Being and Time*; Nietzsche's (1966) *Philosophy on Perspectivism*; Deleuze and Guattari's (1987) *The Concept of the Rhizome*; Lewis Carroll's (2006) *Alice's Adventures in Wonderland*; Ellis's (2004) *Autoethnography as my chosen method*; Moustakas (1990) *Heuristic inquiry to investigate extraordinary human experiences* and Marshall's (1999) approach of 'Living life as enquiry'. This way of being and be-coming represents my search for the discovery of meaning and essence in significant human experience. I also examine the development of meaning making and communicating meaning emphasising the philosophical ideas of embodiment and experience in everyday life. From Denzin's (2003) work 'Performance Ethnography' I am learning how these experiences as performance are connected to the political that becomes the personal and the personal that becomes politicised. I see an increasing scope to connect my experiences to the pedagogical that aims to 'show' not just 'tell' of my embodied experience of the human body in inquiry. I aspire to connect these insights into my being to the organization of and care for the people with MS, other similar chronic conditions and those who care for them.

## General note

Multiple Sclerosis (MS) is a chronic, often disabling, neurological disease. It affects the central nervous system, brain, spinal cord, and optic nerves. MS is characterised by recurrent attacks of inflammation and the development of lesions in the white matter of the central nervous system resulting in neurologic dysfunction. Attacks can last for varying periods of time from hours to a few days or for some weeks. Attacks may cause a variety of more or less disabling symptoms. The progression, severity, and specific symptoms of MS are unpredictable and vary from person to person.

There are about 2.5 million people worldwide with MS.<sup>1</sup> Researchers are investigating numerous aspects of this illness including genetic predispositions, the potential impact of viral infections, environmental influences, and even the effects of migration such as latitudes and distances from the equator. Others are engaged in seeking disease-modifying drugs. Despite all of these studies to date, there still is no known cause for or cure for MS.

I was diagnosed with MS in 1998. I now write from my *body* that hosts this illness. I offer my research as a contribution to the better understanding of how it is to live with this neurological disease for the better understanding and care for those who suffer from it. My chosen form of analysis is autoethnography. The research orientation is drawn from the work of social constructivists, scholars of sociology, social and management science research, organisational change, ethnography and organisational learning. My research contributes to the work on sociology, ethnography, embodiment, and organisational change with acknowledgment of its potential emancipatory contribution to management education and management practice.

---

<sup>1</sup> [www.nationalmssociety.org](http://www.nationalmssociety.org)

## Abstract

Embodiment and experience as a nurse, wife, mother, researcher, and educator living and working with Multiple Sclerosis (MS) is the focus of this study. MS is a chronic de-generative neurological illness. It was confirmed in my being in 1998. Through my chosen approach of autoethnography as method, and on the basis of my work into and on my '*self*' and '*being*', I invite a radical review of the professional organization and medical(ised) treatment of those with MS and with similar chronic conditions.

My aims are to generate research that goes beyond the passive construal of the body typical of medical research to a process through which embodiment can be understood not only as representation of *the body* but as a significant influencer of a semblance of actuality or verisimilitude<sup>2</sup>. In this work I place my experience in conversation with scholarly voices critiquing embodied experiences of *self* and *being* in the world as heuristic inquiry. The intertwining relationships between *self*, *body*, and *work* as mutual organisational relationships are examined through the development of a self-reflexive praxis, in which embodiment, experience, and meaning-making resonate through autoethnography as both topic of study and constituent of the research experience.

By drawing on first person narrative accounts of my experiences since the confirmed diagnosis of MS, I make *visible* some of the seemingly *invisible* effects of living and working with this degenerative illness. I chronicle and analyse my engagement with a profession whose calling is to care for those, who like me, live with chronic health conditions that may periodically present as acute or increasingly debilitating experiences. My voice is clearly present in this text, bestowing an authorial voice from *my body* to re-view, re-veal, re-tell highly personal accounts specifically focusing on how I, the researcher as writer, have explored the impacts of a confirmed diagnosis of MS on my life and the lives of those I care about.

---

<sup>2</sup> Oxford Dictionary (1985:839) - verisimilitude /verisi'militju:d/ n. appearance of being true or real - (*verisimilitude is not proof*). [L.(*versus*, **true**, *similis* like)].

Through this research, I have explored and enhanced an integrated sense of *self* deeply affected by the often-prevailing medicalised change in my identity as *I Carrie, who has MS*. I challenge the separation of mind/body, of conscious/unconscious, of emotion/cognition, and of conceptual/actual as typical and still dominant in medical specialist approaches to meaning making. I also question the institutionalised forms of professionalism that sees the medical encounter as a supreme example of surveillance: the doctor questions and investigates - the patient is the passive object. I propose that meaning resides in embodied experience. I tell of my experiences that seem pertinent to the creation of my best possible life with MS. Yet these experiences seem undervalued or even absent from my diagnosis and treatment in various aspects of the ‘helping role’ and of ‘professional care’ I was able to access:

*I was now being viewed as a disabled person. No abled-bodied person would tolerate this! I wanted to have some control and rights over my changed life. The best way forward was to merge my old and now new ways of being to regain some control and dignity.*

*(Personal Journal, 1998).*

In this research, I focus on everyday performances by stepping consciously and creatively onto the stage as a life-long member of MS. I tell of how, initially from frustration with the medical professionals but increasingly from a source of creative self-direction, I explore the transformation of *my body* through the performance of reconstructing illness. As a consequence of my attention to embodied change, I do not view my perceived physical, psychological, spiritual, artistic, and thus ‘social’ worlds merely as discrete categories of experience commonly isolated by empiricists. It appears to me that this attention I give myself is restoring and empowering this fully alert and engaged ‘*Carrie who flourishes*’ - even with MS. The research approach brings personal experience, reflections, and insights to the fore as heuristic inquiry to join a growing genre of research that embraces subjective matter: the lived experience of research and the insight of living research as inquiry.

This inquiry contributes to modes of research that are intentionally transformational. I contribute to the development of research methods, research

voicing, and ways of writing qualitative research. I connect my research on, from, and with self to the disciplines of organisational learning, management, and teaching. My study has implications for those who like me host MS or similar chronic conditions and for the supporting families, volunteers and communities. In particular, this research has implications for those professionals who provide a diagnosis, prognosis, treatment, and care for those who must live with a chronic condition of any kind. I hope it encourages all people entwined in such stories as mine, to seek life-enhancing communication as the primary responsibility of care for each other.

## Acknowledgements

I want to thank my Chief Supervisor Associate Professor Maria Humphries from the Department of Strategy and Human Resource Management, Waikato Management School, University of Waikato, Hamilton, New Zealand for her sense of humour and commitment to me as doctoral student. I thank her for generating a thoroughly magnificent doctoral learning experience. She showed by example that hard work is always worthwhile – as were the many cups of coffee where some of our most creative work was conceived. Our conversations grew my heart and stretched my brain. She assures me the learning and the joy was mutual. She helped steer the many errant commas and my mercurial ideas towards this now scholarly document and unconditionally supported me at times when my seemingly unstoppable sense of curiosity threatened to make this research a ‘never-ending-story’. This thesis reflects my new way of being - my way of living with the chronic illness Multiple Sclerosis (MS) and its many challenges.

I wish to also thank my second supervisor Dr John Gilbert for his insightful comments, great discussions about my work, and assistances with all my doctoral progress reports, Dr Suzanne Grant, the PhD fellow travellers, and the many people who encouraged me on the way. In particular, I am indebted to the intellectual contribution of Judy Marshall, Carolyn Ellis, Art Bochner, Peter Reason, Norman Denzin, Mike Elmes, Matthew Brannan, Frank Worthington and Ann Cunliffe.

To my nursing colleagues, especially Mary LaPine who shared this extended voyage of literary discovery as a good and critical friend. Marilyn Markman amazing artist, teacher, extraordinary woman, special friend and co-inquirer - who has been inspirational with her candid outlook on showing me how to make the most out of life with MS - thanks for ‘*sitting gently on my shoulder*’.

I wish to thank my family, Geoff my husband, my children Adrian and Simone, and my father for their unconditional love encouragement and support. My heartfelt thanks to Simone Allbon a very talented graphic designer for her assistances with the formatting of dedication page, the two montage pages, and permission to use her original painting ‘*Mother*’ in this work. Thanks also to J. Larmer for her permission to use ‘Celtic C’ image, S. Coldham Colenso BBDO for the human Jenga body image - used in this work, and J. Thorne (illustrator), permission from Macmillan Children’s Books, London, United Kingdom.

## Dedication



To my late mother: for her unconditional love and encouragement; to my grandmother: for the ‘third eye’ brooch and her reverberating wisdom; to all those individuals who suffer chronic illness; to those who share the illness experience of Multiple Sclerosis as members of a wider social circle; to those health professionals who care for all those with chronic illness.

**‘What ever is real has a meaning’...**

Michael Oakeshott (1966, p.58).

## Table of Contents

<b>Prologue: A Morphing of Being</b> .....	<b>i</b>
<b>General note</b> .....	<b>vii</b>
<b>Abstract</b> .....	<b>viii</b>
<b>Acknowledgements</b> .....	<b>xi</b>
<b>Dedication</b> .....	<b>xii</b>
<b>Table of Contents</b> .....	<b>xiii</b>
<b>Table of Images</b> .....	<b>xv</b>
<b>CHAPTER ONE Down the Rabbit Hole into the Home of the Enquiry</b> ....	<b>1</b>
The Vestibule of introductions: Taking off my empiricist cloak .....	2
Introduction from the anteroom.....	6
Introduction to the topic and mode of enquiry .....	11
The positioning of the thesis.....	18
Positioning my-self in the thesis.....	19
The style of the thesis .....	26
<b>CHAPTER TWO Autoethnography</b> .....	<b>30</b>
Introducing the research approach.....	30
Philosophical basis of autoethnography .....	33
A short history of autoethnography .....	35
Autoethnographic forms and approaches .....	41
Benefits and potentials of autoethnography .....	44
Limitations and criticisms of autoethnography .....	46
Reliability, generalizability, and validity in autoethnography.....	48
Autoethnography and ethics .....	51
Ethics and protection of the self.....	52
Ethics and protection of others.....	53
Navigating performance autoethnography as praxis .....	58
<b>CHAPTER THREE The Room of Being and Becoming</b> .....	<b>61</b>
The call of narrative, personal vignettes, and autoethnography.....	65
Drawer One: [E]-merging story and theory- putting self in the enquiry ....	73
Drawer Two: Ontology of Being.....	82
Drawer Three: Being as process of caring for self and other .....	89
Drawer Four: Becoming and autoethnography.....	97
<b>CHAPTER FOUR Room of Demonstrating</b> .....	<b>104</b>
The passage into the story- well and synchronicity.....	105
On being autoethnographic: from interpretation to story .....	108
Doing autoethnography: a storied reality and three vignettes .....	114
Vignette One .....	117
Vignette Two.....	118
Vignette Three.....	120



<b>CHAPTER FIVE The Room of a Learning Self .....</b>	<b>122</b>
Positioning a learning self .....	123
Living and researching my life as inquiry .....	126
Making sense of embodied experience.....	133
Learning how to know and live <i>with (in)</i> the altered body.....	138
Immersion.....	145
Acquisition .....	145
Realisation .....	147
<b>CHAPTER SIX Room of a Realising Self.....</b>	<b>153</b>
Positioning a realising self: authoring a new identity.....	153
Writing self into being [differently] in the world .....	159
Vignette One .....	164
Vignette Two.....	165
Embodied experience beyond the clinical gaze.....	166
Workstation One .....	167
Workstation Two.....	168
Workstation Three.....	171
A continuum not a conclusion .....	176
<b>CHAPTER SEVEN The Porch .....</b>	<b>179</b>
Creating shifts of knowing and learning.....	180
Autoethnography - as guide for developing leadership capacity.....	186
Lived experiences of being in some body .....	192
Unfurling knowledge and meaning - as a gateway to dialogue.....	195
Finding pieces for the organisational puzzle .....	199
Worlds of possibilities .....	204
<b>EPILOGUE.....</b>	<b>207</b>
Reflections and reflexivity.....	214
A postscript of being: re-visiting, re-vising, and re-vealing.....	215
<b>REFERENCES .....</b>	<b>218</b>
<b>APPENDICES .....</b>	<b>237</b>
<b>LIST OF ABBREVIATIONS.....</b>	<b>242</b>

## Table of Images

Image 1: Montage One Celtic ‘C’ .....	60
Image 2: Montage Two.....	63
Image 3: “Mother” .....	152

## **CHAPTER ONE**

Introduction to the Home of the Enquiry



**‘Down the rabbit hole’**

Illustration by Jenny Thorne, after John Tenniel,

A Macmillan Pop-up Book Alice’s Adventures in Wonderland.  
Children’s Books, London: United Kingdom. Re-produced with permission  
from Children’s Right Permission Macmillan, Publishers Ltd.1980.

## CHAPTER ONE

### Down the Rabbit Hole into the Home of the Enquiry

Alice has nothing much to do and is sitting on the bank with her sister. Life, for Alice, is 'fine' - if somewhat predictable. She was a little bored. She had peeped into the book her sister was reading but it had no pictures or conversations in it, "and what is the use of a book", thought Alice, "without pictures or conversations?" Suddenly, seemingly out of nowhere, a White Rabbit with pink eyes runs by. He is wearing a waistcoat holding a timepiece and muttering to himself about being late. He hurries down a rabbit-hole. Alice, full of curiosity, decides to follow him.

(Carroll, 2006, p.5).

In 1998 an excruciating episode of pain in my eye and unexplained tingling in my limbs triggered a search for a diagnosis. Until that day, my life had gone much as I had imagined. From a wonderful childhood I had been able to choose a great career. I had a loving family and treasured home. My future seemed secure. Suddenly, an episode of pain bounded into my life, pain that I, a well-trained nurse, had been unable to recognise or name. Over the next few days the speculation that Multiple Sclerosis (MS) might be an explanation for my symptoms became a distinct possibility. I still had tingling in my hands, legs, and headaches. It was during a particularly long wait for an appointment with a doctor who might provide a confirmed diagnosis that I became conscious that something very important was afoot. Already my mind was searching for explanations and a search that would eventually become formalised as this research. I took some time to reflect deeply before I gathered my resolve to face this illness with a research focus.

In time, my decision to investigate the personal experience of this illness more formally required a way to organise my thoughts and feelings. I came to think of Alice, my childhood heroine. Prompted by the inspirational stories of Lewis Carroll about Alice's Adventures in Wonderland, I found a way to re-visit, re-tell, and re-view episodes of my experiences of MS that I trust will be insightful, revealing, and useful not only to myself, but to all those who have MS,

to those who have a similar chronic illness, and to all those who care for them, as professionals or as family, friends, and caregivers.

On the day in question, I had been sitting waiting for the doctor. I had been waiting for something to happen. I had been waiting, perhaps, for the doctors to decide what I should do. It occurred to me that I could retell this story of my confirmed diagnosis and the episodes that followed by looking to Alice as a model of what it takes to be a good deductive reasoner. I am reminded of Alice's surprise by the unexpected and her courage to follow White Rabbit into the unknown. In the face of repeated challenges posed by my unanticipated diagnosis of MS, I began to think of my illness as my White Rabbit, an animated creature that I could not help but follow and from whom I was likely to learn a lot. Like Alice, I would follow White Rabbit into the rabbit hole that seemed like a tunnel of some kind. Like Alice I slid through this tunnel. I wonder what might happen next. Curious!

I look around. My mystical tunnel stops at the door of a house. Even more curious! Pushing open the door, as I do in this Chapter One, I find myself in a vestibule. I look around and notice an antechamber with a beautifully carved wooden lectern. I see that a booklet is placed on it. I move closer and to my delight it is open at this page: "*Autoethnography*". I read about the highlights of the works of exemplary scholars: Ellis, Ellis and Bochner, Marshall, Denzin, and Moustakas. I read about their passion and achievements in their contribution to ethnography, autoethnography, and heuristic research. In this vestibule I also see portraits of people I want to know more about, and I realise I am in a magical House of Learning. To my surprise, I find Alice enticing me in! She exclaims: "Welcome to your Home of Enquiry we have much to explore! Let's look around us a little more closely before we move on."

### **The Vestibule of introductions: Taking off my empiricist cloak**

The vestibule or antechamber described in this thesis is used to denote a welcoming space where the [auto] ethnographic self, *I Carrie*, author of this document, can meet and greet fellow critical companions. It is a place to introduce and explain to the reader my choice of autoethnography as the method that is used

to explore the deeper meanings of what it is like to live and work with a chronic degenerative illness. I meet some key critical companions such as Ellis (2004) whose methodological approach of autoethnography is so beautifully outlined in *The Ethnographic I*, and I am greeted by Marshall's (1999) application of the notions of inquiry as method in *Living Life as Inquiry* to support theorised writing based on personal experience.

I look around the vestibule I notice a poster with an exquisite image of a root-like stem growing underground. It has many roots and shoots growing from it in seemingly random directions. Underneath the poster is this annotation: *The Concept of the Rhizome* by Deleuze and Guattari (1987) an excerpt from their book *A Thousand Plateaus*. I am intrigued! I see Alice. She is waving to me. In her hands she is holding a paper scroll. Alice says: "I have been here before, a long time ago now. At that time I got tangled up in the many shoots and roots that are embedded in the walls of this vestibule. These shoots seemingly lead off in all directions and to many rooms. I made some tracings of these shoots so as not to get lost ever again. I carry this scroll with me when I want to explore". Holding the scroll in front of the mirror Alice begins to open it. I am mesmerised! As I begin to see what is unfurling before my very eyes in the mirror, I see these beautiful tracings of lines that seemingly go in all directions – just like the roots and shoots on the poster! On the scroll are points that Alice has labelled: "Doors and Rooms". I look to Alice. She says: "This image of the rhizome is what I call my map!" Alice points to a shelf in the vestibule saying: "There are some books for you to look at". And I do!

On this shelf I see some book covers and opened sections of framed writing that I recognise as Denzin's (1987, 1989, 1997, 2003) writings on the critical theoretical positions of interpretive ethnography, performance ethnography, and critical pedagogy, as ways for enacting a performative text. I look further along the shelf and spot Hawkins's (1999) engaging work on reconstructing illness that I believe will provide a profound consideration of what it means to be human in the face of illness. These are ideas/books I recognise as ideas I have come across before. Will I learn more about these ideas in this strange place I have found myself?

As I move away from the wooden shelf. I see and salute the literary work of Lewis Carroll's (2006) *Alice in Wonderland* displayed in a glass showcase along

the far wall of the vestibule. I can see that it contains a stunning collection of images, humour, wonder, and wit. Then, a flicker of light draws my eye! I see a row of mirrors in all shapes and sizes. Some are positioned at seemingly strange angles. Some have special lighting effects that catch my attention. As I look around at these mirrors I can see the front and back of myself. I see Alice reflected at my side. She looks comfortable and secure in this strange place. I know she has been here before and has been careful to take notice! I feel confident that she will be my guide and wise muse. As I come closer to a particularly dark mirror, I see a faint outline of what looks like to me to be the Cheshire Cat. His grin is becoming much larger as the lighting in the mirror reaches its full power. I see his big grin is mouthing phrases that look like they may be a list of labels or signage of some kind. How curious! I no sooner seem to get that he is trying to direct me somewhere, when he dissolves and disappears!

I look into another mirror. This one projects an image forward. Now I can see before me a long passage with doors leading off to the sides. On the doors are labels! Aha! The labels are the phrases the Cheshire Cat has mouthed out. I cannot see them all clearly, but the ones I can see are inviting me to move forward. I read a sign seemingly quite close to me "Room of Being and Becoming". As I speak the words, a small mirror lights up and flashes the words: "Ontology of Being...Becoming and Autoethnography. What could it mean? The thought no sooner passed my mind than the sign on the door not too far from me began pulsating: 'Room of Demonstrating' I read. The pulsating soon stops. Closest to me is a label "Autoethnography exploring the Room of Methodology" I look to Alice. She is smiling. "Yes!" she says! We must start at that door! I think we will find many books, author's writings it is very much like a library.

As I set out to follow Alice I catch a glance of myself in the beautifully bevelled framed mirror. I see myself on the Porch, looking into a set of mirrors reflecting back at me! I see a Journey taken by Alice and me, a journey that began with my falling into the rabbit hole. Being the curious person I am, I wanted to know how deep the rabbit hole was!

As I grew in the pleasure and potential of seeing White Rabbit as a metaphor for MS, and Alice as my Muse and guide, I realise I must find a way as a researcher to show what it is that I am seeing, feeling, imagining, and thinking. The Vestibule in which I find myself provides just such an opportunity. Here the



portraits and images with short annotations provoke my reveries. I am certain to learn more about these people and their extraordinary work as I enter this still mysterious House.

I look around the Vestibule in wonder. As I wonder what lies before me? I am also in awe of this place. In the distance I see a black screen which looks like a partition of sorts. Curious, I can hear a low pitched sound. It sounds a bit like an old movie wheel. I am intrigued. I go and look. Behind the screen I see the movie reel playing images. I see four little icons that are moving around on the screen and a brief summary of the ascendancy of each. How timely and inspirational!

The screen and icons fill me with what feels like a premonition. I appear to be given a magical preview of what may be ahead of me in this magical House of Learning. I will spell them out! Explication of these activities and their influences will underpin the way in which the research methods are employed within this study and how interpretations are formed. I set about to create these as four discreet activities:

- i) A preview of the topic and mode of enquiry.
- ii) Explication of the thesis as useful/insightful ways in autoethnographic research.
- iii) The positioning of myself in the thesis and introduction of the inspirational influence of Alice, as my guide and wise Muse. Introduction of the people in the portraits, and the annotations below their portraits that promise inspirational guidance.
- iv) An illustration of the style of the thesis that is inspired by the collective wisdom of the authors I have read, the mystical characters that have sprung to mind, my extensive education and training as a nurse, and most importantly, my experience of having MS – not only as an illness now metaphorically represented as a White Rabbit, but as a teacher leading me into mystical, magical, and life changing reveries.

With attention now focused to the sequencing of my story line, the last icon I see is David Boje (2001a, 2001b, 2008, 2011). His portrait has two annotations: Storytelling Organisations and The Antenarrative. What a great place to begin my deepening enquiry! I start with the introductions from this anteroom, which I

describe as a way forward in search for meaning to my new way of being in-the-world with MS where, *I Carrie*, am awaiting to meet with fellow companions on this search for meaning and enquiry.

### **Introduction from the anteroom**

I place my hat and coat in the anteroom. I have my satchel that contains my trusted notebooks. Permit me to introduce myself and share the many experiences I have been exposed to and the many roles I embody: I am a woman, mother, grandmother, wife, nurse, educator, researcher, PhD student and, a person with MS (PwMS). I received my confirmed diagnosis of MS in 1998. As a nurse I held a number of nursing positions in both private and public hospitals, in the community sector, and then latterly in nursing education as a lecturer. Being a nurse I was familiar with looking after others who had been diagnosed with MS. With regards to my other life roles I did not have a deeper understanding of what it was like to manage MS. As a nurse I knew a lot about the medical aspects of the illness and I was highly experienced in providing nursing care for the acute stabilisation of those patients presenting with the medical symptoms of MS. With regards to having a good knowledge about the long-term management of MS from a personal perspective I did not know very much at all. How could I? This was a new learning experience for me. I was naturally curious about some of the sceptical comments made from medical professionals about this illness. I was now a PwMS living and working with MS, and an emergent writer of autoethnography. I wanted to build on my prior qualitative research experiences this time using research approach of autoethnography to examine my experiences of MS. I thought would this not make a fabulous topic to explore as scholarly inquiry? In August 2008 I embarked upon my doctoral thesis.

My interest in autoethnography began after my confirmed diagnosis of MS. How I came to incorporate and value autoethnography as a form of enquiry to add to my portfolio of fruitful research methods is the focus of this research study. I was completing my Master's Degree in Health Development and Policy and the required research component when I was diagnosed with MS. One of the lecturers suggested I write about this situation that I now found myself in. I was stunned. I

wondered who would be interested in this account. Would it be deemed as good robust research? At the time, I was also teaching primary health care/public policy and research methods to undergraduate nursing students. I was familiar with both quantitative and qualitative research methods-methodologies and had taught them.

The coincidence of my diagnosis with my need to complete my Master's thesis was fortuitous. The invitation to think about my changes in health circumstances as a research project now became my focus. I began to research the qualitative research approaches that might best align to both my desire and need to think about my life and to do so in a research project that would enhance my life, and inform my practice as a nurse, educator, and researcher. I chose a research design hermeneutic phenomenology that included semi-structured interviews with PwMS and their caregivers and a thematic analysis.

From the findings I noted that communication and listening skills of health professionals and nurses were issues that needed attention. I found that it was not so much that nurses did not want to listen but rather that they did not have the skills to address the complexity, uncertainty, and unpredictability issues regarding the management of MS. Forester (1980) suggests that by not listening health professionals may deny themselves the insight, vision, compassion, and ordinary meaning of others. They abjure their own possibilities of learning, growing and understanding of who they are collectively and individually. In doing so can undermine our understanding of who they are and can be.

For doctors, nurses, and health professionals looking after people who have MS much of the care is assigned to acute stabilisation of the presenting medical symptoms. At any one time symptoms such as pain, numbness, eye problems, vision, loss of balance can present. Many patients may experience one or all of these symptoms at any time without any warning. In situations like this clinical management of MS by doctors can be varied and inconsistent. I come across this article by Rosenberg (1998) who writes in many situations where clinicians face issues with clinical uncertainty, some practitioners may develop maladaptive strategies for coping and dealing with it. He knows of six maladaptive types: i) Dr. Know - doesn't want to admit to uncertainty; ii) Dr. Dolittle - is unsure about everything and afraid of making a wrong decision; iii) Dr. Turf - doesn't make decisions himself/herself; iv) Dr Delegate - relies on steady stream of well-informed juniors; v) Dr. Panic - over investigates every patient then treats them

aggressively; and vi) Dr. Facile - whose philosophy is patients are well most of time, so why expect the worst - he/she waits till patients become obviously ill before he/she treats them. I was intrigued!

I'd not seen any writing like this before. Rosenberg's commentary was indeed judicious and revelatory. His views led me to reflect on my experiences with the medical encounter, my research question, and the communication issues of clinical uncertainty that I faced. I read on.

The needs of communicating and dealing with clinical uncertainty were now an important part of my investigation into the illness and the care for those who had it. I carried on reading extensively about illness experiences, not only the self-help type but those that examine: illness, disability, caring, quantum healing and storytelling as ways to shed light on feelings of the chaos, complexity, and uncertainty with chronic illness.

On this search I was drawn to Frank's (1995) *The Wounded Storyteller* an account of the illness experience based on his experiences of cancer and a heart attack. Frank's (1995) identification of three basic narratives: restitution, chaos, and quest were helpful in the development to find my 'authorial voice'. His restitution narrative is based on basic plot of a story that yesterday I was healthy, today I am not healthy, I am ill, and tomorrow I will be better. I reflect on the restitution narrative. It is a narrative that describes the movement about health as moving back and forth in the direction of health being fully restored. I have MS. As MS is a chronic degenerative illness I will not totally return back to full health or full recovery. In finding my 'authorial voice' I am learning that a restitution narrative illustrates illness as transitory. For these reasons I would not be able to adopt the restitution narrative to my life story.

In the chaos narrative the plot is life will never get better and no one is in control. There is an attraction to being drawn into the undertow of the illness experience alone. In the writing of my living story where I am developing finding my 'voice' I can relate to this chaos narrative. In some instances I experience this feeling of chaos when my MS symptoms flare up. I have pain that at times no one can control. In the quest narrative, an individual accepts illness and seeks to use this, believing that something is going to be gained through the experience. In finding my 'authorial voice' I am questioning my lived experience of MS that is now an impetus for change. Frank (1995) says this differs from the restitution

narrative in that an individual is not just solely seeking recovery from an illness. MS the illness is becoming the motivator and this quest for social action and change that I seek with my new way of being-in-the-world with MS.

The exploration of Frank's (1995) three narratives significantly helped influence the refinement of my research question. Writing my living story about how to make sense from illness through a troubled body will 'show' how stories are an opportunity for self-expression and questioning of self-care practices. Ricoeur (2010) urges a focus with passion on questions. I thought deeply about this point. As I've always aspired to living my life with excitement, feeling, and fervour. I reflect on these feelings which generate these questions: "Does this approach contribute to developing and keeping this dialogue evolving as self-reflexive inquiry? How might others be affected by my focus on self?"

Maybe this says something about the person I am. I had begun another mini cycle of inquiry about exploring human action and embodiment. Was the experience of living and coping with a non-curable illness such as MS, one that was different to experiences of coping with a curable illness or disease? I spot Mairs (1996) *Waist High in the World*, Mairs uses her own experiences of MS to portray and create an ever deeper understanding of the human condition. I then find another article by Mairs (1993, p. 25) *When Bad Things Happened to Good People*. It was in this account that I was deeply touched by Mairs when she makes an offer to provide comfort and 'companionship in a common venture'. Here she asks readers to identify with her plight and gain a heightened emotional sense of what it feels like to live with MS, to enhance their understanding of the contradictions that occur. I reflected on her writings as these offered a point of comparison for my life story. Mine is as an identity and meaning project using my own experience as an internal frame of reference to explore ways of learning about my being and becoming-in-the-world with MS. I rummage about and find Sacks (1984) *A Leg to Stand On*. He uses his own experience of loss and injury where through injury, in the midst of good health; he sustains a neurosensory loss to his injured leg. In writing about his journey in dealing with injury, loss, and illness he returns with another vision of the meaning of disease. I was enthralled reading these. Mairs and Sacks provide insight and understanding that through loss and isolation [whether this is due to an injury or degenerative illness] it is possible to develop a deeper meaning on experiences of disease.

Still being rather inquisitive I carry on with my search. It is Hawkins (1999) positioning of pathography - signifying a style of writing of disease that catches my attention. In *Reconstructing Illness: Studies in Pathography*, Hawkins emphasizes the centrality of narrative as ways of refashioning a life disrupted by illness or disability, locating illness stories within a larger framework of medical discourse and cultural practice. In departing from this way of thinking Hawkins significantly influences this next level of inquiry. I am eager to examine the words difference, irregularity, and disorder within the context of these constantly shifting states of meaning in illness. In thinking about centrality of narrative with living story my thoughts returned to the image of the rhizome seen in the vestibule.

I then see Alice who is pointing to this book by Deleuze and Guattari (1987) *A Thousand Plateaus*. What a timely a find! I eagerly turn the pages and read on. Deleuze and Guattari (1987, p.3-25) developed the concept of the rhizome and consider the rhizome as an image of thought that has the capacity for multiplicities. The rhizome is between things and does not have a beginning or an end - it is 'inter-being' How mesmerising!

I remember Alice saying: "The rhizome is my map". I was attracted to this concept of the rhizome as I believe it would be highly relevant to my discussion of lived experience in the writing of antenarrative and my life story. These rhizomatic pathways will connect self to present and past experiences of living with MS and coping with flare up of MS symptoms. It is in learning how to 'see' and 'notice' the multiplicity of these embodied experiences that will give direction to living story portrayed through antenarrative as human action.

In my quest to develop human action as praxis I am seeking more creative ways to describe my illness experience. That would be well clear of the traditional positivist biomedical models of health/disease/illness. In reading about other's experiences of loss and illness and the seemingly multiplicity of their thoughts, and feelings they encountered, I see how useful Deleuze and Guattari's (1987) concept of the rhizome could be for the application of exploring lived experience. It can enable the connection of any point to any other point through an interpretive construction processes. The rhizome [as concept] seeks to explore these states of individual meaning, where it brings into focus very different states of meaning that can be read in any order in any manner. Deleuze and Guattari (1987, p. 3-25)

describe this as being a ‘map’ that is always detachable, connectable, reversible, modifiable, and has multiple entrance ways and exits. Fascinating!

This led me to explore other individuals’ experiences with illness and disability and how they cope. Spiegel’s research (1993) *Living Beyond Limits* captures a remarkable account of a woman with breast cancer who received social and emotional support in addition to standard medical care. Spiegel recognises the essential healing connection between the body and mind. It was this aspect that I was most intrigued to read about. I was interested to learn whether research that incorporated body/mind focus would also address improving communication issues with medical doctors and allied health professionals. As one of the significant findings from my Master’s study was that of communication and listening skills by doctors, nurses, and health professionals. Spiegel’s research recognising ways of improving communication was timely as my focus now is to build on this in my enquiry.

### **Introduction to the topic and mode of enquiry**

In 1998 I was diagnosed MS. MS had interrupted a happy and comfortable way of life that I had become accustomed to. The search into how I could now live with the insinuation of MS in my being became a significant focus in my life. My decision to include a PhD level investigation as part of my quest ignited vigorous thought about just how I might undertake such research about or into myself. Many ideas, thoughts, and questions about illness, change, embodiment, and experience buzzed around in my head. Something called me to look deeper into myself for the meanings to be made of my new way of *being* and *becoming-in-the-world* with MS.

I yearned for a way of making meaning from this change to my being. Before me now were many potential research threads. Each would make fabulous research studies. But I only wanted to do one PhD study, for the time being anyway! I was drawn to Ellis’s (2009) *Revision Autoethnographic Reflections on Life and Work*. In it, Ellis (2009, p. 83) describes her experiences of her husband’s illness and their many conversations prior to his death; the conversations about illness, emotions, and introspection, and their intersections as aspects in

sociological inquiry. Together, as sociologists, they had worked on papers that sought to bring the study of emotion into studies of human behaviour. When, after his death Ellis returned to teaching, she was acutely aware that the graduate teaching curriculum she was involved with largely revolved around thinking abstractly, building theory, and synthesising results from empirical studies.

Sociology, she realised, did not appear to concern itself with personal stories and feelings. The focus was on theorising, generalising, and manipulating variables primarily in positivist modes of enquiry. Ellis (2009, p. 84) questioned why prevailing social science approaches omit introspective data by writing in a way that makes detailed lived experience secondary to abstraction or statistical data. In *Final Negotiations* (1995) she writes about the experiences of caring for her dying husband and the themes that she drew from this experience. These themes involved negotiating hope and reality, along with hope and truth telling, so that she and her husband could live the best lives possible given the confines of his illness. Ellis (2009, p. 94) says that as she wrote the stories in *Final Negotiations* she felt it important that they evoke reader's emotional experiences and be useful for all of us. She wanted them to offer sociological understanding of grief, illness, relationships, doctor-patient communication, care giving, illness and dying and it to be also useful to the ill, their caregivers and for all of us who will suffer loss someday. Ellis records how some of her colleagues questioned the value of narrative understanding and the therapeutic usefulness in sociology. Some were suspicious of her claim that writing evocative narratives about oneself can contribute meaningfully to the sociological imagination. Her discussion of these suspicions helped me to be more aware of some of the critical responses that I may encounter as I commit personal experiences to the public domain. The risk of criticism did not deter me.

I was deeply moved by the work of Ellis and her claim. It was the notion of sociological imagination that caught my attention I wanted to incorporate this notion in my autoethnographic enquiry. My desire was to do exactly as she advocates for: to write evocatively about experiences with as much rich detail that would be illuminated by reflection and the reflexive process questioning the relationships between research accounts, own social world, and self.

My thoughts about the use of imagination for my inquiry were initiated, as the cliché says, by 'being in the right place at the right time'. I remembered seeing



on the programme of a seminar I was attending that use of ‘imagination as method’ was being discussed by Michael Hayes (2012), a scholar whose research was a focus on intersection of education, social justice and global citizenship. From his presentation entitled: *Imagination as method: Poiesis in ethnographic research*, I learned about how the use of imagination as method could offer new transformational potential in the field of ethnography for creating a just, sustainable, and caring society.

I recall leaving this seminar feeling so excited about this opportunity to re-direct my research to ‘imagining’ possible new worlds like Alice did when she bravely enters into a new world and takes care of herself. I take out my notes from my satchel and re-read them. Imagination is a form of *poiesis* [or making] in which learning and understanding is generated through imaginative and generative activities of the researcher that is intentional and transformative. Hayes (2012) suggests that in highlighting the poetic and imaginative qualities that already exists in ethnography and foregrounding them a method, this will enable researchers to re-direct their research to imagining worlds of possibilities. This was a fantastic opportunity to reflect on the imaginative and poetic qualities that I intended to bring to my inquiry to address the management and care of those individuals who have MS in a more humane manner.

As MS is central to my ‘self’ and the embodied relationship I have with it and with others in my social world. The use of *poiesis* would be both in the focus of crafting imagination in this autoethnographic enquiry and how it is conceptualised and presented in living story. Attention to my experiences, and layers of reflection, would be the means and mode of my enquiry. I would contribute to enhancing the use of imagination as a study option to be used in learning organisations for understanding human action, embodiment, and experience. As an emergent autoethnographer instead of doing to or describing the situation as it is, I am making it anew as I conduct my inquiry. Imagination, images, and imagery would be central to my work a work of reflection and self-reflexivity.

Whilst thinking about how to be reflexive, I encountered a fortuitous opportunity to meet Ann Cunliffe, scholar of and advocate for reflexivity as a developmental and emancipatory process in our lives. In her (2011) seminar on *Research Methodologies – why be reflexive?* I learned that being reflective in my

writings could be a form of self-reflexivity. It was an opportunity to explore what constitutes my social and organisational experiences in my every day interactions with MS. I could (and would) explore possible meanings and interpretations of my (re)actions, and the way my reflection on these experiences came to be the starting point for this PhD and came to entwine inquiry and action in new ways of being. Attending Cunliffe's seminar clarified points of relationality, meanings, and epistemology as theory, issues for form, design, research practice, and strategies for the potential criticisms I would face using reflexive inquiry.

I reflected deeper on Cunliffe's points and how these relate to the writing of a living story. Relationality - describes the type or element in the research inquiry and nature of the relationships. As self is central to this inquiry I draw on Ellis's (2009) concept of relational ethics which are heightened for autoethnographers. Ellis says researchers do not exist in isolation they live connected to social networks. In using personal experience in their work, autoethnographers not only implicate themselves but others. Meanings/living story seeks to explore states of meaning as dimensions of the study. These dimensions are central to the design of the project that does not have the traditional start, middle, and end. My living story is a continuum; there is no traditional conclusion as such it is situated in the middle. The meanings of what my experience entail are located in living story. Epistemology – how does the inquiry serve as for theory of method or grounds of knowledge? Reflecting on these insights helped me enormously to (re)define my 'so-what?' questions, the questions about the implications for writing my research as I now intended to do.

My attention now focused on aligning the process of reflection and reflexivity with the writing of living story of my confirmed diagnosis of MS and embodied experiences. My growing understanding of the value of including narrative, life story, self, and identity was aided by Watson's (2009) *Narrative and Autobiography* notion of the dialectical relationship between the internal/inward facing aspect of identity work and the external/outward facing aspect. It influenced my approach with the writing of my life story and the process of reflection/reflexivity on it.

The evolution of my story illustrates this internal/inward process of reflecting on a MS experience, illustrated in reading about it as well as it then transitions the external/outward response illustrated by emotion, and neuropathic pain I

experience. As I write about this transition of self as a person-without-MS to now being Carrie a person-with-MS. I argue that this is an example of the application and understanding of Watson's notion of narrative identity within this autoethnographic account of my life events involving many different interpretations, meanings, and phenomena of this life transition.

Prompted by Ellis and encouraged by the work of Watson, I committed to making my lived experiences my primary focus for this research. Re-living personal experiences helped me to (re)clarify my purposes by placing importance on evocative detail. This requires a different genre of meaning-making. I have chosen to use storytelling, metaphor, and image as my way of doing this research. My attraction to the use of metaphor in reading and writing of emotional experience is threefold:

- a) it allows focus on image as a creative force in personal story telling
- b) it contributes to growth and diversity of autoethnography, and
- c) it evokes and inspires a commitment to greater social justice.

This threefold summary will be used in the writing of my life story. My attraction to the use and value of metaphor is also an example of what Lakoff and Johnson (2008) in their work *Metaphors we live by* suggests is a device of the poetic imagination. In using metaphor in my living story it allows self to explore the matter of the extraordinary rather than the ordinary. In the re-writing of my life reflections that evolved and from re-reading, revising my journal entries that I have kept all my adult life, but particularly those written around the time the first symptoms of MS appeared in my life. It was the use of metaphor I was most drawn to describe the extraordinary experiences I was experiencing they were most certainly not ordinary ones at all! At that time, writing about experiences in my journal was quite a therapeutic thing to do. I not only recorded my immediate experiences and sense-perceptions of these impressions, I also wrote to explore opportunities to reflect on the many different ways I could visualise the changes to my life. I had an incurable progressive neurological illness. I had somehow to try to work out a frame of reference as a way that I could deal with all the anxiety, uncertainty, emotion, and my growing sense of curiosity about it all.

Being the curious person that I am, I wanted to investigate notions of *self*, *body*, and *work* as basis for a deeply philosophical and personal approach to examining human experience. These were the notions that would now form the shape of this enquiry along with Deleuze and Guattari's (1987) the concept of the rhizome. Alice had adopted this concept as her 'map'. I was assured that with Alice as my guide, I would be well served in finding ways to explore learning about writing and doing autoethnography in the many rooms I was yet to discover.

By drawing on my experiences of MS I wanted to illuminate aspects of the experience of receiving my confirmed diagnosis of MS. I had been well trained in the positivist sciences. Yet, I could not see how its methods of hypothesis testing would serve me. The positivist approach to scientific enquiry relies on objective repeat experiments. I began to explore the notion that *my* experience of *my* experiences couldn't be replicated. Nor could the experiences of others be the same as *my* experiences. I needed a different research paradigm for my research. I wanted to incorporate my creative and imaginative self in this approach. Existing qualitative methods of ethnography, critical theory, and heuristic inquiry as approaches to researching human lived experience became my starting point.

To incorporate *my* experience in a unique way in this thesis I returned to Ellis (2004, 2009) and Marshall (1999, 2001). My growing interest led me to find Chang (2008) *Autoethnography as Method*, and Moustakas (1990) *Heuristic Inquiry*. By drawing on aspects of these works I set about to craft my enquiry using my chosen method of autoethnography. In it I show how the first person narrative, as an emergent process, can be used to explicate the research question that I have sought to explore. My question became: "*What are the relationships between self, body, and work as mutual organisational relationships?*" I ask this question for myself, and in relation to those individuals who have MS. For consideration are the implications and recommendations from this inquiry intended for those carers or health professionals who look after persons with MS, or similar chronic health conditions.

Through autoethnography I am searching for more creative ways to communicate lived experience with others, especially those employed as health professionals. This next level of curiosity led me to explore further the meaning of illness. I find myself drawn to Toombs (1992) *The Meaning of Illness* developed out of her own experience as a patient with MS and in particular her experiences

of communication problems with doctors, resulting from a fundamental disagreement about the nature of illness.

I was vividly reminded of a moment described in my own journal:

*I have pain. It is located in my left eye. The doctors get me to read an eye chart. I can do this. The pain and throbbing is so intense it even starts to make me feel nauseous. I can't tolerate too much bright light or movement. The doctors ask me many questions - I try my best to answer. All I want to do is to lie down in a dark room- and get some pain relief...why is this so difficult? Why don't they want to listen?*  
*(Personal Journal, 1999).*

This entry includes some of the descriptions of doctor-patient communication. I am the patient in pain watching and sitting and asking questions. I now want to explore more deeply some of the challenges of living with MS, especially some of the communication issues I remember encountering when seeking care for an acute flare up of MS symptom. I had from the outset met some remarkable people who for some reason came into my life at this time. At the time of my confirmed diagnosis there was the visiting Ophthalmology Registrar who happened to be working here. He had extensive work experience in the area of Ophthalmology and with MS patients elsewhere. He was the visiting Ophthalmology Registrar I was seen by that explained clinical uncertainty about MS in such a positive manner. His admission that he didn't know everything about MS made me feel like I was not such a difficult patient with a difficult problem. His outlook on managing clinical uncertainty was noteworthy.

Now looking for much deeper learning's of the concepts; illness, loss, change, and uncertainty and what this now meant for me, I did not want to resist the impulse to explore. I felt a persistent call to write my story. It would become the focus of my PhD. I did not however want to portray my experience as some heroic biography, groomed of its uncertainties, angers and fears. Sometimes characters that incorporate dysfunction, deviance and psychological drama seem to always hold ones attention in a story line. My desire was to scope a good story line grounded in a more transformative style of telling one's own story. I would set to work to seek a way to learn and live fully in harmony with life, being ready to encounter some risks along the way as I look inside myself being-in-the-world

with MS and proceed through becoming-in-the-world with MS. Like Alice, I was ready to explore!

### **The positioning of the thesis as ‘insightful’ in a useful sort of way**

This thesis is an autoethnographic account of my *being and becoming-in-the-world with MS*. It is written as first person narrative. A personal story of a profound health change is used to illustrate how research accounts enriched by reflexivity and the addition of autoethnographic detail can provide a look into what Van Maanen (1979), describes as the ethnographers own taken-for-granted understandings of the social world under scrutiny. I focus on reflection and reflexivity as process for learning and understanding more about the illness experience and my perspectives of being newly diagnosed with MS. I commit in this inquiry creative and alternative ways of understanding human experience. I do this on behalf of all those persons who have MS, and for those people who care for them. This work is also for the medical staff, nurses, and allied health professions who deliver health care to persons who have MS, or similar chronic conditions, and to their families, or significant others.

I offer initial autoethnographic vignettes of my experiences of my medical encounter whilst seeking help with an acute flare up of optic neuritis. These vignettes are expanded more fully in later parts of my work. I reflect on the actual event and the lessons that can be learned from it in which the doctor and patient perspectives seemingly collide. I detail how my feelings moved repeatedly between hope and frustration, anxiety, uncertainty, and the practical implications on the matters to be attended with and decisions that had to be made.

Through use of autoethnography [as a process] it is intended that the findings of my enquiry will have implications for a range of fields: i) medical education and research, particularly in nursing; ii) the management of health related processes; and iii) the orientation of support services for the people who have such conditions and the people who care for and about them. I want *my life stories* to evoke reader’s experiences and be useful for all of us those who are ill, their caregivers, and all of us who are afflicted with either an illness, a chronic illness, and, or loss someday.

I undertake to ensure that *my life stories* are meaningful in their context by drawing on my memory and insights into my life pre and post experiences of my confirmed diagnosis of MS. The use of Deleuze and Guattari's (1987) the concept of the rhizome, Boje's (2001) rhizomatic antenarrative pathways, and Ellis's (2009) notion of introspection will be crucial to the development of the person I am becoming *with* MS and the way I am *positioning* myself in this enquiry.

### **Positioning my-self in the thesis- introducing the inspirational influence of Alice**

Initially it felt strange to be at the starting point of a PhD about myself. I understand, however, that a moment in time has its origins in the moments before it and so 'the story of me' prior to diagnosis has some relevance. So much has happened to me since my parents embarked on one of the biggest changes to their personal and family lives to emigrate first from the United Kingdom to Malaysia and then, subsequently to settle in New Zealand. Yet these details are important to why and how I came to believe in the value of doing a PhD about myself.

My place of birth was in a small rural hospital in Kuala Lumpur, Malaysia. Life in this tropical country was what every young child could ever dream of. It was delightful and exciting. Many adventures to the local botanical gardens, seaside beaches, zoos, and aquariums are just a few of my wonderful childhood memories. It was the life threatening event when I was only 19 months old that 'high jacked' some of this nostalgia. It was on one of those usual summer vacations my parents would take annually that a most memorable event took place at Pankor Island, Perak, Malaysia. The island is located on the North West Peninsula; the Malacca Strait surrounds the North West aspect of the island. I am re-calling this event after (re)reading my late mother's notes about the family holiday.

On June 1960, my mother took me for an afternoon swim. It was a beautiful still sunny afternoon. There was not a cloud in the sky nor breath of wind to be felt. My mother stood on what she thought was a piece of seaweed. This was not the case! A Portuguese Man-of-War, a type of jellyfish surfaced from the low tide mobilising all of its defences to attack. They are known to inflict an agonising and lethal sting and its tentacles are over 30 feet long. I happened to be in the way!

The jelly fish's body and tentacles wrapped around my neck, chest, and left arm. I yelled so hard that the beach had to be closed down. Others around at the time came to see what all the noise was about. My father who was swimming further out in the water could hear the commotion. He saw people waving from the beach and could hear them calling. He promptly swam to shore.

The local fishermen on the island familiar with dealing with jellyfish attacks took a hand full of sand and rubbed this onto my neck, chest, and arm area to release the suction from its tentacles. I was taken to the local hospital and given anti-venom treatment. Seriously ill, my parents were told by doctors to expect the worst. I was not expected to survive! I remained in hospital for two weeks. I recovered. I survived the attack! However, following that ordeal my mother noted that I would react in a most violent way to most of my childhood immunisations. Even at the time doctors couldn't adequately explain the reasons for these episodes they termed as an over 'active immune system'. My father often spoke about what effects a venomous attack could possibly have had on a child's very immature immune system. He was understandably interested in this phenomenon as a scientist and concerned as a father. To this day we still speak about this dramatic day on Pankor Island.

We travelled frequently to the United Kingdom where my father held a number of posts as an Analytical Chemist/Scientist. He held many prestigious jobs within the scientific community in Africa and Malaysia where he collaborated with the local people supervising numerous field trials. As a consultant he provided scientific expertise to local industries in Africa and was commissioned to contribute to scientific research on the staple cotton crops grown and harvested in Egypt. In Malaysia, he provided scientific research on the fertilizer requirements for this staple crop, of rubber.

I arrived in New Zealand in 1965 with my parents and two brothers, one older than me, and one younger. I was eight years old. I resumed my education in the local Catholic schools and in time I gained my State Nursing registration. I married and with my husband I began a very busy and happy partnership of raising two children and renovating our home. I have been nursing now for thirty five years. At the time of writing, I have been a partner to my husband for thirty-nine years, a mother for thirty-eight and a grandmother for two years. In my nursing practice and in my personal life I have always had very strong interest in



social justice and an ethic of care, an interest largely influenced and nurtured by my parent's own aspirations to the qualities of caring and social justice. I care about others. I have a strong sense of responsibility to care for those who may experience periods of loss and vulnerability in their lives.

Combining full time nursing work and study was an important dimension of my life. After many years of clinical nursing practice both in private and public hospitals I set about investigating teaching nursing theory and nursing research as preferred components of my professional development. In 1995 I undertook a career change into nursing education. I sought to make sense of change and changing circumstances of health related issues. Unbeknown to me at that point, the changes to my own health signalled one of the biggest changes to my life and the lives of my family members. It has also turned into a most profound learning experience with value that extends well beyond my personal development. The irony, looking back, is that part of my lecturing responsibilities was the re-writing of the teaching component in the nursing study guide for the course: Disability and Chronicity. I was teaching this paper and supervising nursing students in their clinical practice placements in the caring for people with chronic illness when I was diagnosed with MS.

I came across articles about effects on environmental, genetic, latitudinal effects, incidence of MS and an innovative hospital approach on disease management. I will outline aspects of these in coming chapters. I have since wondered then if the attack by the Portuguese Man-of-War all those years ago could have had any long term effects on my immune system. Could it have tricked my immune system into initiating immune attacks on its own nervous tissue? I still have the dark brown marks on my body. There is no known family genetic history of a neurological illness on either maternal or paternal side that we are aware of. I am left wondering about environmental, latitudinal factors. Jelinek (2005, p. 36) a Professor in Emergency Medicine who also has MS writes there are many theories as to what causes MS. In effect, somehow the immune system seems to 'see' the myelin in the Central Nervous System (CNS) as foreign invader and like overcoming an infection, it tries to get rid of it by attacking it. A virus or viruses may somehow trigger the process in susceptible people. Was I one of them?

Regardless of its cause, I now have MS. Its presence in my life has changed some of my views of disability and chronicity. My priorities have shifted and changed. I do not dwell on the questions: “How did it happen?” or “Why me?” I do have to contend with associated MS symptoms of pain, eye pain, tingling in my arms, hands, fingers, legs, feet, toes, and ghastly on-going fatigue. This struggle, however, does not stop me from aspiring to make better use of my illness experience. This spurs me on. I am instantly reminded of this moment described in my journal. It was when I first started experiencing some unexplained responses to a prescribed booster of Hepatitis B Vaccine I was required to have. I was working in the surgical ward and recovery room of this hospital. I remember the shift well. I record:

*I am rostered on an afternoon shift working in the recovery room of the hospital. I had a dull sort of head ache but didn't take any notice of this and kept on going. We had a busy afternoon theatre list to get ready for. I make my way to the ward to collect the patient and take him to theatre. I arrive in pre-operative room and handover is given to theatre staff. On leaving this area I experience a severe headache I clutch my head and walk over to side of the corridor. Thank-goodness I didn't have any more patients to look after. My colleague took me to a spare room to lie down. I never did finish that shift. The anaesthetist doctor came out to check on me in between seeing his patients and then sent me home. I then spent the next six week recovering from this unexplained attack. I couldn't tolerate light or movement. Even tight clothing was uncomfortable. The headaches, pain in arms and legs were excruciating. I had a very bad chesty cough and swelling around my neck. I had numerous blood tests taken. My General Practitioner had been given blood test results. He told me: "The tests show a query positive result of brucellosis". He thought this very unlikely as I had never lived on a farm nor consumed unpasteurised milk products. He felt then the tests didn't add up. I was very ill and had used up all accrued sick leave. I returned to part time work at the hospital*

*(Personal Journal, 1998).*

During the months that followed my confirmed diagnosis of MS I experienced many confusing situations, doctors and specialists appointments, hospital examinations, and even a work place interview that made no sense at the time. It was a time of anxiety but also a time during which my desire to better understand my situation was growing. This diagnosis generated in me a search for a way to create meaning to this profound change in my life and the newly attributed identities of a disabled/woman (scholar/mother/nurse/educator). My life

had been turned upside down. Initial feelings that I had to negotiate with were: i) that the illness is so unpredictable; ii) there were no clear guidelines to show how this illness is best managed; and iii) much uncertainty still lies around what this illness means.

Let me explain. For me each hour and each day is so different. Its unpredictability is a real challenge when attempting to make short or long term plans. I wanted to be able to talk about my experiences with my family and colleagues openly and effectively. I now experienced an overwhelming sense of curiosity followed by a need to explore my new situation. The experience of Pankor Island was for ever etched in my soul and, on my body! My need for greater understanding about uncertainty was immediate. A keen journalist, I took copies of all my notes from the start. I found an article: “Healthy Self Doubt” by Dr William Rosenberg (1998, p. 14), a senior lecturer and honorary consultant physician at the University Of Southampton School Of Medicine. He says: “The expectation that a doctor has all the answers is as bad for patients as it is for doctors. The prevalence and impact of uncertainty is probably underestimated. For example, no one yet knows the cause of MS but more commonly the uncertainty arises from our own ignorance and is of a more personal or ‘subjective’ kind. We may feel uncertain without really knowing why; this sort of uncertainty demands our recognition. Or we may be aware of our ignorance but unable to find answers to a question. I was thrilled to have found this article then as it coincided with the timing of my diagnosis. In time I chose to formalise my enquiry. Research work is work that I love. Research into my situation seemed an appropriate response to this challenging predicament.

The decision to explore my experiences as an enquiry suitable to achieve a PhD raised significant ontological, epistemological, and methodological issues. It was clear to me that the research approach I would engage with needed to reflect the way in which I wanted to interact with my family, my friends, colleagues, and the disabled community of which I was now a life member.

The research process had to reflect my strong aspirations for balancing curiosity and harmony with my way of being. It was necessary to seek a qualitative methodology that offered alternatives to traditional research methods. My desire was to choose a method that would provide a legitimate and authentic research space for me as the researcher [of my condition thus my emerging self]

to explore, describe, discover, and serve my creative side. I wanted a process whereby I would be able to merge my scholar self with my artistic self. Questions of research process thus occupied me before questions about the questions I would subsequently frame. Van Maanen (1990) suggests that the questions themselves and the way one understands the question are the important starting point of research. In general, I would agree. In this instance, however, the reverse was my experience. Van Maanen goes on to suggest that the method chosen should serve to express a certain harmony with the deep interests that shape an individual in the first place. I wanted my lived experience to resonate and be accessible with the experiences of others. I wanted to ensure that, as far as possible, my (re)presentation was authentic and could be made relevant to those with similar life experiences.

Because there is a very close, perhaps inseparable relationship between the subject of this enquiry and that of me as researcher, there is a need to consider these aspects regarding: i) design of document; ii) its selection as method of inquiry in relation to the research and the researcher; and iii) the emotional and professional aspects of its presentation when it moves from my desk into the public domain so that what is disclosed does not cause undue harm. My aim is that it generates helpful insights and contributes to transformational change in the practice of care for those in similar circumstances and those who care for them. This approach of placing the 'self' central to research provides for the illustration of a richness of the material, but also vulnerability. Ellis (1995, 2007, 2009) raises a point about an ethic of care. This will be further discussed in Chapter Two.

Aspects of care and social justice have always been a constant beacon in my life and now influence the way I think about and undertake this inquiry. Explication of these influences largely underpin the way in which I have sought to think about which research method would be most appropriate for my enquiry, how I was going to undertake it, and how to apply a reflective analysis to the numerous journal entries which constitute what a positivist might call 'the data'. I am 'the living data'. As well as my gravitation to social justice and caring that my parents instilled into me, I also adore being with and around people and learning of their experiences. I had read numerous autobiographical accounts about others who had profound revelational changes to their own health and lives.

In searching for a way to further my studies of myself and my life with MS I met Associate Professor Maria Humphries. It was 2008. I had been living with and recording my experiences of MS for over a decade. We talked about many things with regards to my wanting to use my experience of MS in a creative way and representation of it as a PhD research study. Maria introduced me to critical social theory, Marshall's (1999) *Living Life as inquiry*, Reason's (1993) *Reflections on Sacred Experience and Sacred Science*, and many other papers, which provided [for me] the encouragement to step away from the positivistic paradigm I was so highly trained in. It thus provided opportunities to present at conferences, publish, and engage in many conversations that have influenced the positioning of this thesis in the interpretivist genre of enquiry.

I read books on heuristic inquiry and articles on living life as inquiry. I felt the insights found there would illuminate the richness of my narratives and add depth to my chosen method of autoethnography. Through my research I intend to reflect on the 'curious harmonious being with deep interests' that would help shape my emerging *being* and *becoming-in-the-world*, in part through the very process of this research.

My inspiration was emboldened by my reading of Ellis (2004) *The Ethnographic I*; Ellis (2009) *Revision: Autoethnographic Reflections on Life and Work*; Ellis and Bochner (2000) *Autoethnography, personal narrative, reflexivity*; Chang (2008) *Autoethnography as Method*; Moustakas (1990) *Heuristic Inquiry*; Denzin (2003) *Performance Ethnography: Critical Pedagogy and the Politics of Culture*; and Denzin's (2003) *The call to performance*. I had now seen distinctive portraits of following eminent researchers: Ellis, Ellis and Bochner, Denzin, Chang, Moustakas, and Marshall. I felt in awe of such company and had to pinch myself! Was I really standing here in front of all these amazing people who have selflessly contributed so much to literature and learning?

Ethnography, autoethnography, and the move to the development of a call to performance autoethnography were influential and galvanised my intentions to craft my research as an autoethnographic enquiry. This required a choice of style, and the selection of authors that would guide my work. I also wanted to ensure epistemological and ontological congruence throughout the life force of this thesis. Why introduce all these people here? I do so because they are fundamental to the way that I as researcher have i) a unique understanding of the topic; and ii)

for the audience to be able to see more clearly who *I* am in this work and what were the issues that emerged.

### **The style of the thesis and the scholarly companions I chose for this journey**

All life entails adaptation and change. Some changes can be foreseen, others cannot. A constant but unpredictable change in my life is MS. I was now keen to write about these adaptations to my personal life experiences as a research project. This thesis would be written in first person. It is an autoethnographic account in search of and understanding of my *being* and *becoming-in-the-world* with MS. As such it is an evocative and personal account expressed in style of first person narrative. In thinking about the positioning of the 'I' in this enquiry I return to Ellis (2004, p. xix) *The Ethnographic I*. Where Ellis posits these questions for consideration: What is the role of the 'I' in ethnography? Is the 'I' only about the eye of the researcher? Might the researcher also be subject? Might the 'I' refer to the researcher who looks inwards as well as outward? And what can be gained from making the 'I' the part or even focus of ethnographic research? Why highlight these questions here? I do so because reviewing these questions are vital to me as a researcher engaging with writing a first person narrative account about my confirmed diagnosis of MS.

As a reflexive genre of writing, autoethnography situates *self* within context of a culture, sub-culture or group, and studies one's experience along with that of other members of the group (Duarte, 2007, p. 2). Ellis and Bochner (2000, p. 740) write that it is therefore a personal style of research characterised by confessional tales, which do not figure in more conventional style of academic writing. According to Duarte (2007) autoethnography has no pretence of objectivity. Ellis and Bochner (2000, p. 741) argue that it is the researchers' own experience that becomes the central focus of investigation. I took note of these scholars' views and was reassured that my choice to place 'self' at the centre of enquiry was the right place to posit my stories and breathe life into the more passive empiricist ways of describing and conveying lived experience of illness and MS.

By immersing my-self in the research I could now see that the potential for the personal construction of a life event was able to take place, an approach that

would focus on shifts of consciousness in the construction of meaning rather than solely relying on traditional empirical methods of data collection, validation, and analysis for meaning-making. Through transitioning from a healthy and active person without MS to Carrie the person with MS, being immersed in this experience provides much rich and evocative detail to construct meaning. This shift in my thinking reignited a desire to revisit Ellis (2004, 2009) *The Ethnographic I* and *Revision: Autoethnographic Reflections on Life and Work*. It was captivating (re)reading *Storying the 'I'* and *Revisioning the 'I'* and how Ellis advocated for use of 'I' not to be excluded in her writing. I thought seriously about this point and given that the nature of this type of work that includes immersing self in the project - how could one not incorporate use of 'I' in it? Not to do so in my view would certainly compromise the design of autoethnographic research and its goal to provide accessible and evocative literary texts. Use of positioning the 'I' in my living story will do this. 'I' care deeply that my stories will have the transformative and revelatory potential and impact to improve care for those persons with MS and for those people who care for them.

It is through an autoethnographic lens that I would be learning how to notice and identify with myself as an emergent autoethnographer who is interested in studying personal life and poetics of social experience. I identify with the role of a narrator/writer who with use of autoethnographers *eye/I* focuses on the construction of 'I' in the story and its meaning rather than following positivist ways of focusing on data collection, validity, and presentation of evidence. In doing so I do not subscribe to neutrality; instead my focus is to reveal my own experiences of MS, the management of acute flare ups of its symptoms and associated challenges with access to care. I believe being immersed in this enquiry and writing about it in this report was this realisation that prompted me to (re) appraise more critically my experience of MS. I was now both an insider and outsider. Stepping back to reflect on experience would develop meaning to be found in good stories of 'being there' as example of concrete experience. My autoethnographers' *eye/I* would now become the useful researchers 'accessories' to access rich evocative texts. My desire is to record my *life story*.

I learned from the books that I had read that the most effective way when describing personal experiences was with use and positioning of 'I' and poetics. I again returned to Ellis (2004, p. xix-xx). She says: "I wrote this book for those

interested in autoethnography and for those who want to incorporate the 'I' into their research, writing, and teaching". It was inspirational! I needed a way to approach writing about the multi-layered issues of my illness experience within the text of this thesis: i) the recording of introspection; ii) the examination of emotional experiences; and iii) the forms of narrative and imagery that would provide a legitimate but ingenious way of achieving this. Ellis (2009, p. 17) makes reference to this action as the re-visioning of the 'I'. This action will be expanded on in Chapter Three and Four where through my autoethnographers *I/eye*, I story the 'I' and in final chapter where I write as *I Carrie*, who has come to terms with MS and lives with it but who is not defined as a passive construct nor constrained by it. My story will always be open to (re)vision. It is a continuum. MS never goes away completely it is always with me.

Other influences that have helped shape this thesis are the writings drawn from the philosophers Heidegger (1927) *On Being and Time*, Nietzsche (1966) *Beyond Good and Evil*, Charles Lutwidge Dodgson (aka Lewis Carroll) and his inspiring stories about *Alice's Adventures in Wonderland* (2006) from which I draw on aspects of animation, fiction, and imagination. In this thesis the White Rabbit becomes an animated version of MS (the illness). Alice's candid approach to life is the character that I aspire to emulate. She is not trapped by the confines of roles or requirements of everyday life. She is courageous in her pursuit of understanding. She is puzzled but not destroyed by the seemingly unexplainable. To draw on my creative and imaginative self, Alice provides the essences of wit, humour, and whimsical ways of exploring reversed meaning. She helped me to re-shape my insights for discovering, meaning-making, and communicating meaning as an integral part of my life.

While in medical terms I am [still] Carrie who has MS (as in a medical condition of the body to be treated), in this research I am [now] Carrie who is in a relationship with MS. I chose the Alice stories to craft an internal frame of reference for my thesis to *show* how *I Carrie*, once diagnosed as *having MS*, now is *Carrie who lives creatively with MS*. To show this transition, I draw on a metaphoric depiction of the White Rabbit as an animated depiction of MS with whom I have formed a life-long relationship. Initially my following the White Rabbit was erratic and full of confusion. It became increasingly intentional, interactive, and reflective.



I was now committed to research from the point of view of the person who has MS, with many of the private, confusing, and often distressing moments laid open for observation for the knowledge that such exposure might bring. After much searching I had chosen autoethnography as the orientation that would best achieve this aspiration but not without some concerns. For a nurse trained in the positivist sciences, this seemed a highly risky choice. However, it seemed that with MS and its unpredictable manifestations now an unavoidable aspect of my life a fluid research process seemed appropriate.

I next introduce *autoethnography* as an example of where researchers own experiences becomes the phenomena under investigation. Borrowing concepts from *heuristic inquiry* I describe how personal research is a valid research method, and in drawing from *living life as inquiry*, I show how applying notions of inquiry as method help to explain ways for meaning making. It is in a form of narrative writing where in an e-merging theory and story from the eye/I that writes/rights as being, acting in the world *shown* through thinking and poiesis. These narratives creatively display embodied experience that is drawn from body to convey lived experience which is illuminated by autoethnographic vignettes *showing* specific incidents. In these stories, I am present and I *show* how I feel.

What an interesting time I have had in this Vestibule. In here I am now intrigued! I want to find out what thoughts and ideas lay behind the choice to display images of these people and cryptic referral to their work in the portraits and their labels here on display. I look forward to learning more about the characters I have met here, the work they have done, the links I may find to those who have inspired them, and the application of their ideas to life! I now see Alice standing by a door at the end of the vestibule. Above the door is a sign: Autoethnography: The Room of Methodology. Full of curiosity, I follow her in.

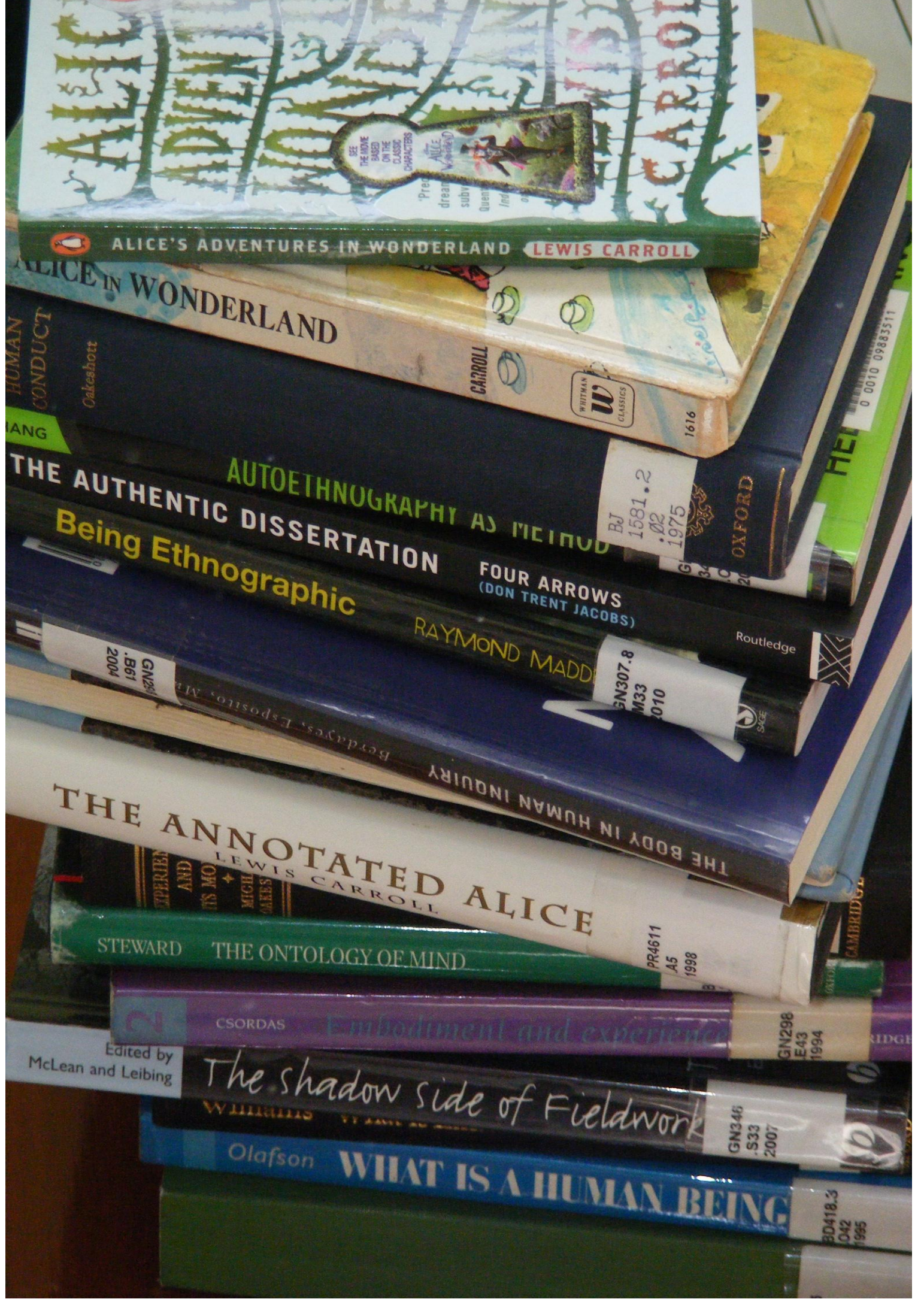
## **CHAPTER TWO**

### Autoethnography

#### Exploring the Room of Methodology

' If we knew what we were doing, it would not be called research, would it'?

A. Einstein. (n.d).



ALICE'S ADVENTURES IN WONDERLAND LEWIS CARROLL

ALICE'S ADVENTURES IN WONDERLAND LEWIS CARROLL

ALICE IN WONDERLAND

HUMAN CONDUCT  
Cakeshott

CARROLL

WHITMAN CLASSICS

1616

AUTOETHNOGRAPHY AS METHOD

THE AUTHENTIC DISSERTATION

Being Ethnographic

FOUR ARROWS  
(DON TRENT JACOBS)

RAYMOND MADDRELL

Routledge

SAGE

BJ 1581.2  
.02  
1975

GN307.8  
M33  
2010

GN298  
.B61  
2004

Berdayes, Esposito, Ma...

THE BODY IN HUMAN INQUIRY

THE ANNOTATED ALICE  
LEWIS CARROLL

STEWART THE ONTOLOGY OF MIND

PR4611  
A5  
1998

CSORDAS Embodiment and experience

GN298  
E43  
1994

Edited by  
McLean and Leibing

The shadow side of Fieldwork

GN346  
.S33  
2007

Olafson WHAT IS A HUMAN BEING

BD418.3  
O42  
1995

## CHAPTER TWO

### Autoethnography

#### Exploring the Room of Methodology

As I enter through the door held open by Alice, I find myself in a room that looks a bit like a library. There are many shelves of books and journals. The shelf adjacent to my eye level is labelled Philosophy. Another is labelled Metaphor and Storytelling and there are a pile of nursing medical journals. In this room I also see many tables, trolleys, shelves, glass bottles, and books of different sizes. On one of the shelves a small book was poking out as if it had not been properly put back on the shelf. The cover has: “*Autoethnography*” beautifully printed on its face. What a curious find! I sit and begin to read this book. This is what I find: An introduction to the philosophical basis of autoethnography, and short history to this research approach. It describes the ‘processes’ of doing autoethnography, the forms this may take, and the ‘product’ typically produced i.e. writing autoethnography is the product. The potentials, issues, criticism, and the [relational] ethics that arise in the ‘living’ of autoethnography are reviewed with a discussion on issues of reliability, generalizability, and validity as they arise in this research tradition. I plan to take copious notes many of which I will leave here in the Room of Methodology [as my Chapter Two] and more that I plan to carry with me as I intend to see how well I can apply these ideas in my own research practice of performance autoethnography that I feel most drawn to.

#### Introducing the research approach

*“He who has health has hope, and he who has hope has everything”...*

(Arabian Proverb, n.d).

As a newly diagnosed person with MS I was searching for a process that would enable me to make sense of this situation that I was struggling to understand. My need for understanding was immediate. I wanted to tell my story of my journey to understanding. I experienced this pressing desire to explore my

situation as a formal scholarly inquiry. In my view, this was a circumstance requiring non-traditional research approaches. The idea of telling my *life story* as personal narrative facilitated by my use of the Alice stories and metaphors had to be congruent with my way of being as a woman, wife, mother, nurse, academic and person with MS. My focus as an emergent researcher was on how I could clearly expose my ontological and epistemological positioning as I came to understand what could be achieved to investigate and relate a personal encounter in a way that was useful beyond my own edification. The choice of an appropriate method then was vital to my positioning and context of the research inquiry. As I fossicked about in this room Alice had led me to I found many articles and books by authorities in this autoethnographic, first person, and narrative style of research. Some of these authors I had met before, seemingly in another life, my life as a health nurse educator and lecturer. Some I had met and re-met in the Vestibule where my initial interest led to some useful revisiting and expansion of my early ideas. I was now in a room filled with books and journals that draws me to re-reading with much focussed attention.

The writings of Van Maanen (1979, 1990); Ellis and Bochner (2000); and Denzin (1977, 1998, and 2003) on display in the Vestibule were pivotal to my initial interest in autoethnography. Here they were again along with some other old favourites! I see books, journals and folders with the names of following eminent researchers: Ellis, Ellis and Bochner, Denzin, Chang, Moustakas, Reed-Danahay, and Marshall. I felt in awe of such company and had to pinch myself!

Was I really standing here surrounded by the work of all these amazing people who have contributed so much to literature and learning? I settled into further reading of researchers Ellis and Bochner (2000); Ellis (1991); Denzin and Lincoln (2000); Van Maanen (1979, 1988, 1990); Patton (2002); Tierney (2000); Tierney and Lincoln (1997). Their writings about representation, narrative voice, and evocative autoethnography connected so well with my present way of being and feeling that, in my view, conventional ways of researching human experience could not. No wonder portraits of these people had be placed in the Vestibule of the House of Learning. Their works I had read earlier now seem to provide vital support for the work that I want to undertake. I knew now that I was looking for an approach that would recognise: i) 'I' was a subject in this inquiry; ii) that nothing can be totally independent of the writer; and iii) it was a legitimate

approach to align to my new way of being. I had a burning curiosity to find out what autoethnography is!

Autoethnography as described by Ellis and Bochner (2000, p. 739) 'is a genre of writing that displays multiple layers of consciousness connecting the personal to the cultural'. Ellis (2004, p. 37) says the autoethnographers gaze moves 'back and forth; first they look through an ethnographic wide angle lens, focusing outward on the social and cultural aspects of their personal experience; then they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations'. Reed-Danahay (1977, p. 3) suggests that 'one of the main characteristics of an autoethnographic perspective is that the autoethnographer is a boundary crosser and the role can be characterised as that of dual identity'. Reed-Danahay (1977) explains that autoethnography has become a term of choice in describing research that connects the personal to cultural, a term Ellis (2004) endorses as her term of choice. It is both a text and method with aspects similar to ethnography. The notable distinction is that the *self* is embedded in the social and cultural context. I found many more books on the shelves that appeared to be placed in no particular order!

I was curious to read more about this research approach and writing through which authors seek to describe and analyse personal experience in order to understand that experience is a form of self-narrative that places self within a social context. I take some notes about how the immediate need for making the contextual meaning I write about is framed within the interpretive work of a variety of academic scholarly disciplines. Examples are drawn from anthropology by Anderson (2006); medical anthropology by Csordas (1994); ethnography by Denzin (1998, 2003, 2006); sociology by Ellis (1991); autoethnography by Ellis (2004, 2007, 2009); Ellis and Bochner (2000, 2006); Etherington, (2004, 2007), Reed-Danahay (1997); and Roth (2005), and from education by Eisner, (1985, 1991, 1993, 1998).

I begin to make my way around this room. A small table with three legs stacked with many journals catches my eye. Suddenly, seemingly out of nowhere, White Rabbit scuttles by and catches his tail on a leg of the table. A journal falls to the floor. I pick it up and turn to read the back cover. I see that there is an article written by McIlveen (2008). I see the words: autoethnography, ontology, and epistemology. I begin to read into the journal and reflect on the wider

implications of the heuristic journey and shifts of consciousness described here. McIlveen (2008) writes the defining of autoethnography entails writing about oneself as researcher to gain insights into a larger culture or subculture of which they are a part. It is not the same as an autobiography. It is a specific form of critical enquiry that is embedded in theory and practice. McIlveen (2008) further adds as a research approach, autoethnography [as a method for reflexive research and practice] can align itself to either constructivist, interpretivism, or the critical ideological paradigms.

This is just the journal I need to grow in confidence that the method holds merit. Is this a coincidence or is there some other explanation? Why this journal? Why right now? I start to notice that we are attracted to things, or things to us, in ways that are very puzzling. I find myself thinking deeply about the ideas that support a world view as held by advocates of autoethnography – certainly a different worldview than the positivist ideas I had been trained in as a medical professional. It seemed I was required to revisit with some care my rusty ideas of ontology and its related lexicon. Clearly, a return to Philosophy (of meaning and of knowing) is needed. I look about me and am pleased to see there is a good supply of reading material to spur me on. I gravitate to the shelves marked: *‘Philosophy’*.

### **Philosophical basis of autoethnography**

In philosophy there is nothing recognisable as a single line of advance. Its questions remain open and its debates continue. A classic work of philosophy must continue to interest all who deal with the main philosophical questions about the making of meaning, the suggestions about the possibilities of knowing, and the criteria for the positing of a truth. I look more closely at these shelves.

I find the works of the ‘great thinkers of philosophy’, Aristotle, Einstein, and Castoriadis. The questions posed by Aristotle some two thousand years ago still remain valid in our world today and his answers to them are still ranked among the most pertinent in the field. As Bambrough (1963, p. 13) outlines these include:

What is the nature of knowledge and what are its ultimate grounds? What are the ultimate categories of thought and the basic constituents of the universe? What is the relation between language, thought and their objects? How is the mind related to the body? To what end or ends is human life to be directed? What is the function and purpose of literature?

How these questions have been answered by Aristotle himself or by his successors are of background interest in this chapter. What is most important to my line of inquiry is to explore the philosophical question ‘How is the mind related to the body?’ Aspects of this philosophical question become an initial focus to highlight the importance of questioning, imagination, and curiosity in this approach. As I start to think about this question, a book containing philosophical quotes by one of my favourite philosophers Albert Einstein comes into my view. I record:

The important thing is not to stop questioning. Curiosity has its own reason for existing. I am enough of an artist to draw freely upon my imagination. Imagination is more important than knowledge. Knowledge is limited. Imagination encircles the world. Learn from yesterday, live for today, hope for tomorrow.

(Einstein, n.d).

What a find! I felt encouraged now to not curtail my curiosity nor my desire to question the medical encounters that had so distressed me. I had more to read. Alice is beside me. She keeps pointing to the same shelf. On it I see tucked away to the side the work by another great philosopher Castoriadis (1997) *World in Fragments: Writings on Politics, Society, Psychoanalysis and the Imagination*. From his philosophy of revolutionary and the imaginary we get the power to create and the capacity to call into question. It is the word imagination that re-ignites this desire to redirect my thinking to how I was now imagining what my life was and would be. I wanted to draw freely on my imagination as I began to undertake my research. In it I read about ‘the imaginary’ an ontological point representing beyond what is already there. Here the terms *praxis* [action] and *poiesis* [to make] are outlined. What a scintillating read. As my desire was to create, I felt most drawn to the use of *poiesis*- or *making* where I could draw on my poetic and imaginative qualities of my self. I look up. Alice is smiling and pointing again. Is she helping me to notice the primacy of the imaginary?



I then see another book Johnson (1987) *The Body in the Mind: The Bodily Basis of Meaning, Imagination and Reason*. I read here that over the last thirty years, Johnson has challenged persistent dualisms such as the separation of mind-body, transcendence- embeddedness, reason-imagination, conscious-unconscious thought, conceptual-real metaphor, cognition and emotion arguing that meaning resides in bodily experiences. His theory of *imagination* is crucial to emphasising the embodied nature of human meaning and in positioning understanding and imagination as central to constituting our ways of being and acting in the world.

I now wanted to understand how these ideas, theories, and philosophies come to inform the genre of research called ‘autoethnography’. I found many interesting books and articles on this matter. Even after having committed to my chosen method, at various times in the project I still questioned what I was doing. I was so reassured by Einstein’s quote, Castoriadis philosophy of the imaginary, and Johnson’s theory of imagination. I remained committed to the importance of questioning the vast literature about: narratives, emotions, and imagination, thinking, feeling, and research methods. What became apparent was this burning curiosity to question and write. I promptly sat myself down to take more notes from which to write a short history of autoethnography to guide my questioning and thinking.

### **A short history of autoethnography**

*“The most beautiful thing we can experience is the mysterious... it is the source of all true art and science”*

Albert Einstein (n.d.).

In the growing literature about ethnography and autoethnography, as a term autoethnography is generated from the interpretative branches of social science methodology, notably by Ellis (1991, 1995, 2004, 2007, 2009); Ellis and Bochner (2000, 2006); Holman-Jones (2005); Denzin (1997, 1989, 2003, 2006,); Denzin and Lincoln (2000); Van Maanen (1988); Sparkes (2004); Spry (2001); Chang (2008); and Muncey (2005). The term autoethnography Reed-Danahay (1997) suggests has been used for at least two decades now by literary critiques as well as

by anthropologists and sociologists. It can have multiple meanings that attempt to characterise autoethnography as method, text, and/or concept that can be traced through two lines i) ethnography and ii) life history. Reed-Danahay (1997, p.9) in *Autoethnography: Rewriting the Self and the Social* defines autoethnography as a form of self-narrative that places self within the social context. It is both method and a text. Autoethnography can be done by either an anthropologist engaged in doing native ethnography or by a non-anthropological ethnographer. Hayano (1979) defines autoethnography as a set of issues relating to studies by anthropologists of their own people. For Hayano it is the insider status that marks the autoethnography and admits that the term autoethnography refers to a mixture of diverse researchers investigating different issues.

In the more recent approaches to writing and ethnography Van Maanen (2011) says that in the last twenty years ethnography has undergone much change, where readers of ethnography are more willing to take chances and be more inventive in their writing. Van Maanen (2011) suggests that the realist genre is most common and popular form of ethnographic writing of which there are four types: i) confessional ethnographies where attention is on the ethnographer; ii) dramatic ethnography which looks at how we stage daily life; iii) critical ethnographies as examples of dynamics interacting between power, politics, and poetics; and iv) self or auto ethnographies where culture of group is textualised.

More recently Denzin (1989, p. 27) distinguishes several different forms of writing which he has referred to as a biographical method comprising of; autobiography, ethnography, autoethnography, biography, oral history, case history, case study and life history, life story, self-story and personal experience story. Denzin (1989) characterises autoethnography as a text, that coalesce ethnography and autobiography and states the important characteristic of autoethnography is that the writer does not adopt the objective outsider code of writing common to traditional forms of ethnography. Denzin (1989) further notes that autoethnography entails incorporating elements of one's own life experience when writing about others through a biography or ethnography. It therefore differs from traditional ethnography, life history or autobiography. I read on and take notes.

Whilst autoethnography as a term has come into usage in the late twentieth century, it is not solely a study of a postmodernist text, but rather that it has been

informed by developments in postmodernism, post colonialism, and feminism as an original contribution to the growing dialogue across disciplines. Polkinghorne (1997) claims the narrative approach provides a more epistemologically adequate discourse form for reporting and assessing research within the context of a post positivist understanding of knowledge generation.

Reading on from my earlier appreciation of autoethnography with this understanding of narrative in my mind, I found Patton's (2002) work on qualitative research and evaluation methods. In it Patton (2002) says the conception of a story as a personal narrative intersects with autoethnography in which the researcher's story becomes part of the inquiry into the cultural phenomenon of interest. Doing autoethnography according to Muncey (2005) celebrates rather than demonises the individual story. Stories can be difficult to tell, and so need understanding in the telling. This is why Denzin (2003) urges researchers to 'show' not 'tell'. Showing makes visible one's story and its goal is to seize the moment whether it is personal or political in all its particularities.

For a researcher who undertakes autoethnography, Ellis and Bochner (2000, p. 739) say these inquiries display 'multiple layers of consciousness, connecting the personal to the cultural'. They further add that as such, the creator may be asking readers to "feel the truth of their stories and to become co-participants, engaging the storyline morally, emotionally, aesthetically, and intellectually" (ibid. p.739). Ellis and Bochner (2000) also suggest that evocative autoethnography departs from the more traditional scientific approach as it leans towards amplifying empathy and resonance with the reader. In writing evocatively Ellis and Bochner (2000) propose that emotional recall is a strategy to be used in the re-writing of events as they actually happened. Such a strategy to re-call experience clearly exposes ontological and epistemological positioning to inform the reader and rather than it being a self-absorbing account, autoethnography produces a narrative that is authentic, evocative and unique enabling the reader to share the experience and grasp interpretation of it.

The concept of autoethnography was now reflecting a change in the conception of self and society and the degree to which autoethnography constituted a resistance to the hegemonic bodies of traditional discourse. As suggested by Ellis, Adams and Bochner (2011) the crisis in confidence in the postmodern era of 1980's gave rise to new opportunities to reform social science

and re-think objectives and forms of social science inquiry. Academics were now becoming increasingly concerned by social sciences' ontological, epistemological and axiological limitations (Ellis & Bochner, 2000). A troubling point in particular as described by Kuhn (1996) and Rorty (1982) was that academics were now beginning to outline how facts or truths found in research studies were inextricably linked to the paradigms and language used to re-present them. Ellis et al. (2011) argue a further limitation was lack of desire in recognising the value of narratives as ways of understanding new relationships between authors and audiences. Stories are in themselves complex and constitutive of meaningful phenomena that could introduce new ways of thinking and feeling.

Ellis and Bochner (2000) suggest that prior to mid-1980s authors located in the social sciences were not encouraged to write re-vealing, evocative narratives in first person. Researchers frequently made reference to themselves in third person. Ellis (2004, 2009) by contrast, posits that the use of *I* in the writing of autoethnographic texts is most appropriate. Ellis (2009) writes as an autoethnographer, placement of the *I* represents both author and focus of the story, the one who tells and the one who experiences, the observer and the observed, the creator and the created. In autoethnography, it is the *I* that tells a situated story, principally constructed for one's current position, one that is always partial, incomplete, told at a particular time, for a particular purpose. Ellis (2004, 2009); Baerger and McAdams (1999); Bochner (1997); Carr (1986); MacIntyre (1981); and Smith and Sparkes (2006) note the use of narrative provides sources of meanings that people can attribute to their experience. For researchers seeking to write about emotionality and lived experience autoethnography provides ways to investigate such issues that are not easily addressed by orthodox social sciences.

Spry (2001) argues autoethnography as a method of inquiry has the personal, professional, and political emancipatory potential for analysis and interpretation. Madden (2010) writes a strong philosophical and intellectual justification for using one's methods defines a good ethnographic methodology. In thinking like an ethnographer Ellis (2004) adds she has intentionally merged ethnography and how this work operates as ways that are methodological and fictional, both inventive in that it creates something that did not take place and ethnographically it claims to describe situation and cultural practices truthfully.

Ellis (2009) says autoethnographic approaches are flexible, reflexive, and reflective of life as lived. They do not follow a ridged set of rule based procedures. The goal is to develop a greater awareness, constantly reframing, and re-storying writing about the *self*-noticing and noting transforming shifts in consciousness. Through the process of autoethnographic writing the narrative text is presented as a constantly changing and coherent account of their lives. Ellis (2009) argues this opportunity to revisit stories told over the course of the event in one's life opens us to the narrative challenge to continue to compose a life story that is worth living. She maintains that even today, the opportunity to re-examine personal texts, re-analyse work done before, is rarely available in academia. Ellis (2009) questions how academics, editors and publishers might be convinced that one's story needs re-telling and re-analysis. I found this comment deeply thought provoking and begin to reflect on the issue of how writing about autoethnography as methodology can be inventive and creative. Leavy (2009) writes the creative arts in social research results from a confluence of many historically specific phenomena. Grounded in exploration, revelation, and representation, art and science work toward advancing human understanding.

I found Leavy's writing enlightening in that narrative inquiry and performance are considered as new areas of methodological innovation. Many scholars now turned their lens to autoethnography as ways to integrate writing about the complex aspects of human life with personal narrative of self. Ellis and Bochner (2000) make reference to the particular ways scholars wanted to concentrate on ways of producing meaningful, accessible, provocative research grounded in personal experience that would sensitise readers to issues of identity, politics, social justice, stigma, experiences shrouded in silence, and forms of representation that would deepen our capacity to empathise with racially, disabled and marginally disadvantaged groups of people who are different from us.

In reading their views I gained a better understanding of the value of self-understanding. Denzin (2006) offers this position for consideration he wants to see a new qualitative research tradition focused on themes that come from this commitment that seeks a writing form that enacts a methodology of the heart. What Pelias (2004) suggests is a form that listens to the heart, knowing that 'stories are the truths that don't stand still' (Pelias, 2004, p. 171). I reflect on this

personal call to write from my heart about the moment – my diagnosis of MS, where I seek to create my story of an embodied ‘self’ as an autoethnographic text.

Importantly to engage in research approaches generated from the self, Ellis et al., (2011) write that researchers using methodology of autoethnography are now recognising that there are a variety of ways that experience can influence the research process. For example, evaluation research studies may be undertaken by large organisations or researchers may study their own experience. Ellis and Bochner (2000) note autoethnographers recognise the innumerable ways personal experiences influences the research process of deciding who, what, when, where, and how to research the event. Fine (1993, 2003) says a researcher may even change name places for protection. Even though as Atkinson (1990, 1997), and Delamont (2007, 2009) suggest some researchers still assume that research can be done and must be performed from a neutral, impersonal, objective stance. Bochner (2002), Rorty (1982), and Denzin and Lincoln (2000) comment that researchers must recognise that this assumption can no longer be upheld. Ellis et al. (2011) note that autoethnography is one of the qualitative research approaches that acknowledges and accommodates subjectivity, emotionality, and the researchers’ influence on research, rather than hiding from these matters or assuming they do not exist or are irrelevant.

The reflection about the legitimacy of reporting personal emotions and observations in fieldwork was further bolstered by ongoing crisis in anthropology. Clifford (1986) makes reference to reflexivity as legitimising the examination of subjective experience as part of the research process and analysis, these subjective experiences could include feelings, empathy, and intuitions. According to Scholte (1974) they could also include sympathetic identity or empathy with ethnographic others. Okely (1992), and Halstead, Hirsch, and Okely (2008) write that reflexivity can promote political praxis and assert that the experience of fieldwork must draw on the whole being and not be reducible to a mere collection of data by a dehumanised machine. They note that a reflexive and autobiographical awareness is now acceptable in the analysis of fieldwork and writing. I reflect on my personal interest of exploring lived experience that includes concrete action; expressed as feelings of neuropathic pain, optic neuritis, emotion, embodiment, self-consciousness and introspection. I carry on reading and making notes.

McLean and Leibing (2007) write that by the late 1980's and 1990's autoethnography provided a new autobiographical outlet for the ethnographic self and a specific vehicle of expression for suppressed feminist and post-colonial voices. McLean and Leibing (2007) further suggest that much autoethnography was written in reaction to positivist ethnographies from which the ethnographic self had been largely excluded from the research. Ellis (1991, 2004) advocates for positioning of an emotional sociology that would defiantly challenge previous traditional methods of researching the *self*. I had experienced this silencing of self from my experiences of when the confirmed diagnosis of MS was made. My perceptions of the medical encounter were that my body was broken and it needed to be fixed! Tests and appointments were now their primary focus.

I am cognizant that health care practices such as these are necessary. Equally so I felt they need not solely be a preoccupation of it at the expense of one's overall well-being. Acknowledgments of my self-hood were much lower down in the order of priorities with regards to delivery of care in wider social context.

Reed-Danahay's (1997, p. 9) says that autoethnography is a 'form of self-narrative that places the self within the social context'. She suggests that autoethnography combines both postmodern ethnography in which the realist conventions and objective observer positions of standard ethnography have been called into question, and a postmodern autobiography in which the notion of a coherent individual self has also been called into question. Ethnographic writing that involves reflections on one's self and one's field experiences can be considered in the broadest sense, autoethnographic. Ellis et al. (2011) claim autoethnography offers many forms for a researcher to make personal experience meaningful in ways that traditional methods usually disregard. As I lift my head from my note-taking about the history of autoethnography, I notice an open cabinet. There is a large brown paper folder in it. On the front cover underlined are: "*Forms of Autoethnography*." Keen to read more I open the folder.

### **Autoethnographic forms and approaches**

The folder I have just opened has a number of academic papers in it. Each, it appears describes some form or approach of autoethnography as research method.

Ellis (2004) states that autoethnography is research, writing and method that connect the autobiographical, and the personal to the cultural and social. This form usually features concrete action, emotion, embodiment, self-consciousness and introspection. Spry (2001, p. 710) offers this description: autoethnography is a self-narrative that critiques the situatedness of self and others in social context. Neumann (1996) adds autoethnographic texts democratise the representational sphere of culture by locating the particular experiences of individuals in tension with dominant expressions of discursive power.

Anderson (2006) suggests that analytic autoethnography has five features. It is ethnographic work in which the researcher; i) is a full member in the research setting or group; ii) uses analytic reflexivity; iii) has a visible narrative presence in written text; iv) engages in dialogue with informants beyond the self; and v) is committed to an analytic research agenda focused on improving theoretical understandings of broader social phenomena. Working with innovative methodologies according to Leavy (2009) requires researchers to work across disciplines, leave their comfort zone and work collaboratively with other practitioner's in other areas.

As a method autoethnography offers many forms for the researcher to make personal experience meaningful in ways that traditional methods disregard. According to Ellis et al. (2011) the forms of autoethnography differ in many ways with regard to how much emphasis is placed on the researcher's self and interaction with others.

Denzin, Lincoln, and Smith (2008) suggest *indigenous native ethnographies* develop from colonised or economically subordinated people and are used to address and disrupt power in research, particularly from an outsider's authority to study others. Ellis (2004) argues that researchers, who share a history of colonisation or economic subordination, including subjugation by ethnographers who have made them subjects of their own work, write indigenous ethnographies. Smith (1999) notes that pedagogies of resistance are those developed in response to the continuing pressures of neo-colonialism and neo-colonisation. Denzin et al. (2008) further add such indigenous projects embody pedagogy of hope and freedom where they turn pedagogies of oppression and colonisation into pedagogies of liberation with opportunities to create, name-re-claim, democratise, storytelling that celebrated lost histories and cultural practices.



*Narrative ethnographies* according to Ellis (2004) focus on a culture or subculture and authors use their own life story in that culture to look more deeply at self-other interaction. This approach offers insight into how the researcher has changed as a result of observing others. Ellis et al. (2011) describe narrative ethnographies as texts that are presented in the form of stories that include the ethnographer's personal experiences into the ethnographic description and analysis of others. With the emphasis here on the ethnographic study of others, which according to Tedlock (1991) is obtained partly by attending to the ethnographic dialogue or encounter between the narrator and members of the group [of people] being studied. Ellis et al. (2011) write that reflexive, dyadic interviews focuses on the interactively produced meanings and emotional dynamics of the interview itself the focus is on the participant and his/her own story. However, the feelings of the researchers can also be considered and the ways in which the interviewer may have changed by process of interviewing. Ellis (2004) writes that although the researcher's experience is not the main focus personal reflection adds context and layers to the story being told by participants.

*Reflexive ethnographies*- Ellis et al. (2011) say, are a process that document ways in which a researcher changes as a result of engaging in doing the fieldwork and exist on a continuum ranging from starting research from the ethnographers biography as described by Ellis (2004) to the ethnographer researching his/her own life alongside cultural members lives. Van Maanen (2011) describes these reflexive ethnographies as confessional tales where the ethnographers endeavours in doing the study become the focus for investigation or what Ellis (2004, p. 49) calls contingent autoethnography.

Where focus is on the author's experience alongside data, abstract analysis, and relevant literature this approach is referred to as *layered accounts* (Ellis et al., 2011). Often these layered accounts characterise the procedural nature of research. Charmaz (1983, 2005) writes similar to grounded theory, layered accounts illustrate how data collection and analysis proceed simultaneously; the existing research is framed as a source of questions and comparisons rather than a measure of the truth. In the time spent outlining the direction of the methodology, as researcher I am already in the mode of doing, building a kind of grounded theory of doing and describing at the same time. Ellis (1991) argues that unlike grounded theory, layered accounts use vignettes, reflexivity, multiple voices and

introspection to engage in what Ronai (1992) describes as accounts that invoke readers to enter into the emergent experience of doing and writing research and consider evocative concrete texts to be as important as abstract analyses.

*Interactive interviews*- provide an 'in-depth and intimate understanding of people's experiences with emotionally charged and sensitive topics; *community auto ethnographies* use the personal experiences of researchers in collaboration to illustrate how a community manifests particular social cultural issues; *co-constructed narratives* illustrate meanings of relational experiences, particularly how people may collaboratively cope with uncertainties, and contradictions of being friends, family or intimate others; *personal narratives* are stories about authors who view themselves as the phenomenon and write evocative narratives specifically focused on their academic and/or personal lives. I am deeply attracted to the form of personal narrative and become increasingly committed to finding out more about it, and how it may satisfy my desire to write an informative, creative, and inspirational PhD. What I need to understand better, are the opportunities and limitations of this approach to research.

I remind myself that all research methods have strengths, weaknesses, validity concerns and ethical considerations. I note that these as headings in my notebook, and set out to 'see' what I can learn about them in relation to my interest in autoethnography.

### **Benefits and potentials of autoethnography**

As a qualitative research approach to enquiry autoethnography as argued by its proponents is a very useful and empowering method for those researchers, educators, nurses and practitioners who seek to explore personal experience, human action, and deal with human relations in settings such as management and learning organisations. According to Ings (2011) autoethnographic inquiries have an established, although contested history. Such an approach by placing the self at centre of the inquiry can offer for those considering using autoethnography as method the following five advantages: i) commitment and transformation; ii) reflection and reflexivity; iii) empowerment of a marginalised voice, for the disadvantaged and the subaltern; iv) authentic links between researcher and

society and finally; v) originality, impact, immediacy, usefulness and relevancy in a rapidly changing world. Chang (2008, p. 52) writes the benefits of autoethnography can principally be found in three areas, these being: i) it offers a research friendly method for researchers and readers; ii) it enhances understanding of self and others; and iii) it has potential to transform self and others. Chang (2008) further says as a method autoethnography is researcher friendly as this approach allows researcher's easier access to the primary source of data from the being as the source is the researcher themselves. In addition autoethnographers are privileged with an intimate perspective of their 'data'. This familiarity gives autoethnographers an edge over other researchers engaged with data collection and in-depth analysis and interpretation.

Another benefit is that autoethnography is reader friendly in that the personally engaging styles used in storytelling can lead to a wider appeal than those conventional methods of research scholarly writing. Richardson (2000) says writing itself is a way of *knowing* a method of inquiry. Ellis et al. (2011) outline that writing an autoethnographic text can be therapeutic for authors who write to make sense of themselves and own experiences. Chang (2008) adds that autoethnography is an excellent means through which researchers can come to understand themselves and others.

A further benefit of writing autoethnography is that it can evoke self-reflection and self-reflexivity. Ellis et al. (2011) comment that writing personal stories can be therapeutic for participants and readers, self-transformation may be manifested in a variety of ways. Foster, McAllister, and O'Brien (2005) write about self-transformation as *process* bringing healings from emotional scars of the past, illuminated in the writing by sharing with others the painful experience of growing up with a mother who had schizophrenia. Through writing autoethnographically Foster experiences liberation and relief from the burden of fear, isolation, and loneliness. This liberating force was a foundation of self-empowerment for her.

Chang (2008, p. 54) says when manifested in increased self-reflection, and the adoption of culturally relevant pedagogy, with a desire to learn about others, the self-transformative potential of autoethnography is universally a benefit to those who work in diverse backgrounds. McIlveen (2008) writes the reader of autoethnography plays a crucial part in establishing its value as research. In

reading an autoethnographic account enriched with theory and embellished with rich descriptions of experience, readers may begin to construct lessons for their own self or sphere of practice - whether this is used within constructivist, interpretivist or critical social ideological paradigms.

Closely related to value and reliability are issues of validity. Ellis (2004), Ellis and Bochner (2000) add that for autoethnographers, an indicator of validity means that a work seeks verisimilitude; it evokes in readers a feeling that the experience revealed is life like, believable, and possible, in that it emphasises the quality of story related and empathic resonances within the reader. Ellis (2009) writes that critiques from outside autoethnography offer a signal that scholars from other disciplines are paying attention to. When they find something of interest to push back or something so irritating they cannot help but respond. Either way, Ellis says she is not too bothered by these criticisms. I have been thinking about the vulnerability of re-vealing myself and possibly not having any control over how readers will interpret my story. In thinking deeply about these potential criticisms I am aware that as with all forms of literary writing there will be these concerns. From my extensive reading I am assured that my chosen approach of autoethnography is the only approach I believe that can illuminate a highly personal experience written from the heart.

### **Limitations and criticisms of autoethnography**

With the rise in interest in autoethnography as a research methodology there are also growing numbers of critical responses to this style of personal writing. Some of the disadvantages of autoethnographic inquiry Ings (2011) notes are risks of: i) narcissism, solipsism, and confusion of purpose; ii) social obligations of who is being represented; and iii) emotional/personal cost. Like any complex undertaking this approach can tax both intellectual and emotional tenacity of the researcher. Ryang (2000) and Behar (1996) argue that *vulnerability* gives authenticity and authority to autoethnographic inquiry. For the researcher the same vulnerability requires careful and attentive supervision. Ings (2011) further argues that without some forms of external feedback purely self-referenced processes can result in research that fails to explore a wealth of rich and diverse

experiences. To that end it can fall well short of its communicative transformative potential.

According to McIlveen (2008, p. 5) the most significant limitation pertains to its epistemological status with respect to the relationship between the *knower* [the participant] and the *would be knower* [the researcher]. When Holt (2003) received the reviewers' questions on his autoethnographic manuscript, they questioned its academic rigor and methodological validity. Chang (2008, p. 54) writes such criticism does not mean that autoethnography is inherently faulty, but that it is helpful to be vigilant with application of this research approach to inquiry. She outlines five potential pitfalls to be aware of: i) excessive focus on self in isolation from others; ii) overemphasis on narration rather than analysis and cultural interpretation; iii) exclusive reliance on personal memory and re-call as data source; iv) negligence of ethical standards regarding others in self-narratives; and v) inappropriate use of the term autoethnography. McIlveen (2008, p. 5) says that the user and reader of autoethnography should accept the limitation that a single autoethnographic narrative analysis has no rightful purchase on its generalizability, it does however have the potential to act as a stimulus for profound understanding of a single case and, act as stimulus to open new intellectual vistas for the reader through a uniquely personal way to portray meaning and empathy.

I read Ellis et al. (2011) who write as part ethnography, autoethnography is dismissed for social science research standards as being insufficiently rigorous, theoretical and analytic and that it is too aesthetic, emotional and therapeutic. Ellis et al. (2011) further add as part autobiography, autoethnography is dismissed for autobiographical writing standards, because it is viewed as being aesthetically insufficient and literary and not artful enough. These criticisms erroneously position art and science at odds with each other, a stance that autoethnography seeks to correct. Chang (2008, p. 56) suggests that with rigorous effort to distinguish autoethnography from other self-narratives. Readers will be able to understand this research method by what it stands for, a highly descriptive autobiography and self-narrative.

## Reliability, generalizability, and validity in autoethnography

When considering choosing a personal story as a topic for enquiry, Ings (2011, p. 3) offers broad guide lines for emergent autoethnographers: i) treat all who are likely to be implicated or exposed in the storytelling, [including themselves] as vulnerable. In this regard, researchers need to acknowledge that they do not own their story and need to make certain where practical, that they have shown what they have written to parties who are directly represented, and ii) talk about research with others. This means as an emergent writer they not only consider the purpose and communicative clarity of their work, but they remain open to reflection and debate regarding reliability, generalizability, validity, and the implications of what they are researching.

This was an interesting point. I thought about these terms in my own research and began to question the validity of my story. Who would be judging it? Would it be useful? My attention is drawn back to the many notes I had made. I seem to have generated more questions than answers. I look up and see Alice pointing to another pile of books. The words validity, accuracy, and verisimilitude attract my attention. Looking at my notes, I find Ellis (2004) who says there is a lot to think about regarding how to define validity in autoethnography, and many ways to consider validity in one's project. I revisit my notes and the work by Lincoln and Guba (2000) who say how we know when a social inquiry is as true enough to the human construction of the experience is that of what we study.

Ellis (2004) says in seeking to redefine validity, authors turn to criteria for judging the process and outcomes of research projects rather than the methods by which outcomes are produced. Ellis (2004, p. 124) says that in autoethnographic work you can judge validity by whether it helps readers to communicate with others different from themselves or offers ways to improve the lives of participants and readers or even your own. It connects the readers and writers by providing continuity in their lives and a coherent story. Keen to learn more I returned to Ellis (1995, 1999) I see written the notion of *evocation* describing how writing evocatively makes you feel you are there continually questioning your own motives. Ellis says this represents the notion of authenticity, and in describing the feeling about what happened as an honest account validates that you are in the situation yourself, feeling the emotion and conflict. Ellis et al.

(2011) note closely related to reliability are issues of validity. For autoethnographers, validity means that a work seeks verisimilitude, it evokes in readers a feeling that the experience described is life like, believable and possible and what was represented could be true.

I now had very good notes on validity and reliability but I still wanted to read more about how this would relate to my own emergent way of writing auto ethnographically. I was looking for a small case study, vignette, or example. Fortuitously for me *Revision* still lay open. My eye caught a passage in which Ellis writes about an experience of presenting a paper at a social science conference (2009, p. 111). This was just what I was looking for! I too would be presenting and defending my work to a critical readership! I read how Ellis explains to her audience that one may use a systematic, scientific form of sociological introspection to understand intersection of personal and social aspects of emotions and raised issues about reliability, generalizability, and validity.

In the audience is Bochner, an eminent ethnographer. Ellis records his comment: “Dr Ellis, I really appreciated your talk. Social Science does indeed need more emotion. I have only one point to raise. You seem to accept the terms that orthodox social scientists use to describe their work - objectivity, validity and reliability. This ends up making you sound very defensive. Why not drop all the science talk? Just take for granted what you are doing is important” (ibid. p.111).

What a timely reassurance. I found this writing so inspirational and revelational. I thought about how the epistemological lexicon of positivists can distract self and reader from the very sense of human emotion that as an emergent autoethnographer I am trying to describe. Were the comments made by Bochner that my eyes were attracted to in the work of Ellis a serendipitous event or an aspect of synchronicity, a concept increasingly drawing my attention? Regardless, I felt reassured through the information/literature by these leading eminent researchers in their respective fields of sociology, anthropology and organisational/management learning. That my chosen approach of autoethnography would not fall short of its potential meant I had a personal story to tell. I wanted to include emotion, introspection and imagination. I would include rigorous critical reflection and review lived experience through my emergent autoethnographic lens that I was developing. I would drop the science talk! I am ready to move on!

Ellis et al. (2011, p. 8) write that generalizability is important to autoethnographers, though not in the traditional social scientific meaning that it stems from, and applies to, large random samples of respondents. Ellis and Bochner (2000) claim that the focus of generalizability in autoethnography, moves from respondents to readers, and is always being tested by readers as they determine if a story speaks to them about their experience or about the lives of others they know. I wanted to seek the most appropriate way to tell a truthful account about my MS experience. What mattered to me was the way in which my story would enable the reader to enter the subject world of mine and be able to resonate with aspects of the human sense/experience of chronic illness, complexity, and MS.

Bochner (1994) and Denzin (1989) write that autoethnographers value narrative truth based on what a sort of experience does, how it is used, understood and responded to for and by us, and others as writers, participants, and audience. Ellis et al. (2011) say that autoethnographers also recognise how and what they understand and refer to as truth changes as the writing representing the experience changes and that the importance of contingency is acknowledged. Memory is fallible. Tullis, McRae, Adams, and Vitale (2009) note that it is impossible to recall or report on events in language that exactly represents how these events were lived and felt, and we recognise that people who experienced the same event often tell a different story.

Ellis et al. (2011) claim that when terms such as validity, reliability, and generalizability are applied to autoethnography consequently the context, meaning, and utility of terms is thus altered. According to Bochner (2002, p. 86) for an autoethnographer, questions of reliability refer to the narrator's credibility. Could the narrator have had the experience described, given the factual evidence? And does the narrator believe that this actually happened to him/her? Ellis (2004, p. 124) writes autoethnography can be judged in terms of whether it helps readers communicate with others different from themselves, or offers a way to improve the lives of participants and readers.

In autoethnography Ellis and Bochner (2000) and Ellis and Ellingson (2000, 2008) suggest that generalizability is determined by whether the specific autoethnographer is able to illuminate unfamiliar cultural processes. As Ellis (2004) and Flick (2010) write, readers provide validation by comparing their lives



to ours, by thinking about how our lives are similar and different and the reasons why, and by feeling that the stories have informed them about unfamiliar people or lives. I had learned so much from reading and taking these notes which all provided me with new insights into representation, ethics, and autoethnography. I was ready to move on to consider the ethical issues that might arise in this type of research.

### **Autoethnography and ethics**

Ethical decisions are required throughout the whole life of a research project and in all aspects of a study regardless of the chosen paradigm. Making ethical decisions nearly always involves facing a series of dilemmas. Ings (2011) offers the view that conventional ethics may be understood as emanating from two fundamentally different stances: i) the deontological; and the ii) teleological. The deontological position argues that the ends never justify the use of research that is unethical. Conversely, the teleological position argues that the ends in some cases, justify the means. There is rarely one straightforward answer. Decisions need to be made on the basis of thinking about balancing some basic ethical principles, rather than ad hoc reactions to emerging situations.

Researchers do not exist in isolation. They live in connected networks, communities that include friends, relatives, and colleagues. Ellis et al. (2011) say when we conduct and write research we implicate others in it. I then thought much about what Ings (2011) and Ellis et al. (2011) have written and began to compile these three fold sets of questions:

- i) What are the ethical considerations of undertaking autoethnographic research?
- ii) Would autoethnographic research require similar guidelines as for those researchers engaged with qualitative socio-economic research?
- iii) What are some of the professional and ethical guidelines for the conduct of socio-economic research?

These questions were ones that I would ask myself and regularly refer to them throughout the duration of this qualitative research study. It was helpful to find and read about The RESPECT project (2002-2004) funded by the European Commission's Information Society Technologies (IST). This programme provides professional and ethical guidelines for the conduct of socioeconomic research, having located international guidelines in this field of qualitative socioeconomic research. My sense was that it is right for me to want to add my stories to literature on MS and on chronic illness literature as autoethnography, as this study positions self and responsibility for self as the 'I' that is storied in my research. Levinas' (1996) posits that the ultimate responsibility of the 'I' for the face, or the other, as our most valuable everyday experience, is one that will allow us to resist a purely hierarchical world.

In this autoethnographic study, I have acknowledged all ethical considerations of The University of Waikato Ethics Committee about its approval requirements for autoethnographic research with regard to my emphasis on *auto* (self), *ethno* (the socio-cultural connection) and *graphy* (the application of the research process). Throughout the duration of this study I have conducted all self-narrative writing in an honest and trustworthy manner, where protection and privacy of others connected to me are kept confidential in all steps of my inquiry. I have ensured a conscious effort to understand the relationship of self and others adhering at all times to University of Waikato Ethical Code of Research.

#### **a) Ethics and protection of the self**

In an auto-ethnographical thesis even when issues relating to others have been addressed and resolved there is another issue that needs to be considered the safety of the researcher is vital when focus of inquiry is entirely centered on revealing the self. Ings (2011) posits this question: "What of the safety of the researcher who *is* researched?" Understanding the relationship of self and others is one of the tasks that autoethnographers must undertake. Clandinin and Connelly (2000) challenge all self-narrative writers with a poignant question: "Do they own a story, because they tell it?" With regard to ethical issues involving the design, and format of my study Chang (2008) highlights that as a researcher one plays a multifaceted role: as researcher, informant, and author. Chang reminds us that

one's story is never made in a vacuum and those others are always visible or invisible in the story. For these reasons' it is useful to consider relational ethics with self-disclosure and qualitative inquiry as suggested by (Ellis, 2004, 2007, 2009). In this thesis I have adopted Ellis's (2007) *Relational Ethics* as way to manage the ethics of gathering and representing autoethnographical information and the protection of self.

### **b) Ethics and protection of others**

At the onset of thinking about writing this study I sought to read as much as I could about ethical considerations in the conduct of the research that could have implications for its textual representation and application. I was further drawn to the literature regarding ethics and autoethnography by Lovell (2005); Kraus (2003); Couser (2004); Spry (2001); Chang (2008); Ellis (1999, 2000, 2004, 2009), and ethnography by Madden (2010). According to Madden (2010, p. 34) at every phase of ethnographic research there is an ethical backdrop in that ethics is everywhere, every time. He argues that ethnography does not have an ethical element as such. Ethnography is an ethical commitment from the very onset, and present through all phases of the ethnographic research and writing. Ethnographers must deal with the responsibilities and obligations that go with the basic ethnographic dictum 'first do no harm' that aligns with human contact and contracts. Chang (2008, p. 68) writes since most autoethnographies focus is primarily on self, one may not feel that ethical issues involving human subjects need apply to one's research design. This assumption is incorrect. Morse (2002) suggests that one should always keep in mind that other people are always present in self-narratives, either as active participants or as associates in the background.

When considering ethics and protection of others in this study I draw on Ellis's (2009) *Relational Ethics* that considers relational concerns as a crucial dimension of the study design throughout the research and writing process. She says the concept of relational ethics is closely related to an ethics of care. Chang (2008) argues that protecting privacy of others in autoethnographic research is more difficult than in other studies involving human subjects. Ellis (2004) writes about the importance of thinking about ethical issues in doing the project. She says it is important to protect the identities of your characters, where appropriate.

Use pseudonyms when necessary. Get consent if possible. Be aware of the ethical issues involved in writing about people who do not want to be written about.

I have disclosed my identity in this research. In protecting privacy of others such as professionals or colleagues connected to me. I created composite figures based on factual details to obscure their identities. I have taken into consideration protection of my family members being part of this project. In the first stages [of the design] of this project I spoke to my husband, my father, and my children those individuals whom possibly would be most easily identifiable: I have been granted their full support. I was drawn to Ellis's view (2009, p. 308) where she comments because one's identity is already disclosed, the identities of others connected to you sometimes become transparent to the broader audience and other times to smaller circles of your acquaintances. Ellis (2009) further comments even after any years of field research, autoethnographic writing, teaching and ethics, these kinds of ethical questions still continue to swirl around her like a sandstorm. Each choice has its consequences, but make a choice we must! She says: 'I still don't have all the answers', but take solace in believing that continuing to ask and reflect on ethical questions is more important than coming up with the answers (Ellis, 2009, p. 308).

I reflect on Ellis' (2009) advice and found it a well-balanced overview of how as researchers, we long to do ethical research that makes a difference. Which is exactly what I aspire to do! I endeavour throughout the life span of this study to stay aware of how these protective devices can influence the integrity of my research as well as how it is understood. I will consider which questions to explore and which truths are worth telling. I am cognizant that I also have to be able to continue to live in world of relationships in which my research is embedded after it is completed.

Couser (2004) adds that there is a need to be concerned about the ethics of representing those who are unable to represent themselves in writing or to offer meaningful consent to their representation by someone else, especially with whom they are involved in a trust based relationship. Fasching, deChant and Lantigua (2001) advise when it comes to communicating ethical consciousness it is more effective to tell a good story than to give an abstract explanation. Beyond the existing university guidelines is the work by Ellis (2007, p. 4) in relational ethics where Ellis adds this is heightened for autoethnographers. In this teleological

approach [where the ends justify the means] that I have adopted for my story my responsibility to others is to write concretely and expressively. I have drawn on Ellis's (2004) guidelines for personal writing. I view writing as a process of inquiry and discovery. In writing evocatively, engagingly, and passionately I endeavour to do just this! I want to write stories that give meaning to my life and have the potential to offer meaning and evoke meaning in others. My aims are to produce accessible and evocative texts that *show* rather than *tell*. I view my social and relational world through my [auto] ethnographer's I/eye interested in researching personal life showing actions, dialogue, and gestures. I write from the heart to find out what it is in the head that I know, or do not know and experience. I return to Ellis who suggests that the researcher must recognise and value mutual respect, dignity and the connectedness between the researcher, and between researchers and communities in which they live in.

In situations where researchers and communities are closely identifiable or entwined ethics becomes a far deeper consideration than consent and information. Ings (2011) draws attention to that fact that the very substance of research is the relationship to and responsibility for a society that becomes deeply embedded into the content and process of the journey of the project and beyond post-lodgement and publication. In writing this short history of autoethnography these discussion points are the means to highlighting the implications of positioning self in centre of research that have been carefully considered. The potentials of autoethnography for analysing and creatively interpreting social cultural issues were outlined as were ethical considerations about what material to include or exclude, and about evolving issues of privacy and confidentiality that can arise in the writing process.

With my mind full of ideas about the processes and ethical issues of autoethnographic work I wonder just how I might conduct such a study on myself. I claim that in writing about my personal struggles with MS I view these lived experiences as helpful accounts. That has the vital ingredients for developing meaning making and the potential to help others understand important aspects of embodied experience in their lives. I have provided a strong philosophical and intellectual justification of the method chosen defined by a robust explanation of why I chose autoethnography as my method to research and write autoethnographically about the human condition. Importantly, I consider how enquiries driven from the self that are extended and represented as narrative

accounts constitute writing as method and therefore an area of a thorough methodological discussion in this chapter.

The distinction between *method* [i.e. or what ‘tools’ I used] the field notes which I refer to as [my journal entries] and *methodology* the explanation of why I used narratives was outlined. I reflect deeply about my lived experience and writing about feelings and emotion. Ellis (2009, p. 104) writes without examining lived experience of emotion, this forces researchers to talk of spiritless, empty husks of people who have programmed patterned emotions and whose feelings resemble the decision making models of positivist theorists. I reflect on her view which in turn helps me to begin to consider my own embodied experience in the research process. I am drawn to Madden’s (2010) suggestion that it is important for ethnographers to be reflexive to understand and manage their influence in the research process and project. He says it allows for the dissolution of any putative opposition between subjectivity and objectivity.

I reflect on my position within this enquiry and the influence it has on the creation of the literary text. I am doing both of these things concurrently. In being reflective I am learning from the experience, I step back to think about it, mull it over and evaluate it. Boud, Keogh, and Walker (1985) write it is this working with experience that is important in learning. In learning how to become *reflexive*, I question *why* at this moment experience is accounted for in the way it is, and *how* exploring alternative ways it can generate and use new knowledge. Cunliffe (2004, 2011) says reflection and reflexivity incorporate very different understandings of the nature of our social realities of who we are in relation to our world and others, and these understanding carry different implications and possibilities for our actions and interactions.

I now make notes about these emergent writing processes which have arisen in response to the challenges I’ve encountered in my personal and professional life since being diagnosed with MS. In the dispute I faced in my work situation I take the stance of emergence within this conceptual framework expressed in the sense of loss, independence and control. I take the position that in writing auto ethnographically things might emerge from me. It is a way of informing me that is giving shape to my way of seeing, noticing and interpreting. I aim to know and understand more about human action that I did when I began this exploration.

I find a most interesting article published in 1958 entitled: *The Human Condition* in which Hannah Arendt argues that Western philosophy has too often focused on the contemplative life and has neglected the active life. This focus on contemplation has led humanity to miss much of the action in and around everyday life and the relevance of philosophical ideas to real life experiences. Arendt's contention is that meaning shines forth only in the memories of human initiative and urges us to not adopt the more reliable mode of being subdued in work and labour (1958, p. 186). In my enquiry I aspire to taking this initiative of writing about the body as *human praxis* by taking human action and experience seriously in the awareness that human beings perform in ways which seem to escape the easy popular or standard medium of communication for academic discourse. In taking initiative there resides freedom to act and speak. Taking initiative calls into question long held ideas about beginning, revealing and disclosing of myself as unique and distinct, as *I Carrie*, who is beginning to learn about making new meaning of human action as praxis. Arendt (1958) proposes that meaning of human action as praxis is dependent upon the durability afforded through poiesis. Key to the success of this approach is to write about the significance of my *being present* in the moment that emerges in the plot of my life story. I *show* rather than *tell* how it with relative persistence of my efforts to create in my writing about the meaning of illness, which I find meaningful to build on existing, views and theories about the human condition.

With this focus on showing rather than telling of the value of autoethnographic writing in mind, I am acknowledging the fact that I am the primary focus of the enquiry and must address the influence that I have on it. Learning how to *show* writing autoethnographically is an essential part of managing the influence of me on the research enquiry and the representations of them. In the following chapters I provide personal dialogue and description of scenes, as ways of bringing the reader much closer into what happened to me. These opportunities for writing genuinely and evocatively constitute this as a mode of narrative and interpretive research in its own right. I know I have a story to tell. I know my story has significance for others. I poke about in the pile of journals and books – and my eye catches the evocative phrase: 'Performance Autoethnography'. I am intrigued!

## **Navigating performance autoethnography as praxis**

“Everybody has a story to tell” - or so I read in a journal that I pick up. I look about a little further and see a book with the title: *The Presentation of Self in Everyday Life* by Goffman (1959), a sociologist and ethnographer who developed the theoretical metaphor *Dramaturgy* a sociological perspective defining the method in which one human being presents to another. Starting with symbolic interactionism it does not intend to examine causes of human behaviour. It analyses its content against the seductive resistance of the conventions of world views. I read from his work how the use of imagination and passion as resources could be seen as most useful ways to illuminate aspects of human life that most of us tend to overlook and show us more humanity that we could see otherwise. I read on, Leavy (2009) says in this work Goffman co-opts Shakespeare’s famous line ‘all the world is a stage’ and develops the term ‘dramaturgy’ to denote the ways social life could be conceptualised as a series of ongoing performances. Gubrium and Holstein (2009) write Goffman repeatedly reminds us of the performativity of everyday life. How we present ourselves to others and how they, in turn, present themselves to us are dramaturgically realised. Not only did Goffman’s work move qualitative research forward at that time, his work has also been foundational for the more arts-based research practice. Drawing on revival of the notion of praxis, Arendt’s (1958) theory of human action represents one of the most original contributions to the twentieth century. By viewing action as a mode of human togetherness, such research can contribute to the development of a conception of participatory democracy to address those problems, which manifest as bureaucratised and elitist forms of politics, so characteristic of the modern era.

I rummage around a little more in this pile of journals and books. I spot an article written by Denzin outlining the need to explore performance autoethnography. I remember seeing his portrait in the vestibule. I find words such as: pedagogical, personal, political, performance and performativity. Denzin (2003) writes that interpretive ethnography is at cross roads. Ethnographers, pragmatists, symbolic interactionists, social constructivists and critical race theorists face the challenge now of how to reclaim the progressive heritage given by Du Bois, Mead, Dewey, Hall, and Jordan. He indicates a need to craft an emancipatory discourse that speaks to issues of racial inequality under neoliberal

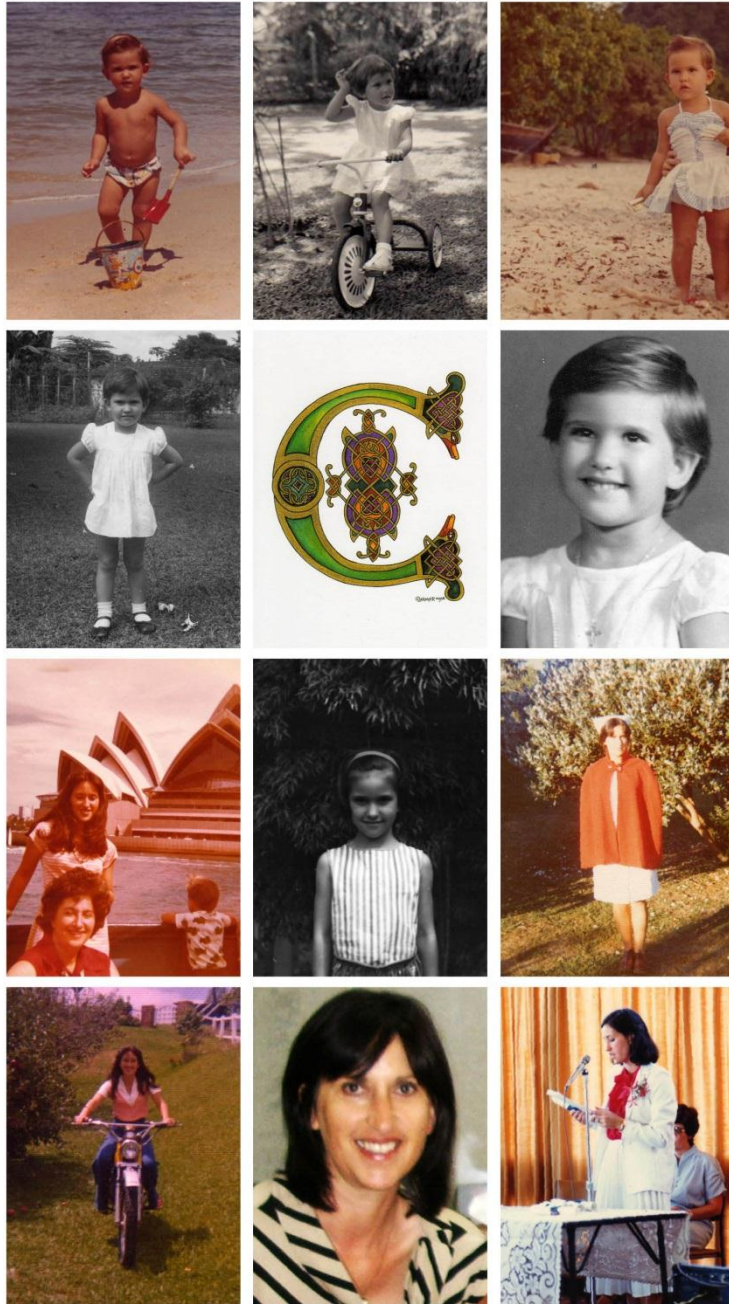


forms of democracy and capitalism. This discourse requires a turn to a performance based approach to culture, politics and pedagogy.

I read Conquergood (1998). He advocates finding a space for cultural studies to change position from textual ethnography to performative autoethnography. Arendt (1958) suggests a move to re-visit praxis as the highest and most important level of active human life be mobilised and the need for ethnography, and ethnographers to engage in everyday political action is our capacity to analyse ideas, wrestle with them, and engage in active praxis that is and what makes us uniquely human. Ellis (2009) offers ways of connecting autoethnographic performance with community practice. But how could I do this? Just as I was about to sit and read more, I notice Alice tapping on my shoulder. “Stop reading *about* the method and its debates because it is time to try it” she said! She nudges me along into a passage. I ask: “Which way?” Alice says: “At the end of this passage are two grey doors they don’t have handles. You will need to gently push the doors to open them. Be careful as they can swing back”. My curiosity was aroused. I cannot wait to open the doors! I set off.

## **CHAPTER THREE**

### The Room of Being and Becoming



**Image 1: Montage One Celtic 'C'.**

## CHAPTER THREE

### The Room of Being and Becoming

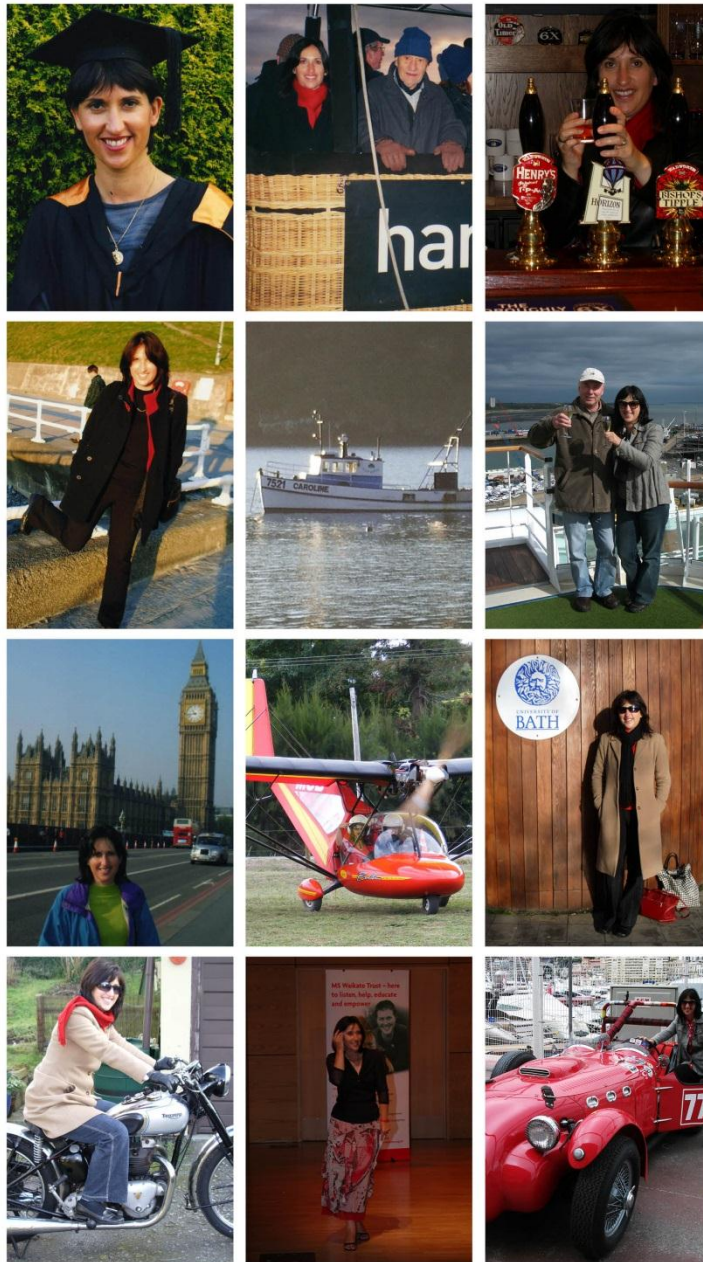
I have arrived at the end of the passage that Alice has pointed me to. I see the double grey doors. In taking heed of what Alice had said about them, I re-position my satchel on my back. I now have my hands free and no satchel straps are in my way. I carefully push the doors open. As the doors close behind me they do swing back just as Alice had cautioned. On entering I find myself in a work-room. It looks like an ‘examination studio’. It has cameras, computers, machines, screens, and tables. I see a cushioned table that has four black wheels sitting inside a big round grey and white machine. It is the recall on my nursing knowledge that allows me to identify this equipment and design of the room. I am reminded of a scanner room and the way skilled radiologists, scientists, specialist neurologists, and brain surgeons alike use very sophisticated diagnostic equipment such as MRI (magnetic resonance imaging) to scan living tissues in the body – morphing one image into another. With use of powerful magnets and sensors, these machines can detect magnetic fields within cells to ‘show’ layers and perspectives of any changes in the human body. To my side I see a screen comes to life. To my surprise, a most exquisite Celtic ‘C’ appears on it (refer to Image 1). The ‘C’ scrolls away and images of my early childhood appear. The time is 1960. I am on holiday with my parents at Pankor Island, Malaysia. As I watch, the image morphs. I now see images of my adulthood. I am in New Zealand. There are pictures of places I have visited. Suddenly there is a change of imagery. I am startled now to see an image of a brain. I see grey, black, and white curling lines appear - 36 of them! I thought: “How amazing”. I realise the brain is mine.

Looking at the images of my head on the screen I remember lying down on the cushioned table and being glided into the scanner. I am expected to keep perfectly still as movement can interfere with the magnetic fields. Nothing touches me. I hear all sorts of tapping and knocking noises. Thank goodness I’m not claustrophobic! I am mesmerized by the memory and the emotions it evoked. I am reminded too of my first experiences of what I now know to call MS. I remember the bizarre feelings in my hands and head. I recall how, on the start of that fateful day, I was feeling reasonably well as I headed off to work. By the end

of the day I was sitting at the hospital awaiting explanation of why I felt so unwell. I vividly recollect being given the provisional diagnosis, the initial suspicion that my sensations might indicate MS. As I see the pictures of my happy life morph into a depiction of the lesions in my brain, I think back to that day my provisional diagnosis was confirmed and the emotions I experienced. I now feel a 'pull' to write evocatively about the things to be done and decisions to be made about the complex and philosophically challenging aspects of this personal journey.

I bring my mind back to my place here in this room. I notice notebooks, pens, cameras and other creative equipment anew. I see! I am urged to be a writer, an artist, a creator. I know I would never be lost for words! I see an article by Engles-Schwarzpaul (2008, p. 5) *At a loss for words? Hostile to language- Interpretation in creative practice led- PhD projects*. She suggests visual, mathematical, verbal, aural and gestural elements can all be drawn into processes of symbolism. These elements allow one to rapidly and reversibly telescope into [or project out of] a scenario that we want to test or explore, be it with ourselves or with others. I was enthralled reading it! I see another article by Hughes (2006, p. 292) who says that a creation of this fusion of images and words allows one to 'hone' our ability to 'see' or make new aspects and connections. While they operate in different ways, images and words can be used in what could be labelled *connotative* and *denotative* ways. Both can speed up and generate novel constellations for clarifying levels of detail. I was heartened to read this. Although this choice of method and style of writing does not use the conventional means of research, my reflections on all I had read, and on the story I wanted to tell, assure me I am at the point of creativity and becoming – becoming not only autoethnographer and researcher, but becoming *Carrie* who lives creatively with MS.

This new image of me is worlds away from *Carrie*, the object of medical treatment, diagnosed with MS, destined to live her life in a wheelchair within six months – or so said the consultant who provided confirmation of my diagnosis (refer to Image 2). I vividly remember him hastily placing results of the MRI film on the screen. He is muttering away to himself looking at the screen and proceeds to count up 36 lesions. I look back to the magical screen. I see the images are morphing again.



**Image 2: Montage Two**

This morphing reminds me of old fashioned hand-held ‘view master’ where, with each click, in 3Dimensional ways, I see more images. There I am, on holiday with Geoff, my husband. We are in a small seaside town. I am not in a wheel chair. I am also taking a flight in a micro-light plane. I am going up in a hot air balloon with my father. Despite the specialist’s projection that I would soon be wheel chair bound, I see myself living my life to the full. The images are inviting me to write!

As an emergent writer I was developing my understanding of the narrative approach and I have begun to recognise that autoethnography [as research method] would be the most appropriate means to craft my story. I wanted to adopt Hughes (2006) notion of connotative and denotative ways of narrative reality and create a fusion of literary textual representation with design and imagery. In *becoming* to know more about clinical uncertainty I am reminded of the medical way of communicating illness. The MRI represents the ‘medical design’ as a way of communicating clinical uncertainty. However, it only shows a part of my brain. To fill in some of the gaps left by the ‘medical design’, the ‘artistic design’ that flows on the screen is morphing images that telescope into and project images out of the scenario being explored. I see Pankor Island, family, places visited. The outdoor and recreational activities are additional evidence that *show* a whole person living life to the full. The morphing of two images ‘medical design’ and ‘artists design’ are autoethnographic techniques I decide to craft to ‘show’ a *becoming* self. With the morphing of these two images I am exploring embodiment and lived experience through autoethnography.

In explicating my narrative reality I had begun to respond to this intuitive call from within me to write creatively and evocatively. I could now articulate the intent of this research to re-call, re-tell, and relate my story in a more creative way than any other research method I know about. I knew that I wanted to learn more about knowing how to know and how to use poesis and imagination in my enquiry. The use of metaphor would be my chosen way to bring new ideas into consciousness to guide the telling of my story as a meaning making research process. I would use the Alice stories and the animated characters as a way to imagine and re-veal the connections between my life experience and MS. The writing of personal vignettes would be the means of denoting a literary and analytical text, and the visual images would be means of enhancing the

representational themes of *being* and *becoming-in-the-world* with MS. I had begun to recognise how to explore the call of narrative.

### **The call of narrative, personal vignettes, and autoethnography**

Having decided that a narrative approach would open the very opportunities I wanted to probe, I needed to decide on just *how* to construct and reconstruct the story of my confirmed diagnosis of MS. I took a moment to ‘take stock’. I remembered I had made many notes whilst sitting waiting in the emergency room on the day when I was first so acutely ill. At that time I had not held back on including descriptions of exactly how I felt about the sort of care I had been given. What to make of these earlier notes? Ellis (2009) suggests that notes on experience can become the basis for showing how to write a meaningful narrative story. I was thinking about Ellis’s suggestion. I now had the confidence and belief to venture further. I am ready to explore more of what I imagined was yet to come, and finding it very nice, I thought: “What a glorious and curious feeling!” I now set to work to incorporate my personal story in a creative way - reassured by the many documents I had studied of the legitimacy of doing so *as* valid and worthy research. With these notes diligently compiled whilst in the Room of Methodology, I am ready to see what all of this means for me in terms of *method* and *process*.

I wanted to include emotion in my research and write evocatively where representations of chronic illness could be faithfully explicated. I felt that these aspects would not be able to be portrayed evocatively in conventional social science research approach. Polkinghorne (1997, p. 7) suggests that, ‘the narrative provides a more epistemologically adequate discourse form for reporting and assessing research within the context of post positivist understanding of knowledge generation’. Dyson (2007, p. 40) says autoethnography is a narrative form of writing and inquiry and can be seen as a ‘way of knowing’ established through thinking in one’s own person and through the making of judgements about what will be attended to and what will not be attended to in the ‘here and now’.



Muncey (2005) *An Ethnographic Account of her own Teenage Pregnancy*, says that she reached a point in her writing where she was grappling with the academic perceptions of a proper research design. When starting out to commence her doctoral studies and at the same time in the pursuit of her own personal curiosity into the explanations for teenage pregnancy, she started to take an interest in personal meanings of events and behaviours not generated by mainstream research, which led her into the world of autoethnography. As an approach Muncey (2005, p. 7) writes ‘autoethnography celebrates rather than demonises the individual story’. I had built up a sound knowledge of this approach. Reading this excerpt from Muncey further galvanised my desire to posit the subjective expression of my personal and professional experiences. I was now growing in confidence that authenticity, truthfulness, and validity could be established and recognised throughout the quality of my research.

As I stepped back to gather my thoughts about all I had read I could hear Alice saying: “There are still plenty of books on these shelves for you to look at and to take notes from”. Keen to explore I take heed of her directions. A book in the middle row on a shelf near the door catches my eye. Curious to know more, I pick up this book. The cover reads: *Alice in Wonderland and Philosophy - Curiouser and Curiouser*. I see it is written by Davis (2010). I had taken the advice from Alice to: ‘look first’. I cannot contain my excitement. It is a sort of ‘take me - do it moment’! I open up a page at random. In this beautifully crafted volume of philosophy of ‘Alice in Wonderland’, I read that Davis recently discovered that if you take Morpheus’s red and blue pills *together*, you can wake up in Wonderland *and* believe whatever you want to believe - all while lying in bed. Davis says: “Does it get any better than that? (Davis, 2010, p. 214). “What a novel discovery! What does all this mean? I read on.

I meet Morpheus, a mythical character consistent with the dreaming of the Matrix, a place, a source where a thing is really developed, a generated illusion that can be unreal or a virtual reality. The Matrix is all around us. Even now it is within us. I meet Neo a fictional character who is offered a choice to remain in his everyday life and to forget about the Matrix or to learn what the Matrix really is. I read that in the Matrix there is a theme of duality: illusion and reality. I wonder is the Matrix a generated illusion or a facet of one’s reality? I was entranced. I wanted to learn more about reality and illusion in the context of these fictional

characters and my story. For some reason I had this most unexplained urge to know. Alice is beside me she says: “Why you don’t look in your pocket? You always carry your note book with you”. Indeed! I had my notebook. I open it and read:

*When the Doctor told me I had MS I instantly thought about Morpheus, Neo, and the Matrix. I felt like Alice tumbling down the rabbit hole. I shake my head! I can't believe what is going on! I don't want to accept this. The irony is that I need to accept something! I don't like this 'loss of control'. For me MS was an uninvited guest. It is not an illusion. Living with MS is my reality!*

*(Personal Journal, 1998).*

I reflected on the words ‘loss of control’ in this journal entry. They were so poignant. These words ignited a yearning to know and explore. Deep down in my soul I had known something was amiss, but in those early days I could not explain what I was experiencing. I felt that there was something wrong. I did not then know what it was, but it was always there, like a constant buzz in my mind that at times would metaphorically speaking drive me ‘round the twist’. Is it my recall of this feeling that has brought the Matrix to me? And what does the Matrix have to do with my situation, MS, and the medical treatments/therapies? I have this aha - ‘do it moment’ again! Could my experience be aligned to the fictional story of the Morpheus, Neo, the Matrix, and the blue/red pill that were the key to the doors of choice for Neo? If it were, is this about (re)-directing my need to know? I think it is! I was so excited to find Morpheus, Neo, and the Matrix. Their depiction aligned perfectly to my situation and story. I had some choices to make. Take the blue pill and I accept the status quo on conventional ways of the medicalization of MS and it’s care of those individuals who have MS. Take the red pill and I would get to stay in my magical House of Learning! As I decide I still have in hand the Davis book, my satchel, notebook, and pencils.

I look up and I can see Alice settling in, waiting patiently while I delve more deeply, she says: “Take your time here and read more of what this book has to say”. And I do. I read: “You take the blue pill,” Morpheus says to the Neo in The Matrix, “you wake in your bed and believe whatever you want to believe...and the story ends. You take the red pill and you stay in Wonderland, and I show you how deep the rabbit hole goes” (Davis, 2010, p. 1). I had to smile reading this. I

was already in the rabbit hole! Was I going to go deeper by following the White Rabbit and Alice in a new direction? I see Alice pointing again at Davis's book.

I read on. Davis says that at one time or another in our lives we all want to escape from the dull, tedious and impossible relationship we have, an escape from a world in which we seem to have little or no control over what happens to us. Whether it's by a red pill, a secret wardrobe, a looking glass, or a rabbit hole, it doesn't really matter. We'll take it (ibid. p.1). So do I take the blue or red pill? What would Alice do? I'll look first. She is still with me. She inspires me to go on. I think I'll take the red pill. And I do!

I was glad I had found Alice as my companion and guide. I was bemused by White Rabbit. And now this book by Davis! In it I read about dreams, perception, and reality. How fascinating! I think about these with regards to my own life. The confirmed diagnosis of MS is my reality. It is not a dream although at times I wish it was! My recognition of the perceptions of MS and its management about clinical uncertainty is a big influence. I still have much to explore. I do want to go deeper into the rabbit hole. As I place the book back on the shelf I hear thump-thump. In the corner of my eye I see White Rabbit running to other side of the room. In the distance I can see some boxes I start to follow him. As I turn around he has gone! There is no rabbit to be seen! What I do see is a box on the floor. I take a look.

On the top of the box is written: "*Life as Inquiry*" I open it. I find some journal articles about Systemic Practice and Action Research with heading: '*Living Life as Inquiry*' by J. Marshall. I sit down to read as I am most drawn to how Marshall uses her own experience to reflect and articulate some of the everyday inquiry practices that she has been adopting. For example, she has an image of living continually in process, adjusting to seeing what emerges, and bringing things into question. As an emergent autoethnographer I am learning to notice, being curious, inquisitive and open to continual questioning of what I feel, know, do and want finding ways to actively engage in this. It is a process writing personal vignettes [to describe an event], questioning and living inquiringly.

In reading Marshall (1999) who shows how to apply notions of inquiry as research method to many areas of a one's personal and professional activities and how research ideas may be generated from and tested throughout one's life space. I now began to gain a better appreciation of how the past and present influences

and many discussions with others in my life have helped shape me and how this informs this enquiry. I had been looking for an effective way to live my life in a meaningful way. Unbeknown to me at the time I *had been* living my life as inquiry for some time. I now had a way to formalise this enquiry. Marshall's work was indeed a stellar find! I make many notes to take with me on my journey.

In the House of Learning I gradually came to recognise that I had the vital ingredients for a good story line. By addressing the issue of subjectivity, researching positioning, and relational ethics in my enquiry [from the notes taken], I now had the means to probe deeper some of the underlying meanings in life's questions through a morphing of the Alice story with my own, and by putting self in the research. I was beginning to have confidence in the notion that exploring the subjective was a legitimate way to approach focusing on the use of personal experience. In realising this, my focus as an emergent autoethnographer evolved more as I became to understand what could be achieved in using narrative to consolidate the notions of 'living in the moment' as scholarly inquiry.

I had at my fingertips the notes in my journal. I had read many books and articles all in their respective ways of, and re-assuring me, that I had the appropriate research methodology to write about my MS experiences of 'being there'. Taking heed of Alice's instruction's time 'to look first' gave me time to step back and reflect. In following White Rabbit I began to realise that not only had I changed as a result of diagnosis of MS but that I was also changing as an individual. I reflected on how: i) I began this formal research enquiry; and ii) reasons for wanting to explore self-consciousness of relationships between *self*, *body* and *work* through narrative writing. All the while I feel much change is happening to me. Davis (2010) describes how Alice's adventures become an exercise in controlling perspectives. Her experiences of growing, shrinking, falling down a rabbit hole, and following White Rabbit all change her perspective. Likewise so many extraordinary things were happening to me. At times I didn't feel quite myself. Some days I would awaken to most bizarre feelings where my legs didn't feel like they were a part of my body. I liken my experiences of MS to those of Alice when she says: "I'm not myself you see" (Carroll, 2006, p. 44). Although I too am not feeling quite myself I continue with my thoughts.

In the corner of the room I see another animated character! It is a cat grinning in an enticing manner. I am bemused by this and I then recall where I have heard

about this. Of course! This is no ordinary cat! I realise this is the Cheshire Cat right out of the Alice story. I am distracted for a moment by a couple of books that have been pulled out from the shelf. I wonder who did this. Alice is here and points to the other side of the room. I see nothing. The Cat only grins when it sees Alice and then seemingly it vanishes. It is all very confusing but I decide to read on in the books that now have my attention. I find autoethnographic writings and projects that emphasise use of qualitative writing as heuristic process, with self-reflexivity and self-transformation. Jordan's (2001) *Writing the Other, Writing through the Self: Transforming Consciousness through Ethnographic Writing* helped me to grasp the methodological concerns of this approach of what I was coming to terms with. I make notes and recognise that sustained attention to detail of experience as well as considerations about language, social, and identity are all heightened as one engages with constructing a written account. Goodall (2000, p. 198) claims what is important is that one becomes intimately involved in the 'dialogic ethic' and the 'transformational vision' which characterise the best of the new ethnography that I was becoming intimately involved with. I had Alice as wise muse, White Rabbit as teacher, and Cheshire Cat that has now joined in with my escapades. I did wait a little while here expecting to see it again, but it did not appear again. It is time to move on.

As I begin to pack up my books I look up. There is the Cheshire Cat again! I turn to Alice in wonder. She quietly explains that she is not much surprised at this as she is getting well used to queer things happening. Alice says to Cheshire Cat: "I wish you wouldn't keep appearing and vanishing so suddenly: you make one quite giddy!" (Carroll, 2006, p. 65). I found all of this most perplexing. What did the Cheshire Cat mean, I wonder when it says: "We're all mad here. I'm mad. You're mad (Carroll, 2006, p. 63). But how do we *know* madness or sanity for that matter? How do we *know* anything at all? I ponder over these questions and how the Cheshire Cat has a curious way of fading in and out of existence. Davis (2010, p. 160) offers this explanation: the Cheshire Cat typifies the transitory and ephemeral nature of truth as Nietzsche sees it. As perspectives fade, the Cheshire Cat fades, illustrating the transitory nature of truth. I found Davis's explanation profoundly thought provoking.

My life as I knew it, my truth and reality had been turned upside down. I now had this feeling of utter confusion. I needed advice on how to proceed. I look to

Alice. From her bag that she is carrying she takes out a book. I see it is her very own copy of *Alice in Wonderland*. She opens the page on a picture of Cheshire Cat in a tree, with an image of Alice herself seeking advice. She reads to me:

“Would you tell me, please, which way I ought to go from here?” “That depends a good deal where you want to get to” said the Cat. “I don’t much care where” said Alice. “Then it doesn’t matter which way you go,” said the Cat”. Alice replies: “So long as I get somewhere.”

“Oh you’re sure to do that” said Cat, “if only you walk long enough”

(Carroll, 2006, p. 63).

Gardner (2001) writes the Cat’s answer expresses very precisely the eternal cleavage between science and ethics. Science cannot tell us where to go, but after this decision is made on other grounds, it can tell us the best way to get there. We owe Carroll a great debt for keeping wonder alive. Davis (2010, p. 142) says it symbolises use of language, and perspectivism and Alice’s unsurprisingly interest in talking to somebody even when the Cat appears. Davis (2010) argues the more we can control our perspectives, the more the world makes sense to us. The Cheshire Cat’s response acknowledges that we are creative artists of our lives when we select our own perspectives. How could I take any perspective on the bizarre manifestations of the symptoms of MS? They would appear unexpectedly and then without much warning disappear but they did not completely vanish. It feels a bit like the Cheshire Cat always there, fading in and only on view and what is left is one’s own perspective of it. Why did this happen? I begin adjusting to this transitory experience adopting a way of knowing by writing about lived experience describing what these symptoms feel like. I learned from Davis’s explanation that I was part of creating my own destiny. How exciting! I see Alice is pointing to another pile of books.

More books! On one I see the words: ‘*Knowledge and Knowing*’. I find Ellis and Bochner (2000, p. 761) who say that: “The goal is to enter and document moment-to-moment, concrete details of a life. That’s an important way of knowing as well”. They further comment that: “Autoethnography provides an avenue for doing something meaningful for yourself and the world” (ibid. p. 761). I now considered my place in the research as the designer and author and claim that interpretation is located and attributed directly to me. I think about personal knowledge does an autoethnographic enquiry presuppose knowledge as

personal? Webb and O'Brien (2008) claim that knowledge and its interpretation may be located in and attributed directly to the art/artist. I was delighted to read this. Art, after all, is such a central part of my being.

I had now been thinking for a long while about self, uncertainty, mysteries, doubt, meaning, and imagination with regards to my own being and MS. I had also formed a relationship with the inspirational guide Alice. I trust her fully as she leads me to another set of shelves labelled: 'Poetry.' I see a book by Keats. He describes a notion he calls Negative Capability. What does this mean? I am intrigued. I had always aspired to being capable but really did not know the significance of the positioning of negative in this context. Keats (2002) explains this as where a person is capable of being in a position to deal within uncertainties, mysteries, doubts, without any irritable reaching for or after fact and reason. Bate (1979) reveals that the key elements of Keats's poetic concept are: disinterestedness, sympathy, impersonality, and dramatic poetry.

I returned to Ings (2011, p. 1) who says the elevation of the self as the focus of an inquiry does not constitute refusal to establish meaning, but rather as Bate (1979) says in defining Negative Capability: "It is the ability to negate or lose one's identity in something larger than oneself, a sympathetic openness to the concrete reality without, an imaginative identification, a relishing and understanding of it enabling an imaginative openness of mind and heightened receptivity to reality in its full and diverse concreteness" (Bate, 1979, p. 249). Unconsciously I had to this point in my life been drawing on my imaginative creative side.

I had been, as Douglas and Moustakas (1985) write in their notion of *immersion*, immersing my self in this enquiry often quite artistically. I think back to the joy of receiving the Celtic 'C' and the images of my early childhood and adulthood that I saw on the magical screen when I first entered this room. Of significant interest then as they are now are the Celtic links of my identity to where my name Carrie hails from. A part that has helped shape who I am today and one that I chose to use in this story about *I Carrie*, the person who is learning how to live creatively in the world with MS. I had been introduced to Ellis (2004) *The Ethnographic I* in the vestibule, and from her work this significantly influenced my desire to incorporate the subjective *I* into this research. Alice points to a cabinet with sets of drawers. There are four. They are labelled: i) [e]-merging

story and theory putting self in research; ii) ontology of being; iii) being as process for caring for self and other; and iv) becoming an autoethnographer. It's now time follow Alice to open up the following cabinets of curiosity. I will summarise what I find in each drawer.

### **Drawer One: [E]-merging story and theory- putting self in the enquiry**

I open the first drawer. I find a small pamphlet that outlines the Cartesian Split - from spirit to matter - body from soul and how this mechanistic metaphor came to prevail. I am drawn to reflect on my life events and changes to my professional and personal life post confirmed diagnosis [a decade ago] of Multiple Sclerosis (MS) as first person narrative research. Through the methodological approach of autoethnography drawn from notable academic scholars Ellis and Bochner (2000); Ellis (1995, 1999); Reed-Danahay (1997); Denzin (1997, 1989, 2003, 2006); and Chang (2008), the crafting of self-narrative stories will need to be reflected upon, critically analysed, and interpreted within their broader socio-cultural context. For this I return to Ellis' (2004) autoethnography as a research method and style of writing. As my confidence grows with this approach I see how I can link the autobiographical to the cultural including features of emotion, introspection, embodiment when writing about my personal experiences of MS that are embedded in the social world. This approach sits so well with me as I am reminded of an article by Synnott (1993) who writes that the body is not merely a biological phenomenon, it is also a social creation comprising of a vast complexity of meanings. I think about how the prevailing positivist paradigms still view my body as broken or needing to be fixed! As Synnott (1993, p. 4) further asserts the dynamics of these paradigm shifts are critical to any understanding of the body and it does make a difference to our lives if one either thinks of the body as a tomb (Plato), a temple (Saint-Paul), an enemy (Teresa of Avila), a machine (Descartes), or the self (Satre).

Writing about the body can be a highly political spectacle and in undertaking an autoethnography writing about the self can sometimes be perceived by other readers in the wider academic audience as being self-indulgent and self-confessional or even narcissistic. Holt (2003) says autoethnography can also be



questioned in terms of its academic rigor and methodological validity. As an emergent writer comments by Holt, Chang, and Ellis were helpful in particular with regards to becoming vigilant with its use and how to avoid any pitfalls in its application. Initially I had had feelings of hesitation of how to place self in the research. On the one hand I understood that I had ready access to such rich information about my lived experiences of the confirmed diagnosis of MS. I knew that this would become the primary source of 'data' a word perhaps too much associated with positivism for my purposes in this work. In becoming adept with autoethnography I prefer the term: '*Living detail*' for this type of research work. In reading widely about autoethnography from eminent researchers in this field I was confident that I had chosen both a researcher and a reader friendly approach.

Chang (2008) writes that autoethnographers are in a privileged position. They have familiar access to the rich, deep, intimate perspective on their focus of enquiry. This aspect of familiarity gives auto ethnographers a stronger position and an edge over other researchers in areas of the collection, selection, reflection, interpretation, and representation of the 'living details' to be examined. Autoethnography is also reader friendly in that personally engaging with this type of writing style tends to appeal to a wider audience than conventional traditional research methods. Foster et al.'s (2005) *Coming to Autoethnography*, uses another form of self-transformation through self-narrative writing whereby the process of healing from the emotional scars of the past are portrayed as inquiry. MS had left an indelible scar on my being but it is one that was now helping me to develop a better understanding of my motivation for self-transformation. Since my diagnosis in 1998, as a woman, mother, wife, nurse, educator I have been learning how to live with MS. The work by Foster et al. (2005) helped me to see my life as an unfurling story and one of emergent self-transformation.

I turn my attention to thinking about how to begin to do autoethnography. I have my notes which say that autoethnography is subject to a process of reflection as one seeks ways to be consistent to the goal of writing with self-reflection. Writing as an emergent process of inquiry about my lived experience of MS is central to this form of research. I want to discuss the connection between *self*, *body* and *work* that influences this theme of writing by considering dimensions of personal change to my being and self as it *affects* my writing. I believe my interest in emergence can be linked back to my nursing training and now myself

as person who has MS that is seeking creative ways of learning and responding to the demands that MS places upon me. What I want to do is learn how I can look at, notice, and see things differently. Following Alice and White Rabbit ‘this way’ animates the questions of: ‘How to re-veal, write more evocatively and how to explore where I am and who I am?’

As I reflect on all that has happened and ways of doing things in this room I am aware of feelings of intrigue and wonder that I experienced here. I have found myself situated amongst the most wonderful array of literary sources, images, equipment, cameras, and even magical screens. They have truly caught my eye and imagination as have Alice, White Rabbit, and the Cheshire Cat who is still a bit of a mystery yet I see that he has an ongoing function here in the work of perspectivism. Portrayed on these magical screens have been pictures of my childhood where I watched as the image morphs. I have diligently taken notes and explored many different ideas and perspectives. I want to accrue a rich and varied number of theorists and theory so that these notes will equip me with the vital ‘ingredients’ in preparation for my enquiry. I take a moment to ensure that all my notes are in order. I look up and whom should I see? It is the Cheshire Cat! Sitting on the top of another set of drawers! As I turn to Alice it vanishes again. Alice remarks: “Over there is another set of books in a box marked: *Habitus*”. This is the most curious thing I’ve ever seen written. What does this seemingly mean? *Habitus*? Have I heard or done this before? I keep saying the word *Habitus*...*Habitus* to myself. I can’t resist. I open this box.

In it I find four books: *Habitus* by Bourdieu (1977), *Shadowing and Other Techniques for doing Fieldwork* by Czarniawska’s (2007), *The Vulnerable Observer* by Behar (1996), and *Analysing Narrative Reality* by Gubrium and Holstein (2009). Another exquisite find! I step back for a moment to dwell on this. I can’t help but think that have I seen these before. If so where? I then have this aha moment! I remember where I re-call this feeling of *habitus*! It is when the picture of my previous self was on that magical screen! So this is why I was still in the examination room. I want to write [for myself] an identity and meaning making process in which I examine how I am coming to terms with my life long relationship with MS expressed as the *being* and *becoming-in-the-world* with MS in this enquiry.

My exploratory work was still not finished. This spurs me on to think about Ellis's (2009) use of introspection in her writing of *Final Negotiations* from introspection to emotional sociology. My desire is to research and write about the chaos of my experience writing evocatively, engagingly and passionately as she has pioneered. Ellis (2009) writes the first step in studying the fusion of private and social is to acknowledge introspection as a sociological technique. One that can provide access to private experiences and generate interpretive material from self and others that is useful for understanding the complex, ambiguous, and processual nature of lived emotional experience.

I was thrilled to read and find this technique where it's focus would lie within me as individual to explore introspectively who I am and was becoming? As a nurse I would be involved with delivering care within the designated parameters of the cause-effect aspects of an illness. As an academic I would talk about aspects of learning about illness and models of care and teach by showing. Now as a person with MS *I Carrie*, have much work to create and *show* others. A bothersome aspect of this illness is that all of my MS symptoms are *invisible* to others. My desire is to explore these seeds of ideas: visible, invisible, expression, and inscription as embodied inquiry. I was enchanted in finding these articles. I know that they will help me further develop the particular point I am alluding to.

I highlight this notion of *invisible* because to many people I meet when I am out and about they cannot see them. When my symptoms are evident because of a flare up of MS symptoms, I tend to stay at home. Beyond family and medical practitioners, my changing identity is not evident. How would I write about this? Despite the invisibility of my symptoms outside my circle of family and medical practitioners, I was becoming increasingly vulnerable to *others* perceptions of the illness. The feeling of vulnerability is whom do I trust to disclose my illness to? Others' in my life are acquaintances, colleagues and health professionals who see me as person who has some health issues. Once they know I have MS then I am treated differently. I feel that I am not acknowledged as *I Carrie*, a nurse, wife, mother and academic. Instead the focus is predominantly on the illness not me as a person. Over time the habitual ways of others' responses to my illness was now becoming [for me] a less than helpful way of learning and of delivering care. My identity as *Carrie*, a fully functional wife, mother, nurse and educator I felt had been covertly undermined.

I have MS. This is a lifelong relationship that I am *coming* to accept. I want to reverse this ‘habitus’ and reclaim my unflappable, assertive, and confident self. I thought of Alice and her brave escapades in Wonderland. Like Alice, I bravely enter into a new world I begin to see myself in this world where being a curious and inquisitive self is an asset. I am *becoming* ready to challenge others, especially those who obfuscate the truth. I was beginning to realise that the approaches of the delivery of care from others [for me] was in fact awaking this dull reality and setting me free to take care of myself. Being the curious and inquisitive being I am I pause for a while re-calling the: ‘*Look first*’ sign Alice had introduced me to. Had I now inadvertently begun stopping my own habitual ways of thinking and perceiving life in this way? In the distance I see the Cheshire Cat appear again and as I take my note book out of my pocket, he fades away. I am beginning to get used to his unexpected arrivals and departures, even though I do not know exactly what they mean. Curiouser and Curiouser!

I open my note book and find the words: ‘motivation’, ‘immersion’ and ‘expression’ albeit in different tenses. These words stayed with me then as they do now. I re-call an experience of seeking treatment for an acute flare up of my MS symptoms. I was waiting in the hospital clinic and noting then how others were interacting with me. I remember the urge I felt to record not only my observations but my feelings. These accounts surely could become my field notes or narratives for conveying lived experience that later on I would draw from describing a specific incident conveyed in a series of vignettes. They were, indeed, recordings of ‘living detail’ in thinking about the process of re-telling my story and how managing an acute flare up of MS symptom of optic neuritis could become a literary event.

As I think about this particular event I re-read Ellis’ (2009, p. 102) writings about introspection and the point she makes that in actuality, observation of one’s own emerging dialogue is a continuing and important part of any introspection as well as being the foundation of role-taking in theory of the self- control of behaviour. I wanted to learn from these acute flare ups. In using ‘self’ as subject, *I Carrie*, am becoming an emergent writer, one who is ‘noticing’, ‘seeing’ and has something so moving, powerful and important to *show*. I was indeed inspired by all I had read to develop this [e]merging story and theory. I was becoming more confident with incorporating application of introspection in my enquiry. I

(re)place notes into my satchel as I know these will be useful to reflect on again. Alice is still with me.

In this venture I have come to appreciate Alice's companionship and candid outlook on matters. One that stands out is her defiance that inspires my own. It provides the opportunity for learning where one can *become* more aware of the many possibilities of working out own problems when faced with challenges and uncertainty. Mine is living with MS.

At the bottom of the drawer, I see a large box file: '*Embodiment Experience and Narrative*.' There I find a very messy folder, with pieces of screwed up paper and pencils left in it. My immediate thoughts are should I should tidy this box file. It is so heavy and I can see it contains copies of Reed-Danahay (1997) *Auto/Ethnography, Rewriting the Self and the Social*, Nash (2004) *Liberating Scholarly Writing: The Power of Personal Narrative*, Gergen and Gergen (2002) *Ethnographic Representation as Relationship*, and journals: Morse (2002) *Writing my Own Experience*, and Wall (2006, 2008) *Easier said than done: Writing Autoethnography*. I am becoming well practiced at taking notes and enjoy doing so! I think back to how these books were placed on the shelf actually they did not look like they were placed at all. They were left untidily. It does seem that whoever has been here also left in a hurry. Was it the Cheshire Cat who likes to sit in the open drawers? Or was it the White Rabbit? I have much to ponder on as well what to do with all these notes. I began to realise that in following the White Rabbit in this 'animated way' I was being introduced and re-introduced to many different books about the ways to write about the self. I still was yet to truly figure out significance of the Cheshire Cat here. Is it another flag? Is it a signal? Ah! Is another piece of the great puzzle! I keep writing as these ways will help de-mystify, interpret, and 'see' something in the 'living detail' that possibly was not there before.

I could sense that I was writing nonstop about what I thought and felt as I was exploring how to write autoethnographically and learning how to know. I have no regrets in making the decision to take the red pill. I did not want the story to end! I wanted to probe more deeply with use of introspection as a way to think about all these unanswered questions. Ellis (2009) claims introspective thinking allows one to address previously neglected experiential questions that can be approached by fusing social and personal experience. Interestingly enough I had

this feeling so early on in the piece that my soul knew something was amiss. What I am finding is that indeed the Matrix is all around us and everywhere! I had now a better understanding of the Matrix! Alice is still here. She now gives me another nudge saying: “There are more brown folders and some books you should look at in this drawer”. I open the first brown folder which has numerous articles in it. I notice some of the pages have been folded back. I wonder why? Is this another flag? I am intrigued!

I begin to unfold these pages and find an article by Wall (2008) *Easier said than done: Writing an Autoethnography*. It provides an interesting view suggesting that writing autoethnography is an intriguing and promising qualitative method that offers a way of giving voice to personal experience for the purposes of extending sociological understanding. She does caution that autoethnography can be a very difficult undertaking. In writing her own autoethnography, Wall confronts such anxiety producing questions pertaining to representation, balance, and ethics. She deals with the acceptability of her autoethnography by informal and formal reviewers. I was pleased that I had found this article. I was confident that this approach would be the most appropriate one to posit issues of lived experience, using techniques of reflection, emotional re-call and introspection. An enquiry I could share with academics, readers of qualitative research, health professionals, and those ‘others’ who care for people with MS.

I pick up the book by Nash (2004) *Liberating Scholarly Writing: The Power of Personal Narrative* and noticed the abbreviation of ‘SPN’ or ‘scholarly personal narrative’. Nash explains that as a result of his 53 years of supervising student papers, theses, dissertations and publications, SPN can provide an alternative to the more conventional modes of qualitative and quantitative inquiry currently used in education. It teaches students how to use personal writing in order to analyse, explicate, and advance their ideas. SPN has been successful with types of writing and projects undertaken by minority students, women, and others to find and express their authentic voice in scholarship. I could not contain my excitement any longer. This was a ‘gem’ of a book. I had now confidently committed to writing autoethnography incorporating SPN as a technique in my enquiry.

I unfold another page. I see writing by Reed-Danahay (1997) which says autoethnography is a form of self-narrative, a re-writing of the ‘self’ and social

that places self within a social context. Her work is familiar to me as I had read about it in previous room. I found it was useful to re-read it as I was thinking about how writing with ‘self’ could explicate importance of me, my voice, and voice of others in the writing of this enquiry. I wanted to explore how self-narrative could reinstate this voice. I take another look at the notes I have been carrying around with me. In a further complementary direction Nash (2004) suggests that scholarly personal narratives can liberate researchers from the abstract, impersonal writings and can touch the reader’s lives by informing their experiences. Gergen and Gergen (2002) claim in using one self as an ethnographic exemplar, the researcher is thus set free from the conventional traditional forms of positivist writing.

I am freely delving about with all these books and journals that are helping to shape my study - a feeling of freedom. In here I find an array of books and articles: Goffman (1959) *The Presentation of Self in Everyday Life*; Ellis (2009) *Revisions: Autoethnographic Reflections on Life and Work*; Spry (2001) *Performing Autoethnography: An Embodied Methodological Praxis*; Denzin (1997, 1989) *Interpretive Ethnography: Ethnographic Practices for 21<sup>st</sup> century and Interpretive biography*; Richardson (1995) *Narrative and Sociology*; Dyson (2007) *My Story in a Profession of Stories: Autoethnography – An Empowering Methodology for Educators*; and Duarte (2007) *Using Autoethnography in the Scholarship of Teaching and Learning: Reflective Practice from the Other Side of the Mirror*. What a magnificent find! I am intentionally crafting my inquiry through a process of narrative writing. I am consciously drawn to the interpretive method of autoethnography inspiring me to re-think who I am, and ‘show’ how MS, in my life is now becoming this transformative generative way of being.

*My story* is not to be a positivist account setting out reasons for cause and effect of illness devoid of amplifying human emotion and experiences. *My stories* include ‘living detail’ that describe experiences of uncertainty, complexity, and my feelings of heightened emotion so that my ‘emotional expressiveness’ as advocated for by Gergen and Gergen (2002) honours my autoethnographic representation as a relationship with MS. *My story* is intentionally supported with rigorous critical reflections that weave narrative with scholarship to portray my voice as narrator of the story. Chang (2008) asserts this unique voice of the autoethnographer is a voice to which the reader can respond to and with. It is a

way of integrating the personal into academic. It is a way of communicating that one is not a lone voice in the wilderness.

As I now think about my notes I still have a persistent desire to learn more about how to write about my own emotional experiences I have living with MS. With the Alice story as my internal frame of reference I believe I have found a good platform to base my enquiry. I had read about emergence in Marshall (1999, 2001) where through a process of emergent writing of self-narrative I could explore more deeply embodiment and experience. MS is a significant part of my personal and professional life through self-narrative I could posit emotion and imagination. Ellis (2009, p. 102) argues for the most part, social constructionists who look at emotions fail to examine their own responses and, instead view emotions as feelings other people have. Goffman (1959) adds that even when they do use own their own experience, they do so in an emotionally detached way. Or as Denzin (1989) writes researchers hide their reactions in an array of participant observation data. Spry's (2001) self-narratives critique the social situatedness of identity by engaging with autoethnography as method, which sets out to critique the situatedness of self and others in a social context. Richardson's (1995) view is that all knowledge is essentially socially constructed, writing is not simply a true representation of an objective reality, instead language creates a particular view of reality. Dyson (2007) offers this explanation autoethnographies are one person's view of reality constructed around and through other people.

I thought I had just about finished reading all the articles in this folder when I see that there were still a couple of articles still in the drawer! Duarte (2007) says autoethnography is a genre of writing in which the researcher 'becomes' the phenomenon under investigation. Ellis (2009) suggests that it is sociologists who can generate interpretive materials about the lived experiences of other's emotions, by studying their own self dialogue in the process. Ellis (2009) further argues who knows better the right questions to ask than a social scientist that has lived through the experience. From the wealth of books and journals I have found in this drawer, I had taken so many more notes. I was now learning to recognise 'self' as an emergent autoethnographer and social scientist! Who in the telling of a story was placing self at the heart of the enquiry that 'becomes' the phenomenon for exploration and is also developing ontology of 'being'. Curiously, the second drawer of this cabinet is labelled: *'Ontology of Being'*. I am eager to open it.



## **Drawer Two: Ontology of Being**

When I open the second drawer of the cabinet, I see many folders. It is the words ‘being’ and ‘time’ that catch my attention. Alice is by my side, she whispers: “Get your notebooks out. There is a lot to learn from in this drawer”. I am curious and very keen to explore. I remove my satchel from my shoulder and reach for my notebooks. I start reading the first article taking notes. The knowledge base within western intellectual traditions, suggests McNiff (1996, 2000) is shifting. The nearly 400-year-old dominance of the Newtonian-Cartesian legacy has encouraged us to see the world as a deterministic machine. Once wound up, it should operate efficiently and predictably in terms of its moving parts and is held together by knowable processes of cause and effect (McNiff, 2000, p. 42). When it does not, a technician can fix it. This mechanistic metaphor is extending to all living matter, including human being(s). Turner (1996) *The Body and Society* writes about a general movement to recognise rational capacity of humans to understand their world through non-religious means.

Hardey (1999, p. 6) *The Social Context of Health* notes Rene Descartes provided the first intellectual case for separating the thinking subject (the mind) from the passive object of thought (the body). This separation of mind and body has left a legacy whereby, until recently, the body was the province of natural science and the mind the focus of the humanities. It was Foucault (1976) who proposes the notion of ‘medical gaze’. The doctor is informed by nothing more than material facts.

I am fascinated by this collection of notes in this drawer and wondered how they all got here? I see Alice saying: “Carry on reading there is still much for you to learn”. I carry on reading. Some of these articles reminded me of my nursing training where as a student nurse I first learned about how doctors first were able to ‘see’ inside a patient. This was in 1816, where Rene Laennec used a piece of wood to listen to the internal workings of a patient, it was the called the stethoscope (Hardey, 1998). This ‘clinical gaze’ argued by Foucault (1976) was now responsible for producing new scientific data. Hardey (1998) says following Foucault this technology gave rise to a new concept of the body symbolising a new relationship where doctors could ‘look ‘inside the body without any active participation of the patient. It marked the beginnings of the new relationship the

‘stethoscope’ which could only be used if a person remained silent and still. I reflect on this point with regards to my lived experience. I could relate to all of this!

When I began inquiry of my new *being* post diagnosis a decade ago, I was most drawn to some of the contemporary ideas about health and illness embedded in the developing biomedical models and approaches. The prevailing notions of cause and effect I felt were so heavily weighted in developing knowledge from past determinants. Reading these re-ignited my strong desire to challenge some of the existing arguments of the science of *being* in which people are represented as fixed entities with fixed interpretations of life experiences, occupying preconceived social roles and physical spaces, being carried along a given, predetermined route (McNiff, 2000). What I am wanting to do in this enquiry is seek different ways to explore fully my potential of being in the world. My new way of experiencing *being* is not a static, complete structure nor is it in a state of rest. Prigogine and Stengers (1984) argue that this view of *being* fails to adequately account for personal-social experience as a creative, dynamic process.

The diagnosis of MS as an unescapable part of my *being* has disrupted all I thought I knew about myself, my being, and my future. As a person living with chronic illness, a nurse and a researcher, I have experienced the difficulties Kleinman (1988) suggests can emerge from the disruption to one’s previous understandings of illness. With this disarray it was bringing an acute realisation of the complex intersection of social location and chronic illness which I was yet to fully understand. He believes talking about lived experience of illness and the consequent ordering of that experience can be of value for the individual and the health professional. I found this explanation helpful. I could ‘see’ more clearly a process of being open where I am learning to ‘notice’ personal experience. Simultaneously it helps to make sense of my being more open in the wider social world. I take more notes about the process. In my enquiry I disclose the highly metaphorical nature of sense making through Alice stories which I argue is of much importance to the health professional’s understanding of clinical uncertainty as it is to the individual’s search for meaning. I reflect on all I am reading.

I see another folder. In it I read how Marshall (1999, 2001) provides the theoretical underpinning of living life as inquiry and professional encouragement to select a self-reflective research mode where qualities of experience,

perspective, with the knowing body, and action are integral to construction of meaning and knowing as new knowledge. I wondered about my own being with MS and could this provide the basis for researching human experience as praxis. Sparshoort (1999) emphasises the necessity [in learning as process] to recognise each individuals experience as human action and its educational potential of it. I am learning that research methods from a post-modernist perspective are choices that align well with explication of human experience as human action that I want to research in my enquiry. For this I sourced Moustakas (1990, p. 9) *Heuristic Inquiry*, where he says the root meaning of heuristic comes from the Greek word *heuriskein*: to discover or find. Moustakas (1990) says that discovery is what lies at the heart of heuristic research. For me the intention to find meaning was the beginning of this self-discovery with deeper ontological development that would subsequently follow. With Alice as my encouraging heroine, and MS as my White Rabbit, I now turned to the great philosophers Socrates, Plato, Aristotle, Descartes, Mills, Kant, Hume, Wittgenstein, Nietzsche and Heidegger.

Heidegger's *Being and Time*, published in 1927, offered an alternative to the then prevailing scientific orientations that view mind and body as compound entities. Olafson's (1995) *What is a Human Being?* This captured my attention. Olafson (1995, p. 244) states that human beings are not compound entities consisting of body and mind. This contrast between an entity and its being has extensively been developed by the Heideggerian view, and the system of thought that grew out of it. Primarily drawn from Heideggerian insight, Olafson provides this summary: I am my body, in the sense that as an existence or an entity it is constituted by presence. I have a world that is essentially encircled with location and an active orientation of my body, which I cannot therefore separate from myself as a locus of presence. I cannot separate it from myself because it is present to me that which makes possible, again through its location and orientation and active powers, the presence to me of other entities in the perspective in which they are so present (1995, p. 245).

As enlightening as Olafson's summary was, I was equally taken by Bertrand Russell's comment. He writes: "I think an almost unbelievable amount of false philosophy has arisen through not realising what 'existence' means" (1966, p. 234). This observation spurred me on a philosophical odyssey, of my own exploration of human existence, and of being-in-the-world. It drew me back to

Heidegger's (1927) *Being and Time*, and his explication of the meaning of being as defined by temporality, and analysis of time as a horizon for the understanding of being. Heidegger presents his view as phenomenological ontology, beginning with the hermeneutics of Da-sein (there-being). It is temporality that I find the most useful to assign meaning of being: i) with MS, and ii) understanding of the associated fluctuating MS symptoms; tingling, pain, numbness that I experience. This view of Da-sein (there-being) as always being-in-the-world was useful in my thesis for positioning understanding and meaning as central to constituting the human experience of *being-in-the-world*.

I thought deeply about Olafson's argument for a humanistic account of what it is to be a human being and Bertrand Russell's concern with existence. By considering Heidegger's notions of there-being I began to muse on notions of body, being, existence, presence, self, and I. This is my summary: I have MS which exists in my body. It is present every day. My body represents who I am. I am an embodied being in the world, who is an endearing self that is enduring constant change. My soul is joined by reality of MS that presents itself to me as the very entity of pathology. I do not want my body to be characterised as a soul-less entity or viewed solely as a quantifiable object or thing. I am a sensing feeling being!

I remember at the time of my diagnosis, scribbling down these words: 'yesterday', 'today' and 'tomorrow'. It is from re-reading my journal that I now think about these words and how I felt about the changes happening to my body. I was reminded of the 'jam rule today' as described in the *Alice and Wonderland* story. The jam rule today is a reference to the Latin rule that the word *iam* or *jam* meaning *now* in the sense of *already* or *at that time cannot* be used to describe *now* in the present, which is *nunc* in Latin. *Jam* is therefore never available today (Wikipedia, 2011, p. 7). I read on to find notes taken from Davis (2010) saying that it would be wise to make sure that we do have some sort of 'jam today rule' to assist us in the recognition of patterns of behaviour, and help to motivate us in order that we might better avoid the temptation of procrastination in life. Davis provides a better understanding of the 'jam today rule' than I had as a small child. At that time I really didn't understand the significance of how this 'jam rule today' could help reveal such rich philosophical life lessons. Faced with making meaning of my illness experience I confidently apply this frame of reference to my 'being'.

My sticky-tenacious situation described as: i) the situatedness of my MS symptoms of pain, tingling, and numbness; and ii) the temporality of my experience of MS that marked radical changes to my way of being, self and my body. I began to wonder if there was any logic to be made of this situated experience that occurred yesterday, that would continue today and for tomorrow. I did not know. What did all this mean? I re-visit the notes I made on the understanding of time.

In Deleuze (1990, p. 162) portrayal of temporality in *the logic of sense* he claims that there are two readings of time: i) chronos, and ii) aion. In chronos the concepts of past, present and future are not three dimensional readings of time. Only the present fills time. The past and future are two aspects of reality to the present. According to aion, there is no 'present' as such. It is the time of the event, of the experience. Only the past and future exist. Curious about Deleuze's philosophical explanation of temporality and puzzled by my thoughts about my changes to self, I returned to Alice's story. Davis (2010, p. 167) describes how Lewis Carroll scintillatingly calls time into question by challenging the way in which Alice, and each one of us, understands the nature of time. Is time a substance? Is it external to us? Or is time, rather something we impose on others in the world in order to make sense of our own experiences? Perhaps the Mad Hatter, who speaks of time as a personal acquaintance, isn't so mad after all when he emphasises the qualitative and experiential dimension of time.

In probing the deeper underlying meaning of the Alice story I re-visit my thoughts about my hospital admission and the cubicle area in the emergency department. I vividly remember where I was: temporally situated physically and spiritually in the moment. I was sitting for such a long time in that hospital waiting room. There was so much activity all around me. Lots of people young and old were arriving by ambulance. The medical and nursing staffs were all hurrying about in all sorts of directions. With my name bracelet firmly attached to my wrist, hand in my lap I sit and wait wishing it were some other time. Then I think what would Alice do? I could never think of past, present, and future ever again without considering the 'jam today' rule! Examining my new way of *being* and learning more about the application of the jam today rule was fascinating. I am still here with Alice.

In the cabinet is another drawer filled with books. This drawer is not labelled. I am still curious as to how untidy this part of the room is. Had someone been here before? I look over to Alice. She doesn't have to say anything but gives a firm nod of her head which prompts me to take a closer look. I see a number of books awkwardly pressed back in the drawer! They certainly have not been replaced back with care! I carefully take Reason (1988) *Human Inquiry in Action: Developments in New Paradigm Research* to read. He states experience, action, and metaphor as dimensions of post positivist inquiry are about reflective action exploring ways of assessing our world. I am delighted to take more notes about this and I do!

As an emergent writer looking for new ways of writing about thinking I find Bateson's (1972, 2000) *Steps to an Ecology of Mind* outlining learning to think in a new way. He advocates systems thinking approach which as Marshall (1999) says places the sense maker and actor participatively within the unfolding world they inhabit. I am drawn to this approach as it does not separate the knower from what is known and avoids making processes into things. It has a deep reverence for all forms of life. I take a look at my notes which read: How I work with interpretation of dialogue of my new way of *being* in this thesis will be translated through who I am and how I am living: as a woman, person with MS, nurse, and researcher with specific life experiences. This new way of my *being* is non-dualistic. I keep taking books out from the drawer. I find Senge's (1990, 2006) *The Fifth Discipline: The Art and Practice of Learning Organization*. I read about ideas on dialogue and its use in learning organisations that are drawn heavily from the work of Bohm, to define and examine such concepts as quantum theory, systems perspective, mental models, incoherent thought, and synergy as they are related to dialogue. In addition Senge (1990, p. 248) writes reflection and inquiry skills provide a foundation for dialogue and that dialogue grounded in reflection and inquiry skills is likely to be more reliable and less dependent on the particular of circumstance such as the chemistry among team members.

My previous orientation with team learning was located in health and sciences. It was heavily influenced from a positivist perspective. Senge (1990, p. 10) says the discipline of team learning starts with dialogue which is the capacity of members to suspend assumptions and enter into a genuine process of thinking together. To the Greeks, 'dia-logos' meant free flow of meaning through a group

allowing the group to discover insights not attainable individually. In my group [nurses, educators], we entered into numerous discussions based on technical rational aspects of critical reasoning with regard to nursing and health issues. We did not talk much about one's own experiences here. We would focus on journal articles of other's experience and relate this to clinical practicum skills. At the time I did not think this was unusual practice. However, it was not till after my diagnosis, reflecting on 'dialogue' [from and with others] that I began to think about why I was getting this unusual response. An almost 'stony silence' exhibited by my colleagues when I spoke about illness and disability. I now wondered who knew about my situation, and why this would matter. I was still the same colleague. All that changed was that I now had a confirmed diagnosis of MS.

Satre (1956) speaks of this 'passed over in silence' as a common manner of experiencing the body as in the mode of near forgetfulness. Initially, I was somewhat hesitant about discussing my illness and questioning my new way of *being* with my colleagues. I have always been more introspective and didn't see this as an issue. What I assumed was that everyone has some sort of awareness in the ways that they seek to be continually more effective at what they do and who they hope to be. They spoke about dialogue in nursing practice I thought who's meaning of dialogue did they aspire to or mean? Looking back it was not in the manner that Senge defines dialogue.

I thought more about the responses the discussions with my colleagues in the early phases of my acquaintance with MS. My inquiry was still in its embryonic phase. It seems presumptuous to give my predicament status through writing. And yet interestingly enough what I thought was dialogue turned out to be a series of quick discussions by the group with little time allocated for genuine reflection or collective thinking together. Senge (1990, p. 10) suggests that dialogue differs from the more common discussion, which has its roots with percussion, and concussion, literally a heaving of ideas back and forth in a 'winner takes all'.

In aspects of my nursing background I was largely socialised in the one for all line of inquiry. I was led to believe that real science was quantitative/experimental and a race to be the owner of knowledge! Denzin and Lincoln (2000) recognise this predominance of positivist research and argue that other ways of inquiry that connect with real people, their lives and their issues were seen as soft and, although perhaps nice, not valuable to the scientific

community. Wall (2006) writes grounded as it is in postmodern philosophy, autoethnography is linked to growing debate about reflexivity and voice in qualitative research to extend meaning about social phenomenon. Ellis (2009) says in seeking to humanise an academic project, introspective ethnography should be included in sociology and could meet the criteria of rigorous inquiry. She advocates for telling sociology in a passionate way including emotions in theory making sociology studies relevant to peoples lived lives. Ellis (2009) further developed the idea that introspection was a scientific approach to social science research as such narrative excerpts would demonstrate its value.

In accompanying Alice [as wise muse] and following White Rabbit [the animated version of MS] on my learning escapades I became to appreciate that symbolic interpretation was central to character development in my story. I had been introduced to Ellis' (2009) introspection as an interpretative technique. I had found a legitimate place to examine emotions how they are experienced. I wanted to explore the constructs of *being* and *knowing* in organisational learning, where putting self in the inquiry would contribute to a more consciously recognised fluid form of a personal and an organisational way of *being*. I am now very keen to open the third drawer of this cabinet.

### **Drawer Three: Being as process of caring for self and other**

The drawer I open reveals some more interesting articles. The rise of interest in post-modern philosophy and my growing concerns about the uncritical perpetuation of the mechanistic understandings of reality coincided with my diagnosis with MS. The considerable interruptions in my personal and professional life post diagnosis could not be fully explained through the dominant positivistic modality. These interruptions were examples at a personal and professional level of the mutually re-organising relationships of *self*, *body* and *work* and entail questions of intellectual, emotional, and spiritual processes. The information-seeking activities that followed my diagnosis in 1998 were an expression of my *being* grounded in a state of open enquiry. As researcher, nurse, and mother, living my life as inquiry led me to be more congruent with a reflexive orientation and approach. Using self as subject was represented in the form of my



numerous journal notes now rebirthed as field notes or narratives. I see how I can now engage in self-dialogue and introspectively think about what I was feeling at another time. Before I caught a glimpse of White Rabbit and decided to follow him, I, like Alice had been sitting on a bank reading old journals in an attempt to make sense of my circumstances. On a particularly distressing day I record:

*The unpredictability of these MS symptoms is such that they are intricately laced with sheer frustration. So how is one to make any plans with a movable feast such as MS?*

*(Personal Journal, 1998).*

In another one of my notebooks I had jotted down a cluster of thoughts that seemed to run so very fast around in my mind so fast that I couldn't help but be reminded of how fast White Rabbit ran by. I record:

*I now host this incurable degenerative illness MS...it is with me 24 hours of the day. I cannot predict from one day to the next how things may be for me. I can only hope that the length of time in remission is far greater than that the time spent recovering from a relapse.*

*(Personal Journal, 1999).*

These excerpts from my journal are my thoughts that capture the 'living detail' of my personal experience that I reflect on taking into account issues of writing truthfully, vulnerably, evocatively and ethically. I read Ellis (2004, p. 118) who suggests analysis on thoughts and feelings should be considered as 'socially constructed processes'. Her comment helped me see why it is so important to reflect and be reflexive with self-narrative. This reflexive orientation in qualitative inquiry as suggested by Foster et al. (2005) is to be self-conscious about how being a researcher plays a part in the constructing meaning in the research; he/she does not simply describe the participant's reality. I now see Alice waiting patiently and beckoning me over she says: "Time to reflect. This is a good place to do this. Take your time. There are many more books here that will be very useful to you. I'll catch up with you later". My first reaction to this was: "I'll just do that". I thought more about this word 'reflect' and my being-in-the-world with MS.

I take my cue from Alice and stop here for a while to gather my thoughts and reflect. It is a very quiet place. These cabinets and drawers I am opening remind me of a medical records room. Maybe subconsciously this says something about the person I am as I've always been attracted to keeping records whether they are written, sketched or painted. I see that the next drawer is a different colour than the others in this cabinet. I am puzzled as to why this could be and open it. In this drawer I find numerous journals of all sizes and colours. A beautifully illustrated journal called: *"Nursing and Caring"* catches my eye. My immediate thoughts are this looks familiar how did this journal find its way to this drawer? As there has been such a lot of mysterious magical happenings around me I am reminded of Alice who is guiding me and has on more than one occasion said take your time to read and make notes. I do just that. What a find and such a treasure! I begin to read. I find much written about my working experiences of being a nurse and caring for patients. Nearing the last few pages is an excerpt about my work as a nurse and the diagnosis of MS:

*As a nurse I always aspired to being able to deliver an excellent standard of patient care. For me this standard was formally acknowledged in my nursing employment appraisals and related nursing career pathways documentation. It stated that I was at a level of expert care: for delivering nursing care to her patients and their families. Following my confirmed diagnosis of MS in 1998, I was now in the position of being the patient. It was very different position! Coming from a health background I was familiar with medical-nursing procedures. However for all this knowledge gained I still was not able to obtain any logical reasons to this change? Was it the immediacy of a response that I was seeking? And was it one that I had been used to as a nurse? Now I'm not sure. What I am sure about are the many riddles the many twists even paradoxical sets of events that I now find myself having to face.*

*(Personal Journal, 2000).*

Reflecting on this excerpt evoked so many reveries of those earlier feelings I had experienced in 1998 and with use of Ellis's (2004) emotional recall I am visualising my presence back in the scene emotionally and physically. Where placing emphasis on 'I' which I have come to think and feel about deeply in my enquiry as subject and object is highlighted.

As well as taking notes I am engaging with the process of self-reflection developing my emergent writing skills to explore meaning of being open to be oneself and narrate a storied reality. Kierkegaard (1980) offers insights to ethical questioning with metaphysical concept of '*being able to be one's self*'. Reflecting on my personal and professional life I find myself orientated more towards a post-modern perspective with interpretive inquiry and writing style of realism and impressionism. Owning more than one style throughout the duration of an ethnographical enquiry is what Madden (2010) says is an important consideration in ethnography. I intend to apply this wisdom!

I think about my enquiry. For this I draw on Ellis (2004) *Ethnographic I*, (2009) *Revision*, and Van Mannen (2011) *Tales of the Field*, using a mixture of realist and impressionist styles to integrate embodiment, feeling and emotion. I continue taking notes capturing significant dates of specific events that are unique to my life and new way of my being-in-the world with MS. I *am* different now and my understanding of *being* and *knowing* has changed and is ever changing. My quest is to explore how post-modernist perspectives can be utilised in describing and guiding this change in my *being*, a change influenced by my choice of narrative inquiry and style of writing. Madden (2010, p. 166) says what an ethnographer has to assimilate is that being ethnographic is not an absolute condition; it is a relative form of being that produces differing expressions or outcomes depending on the context. The variation in my writing style is one that is shaped by each description of a specific event i.e. when I experience a flare up of my MS symptoms. Madden (2010) further writes it is not to suggest that ethnographers are merely shaped by their context and not by their intellectual intent; rather, that being ethnographic is not a singular state of being, it is a way of being that must be sensitive to its surrounds. In choosing autoethnography I do so because I believe it to be the most responsive approach of enquiry to my new way of 'being' and the demands that MS now bestows. Writing is part of my method and the methodology was my justification for its use developing an autoethnographic writing style where focus on the *particular* would be an important aspect and strength of this enquiry.

I am now thinking back to my time in the vestibule. There I had been introduced to many eminent researchers of autoethnography who advocate for a need to craft an emancipatory performance base approach, or as Denzin (2003,

2006) argues a discourse that can speak to issues of inequality under neo-liberal form of democracy and capitalism. Denzin says a good performance text must be more than cathartic. It must be political, moving people to action and reflection. I have my notes and these will be used to organise conscious attention to examine phenomena of my everyday life experiences with MS. In this way I am learning that drawing on personal experience can be the basis of performative narrative which can bring the social and personal aspects of *self*, *body* and *work* into play. I remember reading about performance where ‘all the world is a stage’ in Goffman’s (1959) *The Presentation of Self in Everyday Life*. I immediately felt connected with it as living my life as inquiry was where I could perform an event [MS] in my personal life on this stage. I appreciated the way Denzin and Goffman write about performance and performativity. From their writings I’m learning that in adopting this performative approach I could relate this to my research question. I could also put into action ways of knowing for myself and others who are similarly and necessarily involved in such generative processes that can challenge existing ways of knowledge and representation in the world.

This was inspiring. My early attempts to learn more about MS were largely influenced by the hectic unrelenting pace of attending hospital appointments and having tests. It was not until embarking in this formal enquiry that I found out how much I still didn’t know about my embodied self and my new way of *being*. I glanced over and see Alice who was waiting patiently. She had said to take my time here to read these books and reflect. My desire was to learn more about knowing how to know. I read on. Richardson (1995) suggests that writing is a method of inquiry, a way of finding out about yourself, your topic and a way of ‘knowing’ a method of discovery and analysis. In my enquiry I want to explore embodied experience as means to acquiring new understanding of my new way of being. As an insider and outsider I have ready access to experience. Halstead et al. (2008, p. 93) say access as a process helps shape the research encounter to becoming part of constructing new knowledge.

As an emergent researcher my positioning was as both an insider and outsider would allow access to highly personal embodied experience. In learning how to know I want to piece together an array of conflicting accounts given to me from health professionals. They were interspersed with my own emotions, feelings about *invisible* MS symptoms that were a significant influence of my being. I

reflect on my own self. I have MS symptoms that are *invisible* to non-specialist eye. I hope I can find some interesting work about this here. I look around and placed in a drawer are a number of other books. I am instantly drawn to the titles of these books. Vickers (1997, 1998, 1999) *Chronic Illness an Organisational Perspective Long Overdue*; Boje's (2011) *Storytelling and Future of Organisations: An Ante Narrative Handbook*; Frank (1990) *Bringing Bodies Back In*; Baudrillard (1994) *Simulacra and Simulation: The Body*, and Vickers (2005) *Illness, Work and Organization: Postmodern Perspectives, Ante narratives and Chaos Narratives for the Reinstatement of Voice*. I sit down to write. I read in Richardson (2000) about the rise of post-modern philosophy and the influences of critical theory, reflexivity, and a wide range of published personal narrative as auto ethnography and about what constitutes knowing. I am inspired and deeply moved by what I have read so far. These writings will help me to refine my research question.

I reflect on my own increasing awareness of these influences now as I am exploring where and how I am able to think differently and how the use of personal narratives could illustrate the postmodern existence of my life working and living with MS. Vickers' (2005) writing offers aspects to consider this being: work, illness, and organisation. I wanted to find out if an organisation [whether it is a management or learning based one] would consider the benefits of orientating its way of practice to include increasing its attention to the lived experience of illness. I was now exploring how others see, know, and interpret illness experiences. Heshusius (1994) and Eisner (1998) argue there are many ways of seeing the world and interpreting human interaction. Crotty (1998) adds knowledge is not a given product and coming to know is not a neutral process owned by others. What did all this mean? I take a while to think about this and write the following: I will narrate a story of my *being* to include the telling of my academic journey from the positivist paradigm located in health sciences to a post post-modern stance. This stance of *knowing* will give a different 'voice' to an organisational group who care for people with MS.

In the previous rooms I had read widely about methods and methodology and review my notes on Ellis and Bochner (2000, p. 73) who say 'autoethnography is an autobiographical genre of writing'. Re-reading this confirmed for me that utilising this genre will enable the reader to vicariously share my professional

nursing expertise and in particular embodied experience of MS, bestowing an authorial 'voice to my body' that could now re-veal personal experience, 'voice' feelings and emotions. Madden (2010) suggests where an ethnographer's expertise is part of the authority of the piece. One needs to be a flexible enough ethnographic author to write for these differing expressions and different contexts they encounter. From my reading I am assimilating that in 'being' autoethnographic in its relative form offers these ways to understand the differing expressions depending on the context. Madden (2010) also helped me to appreciate the power of personal narrative. I had a better understanding of how my personal odyssey was being clearly displayed in this emergent writing style of writing capturing *being* as process of caring for self and other. I begin to recognise that it is the most appropriate means to tell my story that would be faithful to it and reflect emotion embedded in the human side of my *being* a person with MS. I can see more drawers that I have not explored. I still have much to do.

I return to my notes and reflect on them. I see that I have written the words: 'care' and 'caring'. I then hear some scuttles. White Rabbit runs by. I look around to see where he has gone and cannot see him. I turn my head around again and who should be there? It is Alice. She points to a small box sitting alongside the cabinet shelf behind me. On the front of the box is written: *Care & Caring*. I am very curious. I remember the Alice instruction of 'look first'. I proceed to open it and find an article written by Boje (2011) *The Heart of Care: Quantum Storytelling and Ontological Inquiry*. What another fortuitous find! I wonder what quantum storytelling means? Alice was right I should take time here to reflect and I do!

I set about to read this article and take notes about the spiral antenarrative journey, life path, heart of care and that quantum storytelling is a way of helping one to grasp the meaning of being. Did this mean that there was a deeper philosophical meaning that I was yet to explore? I think there most certainly is! I wondered how the notions of 'care' and 'caring' that as a nurse I was orientated to would align with what I am reading in this article. As a nurse care would be defined as 'looking after' or 'doing to' the patient in a confined space dictated by certain time constraints. Care was routine, ordered and largely gleaned from positivist, functionalist models in three eight hour shifts, seven days a week. The

only exception to this stance I argue was that of night duty. As a nurse ‘care given’ on night duty would involve being able to have time to sit, listen, and talk to a patient without the constant interruptions from the noise of telephones, cleaning equipment, trolleys, extra staff and visitors about. I thought about the word ‘care’ and what this meant for me now as a patient who has MS receiving and dependent at times on others for care. I was also reading the article from the position as a person being-in-the-world with MS. *I Carrie*, have much to learn as I reflect preparing me to answer what Boje (2011) says is a call to conscience of a heart-of- care. Fascinating!

In thinking more about all I had read this prompted me to re-visit my notes taken in 1998 of when I first experienced unexplained tingling numbness and pain. These changes became my heightened feelings. Formally commencing this enquiry I thought more deeply about these and MS. After reading extensively the many books and articles I had been introduced to in the vestibule and those subsequently that I found whilst being guided by Alice and following White Rabbit. I began to think differently about illness and MS. I was living my life as inquiry. I thought would this not be a fabulous approach as the basis for drawing on rich ‘living detail’ to explicate its transformative and generative potential. I had read Boje’s work (2001a) where moments of experience are first noticed but then do not get incorporated into the transformative meaning about the future end states. I thought about the future, predictions, and end states. With MS this is almost impossible to do. I cannot predict my future or my end states. Can anyone? I live with a chronic degenerative illness. The only certain end state is death and MS may not be a cause of this.

I now turn my thoughts back Boje and am so delighted to read about how he has developed two additional meanings of ante narrative. Ante narrative [3] *antecedent* and ante narrative [4] *anteriority*. Boje (2011, p. 39) *The Heart of Care: Quantum storytelling and Ontological Inquiry* says the third and fourth approaches to ante narrative take on pre-ontological and ontological approach respectively. I am deeply moved by what I have read. I feel these notions do resonate with my thinking and desire to contribute to developing my *being* as process of caring for self and others. Could this extension of the ante narrative align with my emergent writing and inquiry? I am curious to find out. I have my chosen method of autoethnography. I am developing a better understanding of

embodied change and am becoming more adept at learning how to notice and listen. I am developing a better understanding of being as process of caring for self and others. Where I am reminded of Tillich's (1955) *The New Being*. According to Tillich, a theologian and philosopher, a lifelong pursuit of philosophy reveals that the central question of every philosophical inquiry always comes back to the question of being, or what it means to be, to exist, to be a finite human being. One of his famous quotes: "The first duty of love is to listen" (Tillich, n.d.). I reflected on this quote and wondered if it could be applied to my experience now. Of course it could. My duty was to listen to self and body. My body that now in illness was calling itself to attention. With all my notes taken and back in my satchel I have a very good overview and grounding here. I was on the right path of becoming an emergent writer of autoethnography. There was just one more drawer to open in the cabinet. It is the label that intrigues me!

#### **Drawer Four: Becoming and autoethnography**

In opening this drawer I see a few bundles of papers rolled and tied up with some brown string. I rummage about and there loosely sitting in the bottom of the draw are a collection of postcards, letters, hospital appointment cards and my expired passport! I wonder how this got here without further to do I open the passport and see a visa entry stamp dated 1965. My thoughts immediately travel back to the time when I was along with my brothers and parents were preparing to leave Malaysia to come and live in New Zealand. So much had happened since my family immigrated to New Zealand in 1965. I pick out an old hospital appointment card. I wonder how all this memorabilia found its way here! I'm glad it did as when I look back 1998, marked a most significant event - the confirmed diagnosis of MS. This is where my antenarrative begins. I now host an incurable chronic degenerative illness. I had been searching for an approach that would help demystify medical approaches to and with the delivery of care for persons with MS. This need was identified as a result of my experiences with medical encounters. Some were helpful some were not.

By following White Rabbit and Alice I have come to know more about this methodology of autoethnography. Curious to know more I to set to work to find



the way I could express and apply all I have learned about autoethnography, the antenarrative, the narrative and storytelling. Boje (2001b) suggests that the antenarrative is not antinarrative, it complements the narrative. He notes that there are four types of antenarrative: linear, cyclic, spiral and assemblage (rhizomes). These antenarrative types are in intra-play with living story. I was enchanted reading Boje's use of rhizome with living story. I remembered seeing this image of the rhizome in the vestibule. Alice called it her map. I read on. Narrative is defined as retrospective sense-making of a more distant past. Living story is defined as a more immediate-present sense making in the here and now, of a place in existence, and in relationship with others living stories (Boje, 2001b). As a mode of writing, it enables self as subject to draw knowledge from the body by means of embodying and enacting. Drawing on my nursing and research skills provides opportunity to re-consider how my knowledge of illness called MS and the people who have MS had been constructed. I had now morphed into my new way of being in-the-world with MS. In my living story I am constructing what had happened in the medical encounter and deconstructing the embodied experience to make meaning by restorying. Epston and White (1990) say it is possible to shift these accumulations of past morphic fields through storytelling in particular through 'restorying'. Boje (2011, pg.7) says restorying involves deconstructing a dominant narrative of one's past that is stuck, preventing someone in the present from moving on. Restorying is finding those little wow moments of exception to the dominant past narrative, and constructing these fragments of wow moments into a new story - one that changes one's life path and future.

With this in mind knowledge drawn from my body were my wow moments and was my starting point of the antenarrative. Ante-before, thus refers to complex, ambiguous fragmented state before a well-aligned narrative can be said to exist (Boje, 2001a). I see more notes in the drawer.

I untie the string from the rolled up bundle of notes. Where I see an article by Narayan (1993) who suggests that the meaning of pre-existing experience changes with time spent in the field. I began to think about use of antenarrative, narrative in my story line. In the re-telling of my experiences I engage with exploring pre-existing experiences, re-visiting experiences and writing about them. As woman, nurse and academic [who has MS], these new ways of my being are defining the acquisition of new self. I am changing. I have changed. I am becoming the

observing observer. As Boje (2001b) says, this three-ness of time is the essence of the storytelling narrative, living story and the antenarrative. In my enquiry I write about embodiment and personal experience. Ellis (2004) states when writing about personal experience as a coherent story, it should comprise of a beginning, middle and ending. Boje (2001b) suggests that narrative has qualities of coherence, plot, and argues the antenarrative is the previous state of affairs and offers theoretically substantive valid contributions to knowledge.

On becoming an authorial 'voice' in this research process of autoethnography I am positioning the antenarrative here, as it can be a prospective sense making activity to help answer the research question: "What are the intertwining relationships between *self*, *body*, and *work* as mutual organisational relationships?" By reflecting deeply on my experiences described in the antenarrative these are helping to generate useful insights in my 'eureka' moments of learning how to know. I am learning to see what Entwistle (1979, 1981) describes as surface and deep learning. In utilising the antenarrative this will play a crucial role in my making sense of lived experience of MS and out of it, a certain flow of meaning is beginning. Through autoethnography I am writing about personal experience.

I return to Ellis and Bochner (2004, 2000) who say the term autoethnography has been in use for more than twenty years. Originated by Hayano (1979) it has become the term of choice in describing studies of a personal nature. When thinking about how to form my research question at the beginning of this enquiry I found Moustakas (1990) *Heuristic Inquiry* helpful to read. In it he says it is a research method beginning with a question that has been a personal challenge for the researcher. The methods of heuristic inquiry are open ended [with] each research process unfold[ing] in its own way. Moustakas (1990) further adds that heuristic inquiry methods reveal the nature of a phenomenon more completely than would ordinary experience, and is characterised by a process of in-depth rigour and systematicity. I had read widely taken notes on autoethnography and wondered could Moustakas' approach be intertwined within my enquiry and research question. It reinforced that I was addressing all points taking note of ethical considerations as previously discussed in Room of Methodology before plunging into this next challenge of *becoming* an autoethnographer.

I want to *show*, how in my writing, use of autoethnography will help me to unravel some of the complexities of my research into my confirmed diagnosis of MS and new way of being, that have formed my research focus and are a big part of my personal and professional life. I am motivated to move from learning about autoethnography to immersing self into becoming an autoethnographer. I pause for a moment remembering the Alice instruction: 'Look first'. There is much to learn about this step to becoming an autoethnographer. Wall (2006) writes that some readers of this type of inquiry still consider a personal narrative [as inquiry] to be the same thing as an autobiography. I was pleased to have found Wall's comment. It cleared up this lingering hesitation I had in my mind. That it can be anticipated that some readers may confuse autoethnography with autobiography. My job would be to ensure my intentions and performance as an autoethnographer would be clear!

I remove the brown string from the next bundle of notes. I unroll these and begin to read. Ellis and Bochner (2000) say the use of autoethnography is a means to explicitly link concepts from the literature to the narrated personal experience. Holt (2003), and Sparkes (1996, 2000, 2002) support this approach as does Duncan (2004) who further notes it is just as rigorous and justifiable as any other form of inquiry. Richardson (1995, 2000) and Sparkes (2002) claim that narrative inquiry is a form of writing and reflection about the process of writing and the context in which that writing occurred, revealing a highly personalised text, in which the author invites the readers to relive their experiences and events with the writer. Patton (2002) writes that autoethnography intersects with use of personal narrative in which the researcher's story becomes part of inquiry into phenomenon of interest.

In addition Wall (2006) suggests that the associated methods used in autoethnography vary widely. They range from highly introspective processes to more familiar approaches connected to disciplines of qualitative research. They can include experimental literary methods in terms of thinking of the writing as research. Duncan (2001, 2004) introduces sceptics to this form of research in a more gradual way. She demonstrates explicitly how autoethnography can assist in answering otherwise unanswerable questions. Her highly personal accounts have invited me to regard my own chronic illness in a new way. Her compelling inquiries lead me to examine similar highly personalised texts in which other

authors revealed their own lived experiences. Sparkes (1996, 2000) in his narrative account describes his experiences as a white male, middle class, former elite athlete and how a chronic back injury ultimately curtailed his sporting career. Holt (2003) describes in his personal account how he originally developed an autoethnographic account to depict his experiences as a PhD student trying to come to terms with reaching at the university for the first time.

I found these points of views by researchers who use autoethnography to write about personal experiences helpful and enlightening. Their examples became my impetus to begin framing a process of conscious inquiry about what it means to be somebody living and working with a chronic illness. Writing about my story is central to seeing the 'extent' of 'how' my relationships with colleagues, family, and medical professionals are influencing my new way of being-in-the-world with MS. I have many unanswered questions about MS and still do. I am learning more about the power of narrative as I understand what can be potentially achieved in using personal experience as enquiry. I want to include in my enquiry ways to describe my own creative way of *becoming* as I seek new meanings of my life now living with MS. I am developing an increased self-awareness about illness and if I am to write about becoming an autoethnographer I need to explore some of the deeper perceptions of disability, disease and illness.

Annandale (1998) draws an important distinction between disease and illness. Disease, she argues, is an objective measure of pathological change in the body; illness is the human experience of the disease (Annandale, 1998, p. 255). Stewart and Sullivan (1982) suggest that for people diagnosed with a disease, information seeking activities start in the pre-diagnosis period and continue until a diagnosis is confirmed.

Indeed, following my diagnosis, I began just such a process of inquiry to make sense of the many changes interruptions and feelings of disconnection to: *self*, *body* and *work* relationships. These notions of *self*, *body* and *work* became the basis for the development of my research question. I wondered: "*What is this chronic degenerative illness (MS) going to do to my body? Will I be able to continue to work? If so, what capacity will I be able to work in? Do I disclose my illness, and if so to whom?*" Dervin (1992) argues that this period of perpetual interruption and questioning significantly contributes to moments of discontinuity of understanding life as it was and imagining how life in the future will be. My

sense of the physical disconnection with *self* and how to position *self* in my research were examples of this disconnectedness. In addition a further key theme for me in *living life as inquiry* is my understanding of knowledge, and how knowledge is produced and judged for validity.

Muncey (2005) suggests that for those individuals *who* produce knowledge it is important to show *how* status is attributed to it. Sparkes (2000, 2002) argues that the emergence of autoethnography and narratives of the self, have not been trouble free and their status as proper research remains problematic. Muncey (2005) further adds that expanded questions of ‘self as data’ in autoethnography, allow experiences of others to inspire critical self-reflection. I found both views interesting as I was now *becoming* more aware of this relatively new genre. With the Alice story as internal frame of reference my emergent status of *writer* is also evolving. I am becoming more aware of what to look for in terms of understanding how my personal odyssey is intricately linked to the wider web of the social world of illness, disability, and my being-in-the-world with MS that I am researching.

In this process of *becoming* I am using *self*, as a source of ‘living detail’, perhaps the only source of ‘living detail’ in my study that could possibly challenge the expert knowledge socially sanctioned in a way that personal knowledge is not. I have private and professional experience that has helped shape who I am today; I return to Ellis. She says “The first in studying this fusion of private and social is to acknowledge introspection, whether our own or that of others, as a sociological technique that can provide access to private experience and generate interpretive material from self and others for understanding of complex, ambiguous, and the processual nature of lived experience” (1999, p. 99). Creating a process of writing stories using images and icons meaningful to me will allow the complexities, and ambiguities of individual and organisational life experiences to be linked to interpretivist inquiry.

I have my detailed notes about Marshall’s (1999) *Living Life as Inquiry* where ideas are tested through one’s life space as inquiry and Denzin’s (2003) *Performance Autoethnography*. These approaches will provide understanding of how I move from a view of staged performance [or mimesis] to generate and construct ideas testing these through my life space in the many passages that I *could* and was *yet* to fully explore. Told through narrative I aim to *show* how I am

coming to construct meaning of the more complex aspects of MS. Through such purposive inquiry into *self* I take into account theoretical concerns about representation, objectivity, data quality, and associated ethics, and evaluation criteria. Drawing on Ellis's (2004, 2007, 2009) introspection and emotional recall would shape my emergent awareness bringing *self* into consciousness. Along with these shifts of thinking I will re-veal, re-vision, and re-tell, experiences of my new *being* as *I Carrie*, the wife, mother, nurse, researcher that has MS who now is *becoming* an emergent autoethnographer. I was appreciative of the instructions Alice had given suggesting that we stay in here it allowed me the extra time to gather as many notes that I could I take with on my journey in this House of Learning a place where I could question what I am doing. And explore how to know.

As I begin to think about the many exciting opportunities that still lie ahead of me Alice gently points to the various portraits that grace these walls where I am reminded of the good company I am in: Ellis (2004, 2007, 2009); Ellis and Bochner (2000); Anderson (2006); Spry (2001); Sparkes (1996, 2002, 2004); Reed-Danahay (1997); Muncey (2005); Plummer (2001); Holt (2003); McMahon and Thompson (2011); Moustakas (1990); and Marshall (1999, 2001). I was indeed in good hands whilst developing the theme of emergence in my writing and enquiry. Interposing my feelings such as uncertainty, frustration and an ambiguous limb as segments of my *here* in the antenarrative into my *now* as scholarly inquiry, is providing an appreciation of the assorted layers with interpretation of the narrative to emerge and complete the understanding of storytelling as research process (Allbon, 2012).

In seeking to humanise this academic enquiry, I had now found a 'home' and a 'way' to respond to this call of performance autoethnography. In utilising antenarrative, introspection and emotional recall I could creatively write and *show* my life story! Again I see Alice who is saying: "It is now time to describe what you have seen and written in your notebooks and journals. We must take ourselves into a different space. We have examined the design and process deeply enough. It is now time to demonstrate its insightfulness. Go to the room with the red door. I smile and thank this wise muse. I try hard to contain my excitement! But I cannot. With my satchel in hand eagerly I get on my way. Off I go!

## **CHAPTER FOUR**

### The Room of Demonstrating Autoethnography

“Free from desire, you realise the mystery,  
caught in the desire, you only see the manifestations”

(Watts, 2009, p.7).

## CHAPTER FOUR

### Room of Demonstrating

On the front of the red door Alice had pointed me to is a label that reads: Demonstration Room. In this room I find more tables, books, and a satchel sitting on the floor near a bookcase. I open the satchel and take out a notebook. I see the words: “*Art of Creating and Demonstrating*”. Intently I set about to read. Early in my decision to research my experience of MS, I was challenged to find an appropriate research design that would enable me to research and relate a personal encounter in order to present complex issues of MS within health and education using metaphor and the narrative methods of autoethnography. Drawing on Lewis Carroll’s (2006) *Alice in Wonderland*, provided a creative and imaginative way to do this. I want to use the thought provoking images and metaphors of this story to explore ways of knowing illuminated through an autoethnographic framework to *show not tell* about this way of my *being* and *becoming* in- the-world with MS.

In the Room of Being and Becoming I read widely about the potential of autoethnography and I took many notes on its veracity. I experimented, with Alice story as internal frame of reference to help, weave her story into mine. I tried out the ideas on a number of examples drawn from my personal journey. I found myself leaving that room, convinced I could demonstrate the insightfulness of this research method, and through this method of research reveal the actuality of ‘becoming’ Carrie who lives creatively with MS. I plan to demonstrate the revelational potential of how my chosen vignettes can enhance the representational richness and reflexivity of my work. For this I incorporate Moustakas (1990) *heuristic inquiry* phase of immersion in the research design. These vignettes become the rich material for immersion, for staying with, and for maintaining a sustained focus and concentration. Places, people, and meetings offer possibilities for understanding phenomenon. Primary concepts for facilitating the immersion process include self-dialogue and self-searching, pursuing hunches and drawing from a tacit capacity that allows self to sense the unity and wholeness of something from an understanding of the individual qualities of human action. I have a plan! I will craft my story as i) Carrie’s



passage into the story-well; ii) On 'being' autoethnographic from interpretation to story; storytelling, imagination as form of poiesis in autoethnographic research; and iii) Carrie doing autoethnography, a storied reality highlighting poetic and imaginative generative qualities of 'becoming' an autoethnographer.

### **The passage into the story- well and synchronicity**

In this room for demonstration I feel at ease as I've been searching for some time now for a way to align my creative, imaginative self with learning more about embodied experience. From my time in the previous rooms I have been following White Rabbit through the many tunnels, mazes and past some surprising vistas. Just when I think I've got a better understanding of how my MS symptom's present, MS again tricks my body! With more unexplained symptoms that sometimes last hours, sometimes days and at times even weeks. I now want to 'unpack' ambiguity, and confusion. Here I go!

To date there is no medical or therapeutic cure for MS. There are a series of medications called interferon that may be prescribed to help modulate the effects and progression of this illness. To be eligible for this medicine the individual has to be examined by a Specialist Neurologist. A series of tests are performed to ascertain the individual's clinical condition. One of the tests used is the Expanded Disability Status Scale (EDSS 1-9) (Kurtzke, 1983). It is based on the presence of certain symptoms in a typical neurological examination. These observations are evaluated on the scale from 1 to 9 in each functional system (FS) respectively<sup>3</sup>. The higher the EDSS score, the more profound the patient's disability level is deemed to be. When in 1998 my score on the EDDS scale was recorded as 2. At that time I was told by the specialist that on this score it would be unlikely I would meet the eligibility criteria for assistance to access this medication. What a dilemma I now found myself in! I left this consultation feeling stunned. I had an overwhelming desire to find a reason for and substantiate a reason for why I was not deemed eligible for assistance.

---

<sup>3</sup> [www.nationalmssociety.org](http://www.nationalmssociety.org)

I had read widely in the medical literature about MS the advantages/disadvantages of this prescribing regime and the screeds of side effects. As a nurse I didn't think this to be that unusual as with any medication there will always be the potential for side effects. As Carrie who has MS, one aspect that stood out from this plethora of information about interferon medications was how the regime of a modulating therapy should ideally be initiated at the earliest onset of illness. I thought what is meant by ideal? Nothing about this baffling illness seemed to be ideal it really did feel like I was now falling deeper in the Rabbit-Hole. Alice describes this fall: "Down, down, how many times have I fallen now? (Carroll, 2006, p. 7) .With no obvious answers to hand for Alice there is nothing else to do but to begin thinking again. Like Alice I began to think again. Why cannot I find any answers or help to access this medical regime of care? Aghast I cried: Curiouser and Curiouser!

I find myself constantly thinking about this baffling illness and the numerous medical consultations I encountered. I ponder over many questions all racing before me in my mind. I am thinking: i) could this regime possibly assist me to stay well; ii) if so, could it also enable me to stay well and employed; and iii) if it can, would I need to consider other work options? Trying to find answers to these many questions from health professionals is demanding and exhausting. This was an extraordinary situation. Writing about it was most helpful. It evoked this feeling of taking some control. In the previous room I had meet Morpheus and Neo in the Matrix and now wondered would the Matrix help me? Committing this experience to a formal enquiry, developing original ideas for personal stories that would be substances for this project was a way to enter into the fascinating world of storytelling. I reflect on my experiences of following White Rabbit into the Rabbit-Hole. On my way down, with Alice as my companion, I noticed many cupboards, bookshelves, and tables. Here and there I had also seen pictures hung upon the walls. I stopped to muse on the portraits, and read the many books and articles I knew I have. I had a story to tell! I needed a way to creatively show my new way of being and becoming-in-the-world with MS.

When I think about my illness MS and all of my 'foraging' about trying to make sense of the many conversations I had had with others, attending medical examinations, and then writing about my feelings. I wondered is this not a form of storytelling? It would be after all sharing a narrative tale of a real experience

with someone else. In the Alice story there is much of the imaginary interspersed. I too imagine my worlds of possibilities to be creative. In demonstrating this creativity *I Carrie*, become central to my relationship with MS and Alice is still my companion. I hear a sudden ‘thump-thump’ and a loud rustling noise. I see it is White Rabbit. I can *just hear him muttering away to himself*. When I look around he has gone! *There was not a moment to be lost. Away I went to explore.*

I find myself in a corner of this room where I see a bookshelf with an exquisite carved box with an inlaid mother of pearl pattern on the top of the lid. I wonder what is in this beautiful box. Alice says: “This is your compendium in it are a collection of articles and notes. In it you will read about a creative social project and a story well. Keep the compendium it will come in handy”. Bubbling with excitement I cried out: A creative social project, a story well, and a compendium! I wonder what I can do with a compendium the notes look like glowing scrolls! So elated I go over to the bookshelf thinking: “I know! This is where I can merge my creative and generative side of self through writing stories about my being and becoming-in-the world with MS.” I begin to imagine self as *Carrie* an emergent autoethnographer drawing on her stories from this compendium. I then reflect thinking about the many possibilities of re-directing my enquiry to imagining possible worlds for creating a caring and just society. In hand I have my notebooks, pencils, and now a compendium! What an intriguing room.

This room was indeed very different to the others that I had been in. There were so many more nooks and crannies I wondered where each of these would take me. So many more questions! I look to Alice. She says: “Keep going there is so much more for you to find in this room soon you will come across a curtain covering a door”. I carry on. I see a glimmer of light coming from underneath the bottom of a curtain. I am very curious as to what is behind it? Could there be another door as Alice had said? A sudden flurry of thoughts and images literally stop me in my tracks!

These images take me back to my experiences of sitting behind a curtain in the emergency room cubicle at the hospital. They reminded me of my position [pre diagnosis of MS] of where I worked in health care as a nurse and now [post diagnosis of MS]. It evoked many baffling experiences about treatment, care, and the varied opinions of the medical staff that I had been examined by. I am

thinking deeply about my positioning in this enquiry as person who has MS. I give myself a shake and remember the ‘first look’ Alice instruction. I look over and see Alice pointing to the door. I make my way over to this curtain and pull it back. I see written on the door: “*The Demonstration Room*” There seemed to be no use in waiting anymore. I opened the door and went in!

In here I found tables, cubicles, curtains, shelves, and more books all of different sizes. My first impressions were it reminded me of a nursing practicum room. As a student nurse there we would demonstrate some elementary clinical skills of nursing on how to wash hands and make beds. The variety of books on the shelves caught my attention one in particular Madden (2010) *Being Ethnographic*. I am drawn to the words: ‘Being there’. I open it to read. I reach into my satchel taking out my pencils and notebook. I take notes on practical ‘how to’ tips for applying theoretical methods on ‘doing ethnography’, reflexivity, and representational issues of ‘being there’. To me this room resembled another small library. I truly felt like I had found my way to the cathedral of my soul! A place where I creatively focus on ‘being there’. I have my notes taken in previous rooms on the writings of ethnography, autoethnography and my compendium! I can embody Madden’s (2010) tip: doing plus thinking equals ‘being’ in the writing of my story. I am on my way to demonstrating how *I Carrie*, who lives creatively with MS is engaging with ‘showing’ my own personal experience - being autoethnographic.

### **On being autoethnographic: from interpretation to story**

I began this research journey with something that has called to me from within my life experience. That something is a confirmed diagnosis of MS and my new way of being in-the-world. It is a persistent mysterious ‘feeling’ that is luring me to let go of the known and explore the unknown. In such an odyssey I knew little then of the terrain through which I would travel or the people I would meet. In the earliest phase of this research enquiry I thought of childhood heroine Alice in Lewis Carroll’s *Alice in Wonderland* and adopted his approach of symbolism e.g., the ‘Rabbit Hole’ to my experience. In thinking about my story the characters Alice, White Rabbit, and The Cheshire Cat provided the inspiration for ‘showing’

how experiences of my confirmed diagnosis can be portrayed in a creative way. In the writing of my story an important aspect of this odyssey into 'being' autoethnographic is my understanding of how the 'personal story' plays out in the research process. I had, and still have, this unwavering attention, belief, and interest that exists in my consciousness that there is an intentional readiness and determination to discover meaning and the essence of lived experience. I remember Alice saying the compendium will be handy. It certainly is!

In the compendium I find Moustakas (1990) *Heuristic Inquiry*; Ellis (2004) *The Ethnographic I*, (2009) *Revision: Autoethnographic Reflections on Life and Work*, and Marshall (1999) *Living Life as Inquiry*. I had already read these and had made notes in the previous rooms. Now their individual and collective writings significantly together in a compendium endorse my choice to select autoethnography to examine this. My next step is I adopt Moustakas approach of heuristic inquiry. A process begins with a question or problem in which the researcher seeks to explore and or answer. As researcher my question is: "What are the relationships between self, body and work? I remember Ellis's (2009) strategy of introspection. In here placing self at the centre of my enquiry I am incorporating being introspective and reflexive. Autoethnography provides a way of showing my devotion and commitment to pursue a question that is strongly connected to my new way of being, self-hood, and identity of *I Carrie*, who lives creatively with MS in the world.

In balancing all of this change in my new way of 'being' it requires me to be open, receptive, and attuned to all facets of this phenomena. Foremost is my desire to create. My enquiry is my response to a call of performance autoethnography that is a personally challenging and intentional. For the process of portraying my story: i) Alice is wise muse and guide; ii) White Rabbit animated version of MS that I would follow; and iii) the Cheshire Cat that entices me. He mysteriously appears and then fades away until he disappears entirely. I wonder what this means? I opened the compendium to review my notes as this narrating cat that Alice is seeking directions from is still really puzzling to me. I re-read Davis (2010, p. 160) who offers this suggestion that the Cheshire Cat represents notions of perception for example when Alice sees Cheshire Cat in a tree she asks for advice and direction: "Would you tell me, please, which way I ought to go from here?" Davis (2010) further adds the curious way that the Cheshire cat fades

in and out of existence typifies the transitory nature of truth as Nietzsche sees it. As perspectives fade, the Cheshire Cat fades, illustrating the transitory nature of truth. I found this re-reading this explanation from Davis about perspectivism and perception most useful and fascinating. I thought about my experiences with MS and reflected on what I had read. My perspectives on illness were changing. My ways of thinking about the world views now challenged. My experiences of trying to access care for flare up of my MS symptoms were subject to many different interpretations by myself and others.

I keep fossicking about in my compendium. Where I find an article by Hayes (2012) *Imagination as Method: Poiesis in Ethnographic Research*, what a felicitous catch! I had been seeking an approach that would merge the imaginative, creative qualities I bring to my enquiry. I read on. Hayes (2012) says rather than describing the world as it is, ethnographers are making it anew as they conduct their work. Imagination is a form of poiesis, or making, in which culture is generated through the imaginative and generative activities of the ethnographer. He argues imagination as a method offers new potential for the field of ethnography. Reading this article is thought provoking. My own excitement and curiosity inspires my ongoing search in this heuristic journey.

I revisit the Alice story where by in rejecting making daisy chains and following white rabbits, Alice sees through the imaginary another place where she can expect the extraordinary and speak her mind. Thinking about my situation, Alice is this self-confident figure that I wish to look up to. And I do! In making my way along the many passages in the rabbit hole I have seen the extraordinary signs and flags that Alice has alluded to. I have learned to 'notice' my 'being-in-the-moment'. I now trust her as she guides me in this demonstration room. Here I gather my personal notes and begin to place them in a sequence that 'shows' the story illuminating the relationships between various themes of importance thus beginning the process of moving from reflectivity to interpretation and analysis.

In the previous rooms I had read widely on reflexivity, subjectivity, objectivity, methods, and applications in sociology. I found concepts: poiesis and imagination. I now think about my particular research interests where use of poiesis and imagination will offer new potential for doing autoethnography. I will be crafting 'a learning and a realising self'. Madden (2010, p. 20 ) writes that the idea of the ethnographer being central to research process can raise questions

about the 'scientific', or objectivity, claims that ethnographer's might like to make of their research. It also raises an issue of subjectivity as a component of ethnographic research and writing. I began my doctoral enquiry with the confirmed diagnosis of MS being central to the research question and enquiry. Use of metaphor 'reflexive thread' to describe reflection 'on' and reflexivity 'with' experience were paramount for showing human action as praxis. By drawing on my journal notes I am reflecting on my personal experience, some of the notes taken describe some of the familiar social places in which that I had already formed all sorts of subjective attachments. I was unbeknown to me at that time trying to make logical sense of my confirmed diagnosis of MS. My journal notes now being the means for creating a strong reflexive thread being woven 'showing' where *I Carrie*, as 'a reflexive self' am stepping back and looking in, questioning, and reflecting on my experiences of MS.

I was aware of my researcher positioning as both 'insider' and 'outsider' and 'subject' and 'object' in this enquiry from my reading of notes in previous rooms. I revisit this question I've been pondering over: "Will the positioning of self in this enquiry provide options and choices to freely explore this nagging need I have to make visible the invisible aspects of living with invisible MS symptoms". It is a dilemma that I find myself in. I have the many notes and these assure me doing autoethnography is the optimal methodology that will enable me to re-call and re-vision my experiences. I remember Vickers (2000, 2001, 2002a, 2002b, 2010) inspirational writings on invisibility, MS, researchers as storytellers writing on the edge and without a safety net.

I want to explore further the aspects of invisibility that I have with my MS symptoms and how through my enquiry I can build on Vickers research. I find in the compendium work by Rollo May (1967) *Psychology and the Human Dilemma*. In part 1 [self/self-encounter and self/self-encounter] May, a highly distinguished psychologist describes the human dilemma as having to see oneself as object and subject. As object, one is manipulated and used, as subject one has freedom and choice. I'm interested to read more about this. I read on. He argues that one of biggest issues for an individual is that of reconciling what is labelled as the human dilemma, a dilemma May says is our capacity for development of self-awareness. In Silvia and O'Brien's (2004) research *Self-Awareness and Constructive Functioning: Re-visiting the Human Dilemma* I read where they say

that self-awareness is the capacity to focus attention on itself, and thus to self-evaluate is where this activity has gained a bad reputation in clinical psychology because of its links to depression, suicide and social dysfunction. They further add that May's (1976) analysis of human dilemma has provided useful contributions to psychological functioning as without self-awareness, the individual could not reflect on perspectives of others, self-control or produce creative accomplishments. I now had a much better appreciation of the use of word 'human dilemma' and its beneficial contribution to meaning. I've often heard it used in a throw away comment like 'what a dilemma I've found myself in'. Sometimes the emphasis being on it to describe a negative situation, I know that I have I have personally used the word dilemma to describe a perplexing situation that I have found myself in. I now know differently how to use this term! I am interested in learning more about my self-awareness and positioning of self in my enquiry.

I carry on reading the articles in the compendium. Madden (2010, p. 19) says that a key characteristic of ethnography is that it attempts to find a relationship between an 'emic' [insider] and 'etic' [outsider] understandings of human behaviour. I make further notes on positioning and the relationship between emic and etic perspectives in order to explain particular human phenomenon. In the style and flow of my enquiry use of reflexivity as process enables 'self' to make sense of both emic and the etic positioning. I had jotted numerous excerpts in my journal. These faithfully became my recorded 'field-notes' or what I refer to as 'living detail' [drawn from the body] to describe embodied experiences. Madden (2010) writes ethnographers have enthusiastically engaged with embodiment as an organic recording device. The ethnographer's body, and the sensations it records are part of the ethnographic script. A personal challenge began my heuristic journey.

In demonstrating how I am observing, what I 'see' and 'notice' I am using the senses; my eyes, ears, and my hands to record the perceptions from the field. During the organising of notes, reflection, and writing up, touch, smell, sight, and sound came together to form my whole-of-body framework to record emotions, memories, that are jotted in my journal. Coffey (1999) says fieldwork is an embodied activity. Madden (2010, p. 19) writes a good ethnographer uses their whole body to record these senses [as data] of which they then stand back from



bodily experience to reflect, analyse, interpret, draw conclusions, and or make suggestions from these experiences. I now wanted to explore further reflexivity and my positioning in the enquiry. I then spot another book. It is by Marcus (1998) *Ethnography through Thick and Thin*, who identifies four forms of reflexivity operating in the social sciences: i) basic or null form; ii) sociological reflexivity; ii) anthropological reflexivity; and iv) feminist reflexivity. I found Marcus's (1998, p. 194) explanation of Bourdieu's (1977) sociological reflexivity interesting. He says with such a commitment, ethnography retains its identity as a method and reflexivity becomes valuable only in methodological terms as a research tool. Marcus then adds that he is also critical of this approach to reflexivity, and suggests it has a very restricted function and little potential to alter form of sociological practice. Madden (2010) does not agree with Marcus's view. He suggests that his preference is to a reflexivity that enhances the methodological strength of a project (in the stance of Bourdieu's) and one that explores the influence of 'subjectivity' and 'positionality' of the author on creation of their text. I found Maddens views helpful as I am attracted to a reflexivity that enhances the methodological strength of my enquiry.

In this demonstration room I am *thinking* about being autoethnographic, I am seeking to combine poiesis and the imaginary with reflections on theory and subjective experiences. In *doing* [as demonstrating] I draw on embodied experience to provide the rich evocative text that *show* narratively my being and becoming-in-the-world with MS. Madden (2010) says articulating 'doing' and 'thinking' into a logical whole is an approach that he calls 'being ethnographic'. In the previous rooms had I re-read notes from Ellis (1991, 2004, 2009) on introspection and emotional sociology and how it portrays the independent relationship between doing and thinking which plays an important part of the state of 'being autoethnographic'. With this in mind I am accompanying you the reader, through this text, as a narrator.

I have found an internal frame of reference for my enquiry and a place to explore how to 'do' and 'think'. I have my notes and the descriptions of them. My claim is that my creative project will add value to the [e]merging story and theory generated through my creative and imaginative self, which is re-directing research practice to imagining all possibilities from the impossible! Through reflexivity I engage with interpretation of the particular event. I am seeking to

convey lived reality of my being and becoming in-the-world with MS. I am now on my way to doing autoethnography!

### **Doing autoethnography: a storied reality and three vignettes**

I look again in the compendium that Alice said I should keep close to me. I find more notes. Some I have seen previously in the Room of Methodology. Others are new to me. I sit down and begin to re-read. Ellis et al. (2011, p. 3) claim as a method, autoethnography incorporates aspects of autobiography and ethnography. In writing an autobiography the author will usually draw on past experiences and does not live through these experiences solely to make them part of a document. Denzin (1989), Bruner (1986, 2004), and Freeman (2004) suggest that the author's experiences are primarily gathered using hindsight. Denzin (1989), Bochner and Ellis (1992, 2002) claim autobiographers may write about epiphanies or moments that they remember or that they perceive have had a significant influence in a person's life. Bochner (1994) adds while epiphanies are self-claimed phenomena in which a person may call it a transformative moment, others may not. These epiphanies reveal the way a person possibly deals with intense personal crises and the effects such as memories, images or feelings may still dwell within and linger on well after that initial event. I keep reading.

I reflect on Ellis et al. (2011) point when thinking about doing ethnography the writer will study common beliefs, values and shared experiences for the purposes of being an insider and outsider to better understand the socio-cultural reality. As a researcher engages in doing autoethnography the writer will retrospectively and selectively draw on significant experiences or a moment in their life that has originated and made possible by their being in that part of a culture and/or by having a particular cultural identity (Ellis et al., 2011, p. 3). When doing autoethnography researchers write about one specific form of critical inquiry where analysis of experience is incorporated into the methodology to look at the experience analytically and consider the ways that others may experience similar life changing moments or epiphanies (Ronai, 1992, Denzin, 2006). I do not use the term epiphany in my thesis not because I do not like the term. My preference is to use the term vignette for writing a short passage that conveys a

description about my particular MS experiences, the confirmed diagnosis, and my attempts for seeking care for flare up of the MS symptom - optic neuritis. I believe the use of vignette in this demonstration room has the added benefit of signalling aspects of personal experience I write about and analyse, and they have generative /transformative ways of connecting this experience to the disciplines of a learning organisation.

I turn my thoughts to the connections I have made between the internal frame of reference [the Alice story], the subjective stance I continually experience living with MS, vignettes and the influences they have on the development of my topic and storyline doing autoethnography. In preparing to think about doing forms of autoethnography vignettes serve to illustrate aspects of the experience that may also be familiar to others. I think about the journal notes in my satchel. These journals notes are my faithful 'field notes' the means to capture my 'living in the moment' that I document as narrative describing some of my past and present experiences of MS. I see I have underlined I have an inquiring mind and have long appreciated Lewis's Carroll's (2006) *Alice in Wonderland*. I remember reading Davis's (2010) *Alice in Wonderland and Philosophy* whose work probes the deeper underlying meaning in Alice to reveal a world rich with philosophical life's lessons drawing on some of the greatest philosophical minds, Aristotle, Hume, Hobbs, and Nietzsche. I am feeling well endowed with such notes from these great thinkers and my notes taken. In thinking about how I am going to make meaning and interpretation of my story. I remember notes taken from Hayes (2012) about poiesis, imagination and creative abilities in ethnographic research. I wondered how I could use poiesis and imagination to 'show' that style and creativity in autoethnography are very much a part of interpretation or analysis. I am ready to explore!

In my compendium I see notes about interpretation, storied reality, textual and representational aspects in writing ethnography. I am keen to demonstrate through narrative writing an interesting, accessible, and believable account of my lived experience of confirmed diagnosis of MS and associated experiences of managing a flare up of MS symptoms. In this room I want to 'show' how with my authorial voice from the field I can balance rich evocative descriptions of my experiences with the responsibility of ensuring that the written story is a plausible representation of these experiences. I read on. Madden (2010, p. 166) writes

ethnographic writings should aspire to meet the challenge of conveying an interesting, accessible and believable account of a society or an event. To do so an ethnographer has to find balance between the facts and validity and a literary voice that conveys rich, evocative and persuasive description. This is the balanced approach he calls the 'storied reality'.

In considering Madden's (2010) approach of a storied reality [with my experience] I could purposively demonstrate this in my enquiry. I have good access to gathering 'living-detail' and writing evocatively living my life as inquiry. I re-visit Marshall (1999). I read where she has an image of living continually in process, adjusting, seeing what emerges, and bringing things into question. She says this involves attempting to be open to continual questioning about what one knows, feels, does and wants, and finding ways to engage actively in this questioning and process. It is therefore an example of *living life as inquiry* (its topic).

Writing about the diagnosis of MS and my experiences of several flare ups of MS symptoms have become mini-cycles of inquiry in themselves. These rich, descriptive accounts exude a sense of confidence in the process of my demonstrating '*showing*' a storied reality. I will demonstrate my storied reality. When I experience an acute flare up of my MS symptoms this event poses a unique new experience. My MS symptoms are *invisible* to others they cannot not see nor feel the pain I experience. Writing about it acting on my 'being in the moment' along with re-visiting the experience is where I begin a mini-cycle of inquiry to allow for further observation of experience to see or feel something that wasn't visible before. Giving it 'autoethnographic' layering brings new insights for process of meaning making. I continue to rummage about in this compendium. There is so much to do!

I find more notes about Madden's (2010) *Being Ethnographic* and his advice about structure and style of ethnographic accounts. He says there are four elements: i) explaining research question or reason for 'being there'; ii) furnishing the ethnographic description - using authority of 'being there'; iii) engaging with interpretation and analysis; and lastly iv) substantiating reason for 'being there'. I am pleased I found these tips by Madden they will serve me well in my quest of 'being' autoethnographic and 'doing' autoethnography.

I think about my reason for being there. In describing and demonstrating my authority of being there I return to re-visiting my experience of MS. I do so intentionally as I remembered Ellis (2009) saying with personal storytelling it is crucial to re-visit and re-vision experience. I have relapsing-remitting MS. My symptoms are *invisible* to others. When I experience an acute flare up of MS it manifests itself in the sensory symptoms of pain, tingling, numbness and eye pain that are not visible to others. The attack is followed by some recovery which can be partial or sometimes total. It is followed by a period in which I experience no further acute attacks. I am left with some residual discomfort and ongoing pain. Engaging with its interpretation is highlighted by my experiences of others who cannot not see or feel my pain and the expectation from them [at times] is that I should be visibly sicker when presenting for care. Substantiating my reason for 'being there' is that at my time of need I not only have to deal with pain, but the potentially stigmatising view of others. Revisiting these experiences allows for continuation of writing and adding to interpretation to find meaning as 'doing' autoethnography.

I put the compendium aside for a moment. I am ever so pleased I took Alice's advice of keeping hold of it. It certainly has been such a helpful resource a mini-mobile library! I now look in my satchel and again find a journal labelled: '*Vignettes*'. I quickly flick open the pages and see descriptions of the experiences I encountered when seeking help for an explanation of the severe pain in my left eye. I present three of these vignettes that are sourced from my journal that capture the rich, evocative and highly personal accounts of my experience of a particular flare up of my MS symptom, optic neuritis – as a single event.

**Vignette One - *Going to work, doing the job I love, and speaking with others***

The first vignette is an example of stories that demonstrate the conceptual ideas of illness, self, being, embodiment and senses. In this story I portray self as subject and focus of the research. I show through descriptive interpretive narrative style the sudden appearances of painful eye symptoms and how I do not understand its manifestations and am unable to make sense of what is going on at that given moment. It is a story conveying positioning of an emergent

autoethnographer who is in the re-positioning as a learning self and is drawing on embodied experience. I write:

*I felt fine first thing in the morning as I prepared to gather my bag and notes. I was on my way to facilitate one of a two day workshop at a community health centre. As I was driving I felt a tingling sensation in my fingers I thought nothing more and gave both my hands a gentle massage. When I arrived at the health-care centre I had this incredible fuzzy like sensation pass over my eye and head. I thought gosh what is all this about? I went on in to facilitate this workshop but was really struggling to keep the pain I was experiencing from showing. As I was writing up the structure of the day on the whiteboard, I thought: "Why not ask the group about the time frames. Did they want to skip the last interlude following lunch and finish up around at the 3.00pm just before the schedule afternoon tea break?" This was unanimously agreed upon. Pheew what a relief I thought! I went on facilitating the workshop and it finished well before the new allocated time. Everybody was happy. I packed up my notes and went over to my car. I got in and just collapsed in the seat, the pain in my eye was unrelenting. It felt like a sharp burning smarting sensation. I gently rubbed my eye and put on my sunglasses to help shield the glare and drove back to the office. I went to my office closed the door and put my head on the desk. My eye was so painful my head was throbbing. Close to tears now thinking what on earth is going on, I left work early that afternoon and drove home. Being the stubborn person I can be at times I thought if I got an early night and took some pain relief I'd be fine the next day. The next day I still had this dull throbbing headache and thought should be alright and drove to work. When I got there I was clutching my head as I walked to my office. The pain in my eye was ghastly. My boss saw me, had a brief talk with me then sent me home. I said: "What about the weekly board meeting and my second work shop education session"? He said: That can wait. Get yourself up to the hospital and phone me later." I went home and took some more pain relief. My husband then took me to the hospital and then my long wait began.*

*(Personal Journal, 1998).*

### **Vignette Two - The experience of synchronicity and breaking my silence**

This next vignette expands on the confirmation of the diagnosis of MS. The first defining MS symptom was one that originated in my eye. It is referred to as Optic neuritis. The term used to describe an inflammation of the optic nerve

located in the eye, it is a symptom characteristic of MS (Jelinek, 2005). This scene shows an extraordinary moment in time and the coincidence of a series of events. Jaworski (1998) writes that the word that comes closest to describe such events is that of the term *synchronicity*. Largely influenced by classical work of C.G. Jung's (1960, p. 520), classic 'Synchronicity': An Acausal connecting principle, defines synchronicity as a meaningful co-incidence of two or more events, where something other than the probability of chance is involved. Here the health professional's views and dilemmas towards making and delivering a confirmed diagnosis of MS are captured. I am present in the event receiving this explanation so is my husband. My body is now sensing trouble. Price (1996) says in illness the body loses its silence. I record:

*As I sit and wait to be seen there are lots of people coming in and out of the emergency department. Some I recognise and have worked with. I am then called by the triage nurse who asks me questions about my pain, and the sorts of discomfort I am experiencing in my eye. I am ushered to a side room where I wait to be seen. Now I am experiencing intense pain in my back, legs and my head, but it is my left eye that is so very painful. It is hard to see clearly. The fluorescent lighting in the department is causing me more issues. I cover my head and my eye with the pillow that is on the bed. I am sitting waiting to be seen by the Specialist. An Ophthalmology Registrar who had been working in Australia with MS patients now comes into my life. I was thoroughly examined by this doctor who stated that he had worked in a similar department in Australia. He did not reveal that he possibly knew exactly what my symptoms related to. I could however, sense that due to his disposition and manner that this man was most skilled in this particular speciality. I have more tests and move to another side room where the Ophthalmology Registrar sits down to talk to both myself and my husband. He says: "From the tests we have done and symptoms you have been describing it is always difficult to balance up whether or not to tell you what I suspect is causing the trouble". I say: "Please just tell it how it is". And he does. He says "The symptoms are highly indicative of Multiple Sclerosis (MS)". My grandmother's wisdom and comfort seeped into my consciousness. I remember her explanation about the third 'eye'. The eye that is intended to be worn by person inside piece of clothing – it is discrete and its significance is that it keeps the evil or bad influences away from you. The blue brooch in shape of the 'eye' she had given to me as a young girl.*

*(Personal Journal, 1998).*

**Vignette Three - Seeing is believing, a speaking eye, the eye is the I;  
and the I is the eye**

This last vignette shows my responses to being given the diagnosis of MS and how immediately I thought of my grandmothers traditions of the 'third eye', the placing inside a garment a piece of jewellery in shape of 'eye'. To her it symbolised 'the third eye' which warns of visual danger, of being given 'the evil eye' from others to self. I still have this small broach of the 'third eye' that she gave to me. According to Synnott (1993) in language, proverbs, and literature to the ancient Greek and Christian traditions the supremacy of sight has been referred to as the 'noblest sense'. My noblest sense was in trouble and to expand on my description of it I draw on the semiotics of the eye as symbol of self, the *I*. The eye is the *I*; and the *I* is the eye. I record:

*I have just been given the results of the many tests as the diagnosis of MS. The Ophthalmology Registrar asked if I had any questions. I replied: "Not now but possibly tomorrow. Could you please telephone me then". My husband and I make our way home. It is a very quiet drive home. Neither of us is chatting to each other. At home I sit out on the veranda and think: "Now what?" I take some more pain relief and go to bed. I can't sleep very well with all these thoughts going on inside my head. My husband is very concerned. Next day I sit down to write about all that has happened and go to look for the 'third eye'. Not wanting to be thought of or sounding superstitious it was uncanny how my thoughts about the 'third eye' resurfaced from my subconscious to conscious being. I want to make as many notes so as to be well prepared for when the Ophthalmology Registrar does telephone me. He does. I am now booked in to see a Neurologist who has arranged a hospital admission for me. I am to be admitted to commence of high doses of Intra-venous steroids. These are drugs used to treat inflammation and are routine for treatment of acute episodes of MS. My husband accompanies me to the Neurologist appointment. His opening remarks are: "You have 36 lesions. In six month's time you will be in a wheelchair. I would advise that you start on Interferon therapy as soon as possible". How does one even begin to imagine responding to this? Something stirred deep in my soul. I reply: "And how do you know this? Are you God?" Needless to say the remainder of the consultation was rather tense. A friend telephoned me to say that there was going to be a seminar on Interferon therapies and MS. I did attend this. There was much to learn. I went to see another Neurologist this time not in same town that I lived in. I*



*was told I did not meet the current eligibility criteria for medical assistance for commencing Interferon therapy I have lots of ponder over, my future and my family.*

*(Personal Journal, 1998).*

This vignette captures my responses to the experience. Re-reading this all this time later still evokes those same intense feelings that I experienced then. In the vignette I am describing the incredible obstacles I needed to think about in my personal and professional life. As I write about this experience much curiosity still surrounds this meaningful coincidence of more than one event. By committing my experience to this enquiry with reflexivity and analysis I now come to see that this was no coincidence at all. My thoughts are immediately re-directed back to Alice. It spurs my own levels of curiosity to question: “How did I come to be stung by this Portuguese Man-of-War, or be seen by this Ophthalmology Registrar on this particular day? I call this synchronicity working at its best for my situation at that time in my life. I believe initially my being there on that day and time and being seen by this doctor were remarkable moments in time. I’m not sure about the Portuguese Man-of-War though! I do have much gratitude of those fishermen, the doctors, at Pankor and of course my parents.

In revisiting those first memorable events such as Pankor Island, immigrating to New Zealand, completing primary, secondary education, and nursing training these were all experiences I was so deeply immersed in and ones that have helped shape who I am today. For some reason I had never given them individually or collectively any critical thought until I experienced this profound change in my way of being. It is in this time (re)living this story from 1998 through to commencement of this formal thesis that I began to realise how much I did not know. It also foreshadows the direction that my thinking and writing was to take in the years to come. Knowing that I had MS was so different to knowing how to live my life in a different way. My burning curiosity to know and learn is this impetus. I wanted to learn how to ‘listen’ to and ‘notice’ things about my body! In writing about this I now found myself transitioning to a different place where I can (re)vision and (re) learn. I see Alice waiting patiently with another bundle of books. I am curious. She says: “You have a two more rooms to explore”. Again she is waving me on. I am ready to explore this next room. Off I go!

## **CHAPTER FIVE**

### The Room of a Learning Self



## CHAPTER FIVE

### The Room of a Learning Self

*Yesterday I was fine. Then something happened to my head, face, eyes, arms fingers, legs and toes. Today it is spectacular news. As for tomorrow - I simply don't know. Oh my! What a curious feeling this something is!*

*(Personal Journal, 1998).*

I have arrived at another door. On the front is a bright shiny label: “*Self Learning*” I go in and see more books and shelves. A room of learning! I am in awe. It looks most interesting. I wonder what exactly does go on here. I knew from my time in the other rooms that autoethnography was a well-respected research method I could trust. I wanted to see how, through autoethnographical research I could demonstrate *both* the dynamics of my experiences as a person newly diagnosed with MS, as well as test the emancipatory aspirations associated with this way of researching. In those other rooms I had made some preliminary attempts at using my journals to apply the theory I had been reading. Certainly I could see there how digging deeply into my past experiences, my old memories and my current reveries added layers of insight into this world with MS.

I now find myself in a room labelled: *Self Learning*. As I look into the room I see myself looking back at me from a large mirror. A mysterious image of the path I have just come from reflects from behind my image in the mirror. I see some signposts inviting me to review that journey but pointing to a destination called ‘self-learning’. There are four signposts: i) the positioning of a learning self; ii) living and researching life as inquiry; iii) making sense of experience; showing rather than telling; and iv) coming to know and live *with (in)* the altered body. I feel a little thrill as I see a way to think forward that honours the past as a discrete moment with its own presence and at the same time allows me to explore further my life as inquiry. I now plan to ignite my reflections on my experience and make them alive again. My eye follows the direction of the first signpost to a comfortable looking chair and coffee table. The folder on the table carries the same words as the signpost in the mirror: Positioning a learning self. I read on.

## Positioning a learning self

The folder I open has a beautifully scripted version on the title I have been giving this PhD study. There are sketches of the insightful fictive characters I have met in the House of Learning. I see a reference list of the many authors with whom I have already studied philosophical questions regarding existence and being, the meaning of self and self-hood, and what passes for truth. I pause to review these aspects for my work thus far.

The title of this thesis is: *'The Being in some body: An autoethnographic account of Being and Becoming-in-the-world with Multiple Sclerosis (MS)'* represents an exploration that I have been engaged in since I received a confirmed diagnosis of MS in 1998. I have the type of MS called relapsing-remitting MS. I want, in this thesis, to give full attention to researching *lived experience* of the characteristic symptoms of the illness MS: neuropathic pain, tingling, numbness and fatigue and the emotions generated through these manifestations that for me present as *invisible* symptoms. Others cannot feel or see them. Through my initial phase of this research in the Rooms of Methodology, Being and Becoming and of Demonstrating I set out to explore this aspect of invisible symptoms of MS and the associated stress of work issues that I was encountering. I was looking for a way to position myself to learn and make sense of experience. In the Room of Being and Becoming I found Vickers' (2001, 2005, 2010) work written largely about topics including, illness, work, and organisational issues of the lives of people who are working people with unseen chronic illness and MS. Vickers (2010) research focus *Illness onset as a status passage for people with MS* resonated with some of my earliest experiences of MS. I was enthralled to read this I found aspects of it aligned with my own first experiences of transitioning from being a person-without-MS to becoming a person-with-MS now afflicted by these troublesome *invisible* MS symptoms.

By writing about my experiences of illness, work, and organisational issues I illuminate how the *invisible* aspects of the illness significantly influence my life. I express in my emergent writing some very intimate aspects of my life representing an authentic desire of wanting to make the *invisible-visible*. The somewhat bewildering and unpredictable symptoms of MS have provided this opportunity to address as mini cycle of inquiry my levels of curiosity of

embodiment and lived experience. This led to re-visiting and re-reading my journal notes where I describe the feelings evoked by the experience of job insecurity and increased vulnerability in my working life. These judgements from others were made at the time that I was also attending to my heightened feelings about the disruptions, uncertainty, and the impact of these effects of illness and MS on the quality of my life.

I now had the information at hand of my experiences captured in the many journal entries. I had scribbled down many notes about these invisible symptoms and the distress of them as they occurred. When I thought more about committing this inquiry to my PhD I began bubbling with excitement. I had a story in my mind. My eye was painful at times, and my fingers also at times would feel numb but I was ready to bring the story in my head 'to life'. My eyes were the visionary assistants to guide me and my fingers were ready to tap on the key board. In earnest my journey had begun! I wanted more than to be sitting around waiting to be called by the medical specialists to be seen. My intent was to now seek and find meaning in my radically changed circumstances. Where in process of developing a *learning self* I could expect the extraordinary, work out my own problems and speak my mind. I reach for my notes and begin reflecting on my embodied experiences. My thoughts are now centred on where I had seen the articles on reflection and reflexivity. I remembered it was in The Vestibule and in the Room of Methodology. There I had read Cunliffe's (2004, 2011) articles on reflection/reflexivity and why be reflexive. I had taken many notes there and I and now re-read them to reflect on these initial insights. I began to question were there any lessons to be learned from this experience, and on what I have learned and how I have changed.

I refer to my confirmed diagnosis [in this report] as the 'particular event'. Madden (2010) says ethnographic accounts are meant to be particularistic accounts; that's their strength. I return to the particular event. Since my diagnosis I have been exposed to many experiences, attending with feelings and emotions. In this time my responses to new experiences have been influenced by previous encounters. I learned through use of Ellis' (2004) emotional re-call how to cope with the uninvited and unexpected interruptions so characteristic of MS and the associated symptoms of MS. In my story I wanted to explore more deeply *experience* as learning. I open my note book and read: "What is experience, what

is reflection and does learning from experience incorporate a process of reflection?" Boud et al. (1985, p. 19) say reflection is an important human activity in which people recapture their experience, think about it, mull over and evaluate it. It is this working with experience that is important in learning. The capacity to reflect is developed to different stages in different people and it may be this ability that characterises those who learn effectively from experience.

In seeking a way to learn from this particular event I needed to make sense of it. Bolt and Powell (1995) suggest that we interpret our experience all the time, unconsciously in routine or in familiar situations but more consciously in unexpected or unfamiliar situations. I had encountered an unexpected and extremely unfamiliar embodied situation that now resides within me. I was attempting to interpret it. Bolt and Powell (1995) further add to interpret an experience implies that it has meaning, but ask also whether events or situations have any meaning in themselves since any event or situation is subject to a variety of interpretations. The meaning given to an experience can be dependent on the person experiencing it, and their view of it, which Bolt and Powell suggest is where meaning resides with the person. It is not intrinsic to the situation or event being experienced. I was encouraged to read this. I had my chosen method of autoethnography to align with learning, storytelling, interpretation and re-evaluation of the experience. I had a personal story to write about this uninvited illness I host. I was learning that it seems fair to suggest that although all learning stems from experience, however Boud et al. (1985) suggest not all experience results in learning. As I reflected on this point I had this growing assurance that in order to learn from experience I needed to first make sense of it and this is what I was motivated by to search for meaning. For this I returned to my notes from Ellis (2009) where I record that it is useful to re-construct thoughts and re-enact emotional feelings told through narrative story. In these notes I also draw on Marshall (1999) as a valuable path to continue the linking of my emergent relational thinking with interactional practice that directs and (re) directs my attention. I will read her work on this a little more closely.

## Living and researching my life as inquiry

Researching my lived experiences in the manner I have committed to is influenced by Marshall's (1999) *Living Life as Inquiry*. My next steps taken incorporate taking time to reflect on my notebooks in the satchel I am carrying. Alice is by my side. Utilising Marshall's approach I can now see how I have come to 'show' how impressions from my experience [of illness and MS], are linked to notions of inquiry as method with my personal and professional life. In this way these ideas are tested out throughout my own embodied life space and are an example of my desire to get on with making meaning of experience. I now am reminded of the way that Alice in Wonderland also wanted to explore danger and delight in unfamiliar experience. In following White Rabbit an opportunity to explore many paths has now taken me beyond the present. I am exploring and questioning who I am and what I am now a part of. Featured in this text are numerous narratives extracted from my journal illustrating the practice of living my life as inquiry as process. These experiences are later reflected on and analysis is sought to create meaning making as scholarly practice. I see Alice at my side. I have my satchel that I have been carrying with me and the compendium that Alice said I should hold onto. I begin to (re) read and reflect on the notes that I am carrying. I take this note out to read it. It is a comment the doctor made in 1998. It is a very brief almost cavalier remark that moved me deeply then. It is as clear to me now as it was all those years ago:

*You have 36 lesions, in 6 month's time you will be in a wheel chair.*

*I replied: "How do you know that. Are you God?"*

*(Personal Journal, 1998).*

I have revisited this caption from an earlier vignette. It represents a medical description of a health issue that in my opinion lacks any real compassion. I still remember where I was, what the time was and who was present. I was stunned by such a comment then, and still am. I think my direct reply to him says it all. How could one human being [in this case the doctor] make such a statement about another human being [in this case myself as wife, mother, nurse, researcher]? On reflection I could have just accepted this as status quo and not questioned the



doctor however I chose not to accept this explanation. I thought surely there has to be a more satisfactory explanation about the prognosis of this illness and why did this doctor choose to deliver his explanation in this way? This one was certainly a very depressing outlook on matters. I thought that if this explanation had been given to somebody who was not of my disposition to question and question outright. Then I am left wondering how sad this is.

Jelinek (2005) says if the view of the doctor portrayed conveys that it does not matter or that there is nothing more that can be done about it, then it is denying the patient a chance to take control of the illness. The doctor or caregiver who fails to listen does a great disservice to his or her patients. Rosenberg (1998, p. 14) says: "Once we recognise that uncertainty is everywhere we can conquer it". He goes on to say doctors represent a cohort of people selected for their ability to remember facts and be certain. They go through training that favours those who are good at producing instant answers to a wide variety of questions, almost at the expense of the truth. They are fed on fallacies: that all questions are answerable, that doctors know all the answers, that one person can know everything. This explanation from the doctor given to me in 1998, and writings by Jelinek and Rosenberg spurred me on to return to Alice story where I thought: i) did I want to take control of my illness; and ii) make a difference in the world? Of course I do!

I want to learn from lived experience how to be in self-control of my MS amid all the absurdities to be found in either life experiences in my medical encounters. Through use of first person narrative I am crafting ways to live my life as inquiry. Ellis (2009) says telling one's story gives meaning to both present and past human experience. It allows the teller to see the present as part of both. My ability to create meaning resides with me and is being tested throughout my life space by a process of learning to be reflexive. In addition to constructing a version of what happened in the past I explicate the emotional complexities of this experience. In re-visiting the particular experience [of my confirmed diagnosis] I draw on Ellis's (2004) strategy of *emotional re-call* which provides a learning opportunity to revisit the scene emotionally. By placing myself back into the event that I am immersed in, I am remembering the 'added details' of physical presence, time, and place. Ellis (2009, p. 108) adds recall increases when emotional content at time of retrieval resembles that of the experience to be retrieved. This process enhances re-collection of more detail as I am applying this

to living my life as inquiry. I still have my satchel which is getting much heavier. In it are my journals, notebooks and the compendium and more notes on reflection.

In Boud et al.'s (1985) *Reflection: Turning Experience into Learning*, I read about the three components of reflection: i) returning to experience; ii) attending to feelings; and iii) re-evaluating experience. They add that learning effectively from experience is a complex process. The outcomes of which depend, largely to extent, on the cognitive and affective responses of the individual concerned and the context to which he/she is learning. As there was a significant period of time between the events of my diagnosis now a decade ago and my re-telling of them. I found the three stages of reflection (re)turning to experience, attending to my feelings and (re)evaluating my own experience helpful for my learning. As the *learning self* I have the benefit of distance and a greater life experience and personal understanding of this. I carry on reading my notes. I find Kelly's (1955) *Personal Construct Theory*. At the time I was not too sure why I scribbled this down. I just did!

Re-reading Kelly's work helped to explain ways of dealing with present and past experiences, especially in the ways as I chose to think about what my future course of action may entail. Kelly's (1995) theory is based on the assumption that human beings are motivated through life to search for meaning. I was immersed in this experience and motivated to learn. Kelly asserts that we all construct a representational model of the world in our minds that we use to explain our present experiences, this in turn, helps us to chart a course of action in relation to our experience that we revise and replace when what we expect to happen fails to do so. In this way the meaning of experiences can only be assessed when viewed from the unique perspective of the individual. Reading these authors' views reassured me that I was following a process of reflection, learning from experience, and observing how a flare up of my MS symptoms affect me. One such experience that affected me was the medical encounter in trying to seek care for flare up of MS symptom, optic neuritis. On that occasion I felt I was just a number, a code, a troubled body that needed to be fixed. There I was not to question, or be assertive. I look around on the shelves and see Foucault (1976) *The Birth of the Clinic*, keen to learn more I read on. Foucault (1976) writes about

surveillance, regulation and discipline of bodies. The clinic provided an environment for a new form of consultation.

As a learning self-living my life as inquiry, I wanted to reverse this way of being 'done to'. Kelly (1993) writes the constructs an individual form will be determined by, and pertinent to, his or her experience. In my situation each new episode of a flare up of MS symptoms presented different experiences to be learned from. I could not just adopt same learning to each new event. Boyd and Fales (1983, p.100) assert reflection on and from an experience can increase potential for learning. It is the core difference between whether a person repeats the same experience several times becoming highly proficient at one type of behaviour or learns from experience in such a way that he or she is cognitively or affectedly changed. It is in my re-visiting the experience and the emotion I recall, that I am continuously learning.

By living my life as inquiry I strive to embrace reflecting on each relapse of my MS symptoms as potential for learning. Of significant interest is learning about 'being present' in the moment and 'being ready' to express thoughts and feelings about my *invisible* MS symptoms. These invisible MS symptoms are ever present in some form or another. They never totally go away. Let me explain, for some parts of the day I can feel reasonably well then for no apparent reason I succumb to feelings of pain, numbness, and tingling. Because my symptoms can only be felt/experienced by me and because they are not visible to others, I believe each has the potential for misinterpretation, stereotyping, and mistreatment.

There are times when I am bothered by the most troublesome pain located around the optic nerve of my left eye. To deal with this pain I require care. Describing this predicament to health professionals from whom I must seek help has been at times such an ordeal and the related (seemingly unnecessary) stress a very real personal and professional concern of mine:

*One specialist claimed that most of my troublesome symptoms around my eyes were migraine related. He didn't take the time to look at the MRI report and said have you had an eye test done recently? The other Specialist who did look at the MRI report hurriedly counted up the lesions and ordered me to go to hospital. I was to commence intravenous steroid therapy immediately. There was no time to question. The directive from him was that staffs from the ward are expecting you.*

*(Personal Journal, 1998).*

In reflecting on this many of their actions seemed extremely inappropriate at the time and even more so in hindsight. The contexts of these actions were with doctors who knew I have MS. I have been asked by such doctors if the discomfort in the eye might be due to eye strain. Could it be a result of an infection in my eye like conjunctivitis? Or a migraine like headache? I even get offered a pair of reading glasses to read some text! When I repeatedly describe a deep throbbing sensation towards the back of the eye, and stinging sensation in it, I get some very interesting comments: "It's much of a muchness". What do they mean by this? Did it mean that both things I was describing are very much alike surely they did not represent the same thing? Whilst waiting for more tests to be done, I jot down [in my diary] my feelings and their responses. At the time I did not know what I would do with these notes. I do now. It was the use of the phrase much of a muchness that stayed with me. Curiouser and Curiouser!

I still remember this experience and re-calling now with benefit of distance the detail of the experience is still as poignant now as it was then. For example my dogged repeating exactly how I am feeling and so being the determined person I am, I repeat again: "It is not my vision that is bothering me, it is the pain in my left eye." The persistent suggestion that I may have problems with my vision and that I may need reading glasses is a misinterpretation of the situation. Left unchallenged, it could lead to possible mis-treatment of my symptoms and a delay in the appropriate forms of relief I so badly need. The application of unnecessary tests wastes valuable time exploring the inappropriate while I remain in agony. I experience this unwillingness by the doctors to trust my assessment of my pain as examples of possible stereotyping a patient as ignorant, passive, and possibly neurotic. I did not feel listened to.

Vickers (2010, p. 6) writes that MS is typically a disease where the prognosis is very uncertain. Past historical perceptions of neurological illness referred to a less than humanising portrayal of being disabled. It is also a disease that is highly stigmatised. At times I felt stigmatised by fellow health professionals and some work colleagues especially when reference was made to the stereotypical images of people diagnosed with MS ending up in wheelchairs.

For me it evoked an almost punitive response that for some reason my getting ill was my fault. I open my journal and find this description of events on that fateful day.

I was stunned by a fellow colleague's comment:

*As I was packing up my bag to make my way home a fellow colleague stopped me to say this was a 'real stunt' I had pulled to get out of attending Board Meeting.*

*(Personal Journal, 1998).*

I draw on this excerpt because to me it portrays what I refer to as a 'throw away' comment. At the time it really did hurt. I didn't respond. I was trying to get to the hospital. Later on when hearing about the diagnosis that colleague apparently felt most awkward. Goffman (1974) adds that stigma is a deeply discrediting term. Looking back on these initial events possibly my being a nurse was both helpful and unhelpful. Maybe these colleagues were just as baffled as I was. From my perspective I did not want to be treated as some object on show as these symptoms can last hours, days, or months. They can be difficult for medical doctors to decipher and to treat effectively.

I just wanted to feel listened to and be part of the decision making process about my future. I sensed that my work colleagues and the doctors I had seen were not listening to my descriptions of these *invisible* MS symptoms. I felt I had missed out on being given a detailed explanation of the issue at hand. Instead much of the information was skimmed over. A comment was made that I would probably know about these things being a nurse. How could I? I was neither a specialist neurologist nor a medical doctor. Instead they seemed to focus on my being a nurse first, and then secondly as a person who at that time was most unwell. I re-visit the description of this MS event captured in my journal. I re-read it again now applying Ellis's (2004) strategy of emotional re-call. With the benefit of distance and wider personal experience I can, and still do, to this day vividly remember the very first symptoms of pain in my left eye. As *learning self* this distance provides a space to reflect on the responses to my descriptions of the presenting symptom and responses from colleagues and health professionals.

In (re)turning to the experience I remove obstructive feelings about experience and utilise positive feelings to *show* not *tell* what I am learning from experience. I am keeping a track of the questions asked by myself and health professionals about this relapse and episode of optic neuritis. It is through process

of reflection and reflexivity that I re-read my journal entries about them, reviewing my own understanding of the relationship between me, the research inquiry, and my *being-in-the-world* with MS. In questioning the current status quo and exploring alternative ways to describe my *invisible* MS symptoms to different health professionals seated in the examination room I am reminded of Alice.

I then wonder what Alice would do. I return to the Alice story where Davis (2010) suggests that Alice's independent spirit takes her to the all-male world of the Mad Hatter's tea party. There seated were March Hare, Hatter, and Dormouse. The table was large enough, yet all three were crowded together at one end of it. "No room! No room!" They cried out when they saw Alice coming. There's plenty of room said Alice indignantly (Carroll, 2006, p. 67). I draw on this excerpt from Carroll's (2006) *Wonderland* as The Mad Hatter's tea party presents an assertive Alice in a male world who gets stuck at a very messy table. While she's free to join them, she's not obliged to be part of their world. Mine was a very different world. Reflecting on this fictional writing in regards to my experience of facing the numerous differences of opinions of clinical uncertainty.

I could not help but feel like I'd got stuck at such a table with these doctors. In trying to communicate my experiences of optic neuritis and feelings of uncertainty to doctors it still leaves me feeling like I'm constantly living in the position of an ambiguous limbo. This was the stupidest tea party I'd ever been to! It was the just impetus that spurred me on in wanting to find another way to learn.

In adjusting to living with MS and learning as much as I could I turned to my immediate family for support. I also drew on my nursing knowledge. Its training prepared me for looking at the relationships of cause and effect of disease. As a nurse I'm relieved that the doctors who are not necessarily specialists in neurology were being so thorough and treating each new admission as a new entity all of its own. Now as a patient I am appreciative of their objectivity with their approach however am curious of their levels of insensitivity with dealing with clinical uncertainty. Rosenberg (1998) says the prevalence and impact of clinical uncertainty is probably underestimated. Willingly, adaptive strategies for dealing with uncertainty have been developed intuitively by generations of doctors. The shift from teaching by ritual humiliation to the development of self-directed learning represents one of the most exciting developments in undergraduate and postgraduate medical education. I wondered if the medical

professionals that were charged with my care at this time had read about this self-directed way of learning about clinical uncertainty. I was thrilled to have found Rosenberg's article. Seeking timely care for my plight was paramount. It endorsed for me that my feelings of clinical uncertainty were very real. I was not making any of this up!

As time has passed the unpredictability of my symptoms still perplexes me as does the way my descriptions of them are responded to. And if I, as a highly trained nurse, am finding it difficult at times to understand the patterns of this extraordinary illness, how much more so for those who have this illness but do not have my training and my tenacity in demanding appropriate treatment. The baffling aspects of these experiences of 'something' unknown in my life before MS, 'something' that needed investigation, 'something' quite extraordinary. For my exploration of the extraordinary I draw on the Alice story. The symptoms of MS are baffling, as baffling as a muttering rabbit might be to Alice. Like Alice, the situation became more baffling, not less so, as I tried make sense of MS.

### **Making sense of embodied experience: re-visiting, re-vising, and re-vealing**

When Alice first sees a talking White Rabbit with a watch and waistcoat run past her, she does not think it remarkable at all. That in itself is curious, and surely not a conceptual oversight by the author. When Alice thinks about this event later, she wonders why something so extraordinary did not seem that out of the ordinary to her at the time. Davis (2010) suggests that perhaps at the moment the rabbit appears, Alice overlooks how odd the White Rabbit's appearance is. Alice, suggests Davis (2010), desires an adventure to make her life more exciting. She is motivated by her desire to escape from the tediousness of sitting on the bank, reading, or contemplating whether or not to waste her time making daisy chains. Significantly then, when the white rabbit appears, Alice does not stop to question its very weirdness. She follows it. From that point on, her experiences become ever more mystifying, curious, and tumultuous and her questions begin in earnest.

Davis (2010, p. 154) writes that according to Nietzsche we are all a bit like Alice in our quest for knowledge. Alice's willingness to accept the appearance of White Rabbit initially without question is an example of what Nietzsche (1996, p.

35) refers to as 'the will to ignorance'. In Alice's desire for an adventure it impels her to make a choice and to simplify what counts as real. This according, to Nietzsche, is how the will to ignorance is embedded in the will to truth. I began to think deeply about Nietzsche's writings and my thoughts ignited even more curiosity, so much so that I began yet another mini cycle of inquiry within my broader inquiry. Knowledge requires leaving something out so we must recognise the importance of illusion in order to attain knowledge. Did Nietzsche mean that in order to have knowledge of truth we must first embrace some illusion and falsity and become the creators of our own meaning? How mesmerising!

In applying these ideas to my situation where I am learning how to make sense of my experience, I was further drawn to another one of Nietzsche's comments recorded in Davis (2010, p. 154) i.e. that most philosophers cannot distinguish between *finding* and *inventing*. This made me think about my own autoethnographic enquiry. Was I *finding* or *inventing* meaning for the way things are now? For an answer to this question I felt it necessary to revisit the work of Ellis. Ellis (2009) says that with its emphasis on self-understanding, in examining one's own life, autoethnography is a useful way to understand the world one lives in; it is a constructive approach to *finding* meaning. With this explanation from Ellis and my call on the wisdom of Lewis Carroll, I return to apply Nietzsche's philosophy. For this I draw on the characters Alice and White Rabbit. The will to truth is based on my desire [like Alice] to overlook, initially, the very odd appearance of MS [the illness which I liken to the animated character of White Rabbit]. I did not choose MS. It appeared in my life, as did White Rabbit in the life of Alice. I decided to follow it to investigate what is to be learned, to wherever it might lead me to see what is to be found. What is real is the illness MS. How I make sense of what is found, the meaning to be made of it, is in part, of my *inventing* expressed *by* revisiting, revising, and *in* re-vealing experience.

I am not averse to taking advantages of the opportunities afforded to me. Like Alice, as she follows White Rabbit down the rabbit hole to seek out the adventures to be had from examining chaos and madness, I too [had been] plunged into chaos. My adventures happened to be with MS. Was there a reason for why I would want to choose this adventure? As Davis (2010, p. 2) asks: Is Wonderland simply a land of sheer nonsense, or is there method to Carroll's' madness? In drawing on the deeply philosophical lessons about life's enduring



questions regarding meaning-making. As *learning self*-living my life as inquiry my questions are about my life with MS, now so different to what I had imagined it would be, and that the changes that I will now need to address. Alice offers an alluring view on a world of difference.

Following White Rabbit has brought me to a world where I can author my own story and work out my own issues. I can now expect the extraordinary with MS. Knowing that in demonstrating my creative endeavours I am a *learning self*-creating meaning of a new way of *being-in-the-world* with MS. By philosophically delving into the lessons drawn from my experience I now see that my initial encounter was very prescriptive. I was not given much of an opportunity to ask questions. It was expected that I would not. It was expected that I would just accept what I had been told. But I was not content just to experience such bizarre changes to my body. I wanted to see, to know, and make meaning! I am again reminded of Alice. Wise Alice was not going to forgo a chance to 'see'. She said she would look first at the bottle labelled 'drink-me' to see whether it's marked poison or not. However the bottle was not marked poison so Alice ventured to taste it, and she soon finished it off. "What a curious feeling I must be shutting up like a telescope" said Alice (Carroll, 2006, p. 10). Like Alice I wanted to look, discover and create meaning. And I believe that, as Einstein came to 'see' the curve of light, not as a visual sensation, but by intuition, inspiration, scientific/mathematical knowhow, and curiosity combined, I too will 'see' the curve of my life-path and creative insight will come as it did for Einstein and so many others. Living my life as inquiry is my life's adventure to make meaning and create learning. I had a voice!

As narrator *I Carrie*, want to convey voice of woman, educator, researcher, mother, and grandmother with MS. I can't totally take the nurse out of Carrie! Nor do I want to. I have many years of nursing training etched into my being. I reflect back on my nursing training. Here I was simply observing the pathological and epidemiological aspects of the disease as were the medical specialists mandated to 'treat my body'. Through this way of knowing, I could 'see' how MS responds to the drugs that are or are not given. I, however, decided to also 'see' through other 'eyes. I decided to 'sense' experience. Alice drinks potions that appear to change her body from big to small. Perhaps she remained the same size but the world around her changed shape. How could she know? Were her senses deceiving her?

My senses too provided both new puzzles and new insights. As Alice can 'see' her too big/too small body for the circumstances she found herself in, her responses were 'creative'. At some level, it does not matter whether it was Alice or the world that was changing size. Alice was solving her problems with whatever meaning she could make of her situation. I realise I must solve my problems, even if the details of my circumstances are confused.

In finding meaning in my life I argue it was to be found not *by looking at my* life inscribed in 'living' - 'read' off through my observation *only*. Rather meaning making is a more active decision, involving morals. For example an extension of my observing the behaviour of doctors and my emotional response that are 'read off the world' - in a way that how I choose to act for myself, and in relation to organisational issues and ethical responses are a different kind of action. They are creative and *affectual*, in a way merely observing the speed of light cannot be. One can observe the speed of light and use the insight to do all kinds of things but one cannot change the speed of light. In my approach I am implying, like Einstein's observation of the world. This response to my lived experiences of pain and associated MS symptoms is like describing the speed of light and the meaning of being human is to be found in the observation of my imaginative responses.

In the room of methodology I had made notes on imagination. I re-read them applying my meaning of his writing to my situation. Hayes (2012) in *Imagination as Method: Poiesis in Ethnographic Research*, writes that the confident use of imagination would enable a creative side of self, that is wanting to re-direct my own research, to imagining possible worlds for dealing with complexity, unpredictability, and sometimes the chaotic life with MS. I revisit notes made from Davis (2010, p. 154) who suggests that often we may find ourselves in situations where, we are forced to construct a meaningful world in order to survive the chaos and madness that surrounds us. Like Alice I too felt that I had much chaos around me. The chaos in my life was the illness MS. Gardner (1998) suggests that the Alice stories readily lend themselves to any type of symbolic interpretation, whether this is political, metaphysical or Freudian. Being diagnosed with MS was a most frightening experience. MS is characterised by periods of relapses and then remissions. No two people with MS are the same. I remembered Denzin's (2003) writing performance autoethnography and this phrase: 'I universalise my singularity in this historical moment each of our

singularity is unique'. The experience of trying to obtain pain relief for my MS symptoms of optic neuritis was a struggle as was trying to be listened to by medical doctors. It raised many levels of resistance. For me this represents my unique singular moment connecting the personal, political, and cultural.

As MS symptoms and experiences can be difficult to describe to others. I decided to incorporate metaphor and symbolism into my inquiry and to 'personify' MS *as* the White Rabbit because to some extent I must 'follow the symptoms and the feelings' that now appear to reside in my body. At times, when, full of curiosity I was following its manifestations, it would disappear and then reappear. I really did not have any idea what might come next. Through my initial encounter I was at times overwhelmed and disillusioned with the existing levels of health care apportioned to persons who have chronic illness or a neurological condition like my own.

I offer through my life story levels of excitement, imagination, positivity, and hope to individuals who have and live with MS and extend this for those persons who care for them. I aspire to share the lessons told by bold, assertive Alice who prefers to embark on a life changing-absorbing subterranean adventure rather than just sitting around. It is through my life story that I first externalise and then internalise my observations as I seek to learn how to interpret meaning of embodied experience. Like Alice, I follow the White Rabbit deep into the rabbit hole. I also wanted to know how deep the rabbit hole was!

I want to know how to make sense of what I was yet to discover. It is by following the White Rabbit that I am learning how I have come to a very different understanding of this disease that resides in my body that calls me to attention. It is the fictional characters that are assisting me in new ways of learning how to find meaning with embodiment. As I take time to gather up my journals and notebooks I see Alice. She says: "Don't forget your satchel". With my satchel in hand I have this feeling of satisfaction knowing that I am well-resourced to carry on with this odyssey where *I Carrie*, am learning how to live *with(in)* the altered body.

## Learning how to know and live *with (in)* the altered body

An ability to examine one's own actions, thoughts and feelings is regarded by many eminent authors as of particular importance for increasing the potential for reflection and learning from experience. I am still in the room of learning. I see more books and shelves. Alice is with me. I have my satchel, notebooks and journals. I remember from my journal that I had gathered numerous authors' work on concept of disability, chronicity and illness which was helpful to make sense of lived experience. I also had made copious notes in previous rooms on method, methodology, ethnographic strategies, and tips for transformational learning. I now wanted to return to my experiences, attending to my own feelings, and exploring how *I Carrie*, am experiencing embodiment. Let me explain. In illness my body 'loses its silence'. With each flare up of MS symptoms, my body now is calling 'attention to itself'. I re-call Moustakas (1990) from the Room of Being and Becoming. I wanted to revisit his notion of heuristic process. I see Alice pointing. She says: "These are the some of the books you have been looking for. Go and have a look". I go on over. I begin to read.

Hiles (2002, p. 8) *Narrative and Heuristic Inquiry* says narrative plays a crucial role in almost every human activity and it is fundamental to human reality and our understanding of human experience. It offers vital ways to encode human truth and experience, and, in turn, share knowledge and insights with others. For me the use of narrative in living and researching my life as inquiry, captures the imaginative and intuitive dimensions that encapsulate who I am and what I bring to scholarly process as a meaningful premise authentic to human experience. Hiles (2002, p. 18) further comments that narrative is inherently a heuristic process, and as such provides a key way in which to investigate human authenticity.

In this narrative enquiry the author/storyteller *self* is crucial to process of validity, authority and authenticity. It is my story about a particular unique experience that I argue cannot be generalised. Moustakas (1990) says essentially in the heuristic process the individual is creating a story that portrays the qualities, meanings and essences of universally unique experiences. In process of learning how I am coming to know how to live *with(in)* my altered body. My intention is to *show* how insights gained whilst being immersed in this topic have better

equipped me to remain open, receptive, and attuned to all facets of lived experience. I see Alice waiting patiently. As I carry on writing notes.

When first published the steps of Heuristic Inquiry described by Douglass and Moustakas (1985) included three phases; i) *immersion* - exploration of question, problem, themes; ii) *acquisition* - collection of data; and iii) *realisation* - synthesis. Moustakas (1990) then elaborated on this existing model and further identified a number of core concepts and processes: i) identify with focus of inquiry-self dialogue; ii) tacit knowing; iii) intuition; iv) indwelling; v) focusing; and vi) internal frame of reference. These were expanded by Moustakas to include six steps-phases of research; i) initial engagement; ii) immersion; iii) incubation; iv) illumination; v) explication; and vi) creative synthesis.

In living and researching my life as inquiry, my aim is to make sense from experience that results in learning. I aspire to building on the pioneering work of Moustakas and Douglass (1985); Moustakas (1990); Ellis (1999, 2004); and Marshall (1999, 2004) with narrative playing key role. In writing my story something has called to me from within my life experience. This something I have come to know as being MS. It unveils an autoethnographic account of my personal experience with MS. It details a chronology of events beginning with my own initial engagement with the phenomenon then it moves deeper whereby I am immersed in the topic. The narrative highlights a particular experience which in turn led to a feeling of intense curiosity. I use my own illness experience as a window into a very particular soul to provide not a story just about illness, disability, or MS. Rather it is my desire to share an utterly absorbing immersion-experience in acquiring a deeper understanding of the human condition.

This is where I begin with the heuristic journey. At the start I know little about what lies ahead of me however one thing is certain. It is my curiosity and excitement that inspires me on just like it was for Alice when she followed the White Rabbit. It is my desire to let go of the unknown so that I can traverse the unknown terrain with increased confidence. In the telling of my story I am immersed in my topic, virtually anything connected with my research question becomes the raw material for immersion. My research process aligns with Moustakas (1990) phases of heuristic *inquiry*. The research question is: “*What are the relationships between embodiment and experiences of self, body, and work as mutual organisational relationships?*” When considering an issue, or problem as

potentially complex as this research question is. I enter into this process with total commitment.

I focus on this research question with resolute attention. My primary task is to recognise whatever exists in my consciousness as a fundamental awareness, to receive and accept it, and then dwell on its nature and possible meanings. I re-read my notes. The next step as described by Moustakas (1990, p. 11) is to search introspectively, reflectively and meditatively into its nature and meaning. I reflect on these points. I read that I commenced the heuristic investigation with my own self-awareness. I explicate that awareness with reference to my research question. This *initial engagement* and orientation to a meaning-making process establishes a distinctive space for constructing stories of human experience that inform us.

Within in this space I am *immersed* in the topic. It shapes the research question and provides a framework from which the discovery of meaning making can unfurl. I read in my journal how my question is further developed knowing that [as researcher] I have a passionate interest in the topic of illness, disability and wellness. I am captivated. I read on. In the telling of my story I apportion time to retreat from the intense concentrated focus of the topic. This enables *incubation* to take place at a less subtle pace where an inner tacit dimension and level of intuition clarify this extending understanding of my own knowledge in my enquiry.

In this room I carry on re-reading my notes. I reflect on my new way of being and all that had happened to me since my confirmed diagnosis and the experiences at place of work following my disclosure of MS. I read in my journal: “I have this nagging need to make sense of this mayhem”. I had an immediate need to reconstruct a new way of my ‘being’ in which I could live. I draw on use of heuristic inquiry and narrative. I re-tell my story of how it felt like to live though that day of waiting for confirmation of my diagnosis and the following days. I concentrate on describing details of the particular event. I record:

*I have MS. I still have my job. I wonder to whom I should now share this. I am a nurse, and I am patient. I naturally feel comfortable that I can disclose this with my own profession. Why wouldn't I want to? I do and the outcome is very covertly distressing. I thought that my profession would be the most caring and empathetic of my plight subsequently I came to experience first hand that this is not always the case!*  
*(Personal Journal, 2009).*

Reflecting on this short extract is 'showing' how attention to my place of work and profession was heightened in quite a specific way. It is necessary to reflect on the unhelpful dimensions of the response from my fellow nursing colleagues. Their very unhelpfulness, however, was to trigger a second profound change in my life a much greater attention to noticing. I begin to notice many mixed messages I was receiving. I was no longer required to teach 'Disability and Chronicity'. My prospects for career promotion seemed tenuous.

In seeking clarification about the changes afoot I sensed in my place of work, much change was being undertaken within the department including the ongoing review and work on curriculum paper development. I thought this was an unusual remark given that I had been part of this working committee contributing to the re-writing of many papers for this review. I was now left pondering over the significance of this experience. No specific reference was made to my changing health circumstances. I could not help but think about the implications of the disclosure of my illness to my caring profession. Was this why I was now being treated so differently? I was the same person with whom they had shared an office up to this point. For me all that had changed was that I now had a confirmed diagnosis of MS. Was I now thought of as being too big a risk within the department? I had no way of knowing.

Everyone involved in the decisions about work allocation avoided openly discussing my MS and its implications. I carried on teaching till the end of the term. Upon my return to work the next term, an interdepartmental memo was circulated to everyone. It was an example of one of the regular disseminated comments about funding shortages. This memo announced that teaching positions in this new term would be re-advertised. It was suggested that I apply for one of these positions. On the one hand I thought how strange it was that I am being asked to apply for the position I believed I held secure. But, on the other hand, I knew also that this situation was possibly not that unique to me or to my colleagues in this organisation. Staff in many organisations were increasingly required to look at more economic ways of working and restructuring with re-applications for reformulated jobs being widespread. I felt like I was in a sort of ambiguous limbo one generated from my concerns about my illness and the other about my job security that may or may not be illness related. It was impossible to know how far to separate or whether entwine these two strands of concern.

Not wanting to dwell on trying to find a reasonable explanation for the change in the work-place situation, I promptly submitted an application for the positions now vacant. I received an interview time, prepared my notes and attended the interview. I delivered my presentation. I thought it went very well. The panel asked many questions to which I was able to provide eloquent answers. At the end of the time allocated. I was told that they would be in contact with me as soon as all other interviews had been completed. I left thinking all appeared to go reasonably well. I had done my best and that is all I could ask of myself.

It was more than three weeks before I was notified that I was unsuccessful with my application for the tenured position. I was told I interviewed well. I had all the pre-requisites for job description and even exceeded some of these. I asked for some explanation as to why I was unsuccessful. I was told the other candidate on the day interviewed equally well. It was a panel decision to give the job to that person. I did not know what this comment meant nor did I feel I wanted to know. I had this feeling that perhaps they were not being totally upfront with me about employment matters. I did not have then energy to take on an employment/equal opportunities issue at that moment. Even though I might have had good grounds to pursue a challenge to the decision, I didn't. I needed to put my energy into making better plans for my future and for my changed way of being. I needed to explore how I could still stay employed. I was too young to not be contributing to a profession that I adored!

My profession (nursing) is perceived by the general public to be a noble profession. I am saddened to observe, that on reflection, I experienced it to be very ignoble in aspects of my life. My experiences are highly unlikely to be unique. Reflections over time on the miscommunication and the mixed messages from my colleagues that appeared after the employment interview process were the prompt that spurred me to deeper investigation. When I examined the specific elements contributing to these perceived mixed messages a feeling of disillusion as a nurse prevailed. Something within me ignited a need to explore this internal feeling further so that I could find meaning. Douglass and Moustakas (1985:39-55) say that heuristics is a passionate and discerning personal involvement in problem solving, an effort to know the essence of some aspect of life through the internal pathways of the self. The private and imaginative nature of heuristic inquiry introduces a unique challenge in research investigations in the



philosophical conceptualisations of human science. When utilised as a framework for research, it offers a disciplined pursuit of essential meanings connected with everyday human experiences. I remembered my notes from Room of Demonstrating and use of poiesis as means for creating. Instead of doing I am using ideas of poiesis for creating and generating ideas for self-discovery. I am making it intentional to find meaning and purpose for my new way of *being-in-the-world* with MS. So that it also aligns with my creative self to explore as scholarly inquiry *self, body* and *work* as mutual organisational relationships. I find notes by Moustakas (1990) who says heuristic inquiry and heuristic processes that incorporate creative self-processes are self-discoveries. Eureka!

In thinking more about the words ‘meaning’ and ‘to find’ Moustakas writings were inspirational. I am borrowing ideas from his approach to describe how ideas from personal experience can be used as valid research focus. The root meaning of *heuristic* comes from the Greek *heuriskein*, meaning to discover or to find. It refers to a process of internal search through which one discovers the nature and meaning of experience and develops methods and procedures for further investigation and analysis (1990, p. 9). ‘Self’ [of the researcher] is present throughout the process and while understanding the phenomenon with increasing depth the researcher also experiences growing self-awareness and self-knowledge. Moustakas (1990) offers these words of caution. He says heuristic research is a demanding, painstaking, lengthy process. A researcher must be willing to commit to endless hours of sustained immersion and focused concentration on a central question, to risk the opening of wounds and passionate concerns, and undergo the personal transformation that exists as a possibility in every heuristic journey (1990, p. 14). I reflect back on the first medical encounter.

The heuristic inquiry begins with the process of confirming a diagnosis of MS. My journey takes me to a passionate search for greater clarity about the process and outcome of my (re)application for a tenured position within the organisation I had been working in for seven years. I refer to each of my discrete experiences as a piece of the *position-puzzle* and explicate this awareness with references to an issue or a question about personal human experience. Fossicking about I see more books on the shelf. I see the words: ‘*Intuition.*’ Intuitively I believed this experience with job re-application to be transformative. I read on.

Intuitive inquiry is an approach introduced by Anderson (1998, 2004) to study transformative experiences. It has been informed by following: feminist theory, heuristic inquiry, hermeneutics, phenomenology and Gendlin's (1982) focusing and thinking beyond patterns approach. Intuitive inquiry is an epistemology of the heart that joins intuition to intellectual precision in a hermeneutic process of interpretation. Moustakas (1990, p. 23) says that the more that intuition is exercised and tested, the more likely it is that one will develop an advanced perceptiveness and sensitivity to what is essential in the discovery of new knowledge. Intuition makes possible the perceiving of things as wholes - and is an essential characteristic of seeking knowledge.

In wanting to utilise my intuitive feelings that lay at the heart of my inquiry I was delighted to find Anderson's (2004) theory of intuitive inquiry. This was immensely helpful with interpreting the subjective and complex experiences of this new change to my way of being. With the development of my own internal search to know incorporating intuition is connecting these transformative experiences to a topic that I am immersed in. I had these feelings. I was searching for a scholarly way to make these feelings tangible and easier to understand. Gendlin (1982) makes reference to this focusing process as a turning of the *felt sense* to *felt shift* that articulates this not-yet-articulated knowing.

In re-telling my story I express my *felt sense* feelings to *felt shifts* in thinking to develop my guiding question and reason for 'being there'. I am finding and making meaning of my personal experience. Whilst reflecting on working up this question from point of genuine interest to converting personal interest into this autoethnographic setting and then seeing this interest as question to explore. I was drawn again to Moustakas (1990) heuristic inquiry [as process] where he outlines the different stages of heuristic research as: initial engagement, immersion, incubation, illumination, explication, and creative synthesis. Where Moustakas describes the qualities and processes necessary to the process: tacit knowledge, intuition, focussing, indwelling, and an internal frame of reference. I now re-visiting the experience of job re-application I apply Moustakas (1990) three phases of such research: i) *immersion*; ii) *acquisition*; and iii) *realisation* that I explain more fully below drawing on personal narrative.

### **a) Immersion**

I was *immersed* in my life as woman, teacher, wife and mother newly diagnosed with MS. My journey had to take its own course and I would not be content until I had a better understanding of the requirement to reapply for job I had held and loved. I was immersed in this work and the department that I was affiliated with. What emerges is a form of knowing that the philosopher Michael Polanyi, calls *tacit knowing* which he stresses is one of the cornerstones of heuristic research - we know more than we can tell (Polanyi (1966, p. 4). Moustakas (1990) says tacit knowledge cannot be put into words but it is at work behind the scenes, essentially explaining from another view the underlying dynamics of the hermeneutic circle. In this situation I had a vague feeling that things were not quite right given the length of time it was taking to notify me of the outcome of my application. Yet I did have some second thoughts that perhaps there were other reasons for this delay that I could not possibly have known. I had this intuitive feeling. By drawing on Gendlin's (1982) approach I was engaging in focusing on self as centre of the inquiry finding ways to articulate this yet to know series of feelings as scholarly inquiry. Polanyi explicates tacit knowing appears as an act of indwelling by which we gain access to a new meaning...since all understanding is tacit knowing all understanding is achieved by indwelling (1962/1969, p. 160). I now had a better understanding of the notion of indwelling and the importance of Michael Polanyi's (1958) concept of tacit dimension in that it guides the researcher into untapped directions and sources of meaning. Unwittingly I responded to something from the interview process in which I believed I had done so well. I wondered did this vague insight I had precede my intuitive feeling. Douglass and Moustakas (1985, p. 49) suggest that tacit knowledge is the basic capacity of the self. It gives a point of reference to these vague hunches, formless insights that characterize heuristic discovery.

### **b) Acquisition**

Part of a heuristic journey includes obtaining information from other sources. As woman, nurse, scholar diagnosed with MS. I was now addressing a requirement to reapply for my job. I entered into the process with total integrity. I was immersed in its dynamics. I met all person specifications for the job. I was

well qualified. I had contributed to the re-writing of the new curriculum. I was urged to apply for the new job by my colleagues. I would surely be the best person for the job. I was not re-appointed to teach. I was told that much work was now being outsourced. I learned that many new appointments across the sector were now made on a casual basis. I began to wonder. It could not have been my experience or qualifications that were the deciding factor in the decision not to reappoint me. So what could have been the deciding factor? My interview panel all knew that I had MS. They were close colleagues. Their offices were right next to mine. The facts seemed straightforward: all papers for that course were being changed. I was not re-appointed to teach. Many professionals in the restructuring of employment across the health sector were experiencing redundancy. I was the only applicant with a known degenerative disease. I had disclosed my illness thinking this was the correct thing to do. My disillusionment now stemmed directly from my profession's management of the restructuring of which I had become a casualty. I was desperate to make meaning of all this. I wondered if this illness itself could be considered as an event or was it something that just happened that led to this change? In amongst all of this fervour I remembered some notes in my journal. Where I re-read Steward's (1997, p. 1) *Ontology of Mind* where it provides a larger philosophical picture that keeps in focus detailed questions about ontology and causation whereby philosophers now believe in the existence of a substantial soul.

In some contemporary philosophical debates Steward (1997, p. 1) suggests that the mind has lost its status as a special kind of persisting object in the ontological frameworks, but it has not lost its place as a central concept in those debates. On the contrary, it is a concept that organises the very discipline, a field known as philosophy of the mind. Steward (1997) says that philosophers have been somewhat languid in their attempt to ask questions about distinctions between categories and terms that characterise the mind. Her work provides this investigation of differences between events, states and processes. I was relieved to find such work because often the Doctors that I had seen about my MS would describe the illness as an event. At times another cliché I heard was it's in the mind. I thought how could this be so? And what does this mean? As a nurse my understanding was that this illness affected the Central Nervous System, it could also involve areas in the brain and spinal cord. I was perplexed that such a throw

away cliché would be offered as a sort of explanation by some health professionals. As a patient affected by MS I could not believe that this was the way and manner in which some health professionals would want to portray the complexities of this illness. Aghast at such a thought I return to the Alice story. In doing so I am acquiring new ways of constructing something more meaningful in order to survive the chaos and madness of this illness that surrounds my *being-in-the world* with MS.

Davis (2010) suggests that the story of Alice provides us with the metaphysical respite from the chaos, disquietude, and indifference of reality. However my lived reality is embodied change that encapsulates my perspectives of how best to manage the illness. My desire for knowledge [or if I think about Alice] impels me to choose, to select ways to simplify what actually counts as real. I have an incurable degenerative illness. This is my reality. I can choose either to view my experience as some sort of tragedy or channel it into aspects of my life that are indestructibly powerful and pleasurable. I chose the latter, and sought to realise this choice in self-enhancing ways.

### ***c) Realisation***

According to Moustakas (1990) the coming together of immersion and acquisition is the stage of realisation. I was not reappointed to the work and the profession I had been so immersed in. I had gathered facts I could verify (my imminent qualification of the job). I reflected on aspects of the decision. I could not verify (potential discrimination based on unexpressed assumptions about my state of health). I took in all the implications that made 'real-for-me' the new situation I now found myself in. Moustakas posits that personal enrichment arrives only after a journey of self has engaged with the three phases of heuristic enquiry. These dimensions were to become very helpful in arranging my thoughts about my experiences of my circumstances and my intention to investigate my situation more formally.

After being denied the job I had applied for, I was offered casual work. I did not think much of this offer. It really was no offer at all. I made the decision to leave this place of employment. I had much to contend with as I set out to learn more about the vagaries of this illness MS. I had a fabulous farewell. My

colleagues said that they were going to miss me and that they could not understand why I was leaving nursing. I, however, did not think of this as a farewell to nursing as such. Rather, it was *I Carrie*, the academic, leaving her job as a teacher who, as a consequence of restructuring, now had no papers to teach in. I was not abandoning a profession that I am so passionate about and deeply care for.

I cannot *tell* from the re-visiting of this experience of job loss what my colleagues were thinking. What I can *show* is how I responded to this ambiguous situation commencing from i) the confirmation of my illness; ii) my experience of the bizarre way the interview process was managed; and iii) through my exit from the job and my place of employment. In the re-telling of these events as an important part of my story, I signal to reader that I have revisited first vignette in Room of Demonstrating to re-veal the thinker's tale re-told as a plan to re-route personal experience and re-direct existing skills and knowledge to explore: i) knowing; ii) what constitutes knowing as knowing; and iii) why know? Reflecting on some of my colleagues' responses re-directed me back to the moment when I received my confirmed diagnosis. I am still able to re-call with much clarity the levels of much mis-communication from a fellow health professional. He was the specialist. I was the patient:

*I am sitting with my husband in the waiting room. The receptionist calls me over to the reception desk to say that she has just had a message from the specialist to say that he is running a bit late. I am to take a seat. We sit and wait. Then rushing past is a man dressed in a suit. He makes his way to his consulting room and shuts the door. The receptionist says: "He will see you soon". We wait. The specialist comes out from his office and ushers us in. He does not make any eye-to-eye contact with either of us. He did not introduce himself to my husband. He just asks me for my x-rays. I promptly hand these over. He places the x-rays on the viewing screen and begins to count out aloud: "There are 36 lesions. Now come on into the examination room."*

*I get up and follow him into the examination room. He proceeds to show me a set of colour charts. He asks me to read letters on the eye chart and runs a tuning fork over my lower limbs. He then says "I have amended my appointments to fit you in at such short notice as a request from your GP." He then goes on to say that there is much misinformation on the Internet and it is not useful to surf the net for answers. I am surprised at his comment. I had not had any discussion with him about seeking*

*information. I think is he under the assumption that I will surf the Internet for solutions. He then instructs me to follow him back to his desk and to sit down. I do. He then says: "You have MS. In six months you will be in a wheelchair". He asks if I have any questions. I said: "Yes I do. How do you know this to be my future?" He is rather reticent about his reply. He says that I did not follow his instructions easily during his examination. My reply was: "Well, if you had given clear instructions as to which order you wanted these to be done in. I am more than capable to follow your instructions. Also, getting back to you about saying I'll be in a wheelchair in six months, who are you to say this? Are you God?" This assertive reply of mine did not go down that well and the rest of the consultation was very quickly terminated. My husband and me left thinking what was all this about? And I thought I would prove him wrong! If I see him in the next six months, there will not be any wheelchair in sight. I'll walk unaided.*

*(Personal Journal, 1998).*

This was not a good first impression of the person/the specialist that I was going to be reliant on for the management of my degenerative illness. I telephoned my GP the next day to let him know how this appointment went. He apologised and said it is difficult to treat your own: "You are in the profession". I thought this was an interesting comment. Was it made to help keep the status quo? As patient, one is not supposed to question the authority of a doctor, the doctor knows best. What I needed was someone that I could rely on. I did not get any constructive help from the specialist only a statement of the obvious which was relayed from the MRI report. I too can count lesions and can make a pretty good assessment of their significance.

So now, I return to the experience of my leaving my place of employment as nurse, woman, mother, and wife with MS I was dealing with a change in my identity on many fronts. I was curious to know why colleagues had responded as they did. As nurses we have privileged insights into the experiences of those others who are coming to terms with such profound diagnosis. As friends and colleagues, maybe they too were feeling uncomfortable and distancing themselves from the subjective and objective aspects of my altered body. Perhaps to them, I had become two persons i) the person with MS and; ii) the nurse with MS. I did not want to endorse such a perception. I was, at that time, a woman, scholar, nurse, wife, and mother: a multidimensional person with MS. I had begun to realise myself as an engaged enquirer. I had left far behind any possibility at being

treated as a passive object of a medical gaze learning to begin and prepare for the ‘realising self’.

It is time to leave this room. I realise that I was now a researcher using *self* as subject to take into account these issues. I return to my notes where I had been writing about what I was thinking and feeling and what it meant to me. I re-read Ellis’ (2009, p. 103) notion of *introspection* where she defines it as an accomplishment in dialogue with self, represented in a form of field notes, permitting us to look into the processing of everyday emotional life. Polkinghorne (1988) says it provides a link between one’s own experience and expressions of life. I now thought about using introspection incorporating heuristic inquiry to address emotion and personal experience that I believe have previously neglected areas in critical social sciences. Ellis (2009, p. 102) writes for the most part, social constructivists who look at emotions fail to examine their own responses, and instead, view emotions as feelings other people have. Denzin (1985) comments, those few sociologists who do explore biological parts of emotions tend to sever the body from the lived experience. Denzin (1987) says even when they do use own experiences they do so in an emotionally detached way or they hide reactions in an array of participant observation data.

I read on wanting to find way to re-live my emotion and talk about it as I experience it. Moustakas (1990, p. 16) says with use of components of the experience, and details that could have been omitted had one not been immersed in and with the topic. Researchers find use of self-dialogue does make it possible for one to understand the significance of becoming one with what one is seeking to know. I found his explanation of phases of heuristic inquiry helpful as naturally leaning towards being more introspective. Unbeknown to me I was entering into dialogue with the phenomena, allowing the phenomenon to speak directly to my own experience, and to be questioned by it. I see a couple of books on the shelf. The words: ethnographic self, representation and identity catch my attention. I read Coffey (1999) *The Ethnographic Self: Fieldwork and the Representation of Identity*, where Coffey says field work is an embodied activity and in calling for a more embodied sociology the implications of this move will lead to creation of ethnographic self-exploring issues of embodiment and self. I am assured by reading Coffey’s work that my approach of autoethnography addresses the personal, emotional, and identity dimensions of undertaking fieldwork. In writing



about experience I am remembering and I am representing my lived experiences from the field. The last book with words: 'knowing how to know' again catch my attention. I re-read Halstead, Hirsch and Okely (2008) who suggest how we come to know is also about how we experience and question what is given. We come to know by *becoming* or re-positioning the other in my enquiry constructing embodied knowledge interfaces between self and other. The [auto] ethnographic self-present emerges in this process and what is produced as continual.

I reflected on this Halstead et al. (2008) writing. I thought how does knowing how to know apply to me? I have MS. This is a continual dynamic continuum in my life. I will always have more questions about embodiment and experience. Learning how to be a learning self-demonstrating autoethnography is a creative way of knowing beyond writing notes, where constant reflection and reflexivity is bringing out present feelings that are intertwined with emotions in those singular moments. In living and researching my life as inquiry I am constructing new knowledge as a learning self who is preparing ways of making sense with coming to know how to know as a realising self.

Within my own voyage with self-discovery, self-awareness and understandings of all I have read whilst being in this room of learning. As a *learning self* and with use of Alice story, I am attending to own feelings, thoughts and beliefs as prelude to the understanding that will be derived from this dialogue with self as a *realising self*. The satchel is now full. I see Alice standing at the back of the room. She is saying: "There is one more room to explore". I stop to pause to think. Only one more room and then where? Alice sees me stopping and in getting my attention again she waves to me saying: "It's not far now. It is the blue door". In earnest I set off to explore this last room!

## **CHAPTER SIX**

### The Room of a Realising Self

*'Mother'*

Original art work reproduced with permission from artist.



**Image 3: "Mother"**

## CHAPTER SIX

### Room of a Realising Self

I have arrived at the blue door Alice has directed me to. I see written in striking black letters the words: “*Self-discovery*”. I go in. I place my satchel on the wooden bench. I see mirrors, book shelves and pencils. I am filled with sense of wonder, intrigue and a craving for understanding. I am hopeful that in this room of self-discovery I can find ways to continue with my exploration of *self*, *body*, and *work* in different contexts. I want to explore how ‘being there’ can be portrayed as an extension of myself and the authority of ‘being there’ can be connected to the narrative vignettes and to my life now as I have been learning in the rooms I have visited. I know from those rooms that as an emergent autoethnographer developing a style is an important consideration for purposes of maintaining original meaning as well as informing the ways I think and write at this time. Using a mixture of insights drawn from Moustakas (1990), Marshall (1999), and Ellis (2004, 2009) I can trust that it is reasonable to own and show more than one style to create the representational qualities of ‘being there’ and thinking about ‘being there’. I now wish to outline more fully i) positioning of a realising self; ii) writing self into being differently in the world; and iii) embodied experience beyond the clinical gaze. In the re-telling of my story I can draw on selected vignettes describing embodied experiences. In this way I can portray human illness as a teaching device. This portrayal is intentional and revelatory. Writing as enquiry affirms a learning *self*-seeking new ways of thinking that is playing an integral part in shaping the identity and positioning of a *realising self*. What can this mean? I enter further into this room.

#### **Positioning a realising self: authoring a new identity**

I see a wooden bench on which I put my satchel. Alongside it is a long mirrored cupboard. I see myself mirrored in its reflections. I also see a portrait that hangs on the back wall of this room. Alice is standing alongside it. I turn around to look more directly at the portrait to take a closer look. I see now that the

portrait is an image of me. It is entitled “Mother” (refer to Image 3). I re-call now that it is a portrait of me painted by my daughter. In the portrait, I have my eyes closed. I wonder why I am depicted like this by her in this painting. I am reminded of why I am thinking of myself in this way right now. The reflection of the portrait ignited memories of that fateful day I had received the confirmed diagnosis of MS and this became known to friends and family. I remember the house being full of flowers, many cards, and letters. Other friends or family members calling by would comment: “It looks like a florist shop”. There were so many bouquets that I was running out of vases for them all. The care and attention I was receiving reminded me of what I had experienced when a loved person dies or is seriously ill. I thought about the cards and letters still stored in a craft box. My intention was to use them to make a decoupage framed mirror. Each of the layers of varnish placed over the pictures and excerpts of written notes would comprise an heirloom mirror of memories. Each of these memories evoke the thoughts, emotions and feelings that take me back to experience that time when my family, friends, and colleagues were told about my diagnosis. I remember writing about this in my journal. I take it out of my satchel and find the page. I read:

*Our house looks like a florist shop with so many flowers cards and letters that friends and family have sent. There is so much to absorb. I feel it is so unfair! My time now is spent reading about MS and resting in my chair. I spend much time thinking deeply about my children, husband, parents, and extended family. For them I want to try and ‘normalise’ as much as I can about this experience so that they can carry on with their own routines at home, at work and with school. I agonise over what should I tell them and when.*

*(Personal Journal, 1998).*

Re-reading, remembering, and reflecting on what I wrote in my journal that day I notice how memory, thoughts and feelings merged and reappeared in a different context. Ellis (2004, p. 118) writes that the value of ‘making memory more complex is that it doesn’t work in a linear way, nor does life’. Instead, thoughts and feelings circle around us, flashback then forward. The topical is interwoven with the chronological. In real life, we always know when we know something. Events in the past are interpreted from our current position. Reflecting

on this comment drew me to pull out my notebook from my satchel. I re-read my notes on Heidegger's notions of being and time, and Deleuze's ideas about temporality. I now had a much better understanding of past and present in relation to my current standing. Much is to be said for the value of non-linear reflection, I mutter to Alice. She nods in agreement.

I find myself motivated to read on in my notebook. I read my notes taken from Ellis (2004, p. 118). She suggests that valuing non-linearity does not mean that there is no value in trying to disentangle now from then, so long as you realise it is not a project you'll ever get right. Instead one should aspire to what Richardson (2009) suggests. You endeavour to ensure that subtle differences are profiled in a meaningful way. How useful these notes are for my reflection on what I am to think of as my unexpected life with MS as my reality.

In thinking about the reality of my life with MS in a meaningful way I remembered some of my late grandmother's musings on adversity and ill-health. She said: 'First and foremost you must put yourself first'. Intuitively I knew she was right. I was not to know then as I do now that my grandmothers' advice would itself be the start of a mini-cycle of inquiry that was to lead to my investigation into how my outwardly appearing 'perfect' life seemed to fall apart in directions I had never anticipated. My journal entry shows me that I was much concerned about the effects of my MS on those I love. However as I thought about what lay ahead of me I was also dealing with my inner turmoil. I was discovering much weakness in my health but there was also much inner strength. I was at a cross roads in my life. I realised that MS was a permanent addition to my life. The desire for a creative way to study and perhaps transform this turmoil brought Alice to become my companion and White Rabbit to be my teacher. In realising the potential of my time with Alice and White Rabbit, surely anything was yet possible!

I catch a glimpse of myself in a mirror. I look both very familiar and somehow different. I realised I am living continually in process, adjusting, seeing what emerges, and bringing things into question. Marshall (1999, p. 2) says this way of living as a researching self involves attempting to be open, to continually question and find ways to engage actively in this questioning and processing it in stages. I had started to realise that I could do this because inquiring is a compelling aspect of being inquisitive and curious. I was indeed both of these! I

was curious and open to testing myself. In writing about my experience, I am learning that MS is more than just a medical story. It is a sensing, feeling story filled with intrigue, emotion and wonder. Reflecting on my storied reality and showing the feelings, emotions and vulnerability experienced I have learned in the previous rooms is a part of living inquiringly. I sense that a knowing and a realising self is now coming to surface. In previous rooms I learned that writing about embodied experience is the shaping of forms, tones, and coherence of storyline. Ellis (2004), Marshall (1999) and Moustakas (1990) have clearly influenced the interpretive approach I embrace in my enquiry. Marshall (1999, p. 2) says this involves attempting to be open to continually question what I know, feel, do and want, and finding ways to engage actively in this questioning and process it stages. The Alice story offered an opportunity to imagine living like this is adventurous. It has the capacity to turn what might otherwise be daunting, mundane or the tedious into activities which are engaging, interesting, playful, and imaginative opportunities for learning. Reflecting on my life story I can show full emotion and re-call. The process of choosing what to write, deciding how to do so, and when to do it, is an aspect of living inquiringly and realising an emerging self.

I reflect again on the notes about emotional re-call that I made in the Rooms of Methodology, Being and Becoming, and Demonstrating. I revisit Ellis' (2004) strategy of *emotional re-call* of imagining oneself being back in the scene emotionally and physically. By revisiting the scene emotionally this helped me to remember other intricate details where thoughts immediately went back to the emotion of my being present in that moment. In applying emotional re-call I am retrieving many more details about the feelings on that day. I remember so well that the first few days following the diagnosis were ghastly. I felt so unwell. My husband and I had so many questions: "What should we tell our children? Who else should we tell? Would I be able to resume work and what would the financial implications of this be if I couldn't?" Then there were my feelings about why did I have MS and why now. We still had our children to educate. Our son had just commenced university and was living in another town. It was also the year that our daughter was choosing an artist's theory to base her own original art work on that she was undertaking for an external school art examination. She chose Modigliani. Then I was not sure why she did. I saw the finished painting and off it

went for examination. I made a comment about eyes being closed and remember her saying: “You spend a lot of your time with your eyes closed as well”. Indeed I was and how perceptive of her! At the time and still do I find this image so deeply thought provoking. It leaves the person looking at it with many images of what that person is thinking and feeling. Her eyes are not open and deliberately painted in this way by the artist. Was this her message to me? If so how special!

The portrait painted by my daughter became an internal frame of reference for me. It offers an imaginative way of contouring and nuancing feelings in a meaningful way. My daughter’s way of showing her insights and feeling about my illness was through art. Mine is shown in written text about it. When I commenced this heuristic process it began with a question in which I was seeking to answer; one that is a personal challenge in the search to understand myself in the social world in which I live. I was realising the influence my embodied change was having on my family. I knew I needed fresh insights.

I contacted the local MS centre of which I was already a member. I visited their library. I found a book: *‘Taking control of Multiple Sclerosis’* by Professor George Jelinek (2005). Reading the front cover I could hardly contain my excitement! It says everyone affected by MS, either directly or indirectly needs to read it. I had it issued and took it home. I read about the author who as a Professor of Emergency Medicine and Editor of a medical journal was diagnosed with MS at the age of 45. This came as a big shock to him as his mother had died 18 years earlier severely disabled by MS. When he became affected by MS as a patient the experience took on a whole new world view, a whole new experience, and a whole new imperative. I took many notes. Re-reading my notes from Jelinek left me thinking what an extraordinary gift this man brings to the conventional medical ways of managing and treating MS. It helped me to re-assess my life, work, relationships and family. Jelinek (2005) says when you find out that you have MS it not only affects you the person with the illness, it affects those closest to you as well. Thinking about his comments re-directed my own thoughts and feelings back to that day. For us, at that time, there were no ready answers to our questions. There was just a lot to think about.

As time went on post diagnosis I was developing an ability of being more receptive to learning about the type of MS that I have. I am becoming attuned with all facets of MS. It is called relapsing-remitting MS for a reason. I



experience an attack, followed by some recovery, partial or sometimes total, then a period in which I have no further attacks. Jelinek (2005) says this period may be called remission, because the symptoms remit. He argues remission is a bad term, because it implies the disease is not active during that period. We know that it is, says this expert. The medical specialists I had been to never explained it like this either. According to Jelinek (2005) every person with MS will have and experience different MS symptoms because the lesions can occur anywhere in the Central Nervous System (CNS). The symptoms depend entirely on where the lesions are. There is no such thing as a typical MS patient. In effect, what typifies MS is the range of neurological disturbances found in a single patient. I never knew this. This concise description by Jelinek who himself has a very long and solid grounding in medical science helped me tremendously as I began to realise what the nature of this illness was and how best to manage it. This information was incredibly useful to position myself as 'realising self' who is taking control of her MS in a meaningful way.

Because I am an inveterate note-taker and learner, I had built up a useful set of notes. I had recorded how long each relapse was and what sort of care I needed. I was 'noticing' and recording different symptoms experienced in any new relapse encountered and I was writing about these. Unbeknown to me then I was taking autoethnographic field notes capturing experience through memory and recall. I found writing about experience cathartic at times. I then remembered reading Ellis's (2009) *Final Negotiations* written by her, about the chronic illness and death of her first husband and the notes I had made that led me to re-examine advantages and disadvantages of emotion, recall and memory. Ellis (2004, p. 118) writes the advantage of writing close to time of event is that it does not take much effort to access lived emotion they're often there whether you want them to be or not. The disadvantage is that being so involved in the scene emotionally means it can be difficult to get outside it to analyse from a distance.

I found this explanation helpful in that it endorsed my queries of was it good to write when feelings were so heightened. Ellis says, that is why it is good to write about an event while your feelings are intense, and then you go back to it when you're more emotionally distant (ibid. p.118). Going back to it when I was more emotionally distanced helped me to realise how both of these processes of

moving in and out are necessary to write an effective autoethnography and I wanted to do just that.

In the Room of Demonstrating and Room of Learning I found imaginative ways to learn and write introspectively. Alice had been guiding me and in following White Rabbit along the many passages there were lots of adventures and events to recall. I reflect back on the seemingly absurd and at times chaotic experiences of MS that embodied me. As a *realising self* who does not want to exclude lived emotion or recall from human experience. The use of emotional recall [as process] enables me to author a new identity. I am *Carrie* who in writing of self being differently in-the-world is *showing* how to live creatively with MS in a meaningful way. With the knowledge to recognise how each relapse manifested and in writing about how I am coping with it I realise I am empowering myself. I am writing my new self into being. I wonder what this means.

### **Writing self into being [differently] in the world: showing rather than telling**

On the walls of this room of Self-Discovery Alice has urged me to enter, I see pictures of Denzin, Buber, Marshall, Ellis and some smaller mirrors. Alice is here with me. I take out my note book to read: “There has to be a better way to show others what a flare up of MS is like for me”. I think about the many multi-dimensional experiences that have shaped who I am. As woman, spouse, mother, nurse, educator, academic, and researcher, I live and work with MS. Since my diagnosis in 1998 I have been ‘researching my body’ but in more elaborate ways than the doctors who have been treating my condition. My training in the very biomedical approach to health care to which I am now subjected enables me to situate the embodied experiences of a flare up of my disease fairly precisely in terms of one who *observes* a patient presenting with diagnosable conditions in terms of this model.

I take stock of these experiences to now report on two distinct dimensions I am now focussed: i) my experience of the symptoms of this illness; and ii) my experiences of the behaviour of health professionals whose responsibility it is to care for me. These dimensions were central to the decision to undertake this research as part of my commitment to a full and fabulous life post diagnosis, and as a contribution to ‘*show*’ a better understanding of this illness for others who

have it, and for those who live with or care for those who have a similar chronic illness. I do realise that I had set myself quite a brief! I need to take a short break from reading my notes. I look up and see some books sitting on shelf of the glass mirrored cupboard. The words are hard to decipher. I wonder why. Alice is at my side. She says: “If you hold them up the glass the words will go the right way again”. I do just that it reads: “*Wanting to show*”.

Did I imagine it, or was the portrait of Denzin smiling at me? I remember reading Denzin’s (2003, 2006) call to explore the notion of ‘performance autoethnography’. I am keen and motivated to respond to Denzin’s call by drawing ever more deeply on my experiences of living with MS. I want to make the ‘invisible’ ‘visible’. My story must be retold from the moment I experienced my first encounter of an acute attack of inexplicable pain, the process of being given a confirmed diagnosis of MS, and the dramatic change in my employment status along with all the subsequent peculiarities that have shaped my view of MS. Buber’s portrait now seems to call attention to itself. Of course! I can draw from Buber’s (1958) notion of ‘encounter’. All real living is meeting! Buber calls it encounter [*Begegnung*] and relation [*Beziehung*]. According to Buber (1958) we grow and develop once we have learned to live in relation to others, to recognise the possibilities of the space between us. The fundamental means of this relationship is dialogue. I can utilise my lived experiences to engage fully through dialogue with ‘self’ - a self-realising new ways of being through performance, a performance whereby my body is calling attention to itself.

By *showing* rather than *telling* I can illustrate through my writing how I am exploring and still traversing my way through much inner pandemonium. I can show how I am trying to understand the lessons life is now placing before me. I can show how I am discovering how to trust my ‘inner self’ learning to trust my feelings and going where they lead me. As with previous changes in my personal and professional life I *must* trust myself to make sense of my world and to act with care (for myself – as I would for others).

I am, in this House of Learning re-living and exploring issues, re-defining some of my values, re-discovering the poignancy of simple moments. With MS my life is different to what it was before MS. I have a whole new set of perspectives to concentrate on whilst taking into consideration things or matters that perhaps, I had not paid enough attention to in the past. My experiences *are*

the phenomena under investigation. I can ask: “*What is life like now for ‘Carrie with MS?’*” How “*has the experience’ of a disruption of the lived body influenced my way of seeing and being?’*” And “*What are we like when we engage in caring encounters of the sometimes - abstract [as invisible to others] presentations of MS experience?’*” This account bestows an authorial voice from the body that is not merely *about* the body. It is *from* the body to *show* not *tell* how enhanced understanding of the embodied self in chronic illness can contribute influencing the development of better management systems of care for self and others.

I am drawn to stories as a way to portray the dramatic, intense moments of my encounter with MS my emerging self and for conveying many aspects of lived experience. I want to revisit my notes again. But where will I look? It seems as if the portrait of Ellis guiding my search. Ellis (2000, 2001, 2004) describes autoethnography as a genre of writing and research through which to display multiple layers of consciousness. By using autoethnographic research methods, my insights are presented as *my life stories*. Stories that became both revelational to me and transformative of the way I have subsequently approached my emerging ‘realising self.’ I am going to think a little more about a particular ‘flare up’ of a MS symptom called optic neuritis [a severe pain episode located in my left eye] as a single event that does re-appear. As time progresses there is [for me] the reality that I will from time to time endure another flare up.

Each time I sustain a flare up of optic neuritis it presents in a similar manner. However levels of pain are more intense with the levels of swelling around the optic nerve. Attempts to access help from the medical/health professionals suggest that they just do not seem to believe that I’m so unwell. Outwardly I look reasonably well. I may be rather pale and am obviously uncomfortable but overall their perception is that I am not seriously unwell even though they can see that I am having trouble with my eye and even though they should know (as professionals) that in a worst case scenario I could develop irreversible issues with my eyes or go blind! What more do I have to do to get seen as a perfectly reasonable person who just wants help to relieve her ghastly intense pain? Aghast I think Curiouser and Curiouser!

Autoethnography allows a researcher to re-visit a particular experience and to illuminate the lessons that can be learned from many revisits. I re-turn to use optic neuritis as specific event intentionally. In my journal I find notes about a

particular visit to obtain pain relief and with it are two articles, one written by Gorman and another by Synnott. Gorman (1977) describes her experience of severe optic neuritis in both eyes, as enabling her to look back into the past. Synnott's (1993) *The Body Social: Symbolism, Self and Society* significantly influence my inquiry, as I explore the phenomenology of sight: *What does seeing mean? How is seeing seen?* Examining the relationship of sight is where I view the semiotics of the eye as symbolic of the self. The *I/eye* provides the opportunity to discuss self. It is the *I/eye*, who is experiencing this pain. The *I/eye* is observing its manifestation and treatment by looking out from the suffering body differently from those looking in. It is the *I/eye* that contributes to making meaning in my enquiry that I wish to draw from to illustrate learning. It is my eye that is very painful. I am in pain and require care for my flare up of optic neuritis. My journal entry made after a visit to a clinic to obtain adequate pain relief reads:

*Sitting in the waiting room I notice a narrow corridor with many small rooms leading off it. Some of these small rooms are very dark. At the time they seemed to symbolise the 'rabbit hole' that I felt I'd fallen down. I remember reading about the rabbit-hole in Alice in Wonderland. In the midst of waiting for pain relief thinking about my disease. I wonder will there be any light at the end of this? I waited patiently in pain. Even the doctor who finally saw me didn't think I looked that bad.*

*(Personal Journal, 2011).*

Reflecting on this excerpt of my experience with the use of introspection and emotional re-call still ignites an intense feeling within me. That day, trying to obtain adequate pain relief from the medical doctors, felt like a struggle without end. For me this was my *unique singular moment* connecting the personal, political, and cultural in a moment from which wider lessons can be drawn. Re-visiting it brings the emotional experience back to me. Ellis (2009, p. 104) argues that in order to bring emotion into the sociological study of human behaviour we must address the descriptive and analytical task of precisely detailing the moments in the complex process through which it is experienced. Unless this is done, it is not the whole emotion we are bringing into our sociological studies, but a severed, edited version of emotion. She says if the field as a whole ignores lived experience, our interpretations of emotions will be as incomplete as was our

understanding of social life before we took emotions into account. I found this statement deeply thought provoking.

A flickering in one of the mirrors calls my attention. Magically, I can see right back into the Room of Learning and beyond, all the way to the Vestibule. I can see myself in different rooms, writing myself into being differently in the world. In the Room of Learning, freshest in my mind, I learned how to ‘notice’ subtle changes in the body. As a learning self I am now more aware how severe neuropathic pain informs my way of being. With an enquiring spirit use of introspection and emotional re-call *I Carrie*, am becoming a realising self who is moving in and moving out to look back at experience. Through performance autoethnography I make visible the complex experiences and my interpretation of my admission to the eye clinic as a critical single event. To illustrate the complex meanings I convey through this work, the use of symbolism and riddle, and the invitation to curiosity that Lewis Carroll (2006) conveys so well. I return to Gardner (1998) *The Annotated Alice* where he writes inversion themes occur throughout all of Carroll’s writing. These changes in size which take place so often in Alice’s Adventures are themselves examples of reversals, outside-inside, and inside-outside. I draw extensively on this notion of inversion to illuminate symbolism, and reversed meaning through fictional characters used in my story line to *show* how as performance I am living my life as inquiry with MS.

The two vignettes below include some of the stories captured in my journal. By focusing on the particular MS symptom of optic neuritis in these vignettes I attempt to bring ‘sound’ out of the ‘silence’ coaxing the *invisible* to become *visible* as a meaning-making process. I describe the *invisible* MS symptoms I present with. When I experience a MS relapse it is the sensory neuropathic pain in my left eye that continues to cause me this level of discomfort. I live with some of the residual effects of each relapse. It is distinct ongoing neuropathic pain. With each relapse I am learning how it presents and how to better communicate this. In describing my interpretation of symptoms and feelings [of the intensity] of the pain as: stinging, burning, and throbbing deep from behind my eye to health professionals. I am writing evocatively about my need to access care in a timely manner and to be listened to.

## Vignette One - Writing evocatively: Calling myself into being

*"Please do not make me beg... I just want some pain relief"...*

*(Personal Journal, 2011).*

Having made it from the waiting room to the examining eyes of a doctor, the words above are part of the conversation between the doctor and me. The words reveal my physical pain and emotional torment. I re-visit the experience and I re-tell this event as *a life story*. A life story of an 'encounter' with my new way of being as '*I Carrie*, with MS' who through autoethnography is able to re-view phenomena embedded in the layers of complexity associated with illness. I write:

*It is a late summer's day. I am troubled with intense pain and blurred vision in my left eye. My usual medications do not help. I make my way to the doctor's surgery. When the doctor and I meet, I request the stronger pain relief. I explain to him that it had been given to me by a hospital specialist when I first presented with these symptoms. Despite almost begging for the pain relief that I knew to be effective, I am given instead an explanation as to the potential addictive properties of this drug. As a qualified nurse and nurse manager I could appreciate his concern. My own professional knowledge, as well as my proven history of deep personal responsibility in the area of self-medication however, assures me of the manageability of a small amount of these drugs under these circumstances. I continued the conversation: "I'm not a drug addict! I do not intend to be on this for long periods or dispose of this drug in other ways. I just want to deal with this excruciating pain". Despite my plea I receive no pain relief. Instead he gives me a form for an eye test. I am asked to phone in again the next day if things have not settled.*

*(Personal Journal, 2011).*

I appreciate perhaps better than many lay people the hesitation in prescribing the pain relief I was asking for. I am well aware of the implications of prescribing strong medications for self-administration. Yes I have chronic pain but I do not have to suffer! Ellis (2009, p. 94) says it is important to write evocatively and to evoke readers' experience so that this is useful for all of us, the ill, their families, caregivers, and all who suffer illness and loss. I felt my own professional knowledge and my sense of personal responsibility were made irrelevant at this

meeting. What I was experiencing I believe was an example of medically fixed intent to look at or on *my body* as an object bereft of any other relevant characteristics. Foucault (1976) argues that in the biomedical understanding the body is shorn of mysticism, magic and faith because the medical gaze of the scientist or medical doctor is informed by nothing more than established material facts. My authoritative 'voice' from the field was not acknowledged.

### **Vignette Two - My Body-part: Eye/I on View**

When I met with the doctor, the clinical evidence pointed to changes in my body that give rise to a type of flair up of a known MS symptom. It is a phenomenon visible in time and space (i.e. in the tissue and nerve connections of my eye at that moment). The ability to note such changes in the physical body in an ordered and systematic manner have had far reaching implications for the shaping of the medical profession and the growing and intensifying related biochemical industry. Doctors could now be taught to believe that they could know the illness and its treatment. A disembodied knowledge was now connected to some sort of mechanical doctoring machine. It was *their* knowledge of the disease and *their* understanding of medical science that would prevail. Foucault's (1976) notion of spatialisation invites a re-visiting and re-telling of the professional position taken by the doctor in this story. I write:

*The doctor sits separate from me. He views my eye (body-part). He does not appear to see or feel connected to Carrie-in-pain. He informs me of his decision on the material facts (as he understands them) that involves also his understanding of the regulation and discipline of my body. He expresses an assumed responsibility for the affective properties of the drug on my psyche and an implied responsibility for any illegal on selling I might engage with once 'out of sight'. My own assessment of the medical risk, the potential effect on my psyche, and my ethical commitments to no on selling of these drugs are made irrelevant.*

*(Personal Journal, 2011).*

The doctor observed my eye in order to write in his clinical report about a particular dis-functioning eye in at a particular time and place with a particular set of symptoms for which he had the power to administer or withhold relief. He was



doing his job. He will unlikely remember this as an extra-ordinary day or an extraordinary story. How curious that a life changing event of some magnitude for me appears to be a mere technical issue for him. I needed more explanation, more engagement. I think of Alice's need to know:

... It flashed across her mind that she had never before seen a rabbit with either a waistcoat pocket, or a watch to take out if it, and burning with curiosity, she ran across the field after it. Alice follows rabbit down a rabbit hole when she suddenly falls a long way into a curious hall with many locked doors of all sizes...

(Lewis Carroll, 2006:6).

Early in my writing about this experience, I too was burning with curiosity. As I sat here with closed painful eyes I began to imagine the wonder of all possibilities in the real world I occupied. In committing this experience to formal enquiry, I found Alice. Like Alice in the stories that I have found so useful, exploring life's mysteries began to reveal how relentlessly I wanted to create and portray my artistic being. Alice offered another world to explore that need. Life need not be dull at all. We do not need to stay where we seem to be put. Alice, leaving the safety of the bank to follow White Rabbit into the rabbit hole demonstrated this very well. Like Alice I chose to jump into the rabbit hole. I have allowed White Rabbit to become my wayfarer. In search of potential answers I have followed this rabbit ever more deeply down the rabbit hole.

### **Embodied experience beyond the clinical gaze**

I am thinking about my search to better understand my post diagnosed self. The increasing and ever more affective visits to medical specialist began to draw my gaze to elements of the commonalties of attitude that seemed to inform almost all of the specialists I came into contact with. I am re-viewing and reflecting on this attitude as an outcome of the biomedical model in which I myself have had a very good training. But it seems I am not to rest for long. I find myself transported through a trap door that was hidden in the corner of this room. I am tumbling down a number of steps. I notice that I have my satchel, notebooks, journals and the compendium. Thank goodness! I'd be lost without them! Alice is

here with me too. At the bottom of the steps I am in a basement. She says: “You are now in a curious basement. There are three workstations here. At each workstation you will find much to explore. It is time to show how you have realised and acquired an understanding of embodied experience.” I make my way over to the workstations.

**Workstation One - *The Cartesian Split: Treating the body [as soulless object]***

I enter the first workstation. It contains the images and icons of the biomedical model through which I am now being observed and treated as a patient that has MS. An imposing portrait of René Descartes is prominent in this workstation. He has often been described as the founder of modern philosophy and credited with philosophical separation of spirit from matter - the Cartesian Split a philosophical tradition that can be traced to Aristotle’s materialism and Plato’s dualism. Descartes’ discourse on method is known for the famous dictum: “Cogito ergo sum” – “I think therefore I am”. From these early writing the use of ‘I’ by whom I am what I am was referenced to the mind and deemed separable from the body (Synnott, 1993, p. 22). Descartes compares the body to a clock, which operates in the absence of a mind. The body is reduced to a machine. Descartes’ thinking is entwined with the much wider de-spiritualisation of the universe occurring in his day.

Synnott (1993) describes the reach of Cartesian dualism that infiltrated the wider social, political and philosophical practices as becoming so powerful a philosophy that it was applied not only to the body but it also reinforced the mechanistic and materialist constructions of the body. Coupled with such reductionism and contributions to ascendancy of positivism based on nineteenth century concepts of cause and effect to discover knowledge. The validity of which is dependent on perceived researcher objectivity the body has been, and still is constructed in almost as many ways as there are individuals. Curious!

Positivists, as observers of material facts, have influenced the development of science and what has come to be understood as knowledge in ‘the west’ for several hundred years. Along with the associated ways of conceptualising objectivity and by pursuing truth through philosophic reflection within the practice of scientific inquiry in this form, a certain level of disdain for the body

was being embedded. Grosz (1994) argues that the Western philosophical tradition reflects a profound somatophobia to be found also in the philosophies of Plato and Aristotle with the most explicit statement from Descartes – psychophysical dualism. Berdayes, Esposito, and Murphy (2004) suggests that the somatophobia of western philosophy is not only limited to mind body dualism but is reflected in broader traditions of dualism in western philosophy thus contributing to the practice of *somatophobia* - a generalised distrust of the human element that is reflected in the broad attempts to constrain human subjectivity. I leave this workstation with much to think about not least my intuitive rebellion against being treated so mechanically while currents of emotions and spiritual considerations were colouring *my understanding* of this story. Still in the basement, I make my way to next workstation.

**Workstation Two** -*The Observatory: The observer and the observed who observes*

Stepping into the second workstation, I see a collection of instruments for observation on a workbench. Curiously, each is pointing to another. Wait! There is a sign: “SSSSHHH! *Post-modernists at work*”. I find a note of explanation attached to the workbench: “Researchers’ subjectivities are central to the research process and must be recognised. These scopes have multidirectional lenses. Using these scopes may defrock you of your assumed garb of emotional objectivity. Working at this bench with your attitudes exposed to fellow observers will broaden your horizons immeasurably. Beware!”

I would like to give one of these scopes to my specialists. I am certainly planning to direct various scopes onto him as I am doing onto myself! Under the influence of the icons set out in the first workstation, the specialist had isolated my eye as the visible focus of inquiry. It was considered in its contribution to my (mal)functioning body. But *I Carrie*, woman-in-pain, nurse with a sound understanding of a viable remedy was not being fully considered seemed an invisible aspects of this painful event. Carrie the patient, woman in pain, and skilled nurse had several views on her own eye/I and on the processes of being

observed. As the observer who observes overstepping this limited view. I took matters into my own hands. I record:

*By 9.00am the next day I phoned my GP to tell him how uncomfortable I am now feeling. I have had no relief from the drugs I have at home. The earliest I could get to see an optician was in 2 days. Again I ask: "Why are you making me beg for help? I do not need a routine check for prescription glasses! Supposing the optician has to refer me to the hospital for further tests - then what? So why won't you at least admit me to hospital where the drugs can be administered under supervision? I really am desperate to get some pain relief." In a change of tack, with a very polite tone in my voice, I said: "If you won't admit me to the hospital. I will make my own way there I'm now feeling very nervous about this flare up and the severity of it. I don't want to wait any longer...please send an urgent fax to the hospital to inform them of our meeting and to my pending arrival. Thank you". My GP gave in. He said that he would ring the Ophthalmology Registrar at the Hospital and explain the situation. Hooray! At last some movement. I waited patiently at home for the phone call from my GP to say that the Registrar was now expecting me and to make my way up to the Emergency Department. I knew that part of the test would involve instilling drops of medicine in my eyes and I would not be allowed to drive. I phoned my husband who took the rest of the day off work. I suggested that he drop me off at the clinic and I'd phone him when I was ready to be collected, as there could be a very long wait We said our goodbyes and made our respected ways - me to the eye clinic, my husband to our home".*

*(Personal Journal, 2011).*

To write as I am writing about this experience, I make myself very vulnerable to literary critique. Behar (1996) notes what bothers some readers is the insertion of personal story writing alongside impersonal social facts. When one writes vulnerably, others respond vulnerably. This expression of vulnerability is my intent. As humans, we are vulnerable to each other. Understanding this better is one step to closing the Cartesian Split. It has the potential to re-define centuries of debates about meaning of body. To do so requires a 'two-way-looking' approach. Words are the oblique mirrors which hold one's thoughts. I gaze into these word mirrors and each catches a glimpse into meaning, belonging, and realising. In this layer of my story, I am observing much more closely the doctor who is observing my eye/I. Use of words to describe it is intended as an oblique mirror in which I

am interested in what my I/eye can see from my vantage point when I allow more than a material, mechanistic understanding of my humanity to enter. Reflecting on words and meaning of them I wrote:

*During this acute admission to the hospital and subsequent arrangements made for my follow-up appointments, I found myself thinking about how to report on, reflect in, and write about this experience. This led me to explore meaning of words more elaborately. I now began to re-view and rewrite the process that had me agree to engage (against my better judgement) in reading and agreeing to follow the oral instructions for these eye tests. As my understanding of the investigations developed, my awareness also developed. It now felt like I was back in control of my observed body.*

*(Personal Journal, 2011).*

A much closer ‘look’ at processes opened another important prospect for inquiry. In fostering this inquiring approach to my own life, living my life as inquiry. It encouraged acting with an awareness and ability to assess this action, and thinking systemically, Marshall (1999), whilst at same time being part of this action. By placing my bodily experience in conversation with other scholarly theorists critiquing organisational change I am able to contextualise the ideological issues around visible/invisible chronic illness/disability. In bringing my authorial voice ‘as nurse’ or even as ‘unsatisfied customer’ to direct the specialist and to care for ‘Carrie’ more sensitively required an activism that saw more than the specialists lens allowed for. This two-way-looking approach now began to inform the inquiry as I more artfully and evocatively continue to explore. I am reversing the gaze of a medical encounter from surveillance, regulation and discipline of the body to an expression of a self-actualising [re-animated] body - becoming what one is capable of becoming to *show* not tell how I am *re-visioning, re-thinking, and re-vealing* ideas that are unique to me and unique to the embodied experience. My success at bringing complexity to the process in my own interest pressed me to ‘think on’ in this puzzle about my new life with MS.

With an *eye/I* on my future, I press on and make my way to the third workstation. This workstation is not like the others. The others were open workspaces. This is a smaller work station From my previous exhilarating experiences I encountered along the way in the rabbit hole I am reminded in my experiences of following White Rabbit, of wanting to know how to make sense of

what I have discovered in 'being there'. Alice had said this was place to show how I recognise and understand embodied experience. With my satchel and notes carefully in hand I take time to pause. If I keep very still I think I hear the thump-thump of the rabbit's paws urging me on!

### **Workstation Three - *The Maze-reversing the gaze as a new way of being***

In the third workstation I see a green maze like configuration before me. It is lit up by a row of lights along a mirrored wall. Alice is here. White Rabbit on the other hand is nowhere to be seen! I look around and see a sign: "*The Maze*". I find the colour here very restful. As a nurse I recall that the colour green is deemed to be soothing and calming. This colour is often assigned to the hospital curtains that provide privacy from the gaze (but not the overhearing) of others! I place my satchel down and I take out my notebooks. I liken this maze to a space where I/eye can transition, take time to pause before, during and after the next step of this journey as a performance. I return to the Alice story. The mirrors in this maze remind me of ways that Alice explores changes in her size and the strange spaces she finds herself in the rabbit-hole. I am learning to understand what key aspects of reversed meaning in developing a realising self are most important. With my ethnographic lens in place I bring into focus the social world and topic I am inquiring. Writing evocatively I argue takes a willingness to follow through on all ramifications of a complicated idea as line of enquiry so that a reader can see a connection to some aspects of my experience and perhaps connect it to themselves despite our differences. In Room of Methodology and Room of Being and Becoming I had made notes about the approaches to inquiry, systemic thinking, reflexivity, and call to performance autoethnography from a sensate body. I now re-read them.

As I set out to learn more about and develop how my new way of being informs my realising self, I revisit my notes taken from Marshall (2004, p. 3) on living systemic thinking. She says thinking systemically includes often holding in mind ideas of connectedness, systemic properties and dynamics, persistence of patterns, and resilience, respecting emergence and unfolding process, believing that often 'parts' cannot change unless there is some kind of shift in systemic

patterns, and that sometimes ‘parts’ can change and influence change in a wider system. I think more about this. In following White Rabbit my sense was that this activity was in part my tracking a life story of enquiry. With Alice as my companion I was questioning these embodied experiences in my ‘learning’ and ‘realising’ escapades with MS.

When I experience a relapse of my MS symptoms a sense of curiosity or a new question surfaces through illness, my sensing body is no longer silent. It is again calling attention to itself. This experience that challenges me becomes stronger. It takes me to a new learning. Living systemic thinking is integral in reversing the ‘gaze’ as a new way of being in this enquiry largely in part of who I am, what I study and where I work. The sensing body, I can now confidently claim, has been largely and short-sightedly neglected from research analysis as it cannot be seen or talked about by the other. By being immersed in the topic, I am letting experience inform me, and form how I create my own interpretations, as I set out to develop my trio of concepts; *re-visioning*, *re-thinking*, and *revealing* as heuristic ways to explore sensory experience. I look in my journal where I re-veal this depiction of an illness encounter drawn from my sensing body. I now see a group of more mythical actors waiting as I present this narrative as a next record of this event:

*I was taking the time to carefully focus and look around the room, in order to be ready to be instructed by others i.e. the health and allied health professionals on duty. Feeling vulnerable both as a person with MS presenting at this clinic [with acute optic neuritis] and as a health professional now on the other side (as an observer and now being observed) I noticed lots of instructions, files being placed on the reception desks, staff exchanging notes, staff ushering other people into the clinic. The clock is ticking and it is now the late afternoon. Still no further ahead. I've been waiting here now since the start of this early morning and feel that the time spent here in this clinic is like an eternal time stand still. I am still no further ahead in terms of gaining any relief or explanation...just lots of, "Oh I'm sorry to keep you waiting" and then the riddle..." Oh we have the wrong date can you come back tomorrow?*

*(Personal Journal, 2011).*

I return to the Alice story ‘A mad hatter tea party - where Alice says: “I think you might do something better with the time, than wasting it in asking riddles that have no answers” (Carroll, 2006, p. 70). I am drawn to this comment by Alice as I

reflect on my analysis. I left the doctors examination room feeling that this truly was the stupidest ‘tea party’ I had even been to! I felt that I was being punished by this eternally standing still [tea time] behaviour. I felt insulted and vulnerable. Adapting to the different situations at different times was the impetus for me to capture this event as a lived experience – as my performance. The use of metaphor and narrative woven in and with process of systemic thinking has the potential to act as a stimulus for profound understanding of phenomena through generating new vistas for the reader to view seemingly unique personal events. In providing a record of the encounter to make meaning I expose elements of pain as phenomena that are not seen by others in doing so making ‘*visible*’ the ‘*invisible*’. By offering this unique personal experience of a single event as a story I draw on Ellis (2004) and Denzin (2003) as a source of inspiration in supporting my claim that *my stories* as a call to performance are authentic- truthful accounts.

There is still among some scholars the pressing concerns about the truth of these stories. Hawkins (1999) suggests that to emphasise the story-value element in narratives is in no way a means to denigrate its truth-value. It is important to recognise that in analysis of narrative description of the phenomenological expression of illness experience. The narrative form alters the experience, giving it a definite shape, organisation of events into a beginning, middle, and end, adding emotion and feelings. As Ellis (2004) notes by writing evocatively, engagingly and passionately, the reader will experience what you experience, or remember a similar experience. One should know and understand more at the end than when you began. In writing about my experience, overtly blending a personal account of illness with practical information I was using authorial intent as an organising principle.

For this I was again drawn to Hawkins (1999) studies in pathography, specifically her work on pathographical narratives which offer cautionary stories depicting what it would be like if our ordinary life-in-the world suddenly changed, thus providing a glimpse of what it is like to live in the absence of order and coherence. These are often written with the expectation that the author’s experience might serve as a model, for the prospective reader. Use of dialogue and imagery brings the reader closer into what has happened to you. I set out in the other rooms learning more about how to describe, find and narrate to ‘others’.



Doctors cannot *feel* my pain or psychological distress. They *must* rely for their understanding on the ‘telling’ of those who experience it.

The next part of my story illustrates the reversing of my gaze from the event as they were occurring to much closer reflection on the behaviour of people around me. The positioning of the *realising self* as researcher and the re-telling of my story from a sensing body is intentional and revelatory where in process of enquiry and self-discovery. I write:

*It is now mid Friday afternoon. I have been sitting in the Eye Clinic with my dark glasses on for most of the day... The pain in my left eye absolutely unbearable I feel like I'm going to explode! I am given lots of forms to complete. The irony of the situation is that I am in extreme pain and I am now required to complete detailed forms requiring visual attention before visual eye test can be undertaken. Here I am now, asking permission to wear sunglasses in order to temporarily shield the bright fluorescent light that is causing me more discomfort. Why do I or should I have to be constantly be on guard? Is this not a place where health care and well-being are paramount? To the untrained eye I do not look unwell I am able to communicate despite my excruciating eye pain. I am able to complete forms. It is not my sight that is at issue here – it is my pain. I can still see single objects, it is this intense pain in the back of my eye that is really bothering me: "Please can you tell me how long it will be before I'm seen?" I ask the staff. The nurse in the eye clinic calls me in to perform a routine eye test, which consists of me reading letters from the top of the chart to the bottom of the chart; at a certain distance - this is the test for testing vision. I know I can see. I have completed the forms. It is my PAIN I am seeking treatment for. But I comply.*

*(Personal Journal, 2011).*

I sense that there are still the notions of mechanistic elements ‘man the machine’ present in this encounter. As Hardey (1998) suggests this mechanistic element in the biomedical view, points to a causal chain of events that are governed by complex universal rules. These causes and rules are now open to discovery aided by the use of technology. The last part of my story captures my final attempt to obtain some pain relief:

*With that simple test completed, I am ushered back to the waiting room. The pain in my eye is unrelenting. The lighting in the waiting room is fluorescent, and I keep my dark glasses on for comfort. The nurse gets me a couple of magazines to read.*

*I thank her for this kind thought. I wonder why a health professional, knowing of my condition and distress, would assume that I could tolerate reading. It is now 4.00pm Friday. I am again seated in the examination room. The Ophthalmology Registrar explains what the procedure will entail. I am given a list of instructions to follow. My eye is still so painful and now weeping. I am not able to focus clearly. I follow all of the instructions. I am now seated face to face with the medical specialist. Through a very sophisticated piece of equipment, the Ophthalmology Registrar and I engage in a series of eye tests. I am listening to the instructions and he is looking into my eyes - one at a time. When the tests are over, and I am still in a lot of pain, I ask again about some stronger pain relief to help me get a good night's sleep. Again there is a high level of resistance to my request. I now ask: "What is your problem with giving me, a patient who is in severe agony, some strong pain relief?" The reply was: "We do not want you to become addicted to this medicine." I replied: "Oh please! Do I look like some sort of addict who is going to try and squeeze ever more hard core drugs from the system.*

*(Personal Journal, 2011).*

I was now aware that my attempts to engage in robust open-ended dialogue were fraught with resistance. I was the patient and he the doctor. The doctor embodying this mechanistic stance was defining and treating me. I was supposed to listen and not question. Hardey (1998) writes that essentially medicine was thought of as a mechanism of social control. I was obliged to co-operate with whatever treatment was prescribed not be begging for pain relief. Eisenburg's (1977) distinction between illness and disease attempts to separate a number of dimensions and distinct realities of health: i) patients suffer illness; ii) doctors diagnose and treat; and iii) illness are experiences of disvalued changes in states of being and social function. Toombs (1992, 1995, 2001), a phenomenologist who also has MS, describes similar lived experiences of communication issues with doctors resulting from a fundamental disagreement about the meaning of illness and models of care. In my attempt to access a good model of care I did not want to be labelled as difficult patient or an addict. I simply wanted to 'voice' my subjective feelings of troubled body in pain as a fundamental social right and be granted access to timely pain relief. In the final part of my story I highlight how my body is still being socially controlled and devalued by these prevailing biomechanical dualisms:

*In the midst of pondering over my limitations again I feel that I'm being drawn to the rabbit-hole. Concerned with how things would end up, exhausted and still in pain the thought of returning back again for more tests the next day was unbearable. My subjective experiences of pain were viewed by the doctors a malfunctioning thing in my body - labelling the condition on appearance of signs and symptoms only as a body that needed to be fixed. Finally, I am given a prescription for a medication that I must now self-fun.*

*(Personal Journal, 2011)*

I also feel elements of sadness that as an educated woman and a highly trained nurse, in my hour of need I was let down by a system that would not listen to my body. How does someone who does not have my training get on? I am left with mixed feelings. With all the frustration, anger, and fear, there is also sheer delight that I was able to capture the essence of these experiences as not only a research project that has been able to show my experiences and one that has been able to showcase autoethnography as a valuable research method. I have shown also how the process itself has changed me. I wrote:

*Is the illness that co-habits my body a destroyer or liberator? I chuckle...why it is a liberator... This was a liberating dream!*

*(Personal Journal, 2011).*

I need to make some time to think through all that has happened. All of a sudden, it came to me! I had it! "Carpe diem"- I fondly remembered the phrase from my school Latin days. "Seize the day"! That's an inspiring thought. Yes! It is time to go home! I picture myself back on the porch at my home, thinking about all of my adventures. How I long to curl up on my favourite red rattan chair and think about all that has happened to me in this House of Learning.

### **A continuum not a conclusion**

"Wake up, Alice dear!" said her sister. "Why, what a long sleep you've had! Oh, I've had such a curious dream!" said Alice. And she told her sister, as well as she could remember them, all these strange adventures of hers it was a curious dream what a wonderful dream it had been.

Lewis Carroll, (2006, p. 127).

As a *learning* and *realising self* my new way of being equips me to testify that I now have the capacity to transform my experience with MS in ways that focuses on the cultural as well as individual methods of coping with illness. In the various rooms in this magical House of Learning, I have been following White Rabbit. Alice has been my companion. For the last time I look to Alice. She is saying: “You have reached the end of your stay in this House of Learning. It is now time for you to go back to your home. I have one last direction. Ahead is a staircase with eleven wooden steps. Climb all eleven of them up to the top landing. From the landing walk on towards the exit sign. There you will find a door to open and yet another set of steps leading outside towards a path. Follow the path. It is familiar to you. Soon you will arrive at an enclosed area. It is called ‘The Porch’. This will be a very good place to sit and think about all that we have experienced in our time in the House of Learning. Good-bye Carrie”. Before I set off I say: “Good-bye Alice! I shall never forget you. I’ve had such a splendid time”.

I look back and I see Alice waving me on. White Rabbit scurries by. I follow him to the staircase. Sure enough there are eleven wooden steps leading up. There is a beautifully carved handrail. I can see a door on the landing above. As I start climbing the stairs I wonder how I will remember Alice and White Rabbit once I leave this House of Learning. I have another ‘Aha! Take me’ moment prompted as before by my thoughts of Alice: “They will be my ‘Alice & White Rabbit’ bookmarks”. I will carry these with me should I ever need a guide or two for another adventure. This one has been most exquisite! My time in the House of Learning has felt like one very long dream. But it must have been real because I have with me a compendium full of notes about the insightful writings from an array of wonderful literary people whose work was so inspirational for the storying of my *being* and *becoming-in-the-world* with MS.” I keep climbing the stairs and step out onto the landing. I make my way towards the exit sign and open the door. I see the next set of steps leading outside towards the path, just as Alice said I would. It was indeed a very familiar path. I soon see the place she called “The Porch”, the place I would be able to sit and reflect, and if I want, to (re)vision my story.

I want to revisit a couple of the theorists I met in *The Vestibule of the House of Learning*. I also want to reflect a little more on the value of Marshall's ideas about living life as inquiry she published in 2001 and 2004. Her notions of quality note/inquiry intent in first person inquiry invite more questions about the intent of my journal entries and my choice of their re-telling. The challenge for me remains how I make sense of these narrative accounts and how to utilise this journaling towards deeper learning. For that, I would surely need to revisit Ellis's work *The Ethnographic I and Revision* published in 2004 and 2009 respectively. These works provide the approach through which to *show* how in personal storytelling revision(ing) is crucial in the re-visiting and writing these personal vignettes that have come to show me so much more than on their first reading. I want to reflecting anew on the related experiences of living and working with MS I have been thinking about in this House of Learning. I can see now how all experiences can be re-viewed as 'a performance' and as such are contributing to how I view and produce the autoethnographic layering in my story. The additional rewards of new interpretations enable me to keep the story line alive in my head as well as on the page. It might be expected that I should provide a conclusion to the story of my escapades in the House of Learning. But there will be no conclusion. MS will stay with me. I will keep learning. I prefer use of continuum as MS is a never ending storied reality for me. It will provide the substantiating reason for 'being there'. I am quite giddy with all the thoughts in my head. I need to sit down!

As I make my way to The Porch I see a small table and my favourite red rattan chair. Now how did this get here? I stop wondering! Given the mysteries I have experienced, I am just glad to see it! Perfect! This is where I can sit and reflect. I now have so many images, notes, visions to *show* how events on the fateful day of my diagnosis with MS changed my self/hood, being, and worldview of embodiment and experience. I have my compendium in my satchel that Alice said I should keep as it would come in handy. It certainly has! I have added more notes and made some concise summaries. It will be good to look back over these to see what stands out!

## **CHAPTER SEVEN**

### The Porch



## CHAPTER SEVEN

### The Porch

*"Look deep into nature, and then you will understand everything better."*

*(Albert Einstein, n.d).*

I am sitting in the red rattan chair in The Porch that Alice has directed me towards. It is a beautiful summer's day with not a cloud in the sky. As I look around me I place my satchel beside the chair readying myself as I think about all that has happened since my confirmed diagnosis of MS in 1998. I take out my compendium and the collection of notes and re-read the story I wrote to describe the metaphorical home of this enquiry - the rooms, people, books, and gadgets I found there. I think of the fictional characters of Alice, White Rabbit, and the others and all the curious adventures I encountered in the House of Learning. What an exciting time I have had on these subterranean adventures! Out of the meetings with these remarkable literary people and in the writing of my life story, I have concluded that the transformational learning and leadership that can bring forth such generative change is more about 'being' than 'doing'. The decision to use poiesis [as process] has shown its appropriateness for the purposeful and intentional creation of meaning in my work.

I created the Alice and White Rabbit bookmarks [as product] for purposes of revising, re-thinking, and re-imagining ways for learning and realising embodied change that *I Carrie*, embrace. It feels fine to now report from The Porch that the rooms have been explored and the bookshelves are restored. In my compendium I have a collection of the summaries of notes placed in six folders. These will be references points from where to source the ideas from this enquiry that offer nourishment and relevance for organisational learning. I now see that the material in the compendium can be used to 'show': i) creating shifts of knowing and learning; ii) autoethnography as guide for developing leadership; iii) lived experience of being in some body; iv) unfurling knowledge as meaning; v) finding pieces for the organisational puzzle-implications for health professionals; and vi)



worlds of possibilities recommendations that have come to me from my time in the rabbit hole.

### **Creating shifts of knowing and learning**

The Caterpillar and Alice looked at each other. "Who are you?" asked Caterpillar. "I-I hardly know, Sir just at present—at least I know who I was when I got up this morning, but I think, I must have been changed several times since then". "What do you mean by that?" said Caterpillar—"explain yourself"? I can't explain myself, I'm afraid, Sir", said Alice, "because I'm not myself you see" and she admits to her current identity crisis, compounded by her inability to remember a poem.

Lewis Carroll, (2006, p. 43).

I open the compendium and I 'see' that the first folder is labelled: "*Creating shifts of knowing and learning*". The title ignites my curiosity. Keen to read more about all I have seen and learned about from my time in the House of Learning I open it. I 'see' a summary of my notes about the inspirations I have drawn from Lewis Carroll's *Alice's Adventures in Wonderland*. I 'notice' an excerpt: "Advice from a Caterpillar" from the Lewis Carroll's story. I remember choosing this extract because it playfully aligns with how I was feeling at that time about my illness. With MS I could never know what would happen next. Like Alice I too was being transformed and there was much to learn. I was drawn to the storyline as it intentionally plays with reversed meaning; its narrative course provided some respite from the brutal and at times harsh world of MS. With Alice as wise companion, and in following White Rabbit [the animated version of MS] as a teacher I read about my experiences in learning to 'see' and 'notice' and what lessons might be drawn from all I have learned. One memorable experience that immediately came to mind was the skill of: 'How to look first'. Now adept at this I put it to good use.

I now 'notice' a small lectern that has a wooden carving of griffon at the top and a rabbit prominently placed at the bottom of it. A griffon and a rabbit! What did this signify? Seeing the carving of the rabbit evoked so many wonderful memories of my subterranean adventures. Like Alice, I had been getting very tired of sitting and waiting when suddenly I noticed White Rabbit, followed him, and

jumped into the rabbit hole! I re-visit my scintillating experience in the Vestibule. There I had found a beautifully carved large lectern and a book opened at the page: “*Autoethnography*”. There I met some wonderful literary people and fictional characters that have become embellished this storyline. When I look back on all that has happened these figures are symbolic and have provided much exaltation. I remember some of my reveries in the prologue where my wise grandmother mused on life. She commented on her intuitive way of knowing as seeing with the third eye: “The ‘blue eye’ is to ward of the evil eye”. I did not know what she meant when she gave me that ‘blue eye’ pinned in the inside of my coat. Her words and the image of the blue eye have stayed with me. Years later, I still carry this image and reveries of it. I have MS. I read my notes. I see how I have been learning how to ‘see’ and ‘notice’ the *invisible* MS symptoms that only I feel, and that others seemingly do not ‘see’ or ‘notice’. It is a narrative of the day-to-day life with MS that illustrates what my life with MS entails.

It is through these narratives that I can show what adjustments have been made, how I have changed, how I have adapted and re-adapted again and again in keeping up with the demands this illness makes on my being. With my new way of being *I Carrie*, have transitioned from being a person-without-MS to being a person-with-MS. I have transformed the object of the medical gaze, the body that has MS, to *Carrie* who lives creatively and positively with MS. I turn the page and read on with tremendous enthusiasm. I can see now the rooms I have visited are chapters of this thesis! My story as a report – perhaps somewhat unusual for a PhD – has been crafted to show my struggles and growing insight – just as they occurred. I am the living detail. This is my *life story* about my research into concepts of *self*, *body* and *work* and the emancipatory promise of autoethnography. I have been researching these by ‘doing’ autoethnography and by ‘being’ there in the House of Learning.

[E]ngaging both a description of autoethnography as research method with which to write evocatively about lived experience, and as an argument for the benefits of autoethnography to present issues in our lives in creative ways in the exploration of human caring, the following summaries of my chapters can now be written. The discussion in *Chapter One: Introduction to Home of the Enquiry*, in its factual content, humour, and honesty were revelatory to me; it enabled frank disclosure of personal experience in a way that makes this approach to research

deeply insightful. My use of Lewis Carroll's *Alice in Wonderland* became my internal frame of reference for the story I wanted to tell. Fictional characters were intentionally crafted to align with the use of metaphor. Images were the embellishments to carry the storyline. I created a metaphorical home 'A House of Learning' where rooms, bookshelves, passages, mazes, and doors are 'devices' for crafting the storyline that was to carry my narrative. Within my auto-ethnographical framework these devices allow the intertwining of key concepts of *self*, *body* and *work* as mutual organisational relationships. The congruency with positioning of researcher, location, focus of research topic are outlined and revealed.

An important part of my life story in this enquiry is honouring the memory of discrete experiences and seeking ways to describe, explain and understand what had happened to me. Drawing on Ellis's (2009) approach of autoethnography significantly influences use of storytelling as the means to 'see' and re-discover the past not as a succession of events but as a series of scenes, inventions, emotions, images, and stories written by author within the particular conditions applied by author. In autoethnography Ellis (2004, 2009) adds the story and the 'I' in the story comes into being in the producing and in the telling. As an autoethnographer, I am author, creator and focus of the story, the one who shows and experiences, the observed and observer who 'sees' and 'notices'. I purposively aligned my thinking and observing with internal frame of reference as ethnographer and in the writing and describing I am storyteller. In drawing on personal experience multiple layers of consciousness were being brought to new levels of perception connecting the personal to the cultural and social (Reed-Danahay, 1977; Ellis, 2004, 2009). These have become experienced as a way of transforming self to 'a *learning* and a *realising* self'.

Embracing the Alice story and personal writing has helped me draw out and let go of some of the doubts and feelings of bewilderment I had experienced after being given the confirmed diagnosis of MS. Presenting my narrative in this way was intentional as I set about creating these distinctive shifts of learning as ways of knowing, use of reflection and reflexivity as process were pivotal in questioning the relationship between myself, the research account, and my being in the social world. As such a particular moment of my life the confirmed diagnosis of MS was the impetus to craft this autoethnographic enquiry and

incorporate use of metaphor in my writing. I decided to use metaphor because it generates lifelikeness and has the capability of bringing new things into consciousness leading to initially unperceived understandings of knowledge. The metaphor I used is a journey ‘down the rabbit hole’. This journey is centred on my way of giving meaning to my life after my confirmed diagnosis of MS.

Still intoxicated by these captivating experiences and an unbounded curiosity with the antenarrative, the narrative, and my life story I fondly remember seeing Boje’s (1991, 2001a) annotation in *Vestibule* and I think on the notes taken in the *Room Being and Becoming*. I re-call that my antenarrative began in 1998. I was searching for a way forward to make meaning of my new identity and way of being. Use of the ante narrative provided access to bodily knowledge and a glimpse into what Van Maanen (1988) calls the ethnographers own taken for granted understandings of social world under scrutiny. From my exploration of poiesis in developing creative ways to write about a new way of being I learned that through being immersed in experience, motivated, and in expressing it, these ways of learning and knowing breathed new life into my thinking my life story. The method of autoethnography as ‘process’ and ‘product’ allowed for a focus on life experiences as centre of interest that become my stories as autoethnographic representations of the ‘process’ depicting the difficulties and challenges of living and working with MS. As ‘product’ it enabled the laying of narrative positioning of ‘being there’ as the various parts of the journey portrayed in the story are pondered, explored, and explicated.

In writing autoethnographically I describe a situated story constructed from my current position of person with MS. It is a story that uses excerpts from personal journal entries that sometimes contain partial comments of an event, captured at a particular time and for a specific purpose of constructing a reality, meaning-making, and narrative positioning. In constructing a reality ‘being there’ is conveyed by my narrative positioning. I argue I am the best informant from whom the ‘deeper’ experiences regarding complexity and clinical uncertainty can be sourced. Gubrium and Holstein (2009, p. 213) claim that narrative positioning of ‘being there’ provides a figurative as well as empirical anchor for description, supplying a basis for treating accounts as factual because the author is in the know. From firsthand experience I reflect on what it is to be a good storyteller and what constitutes a good story.

In in the context of writing narratively I am constantly in touch with my feelings and emotional experiences re-vealing, re-visiting, and re-visioning embodied experience of MS as my storied reality. Gubrium and Holstein (2009, p. 212) tend to consider that a storyteller who has access to the experience being narrated is a good storyteller. Those with privileged knowledge are also regarded favourably. An authentic storyteller is one that is in touch with his/her phenomenological and emotional experience and one who will reveal his or her own true experience. I 'show' that my narrative positioning incorporates all these aspects of access, privilege and authenticity when exploring questions of embodiment and experiences. Sparkes (2004) suggests that such questions relating to embodiment can reflexively shape meaning and analysis. So what do my experiences of MS now reveal? In writing about them I borrowed terms 'particular' and 'singular' to describe what my embodied experiences reveal, each was unique and could not be replicated. Madden (2010, p. 162) writes all ethnographic projects have more or less limited scopes and general questions, and to a greater or lesser extent reflect the intellectual motivations of the ethnographer. They are meant to be particularistic accounts that are their strength.

By revealing experiences and feelings of self, I share intimate and emotional accounts of my experiences with MS. Some of my stories are painful and some are amusing. Often they are both. Some I re-visit, revise, and restory. This cyclical reflexive process is purposeful as I signal for reader the 'particular' and the 'singular'. The confirmed diagnosis of MS was the particular event that is woven throughout my enquiry. I draw on Johnson's (2007) approach with meaning-making activities as ways to equip 'self' to notice and know as ways of learning and realising. In making visible the invisible troublesome MS symptom of optic neuritis I am noting this in my journal as the singular event. As an autoethnographer I re-visit, re-think, and observe in writing as storyteller how I may re-veal the particular and singular conveyed in vignettes [as performance] showing a learning self, writing evocatively about a troubled body. Focusing on Denzin's (2003, 2006) notion: 'I universalise in my singularity this historical moment - each of our singularity is unique' was revelational. Each MS relapse I reveal is unique it was my singular historical moment.

Through autoethnography I respond to Denzin's (2003, 2006) 'call to performance' an act of intervention, in the singular to be used as an organising

concept for examining phenomena that connects reflexive autoethnography with critical pedagogy. I argue that as performance, my stories reveal experience as ways of writing that illustrate a release of human possibilities enabling self to break free of limitations created organisationally or self-imposed. These stories create shifts of knowledge. In making visible highly personal aspects of my life I am able to go more deeply into the enquiry. I can now offer to connect this to learning organisations and to management studies where credibility of this research report is established through the verisimilitude revealed in the 'particular' and 'singular' as truthful storied accounts where the political becomes personal and pedagogical.

My quest in these creating shifts of knowledge arose out of a particular event in my personal life forever etched in my soul: my confirmed diagnosis with MS. Facing this change in my life has led me to explore Jaworski's (1998) notion of synchronicity as a process of inner transformation. By living in the moment learning to 'see' and 'notice what changes have occurred to my body I gained a better understanding of the uncertainty and complexity of neuropathic pain. Through my reflection on the traumatic attempts to get relief for my pain I have recorded questions about the residual damage I would be left with [if any]. Would I be able to regain normal vision from the left eye? These questions prompted more mini shifts of enquiry within a larger action inquiry. Marshall's (1999) living life as inquiry influenced my thinking as I tracked back and forth, between now and then. I saw tracking as a developmental opportunity to research the deeper transformational meanings of being human and of always becoming. Braud and Anderson (1998) argue personal transformation of an extraordinary experience has been systematically excluded from conventional research. The methodological approach of autoethnography would enable self to reflexively revise aspects of own life exploring uncertainty and emotionality. Ellis (2009, p. 16) states autoethnographic approaches are flexible, and reflective of life as lived; they do not follow a rigid set of rule based procedures and often they are multi-voiced.

These unbounded ways of crafting layers of story with use of metaphor and narrative positioning generate the development of [e]merging theory and story with interpretation of this new way of my being and becoming-in-the-world with MS. I live with uncertainty. Uncertainty hurts. It is my hope that once health

professionals recognise that uncertainty is everywhere and why this level of uncertainty demands their attention, they can address it. Rosenberg (1998) suggests adaptive strategies for dealing with uncertainty with the shift from ritual humiliation to the development of self-directed learning represents one of the most exciting developments in undergraduate and postgraduate medical education. Coping strategies involving psychological preparation and effective communication techniques that 'recognise' and 'not fear' clinical uncertainty, as well as practical techniques for converting clinical uncertainty into answerable questions will ensure that best practice and learning is kept up to date. The approach of autoethnography will assist in describing lived experience of 'clinical uncertainty' with MS so that in the future *I Carrie*, will be better prepared to address with health professionals and carers, uncertainty and unpredictability with MS and illnesses such as these. The folder I am still holding in my hands is called: Creating Shifts of knowing and learning. This has certainly been occurring for me. I am captivated by all I have read so far! The sun is still shining. I delve further into the compendium and see the second folder I prepare myself to read on.

### **Autoethnography - as guide for developing leadership capacity**

The folder I open is entitled '*Autoethnography as guide for developing leadership capacity.*' I 'notice' the words autoethnography and leadership. These words suggest scholarly and yet most interestingly profound messages that were not so clear to me at the outset of my enquiry. These concepts, I 'see', are equally important for those interested with and participating in, shaping the future. I also 'see' from the notes taken when exploring the Room of Methodology in *Chapter Two* an in-depth discussion on autoethnography as method and methodology. Written predominantly in first person, autoethnography is a style of theorised writing based on personal experience. I learned that in this approach the defining feature of autoethnography is that the gaze of researcher is turned on self rather than on defining and representing others. The writer does not adopt a presupposed objective outsider position when writing about others. Autoethnography entails writing about oneself, as a researcher performing a narrative analysis pertaining to one self that is intimately related to particular

phenomena. It is not an autobiography in the literary sense. My report is a specific form of critical enquiry embedded in theory and practice incorporating elements of my own life, transcending everyday conceptions about self and social life. I have my notes from Ellis (2004, 2009), Ellis et al. (2011), Chang (2008), and Reed-Danahay (1997), who write in the broadest sense this writing can be considered autoethnographic or doing autoethnography. Their comments further endorse my approach where through my autoethnographers eye/I and with my investigative gaze this report represented doing autoethnography as process and textual product.

I learned in being autoethnographic what definitions and applications of research term methods are. Simply put these are the 'tools'. My reflections on methodology provide an explanation of how and why I came to use these 'tools'. Journal notes as entries used in my writing denote personal experiences written in first person narrative crafted as *my life stories*. These stories, I (as Carrie) might be said to represent 'the data' [to use a familiar but not uncontroversial noun]. I have chosen to use the word 'detail' rather than 'data' to describe my individual experiences fully. I am 'the living detail' [perhaps better thought of as a verb, a process, or an energy]. My stories and my journal entries are my 'field-notes'. The use of the autoethnographic framework provides for use of "*I*" as positioned in this narrative inquiry - an 'I who provides' an 'eye that sees' differently to that of the medical gaze. As an inquirer I conducted an extensive review of the literature drawn from theory of sociology, anthropology, ethnography, autoethnography, organisational learning, management studies, nursing, philosophers Aristotle, Heidegger with the combination of research and writing about the human condition.

The research terms ontology, epistemology, axiology, rhetorical structure, and method that were outlined in order to discuss the strong philosophical grounding and intellectual justification of insider/outsider, subjectivity/objectivity were explored as were ethical requirements from the very outset of the enquiry, and throughout all stages of the research and writing. I learned that *ontology* is the study of being(s). I used my topic to explore some of the fundamental aspects of human experience dealing with the nature of being. *I am Carrie* who lives creatively with MS – a very different being from 'Patient Caroline' who has MS and is the object of the medical gaze. Autoethnography as used in this study aligns



with notions of lived experience, subjectivity, and meaning of knowledge. It is my way of coming to know. I make distinctions between constructivism and social constructivism through my reflections on the topics of pain and illness. Each itself are highly conceptual topics that I argue are often the most difficult to access through traditional research methodologies, or as Leavy (2009) suggests, which may fail to get at the particular issues they are interested in or fail to represent effectively. In terms of its *axiology* this autoethnographic account is upfront and transparent in that it combines the method with the writing of the text, which in turn explicates the personal story of the writer, within the social cultural environment in which experience took place. The *rhetorical structure and method* in autoethnography may vary because, as McIlveen (2008) notes, there are few regulations on how to write an autoethnographic narrative. As it is the meaning of the story that is important - rhetoric and method are closely aligned in autoethnography because method requires rhetorical expression in reporting.

I became interested in the distinctions within genres of social sciences between possibility or desirability of assumed objectivity and subjectivity. Chang (2008) notes the objectivity position promotes a scientific systematic approach to data collection, analysis and interpretation can be validated by more than researchers themselves. The subjectivity position allows researchers to incorporate their personal interpretations into research process. Atkinson (2006) aligns with Anderson's (2006) stance towards objectivity - the analytical, theoretical, and objective approach to autoethnography. Ellis and Bochner (2006), and Denzin (2006) argue for a more evocative and emotional approach engaging in more subjective autoethnography as narrative method. If autoethnography is to be viewed as a narrative form of writing Pentland (1999) says it can be seen as a way of knowing constituted by one's thinking and making judgements, about what can or cannot be addressed in the here. Narrative is relevant to analysis of organisational processes because people do not simply tell a story - they enact it. Dyson (2007) says that it is essential that autoethnography as a narrative form of writing is re-vealing and be written in first person. There are still some debates about the efficacy of writing in first person. Conventional forms of research compel authors to refer to themselves in third person, as the researcher reinforcing the passive voice. I can almost hear Alice say: "How curious!" With forms of

ethnography and autoethnography gaining popularity writing in first person brings with it a personal accountably and an active voice.

In my enquiry I align with the subjective stance of writing about a personal topic constructed from self-narratives about my *being* and *becoming-in-the-world* with MS. I use emotional re-call, Ellis (2004), and critical reflexivity, Cunliffe (2011), to *show* how self-reflection offers an opportunity for self-transformation through learning and realising. I argue in choosing to write openly about my personal experiences, autoethnography is the most appropriate choice to author a personal journey that can provide an inspirational guide for developing the most essential leadership capacity in learning about organisational learning and its effectiveness. On a personal level it can offer a transformative liberating influence from this all too at times painful oppressive illness. Through this relationship, *I* am *Carrie* who makes active choices to sometimes follow White Rabbit and sometimes to engage with him in a vigorous discussion. I have created a Carrie who engages with White Rabbit enriched through reflections on Alice's thoughts, processes, and decisions in times of confusion and distress. I have found this to be a passionate and evocative way of humanising this experience of living with an incurable degenerative illness. This research has allowed me to *make rather than discover* meaning that for me engender a fruitful future for myself and provide an evocative insight for those who care for people with chronic health conditions. I have introduced Alice whose story came to inspire my own and whose journey into the rabbit-hole provided the inspirational arrangement of my investigation as a research story which in following chapters followed being my storied reality.

In the storyline I view semiotics of the eye as symbolic of the self, the I. Where the eye is the I; and the I is the eye. With the *eye/I that-sees-and-writes it becomes* the *I/eye-that-writes-rights*. The growing story of my illness experience of *being* and *becoming* in the world with MS beginning with the prologue then crafted across Chapters One to Six. I show how, as I stepped up my pace on this path, I gathered companions from several disciplines and associated characters from Lewis Carroll's' inspiring take of *Alice's Adventures in Wonderland*. Although initially I did expect some confusion from myself about my own understanding about MS it was the many contradictory and ambiguous remarks made by health professionals that I found most perplexing. It was this personal call to create a life story of identity and meaning, that I wrote this meaning

making autoethnographic inquiry in which I could tell my story. In doing this I was coming to terms with my confirmed diagnosis of MS, learning about it, and facing a new future life beyond the diagnosis. Of great importance in this process was my desire to imbue this inquiry with my compassion including personal emotional experience, a greater self-awareness of the experience of MS, sense of confidence, purpose and meaning.

The passion that I have for the care of others affected by MS affects my own life. I have sought to authentically humanise what can be a most devastating, and profoundly life changing ordeal. Reflecting on this now a decade on has provided me with a some different perspectives: i) I have re-defined some of my values; ii) I have discovered the pleasure of learning how to live in the moment; iii) I am more trusting of where the winds of change may take me; and iv) I view this change as an opportunity to embrace the challenges of living with MS. My confirmed diagnosis of MS started me on this odyssey of learning that has been invigorating and very difficult at times. For me, the medical care and prevailing views on illness were the impetus to seek ‘other’ ways of thinking about the meaning of the body. Conventional methods of care viewed my body as broken and needed to be fixed. Within this body are my soul and an enquiring mind. I wanted to look more deeply at ‘self’- ‘other’ interactions of those health professionals who deliver care for chronic illness and MS and for those who must seek it, as I do. I wanted to uncover the personal meanings and implications of my diagnosis. These hunches, intuitive feelings, journal writings were supportive of my unconventional approach of exploring embodiment and experience. My journal notes emboldened the possibilities for exploring the benefit in treating ourselves as enquiring minds and soulful persons, not just broken bodies. Unbeknown to me then, I was at the start of my heuristic odyssey. Einstein (n.d) says *‘curiosity has its own reason for existing’*. Curiosity has led me to explore alternative ways of making and finding meaning. My writing up of it is intended to gently push the boundaries of ethnographic research, social critical learning, and organisational learning and management studies.

In looking to align my personal story within the disciplines of leadership theory and organisational learning it was to Ellis (2004, 2009) *Autoethnography*, Moustakas (1990) *Heuristic Inquiry*, and Jaworski (1998) *Synchronicity* that I returned to for inspirational guides for developing new understandings and new

learning. I wanted to create, show, and do something personally rewarding and beneficial for learning organisations and health care delivery practices. In order to bring this about and to arrive at a new level of consciousness it required of me to think and reflect in a state of mind grounded in this different commitment to my new way of being with MS. Jaworski (1998) says something starts to operate around us. One could call it attraction - the attractiveness of people in a state of surrender. He comments when we are in a state of surrender we begin to experience synchronicity. Moustakas (1990, p. 24) calls this indwelling which involves the willingness to gaze with unwavering attention and concentration into some facet of human experience in order to understand its constituent qualities and its wholeness. It is conscious and deliberate rather than logical or linear. As an emergent autoethnographer seeking new ways of learning I was living embodied change, virtually any feeling, hunch, or emotion connected with my research question became rich material for immersing self in the research enquiry. This involved taking journal notes and expanding their meaning and associations until a fundamental insight was achieved by *tacit knowing*. Schon (1983, p. 49) writes our knowing is ordinary tacit, implicit in our patterns of action and in our feel for the experiences with which we are dealing with. Polanyi (1966) says we know more than we can tell it cannot be put into words but is at work behind the scenes. As a learning self the tacit dimension was my guide into the untapped directions in the rabbit-hole. These synchronistic experiences launched the utilisation of this tacit sense expanding my self-awareness of being in the world with MS. Personal experience now beckons me to see things in a unique way that is different from my predecessors and how others may see things. Quantum physicist Goswami (2001) describes this idea of personal knowing. We are each one eye in the big eye of consciousness we each have something unique to contribute - our own personal perspective.

It is through autoethnography that I now make some suggestions for those who must, as I must, live with MS. I think of those others who have a chronic illness and for all those who care for them, professionally and as caregivers, families and friends. I am intentionally contributing to shaping the future by making a contribution to the craft of action research and heuristic inquiry. I do so by the amplification of Nash's (2004) Scholarly Personal Narrative (SPN) expressing an 'authentic voice' in scholarship and its emancipatory approach to

organisational learning and management disciplines. I show that leadership and institutional change can and must occur. I offer this example as a guide to develop the leadership capacity for those who work with and those who care for individuals who have a chronic illness. It will strengthen and contribute to fostering personal mastery of living systemic thinking and its emancipatory aspirations for self and others for source of meaning. I now reflect picturing all that has happened to my selfhood since the diagnosis of MS, it is in crafting a personal story of personal and professional change using autoethnographic vignettes that illustrated what Van Maanen (1998) calls the ethnographers own taken for granted understandings of the social world under scrutiny. It was a means of enhancing reflexivity 'showing' how I managed such a profound embodied change to my way of being. Leadership! Of course! What an important dynamic of being-in-the-world *as nurse, as teacher, as researcher living creatively, generously, and courageously with MS*. I can lead change! What a useful folder! I carry on rummaging in the compendium and take out another folder. Its title is: *Lived experiences of being in some body*. How apt!

### **Lived experiences of being in some body**

I open the folder: "*Experiences of being in some body*". I read as to why, with some trepidation, I committed to researching 'how' to become an emergent writer of autoethnography. Having taught papers in nursing knowledge and research methods in my nursing career, I was familiar with the work of Ellis, Denzin, and Moustakas. From the position of a person with MS however, I had only the barest understandings of what it might be like to write self into an enquiry and what this process might mean. An interesting change in life style and identity had now surfaced. This challenge presented by MS became a crucial and conscious turning point in the sense of self and my being-in-the-world. *Chapter Three – The Room of Being and Becoming* is told through autoethnography and call of narrative. Personal vignettes are incorporated in body of text with reflection analysis. The discussion [e]merging story and theory outlines placement of self in the enquiry. I am following White Rabbit and Alice is my guide. As researcher I 'become' the phenomenon under investigation. The adaptation of the

Alice story was the internal frame of reference for highlighting feelings of curiosity, a need to know, and how in the process of be-coming every time *I Carrie*, encountered something new, *I Carrie*, became something anew. Living embodied change and this idea of personal knowing corresponds to and is illuminated in what Goffman (1959) repeatedly reminds us of: the performativity of everyday life.

In the preceding room discussion of the philosophical basis of autoethnography is kept in focus with Ontology of being where detailed questions about ontology and philosophy of being are robustly discussed. From my earlier beginnings of when I was first thinking about this topic, it was the formal commitment to this thesis that enabled me to explore how to be an emergent writer of first person narrative. I learned how to make sense of a narrative account of identity and meaning-making in ways I never have or had thought to. Through autoethnography I position myself as work in progress - a work of poiesis, creativity, inspiration and imagination. I explain in my research project intentions about being as caring for self and other, where through being and becoming I become Carrie who lives creatively with MS. I discovered that learning to be an autoethnographer is now wholly entwined with what it means to learn about how *I Carrie*, am learning to live creatively in the world with MS. It is a path of learning that has become the substance of this PhD. This publication is the life story of a research odyssey that, had it been undertaken in another genre, might be called a report of findings. I prefer to call it showing how *I Carrie*, morphed from being diagnosed as an object of medical concern [a medically framed de-animated body damaged by MS] to *Carrie* who lives creatively with MS [as a whole and spirited being] determined to live life to the full. I have undertaken to build on the inspirational work of Ellis (1991, 2004, 2009) to write an evocative narrative: *I Carrie*, who has MS that draws on introspection to examine what these emotions felt like and how they were experienced.

I do so in this report, by what Freire (1970, 1972) advocates for in times of uncertainty: to make the path by walking. As my feet became more secure on this chosen path of autoethnography I found the creativity to be found there to be inspiring. This genre demonstrates the appropriateness for there to be more than a de-animated reading of what embodiment and experience entail. It provides an opportunity to contribute to the paucity of literature that reflects what it is to make

meaning of a confirmed diagnosis, or the finding of MS in one's body. Feelings and confusions must be made sense of. To do so requires use of reflection and reflexivity. I re-visit the experience by using Ellis's (2004) strategy of emotional re-call of the event enriched with the greater advantage of distance and life experience between it and this how I am showing it. Reflection on the experience itself providing for the transition from being immersed in the experience to becoming a learning self from the enquiry. Showing one's story through revisiting experiences constitutes an active and reflexive form of enquiry. Experience sourced from memory (aided by journals), is drawn into vignettes, and interpreted with layers of analysis gained from the intellectual tasks of self as researcher. Many threads of my personal story with emotion are woven tougher and made visible through the evocative style of self-narrative providing the means for re-negotiation [with self] as I continue to interpret, question, re-interpret and re-story subjective experience. I am aware of criticisms of this approach by some scholars who claim it is narcissistic, self-indulgent and not objective. I make no apology for positioning myself as the centre of this enquiry. I concur with Ellis (2009) who argues that by including emotion and acknowledging the importance in writing personal narratives, one does not need to apologise for its lack of objectivity. I have adhered to Ellis' (2009, p. 308) relational ethics where she encourages researchers to act from our hearts and minds, to acknowledge our interpersonal bonds to others. The concept of relational ethics is closely related to an ethic of care (Noddings, 1989, 1984).

This study makes a worthy contribution to study a call for organisational change in health care communities - in its advocacy of narrative and autoethnographic vignettes as a means of enhancing the representational richness and reflexivity in qualitative research. It is my hope that this research and its creative approach will breathe new life into disciplines of social sciences, organisational management, and critical social theory, responding to Denzin's (2003) call to performance ethnography by gently expanding the scholarly work/horizons of ethnography, autoethnography as an emancipatory discourse connecting critical pedagogy with new ways of poiesis, imagination, and meaning-making contributing to and influencing radical social change. A change, according to Denzin, autoethnographers should be part of. It is a change I aspire

to becoming a part of! In which progress can be made in improving health care practices of caring for PwMS, as well as leadership and organisational learning.

I had now spread the entire contents of the folders from my compendium about on the table. As I continue to reflect on all I have read about ‘self-other’ interactions I realise how these notions are so entwined! I see two more folders left and pick up one of them to read on. Its title is: Unfurling knowledge and meaning - as gateway to dialogue. Fascinating!

### **Unfurling knowledge and meaning - as a gateway to dialogue**

I pick up one of the two folders yet unread. On the cover of this folder are the words: “*Unfurling knowledge and meaning*”. I am enthralled. I read where in *Chapter Four - The Room of Demonstrating* is narrated through use of autoethnographic vignettes which discussed use of poiesis, fiction, imagination, and mythical characters as creative ways of demonstrating my being and becoming an autoethnographer. There we met Morpheus and Neo who were integral parts of the emerging storyline and meaning-making of the matrix. Here my focus was to de-mystify the dominant ways of looking and writing about illness and disability. By shifting the textual and representational issues ‘showing’ that style and creativity in autoethnography is about ‘caring’ and about ‘dialogue’ and that these are not in opposition to, or somewhat removed from methodology, reflection, analysis and interpretation. An example of textual strategies was my use of personal vignettes to re-veal, re-visit, and re-vision feelings embodied in the human side of illness. ‘Being there’ was described as being immersed in extraordinary moments. Living in these moments also involved a full examination of what has been experienced. Being thoroughly familiar with the ‘living detail’ [data] provided internal frame of reference in terms of knowledge and experience. The focus is the transformative effect [of the enquiry] on researchers own experience. In autoethnography this is achieved by writing evocative, rich narrative accounts that are at its most elegant and persuasive when they exudes confidence and verisimilitude.

On becoming autoethnographic my attention was turned to structuring the autoethnographic story to explain the projects guiding question and reason of my



'being there' living in the moment with managing a flare up of a MS symptom. It was also the substantiating reason for 'being there' researching my lived experience. I wanted to know how I could transform this experience in ways that are beyond our current understandings of this degenerative illness MS. As a self-reflective researcher, I was noticing things around me that in a way were very puzzling - this puzzle now being my confirmed diagnosis of MS which I referred to as my gateway to dialogue. I recalled how Jaworski (1998) notes that the ancient meaning of dialogue [*dia-logos*] means flow of meaning. I used Jaworski's explanation of this meaning to 'create' *showing* the illness MS as a structure whereby a set of associated symptoms [forces of the illness] began to operate in and surround my body. I began to 'notice' and 'see' that this experience was contributing to a fundamental shift in my mind and body that in turn was making a connection between a sense of curiosity and a commitment to exploring meaning.

I saw my self, as being part of thus unfolding meaning - my lived reality of embodied experience now part of the transformative effect of the enquiry creating this shift. I elected to learn more about autoethnography and its potential contribution to the understanding of MS, chronic illness in general, and personal and professional insights that can be generated to unfold meaning in this way of researching. Marshall's (1999) living life as inquiry and Ellis and Bochner's (1992, 2000) autoethnography connect this narrative account in ways that explore deeper levels of thinking and meaning as dialogue. Schöns (1983, 1987), and Cunliffe's (2004, 2011) reflection and reflexivity enhances the reflexivity of my work. Reflecting on experience I am re-living this event of a flare up of MS symptom whereby my sensing body is now calling itself to attention.

I believe this type of enquiry has benefits for those who have a chronic illness as well as those who do not. It offers the reader a better understanding of the myriad of symptoms of MS that can occur for the people for which they are providing care for. *Chapter Five - The Room of a Learning Self* is told through a narrative of how *I Carrie*, was positioning a learning self, learning from unacceptable action of others and also learning from the body that in illness loses its silence. By reflexively looking deeper at 'self' and 'other' interactions within this prevailing medicalised view of my body in illness, it is through a process of autoethnography that I am deconstructing this fixed medicalised way of looking at

embodiment and lived experience. *I Carrie*, am turning my autoethnographic I/eye inward on ‘self’ to uncover personal meanings and implications of embodied experience as I am coming to know and live within altered body. *I Carrie*, am striving to regain self, merging old and new realities of my being in the world. I see a book by Jacobs (2008) *The Authentic Dissertation* and read how it offers alternative ways of writing meaningful dissertations that honour i) the centrality of the researchers voice; ii) focus more on important questions than research methodologies per se, and; iii) reveal virtues: courage, humility, fortitude and a regard of peoples version of reality. I found this writing most encouraging and I am emboldened by its emphasis on the approach of critical autoethnography which seeks to ‘see’ creative abilities as ways of producing truly credible research reports. I have MS, and at times I struggle with accessing timely care for my MS symptoms. I was drawn to critical autoethnography because it allowed me to explore the ‘power’ relations and its effects on societal relationships. My relationships I have with medical health professionals and the pharmaceutical companies.

Through this authentic-heuristic approach I can act as an agent for change using critical autoethnography to uncover personal embodied meaning. Using a mixture of realistic and interpretive styles my experiences are reported in much of impressionist style required in the writing up of storied reality. This enquiry does not seek answers to many of the empirical research questions related to chronic illness, disability, trauma, mental health, and their related employment issues, or to settle diverse feminist theories about them. Exclusion of such in-depth reviews of empirical research on these associated concepts is not intended to diminish each of their valuable positions in contemporary medical, psychological, and sociological inquiry – feminist or otherwise. That I am a woman, nurse, wife, mother, daughter, and academic does have bearing on my particular experience of this disease and feminist orientations contribute much to recognising gender(ing) as pertinent – particularly in the realms of medical treatment. Each of these aspects of *self*, *being*, and *becoming* in my life influenced how I chose to tell my story. Bullough and Pinnegar’s (2001) research link my centrality to my enquiry because as researcher I am central to what the researcher does and it is possible to draw into close proximity the relationships between an enquiry and development of person. As a learning self *I Carrie*, incorporated these shifts of knowing and

learning drawn from the body as ways to ‘see’ and ‘notice’ embodied change assigning meaning for the development of a realising self.

I believe writing autoethnographically about my personal experiences of accessing care for my flare up of my MS symptom - optic neuritis also provides for the reader an opportunity to share my lived experience of managing this embodied change. *Chapter Six - A Realising Self* is told through narrative writing styles and themes of autoethnography as an account of embodied nerve pain - re-storying the experience of optic neuritis by writing self differently into the world. Writing evocatively I ‘call myself into being’ where my body is on view by medical doctors. I revisit the Cartesian split to briefly posit my learning and realising self that is being observed and self who observes. Use of metaphor illuminated the discussion of reversing the gaze of medical encounter as new way of re-visioning, re-thinking and re-vealing the senses of a troubled body. In my enquiry a particular event is used to illustrate substantiating reason for being there and re-iterating the original issue [confirmed diagnosis of MS] by re-visiting key points of experience and analysis of it – these are intended to be a particularistic account that is their strength. I concur with Madden (2010) who claims their strength is that by arriving at partial truths, by saying only so much and not too much, ethnographies remind us that there is more to do. Because MS never really goes away I could keep writing about many more experiences, each becoming worthy topics of their own.

However for the purposes of this enquiry I make strength of the *particular*. As a realising *self* who observes and is observed this is my authorial voice engaging in dialogue to *re-veal* experience and undertake meaning-making from these shifts of the mind and body and consequences of these shifts. It is through my autoethnographers *I/eye* that *I Carrie*, story [in my journal] examples of human action. *I Carrie*, am responsible for the interpretations of experiences that I have described. Through use of Ellis’s (2009) emotional re-call *I Carrie*, understand that feelings such as emotion, loss, complexity, uncertainty are valuable perspectives not only for me but for others who may read this work. I describe many challenges of accessing care these are portrayed as evocative and introspective accounts of my experiences of MS as *I Carrie*, who lives creatively with MS. In search of new meanings this thesis displays a highly personal form of narrative *showing* a shift in thinking describing a learning and realising self *being*

and *becoming-in-the-world* with MS. The congruence of my positioning was explicated throughout my writing in Chapters Three, Four, Five and Six.

In doing so I weave together ‘personal narrative’ and the ‘Alice story’ [in the heart of the enquiry] as imaginative ways for creating meaning-making and understanding of my *being* and *becoming-in-the-world* with MS and my relationships with medical organisations. I reflect on my journal entries that have been filled with reflections on issues of resistance, inequity, misinterpretations, and my struggles to understand those ‘others’ that are in positions of power and authority that control us, control me, and how my life is still *affected* by such power relations. Through process of critical autoethnography and reflexivity my enquiry seeks to address issues of resistance, inequity and move on from these ‘roadblocks’. It paves the way for me to step up and answer Denzin’s (2003, 2006) *Call to Performance* and Boje’s (2011) *Heart of Care* with my new way of ‘being’ and ‘becoming’ as I walk along and find new paths that are more caring and concern(ful) of people who live with chronic illness. The two messages that hit home with greatest impact for me are the medical professionals who fail for whatever reason to listen and for self as patient to be heard.

As a nurse I have been caring for people for the last thirty-eight years, but until embarking on this writing I never fully understood the depth and ‘suffering’ that a person with MS endures - I am one! It is this folder called: *Finding pieces for the organisational puzzle*- that I’m most eager to open and read.

### **Finding pieces for the organisational puzzle - Implications for health care professionals**

What we call the beginning is often the end  
And to make an end is to make a beginning  
The end is where we start from.

T.S.Eliot (1994, p. 42).

I commenced this writing describing lived experience of my confirmed diagnosis of MS. At that time there was much confusion, mixed messages and an overall sense of heightened distress and emotion. As a trained nurse I am aware of the many demands made upon oneself to complete many task orientated nursing-health care procedures. I am also a person with MS (PwMS), this experience of

coping with an acute relapse drew on many levels of personal experience and emotions. As a nurse my insider nursing/medical knowledge was useful about the illness however as a PwMS many emotions were challenged such as uncertainty, loss, anxiety and sheer frustration. My nursing colleagues also were finding this change perplexing as I did not visibly look that different now. I felt like I had just inherited a double dose of caring for others! Explaining this to my nursing colleagues what this illness entailed, and then again to my family and lastly myself dealing with how best to manage this uncertain illness. I felt like I was living two lives and in a state of ambiguous limbo!

As I reflect on this last decade and the care that I have been given to manage this illness, some of the approaches by health care organisations and management has left me feeling somewhat puzzled. I say puzzled as this is such a baffling illness and each case must be managed and treated on a one-person case-by-case basis. I found from personal experiences trying to access the appropriate care for management of these acute relapses was fraught with many difficulties. Many of the specialists did not seem to communicate well to the PwMS and their families. Some specialists had some very conservative approaches to dealing with acute relapses. Some specialists also appeared not to 'listen' to the PwMS who was actually experiencing first hand these painful exacerbations of neuropathic pain and clinical uncertainty of managing chronic pain in MS. Rosenberg's (1998) approach in recognition of clinical uncertainty and development of practical coping strategies offers much hope for doctors in learning how to manage clinical uncertainty. He says: "Once we recognise that uncertainty is everywhere we can conquer it. What it takes is judicious use of communication skills and a structure approach to self-directed learning and research, best summarized as the practice of evidence-based medicine (Rosenberg, 1998, p. 15). I reflected on these experiences and always asked myself - how could this have been managed better? - Should I not be so open and direct with my explanations about my pain - as I did not visibly look like I had any pain to some of the medical professionals? My symptoms were invisible and the puzzle for me was how to best communicate my presenting symptoms so that health professionals would actually listen to and believe me. Autoethnography as methodology, I believe, has enhanced the reflexivity of my work and will enable myself to become a better

autoethnographer and teacher of the practice of personal narrative and first person research.

*Being* and *becoming-in-the-world* with MS is my call to performance autoethnography as a woman, nurse educator and researcher who lives and works with MS. As readers, we can look to Alice for a transformative model of what it takes to be a good deductive reasoner. I am a nurse and am passionate about my profession so as I write this thesis it is not intended to criticise my profession, on the contrary I hope to provide some evidence based critique that can serve as exemplars for future organisational management in learning organisations such as schools of nursing or non-governmental health and disability agencies. These ‘conversations’ have highlighted some interesting implications for health professionals, and health care providers who work in the health and disability sector and for nurses working in this area of neurology. It also provided some interesting first hand performances of how health care professionals currently manage the PwMS.

It is intended that this report could serve as a basis to develop policies and procedures with [*Heart-of-Care* as focus] in a collaborative approach whereby PwMS also have some input into these policies. So that health care professionals, doctors, and nurses can in the future better manage, listen and work collaboratively for the advancement and management of the invisible aspects of this illness. I concur with Vickers’ (2010) findings as these also allude to a need for better understanding of this changed life with MS, for the person with the illness and other stakeholders in this picture. She writes firstly people newly diagnosed with MS could benefit from better understanding of the diagnosis, and what is happening to them during illness thereby enabling them to proactively engage with understanding the management of their illness. Secondly for carers, MS can be a very confusing illness to understand. Many of the symptoms can sound very strange, they are not often visible and it is extremely hard for the person experiencing it to describe this to their carer. For family and friends if they are better informed about this illness and MS symptoms then they too may acquire a better understanding. For health professionals, nurses, doctors, and allied health workers, they would also benefit from having a better understanding of lived experience of the onset of MS especially early diagnosis and ongoing management of MS.

My responses described in vignettes are the culmination of my 'being' immersed in this enquiry and in the process of doing autoethnography and becoming where *I Carrie*, am creatively living and working with disability *being* and *becoming* in-the-world with MS. I believe my stories will be of interest in a learning organisation and contribute to developing new capacity for transformational change, offering generative learning opportunities to 'see', 'notice' and engage with inquiry that is drawn from lived experience. For health care professionals Rosenberg (1988) suggests under the umbrella of communication training and evidence based medicine are the skills necessary for self-directed learning skills which can be used throughout their professional lives to help maintain doctor's knowledge base and educate themselves, their colleagues and their patients. It is my hope that with the judicious use of communication skills and a structured approach to self-directed, as described by Rosenberg, health professionals will provide better information, improved support/care, and timely service provisions for the PwMS.

It is a real challenge to align the invisible symptoms to this EDDSS model and for these reasons I believe this study will hopefully contribute to gently influencing future policy makers. My MS symptoms are invisible to health professionals, colleagues, family, and friends and I still am challenged by the current models of the EDDSS scale. I am pleased to report that I am not currently so incapacitated by this illness and it is my hope that I will remain within this range. According to the Multiple Sclerosis International Federation <sup>4</sup> for researchers there is an interesting study afoot being undertaken where uncertainty over a diagnosis of MS versus another medical condition exists. I believe this research represents one of the many exciting developments for health professionals, doctors, nurses, and carers who have an interest in this speciality of Neurology.

In seeking to portray exploration of human action of my illness MS which is an ongoing thing, in this research I intend on contributing to the literature on illness, MS, invisibility of chronic illness, and to the literature undertaken by

---

<sup>4</sup> [http://www.msif.org/en/research/ms\\_research\\_news/no\\_mri\\_evidence.html](http://www.msif.org/en/research/ms_research_news/no_mri_evidence.html)

Vickers (2005) about re-instating a voice to an invisible and marginalised group in the workplace. Through autoethnography [as process and product] I want to contribute to improving understanding and recognising the nature of this illness, the disorder, and the stress associated with trying to live with a chronic illness. For me at the time of my confirmed diagnosis, I had also encountered the distress of possible redundancy, and future job insecurity was another invisible stress, that I was faced with and had to contend with. If this study had been available at the time of my diagnosis in 1998 I would have been most interested to read it and it would have allayed some of the distress and mixed messages and time wasting!

In *Chapter Seven – The Porch* is used to denote reflection and reflexivity where *I Carrie*, have morphed from being a person without MS and in a process of learning and realising has now become a person with MS who is now living creatively in the world with MS. I amplify my subterranean adventures with Alice and White Rabbit and lessons learned from them. It is a creative synthesis of my ideas and findings from approaches of autoethnography, heuristic inquiry, and living life as inquiry of what I have to say about my original research question the energy and levels of curiosity akin to those in Alice stories that spurred me on to delve deeper into the notions of being and becoming in the world through the philosophical writings of Nietzsche, Aristotle, and Heidegger.

In my enquiry I also address some of the issues of mis-communication where doctors in the medical field I feel need to learn how they can do a better job for their patients. Rosenberg (1998, p. 14) writes in many situations where clinicians face issues with clinical uncertainty, some practitioners may develop maladaptive strategies for coping with it. He knows of six maladaptive types: i) Dr Know - does not want to admit to uncertainty; ii) Dr Do little - is unsure about everything and afraid of making wrong decision; iii) Dr Turf – does not make decisions himself; iv) Dr Delegate - relies on steady stream of well- informed juniors; v) Dr Panic - over investigates every patient and treats them aggressively; and vi) Dr Facile - whose philosophy is patients are well most of time, so why expect the worst - he waits till patients become obviously ill before he treats them.

I was intrigued! I'd not seen any writing like this, Rosenberg's commentary was indeed judicious and revelatory for me. His views led me to reflect on my medical encounter communication and clinical uncertainty. At least in regards to



my medical encounter at least three maladaptive types came to mind they are: Dr Know, Dr Turf and Dr Facile! Gaining a better understanding of MS care in narrative and meanings are made explicit in the description of tensions I encountered with medical appointments, examinations and re-admissions for my care of MS. Being ‘heard’, I argue, is mandatory for any healing process to begin. I offer recommendations for those allied health professionals, nurses and doctors who look after and provide care for persons with MS.

As worlds of possibilities I propose living systemic practice as ways for generative learning for learning management organisations that train educators, nurses and managers that choose to work in the health and education related organisations. As I rummage in my compendium I ‘notice’ that this is the last folder in it. I am amazed at how many notes and summaries I have made. Returning to the challenges of doing autoethnography that I noted in the introduction, and Chapter Two, it is in Chapter Four that I ‘show’ how I’ve worked with experiencing. I have given my time to self-reflection and how living systemic thinking in this enquiry contributes to generative practice which I feel I have authority to ‘speak’ from. It is the title of: *Worlds of possibilities living systemic thinking as generative practice* that I’m drawn to. Sitting comfortably in my favourite red rattan chair I begin to read.

### **Worlds of possibilities - living systemic thinking as generative practice**

The Hatter opened his eyes very wide and said: "So why is a raven like a writing desk?" "Come, we shall have some fun now!" thought Alice. "I'm glad they've begun asking riddles I believe I can guess that," Alice added aloud"

Lewis Carroll, (2006, p. 68).

It has been an interesting decade since my diagnosis. In the telling of my story, this method of autoethnography tantalisingly opened many possibilities for me as author creator, revealing *I Carrie*, who express my ‘being’, capturing the adventures, uncertainties of what it like being in the world with MS. These stories also serve to extend descriptions of my being in the world into the literary space for you the reader – in which my ‘voice’ can be heard and received as intended. I share my experience that is ringing true to my story-line. Autoethnography was

the methodological means as an emergent writer to bring myself into critical view and reveal phenomenon. Through reflectivity I was able to question the why and how at this moment and account for experience in the way that one does. Like Alice there are so many questions to be answered. I was determined to understand why people who report pain such as I did, are in turn profoundly mis-understood by those who do not experience such a reality. Schultz and Hatch's (1996) notion of living with multiple paradigms addresses language and pain suffered and opinions of lived pain by sufferer are which can be useful communication notions to explore these multiple paradigms. I began to engage in information seeking activities and with living systemic practice to transform and generate new lines of inquiry. In 'doing autoethnography' I was now positioning myself as an autoethnographer to address the associated management of an acute flare up of MS that still happens from time to time. I will continue to experience relapses or acute exacerbations, this is my lived reality. I reflect on my life story where all I do in the face of repeated challenges of living with MS is to justify my reasoning for what I do. I am reminded of the Alice story. In Wonderland Alice explored the mysterious, the complex and such oddities as a White Rabbit with pink ears taking a watch out of his waistcoat pocket! The Cheshire Cat whose grin remains after its heads has faded and the Mad Hatter who speaks to Time. Wonderland I argue serves as a good reminder that not all reasoning is pointless and that a good reasoner is where I argue much generative learning can be practiced by those individuals residing in both Wonderland and in their own social world.

Like Alice, we depend on narratives that keep us engaged. This work has allowed me to understand my reality of living with MS where in following the animated version of MS - White Rabbit and having Alice as my companion I was able to author my own life story, work out my own problems, and not be daunted by the unexpected, nor fear uncertainty, or disenfranchisement and to speak out. My 'authorial voice' is now speaking as I described my experiences of the medical trap I found myself in highlighted in Chapter Three where 'you take the blue pill' Morpheus says to Neo in the Matrix, and the story ends.

You take the red pill and you stay in Wonderland, and I will show you how deep the rabbit hole goes (Davis, 2010, p. 1). These were creative opportunities to demonstrate use of *poiesis* as was discussed in Chapter Four. In Chapter's Five and Six meeting another animated character introduced to my *life story* helped

portray the dramatic changes that I was enduring and constant changes in appearance of MS and ways it would manifest in my body. Drawing on my own experience was a significant *affect* in my learning and realising to inform me about how to know and understand embodiment and experiences of MS. I was now noticing and seeing things differently as I transitioned from person without MS to person with MS.

For people who are ill, people who care for them and importantly for health professionals and other researchers, autoethnography is a way of experiencing learning and realising that challenged me to become stronger. It took me to a new way of learning. Living systemic thinking drawn from Marshall (2004) is integral in reversing the 'gaze' as new ways of being in this enquiry largely in part of who I am, what I studied and where I worked. With my sensing body I learned to 'see' and 'notice', I confidently claim, this aspect of the sensing body has been largely and short-sightedly neglected from qualitative research analysis as it cannot be seen or talked about by others.

What I seek to offer through my 'life stories' are some levels of excitement, imagination, positivity, and hope to individuals who have and live with MS, and extend this also for those persons who care for them. I also share the lessons told by bold, assertive Alice who prefers to embark on a life changing-absorbing subterranean adventure rather than just sitting around. It is through the 'life story' that I first externalised and then internalised my observations as I sought interpretation on meaning of embodied experience. Like Alice, I would follow the White Rabbit deep into the rabbit hole. I did not just only want to know how deep the rabbit hole was. I wanted to know how to make sense of what I was yet to discover. By following White Rabbit I have now come to a very different understanding of this disease that resides in my body and calls me to attention. My thesis reports on this journey of discovery and the fictional embodied characters that have assisted me.

## **EPILOGUE**

## EPILOGUE

We shall not cease from exploration  
And the end of all our exploring  
Will be to arrive where we started  
And know the place for the first time.

T. S. Eliot, *Four Quartets* – (1944, p. 43).

My concluding moment is reported from *'The Porch'* where at the end of the day I am sitting in my red rattan chair thinking back on this work. The many activities each in their unique ways bringing me back to full circle, as I prepare to embark on the next part of my life. Writing evocatively about embodied experience is an example of my life experiences infusing and influencing my writing style. Many other feelings have emanated from the realisation of MS in my life.

I liken what happened to me following my diagnosis of MS to 'falling down the rabbit hole'! The quote above brought me to reflect back on the emotions, the exhaustion, the uncertainty, and now the curiosity. At first I was bemused and daunted at how I could undertake such a literary exploration. However, as I read more I could not stop myself reading, I had to begin exploring it. Once I began, I discovered something ignited my 'curiosity'. This way of exploring was familiar as I had grown up in a household with quantitative research. My approach was qualitative where the layers of exploring lived experience through narrative *showing* my stories were the wallpaper of my life.

I have been thrust into a profound embodied experience in the now - living for a decade with relapsing-remitting MS manifesting at the prime of my professional career and personal life. The shock of the illness and confirmed diagnosis affected my family. In their own ways they too set about adjusting to living with a person who has MS. For them it spurred many questions about themselves, what MS is and what did the future hold for their mother who has MS. I have the type of MS known as Relapsing-Remitting Multiple Sclerosis (RR-MS). Many changes have occurred in my way of being with my-self and my body. In writing about my experience I used the writing style of autoethnography to explore personal meaning and experiences of MS and the journey metaphor of

following the White Rabbit and Alice in the rabbit hole. In the rabbit hole there was so much to explore!

It was important to me that my writing would evoke readers experience and be useful. I thought back to the portraits in the vestibule. I remember under the portrait of Ellis there was a brief caption: *The Ethnographic I*. I also remember Denzin's picture with the caption: *The Call to Performance*. I recall the copious notes I had taken when reading the books I found in Chapter One that helped me make sense of those captions. I revisit my notes. Ellis (2004, p. xix) writes that autoethnography is research, writing and method that connects the autobiographical, and personal to the cultural and social. This form of research usually features concrete action, emotion, embodiment, self consciousness, and introspection. I had this moment of sheer elation! I realised why my thoughts were redirected back to the vestibule!

I was examining the positioning of self in this inquiry and Ellis's explanation about introspection was timely. I had learned how to become introspective. Although this choice of method and style of writing does not use the conventional means of research, my reflections on all I had read, and on the story I wanted to tell, assured me I was at the point of creativity and becoming. At the time I had decided to formalise my study of my experiences [of my confirmed diagnosis] I had formed a picture in my mind about how this project might look. I had already begun to move my thinking from engaging with research from a scientific data gathering approach to now viewing it from the perspective of an interpretive-intentional method. I no longer wanted to just be 'doing'. I wanted to 'create'.

I had adopted Deleuze and Guattari's (1987) concept of the rhizome as image and map for the intra-weaving of my life story with narrative. In taking note of the 'signs': *Of look first* that Alice had introduced me to, I now sought to creatively craft this autoethnographic study to find meaning and purpose. I could now see how I could further adapt living story with narrative by re-visiting, and re-visioning my story incorporating Epston and White's (1990) notion of 'restorying'. The use of poesis and imagination enabled *I Carrie*, to write creatively about my singular moment of embodiment and experience. Drawing on Boje's (2011) notion of finding little 'wow' moments was how I constructed an experience of a singular embodied experience as my wow moment into a 'new story. By now, I had read widely about autoethnography and what prominent

researchers in the field had to say about its styles, usefulness, and validity. I was more acutely aware than ever that my nursing background was steeped in positivist traditions that contrast so markedly with this personally engaged way of researching. The beginnings of my attempt to describe present 'rich and active' experiences and the value of retaining in the text a link to its origins in experience and emotion are part of writing emergently as a storyteller and autoethnographer.

I am increasingly convinced that writing authentically about my life enabled me to introduce questions concerning bewilderment, uncertainty, and wonder about my *being* and *becoming-in-the-world* with MS. I recalled the article by Dr William Rosenberg (1998) where he said as doctors, we spend much of their lives making decisions or expressing opinions. From early in their medical training, doctors are encouraged to avoid uncertainty. But in all aspects of everyday practice, from diagnosis and treatment to prognosis, they seem beset by questions and uncertain of the answers. He applauds the University of Southampton's School of Medicine in taking stance in the development of new strategies for dealing with clinical uncertainty. This is where I immediately thought back through use of emotional recall (Ellis, 2004, 2009) about my experience as a young child, aged 19 months old, re-told through my late mother's notes about that holiday at Pankor Island where I sustained that agonising lethal sting from the Portuguese Man-of-War!

In my thesis researching this part of my childhood puzzle provided an essential grounding for the re-tracing of how and where I belong in the world since my confirmed diagnosis of MS. I included pictures of images morphing from early childhood to adult hood in the body of this thesis as ways to creatively illustrate ways of demonstrating autoethnography. It may be that intuitively in some way my own inner journey would take me, along this path even before I had had a chance to consciously articulate it as I have now had the opportunity to. I have thought often about all the researching I did as part of my information seeking activities.

Another piece the puzzle was when I emailed numerous scientists at Auckland School of Medicine in New Zealand to seek opinion about this venous attack on immune system. It was suggested I email scientists in England, and Australia about this matter. I did and did not really get any comprehensive information about attacks on immune system of a young child. They were all very

interested in my story. I then decided to not carry on with this as actively I had been, it was all very tiring. After a short break I decided to write to the then Minister of Health and Pharmac about my possibilities regarding my eligibility for consideration of assistance with commencement of interferon treatment for MS. My father even wrote to the then Prime Minister of New Zealand the Honourable Helen Clarke. We had replies from all stating that basically it was a dreadful predicament, one that at this stage not much could be done about it and they wished me all the best.

I had then joined the local MS Society and found many interesting articles and was able to speak about many things to the local field officer. It was in 2006 that I was approached to see if I would be interested in taking part in the New Zealand MS Prevalence Study conducted from Otago University about prevalence rates in NZ ethically and latitudinally. I agreed to be part of this study and met the inclusion criteria of the study. In that study I wrote about this experience of being attacked by Portuguese Man of War at the age of 19 months, and queried if this was of interest to researchers of tropical medicine and immunology. I specifically asked if or what affects could or would, this exposure to a known jelly fish-like marine creature have on such an immature immune system of a child aged 19 months old. I will never know whether researchers who were collating this information thought it had any relevance to their design of the study. I also provided information regarding emigration from an equatorial climate to temperate country such as New Zealand at the age of pre-puberty. It is my hope that medical researchers will pick up on some of the points I have made in this thesis about if in fact there is a causal relationship of venomous attacks on immune system of young children and if this specific hypothesis is worthy of future research.

I set to work to seek a way to learn and live fully in harmony with life, being ready to encounter some risks along the way, as I look inside myself being-in-the-world with MS and proceed through becoming-in-the-world with MS. I was now exiting from my former self a woman, wife, mother, educator, and nurse-without-MS to a new identity of *I Carrie*, a woman, wife, mother, grandmother, educator, and nurse-with-MS. This journey became the story of my *being* and *becoming*-in-the-world with MS. I have also met and read Marshall's (1999) *Living Life as Inquiry* which helped shape the style and flow of this thesis. Where *I Carrie*, am



living and researching my life as inquiry that becomes a significant part of my *being* and *becoming-in-the-world* with MS.

My experiences of communicating with others regarding management of MS were now situated ‘outside’ the immediate proximity of the experience. This now in turn impacted on myself and positioning ‘inside here’ a researcher. I had recognised issues of self, others, and subjectivity in the design of this research. This was supported through my notes taken and drawn from Ellis (2009) *Relational Ethics*, Chang (2008) *Researcher Ethics*, and Ings (2011) *Self Reference and Representation* scholarly articles I had read about in the Room of Methodology. With the wise guidance from Alice as my muse, I have begun to recognise the legitimacy of self as subject of this research as well as researcher of the phenomenon of MS and associated embodied change. This in turn led me to what would eventually become my chosen methodology and my creative style of writing intentionally embellished with metaphor and use of my life story.

*The being in some body: an autoethnographic account of the being and becoming-in-the-world with MS* is my attempt to provide first person narrative research as autoethnographical writing based on personal experience with aspects of self as a subject with a subject - a valid topic of inquiry and an appropriate process for the task at hand. Through my storying, and reflections on these stories, I am able to bring to the health care management organisations the total resources of my *mind, heart, spirit* and *soul* as a whole learning system where ‘everybody tells a story... this is *‘my life story’*’.

My escapades in the rabbit hole have been the source of much writing and reflection. When I think about the changes having MS has demanded from me I do feel different now than I did pre-diagnosis. It is as though I am ‘seeing’ life from the other side and every experience in the rabbit hole reminds me of the saying ‘there is light at the end of the tunnel’. I believe inside personal tragedy are the ‘threads’ to create a new beginning - a new way of being living life as inquiry.

In writing this enquiry, I am narrating a story – which is an expression of my being:

*I think that if in telling a story one can find self - then we will also find our own human purpose of embodiment and experience that allow life to unfold through self ultimately creating new realities.*

*(Personal Journal, 2010).*

Many changes have occurred in my way of being with myself and my body. Numerous questions were begging to be answered, each setting new lines of inquiry. *Will the Carrie, as I now know her, still be able to work? Who is the emerging Carrie going to look like and to whom?* I was apprehensive about writing this paper - *How much should I reveal? Who would be interested in my story?* I thought about the headings to capture the fundamental shifts of my thinking that had emerged from my experience - the shifts in how I see the world and how I understand the organisational relationships of change, embodiment and learning. Having insisted on a hospital admission, the sequence of events turned to the better:

*Waiting in the Accident and Emergency a colleague of mine quickly came to see me and took over coordinating all the tests that needed to be done before visiting Ophthalmologist who had worked in this specialised area in Australia was paged.*

*(Personal Journal, 2010).*

I remember Jaworski's (1998) work *Synchronicity – Meetings with Remarkable People*. It made me think deeply about this experience at the hospital and who was present at that time. I now experienced firsthand meetings with remarkable people - these people each contributing to inquiry in some way.

The experience of attempting to get relief for my pain in a responsible and well-informed manner is still as clear today as it was all those years ago. It has made an indelible mark in my new identity. The lessons learned from this experience were both transformative and generative to my learning. They enabled me as the researcher to pay close attention to myself in relation to issues of quality and access of bodily knowledge. It is my desire to contribute to the transformation of institutional knowledge in order to ensure that this experience of clinical uncertainty of MS for newly diagnosed persons with MS is better resourced by education and research. I believe this change must occur at the organisational level. Rosenberg (1998) applauds the development of new strategies for dealing with clinical uncertainty. It is my hope that health professionals, doctors, nurses and carers will share his level of optimism and embrace the development of

practical coping strategies acquired through effective-techniques for acquiring knowledge.

Aligning this inquiry to the Alice story represents the manifest process I experience as I search for meaning in order to decode and unlock my new identity. As a consequence of this style of writing *I Carrie*, now remembered all those boxes, folders in the rooms that Alice had helped me to ‘notice’. Following the White Rabbit conveyed the whimsical and at times bemusing aspects of the illness that I must now follow. Alice and White Rabbit provided the imaginative inspiration to explore meaning-making and application of poiesis in demonstrating living life as inquiry as a learning self who was coming to a better realisation of own embodied experience of self, body and work. Looking back on the use of heuristic inquiry and the Alice story these approaches to learning and enquiry both enabled me to convey how I was feeling about work related and personal uncertainty. How could I know if the job I once held was the right one for me now if I did not know who this new me was? *My life story* became my guide to answering some of life’s most profound questions and in my case at times an impossible yet philosophically addicted relationship I now have being-in-the-world with MS.

Through the processes of self-exploration and reflexive inquiry I was accounting for embodied experience as vignettes and providing these as examples of an audit trail in the research report. My intention was to connect lived experiences derived from these three facets of *self, body* and *work* with the social and cultural looking at the larger context wherein self-experiences occurred. As I continued exploring these highly personal accounts conveyed as vignettes I drew on Schön (1983, 1987), Cunliffe (2004, 2011), and Ellis’ (2004, 2009) notions of the reflective practitioner and autoethnographic vignettes as means to enhance the representational richness of the use of reflection and reflexivity in qualitative research, organisational learning, critical management studies, and nursing-allied health organisations.

## Reflections and reflexivity

By incorporating process of reflection and reflectivity I became more self-reflexive regarding interpretation of how the previous effects of a flare up of MS symptoms manifested and presented. This distinction was very important and could only be understood by working with lived experience. It helped lead me to develop ways of realising where I now understood my own readiness for embracing embodied changes incorporating reflection and reflexivity.

These stories about my experiences exploring meaning of MS and changes to self were described drawing on Ellis' (2004) strategy of emotional recall and memory of the event. In my stories, I placed myself back in the event-the hospital waiting room and re-call the doctors account of my presenting symptoms. As I thought about it, I re-call how busy the department was, and how long the wait was for me before I was given an update. I still vividly remembered too the sounds of the medical alarms in each cubicle beeping and the chattering of nurses and allied health staff to each new patient. I remember the intense pain in my fingers, legs and left eye - which I described as a burning/stinging-sort of sensation that is so unrelenting that the basic pain relief medications that I was given did not seem to touch the pain at all, my head was still throbbing, my eye painful and the noise and fluorescent lights in the cubicle became so unbearable.

In taking a reflexive stance it could be argued that this doctor was paged because of his speciality experience - and he was still around on his rostered duty. However another way of looking at this - was from my perspective as a nurse I could intuitively sense when a person who was skilled in their particular area - was doing an exceptional job - it is by their actions and smooth management of acute rapidly changing situations. As a patient I was also relieved that this was the person that I was seen by. I argue that is a great example of my application of my lived experiences to what Jung's philosophy means in terms of i) the grouping one or more events by; ii) virtue of providing meaning that; iii) need not necessarily derive explanation of such in terms of cause and effect. This Doctor came into my life because of my admission to the emergency department. I had symptoms that needed to be examined and together these events: i) this medical encounter and ii) his expertise came together in a meaningful way. It could have been a very different outcome for me had I been seen by a person who did not have this extra

speciality of working with MS patients and ophthalmology experience. In a very professional manner and after completing all his examinations he then discussed the results that he had to hand with my husband and me. I still believe to this day that he changed the course of my life from that day in October 1998, for the better unbeknown to me. Is this an example of a meaningful coincidence? I believe so.

Through the telling of my story I am intentionally contributing to shaping the future. I want to show that leadership and institutional change can and must occur. I offer this example as living life as inquiry as a guide to develop leadership capacity for those who work with and those who care for individuals who have a chronic illness. *'The being in some body'* is my call to performance autoethnography as a woman, nurse, educator, and researcher who lives and works with MS. We can look to Alice for a transformative model of what it takes to be a good deductive reasoner. I am passionate about my profession. I write this report to provide some evidence-based critique to serve as exemplars for future organisational management in learning organisations, schools of nursing, or non-governmental health and disability agencies. I had a two-fold purpose in mind: i) to gain a better understanding for myself, the person who must live with this disease, and ii) always the nurse, to bring a better understanding to others who have a disease such as this, to the nursing profession, and to all those who care for people whose health is in some way compromised as mine is now, to live in a more ethical and caring way of being.

### **A postscript of being: re-visiting, re-vising, and re-vealing**

I have intentionally revisited some of the examples drawn from my journal entries, and the personal vignettes as ways of *'showing'* motivation, immersion, and expression as creative ways to honour Ellis's (2009) notion of (re)vision: autoethnographic reflections on life and work. Ellis says in personal storytelling revision(ing) is crucial (2009, p. 354). In the writing up of the analysis of this thesis I highlighted some implications for health professionals and health care providers who work in the health and disability sector and for nurses working in this area of neurology. This report could serve also as basis to develop policies and procedures utilising a collaborative approach whereby a person with MS has

input into policy making so that health care professionals, doctors and nurses can in the future better manage, listen to and work collaboratively for the advancement and management of the invisible aspects of chronic illness. While learning about MS I was now exiting from my former self a woman, wife, mother, educator, and nurse without MS to a new identity of a woman, wife, mother, grandmother, educator, and nurse with MS. This journey became the *life story* I tell of my *being* and *becoming-in-the-world* with MS. As it is, the notes conclude with a review of the call to performance autoethnography and, as I will show, it is to this interpretive style, embedded in the flow of everyday life I feel most drawn. In this research process I have amplified the importance of positioning *myself* as 'the inquirer's voice' to report an inquiry in which I sought to develop my understanding of how embodied change informs me as an embodied '*realising self*'.

In living my life as inquiry in this way I reflected on the 'organisational voice' of the other, the people, situations and organisations that have influenced my inquiry into management of my neuropathic pain. I do so in part, through my re-presentations of experiences captured as learning moments of these phenomena and as a phenomenological approach that influences social change, and the amplification of its emancipatory potential to breathe life back into organisational learning. This revelatory experience of embodied change and its emancipatory potential for storytelling learning organisations with positioning of self in narrative, access and authenticity are key aspects for narrative adequacy.

In having direct access to own experience, privilege, and authenticity these were the key aspects that highlighted creative ways of expressing who is a good storyteller and what constitutes a good story is. Gubrium and Holstein (2009) suggest these attributes are often considered representative of a good storyteller. I believe my stories will be of interest in a learning organisation and contribute to developing new capacity for transformational change, offering generative learning opportunities to 'see', 'notice', and engage with enquiry that is drawn from the sensing body-through lived experience. I feel transformed 'magically'- into a literary world of writing about lived experience.

Each time I think about or ask a question, this learning activity becomes the potential for another mini-cycle of enquiry as I did for the main part of the thesis,

for I am still a part of the ongoing story of *I Carrie*, who is creatively living in the world with MS.

My work as an autoethnographer expressed in this thesis reflects a creative way to investigate human authenticity. The story I have presented has been a way to show strategic foresight and the validity of my work as a study of self-in-action. A wonderful summary of my journey into the House of Learning that captures completely what this thesis is all about, that give expression to what my heuristic journey has entailed, and that expresses the demonstration of doing autoethnography as a creative synthesis, are the words attributed to Johan Wolfgang von Goethe:

Whatever you can do, or dream you can, begin it.

Boldness has genius, power, and magic in it.

Goethe (1749-1832).

## REFERENCES



6



**WITH MS, YOU NEVER KNOW WHAT WILL GO NEXT**

People with Multiple Sclerosis live in a frightening reality where parts of the body can shut down without warning. Help the search for a cure, visit [mswaikato.org.nz](http://mswaikato.org.nz)

**ms.**  
Waikato

## REFERENCES

- Allbon, C. (2012). "Down the rabbit-hole"-“Curiouser and Curiouser”’: Using autoethnography as mode of writing to re-call, re-tell and re-veal bodily embodiment as self reflexive inquiry. *Journal of Organisational Ethnography*, 1(1), 62-71.
- Allen, R.E. (Ed.). (1985). *The Oxford Dictionary of Current English*. Oxford, United Kingdom: Oxford University Press.
- Anderson, R. (1998). Intuitive inquiry: A transpersonal approach. In W. Braud., & R. Anderson (Eds.), *Transpersonal research methods for the social sciences: Honouring human experience* (pp. 69-94). Thousand Oaks, CA: Sage.
- Anderson, R. (2004). An epistemology of the heart for scientific inquiry. *The Humanistic Psychologist*, 32(1), 307-341.
- Anderson, L. (2006). Analytic autoethnography. *Journal of Contemporary Ethnography*, 35(4), 373-395.
- Annandale, E. (1998). *The sociology of health medicine: A critical introduction*. Cambridge, United Kingdom: Polity Press.
- Arendt, H. (1958). *The human condition*. Chicago, IL: University of Chicago Press.
- Atkinson, P. (1990). *The ethnographic imagination: Textual constraints of reality*. London, United Kingdom: Routledge.
- Atkinson, P. (1997). Narrative turn of blind alley? *Qualitative Health Research*, 7(3), 325-344.
- Atkinson, P. (2006). Rescuing autoethnography. *Journal of Contemporary Ethnography*, 35(4), 400-405.
- Baerger, D.R., & McAdams, D.P. (1999). Life story coherence and its relation to psychological well being. *Narrative Inquiry*, 9(1), 69-96.
- Bambrough, R. (1963).The philosophy of Aristotle. (New translation by A. E. Wardman., & J. L. Creed (Eds.), *A mentor classic* (pp.1-13.). New York: The New American Library of World Literature.
- Bate, W. J. (1979). *John Keats*. Cambridge, MA: The Belknap Press of Harvard University Press.
- Bateson, G. (1972). *Steps to ecology of mind*. New York: Ballantine.

- Bateson, G. (2000). *Steps to ecology of mind: Collected essays in anthropology, psychiatry, evolution and epistemology* (2<sup>nd</sup> ed.). Chicago, IL: University of Chicago Press.
- Baudrillard, J. (1994). *Simulacra and simulation: The body* (Trans. S. F. Glaser). Ann Arbor, MI: University of Michigan Press.
- Behar, R. (1996). *The Vulnerable observer: Ethnography that breaks your heart*. Boston, MA: Beacon Press.
- Berdayes, V., Esposito, L., & Murphy, J. W. (Eds.). (2004). *The body in human inquiry: Interdisciplinary explorations of embodiment*. Cresskill, NJ: Hampton Press.
- Bochner, A. P. (1994). Perspectives on injury 11: Theories and stories. In M.L. Knapp., & G.R. Miller (Eds.), *Handbook of interpersonal communication* (pp. 2141). Thousand Oaks, CA: Sage.
- Bochner, A. P. (1997). It's about time: Narrative and the divided self. *Qualitative Inquiry*, 3, 418-438.
- Bochner, A. P. (2002). Perspectives on inquiry 111: The moral of stories. In M.L. Knapp., & J.A. Daley (Eds.), *Handbook of interpersonal communication*. (3rd ed., pp.73-101). Thousand Oaks, CA: Sage.
- Bochner, A. P., & Ellis, C. (1992). Personal narrative as a social approach to interpersonal communication. *Communication Theory*, 2(2), 165-172.
- Bochner, A. P., & Ellis, C. (Eds.). (2002). *Ethnographically speaking: Autoethnography, literature and aesthetics*. New York: Rowman and Littlefield.
- Boje, D. M. (1991). The story telling organization: A study of story performance in an office supply firm. *Administrative Science Quarterly*, 36(1), 106-126.
- Boje, D. M. (2001a). Using Narrative and Telling Stories. In Holman, D., & Thorpe, R. (Eds.), *The manager as practical author* (pp.32-60). New York & London: Sage.
- Boje, D. M. (2001b). *Narrative methods for organizational and communication research*, London, Thousand Oaks, CA: Sage.
- Boje, D. M. (2008). *Storytelling organisations*. London, United Kingdom: Sage.
- Boje, D. M. (2011, December). *The heart of care: Quantum storytelling and ontological inquiry*. Paper presented at the Quantum Storytelling Conference, Las Cruces, New Mexico, United States of America.

- Boje, D. M. (2011). *Storytelling and the future of organisations: An ante narrative handbook*. London, United Kingdom: Routledge.
- Bolt, E., & Powell, J. (1995). *Becoming reflective*. Southbank University, South Bank, London, United Kingdom: Ashford Press.
- Boud, D., Keogh, R., & Walker, D. (Eds.). (1985). *Reflection: Turning experience into learning*. London, United Kingdom: Kogan Page.
- Bourdieu, P. (1977). *Outline of a theory of practice*. Cambridge, United Kingdom: Cambridge University Press.
- Boyd, E. M., & Fales, A. W. (1983). Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology*, 23(2), 99-117.
- Braud, W., & Anderson, R. (Eds.). (1998). *Transpersonal research methods for the social sciences: Honouring human experience*. Thousand Oaks, CA: Sage.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Bruner, J. (2004). Life as Narrative. *Social Research*, 17(3), 691-710.
- Bullough, R. V., & Pinnegar, S. (2001). Guidelines for Quality in Autobiographical Forms of Self-study. *Educational Researcher*, 30(3), 13-21.
- Buber, M. (1958). *I and thou*. (Trans, RG Smith.). New York: Scribner's.
- Carlyle, T. (n.d.). *He who has health, has hope; and he who has hope, has everything*. Retrieved from <http://www.brainyquote.com/quotes/quotes/t/thomascar1118220.html#VMM D3ckEEUXPTbVm.99>
- Carr, D. (1986). *Time, narrative, and history*. Bloomington, IN: Indiana University Press.
- Carroll, L. (2006). *Alice's Adventures in Wonderland*. (8th ed.). London, United Kingdom: Pocket Penguin Classics Books Ltd.
- Castoriadis, C. (1997). *World in fragments: Writings on politics, society, psychoanalysis and the imagination*. C. Castoriadis (Ed.). & (Trans D. A. Curtis). Stanford, CA: Stanford University Press.
- Chang, H. (2008). *Autoethnography as method*. Walnut Creek, CA: Left Coast Press.

- Charmaz, K. (1983). The grounded theory method: An explication and interpretation. In R. M. Emerson (Ed.), *Contemporary field research: A collection of readings* (pp.109-125). Prospect Heights, IL: Waveland.
- Charmaz, K. (2005). Grounded theory in the 21<sup>st</sup> century: Applications for advancing socially just studies. In N. K. Denzin., & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3<sup>rd</sup> ed., pp.507-535). Thousand Oaks, CA: Sage.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass.
- Clifford, J. (1986). Introduction: Partial truths. In J.Clifford., & G. Marcus (Eds.), *Writing culture: The poetics and politics of ethnography*. (pp.1-26). Berkeley, CA: University of California Press.
- Coffey, A. (1999). *The ethnographic self: Fieldwork and the representation of identity*. Thousand Oaks, CA: Sage.
- Conquergood, D. (1998). Beyond the text: Toward a performative cultural politics. In S.J. Daley (Ed.), *The future of performance studies: Visions and revisions* (pp.25-36). Annadale, VA: National Communication Association.
- Couser, G. T. (2004). *Vulnerable subjects: Ethics and life writing*. Ithaca, NY: Cornell University Press.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, United Kingdom: Sage Publishers.
- Csordas, T. (1994). *Embodiment and experience: The existential ground of culture and self*. Cambridge, United Kingdom: Cambridge University Press.
- Cunliffe, A. L. (2004). On becoming a critically reflexive practitioner. *Journal of Management Education*, 28(4), 407-426.
- Cunliffe, A. L. (2011). *Why be reflexive?* [Lecture notes]. Hamilton, New Zealand: The University of Waikato.
- Czarniawska, B. (2007). *Shadowing and other techniques for doing fieldwork in modern societies*. Norway: Universitetsforlaget.
- Davis, R. B. (2010). *Alice in Wonderland and Philosophy: Curiouser and Curiouser*. N J: John Wiley & Sons.
- Delamont, S. (2007). Arguments against autoethnography. *Qualitative Researcher*, 4, 2-4.

- Delamont, S. (2009). The only honest thing: Autoethnography, reflexivity and small crisis in fieldwork. *Ethnography and Education*, 4(1), 51-63.
- Deleuze, G. (1990). *The logic of sense*. (Trans. M Lester). NY: Columbia University Press.
- Deleuze, G., & Guattari, F. (1987). *A thousand plateaus*. (Trans. B. Massumi). Minneapolis: University of Minnesota Press. (Original work published 1980).
- Denzin, N. K. (1985). Emotion as Lived Experience. *Symbolic Interaction*, 8(2): 223-240.
- Denzin, N. K. (1987). *The alcoholic self*. Beverly Hills, CA: Sage
- Denzin, N. K. (1989). *Interpretive biography*. Newbury Park, CA: Sage.
- Denzin, N. K. (1997). *Interpretive ethnography: Ethnographic practices for the 21<sup>st</sup> century*. Thousand Oaks, CA: Sage.
- Denzin, N. K. (2003). *Performance ethnography: Critical pedagogy and the politics of culture*. Thousand Oaks, CA: Sage.
- Denzin, N. K. (2003). The call to Performance. *Symbolic Interaction*, 26(1), 187-207.
- Denzin, N. K. (2006). Analytic Autoethnography, or déjà vu all over again. *Journal of Contemporary Ethnography*, 35(4), 419-428.
- Denzin, N. K., & Lincoln, Y. S. (2000). The Discipline and Practice of Qualitative Research. In N.K. Denzin., & Y.S Lincoln (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed., pp.1-28). Thousand Oaks, CA: Sage.
- Denzin, N. K., Lincoln, Y. S., & Smith, L. T. (2008). *Handbook of critical and indigenous methodologies*. Thousand Oaks, CA: Sage.
- Dervin, B. (1992). From the minds eye of the user: The sense making qualitative-quantitative methodology. In J. D. Glazier., & R. R. Powells (Eds.), *Qualitative research in information management*. Englewood, CO: Libraries Unlimited.
- Douglass, B. G., & Moustakas, C. (1985). Heuristic Inquiry: The internal search to know. *Journal of Humanistic Psychology*, 25(3), 39-35.
- Duarte, F. (2007). Using autoethnography in the scholarship of teaching and learning: Reflective practice from the other side of the mirror. *International Journal for Scholarship of Teaching and Learning*, 1(2), 1-12.

- Duncan, M. (2001). *Principles of hypermedia design: An Autoethnographic case study* (Unpublished doctoral dissertation). Queensland University of Technology, Brisbane, Australia.
- Duncan, M. (2004). Autoethnography: Critical appreciation of an emerging art. *International Journal of Qualitative Methods*, 3(4), 2-14.
- Dyson, M. (2007). My story in a profession of stories: Autoethnography an empowering methodology for educators. *Australian Journal of Teacher Education*, 32(1), 36-48.
- Einstein, A. (n.d). *Albert Einstein quotes*. Retrieved from [http://www.goodreads.com/author/quotes/9810.Albert\\_Einstein](http://www.goodreads.com/author/quotes/9810.Albert_Einstein)
- Eisner, E. (1985). Aesthetic Modes of Knowing. In E. Eisner. (Ed.), *Learning and teaching the ways of knowing* (pp.23-36). Chicago, IL: University of Chicago Press.
- Eisner, E. W. (1991). *The Enlightened Eye: Qualitative Inquiry and the Enhancement of Educational Practice*. New York: Macmillan Publishing.
- Eisner, E. W. (1993). Forms on understanding and the future of educational research. *Educational Researcher*, 22(7), 5-11.
- Eisner, E. W. (1998). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. Upper Saddle River, N.J: Merrill.
- Eisenburg, L. (1977). Disease and illness: Distinction between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry*, 1(1), 9-23.
- Elliot, T. S. (1944). *Four quartets*. London, United Kingdom: Faber & Faber.
- Ellis, C. (1991). Sociological introspection and emotional experience. *Symbolic Interaction*, 14(1), 23-50.
- Ellis, C. (1995). *Final negotiations: A story of love, loss and chronic illness*. Philadelphia, PA: Temple University Press.
- Ellis, C. (1999). He(art)ful autoethnography. *Qualitative Health Research*, 9(5), 669-683.
- Ellis, C. (2000). Negotiating terminal illness: Communication, collusion, and coalition in caregiving. In J. Harvey., & E.D. Miller (Eds.), *Loss and trauma: General and close relationship perspectives* (pp. 284-304). Philadelphia, PA: Bruner-Routledge.
- Ellis, C. (2001). With mother/with child: A true story. *Qualitative Inquiry*, 7(5), 598-616.

- Ellis, C. (2004). *The Ethnographic I: A methodological novel about Autoethnography*. Walnut Creek, CA: AltaMira Press.
- Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry*, 13(1), 3-29.
- Ellis, C. (2009). *Revision: Autoethnographic reflections on life and work*. Walnut Creek, CA: Left Coast Press.
- Ellis, C., & Bochner, A. P. (1992). Telling and performing personal stories: The constraints of choice in abortion. In C. Ellis., & M. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp.79-101). Newbury Park, CA: Sage.
- Ellis, C., & Bochner, A. P. (2000). Autoethnography, personal narrative, reflexivity. In N.K. Denzin., & Y.S. Lincoln (Eds.), *The handbook of qualitative research* (2<sup>nd</sup> ed., pp.733-768). Thousand Oaks, CA: Sage.
- Ellis, C., & Bochner, A. P. (2006). Analysing analytic autoethnography: An autopsy. *Journal of Contemporary Ethnography*, 35(4), 429-449.
- Ellis, C., Adams, T., & Bochner, A. P. (2011). Autoethnography: An overview *Forum Qualitative Sozialforschung/ Forum: Qualitative Social Research*, 12(1), 1-14.
- Ellis, C., & Ellingson, L. (2000). Qualitative methods. In E. Borgatta., & R. Montgomery (Eds.), *Encyclopaedia of sociology*, (pp.2287- 2296). NY: MacMillan.
- Ellingson, L., & Ellis, C. (2008). Autoethnography as constructionist project. In J.A. Holstein., & J.F. Gubrium. (Eds.), *Handbook of constructionist research*. (pp.445-465). N Y: Guildford.
- Engles-Schwarzpaul, A-C. (2008). At a loss for words? Hostile to language? Interpretation in creative practice- led PhD projects. *Working Papers in Art and Design*, 15, 1-11. Retrieved from [http://sitem.herts.ac.uk/artdes\\_research/papers/wpades/vol5/tesfull.html](http://sitem.herts.ac.uk/artdes_research/papers/wpades/vol5/tesfull.html)
- Epston, D., & White, M. (1990). *Narrative means to therapeutic ends*. NY: Norton & Company.
- Etherington, K. (2004). *Becoming a reflexive researcher: Using ourselves in research*. London, United Kingdom: Jessica Kingsley Publishers.
- Etherington, K. (2007). Ethical research in reflexive relationships. *Qualitative Inquiry*, 13(5), 599-616.
- Entwistle, N. J. (1979). *Styles of learning and teaching: An integrated outline of educational psychology for students, teachers, and lecturers*. Chichester, West Sussex, United Kingdom: John Wiley.



- Entwistle, N. J. (1981). Stages, levels, styles or strategies: Dilemmas in the description of thinking. *Educational Review*, 31, 123-132.
- Fasching, D. J., deChant, D., & Lantigua, D. M. (2001). *Comparative ethics: A narrative approach to global ethics* (2<sup>nd</sup> ed.). West Sussex, United Kingdom: Wiley-Blackwell.
- Fine, G. A. (1993). Ten lies of ethnography. *Journal of Contemporary Ethnography*, 22(3), 267-294.
- Fine, G. A. (2003). Towards people ethnography: Developing a theory from group life. *Ethnography*, 4(1), 41-60.
- Flick, U. (2010). Gutekriterien qualitativer Forschung. In G. Mey., & K. Mruck (Eds.), *Handbook Qualitative Forschung in der Psychologie* (pp.395-470). Wiesbaden: VS Verlag/Springer.
- Forester, J. (1980). Critical theory and planning practice. *Journal of the American Planning Association*, 46(3), 275-286.
- Foster, K., McAllister, M., & O'Brien, L. (2005). Coming to auto ethnography: A mental health nurse's experience. *International Journal of Qualitative Methods*, 4(4), 5-13.
- Foucault, M. (1976). *The birth of the clinic: Archaeology of medical perception*. London, United Kingdom: Tavistock.
- Frank, A. W. (1990). Bringing bodies back in. *Theory and Culture*, 7(1), 131-162.
- Franks, A. W. (1995). *The wounded storyteller: Body illness, and ethics*. Chicago, IL: University of Chicago Press.
- Freeman, M. (2004). Data are everywhere: Narrative criticism in the literature of experience. In C. Daiute ., & C. Lightfoot, (Eds.), *Narrative analysis: Studying the development of individuals in society* (pp.63-81). Thousand Oaks, CA: Sage.
- Friere, P. (1970). *Pedagogy of oppressed*. New York: Herder and Herder.
- Friere, P. (1972). *Pedagogy of oppressed*. (Trans. M.B. Ramos.). London, United Kingdom: Sheed and Ward.
- Gardner, M. (1998). *Lewis Carroll the Annotated Alice: Alice's Adventures in Wonderland and Through the Looking Glass*. New York: Wings Books an Imprint of Random House Value Publishing.
- Gardner, M. (1998). Introduction and notes. In *Lewis Carroll: The Annotated Alice: Alice's Adventures in Wonderland and Through the Looking Glass*. New York: Wings Books. (Original work published 1960).

- Gardner, M. (2001). *The Annotated Alice: The definitive edition*. London, United Kingdom: Penguin Books.
- Gendlin, E. T. (1982). *Focusing*. (2<sup>nd</sup> ed) Bantam Books. Available also from <http://www.focusing.org/focusingbook.html>.
- Gendlin, E. T. (1991). Thinking beyond patterns: Body language and situations. In B. den Ouden., & M. Moen (Eds.), *The Presence of Feeling in Thought*, pp.21-151. New York: Peter Lang. Available also at <http://www.focusing.org/tbp.html>.
- Gergen, M., & Gergen, K. (2002). Ethnographic representation as relationship. In A.P. Bochner., & C. Ellis (Eds.), *Ethnographically speaking: Autoethnography, literature, and aesthetics* (pp.1-33). Walnut Creek, CA: AltaMira Press
- Goethe, J. W. (n.d.). *Whatever you can do, or dream you can, begin it. Boldness has genius, power, and magic in it*. Retrieved from <http://german.about.com/library/blgermyth12.htm>
- Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, New York: Doubleday/Anchor Books.
- Goodall, H. L. (2000). *Writing the new ethnography*. Walnut Creek, CA: AltaMira Press.
- Goswami, A. (2001). *Ecological and cosmological studies* [Lectures, Spring Quarter]. Carpinteria, CA: Pacifica Graduate Institute.
- Grosz, E. A. (1994). *Volatile bodies: Toward a corporeal feminism*. Sydney, NSW, Australia: Allen & Unwin Press.
- Gubrium, J. F., & Holstein, J. A. (2009). *Analyzing narrative reality*. Thousand Oaks, CA: Sage.
- Halstead, N., Hirsch, E., & Okely, J. (Eds.). (2008). *Knowing how to know: Fieldwork and the ethnographic present* (pp.55-73). Oxford, United Kingdom: Berghahn Books.
- Hardey, M. (1998). *The social context of health*. Buckingham, United Kingdom: Open University Press.
- Hawkins, A. H. (1999). *Reconstructing illness: Studies in pathography* (2<sup>nd</sup> ed.). Purdue Research Foundation West Lafayette, IN: Purdue University Press.
- Hayano, D. (1979). Auto-ethnography: Paradigms, problems, and prospects. *Human Organisation*, 38(1), 99-104.
- Hayes. M. (2012). *Imagination as method: Poiesis in ethnographic research*. [Presentation] Hamilton, New Zealand: University of Waikato.

- Heidegger, M. (1927). *Being and Time*, (Trans. by J. Macquarrie., & E. Robinson). (London: SCM Press, 1962); (Re-translated by J. Stambaugh). Albany: State University of New York Press, 1996).
- Heshusius, L. (1994). Freeing ourselves from objectivity: Managing subjectivity or turning toward a participatory mode of consciousness? *Educational Researcher*, 23(3), 15-22.
- Hiles, D. (2002). *Heuristic inquiry and transpersonal research*. [Presentation] London, United Kingdom: CCPE. Retrieved from <http://www.psy.dmu.ac.uk/drhiles/Hipaper.htm>.
- Holman-Jones, S. (2005). Autoethnography: Making the personal political. In N. K. Denzin., & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. (3rd ed. pp.763-791). Thousand Oaks, CA: Sage.
- Holt, N. L. (2003). Representation, legitimation and autoethnography: An autoethnographic writing story. *International Journal of Qualitative Methods*, 2(1). Retrieved from [http://ualberta.ca/~iiqm/backissues/2\\_1final/html/holt.html](http://ualberta.ca/~iiqm/backissues/2_1final/html/holt.html)
- Hughes, R. (2006). The poetics of practice-based research writing. *The Journal of Architecture*, 11(3), 283-301.
- Ings, W. (2011). *The internal pathway of the self: Supervisory implications of autobiographical, practice led Ph.D. design theses*. [Presentation]. Hong Kong, Peoples Republic of China: AUT University; Hong Kong Polytechnic University School of Design; Swinburne University of Technology Faculty of Design.
- Jacobs, D. T. (2008). *The authentic dissertation: Alternative ways of knowing, research, and presentation. Four arrows (Don Trent Jacobs)*. Wiltshire, United Kingdom: Routledge.
- Jaworski, J. (1998). *Synchronicity the inner path of leadership* (1st ed.). B.S. Flowers (Ed.), San Francisco, CA: Berrett-Koehler Publishers.
- Jelinek, G. (2005). *Taking control of Multiple Sclerosis: Natural and medical therapies to prevent its progression* (2nd ed.). Flemington Victoria, WA Australia: Hyland House.
- Johnson, M. (1987). *The body in the mind: The bodily basis of meaning, imagination, and reason*. Chicago, IL: The University of Chicago Press.
- Jordan, S.A. (2001). Writing the other, writing the self: transforming consciousness through ethnographic writing. *Language and International Communication*, 1(1), 40-56.

- Jung, C. G. (1960). Synchronicity: An Acausal connecting principle'. In *The structure and dynamics of the psyche*, vol.8 of *The collected works of C. G. Jung*, (Trans. R.F.C. Hull). Princeton, N.J: Princeton University Press.
- Keats, J. (2002) *Selected letters*. Oxford, United Kingdom: Oxford University Press.
- Kelly, G. A. (1995). *The psychology of personal constructs*. New York: W. W. Norton & Co.
- Kierkegaard, S. (1980). *The sickness unto death*. (Ed. and trans. by H. V. Hong & E. H. Hong). Princeton, NJ: Princeton University Press.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books Publishers.
- Kraus, C.W. (2003). On hurting people's feelings. Journalism, guilt and autobiography. *Biography*, 26(2), 283-297.
- Kuhn, T. S. (1996). *The structure of scientific revolutions* (3<sup>rd</sup> ed.).Chicago, IL: University of Chicago Press.
- Kurtzke, J. F. (1983). Rating neurological impairment in Multiple Sclerosis: An expanded disability scale. *Neurology*, 33, 1444-52.
- Lakoff, G., & Johnson, M. (2008). *Metaphors we live by*. Chicago, IL: University of Chicago Press.
- Leavy, P. (2009). *Method meets art: Arts-based research practice*. New York: Guilford Publications.
- Levinas, E. (1996). *Emmanuel Levinas: Basic philosophical writings*. (Ed. Paperzak, Adriaan, et.al.).Bloomington, IN: Indianapolis University Press.
- Lincoln, Y. S., & Guba, E. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin., & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (3rd ed., pp.191-216).Thousand Oaks, CA: Sage.
- Lovell, S. (2005). Seductive whisperings: Memory, desire and agency in auto/biography. *Third Space*, 4(2): 32-44. Retrieved from, [http://www.thirdspace.ca/vol4/4\\_2\\_Lovell.htm](http://www.thirdspace.ca/vol4/4_2_Lovell.htm).
- Madden, R. (2010). *Being ethnographic: A guide to the theory and practice of ethnography*. London, United Kingdom: Sage.
- Mairs, N. (1993, February 11).When bad things happen to good writers. *New York Times Book Review*, 1, 25-27.

- Mairs, N. (1996). *Waist-high in the world: A life among the nondisabled*. Boston, MA: Beacon Press.
- Marcus, G. (1988). *Ethnography through thick and thin*. Princeton, NJ: Princeton University Press.
- Marshall, J. (1999). Living life as inquiry. *Systemic Practice and Action Research*, 12(2), 155-171.
- Marshall, J. (2001). Self –reflective inquiry practices. In Reason, P., & Bradbury, H. (Eds.), *Handbook of action research* (pp. 433-439). London, United Kingdom: Sage.
- Marshall, J. (2004). Living systemic thinking: Exploring quality in first person action research. *Action Research*, 2(3), 309-329.
- MacIntyre, A. (1981). *After virtue: A study in moral theory*. Notre Dame, IN: University of Notre Dame Press.
- May, R. (1967). *Psychology and the human dilemma* (pp. 78-79). Princeton, NJ: D. Van Nostrand Company.
- McIlveen, P. (2008). Autoethnography as a method for reflexive research practice in vocational psychology. *Australian Journal of Career Development*, 17(2), 13-20.
- McLean, A., & Leibing, A. (Eds.). (2007). *The shadow side of fieldwork: Exploring the blurred borders between ethnography and life*. Oxford, United Kingdom: Blackwell.
- McMahon, J., & Thompson, M. D. (2011). Body practices- exposure and effect of a sporting culture? Stories from three Australian Swimmers. *Sport, Education and Society*, 17(2), 181-206.
- McNiff, J. (1996). *How can I promote an understanding of the generative transformational nature of lifelong learning?* [Presentation]. New York: American Educational Research Association.
- McNiff, J. (2000). *Action research in organisations*. London, United Kingdom: Routledge.
- Morse, J. (2002). Writing my own experience. *Qualitative Health Research*, 12(9), 1159-1160.
- Moustakas, C. (1990). *Heuristic research: Design, methodology and applications* (pp. 8-55). Newbury Park, CA: Sage.
- Muncey, T. (2005). Doing Autoethnography. *International Journal of Qualitative Methods*, 4(1), 1-12.

- Narayan, K. (1993). How native is a native anthropologist? *American Anthropologist*, 95(3), 671-86.
- Nash, R. (2004). *Liberating scholarly writing: The power of personal narrative*. New York: Teachers Collage Press.
- National Multiple Sclerosis Society United Kingdom. (2013). Retrieved April 8, 2013, from <http://www.natioalmssociety.org>.
- Neitzsche, F. (1966). *Beyond good and evil* (p.35). (Trans. W Kaufman), New York: Vintage Books.
- Neumann, M. (1996). Collecting ourselves at the end of the century. In *Composing ethnography: Alternative forms of qualitative writing* (pp.172-198). C. Ellis., & A. P. Bochner (Eds.), Walnut Creek, CA: Alta Mira Press.
- Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education*. Berkeley, CA: University of California Press.
- Noddings, N. (1988). An ethic of caring and its implications for instructional arrangements. *American Journal of Education*, 96(2), 215-230.
- Oakeshott, M. (1966). *Experience and its modes*. Cambridge, United Kingdom: The Cambridge University Press.
- Okely, J. (1992). Anthropology and autobiography: Participatory experience and embodied knowledge. In J. Okely.,M. & H. Callaway (Eds.), *Anthropology and autobiography* (pp.1-28). London, United Kingdom: Routledge.
- Olafson, F. A. (1995). *What is a human being? A Heideggerian View*. New York: Cambridge University Press Syndicate.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Pelias, R. (2004). *A methodology of the heart*. Walnut Creek, CA: AltaMira Press.
- Plummer, K. (2001). The call of life stories in ethnographic research. In P. Atkinson., A. Coffey., S. Delamont., J. Lofland., & L. Lofland (Eds.), *Handbook of ethnography* (pp.393-406). Thousand Oaks, CA: Sage.
- Polanyi, M. (1958). *Personal knowledge*. Chicago, IL: The University of Chicago Press.
- Polanyi, M. (1962/1969). Tacit knowing: It's bearing on some problems of philosophy. Reprinted in *Knowing and Being: Essays by Michael Polanyi*, (Edited by M. Grene). Kegan & Paul: Routledge.

- Polanyi, M. (1966/1983). *The tacit dimension*. London, United Kingdom: Routledge.
- Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Polkinghorne, D. (1997). Reporting qualitative research as practice, In W.G. Tierney., & Lincoln, Y.S. (Eds.), *Representation and the text*. Albany, NY: State University of New York.
- Price, B. (1996). Illness carers: The chronic experience of illness. *Journal of Advanced Nursing*, 24(2), 275-279.
- Prigogine, I., & Stengers, I. (1984). *Order out of chaos: Man's new dialogue with nature*. London, United Kingdom: Heinemann.
- Reason, P. (1993). Reflections on sacred experience and sacred. *Journal of Management Inquiry*, 2(3), 273-283.
- Reason, P. (1988). *Human inquiry in action: Developments in new paradigm research*. Thousand Oaks, CA: Sage Publishers.
- Reed-Danahay, D. E. (1997). *Autoethnography: Rewriting the self and the social*. Oxford, London, United Kingdom: Oxford International Publishers.
- RESPECT Project. (2002-2004). European Commission's Information Society Technologies (IST) Programme. Retrieved from <http://www.respectproject.org/main/index.php>
- Ricoeur, P. (2010). *A Passion for the possible. Thinking with Paul Ricoeur*. (1<sup>st</sup> ed.). In B. Treanor., & H. I. Venema (Eds.), New York: Fordham University Press.
- Richardson, L. (1995). Narrative sociology. In J. Van Maanen (Ed.), *Representation in Ethnography* (pp.198-221).Thousand Oaks, CA: Sage.
- Richardson, L. (2000). Writing: A method of inquiry. In N. K. Denzin., & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 923-948).Thousand Oaks, CA: Sage.
- Richardson, L. (2009). Writing: A method of inquiry. In N. K. Denzin., & Y. Lincoln (Eds.),*Handbook of qualitative research* (pp.923-48). Thousand Oaks, CA: Sage.
- Ronai, C. R. (1992). The reflexive self through narrative: A night in the life of an erratic dancer/researcher. In C. Ellis., & M. G. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp.102-124). Newbury Park, CA: Sage.

- Rorty, R. (1982). *Consequences of pragmatism (Essays 1972-1980, P.197)*. Minneapolis, Minnesota: University of Minnesota Press.
- Rosenberg, W. (1998). Healthy self-doubt: The view from here. *Odyssey. The Glaxo Wellcome Journal of Innovation in Health Care*, 4(1), 14-15.
- Roth, W. M. (2005). Auto/biography and auto/ethnography: Finding the generalised other in the self. In W.M. Roth (Ed.), *Auto/biography and Auto/ethnography: Praxis of research method* (pp.3-16). Rotterdam: Sense Publishers.
- Russell, B. (1966). Lectures on the philosophy of Logical Atomism. In R. C. Marsh (Ed.), *Logic and knowledge* (pp. 234). London, United Kingdom: George Allen & Unwin.
- Ryang, S. (2000). Ethnography or self-cultural anthropology? Reflections on writing about ourselves. *Dialectical Anthropology*, 25, 297-320.
- Sacks, O. (1984). *A leg to stand on*. New York: Summit Books Publishers.
- Satre, J. P. (1956). *Being and nothingness*. New York: Philosophical Library.
- Scholte, B. (1974). Toward a reflexive and critical anthropology. In D. Hymes (Ed.), *Reinventing anthropology* (pp.430-458). New York: Vintage Books.
- Schön, D. A. (1983). *The reflective practitioner: How professionals think in action* London, United Kingdom: Maurice Temple Smith.
- Schultz, M., & Hatch, M. J. (1996). Living with multiple paradigms: The case of paradigm interplay in organizational culture studies. *Academy of Management Review*, 21(2), 529-557.
- Senge, P. (1990). *The fifth discipline: The art and practice of the learning organisation*, New York: Currency Doubleday.
- Senge, P. (1990). *Peter Senge and the theory and practice of the learning organization*. Infed, ideas, thinkers, practice. Retrieved from <http://www.infed.org/thinkers/senge.htm>.
- Senge, P. (1990). The leader's new work: Building-learning organizations. *Sloan Management Review*, Fall, 7-23.
- Senge, P. (2006). *The fifth discipline: The art and practice of the learning organisation*. (Revised and updated). London, United Kingdom: Random House Business Books.
- Silvia, P. J., & O'Brien, M. E. (2004). Self-awareness and constructive functioning: Revisiting "The Human Dilemma". *Journal of Social and Clinical Psychology*, 23(4), 475-489.



- Smith, L. T. (1999). *Decolonising methodologies: Research and indigenous peoples*. Dunedin, New Zealand: University of Otago Press.
- Smith, B., & Sparkes, A. (2006). Narrative inquiry in psychology: Exploring the tensions within. *Qualitative Research in Psychology*, 3(3), 169-192.
- Sparkes, A. C. (1996). The fatal flaw a narrative of the fragile body-self. *Qualitative Inquiry*, 2(4), 463-494.
- Sparkes, A. C. (2000). Autoethnography and narratives of the self: Reflections on criteria in action. *Sociology of Sport Journal*, 17(1), 21-43.
- Sparkes, A.C. (2002). Autoethnography: Self-indulgence or something more? In C. Ellis., & A. P. Bochner (Eds.), *Ethnographically speaking: Autoethnography, literature, and aesthetics* (pp.209-323). Walnut Creek, CA: AltaMira Press.
- Sparkes, A. C. (2004). From performance to impairment: A patchwork of embodied memories. In J. Evans., B. Davies., & J. Wright (Eds.), *Body knowledge and control: Studies in the sociology of physical education and health* (pp.140-155). London, United Kingdom: Routledge.
- Sparshoort, F. (1999). On what dancing is. In G. McFee (Ed.), *Dancing, education and philosophy* (pp.63-84). Oxford, London, United Kingdom: Meyer & Meyer Sport.
- Spiegel, D. (1993). *Living beyond limits*. New York: Ballantine Books.
- Spry, T. (2001). Performing autoethnography: An embodied methodological praxis. *Qualitative Inquiry*, 7(6), 706-732.
- Steward, H. (1997). *The ontology of mind: Events, processes, and states*. Oxford, London, United Kingdom: Clarendon Press.
- Stewart, D. C., & Sullivan, T. J. (1982). Illness behaviour and the sick role in chronic disease. *Social Science and Medicine*, 16(15), 1397-1404.
- Sutherland, J. M. (1986). Multiple Sclerosis-clinical. In Downie, P. A (Ed.), *Cash's text book of neurology for physiotherapists* (4<sup>th</sup> ed., pp. 296-313.). Philadelphia, PA: J. B. Lippincott.
- Synnott, A. (1993). *The body social: Symbolism, self and society*. London, United Kingdom: Routledge.
- Tedlock, B. (1991). From participant observation to the observation of participation. The merngence of narrative ethnography. *Journal of Anthropological Research*, 47(1), 69-94.

- Tierney, W. G. (2000). Undaunted courage: Life history and the postmodern challenge. In N. K. Denzin., and Y. S. Lincoln (Eds.), *Handbook of qualitative research*. (2nd ed.). CA: Sage.
- Tierney, W. G., & Lincoln, Y. (1997). *Representation and the Text: Re-framing the Narrative Voice*. Albany; NY: State University of New York Press.
- Tillich, P. (1955). *The new being*. New York: Scriber.
- Tillich, P. (n.d.). *The first duty of love is to listen*. Retrieved from [http://thinkexist.com/quotation/the\\_first\\_duty\\_of\\_love\\_is\\_to\\_listen/218174.html](http://thinkexist.com/quotation/the_first_duty_of_love_is_to_listen/218174.html).
- Toombs, S. K. (1992). *The meaning of illness: A phenomenological account of the different perspectives of physician and patient*. Dordrecht, Holland, Netherlands: Kluwer Academic Publishers.
- Toombs, S. K. (1995). Sufficient unto the day: A life with multiple sclerosis. In S. K. Toombs., D. Barnard., & R. Carson (Eds.), *Chronic illness: From experience to policy*. Bloomington & Indianapolis: Indiana University Press.
- Toombs, S. K. (2001). Reflections on bodily change: The lived experience of disability. In S. K. Toombs (Ed.), *Phenomenology and medicine*. Dordrecht, Holland, Netherlands: Kluwer Academic Publishers.
- Tullis, O., McRae, J. A., Adams, T. E., & Vitale, A. (2009). Truth troubles. *Qualitative Inquiry*, 15(1), 178-200.
- Turner, B. S. (1996). *The body and society* (2nd ed.). London, United Kingdom: Sage.
- Van Maanen, J. (1979). The fact of fiction in organisational ethnography. *Administrative Science Quarterly*, 24(4), 539-550.
- Van Maanen, J. (1988). *Tales of the field on writing ethnography*. Chicago, IL: The University of Chicago Press.
- Van Maanen, J. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario: SUNY Press.
- Van Maanen, J. (1998). Different strokes: Qualitative research in the Administrative Science Quarterly from 1956 to 1996. In Van Maanen, J. (Ed.), *Qualitative Studies of Organizations* (pp. ix-xxxii). Thousand Oaks, CA: Sage.
- Van Maanen, J. (2011). *Tales of the field on writing ethnography* (2nd ed.). Chicago, IL: The University of Chicago Press.

- Vickers, M. H. (1997). Life at work with "invisible" chronic illness (ICI): The "unseen", unspoken, unrecognized dilemma of disclosure. *Journal of Workplace Learning*, 9(7), 240–252.
- Vickers, M. H. (1997). *Life and work with "Invisible" Chronic Illness (ICI): Authentic stories of a passage through trauma*. (Unpublished doctoral thesis). University of Western Sydney, Sydney, NSW, Australia.
- Vickers, M. H. (1998). Life at work with "Invisible" Chronic Illness (ICI): A passage of trauma turbulent, random, poignant. *Administrative Theory and Praxis*, 20(2), 196- 218.
- Vickers, M. H. (1999). "Sick Organizations", "Rabid Managerialism": Work-life narratives from people with "Invisible" Chronic Illness. *Public Voices*, 4(2), 59-82.
- Vickers, M. H. (2000). The "Invisibly" Chronically III as unexamined organizational Fringe-Dwellers: Voices of ambiguity, confusion and uncertainty. In R. Hodson (Ed.), *Marginal employment* (pp. 3-21). Greenwich, Connecticut: JAI Press.
- Vickers, M. H. (2001). *Work and unseen chronic illness: Silent voices*, London, United Kingdom & New York: Routledge.
- Vickers, M. H. (2002a). Bullying as unacknowledged organizational evil: A researcher's story. *Employee Responsibilities and Rights Journal*, 13(4), 205-217.
- Vickers, M. H. (2002b). Researchers as storytellers: Writing on the edge - and without a safety net. *Qualitative Inquiry*, 8(3), 608-621.
- Vickers, M. H. (2005). Illness, work and organization: Postmodern perspectives, ante narratives and chaos narratives for the reinstatement of voice. *Tamara: Journal of Critical Postmodern Organisation Science*, 3(2), 1-15.
- Vickers, M. H. (2010). Illness onset as status passage for people with multiple sclerosis (MS). *Journal of Health and Human Services Administration*, 33(2), 1-12.
- Wall, S. (2006). An autoethnography on learning about autoethnography *International Journal of Qualitative Methods*, 5(2), 1-12.
- Wall, S. (2008). Easier said than done: Writing an Autoethnography. *International Journal of Qualitative Methods*, 7(1), 38-53.
- Watts, A. W. (2009). *What is tao?* New World Library.
- Watson, T. J. (2009). Narrative, life story and manager identity: A case study in autobiographical identity. *Human Relations*, 62(3), 425-452.

Webb, J., & O'Brien, D. L. (2008). Agnostic thinking: Creative writing as practice-led research. Working papers in Art and Design. Retrieved from [http://sitem.herts.ac.uk/artdes\\_research/papers/wpades/vol5/jwdoobfull.htm](http://sitem.herts.ac.uk/artdes_research/papers/wpades/vol5/jwdoobfull.htm)

Wikipedia. (2011). Alice's adventures in wonderland- Wikipedia the free encyclopaedia. Retrieved from [http://en.wikipedia.org/wiki/Alice%27s\\_Adeventures\\_in\\_Wonderland](http://en.wikipedia.org/wiki/Alice%27s_Adeventures_in_Wonderland)

## APPENDICES

### Appendix A:

Supplementary visual images material associated with the development of the research process for my thesis.

Author's own photographs that were formatted into montage. ©

Author's own photographs that were specially chosen to adorn cover page of each chapter linking visual picture to story line. ©

- i) Books - exploring room of methodology
- ii) Montage - being and becoming
- iii) Living life as inquiry - a learning self
- iv) *'Mother'* - original painting – artist: Simone Allbon
- v) Reflections from the red rattan chair- author's favourite chair

## Appendix B:

**Listing** of relevant publications, conference papers written and presented that helped shape the development of my thesis.

NB. This thesis does not contain these papers. They are available by emailing Caroline Allbon at: callbon@xtra.co.nz

### Journal publication

Allbon, C. (2012). ‘Down the rabbit hole’- Curiouser and Curiouser: Using autoethnography as a mode of writing to re-call, re-tell, and re-veal bodily embodiment as self reflexive inquiry. *Journal of Organisational Ethnography* 1(1): 62-72.

Allbon, C. (Under review). “Seeing eye-to-eye”: An autoethnographical account of embodied nerve pain as a lived experience. *First Person Research Journal*.

### Conferences

Allbon, C. (2012, November). *On being and becoming reflexive in Autoethnography as mode of reflexive practice in qualitative fieldwork*. The 2<sup>st</sup> Contemporary Ethnography Across the Disciplines (CEAD), Hamilton, New Zealand.

Allbon, C. (2011, October). “*Seeing eye-to-I*”: *Sensing corporate culture through the eye/I that writes/rights*. 15th Annual Waikato Management School Student Research Conference, Hamilton, New Zealand.

Allbon, C., & Humphries, M. (2010, February). *From OIL to LIO: Location, Identity and Organization(s) for human and environmental flourishing- Inside, outside, upside down: autoethnographic reflections on the role of location, identity and organization(s)*. Organization, Identity and Locality, Wellington, New Zealand.

- Allbon, C., & Humphries, M. (2010, July). *Of three's...motivation, immersion, and expression a triptych in the quest of human purpose and significance*. 10th International Federation of Scholarly Associations of Management (IFSAM), Paris, France.
- Allbon, C., & Humphries, M. (2010, July). *Justice and Sustainably in Global Economy-Consequences of [15h century] colonisation and [21<sup>st</sup> century] decolonisation*. Paper presented at the 10<sup>th</sup> World Congress Conference-International Federation of Scholarly Associations of Management, Paris, France.
- Allbon, C. (2010, October). *Of three's... motivation, immersion, and expression a triptych in the quest of human purpose and significance*. 14th Annual Waikato Management School Student Research Conference- Hamilton, New Zealand.
- Allbon, C. (2010, November). *Ethnography on the move... "Venturing into the shadow side of the self who observes*. The 1<sup>st</sup> Contemporary Ethnography Across the Disciplines (CEAD), Hamilton, New Zealand.
- Allbon, C., & Humphries, M. (2008, November). *We live in our metaphors...story telling as sacred inquiry for wellbeing of people and our planet*. Australia and New Zealand Third Sector Research Ninth Biennial Conference. Auckland, New Zealand.
- Allbon, C. (2009, August). *Of three's...Autoethnography, Research and Teaching: rethinking the politics and practice of identity through a third space*. International Conference, Liverpool, U.K.
- Allbon, C. (2009, October). *Of three's ...Autoethnography- Research- and Teaching: rethinking the practice of identity through a third space*. 13th Annual Waikato Management School Student Research Conference, Hamilton, New Zealand (Commendation Highly Rated Presentation of a paper).

## Appendix C:

### Secondary resources used to that have influenced the shaping of this thesis

- Adams, T.E. (2006). Seeking father: Relationally reframing a troubled story. *Qualitative Inquiry*, 12 (4), 331-345.
- Alvesson, M., & Sköldbberg, K. (2000). *Reflexive Methodology: New vistas for qualitative research*. London, United Kingdom: Sage.
- Alvesson, M., & Deetz, S. (2000). *Doing Critical Management Research*. London, United Kingdom: Sage.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *Sociological Quarterly*, 35(2), 269- 288.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36(4), 657-680.
- Denzin, N.K. (2006). Analytic autoethnography, or déjà vu all over again. *Journal of Contemporary Ethnography*, 35(4), 419-428.
- Gadamer, H. G. (1992). *Truth and Method (2<sup>nd</sup> revised ed.)*. New York: The Crossroad Publishing Company.
- Gadamer, H.G. (1988).On the circle of understanding. In Hermeneutics versus science? *Three German views*, J. Connolly & T. Keutner (Eds.), (pp. 68-78).Notre Dame, IN: University of Notre Dame Press.
- Giblett, R. (2008). *The Body of Nature and Culture*. Chippenham and Eastbourne, United Kingdom: Palgrave Macmillan.
- Geertz, C. (1989). *Works and Lives: The Anthropologist as author*. Stanford, CA: Stanford University Press.
- Grimshaw, A. (2001). *The Ethnographer's Eye*. Cambridge, United Kingdom: Cambridge University Press.
- Gorman, J. (1997). *The Seeing Glass: A Memoir*. New York: Riverhead Books.
- Eisenburg, L. (1977). Disease and illness: distinction between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry*, 1, 9-23.
- Peias, R.J. (2004). *A Methodology of the Heart: Evoking academic and daily life*. Walnut Creek, CA: Alta Mira Press.
- Phillips, B. (2007).Nursing care and understanding the experiences of others: a Gadamerian perspective. *Nursing Inquiry*, 14(1), 89-94.
- Pinar, W, F. (2004). Foreword. In R.L.Irwin & A. de Cosson (Eds.). *A/r/tography; Rendering Self through Arts Based Living Inquiry* (pp.9-25). Vancouver, BC: Pacific Educational Press.
- Reason, P., & Bradbury.H. (2001). *Handbook of Action Research*. London: Sage.
- Rose, N. (1990). *Governing the Soul: The shaping of the private self*. (2<sup>nd</sup> ed.). London, United Kingdom: Routledge.
- Shenkman, M.H. (1996). *The Strategic Heart: Using new science to lead growing organisations*. Westport, CT: Greenwood Praeger Publishers.
- Wenger, E. (1998). *Communities of practice, learning meaning and identity* Cambridge, United Kingdom: Cambridge University Press.



- Wenger, E., McDermott, R., and Synder, W. (2002). *Cultivating communities of practice: A guide to managing knowledge*. Boston, MA: Harvard Business School Press.
- Weston, A. (1992). On the medical self-care and holistic medicine. In D.Leder (Ed.). *Medical thought and practice*. The Netherlands: Dordrecht: Kluwer.
- White, R. (2000). *Multiple Sclerosis: Health Professional Handbook*: (pp.19-27). National Multiple Sclerosis Society of N.Z .Inc. Wellington, New Zealand.
- White, S. (2003). Auto ethnography: An appropriate methodology? *Qualitative Research Journal*, 3(2), 22-32.
- Whitehead, J. (1989). Creating A Living Educational Theory From Questions Of The Kind, 'How Do I Improve My Practice?' *Cambridge Journal of Education*, 19(1), 41-52.  
Retrieved from <http://people.bath.ac.uk/edsajw/writings/livtheory.html>
- Whitehead, J. (1993). 'How do I improve the quality of my management? A participatory action research approach, *Management Learning*, 25(1), 137-53.
- Whitehead, J. (2000) 'How do I improve my practice? Creating and legitimising an epistemology of practice' *Reflective Practice*, 1(1), 91-104.
- Whitney, D., Kaplin, D., Cooperrider, D., and Trosten-Bloom, A. (2003). *The power of appreciative inquiry: A practical guide to positive change*. San Francisco, CA:Berrett Kochler.
- Wieck, K.E. (1995). *Sense making in organisations*. London, United Kingdom: Sage.
- Wieck, K.E. (2001). *Making sense of the organisation*. Oxford, United Kingdom: Blackwell.
- Willis, A.I. (1998). In their own words: Stories of the interconnectedness of life, teaching and research. *Reading Research Quarterly*, 33(4), 487-497.
- Willoughby. (1993). *Excerpt from Multiple Sclerosis*. New Ethical Disease Index (3<sup>rd</sup> ed).Newton, Auckland, New Zealand: Medical Publishing Company Limited.
- Wittgenstein, L. (1969). *On certainty*. San Francisco, CA: Harper Torch.
- Willis, P. (2001). *The ethnographic imagination*. Cambridge: Polity Press. Weick, K.E. (2005). *Sense making of the organisation*. Oxford, United Kingdom: Blackwell.
- Zola, I.K. (1983). *Socio-Medical inquiries: Reflections and reconsiderations*. Philadelphia, PA: Temple University Press.

## **LIST OF ABBREVIATIONS**

**PHCO** - Primary Health Care Organization

**NGO** - Non Government Organization

**GP** - General Practitioner

**MS** - Multiple Sclerosis

**PwMS** - Person with Multiple Sclerosis

**IST**- Information Society Technology

**EDDS**- Expanded Disability Status Scale

**CNS** - Central Nervous System

**RRMS** - Relapsing Remitting Multiple Sclerosis

**Pharmac**- The New Zealand Pharmaceutical Regulating Authority