‘Reimagining a self’: an evocative autoethnography of living alongside Myalgic Encephalomyelitis (ME)

Orlagh Farrell Delaney RGN, MA

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Department of Applied Social Studies

Supervisor and Head of Department:

Professor Maurice Devlin

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TABLE OF CONTENTS

List of Figures *(photographs, pages 161-178)*

Poems *(pages 229-252)*

ABSTRACT

This doctoral thesis research aims to explore and explain the day to day realities of living long term with Myalgic Encephalomyelitis (ME). ME is an acquired complex disorder characterised by a variety of symptoms affecting multiple systems of the body. Marked fatigue and weakness, sickness, cognitive dysfunction and symptom flare-up can follow any physical or cognitive exertion. ME is a chronic and disabling disorder and severe or moderately severe cases can leave patients bed or house bound. It is estimated that there are 12,000 people with ME in Ireland and an estimated 17 to 24 million sufferers worldwide. Despite this there is a dearth of research on the experience of living with ME.

I have lived with moderately severe ME for the last 16 years. Utilising autoethnography as a methodology and drawing on multidisciplinary social science theory, I aim to tell the story of my own lived experiences of the illness, and how I sought to reimagine a 'self' or a life living alongside the illness, that could still be considered a good life. Autoethnography is an autobiographical genre of writing and research, that displays multiple layers of consciousness connecting the personal to the cultural. Autoethnography uses the researcher's experience as primary data and in this thesis I utilise field notes kept over the years, journal entries, photography and my own poetry.

The data is presented as a series of four narratives. These narratives are then analysed using three interrelated conceptual and theoretical frameworks. The first is an original conceptual framework, 'The Struggle Cycle', designed for this study. It draws on and integrates two others: Witkin's (2014) Four Conditions Facilitative of Transformative Change, and the Buddhist philosophy of the Four Noble Truths. Too often people with illness are the passive subjects of investigation by researchers who do not have experience of illness. An autoethnographic approach helps to redress this imbalance and generate unique insights.

I intend that my study will help those who live with ME to reflect on and understand their own experiences, and will help to inform medical professional and other support services dealing with ME, as well as the general public and those who share their lives with people affected with ME, who can often struggle to understand. The insights generated could also apply to many other chronic illnesses.

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Thank you to all my family, friends and neighbours, who patiently, and in so many ways, loved, supported and provided.

Thank you to my beloved 'good life critters' who spent too much time waiting patiently, sitting looking at me, sitting looking at books.

> He prayeth best
>
> Who loveth best
>
> All things great and small
>
> Coleridge

To the ME "millions missing" – may we all find a way home.

Finally, I would like to dedicate this thesis to my Mom and Dad, to whom I owe anything that is good about me. Happy 90th birthday Dad – we made it!

GLOSSARY

Autoimmune disorders: An autoimmune system disorder cause abnormally low activity or over activity of the immune system in which case the body attacks and damages its own tissues. Common examples of autoimmune disorders are Rheumatoid Arthritis and Inflammatory Bowel Disease (IBD).

Biomarkers: In medicine, a biomarker is a measurable indicator of the severity or presence of some disease state.

Cytokines: Cytokines are a large group of proteins that are secreted by specific cells of the immune system. They signal and mediate inflammation and immunity.

Encephalomyelitis: This is inflammation of the brain and spinal cord, typically due to acute viral infection.

Fibromyalgia: Fibromyalgia is a disorder characterised by widespread musculoskeletal pain accompanied by fatigue and sleep issues.

Gulf War Syndrome: Gulf War Syndrome is a chronic and multi-symptomatic disorder affecting returning military veterans of the 1990-1991 Persian Gulf War.

Irritable Bowel Syndrome (IBS): IBS is a common long-term condition of the digestive system which can cause bouts of stomach cramps, bloating and diarrhoea and or constipation.

Immunological Circuits: The immune system must detect an incoming pathogen and initiate complex circuits to regulate this response.

Interstitial Cystitis (IC): IC is a chronic bladder health issue that causes bladder pressure and pain.

Lymphadenopathy: This is a disease of the lymph nodes producing swollen enlarged or painful lymph nodes.

Mitochondria: Mitochondria are called the powerhouse of the cell. They are free floating organelles floating free throughout the cell that keep it full of energy.

Multiple Chemical Sensitivities (MCS): Multiple Chemical Sensitivity is a medical condition characterised by a heightened sensitivity to chemicals many of which are commonly encountered in daily living such as perfume and cleaning products. Disagreement remains within the medical profession about this condition, it is a contested illness.

Myalgic Encephalomyelitis (ME): This is a systemic neuroimmune condition characterised by a reduction in functioning and a severe worsening of symptoms after even minimal exertion. It causes dysregulation of the immune, nervous and energy metabolism systems.

Neuroimmune System: the neuroimmune system is a series of structures and processes and interactions between the nervous and immune systems in order to protect neurons (nerve cells) from pathogens.

Neuropathology: The branch of medicine concerned with diseases of the nervous system.

Pathophysiology: The disordered physiological processes associated with disease or injury.

Prodromal Event: In medicine a prodrome is an early sign or set of signs and symptoms which often indicate the onset of a disease before more diagnostically specific signs and symptoms develop.

Psychogenic: Psychogenic disease or illness is a name given to a physical illness that is believed to arise from emotional or mental stressors, or from psychological or psychiatric disorders. It is commonly applied to illnesses where a physical abnormality has not yet been identified.

Raynaud's Syndrome: This is a medical condition in which spasm of arteries cause reduced blood flow which typically cause areas of the body such as fingers and toes to feel numb and cold in response to cold or stress.

TMJ Disorders: The temporomandibular joint (TMJ) acts like a sliding hinge connecting your jawbone to you skull. There is one joint on each side of the jaw. Disorders of the TMJ can cause pain in the jaw joint and in the muscles that control jaw movement. It can also cause severe headaches and pain with chewing.

Somatization: Somatization is a tendency to experience and communicate psychological distress in the forms of physical symptoms.

CHAPTER 1

INTRODUCTION

As a woman who has lived with Myalgic Encephalomyelitis (ME) for the last sixteen years, I am personally aware of the dearth of research on the lived experience of ME and the knowledge and information gaps that such a paucity of useful information and experience creates for sufferers, who often must struggle alone to find a way through an illness such as ME. I am moderately affected by the illness. The estimated percentage of the ME population considered to be moderately affected by the illness is 60% (MacIntyre 1998). Although this population cohort is frequently discussed within the medical research literature, they are not as visible as the severely affected category in terms of the portrayal of their lived experiences. As an incurable, invisible contested and unsupported illness (Jason 2007; Dimmock & Lazell-Farnen 2015) the lived experience of the illness is mostly portrayed in pessimistic, hopeless and option-less terms (Munson 2000; Mitchell 2003).

Myalgic Encephalomyelitis (ME) as a chronic, invisible and contested illness

Myalgic Encephalomyelitis ME is described as an acquired, complex disorder characterised by a variety of symptoms, principally extreme fatigue or malaise following exertion lasting six months or longer (Carruthers et al. 2011). ME is revealed as a chronic, invisible, contested illness (Blease et al 2017) with a global prevalence of 17-24 million sufferers (www.meaction.net). It is estimated that 12,000 people in Ireland live with ME. ME and Chronic Fatigue Syndrome have been entwined in a 'web of confusion' (Carruthers et al 2011) for thirty years. This has delayed research into the illness and fostered stigma and disbelief within the medical profession (Dimmock & Lazell-Farnen 2015). ME is a spectrum illness with patients falling somewhere under or within the categories of mild, moderate or severe (Twisk 2014). To date there are no laboratory or diagnostic tests to identify ME, and no cures or treatments (Green et al 2015). The causes of the extreme nature of the fatigue and related symptoms associated with ME are not yet understood, although recent biomedical hypotheses have been contributed from various medical specialities. However of greatest relevance to this thesis is that ME is considered a contested illness. A contested illness is a disorder that is considered medically suspect because it is not associated with any known physical abnormality (Conrad & Barker 2010). The legacy of this contested nature is that the ME patient's credibility is undermined and as a result diagnosis and adequate treatment and support are delayed. Patients are wrongly psychologised and not appropriately referred (Blease et al 2017; Jason et al 2009). Patients who feel disbelieved, mistrusted or misjudged by the healthcare system may choose to withdraw from healthcare altogether and go it alone. It is the contested and unsupported nature of the illness that is most burdensome to the ME population. ME constitutes a relatively new area of research, as the first outbreak of the illness only occurred in the late 1980s (Ramsey 1988). The recent increase in research interest is biomedical in origin (Montoya et al 2017; Naviaux et al 2017) and a dearth of research on the experience of living with ME persists (Bell 2000).

The central aim of this thesis is to explore and explain the experience of living alone with a chronic, invisible, contested illness such as ME. Given the pessimistic, hopeless portrayal of ME, my research questions ask: is it possible to reimagine a self or a life living with a chronic invisible illness contested illness like ME? If it is, can such a life be considered a good life?

The methodological design of this thesis is an evocative autoethnography. Autoethnography is research writing and method that connect the autobiographical and personal to the cultural and social (Ellis 2004). Evocative autoethnography is a research process that allows for expression of 'the consciousness and subjectivity of the author/researcher through a personal, vulnerable, reflective, self reflexive narrative voice' (Bochner & Ellis 2016). I came to autoethnography as a research method as a result of an encounter in July 2009, at the 5th Annual Mixed Methods Conference at Leeds University. I was co-presenting a paper with a colleague and dear friend on our experience of making a radio documentary about both our experiences of getting divorced in Ireland and the resilience of our friendship (http://www.rte/doconone/therewaslove). Following our presentation, the conference organiser Dr Tessa Muncey (who had just written a book *Creating Autoethnographies*, 2010) named our research as autoethnography and identified it as a relevant and potential method for my research interests.

Story

I am standing with you at the conference.

You are fluently academic

I have been sick and silent for years.

All around me I hear "nomothetic" and "idiographic"

These are no longer my words

this would not be my message now.

"Who are these people? " I ask.

"That doesn't matter" you smile.

But I have changed.

Now if I do not know who you are

I cannot take to heart what you say.

Too often people with illness are the passive subjects of investigations by researchers who do not have experience of illness. An autoethnographic approach can help to redress this imbalance and generate unique insights (Ettore 2010). My primary data in this thesis is drawn from some field notes but principally from journal entries kept over the course of my illness. The early years of illness, from 2002 to 2008, are presented as vignettes written from field notes and from journal entries. A narrative gap between 2009 and 2013 is identified as a result of relapsed illness following a lengthy divorce. Vignettes describing memories of events relevant to this timeframe are presented. Journal entries cover the period of 2014 to late 2018. The journal entries are written in narrative form, in the first person voice and are by their nature evocative. I also include my own photographs as data in this thesis. I received a gift of a small, light digital camera in 2009 which lived constantly in my pocket and I began capturing moments in time. Often, over the many years of my illness, my only capacity to record a moment or a fleeting story, was to capture it in a photograph. In 2015 an unwanted iphone replaced the camera in my pocket and captured moments in time from then to 2018. Finally, I include poetry in this thesis and the majority of it is my own poetry written over the course of my illness.

Thesis structure

Following this chapter, Chapter 2 outlines the nature of ME, its conflicted history, its contested nature and the thirty years of disagreement with regard to the naming and diagnosing of the illness. The medical and psychosocial natures of the illness are also discussed, along with the consequences for the ME community of the negative legacy from the years of disagreements and misunderstandings.

Chapter 3 outlines the methodology and conceptual frameworks employed in this thesis. An evocative autoethnography is adopted using personal journals, field notes, photography and poems as data. Four narratives spanning the length of the illness are presented and subsequently put under analysis in four corresponding chapters. The ‘Struggle Cycle” is an original conceptual framework created by the author which is influenced by and also draws on Witkin’s Conditions Facilitative Of Transformative Change (2014) and the Buddhist philosophy of the Four Noble Truths. These three conceptual frameworks are used in collaboration to analyse the narratives.

Chapters 4, 5, 6 and 7 present the four evocative autoethnographical narratives which express the lived experience of ME through the lenses of ‘struggle’, ‘surrender’, ‘seeing’ and ‘sanctuary’ respectively. The narratives are comprised of journal entries with the first (‘struggle’) also containing vignettes and poems. I present the narratives in the language they were written in in my journal entries which is creative, prosaic and at times poetic. Evocative autoethnography employs the tools of literary and aesthetic practitioners. I was influenced in my writing by the literary works of John O’Donoghue, John McGahern, May Sarton and the Zen poets. Poems can also be found in the other narratives. The evocative narratives also reveal the ‘story’ of a woman living alone over a sixteen year period, in a remote, rural setting, alongside rescued animals and aspiring towards a Buddhist philosophy. Photographs revealing the ordinary moments of such a life conclude this narrative section. I selected thirty eight photographs from a collection of over a thousand. My methodology is not to narrate them individually, but instead to allow them to portray visually, and reflect, images and stories already described in the narratives themselves.

Chapters 8, 9, 10 and 11 put the four narrative chapters, ‘struggle’, ‘surrender’, ‘seeing’ and ‘sanctuary’ under analysis using the conceptual frameworks already mentioned. Salient concepts and themes are identified and discussed including: voluntary simplicity and authenticity, enoughness, compassionate and harmless living, reverence for nature, gratitude and Zen consciousness. The trajectory of the transformative process or reimagining of a ‘self’ living with ME is illustrated using the ‘struggle cycle’.

A collection of my own poetry, *SIT*, is included after this narrative-under-analysis section. The poems reflect the sentiment in both the narrative and narrative-under-analysis sections as well as reflecting the photographs.

Chapter 12 presents a discussion of the overall ethnographic framework, along with its original contribution to knowledge, and Chapter 13 provides a brief conclusion.

Finally, there is a narrative Epilogue.

Original contribution to knowledge

The experience of living alone with an invisible, chronic, contested illness like ME is under-researched and under-reported. This is not unrelated to the nature and constraints of the illness. Using autoethnography as a method made undertaking this research possible, while still taking its toll. The contribution to knowledge of this autoethnographical research thesis is that it can serve to inform medical professional and other support services dealing with ME patients. It can also inform the general public and those who, although they share their lives with people who live with ME, can struggle to understand. This thesis can assist others who live with ME to reflect on and understand their own experiences and increase their own options for change. This thesis makes a methodological contribution because an autoethnography on living with ME has not been written to date. Also, an evocative autoethnography with the additional creative strands of original poetry and photography is an emergent research approach at doctoral dissertational level and it is hoped that this thesis will pave the way for others interested in this field.

CHAPTER 2

UNDERSTANDING MYALGIC ENCEPHALOMYELITIS (ME)

Introduction

In conducting a literature review on a medical condition, it might be expected that it could be explained quite succinctly in terms of definition, symptoms, diagnosis, causes, treatments and outcomes. What becomes clear early in a literature review of Myalgic Encephalomyelitis (ME) is that ME is considered to be a contested illness. A contested illness is an illness that is questioned or disputed by members of the medical field (Blease et al 2017). There is dispute over what the illness should be called, how to define it, and how to separate it from Chronic Fatigue Syndrome (CFS) (Hyde 2009) and the complex relationship that they have shared since the late eighties (Dimmock and Lazell-Farnen 2015). The contested nature of ME is also dominant in the dichotomous nature of the research in terms of the biopsychosocial or psychogenic theory, and the biomedical theories of the illness (Maes & Twisk 2010). The result of this dichotomy is that ME advocacy groups and the world of medicine differ greatly on how to view and manage the illness (Hossenbaccus & White 2013).

Myalgic Encephalomyelitis: ME

Myalgic encephalomyelitis (ME) is an acquired complex disorder characterized by a variety of symptoms, primarily extreme fatigue or malaise following exertion lasting six months or longer (Carruthers et al 2011). Many cases are preceded by a viral infection, usually a flu-like or upper respiratory illness It can also be preceded by a non-viral illness or other trauma such as chemical exposure. Onset is usually rapid (acute) but gradual onsets are reported (Ramsey 1988). Affected individuals do not recover from the infection and instead experience a wide variety of inflammatory type symptoms, including an inability to produce sufficient energy to meet daily demands (Klimas & Koneru 2007). Marked fatigue and weakness, sickness, cognitive dysfunction and symptom flare–up follows physical and cognitive exertion. ME represents a complex, multi-system group of afflictions adversely effecting the brain, heart, neuro-endocrine, immune and circulatory systems (Hyde 2003) Myalgic encephalomyelitis is a chronic and disabling disorder. Moderate to severe cases leave patients housebound or bedbound respectively. (Jason et al 2015). People with ME may not look ill but maintaining employment or study may prove difficult or impossible. Family and social interactions may also be compromised (Institute of Medicine 2015). To date there are no laboratory or diagnostic tests to identify ME, and no cures or treatments (Green et al 2015). ME is a spectrum illness but it is widely accepted that patients fall under or somewhere within one of three sub-groupings (Twisk 2014; Brurbeck et al 2014). The UK National Institute for Health and Clinical Excellence (NICE) guidelines (2007) describe them as follows:

> MILD: where people are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.
>
> MODERATE: where people have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their levels of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for one or two hours. Their sleep at night is generally of poor quality and disturbed.
>
> SEVERE: where people are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing and cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

Disease Prevalence

The Institute of Medicine (IOM) in the USA reviewed the ME/CFS literature in 2015 and estimated that between 836,000 and 2.5 Americans have ME/CFS. It is most common in people between forty and sixty years old with a female to male ratio of 6:1. The estimated prevalence of ME/CFS is 0.4-1% or between 17 to 24 million sufferers worldwide. Mean illness duration ranges from 3-9 years (Capelli et al 2010). It is estimated that there are about 12,000 people with ME in Ireland. (www.imet.ie)

Myalgic encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS)

Myalgic Encephalomelitis (ME) is the original term for the illness. It was re-categorised by the CDC (Center for Disease Control) in the USA in 1988, who considered the illness to be more about fatigue than neurology, and renamed Chronic Fatigue Syndrome (CFS). The name CFS, despite objections from clinical, research and patient groups, persists today in the USA, and has far reaching effects globally on the reality of ME. There are experts who consider it to be a matter of 'semantics' and argue that CFS is 'American' for ME and therefore, particularly in more recent times, they are used interchangeably in both research and clinical environments, particularly in the US but increasingly in research parlance globally. I am discussing the realities of ME but when quoting research and clinical experts that speak and publish in terms of ME/CFS or CFS/ME I must refer to it as it is quoted. However, as will become clear, when the CDC renamed ME as CFS in the USA in 1988 they changed the identity and integrity of the classical ME disease entity and made it a syndrome (a collection of disorders) (Johnson 1996). They also introduced psychiatry whose legacy has been very damaging for ME patients and their families (Deale et al 2001). CFS as a 'syndrome' has become an umbrella term under which some true ME patients have had to shelter, sharing it with other related and unrelated illnesses and conditions. ME is a neuro-immune condition of severe onset whose degree of central nervous system dysfunction and post exertional malaise are its identifying features and are in a different severity league to those of CFS as defined in its criteria (Hyde 2003, 2009).

A web of confusion

ME and CFS have been entwined in a 'web of confusion' (Caruthers et al 2011) for thirty years now. This 'web of confusion' has particularly delayed any focused investigation into ME as it laboured under orphan medical status, stigma and disbelief. Research was unfunded until the last decade when it became funded privately in the majority (www.meresearch.uk.com). Significant other contributing factors to this web of confusion, have been the constant disagreement about, and re-categorization of, the diagnostic criteria for ME internationally. For the purpose of this chapter and to expose the sources of the contested nature of ME, which again is central to this work, a short overview of the most relevant major criteria consensus findings is provided here, with some additional criteria provided in Appendix 1.

In the UK in the 1950s a series of outbreaks of a mysterious illness similar to poliomyelitis occurred. A Dr Ramsey, after studying such an outbreak that had occurred principally among doctors and nurses at the Royal Free Hospital in London, declared it to be 'benign encephalomyelitis'. What each outbreak had in common were symptoms of sore throat, tender lymph nodes, pain and signs of encephalomyelitis (Acheson 1955). The term 'benign' was used as it was not proving fatal (as opposed to a malignant nature), and the encephalomyelitis because of the 'evidence of parenchymal damage to the nervous system and the presumed inflammatory nature of the disorder' (Acheson 1959: 593). However, in 1970 two psychiatrists concluded that the outbreaks were 'psychosocial phenomena' caused either by 'mass hysteria on the part of the patients' or 'altered medical perception in the community' (Mc Evedy & Beard 1970: 13). They came to these conclusions because of the lack of physical signs in the patients and because of the considerably higher prevalence of the disease in women. They never actually saw or interviewed any of the patients at the time. Despite all Dr Ramsey's science and his objections (Ramsey et al, 1977) health professionals at that time subscribed to hysteria as a plausible explanation for the condition (Speight 2013). In 1984 there was an outbreak of an ME type illness in Incline Village, a popular ski town in Lake Tahoe, Nevada (Johnson 1996). In 1985, there was a similar type of outbreak in a relatively poor country town in Lyndenville, upstate New York (Bell, Jordan & Robinson 2001).

Subsequent to these two significant outbreaks, in 1986 Ramsey became the first to coin the term myalgic encephalomyelitis based on his description of symptoms of the 1955 Royal Free outbreak. Myalgic = muscle pain, encephalomyelitis = brain and spinal column inflammation. His categorization and identification of symptoms has been refined several times since 1986 including his own modifications in 1988, but they have never been deviated from substantially in terms of ME. He identified:

(1) Muscle phenomena: Fatigability, pain, clumsiness.

(2) Circulatory impairment: Cold extremities, hypersensitivity to climate change, ashen grey face pallor 20-30 minutes before the patient complains of feeling ill.
(3) Cerebral dysfunction: Impairment of memory, impairment of concentration, emotional lability. Alteration in sleep rhythm, vivid or violent dreams. Autonomic nervous system symptoms including orthostatic tachycardia (increased heart rate on standing), frequency of urination.
(4) Symptoms and physical findings may vary greatly in the course of any day.
(5) This illness has ‘an alarming tendency to become chronic’ (Ramsey 1988).

In 1988, the Center for Disease Control (CDC) in the USA, having visited the outbreak site in Incline Village, but *not* in Lyndonville wrote a report. They based their findings largely on one symptom; fatigue and renamed the illness chronic fatigue syndrome (CFS). They also included neuropsychological symptoms in their criteria.

In 1991, a group of British doctors unhappy with some of the American CFS criteria, met at Oxford to discuss and subsequently publish their own criteria for CFS. The Oxford Criteria for CFS (of which Sharpe and Clare, both psychiatrists, were the main protagonists) included fatigue as the main symptom (as opposed to post-exertional malaise) and included depression and anxiety disorders as criteria (Sharpe et al 1991). The Oxford criteria did not require a patient to have any of the cardinal, distinguishing features of ME that Ramsey had identified:

- abnormal muscle fatigue after trivial exertion with abnormally prolonged recovery.
- neuro-cognitive symptoms such as loss of memory and concentration.
- variability in severity from day to day or longer.
- the tendency for the illness to become chronic.

Also the Oxford Criteria included people with fatigue due to burn out as a result of stress of overwork or over training.

In 1994 the CDC updated their 1988 Criteria (Fukuda et al 1994). As Fukuda was the first research author listed, these have become known as the Fukuda criteria. The main difference between the 1988 and 1994 versions was that now the 1994 criteria also allowed minor psychiatric disorders such as anxiety, depression as causes for fatigue in CFS. Oxford and Fukuda's new criteria for CFS had moved away from Ramsey's initial descriptions of ME.

As a new millennium dawned, there were significant consequences for ME as a result of the name change to CFS, and the changing of the diagnostic criteria, particularly to include psychiatry and somatization or when psychological concerns are converted into physical symptoms. Anne Macintyre, a British medical pioneer in ME (who also had the condition herself for many years and sadly passed away in 2018) offers this summary:

- CFS now covers a broader range of conditions causing fatigue, not only ME.
- These criteria concentrate on one symptom, 'fatigue', which is part of everyday life and present in many illnesses and has meant that the many neurological symptoms and disabling aspects are ignored and denied.
- Cases are included whose fatigue is due to depression, anxiety, stress or burn out which dilutes the potential severity of some patients' illness.
- This has posed difficulty in qualifying for social security or illness pensions because the illness is perceived by many doctors and officials as being mainly psychiatric.
- Conflicting results in research studies as different criteria are used and the characteristics of patient groups used in research may not be the same (1998, p.93).

The Canadian Consensus Criteria 2003

Up to this point Canada was using Fukuda's (revised 1994 CDC) definition for ME/CFS. However as this was primarily designed to standardize *research* processes and not for use as a *clinical* case definition for ME/CFS patients, family physicians and other clinicians were in need of a clinical case definition. By the CDC singling out prolonged fatigue as the sole compulsory criterion, it minimized and de-emphasized the importance of the other cardinal and identifying signs of ME/CFS (post-exertional fatigue/malaise, cognitive dysfunction, pain and sleep disturbances etc). This made it increasingly difficult for a clinician to distinguish the pathological fatigue of ME/CFS from other fatiguing illnesses and indeed ordinary fatigue. In response to this, in 2001, Health Canada in co-operation with the National MEFM Network (FM is fibromyalgia), established terms of reference and formed an expert medical consensus panel, comprising treating physicians, teaching faculty and other researchers (www.me/fmaction.co). This panel had collectively either diagnosed or treated (or both) 20,000 patients with ME/CFS. Their task was to conduct a review process and establish consensus for a clinical working case definition and diagnostic and treatment protocols. In 2003 they published the Canadian Consensus Criteria (CCC) which provided a working clinical case definition (Caruthers et al 2003). This clinical case definition would include the pattern of positive signs and symptoms unique to ME/CFS. These signs and symptoms would identify ME/CFS as a distinct entity and distinguish it from other overlapping clinical entities. In fact the panel concluded that the more prominent signs which it identified (see criteria categories to follow) should be considered as compulsory for a positive ME/CFS diagnosis. In order to help focus a clinical encounter and facilitate a diagnosis, the panel grouped together symptoms which shared a ‘common region of pathogenesis’ versus the patient presenting with a ‘laundry list of seemingly unrelated symptoms’ (Carruthers et al 2003: 10).

Diagnostic Criteria as proposed by the Canadian Consensus

A patient with ME/CFS will meet the criteria for all of 1-4 below*

1. Fatigue of recent onset, unexplained, persistent or recurrent physical and/or mental fatigue that restricts activity.
2. Post-exertional malaise (PEM) – inappropriate loss of physical and mental stamina, cognitive and muscle fatigability post exertion, tendency for clusters of symptoms to worsen on activity, pathologically slow recovery periods.
3. Sleep dysfunction: un-refreshed sleep, decreases in sleep quantity and quality and/or significant dream disturbances.
4. Pain: significant degree of myalgia, pain in muscles and/or joints, that is widespread and migratory. Headaches of new and/or severe origin.

A patient will have two or more of the following neurological/cognitive manifestations:

5. Impairment of concentration, confusion, short-term memory problems, disorientation, difficulty processing information or finding words. Muscle weaknesses, overload

phenomenon: sensory (photosensitivity, hypersensitivity to noise) and/or emotional overload which can lead to ‘crash periods’.

A patient will have at least ONE symptom from 2 of the following 3 categories (6) a, b, c:

6. a) Autonomic disorders: orthostatic intolerance (light headedness on standing), POTS, (fast heart rate on standing), neurally mediated hypotension (low blood pressure on standing from faulty brain signals), extreme pallor, nausea, Irritable Bowel Syndrome (IBS), urinary problems, palpitations with or without cardiac arrhythmias.
   b)Neuroendocrine manifestations: Loss of thermostatic stability, intolerance of extremes of heat or cold, subnormal body temperature, feverless sweats, anorexia or abnormal appetite, loss of adaptability and worsening of symptoms with stress.

   c) Immune manifestations: tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, new food sensitivities, new medication and chemical sensitivities.

   7. The illness persists for six months or more. It is usually of distinct sudden onset although it may be gradual. To be included under this diagnosis criteria the symptoms must have begun or have been extremely altered after the onset of this illness. The physical disturbances tend to form ‘symptom clusters’ which fluctuate over time. It is unlikely a patient will suffer from all the symptoms in 5 & 6.

   *Condensed for convenience of reading purposes from MEpedia.

The Canadian Criteria framework was welcomed internationally and is still used widely today with many ME patient advocacy groups and ME support organizations and charities advocating its use. However it was improved upon by another international consensus criteria body (ICC) in 2011. This body in particular wanted to dissociate ME further from CFS. Due to the constraints of this chapter, I refer the reader to Appendix 1 for details of the ICC criteria for the diagnosis of ME. Principally, and of most relevance here is that because of the more recent research findings that had become available since 2003 when the Canadian Criteria was written, the ICC (Carruthers et al 2011) asserted that the research strongly pointed to widespread inflammation and multi-systemic neuropathology that indicated a specific underlying pathophysiology peculiar *only* to ME. Therefore, ME having its own identifiable pathophysiology suggested the need for a refinement of patient stratification. It also recommended that the illness once again be called ME. It suggested it was the most accurate term as it reflected the underlying multi system pathophysiology of the disease. It considered ME and CFS to be two widely diverse conditions. It rejected the interchangeable uses of the terms ME and CFS and it rejected their combined uses as ME/CFS or CFS/ME. It suggests again that a disease entity should have only *one* name consistent with the WHO classification rule that a disease cannot be classified under more than one rubric. Finally of interest here is that the ICC (similar to Ramsey) also put as its major criterion post exertional fatigue or malaise, although it chose to rename it with a more descriptive term: ‘post exertional neuroimmune exhaustion’ (PENE). The ICC maintains that patients who exhibit low thresholds of physical and mental fatigability in response to exertion (which can be confirmed scientifically) along with the multi-system pathophysiology *have* ME. Others that do not fit this criteria, belong under the more encompassing CFS classification. It subscribed to the belief that science cannot be advanced without a relatively homogenized patient group. Other researchers agreed that it was counterproductive to use inconsistent and overly inclusive criteria to glean insight into the pathophysiology of ME, if up to 90% of the patient sets researched may *not* meet the criteria (Jason et al 2009).

This lengthy web of confusion in terms of naming the illness and agreeing on the criteria for its diagnosis had not occurred without a significant impact on the ME community. In *Thirty Years of Disdain* Mary Dimmock explains the impact of bad definitions and their legacy for ME patients, firstly in terms of research and secondly in terms of clinical practice (Dimmock & Lazell-Farnen 2015). In research:

- It has resulted in flawed epidemiological studies, faulty prevalence numbers and erroneous claims of risk and prognosis (Jason & Richman 2007).
- It has virtually stalled drug development and severely impacted the ability to attract private and commercial investment into the disease (the primary clinical trials for disease modifying treatments for this disease have been Ampligen in the USA and Rituximab in Norway, neither of which have become available).
- It has impaired the development of diagnostic biomarkers leaving the diagnosis one of subjectivity and exclusion (Jason at al 2009).

- It has generated such disdain and scepticism in the research community that researchers avoid the disease like leprosy out of a fear that it could kill their careers. (One such example is Stanford's Professor Jose Montoya whose early mentor suggested that he could end up homeless if he pursued research into ME).

Secondly, in clinical care and practice the lengthy web of confusion that has surrounded ME:

- Has warped the physician's understanding of the disease leading to medical disbelief, hostility and inappropriate treatments.
- Has facilitated and allowed flawed 'evidence based' clinical guidelines that include maladaptive personalities and recommendations for Cognitive Behavioural Therapy CBT and Graded Exercise Therapy GET which continue to hurt patients today.
- Has made it very difficult for patients to get disability payments and insurance reimbursements because most tests and treatments are considered experimental.
- Has stigmatized disabled patients terribly and sentenced them to abysmal clinical care.
- Worst of all, has directly enabled and nurtured psychogenic views. This has dramatically altered the perception of ME by the public at large ensuring that neither the disease or its victims are taken seriously by anyone (Jason et al 2004).

The psychogenic view

Undisputedly the greatest obstacle to both scientific and medical/clinical progress in ME has been the psychogenic view and its legacy. After one of the first American ME outbreaks at Incline Village, Nevada, Dr William Reeves (2005) of the Center of Disease Control (CDC) characterized the outbreak as hysteria. He would go on to lead the CDC CFS program, the biggest in the world, for ten years. Known as 'the dictator' within his own organization, his contribution was a CDC 'toolkit' of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) and sleep hygiene for a 'condition of un-wellness' not a disease (www.Pheonixrising.me 2012). In 1988, Dr Stephen Strauss of the National Institute for Health (NIH) published that patients with CFS:

> were educated white women, were more likely to get the disease which could either reflect their resources to access evaluations or some unique constitutional frailty of such individuals. Most had excellent health

> and some were competitive athletes at least with aggressively maintained physical conditioning. A less casual approach however often uncovered histories of unachievable ambition, poor coping skills and somatic complaints. It is difficult and at times unpleasant to address the demands of such patients or to test the hypotheses as to the etiology of their woes (Straus et al 1988: 793).

In 1988, Simon Wessely, a British psychiatrist at Kings College, promoted the 'biopsychosocial' theory of ME, saying it was caused by psychological factors and physical deconditioning. Wessley has recently retired from the ME field as he has been severely trolled and threatened on the internet because of his views. By the late 1980s and early 1990s the mainstream press began to reflect these views and the dismissive term 'Yuppie Flu' appeared (Boffey 1987). Munson (2000: 108-109) describes how ME/CFS became an 'accepted social parody', the yuppie flu serving as a 'catchall metaphor'. The biopsychosocial theory persists today despite all the evidence that ME is an ongoing organic disease. Its theory suggests ME patients 'maintain' or 'perpetuate' their illness by activity avoidance, which causes deconditioning, which causes the ongoing disability and symptoms that patients experience. ME patients' beliefs, behaviours and other social factors are 'keeping them sick' (Prins, van der Meer & Bleijenberg 2006). In order for the ME patient to combat these beliefs, biopsychosocial theory recommends CBT (cognitive behavioural therapy) to reverse the patients' presumed 'fear of activity' and 'false beliefs' that their disease is actually 'organic'. It also recommends GET (graded exercise therapy) to reverse their presumed deconditioning (White et al 2011). The claim that patients can recover as a result of CBT and GET is not justified by the data and is considered to be highly misleading.

In 2011, the largest clinical trial conducted to date in the UK on ME was called the PACE trial (Pacing, graded Activity and Cognitive behavior therapy: a randomized Evaluation). It was funded by the National Health Service, the Medical Research Council and the Department for Work and Pensions for a cost of £5million. The published results, which claimed a recovery rate of 20%, are still a source of controversy (White et al 2011; see also Wiltshire et al 2017; Kindlon 2017). Biopsychosocial theory explains patients' poor response to treatment and poor prognosis overall as stemming from the patient's own beliefs that they have an organic disease, or their desiring to be in receipt of disability allowance (Yancey & Thomas 2012).

Even though the long awaited Institute of Medicine (IOM) (2015) report declared ME a 'serious chronic, complex, multi-system disease that can consume the lives of those whom it afflicts' and went on to highlight how ' the proposed psychological etiology created great controversy and convinced health professionals that this was a plausible explanation for the condition', the psychogenic view still has its proponents today (Wessley, Nimnunan & Sharpe, 1999; Knapson, 2015). The enduring legacy of the psychogenic bias and actual unproven biopsychosocial theories are, according to Dimmock in *Thirty Years of Disdain*, responsible for the way the Human Health Services (HHS) in the USA, the UK government and the international research community as a whole have viewed, studied and treated ME for the last 30 years. Mary Dimmock summarizes the era of the psychogenic view and misjudged interventions as follows:

> Medical mistreatment can cause great physical harm from inappropriate treatments. But the neglect ,stigma and disbelief they [ME patients] experience are crushing to the psyche. When a horrible disease has ripped your life to shreds, isolated you from your family and friends, destroyed your career, left you destitute and grasping for a life you no longer have, it is deeply demoralizing and heartbreaking to have to fight off suggestions that you just want to be on disability or that you could overcome your ill health with 'positivity' and exercise (Dimmock & Lazell-Farnen 2015: 13).

The drive for a wholly physical etiology, according to feminist health psychologist Lara Stapleman, does not allow for the inclusion of other 'empirically supported and /or theoretically grounded possibilities for disease etiology...that consider the complex relationship of biological, social and psychological phenomena to medical illness' (2005: 264). However, Stapleman can concede that that is a 'luxury' afforded to illnesses that are 'visible and accepted by conventional medicine' and certainly not psychologised and contested like ME.

Another unfortunate legacy from the psychogenic view of ME is the subsequent portrayal of the illness by the media, on which the public depends for its social view. A 2017 analysis of the content of American newspaper articles (n=214) from 1987-2013 revealed the following. The etiology (cause) was portrayed as organic in 138 of the articles (64.5-%). There was no mention of case definitions or diagnostic criteria in 120 (56.1%) of the articles. The most common co-morbidity was depression in 49 (22.9%) of the articles. In 42 of the articles (19.4%) the headlines mislabeled the name of the illness. In 109 of the articles (50.9%) there was no mention of any form of treatment for the illness. In 119 of the articles, (55.6%) there was no mention of the prevalence rates (Siegel, Brown & Devendorf 2017).

Recent research and the physiological view

In recent years there has been an increase in biomedical research almost entirely funded from within the ME advocacy community. In the USA, the Open Medicine Foundation has raised and funded 8 million dollars of research into ME since its inception in 2012. Its CEO is Linda Tannenbaum who founded the foundation after her 16 year old daughter became ill with ME/CFS. In the UK, charities like Invest in ME (www.investinme.org) fundraise for research. The charity is run by volunteers with no paid staff. They have never received any government funding. Pia and Richard Simpson, are two such volunteers, they are parents of two daughters with ME. Every year since 2006 they have organized an annual 'Invest in ME International Conference' which brings together world leaders in biomedical research, from 15 countries, to share research and ideas.

ME Research UK (www.meresearch.org.uk), exists to fund biomedical research into ME/CFS, to find its cause, develop treatments and find a cure. In fifteen years it has funded 38 specific research projects in the UK and beyond, which is more than any other organization outside the USA. It is estimated that there are approximately 250,000 people in the UK with ME (www.meaction.net). In Ireland it is estimated that there are approximately 12,000 people with ME (www.imet.ie). The ME community in Ireland is supported by the ME Association (www.irishmecfs.org) and the Irish ME Trust (www.imet.ie). In 2002 the Irish ME Trust sent a questionnaire to all GPs in the country. Of those that responded 85% favoured a properly structured referral system orchestrated by the Department of Health. They are still lobbying the government for a medical consultant to oversee ME patients in Ireland. To date there is none. The Irish ME Trust offers information and support to ME patients in Ireland along with free classes and subsidized mini breaks away, in safe (chemical free) and supportive environments. However it has not generated any research of its own. It contributes its fundraised monies to ME Research UK (www.meresearch.org.uk) and is a sponsor for the Invest in ME Research Conferences (www.investinme.org/iime.shtml). Tom Kindlon, the Assistant Chairperson for the Irish ME/CFS Association, is himself a longtime ME patient and an independent researcher. He has published widely, particularly in relation to the PACE trial (the use of graded exercise and cognitive therapy as ME treatments) and its ongoing controversy (Kindlon 2017; Wiltshire et al 2018).

Possible causes of ME

The cause of ME remains unknown. Generally symptoms are triggered by some sort of 'prodromal event' such as 'infection (which is the most common) immunization, anesthetic, physical trauma, exposure to environmental pollutants, chemicals and heavy metals and rarely blood transfusions' (Carruthers & Van der Sande 2005). It is generally accepted that a precursor, such as a virus, occurs with ME. There can be other factors such as an accident or trauma coupled with a genetic predisposition. Klimas (2019) asserts that genetics loads the gun and environment pulls the trigger. What follows the prodromal event is some type of encephalitis or brain inflammation causing cerebral and multi systemic dysregulation. There are inflammatory responses which become chronic. Over time comorbid diseases are common such as Migraines, IBS, Fibromyalgia, Interstitial Cystitis, Raynauds, TMJ disease. These types of symptoms have been highlighted when discussing the diagnostic criteria previously. However #MePedia lists over 50 commonly reported symptoms by ME patients.

As a result of relatively recently funded biomedical research, there are several widely accepted causal hypotheses. It is not within the remit of this literature review to elaborate on the nature of these emerging hypotheses. However a very brief description is relevant here in terms of how they validate the very 'real' physiological nature of the illness and the subsequent physiological realities that ME patients must deal with or manage every day.

The neuroimmune hypothesis

Jose Montoya, Professor of Medicine (Infectious Diseases) at Stanford University Hospital, California, revealed abnormalities in the levels of 17 immune-system proteins called 'cytokines' in patients with severe cases of ME (Montoya et al 2017). What disrupts the normal inflammatory response is not yet known (Komoroff 2017). One theory is that the T cells mistakenly become alarmed by one of the host's own proteins rather than an invader, and the fighter B cells secrete self reactive antibodies which would be evidence of an auto immune disorder (Montoya et al 2017; Sotzny et al 2018). Professor Nancy Klimas is a clinical immunologist who leads the ME research and treatment centre at Nova S.E. University, Fort Lauderdale, Florida. This centre has 58 staff dedicated to Gulf War Syndrome, ME/CFS and

HIV. In 60-80% of published samples ME/CFS presents with acute onset of illness, with systemic symptoms similar to influenza infection, but they do not subside (Underhill 2015). Many of the symptoms are inflammatory in nature (myalgia, arthralgia or joint pains, sore throat and tender lymphadenopathy (Evangard et al 2003; Russell et al 2016). Klimas is adamant that immune findings in ME/CFS is proven. 80% of patients with ME/CFS in the USA are women (Jason et al 1999). In a particular study of plasma cytokines in women, Klimas concluded that: 'cytokine abnormalities are common in ME/CFS. However to date the cytokine changes observed are likely to be more indicative of immune activation and inflammation rather than be specific to ME/CFS' (Fletcher et al 2009; Klimas & Koneru 2007).

The microbiome hypothesis

The microbiome is the ecological community of commensals (organisms) symbiotic (mutually beneficial) and pathogenic (disease causing) microorganisms, that live on the skin and genitals and in the nose, ears, mouth and gut. Dysbiosis, is when there is an imbalance in this community of commensals. Recently a lot of attention is being paid to dysbiosis and the pathophysiology of ME, particularly in the area of 'gut health'. Intestinal microbiote play a major role in the gut-brain axis, with neurological consequences. Viral infections and stressors can cause alterations in the microbiome, increasing intestinal permeability. The extent to which the gastrointestinal microbiome and peripheral inflammation are associated with ME are as yet unclear (Komoroff 2017). 33-90% of ME patients report abdominal discomfort consistent with Irritable Bowel Syndrome (IBS) (Aaron et al 2001). This causes intestinal dysbiosis which can in turn alter immunological circuits and cognition and mood (O' Malley 2015).

The mitochondrial failure hypothesis

Researchers have recently become interested in the role of possible mitochondrial failure in ME (Myhill et al 2009, 2013). Mitochondria are the powerhouses of every cell (except red blood cells) in the body. They generate most of each cell's energy by manufacturing ATP (adenosine triphosphate). Infections with pathogens, including viruses, bacteria, parasites and toxins can cause changes in the function of mitochondria and in turn energy metabolism. Metabolomics, refers to the systematic identification of the small molecule metabolic products (the metabolome) of a biological system (such as a cell, tissue organ or biological fluid) at a specific point in time.

It is the systematic study of the unique chemical fingerprint that specific cellular processes leave behind. Metabolomics has revealed a *chemical signature* of ME. It has identified a pattern of chemical abnormalities or metabolite abnormalities in ME patients. Professor Robert Naviaux, a world leader in Mitochondrial diseases and Director of The Mitochondrial and Metabolic Disease Centre at University of California, San Diego, writes that ‘the findings of an objective chemical signature in ME/CFS helps to remove diagnostic uncertainty, and will help clinicians monitor individualized responses to treatments and will facilitate mitochondrial clinical trials’ (Naviaux et al 2016).

ME as a contested illness: the greatest burden

People living with ME share in the burdens that are common to many chronic invisible illnesses but without doubt the greatest burden of all is the fact that ME is a controversial illness. In fact it is classified as a contested illness along with other illness such as Gulf War Syndrome, Multiple Chemical sensitivities (MCS) and to a degree Fibromyalgia. Contested illnesses such as ME are disorders that are ‘medically suspect because they are not associated with any known physical abnormality’(Conrad & Barker 2010: 70).

ME is an illness that is pervaded by medical, social and political uncertainty (Dumir 2006). ME is accepted as a chronic illness by the World Health Organisation (WHO 2007) yet there is huge disagreement within medicine and now science, as to its aetiology or pathophysiology, and how to conceive of the illness and how to treat it (Blease et al 2017). It is the personal, lived legacy of this contested view of ME that most people living with the illness find the most difficult to bear. They report feeling devalued and disbelieved, or defending their moral characters and their experiences of illness and having to deny malingering as the most burdensome aspects of the illness (Asbring & Narvanen 2002). The outcome of protracted exposure to such medical disbelief is very often a distancing of the person with ME from the medical world (Bowen et al 2005; Raine et al 2004). This in turn contributes to the extent that ME can impinge on quality of life, to a greater extent than other chronic illnesses including cancer (Dancey & Friend 2008).

Studies show that many if not most people with ME report negative medical encounters with outcomes of dissatisfaction, distress and being disbelieved (Deale et al 2001). Almost all anecdotal evidence reveals the same outcomes (www.imet.ie, www.meaction.net). This has been the inevitable dynamic for thirty years with ethical repercussions in medical education and policy making. Havi Carel and Ian Kidd (2014, 2016) employ Miranda Fricker's (2007) concept of epistemic injustice (where a specific kind of injustice is done to someone in their capacity as a knower which undermines their credibility), to examine and name this thirty year dynamic. The aetiological (causal) and nosological (classificational) uncertainty attributed to ME to date by medicine and science, arguably affects medical professionals' judgement of the testimonies of those presenting with ME. This leads to what Fricker calls testimonial injustices. A testimonial injustice occurs when a speaker is unfairly considered to be less credible as a result of prejudice concerning their membership of a negatively stereotyped group, this prejudice in turn leads to the speaker being considered untrustworthy or unreliable.

When an illness such as ME is contested and or given a negative stereotype and the person with ME has been victim to testimonial injustice, their epistemic contribution to consultations and wider conversations about their health and future well being are unfairly compromised (Carel & Gyorffy 2010; Carel & Kidd 2014; Kydd & Carel 2016; Wardrope 2015). Kidd & Carel (2016) consider the theoretical underpinnings for such stereotyping also to be an epistemic injustice of the hermeneutical type. While Fricker considers testimonial injustice to be within the realm of the individual, hermeneutical injustice is also present and is considered to be a structural problem (Fricker 2007). If hermeneutical resources (concepts, ideas and narratives) are absent or sub-standard, hermeneutical injustice occurs. It also occurs when such resources are 'not respected and/or ignored by members of other social groups' (Blease et al 2017: 552). Hermeneutical resources such as concepts of health and illness and disease enable interpretation of negative physical experiences such as for example pain. The positioning of illness narratives within a social context are basic to all health care. Without these resources, it is not possible for patients to turn bewildering, challenging and unwelcome symptoms into an understandable illness. Nor can they, without a provided treatment protocol, learn to self manage their illness (Blease et al 2017). This has proven to be particularly true in the case of ME.

After many years of disagreement and struggle, conceptual resources for identifying and understanding ME are available to mainstream medicine, particularly at a patient's first port of call, the GP's office. They are supplied in both Ireland and the UK by the ME societies (Thomas

& Smith 2005). The WHO recognises ME to be a disabling, debilitating condition of prolonged unexplained fatigue lasting 6 months or longer, together with other symptoms such as post-exertional malaise, cognitive problems and pain (Carruthers et al 2011). Yet surveys of GPs in the UK reveal that up to 50% of GPs did not believe ME was a real illness (Thomas & Smith 2005). Of GPs surveyed who did recognise ME as a clinical entity, 50% of them expressed a lack of confidence in diagnosing the illness (Bowen et al 2005). This lack of belief and difficulty in diagnosing on behalf of the doctor is in direct proportion to the lower credibility they attribute to the reporting patient in front of them (Blease et al 2017). If in the UK you do receive a diagnosis of ME, it is only usually after approximately six medical appointments (Raine et al 2004). In Belgium research reveals that patients wait an average of 5 years for a diagnosis (Van Hoof 2009). This lengthy period prior to a diagnosis is often when the patient is very ill with symptoms which are not helped by the uncertainty and stress associated with their medical care or lack of it. There is research to prove that (as with most illnesses) the earlier the diagnosis of ME the better the prognosis (Joyce et al 1997; Nisenbaum et al 2003). Recent research reveals that the situation has not improved for patients to date. According to Professor Nancy Klimas:

> Women still suffer from dismissive misogynistic assumptions. Doctors probably never even had an hour in their medical school curriculum on ME/CFS...I have been at this now for 32 years and while there are more doctors now that do understand, I still hear the same shameful stories of derogatory experiences. We have a lot of medical education work ahead (Klimas 2019).

Negative stereotyping of patients with ME by their doctors is well documented. ME patients can be described as ‘heartsinky’ and a ‘burden’ or as ‘giving up’ and they are often not considered worthy or in need of referral to specialists (Najman et al 1982; Ward et al 2008). The roots of this hermeneutical injustice can be found in the medical schools where training and education relating to ME is sparse or non-existent. Less than one third of medical schools include ME/CFS on their curriculum (Peterson et al 2013). Only 40% of medical textbooks include information on ME/CFS. As recently as 2015, Stenhoff et al carried out a study of medical students at the University of Manchester School of Medicine. The students revealed that ME to them was mere ‘tiredness’, ‘...you think god they are just knackered [...] like everyone gets knackered no-one really cares’. All the students in Stenhoff et al’s study admitted to no training in ME, yet some would have considered it a waste of an academic week.

The negative stereotyping that ME patients endure is as a result of the controversial nature of their illness or it being a contested illness (Blease et al 2017: 553). This also puts them on the receiving end of both testimonial and hermeneutical injustices. Their credibility is undermined, diagnosis is delayed and adequate treatment and support denied. Patients are wrongly psychologised and not adequately or appropriately referred. This stereotyping is not just contained within healthcare but has filtered out and is evident more broadly in society. Studies have endorsed that one of the most difficult legacy issues of such negative stereotyping for ME patients is the difficulty in relating to others due to misunderstandings about and incorrect attitudes to ME (Ward & Hogan 2009). As a result, patients who feel disbelieved, mistrusted or misjudged by the healthcare system, may choose to withdraw from healthcare altogether (Bowen et al 2005; Van Hoof 2009). ME patients also report feeling the need to adopt social distancing and concealing strategies to avoid stigmatisation by others (Bowen et al 2005). Epistemic injustice can therefore cause harm (Blease et al 2017: 555).

Illness management

While researching this work over recent years it has become apparent that biomedical research is of primary interest to ME advocacy and support groups, and that financing it is the main use for their fundraised income. In reviewing the annual Invest in ME Research Conferences (of which there have been 14) the same central cohort of international, multidisciplinary experts are to be found repeatedly at this annual events (www.investinme.org/iime14.shtml). They are leaders in their field who speak to each other about their specialist, scientific and medical expertise, and their findings. However, conspicuous by their absence is the ME patient. They are mostly too unwell and unable to attend, but their ‘voice’ is also missing as a priority. Despite this, the closing lines of Dr Roz Vahlings’s 2019 IIME14 conference summary report struck an optimistic note:

> …there has been enormous development in research and management over the years, leading to a greater understanding of this complex disease which seems to become more complicated as we learn more... [and] that the answers are getting closer and there is so much more hope now for the potential biomarkers to be confirmed and treatment options to be forthcoming (p.9).

However, while the ME community waits (in various states of ill health and with varying levels of coping skills) for science and medicine to both discover and agree, all they can do is learn to ‘manage’ their illness. Not alone must they learn to manage their energy in order to care for themselves but they also have to manage ‘others’ in terms of relationships and expectations and attitudes. They have to manage to balance the see-saw like motion between loss and hope. Nancy Klimas is a leader in the field of ME research and treatment. In response to the challenges just described, her practice has recently shifted from the immunological support approach to integrative and functional medicine where she aims to care for the whole patient and their society (Klimas 2019). She has come to realise that the scientific model does not always work for chronic disease. Integrative medicine advocates for clinicians to be partners with their chronically ill patient, providing care for mind, spirit, community and body. It combines the conventional and alternative medical approaches, employing natural and less invasive interventions when possible. ME/CFS is a complex multisystem illness and treatment approaches should include diet and suitable supplements, sleep management, appropriate exercise, pain relief, detoxification and emotional support (Klimas 2019).

A management theory that is frequently encouraged for consideration for ME patients is the theory of pacing one’s energy or the ‘energy envelope’. This posits that maintaining one’s expanded energy at the same level as one’s available energy may help reduce the frequency and severity of symptoms (Jason et al 2013). Patients speak of trying to avoid the ‘boom and bust’ of energy scenarios. Sally Burch (a science teacher before ME) advises to only do 60% of what you can sustain without producing symptoms – this is ‘pacing’:

> …we attempt something we really ‘want or need’ to do. The thrill of ‘doing’ releases adrenaline so we keep doing. This is the boom scenario, riding that boom and getting as much done as possible. However this high is generally short lived and as we come down off it we experience a big ‘crash’ downwards for several days or much longer, this is the bust. If we are lucky Burch states, we can boom and bust and not lose any long term ability. However the boom and bust can lead to permanent decline. (2014).

Dr David Bell, a family practice physician in Lyndonville, New York, at and since the time of the ME/CFS outbreak there in the mid 80s, has been caring for and listening to ME/CFS patients for thirty years. He writes in his Ebook ‘Faces of CFS’:

> Many who suffer from CFS experience a period of relief at some point in their day. During this period patients are able to undertake some of the activities that are ordinarily too difficult to manage…before total disability claims them again, stealing hope for at least another day. Most CFS sufferers live for this window of time and typically they will try to accomplish as much as possible when it opens, even though they have learned through experience that any exertion will make them feel even worse when the window closes again. Nevertheless, I have observed that most patients prefer to fly for two hours and then ‘crash and burn’ afterward rather than stay within the confines of the hangar’ (Bell 2000: 40)

Managing the ‘fatigue’ of ME is complicated by the inability of the ME patient to describe or explain the ‘nature’ of their fatigue, which in turn contributes to the inability of others to understand and accept the ‘tired behaviour’ of the ME person. Ironically it is the sheer exhaustion and the subsequent silent and invisible nature of the chronically ill person in general but the ME patient in particular that can be incorrectly perceived as tacit agreement with the ill informed notions of ME exhaustion.

> Most descriptions of ME miss the essence of it and fall short of capturing its reality. Part of the problem is the word ‘fatigue’. It is both a red herring and a hopelessly inadequate description of how people feel. ME sufferers are not tired in a floppy, nice-to-have-a-nap kind of way, such as after the flu when bed feels good and snuggling under the covers for a few days brings a gradual return to well-being. It is as if someone had frayed the ends of every nerve in the body and left them raw and exposed. It brings an overwhelming need to close down sensory input and, for many to retreat from everyday ordinary stressors – conversation, noise, light, movement, TV – since they are agonizing to deal with (Mitchell 2003).

While the ME community must rest in Vahling’s (2019) ‘optimism and hope’, it must be balanced with the reality of considerable loss. In the words of a doctor, himself suffering with ME, ‘there is nothing that you hold dear that this illness cannot take from you. Nothing’ (English 1991).

ME patients lose partners, friends, jobs, careers, hobbies and financial security, at times being denied social welfare benefit. In the UK, ME is not treated as a disability under the Equality Act 2010. ME is listed amongst ‘impairments with fluctuating or recurring effects’ in the 2010 Equality Act Guidelines, and ME patients may be only considered as disabled depending upon the effects the illness has on their daily lives. In Ireland, disability or invalidity payment is provided by the Department of Social Protection. The disability benefit equals 29% of the average industrial wage (Central Statistics Office 2018). The 2010 Canadian Community Health Survey (CCHS) discovered that 29% of patients with ME/CFS had unmet health care needs and 20% had food insecurity (Seligman et al 2010). ME patients lose their voice, their power, at times their sense of hope and self worth (Horton et al 2010). They lose the future they had dreamed of, their ‘old lives’ are taken, yet ‘they’ remain. In the ‘#Millions Missing’ campaign (www.millionsmissing.meaction.net), protests are held on World ME day, May 12th, outside government buildings in 12 cities to raise awareness of the millions of ME patients ‘missing from life’ and ‘missing their old lives’. A variety of pairs of shoes with an explanatory tag and a photo (if the person is too sick to be there), are laid out in front of the buildings. Hundreds of pair of running shoes, hiking boots, beach shoes, dancing shoes, or diving flippers, all signify lives lost, and old ways of being, taken. Yet ME patients struggle with what David Bell calls ‘health identity confusion’:

> They remember what it was like to be confined to bed and are now just so grateful to be able to be ‘up’ or to ‘make it to the store’. They consider themselves well now because they have learned how to cope and to be able to function with tremendous adaptation. If recovery is coping, does this coping lead to confusion and false perceptions of health? If you mostly have normal appearance, are misunderstood by the public and medical opinion, if you have largely negative lab results and have learned to adapt to survive, then you labour under, ‘health identity confusion’ (Bell 2012).

ME patients know that nothing is certain about their prognosis, and must wonder how long they will be sick, or how long they will live? Little research is done on examining mortality. Anecdotal information as well as some small studies indicates there is a higher risk of suicide in the ME community (Jason et al 2006). These studies show an increased risk of earlier all-cause and cardiovascular related mortality along with a lower age of suicide and cancer (Smith, et al 2006; Kapur & Webb 2016; Roberts et al, 2016).

Conclusion

Carel (2013) argues that conceptions of the lived experience of chronic illness are under-represented in healthcare theory. However, the faces and the voices of people living with ME are sometimes evident in the literature. In *Stricken* (Munson 2000) and *Lost Voices* (Boulton 2009), essays are contributed by people living with ME, or caring for people with ME. Mitchell (2003) and Whitehead (2006) both conducted interviews with ME patients for their research. Tova-Bailey (2010) and Duyn (2006), both severely affected by ME, have written creative, personal accounts of their illnesses. Due to the severe cognitive impairment that accompanies ME, and since the advent of social media, it is now more common for online blogs (www.phoenixrising.me, www.chronicallyhopeful.com) and patient fora (www.smartpatients.com>me, www.healthrising.org>forums) to provide expressive outlets for the ME community (Carel and Kidd 2014). Naomi Whittingham, herself severely affected by ME for many years, writes a blog ‘to those shut away from the world because of intense suffering with ME’ (www.alifehidden.com). Recent documentary films ‘Voices from the Shadows’ (2011), and ‘Unrest’ (2017) document the consequences for ME patients of psychiatric prejudice and medical ignorance about the illness, particularly for those who are in the severely affected category. It is evident from reviewing the literature that those who are severely affected by ME (bedbound and requiring care) and are estimated to constitute 20% of the patient population (Macintyre 1998: 117) are portrayed more frequently in documentaries (as evidenced above) and by the patient support and advocacy groups and charities. In the USA, Whitney Dafoe is very severely affected by ME. He is the son of Professor Ron Davis, Director of the Stanford Genome Technology Center, California. Davis now leads a dedicated research centre for ME/CFS within the Genome Department (CFS Research Center). Davis also, along with his wife, Janet Dafoe, a child psychiatrist, cares for his son full time. Dafoe, though unable to move or communicate, has become the face of severe ME/CFS, as portrayed by the Open Medicine Foundation (www.omf.ngo). Davis, already in his late seventies, feels a personal responsibility and burden to solve the illness (White 2016).

Although these lived experience accounts and exposures of ME patients afford the reader some insight and a necessary and valuable glimpse into a point in time, or particular aspect of living with ME, a gap in the literature was identified. No autoethnographic accounts or complete narratives with analysis were identified. Also, the moderately affected category was not as visible as the severe category, in terms of the portrayal of lived experiences, although it is estimated to constitute 60% of the ME patient community and is frequently discussed in the research literature (Macintyre 1998: 117). The original contribution to knowledge of this thesis therefore, is an evocative autoethnographic account of living with moderate ME, which broaches the length of the illness (16 years), and despite the contested and pessimistic nature of the illness, seeks to reimagine and transform a ‘self’ that, without the need to transcend the illness, endeavors to find a way to live a good life.

CHAPTER 3

THE STRUGGLE CYCLE:

A CREATIVE METHODOLOGICAL AND CONCEPTUAL FRAMEWORK

Introduction

The methodological design of this thesis is that of an autoethnography, specifically an evocative autoethnography. As revealed in the previous chapter, the literature review on ME revealed an abundance of biomedical research and opinion on the illness (Naviaux et al 2017; Montoya et al 2017) and a limited amount of literature revealing the lived experience of the illness (Munson 2000; Tova-Bailey 2010). The biomedical research and statistical information retrieved from the literature review was presented as largely quantitative research data. The more personal reality of ME, though obtained through qualitative methods such as interviews, only provided for glimpses into individuals' realities along with what constitutes a long timeline with an illness such as ME. There were no autoethnographical accounts of living long term with a chronic, invisible, contested illness such as ME. This gap identified in the literature, along with my own lived experience with the illness, made autoethnography the method of choice for this thesis. Also relevant to choosing autoethnography as a research method is the deeper nature of my research questions: can one reimagine a 'self' living alone, with a chronic, invisible, contested illness? If so, how? Could such a life be considered a good life?

Prior to commencing the PhD, I conducted two interviews with two long term ME patients who were moderately to severely affected by the illness and whom I knew personally through the ME community. The outcome of those interviews quickly proved that qualitative interviews were not going to be a suitable method for me personally as it was beyond my physical capabilities to travel the required distances in addition to managing the interview situation. Secondly, the content of the interviews proved to be both emotional and pessimistic. The time limitations of the interviews, and consequent limitations to questions and discussion, could only produce a narrow view of the participants' experiences, which in both their truths proved to be both negative and hopeless. This in turn provided two further outcomes for me. Firstly, I became quite ill as a direct result of the attempt and secondly, I realised that the hopeless, option-less 'life sentence' nature of the illness was not the view I shared, or considered the most useful to portray in my research. Also, I was aware of the predominance of that view in both the biomedical and biographical literature. Consequently, I recognised the potential to fill the gap in the literature with another view, another way of living with the illness, which for all 'of us' was proving to be long term. These considerations along with a previously positive research experience, when I co-wrote a chapter for an academic text book on autoethnography (Farrell-Delaney & Kennedy 2014), confirmed autoethnography as my chosen method for this doctoral research thesis.

Autoethnography

> Autoethnography is research writing and method that connect the autobiographical and personal to the cultural and social. This form usually features concrete action, emotion, embodiment, self-consciousness and introspection (Ellis 2004: xix).

Autoethnography exists on a continuum from highly fluid and artistic to formulaic and highly analytic (Tullis 2013: 245). It can simply involve the inclusion of personal experience within an otherwise traditional social scientific analysis (Anderson 2006; Chang 2008; Tullis, 2014) or, in the case of evocative/artistic/performative autoethnography, can include poetry, prose, films, dance, philosophical essays and performance or ethnodrama (Bartleet and Ellis 2009; Pelias 2011; Saldana 2008; Spry 2011; Weems, 2013). Witkin (2014) identifies two basic subtypes of autoethnography: analytic and evocative. In analytic, the emphasis is on 'improving theoretical understandings of broader social phenomena' (Anderson 2006: 375), whereas in evocative autoethnography, the consciousness and subjectivity of the author/researcher is revealed through a personal, vulnerable, reflective, self-conscious, self-reflexive, narrative voice' (Ellis and Bochner 2016: 51). There are varying degrees of analysis to be found within the evocative form of autoethnography, so that is not what separates it from the analytic stance. It is analytic autoethnography's adherence to the traditional ethnography school and its distaste for the 'personal' that creates the gap between them. However, recent research shows that the almost twenty five year 'evocative versus analytic' debate is being played down in favour of accepting their differing purposes to suit different research audiences (Holman Jones et al 2013; Hughes & Pennington 2017). Many autoethnographers belong explicitly to one or other camps, but many move between both genres, braiding and weaving both approaches to good effect.

I selected evocative autoethnography as the most appropriate approach for this research, which sought to examine the physical and emotional challenges faced daily while living alone with a chronic and unsupported illness, yet trying to maintain dignity and a sense of purpose. The central tenets of evocative autoethnography facilitated the aim of my thesis, in that it sanctions writing in the first person and allows me to be the principal object of the research. It permits me, while concentrating on a 'single case', to highlight the reality of a group of similar individuals previously under-researched by social science inquiry. In promoting a writing style that is emotional, vulnerable and heartfelt, it diminishes the need for dense jargon therefore widening the accessibility of the work (Ellis & Bochner 2016: 57).

Autoethnography as a method constitutes a stalwart bridge between 'passion and intellect, analysis and subjectivity, ethnography and autobiography and art and life' (Behar 1996: 174). As a result of being grounded in postmodern philosophy, autoethnography also facilitates 'diverse and non-traditional epistemologies, epistemologies that draw from the experience of the author/researcher for the purpose of extending sociological understanding' (Sparkes 2000: 21). As previously discussed, autoethnography does not just comprise a method but by its nature permeates all aspects of methodology. It is both product and process (Ellis et al 2010: 273), each 'part of the process enriching all the other parts' (Kidd & Finlayson 2009: 990). In the methodological design of this thesis, I use autoethnography as a larger ontological and epistemological foundation (Hughes & Pennington 2017: 12). The data/fieldwork section of this thesis is presented purposely in the evocative autoethnographic, narrative voice, with a narrative analysis/interpretation provided in the following sections. This is not to fully subscribe to Sarah Wall's (2016) call to a 'moderate autoethnography' but it does agree with her proposition to tap into the unique value of personal experience while maintaining the 'scholarly potential' (p.3) and value of an autoethnography. An evocative autoethnography that is designed to be read in its entirety, and is closely followed by an analytic or interpretive section, is my method of choice in this thesis. In this way the work combines the 'power of the personal perspective with the value of analysis and theory so that sociological understanding is advanced in ways it might not have otherwise been' (Wall 2016: 8). The attempt of the evocative autoethnography is to provide an in-depth and embodied experience of the life of the writer (Bochner & Ellis 2016). In the evocative text, the reader is 'brought into a posture of caring, of compassion, sadness, anxiety, love or anger (Gergens & Gergens 2018: 276). An evocative narrative form of autoethnography also ‘shows struggle, passion, embodied life, and the collaborative creation of sense-making in situations in which people have to cope with dire circumstances and loss of meaning’ (Ellis & Bochner 2006: 433). The ‘methodological openness within autoethnography’ (Anderson & Glass-Coffin 2013) facilitates the investigator’s freedom and space to shape their work in terms of its own necessities rather than according to received ideas about what must be done (Geertz, 1988).

Researcher standpoint

My standpoint (Smith 1987) in this research is not singular. It primarily reflects my own ‘unique experience and asserts membership in a community who understand shared experiences’ (Frank, 2000: 356). It is a standpoint that although ‘personally forged’ (Thomas 2010: 656) is professionally informed by postmodernist sociological perspectives. My epistemological stance is also both personally and professionally informed. I *know* about ME primarily experientially (personally) and that experience is informed (professionally) by medical and social science research and by my own background as a health services practitioner and manager. I view my research through the postmodern sociological lens that accommodates epistemological variety, practices reflexivity, is motivated by ethical ideas, acknowledges feeling states and openly sympathises with and offers support to those who suffer (Frank 2000, 2002; Bochner 2000, 2001). These research motivations are akin to a central feminist tenet which is to make public issues out of private troubles (Thomas 2010: 656). The postmodernist view also allows for my research choices or criteria to ‘be ultimately and inextricably tied to [my] values and subjectivities (Bochner 2000: 266). In researching this thesis on the lived experience of ME, I have insider status by merit of being a member of the ME community, which comprises a social minority. The majority of society do not have ME and for them, imagining such a counterfactual situation is understandably difficult (Gilbert 2006; Haidt, 2006). Also, by virtue of having ME as a contested illness, I also find myself occupying outsider status in society. The research contribution in this instance of the insider/outsider combined status is that ‘those who endure the subtle alienation mirrored in the eyes of their doctors, friends and strangers, have a unique ability to reflect back on the society that struggles to understand them’ (Birk 2013: 398). Autoethnography works from ‘insider knowledge’. Many of the subjects and cultural experiences that autoethnographers research can be highly sensitive and personal and the nuances and details conveyed through the ‘thick descriptions’ of evocative autoethnographic writing would be difficult if not impossible to discern through surveys or interviews by a researcher who has never personally experienced the issue being explored (Tillman 2009; Rambo Ronai 2005).

Data collection, narrative construction and meaning making

My personal journal entries are the main data source in this autoethnography. In this way I have consciously used my identity and experience as my epistemology (Hermann-Wilmarth & Bills 2010). The journals range from 2007 to 2018 with an explained gap due to illness between 2009 and 2013. The journal entries are written in narrative form, in the first person voice and are by their nature evocative. For the first years of my illness, from 2002-2006, when I was too ill to keep a journal, I kept sporadic notes, and in my autoethnography, this time period is narrated for the reader through vignettes, poems and other creative pieces. My journal entries begin in 2007. In autoethnography, journal entries serve as field notes, and reflexivity may occur at the time and be revisited many times later. The 'field' may in fact be the researcher's state of mind. Field notes can become 'a way of knowing, a method of discovery and analysis' (Richardson 1994: 516). Their value to the researcher is their evocative potential and their ability to connect with, and elicit, emotions (Sparkes 1996; Anderson 2011, Fullagar 2002). My journal entries were written in real time so they provide a real time record of events and emotions. Unlike conducted interviews they are not social performances with socially constructed content (Thomas 2010: 657). I have used pseudonyms and have creatively modified personal details of characters in the narrative for ethical reasons (see below). Editing decisions were required in order to eliminate repetition and adhere to constraints of length. I am aware of the risks of using the self [myself] as the only source of data but I am aware also of 'the resilience and conviction vital to writing in this genre' (Holt 2003: 19). I am prepared in this thesis to become a personification of the data uncovered in the literature review.

I also include photography in the thesis. In visual autoethnography (Smith-Shank & Keifer-Boyd 2007; Quinney 1996), photographs are used in collaboration with the researcher's narrative of the meaning and significance of the photographs. Often, over the many years of my illness, my only capacity to record a moment or a fleeting story was to capture it in a photograph. In including the photographs in the thesis, my approach is not to narrate them individually, but instead to allow them to portray visually (in companionship with my words) images or stories already portrayed in the narratives themselves. As Muncey (2010: 57) advocates, I allow the photographs ‘to capture episodes of life, like stills in a film...to convey the skeleton of a life, without the flesh and consciousness of the being’.

I also include poetry in the thesis and most of it is my own poetry. The narrative within evocative autoethnography is what Bochner (2005) calls ‘poetic social science’, or what Brady (1991) calls art-ful-science. Within evocative autoethnography, narrative inquiry can search for language that is ‘adequate to the obscurity and darkness of experience’ when experience ‘presents itself in a poetic dimensionality’ (Bochner 2005: 270). This ‘poetic dimensionality’ becomes a frequent motif in the narratives of my autoethnography and in its following interpretation (Richardson 1992; Tillman-Healy 1996). One of poetry’s significant contributions to the narratives is its potential to disrupt the taken-for-granted (Kinsella 2006).

Presenting the evocative autoethnographic narrative

The story or narrative which is central to the evocative/interpretive school of autoethnogrphy serves as a starting point in the research and the research data, as a tool for interpretation and a method of dissemination (Ellis 2004). Narrative forms are produced by ‘constructing a coherent story from the data and looking at the data from the perspective of one’s research question’ (Polkinghorne 1995). Narrative inquiry or analysis uses field texts or notes, journals, autobiographical texts, photographs and life experience as units of analysis to research and understand the way people write meaning into their lives as narratives (Clanandin & Connolly 2000). Narrative then can be a powerful and effective way of transferring knowledge and communicating meaning (Bruner 1990). In evocative autoethnography, personal narratives enable us to understand a self or some aspect of a life as it intersects with a cultural context, they invite readers to enter the author’s worlds and to use what they might learn in the narrative to perhaps better understand and cope with situations in their own lives (Ellis 2004; Ellis et al 2011).

Knowledge is rooted in experience and that personal experience requires a method for its representation (Eisner 1988). Presenting an autoethnography is what Holman Jones (2005: 765) calls a constant ‘act of balancing between showing and telling, how much and what about ourselves to include, holding together a “self” and a culture in a world that is totally in flux’. Although my journal entries are loyal to the sufficiently explicit realities of living with ME, they are equally loyal to the expression of the reality of living a quiet, peaceful, if profoundly altered life, in a beautiful, rural environment. This set the tone for my narratives, which in becoming an embedded personal narrative of living alongside illness, had no need or desire to become an ‘autoethnography of affliction’ (Denshire 2013: 5). I share Bochner’s opposition to excessive ‘slicing, dicing and cutting out’ (2001: 141) which may destroy a story’s integrity. However, a personal narrative with content spanning sixteen years requires a literary convention or a device on which to frame the story and to move it from the ‘power of one’ (Gibbs, 2013), or an exploration of a particular life, to an understanding of a way of life (Ellis & Bochner 2000: 727). This is accomplished by dividing the narrative into a series of stages. Firstly there are the early years of illness, 2002-2008, which are presented as vignettes and journal entries for the years of ‘Struggle’. A narrative gap between 2009 and 2013 is identified as a result of years of relapsed illness following a lengthy divorce process. However, four vignettes and a poem are provided here to describe memories of events which are true to this timeframe and which describe episodes of both struggle and loss and episodes of rethinking and reimagining struggle. Secondly, a resumption of the story for the years 2014-2016 is presented as journal entries, entitled ‘Surrender’. Thirdly, 2017 is presented again as journal entries, entitled ‘Seeing’ and fourthly, 2018 is presented as journal entries, entitled ‘Sanctuary’. These same four narrative classifications are employed later as a framework for analysis. It is essential to the integrity of the methodology of this thesis that these four evocative autoethnographic ‘chapters’ – Struggle, Surrender, Seeing and Sanctuary - are presented to the reader in their entirety, that is without interruption by analysis or interpretation. This allows for resonance, for a story to ring true for a reader, to allow for connections amongst lives ‘lived apart and often far away from the time and place of the story’ (Ellis & Bochner 2016: 237). It also allows for the reader to be moved from ‘aboutness to withness’ (Shotter 2010). It poses the autoethnographic question for the reader: ‘what if this were true for me? What then?’ (Bochner 2000: 267). Presenting an evocative autoethnographic narrative in its entirety facilitates the revelation of its usefulness (Bochner 1994) and verisimilitude or narrative integrity (Ellis & Bochner 2016) both of which are central tenets to productive autoethnography. Ultimately, it can call the reader to action, transformation, or social justice (Gibbs 2013). Seeking social justice is also about examining and interpreting the minute moments of social *injustice* that permeate our everyday identity performances. Autoethnographers as inter-subjective, social and dialogical selves possess potential in rendering a critical impetus to promote social justice (Toyosaki & Pensoneau-Conway 2013). Social justice is about ‘seeing the world in all its loss and imagining ways of healing’ (Warren 2011: 30). Finally, in evocative autoethnography the principle method is the story or narrative. In using the tools of literary and aesthetic practitioners, along with mixed genres such as prose, poetry and photography, there is less need for the use of dense jargon, and more scope for ‘connection with diverse and diffuse audiences’ (Holman Jones et al 2013: 37). Such increasingly accessible narratives allow for ‘meaning making’ on the part of the reader.

The literary and aesthetic practitioners who were examplars for me and influenced my narrative writing, at both a conscious and subconscious level, were John O’Donoghue and John McGahern. Their works on landscape and beauty and the rhythm of ordinary rural days where nothing much happened I found inspirational. Eckhard Tolle’s writing on present moment living revealed to me the importance and beauty of silence, stillness and solitude. Maura Soshin O Halloran, and other Zen writers and poets put me on the path of Zen flavoured writing, perhaps suffusing my poetry in particular with the ‘scent of Zen’. May Sarton’s journal writing, particularly *Journal of a Solitude* inspired me to keep a journal (when I could) throughout my illness. I am grateful to these writers who became for me literary exemplars and ‘bringers of light’ in darker times. Autoethnographic stories can become forums for social critiques and facilitate readers’ understandings of the writer’s social realities, and the social and cultural forces that contextualise the experiences written about. The researcher’s stories ‘reveal their methodology and themselves as the instrument of data generation’ (Ruby 1980: 153), they ‘usefully place methodology and theory at the service of life and not the other way round’ (Mboti 2012: 59).

Memory work and autoethnography

Memories are often referred to as ‘the building blocks of autoethnography’ (McGlashan 1986: 6). Within the literature, caution is advised around memory work (Onyx & Small 2001; Poulos 2008; Muncey 2010) in particular with regard to ‘truth replication’ and ethical concerns in relation to others’ memories and truths (Giorgio 2009). However, this methodological concern is not relevant to the writing of this thesis as I do not include any other person’s memories. With the exception of the early vignettes presented in the chapter ‘Struggle’, my journal entries/narrative accounts were written at the time or within a few days of the event. As mentioned, I exclude the years that I was too ill to keep a journal, and subsequently my memory of that time is unreliable in terms of chronology or detail. (I remember broad brush strokes in terms of adopting the animals and building the small farm.) Bochner (2013) argues that in practice autoethnography is not so much a methodology as a way of life. This way of life acknowledges contingency, finitude, embedded-ness, encounters with others and a constant appraisal of ethics. He concludes that what is most important to an autoethnographic storyteller is meaning and feeling, the stuff of memory and experience, how the story makes you feel now and made you feel then, and how the story is both told and listened to. These concepts both inform and infuse my methodology.

Analysis of the narratives

Autoethnographic ‘self’ narratives largely involve looking back at the past reflexively through the lens of the present. In tandem with autoethnography’s desire to do meaningful and significant and valuable work, it also seeks to contribute to the multiplicity and plurality of legitimate goals for social science inquiry (Bochner 2000). However, Bochner argues that ‘a multiplicity of goals implies a multiplicity in standards, and where there is no agreement on goals there can be no agreement on the terms by which those goals can be judged as successfully or unsuccessfully achieved’ (Bochner 2000: 268). There is very little in the literature about analysing an evocative autoethnography, particularly at doctoral dissertation level.

Polkinghorne (1995) identifies two types of analysis that are relevant here: ‘narrative analysis’ and ‘analysis of narrative’. Bochner prefers to call the latter ‘narrative-under-analysis’ (Bochner and Riggs 2014). In narrative analysis, the story or research product is in the form of a case study or a life history or an autoethnography that the author/researcher has composed to represent the character, issues or events that have been studied. Such an autoethnographical narrative serves to: evoke responses from the readers, cause change in institutions, promote social justice and help us (writer and reader) work through values and moral dilemmas (Bochner 2002; Rorty 1991; Ellis 2004). In narrative-under-analysis, stories are treated as data and analyzed to identify themes or generalize truths. Stories are analyzed from the perspectives of the analyst or writer and presented in forms similar to more traditional social science reporting (Bochner and Riggs 2014; Greenspan 2010; Kim, 2015).

In narrative analysis, how a story makes sense is an ethical, relational question; in narrative-under-analysis, analyzing a story is a way to advance theory (Bochner and Riggs 2014: 205). In narrative analysis, you think *with* a story (Frank 1995), you take the story as complete, as theoretical in itself; whereas in narrative-under-analysis you think *about* the story, reducing it to content in order to analyze it for themes or patterns (Frank, 1995; Ellis 2004; Bochner and Riggs 2014). Autoethnographers mostly exist somewhere along a continuum that ranges from thinking about stories (Anderson 2006; Chang, 2008) to thinking with stories (Ellis 2004; Ellis & Bochner 2006). It is possible to blend both these approaches when analyzing evocative autoethnographies but the story will always occupy the main position.

In undertaking the analysis of the evocative autothnographic narratives in this thesis, I avail of both approaches. My narratives are allowed to be read as a story initially and are subsequently put under analysis, and supported with evidence from theory and literature. This serves to facilitate the readers' ability to recognize the 'authority of the scholarly voice and not just its authenticity' (Bullough & Pinnegar 2001: 20). As mentioned it is rare to find any direction in the literature for the analysis of evocative autoethnographies, particularly any direction at doctoral level to satisfy the academy. However, in my methodology, I subscribe to Bochner & Riggs' (2001: 210) directions to:

> tease out the concepts and patterns within the text: work back and forth with available literature to compare similar insights or patterns in other stories that might be relevant; determine the main argument of [my] piece; frame [my] work accordingly in terms of this idea or problem; then show how [my] story and its analysis make a contribution to theory.

Also, by employing the method of narrative-under-analysis I am telling 'about' the story (Ellis 2004; Bochner & Riggs 2014). This requires a reflexive examining of the story using a tailor-made theoretical framework that facilitates the extraction of salient themes and concepts that will point the story back towards the culture and society that influenced and helped create it. This framework must also help to analyze the narrative to answer the research questions: how does one consider the trajectory of reimagining the self while living alone alongside ME and its contested nature and assortment of challenges and misgivings? Can such a life be a good life? In approaching this task I make use of an original creative framework, a narrative and analytical device which I call the ‘struggle cycle’, which is in turn influenced by two existing frameworks, Witkins’ (2014) ‘conditions facilitative of transformational change’ and the Buddhist philosophy of four noble truths.

The Struggle Cycle

> When there are no cultural scripts available we have to create our own scripts to produce narratives that help us cut through the taboos and integrate these painful experiences into new and more complete understandings of ourselves and our social worlds (Davidman 1997: 514).

The Struggle Cycle is an original conceptual framework which, as stated above, I put to both narrative and analytical uses. It consists of four stages (taking the form of four narrative chapters) to depict the trajectory and progression of changing/transforming/reimagining a ‘self’ from a situation of ‘struggle’ through ‘surrender’, through ‘seeing’ to ‘sanctuary’. This cycle facilitates each narrative to be put under analysis and the emergent themes and concepts to be reviewed in the light of the literature. This original conceptual framework was informed by two other frameworks and the three were found to work effectively as three braided strands which is how they are presented in the analysis.

Witkin’s Conditions Facilitative of Transformative Change

This theoretical framework was devised by Professor Stanley Witkin, University of Vermont, who is co-founder of The Global Partnership for Transformative Social Work, which provides support for ‘thinking differently’ and exploring unconventional pathways in social science theory and practice.

Witkin (2014) identifies four interrelated, non-exclusive conditions facilitative of transformative change. In my narrative-under-analysis, I thread each of his four conditions (to be described below) in sequence through the four stages or chapters (struggle, surrender, seeing and sanctuary) of my analysis. This helps to provide a workable timeline and analytical milieu within which to reflexively examine the progressive nature of the transformation of the self in the narrative. It also helps to identify and discuss the reasons for such change, and the directions taken and the influences absorbed in the process of reimagining the self.

The first condition facilitative of transformative change is that there needs to be some ‘inducement to change that is stronger than the inclination to maintain the status quo.....change generates uncertainty.....[the] sense making templates that provide a sense of stability, predictability and understanding to our lives.....are not easy to give up’ (Witkin 2014: 309). I suggest that this condition resonates with Chapter 4, ‘Struggle’, the first in a cycle of four chapters in my narrative: things are not working as they are, change must be a consideration. This is further explored and discussed in Chapter 8, ‘Struggle-under-analysis’.

Secondly, Witkin states that ‘there is an awareness that certain assumptions, beliefs, perceptions, or understandings, are connected to the troubling state of affairs’, that it can be ‘difficult to let go of assumptions and beliefs that serve us in various ways’, and that ‘beliefs become manifest in action’ (Witkin 2014: 310). This corresponds with Chapter 5, ‘Surrender’, as it facilitates an analysis of the beliefs and assumptions that have not served well to date and may need to be surrendered by the existing self in order to allow a new self to emerge. This is explored further in Chapter 9, ‘Surrender-under-analysis’.

Witkin’s third condition facilitative of transformative change ‘is the recognition and availability of a constructive alternative.’. Alternative positions can ‘help us make sense out of situations in ways that the previous ones did not and they enable us to move forward...’ (Witkin 2014: 310). This facilitates the ‘Seeing’, in Chapter 6, that over time allows for the recognition of the availability of other, constructive, better serving selves. This is explored and analysed further in Chapter 10.

Fourthly, Witkin proposes the need for social support. ‘Role models or experienced others can facilitate the articulation of ideas, boost self-efficacy, allay fears of isolation or “craziness”, and provide living proof that “it” can be done’ (Witkin 2014: 311). This concept of transformative change can be seen to correspond to Chapter 7, ‘Sanctuary’, in that it provides the potential to examine the need for support and role models. I would add to these ‘exemplars’, that facilitate the self to construct long term, more certain ways of being in the world, finding or creating sanctuary for self and if desired, others. I explore this further in Chapter 11, ‘Sanctuary-under-analysis’. (I also comment further on exemplarism below.)

Although it is intended that Witkins' framework of conditions that facilitate transformative change might meld with and help illuminate the stories of struggle, surrender, seeing and sanctuary it is important to acknowledge that this process cannot exactly take the form of a linear, one-directional trajectory. The nature of life and its living will never be that straightforward. In essence there will be some overlap and interconnection and a sharing of relevancies and ideas between stages and stories, but for the purpose of this analysis it is hoped that it will contribute structure and insight and make a significant contribution to unravelling and answering the research questions.

The Buddhist philosophy of the Four Noble Truths

The second framework that has influenced the presentation and analysis of the narrative in this thesis is the Four Noble Truths, central to Buddhist philosophy. This philosophy facilitates change at a deep and fundamental level of consciousness, which proves essential to the process of reimagining a self, as investigated in this thesis. I was inspired to use this framework by the recent work of sociologist Janine Schipper (2012), from whose work the description below is adapted. Schipper was herself influenced by the earlier work of the pioneering Buddhist sociologist Inge Bell (1979, 2004). Schipper explored the Four Noble Truths in terms of their potential contribution to sociological theory. The Four Noble Truths are:

1. There is suffering (dukkha)
2. There is a cause of suffering.
3. Suffering can cease.
4. There is a path that leads to the cessation of suffering.

The First Noble Truth, there is suffering, corresponds with my concept of 'struggle'. There is always suffering and struggle in life, we suffer in life when we experience pain of some description. That is the 'first arrow' of suffering. This also corresponds with Witkin's first condition facilitative of transformative change. The Second Noble Truth states that there is a cause for suffering. The main condition of suffering is our attachment or clinging to a perception or idea that is not in our interests, along with our fear of changing that perception or idea. This is known as the second arrow of suffering, which is optional. This corresponds with my concept of ‘surrender’ or surrendering the old in favour of the potential for a change to something better, which will not cause us suffering. It also corresponds with Witkin’s second condition facilitative of transformative change. The third noble truth states that suffering can cease, and that through an authentic spirit of inquiry we can ‘see’ how our minds can create the second arrows of suffering. This corresponds with my concept of ‘seeing’ and also with Witkin’s third condition facilitative of transformative change. The Fourth Noble Truth states that there is a path that leads to the cessation of suffering, this is the Eightfold Noble Path. The Eightfold Noble Path, suggests that there are prescribed ways of being in the world which support the pursuit of the good life, and avoid afflicting harm on others. This corresponds with my fourth concept ‘Sanctuary’, and also with Witkin’s fourth condition facilitative of transformative change.

Finally, Buddhist philosophy emphasises a movement away from conceptual knowledge to embodied knowledge (Pagis 2010), which proves central to the movement away from ‘struggle’ (suffering) to ‘sanctuary’ (non-suffering) as portrayed in the final theoretical framework.

Emergent Themes

The principle themes which emerged were: voluntary simplicity and authenticity, enoughness, compassion, harmless living (ahimsa), reverence for nature, reciprocal gratitude and Zen mind. Autoethnography is informed by a range of disciplines from anthropology to literature, and in exploring the concepts derived from putting the narratives-under-analysis, my ontological decisions are also informed by a variety of interdisciplinary domains, such as; phenomenology, social psychology, ecopsychology, Buddhist philosophy, literature and poetry and exemplarism, which is derived from virtue ethics (see below). The ontological contributions of the other disciplines to the narratives-under-analysis is that they contribute to the sociological interpretation of a ‘disrupted biography’, where there were few cultural scripts available. In fact postmodern thought points out that ‘overarching metanarratives through which groups of people had understood their lives no longer exists’ (Davidman 1997: 508). The research question posed in this thesis - how to reimagine a ‘self’ living alone with a chronic, invisible, contested illness - resonates with Bury’s (1982) inquiry into how people make sense of and rebuild their lives after experiencing a major unanticipated disruption of their biography. Such ‘disruptions’ are described by Davidman (1997: 509) as ‘events that shatter people’s culturally derived expectations of their life course'. In writing and analysing an evocative autoethnography that describes and examines such a set of circumstances, the methods chosen and described are conducive to the narrative production of essential new identities.

Exemplarism as a tool of inquiry

The lack of availability of cultural scripts that might have proved useful in my process of living and coping with ME led me to the concept of exemplarism. I came to value exemplarism as a relevant concept for this thesis through the work of the contemporary philosopher Ian Kidd (2017,2018) on moral pathography (diverse and creative practices through which people document and describe the lived experiences of illness). Kidd builds on Linda Zagzebski's (2017a, 2017b) pioneering work *Exemplarist Moral Thinking* to explore deviating from the inferentialist style of moral reasoning (a process of argumentation in order to persuade) to an exemplarist style, based on encounters with exemplars. An exemplar is defined as a 'person who exemplifies or manifests a moral quality, role, or even whole "way of life" to an advanced or superlative degree' (Kidd 2017: 330). One admires an exemplar and is attracted to them and seeks to emulate the exemplar's way of thinking and being for the reasons (moral) that the exemplar thinks it or does it. Although exemplarist moral reasoning still involves argumentation, it is 'sequentially and conceptually secondary to the stages of emulation and experience' (Kidd 2017: 331). The epistemological contribution of exemplarism to this thesis is that it allows me to examine my autoethnographic narratives not alone in terms of what I learned but how I learned it and who might have taught or influenced me. A second advantage is the non-inferentialist style of persuasion, which resonates with the 'showing' versus 'telling' of an evocative autoethnography. Thirdly, exemplarism facilitates the possibility to explore if moral or virtue ethics could contribute to answering the second research question: In living alone with a chronic, invisible, contested illness, is it still possible to live a good life?

Reflexivity and rigour

Reflexivity, defined as 'that rich sociological practice of reflecting back upon ourselves as researchers' (Schipper 2012: 222) permeates my evocative autoethnographic narratives and the iterative engagement required for their subsequent analysis and interpretation. I have aimed to write from the embodied mindset of autoethnography, that consists of 'ethical commitment, methodological pluralism and reflexive self consciousness' (Schipper 2012: 363). My autoethnographic methodology was informed by a relativist ontology or one which subscribes to the subjective nature of truth, and how truth can evolve and change. Similarly, by virtue of my autoethnographic approach, my epistemology is emic. I have embraced a subjective approach to an in-depth qualitative inquiry into my own lived experience of a phenomenon. I am highly visible in the work, both as the researcher and the researched. To this end, this thesis is reflexive. Reflexivity as self-awareness or reflecting back on oneself constitutes the very essence of the narrative-under-analysis sections of this thesis, where such 'findings' are revealed and examined. The argument often levelled at autoethnography from the quantitative research camp is that such findings are not generalisable, as they are not generated from the same sources or result driven nature of realist research. I assert that the degree of reflexivity employed in my micro sociological research contributes to knowledge by considering the 'macro and micro linkages' (Laslett 1999: 392) necessary for social change. Autoethnography has tremendous potential for building sociological knowledge by 'tapping into unique personal experience to illuminate those small spaces where understanding has not yet reached' (Wall 2016: 7) In conceptualising my study in ways that understand that the foundation of my work is reliant on the study of my self (my lived experience) with the aim of bringing previously silenced perspectives to the forefront, it was necessary that my autoethnography be a critically reflexive self–study or narrative inquiry, systematically constructed and reviewed to allow for the findings of a 'single case' to be transferable to similar contexts (Bochner 2000). Autoethnography is a method that makes it possible to study the uniquely deep and rich experience of a single life which when analysed has social relevance and utility (Vryan 2006). Finally, autoethnography provides an opportunity for a researcher to 'write to right' (Ellis 1997) or to write to highlight a social injustice. In this thesis I write to highlight the misunderstandings that have been attached to ME as a contested illness.

It is difficult in this thesis to separate such reflexivity from the rigour relevant to autoethnographers. That rigour is one that 'obliges us to turn our lives inside and out and upside down, to investigate what it means to be alive' (Bochner 2018: 366). It requires the commitment to be less concerned about scientific 'judgement', than 'whether our work is useful, insightful or meaningful and to whom' (Bochner 2000: 266). Meaning making is central to autoethnography with the desired outcomes being the alleviation of human suffering and social injustice. Autoethnographers subscribe to scientific rigour and are not averse to its accompanying etic distancing, but they also advocate creative, artistic representations of lived experience as valuable research (Bochner 2018). In moving beyond a narrow definition of methodological rigour in this thesis, I have also aimed to produce work that allows for non-humans to be brought into empirical discourse and to ‘eschew certainty and to imagine and advocate for better futures that we might live’ (Bochner 2018: 365). In producing an evocative autoethnography which is self reflexive, reflective and rigorous, I aim to fulfil Bochner’s criteria (2000). I seek to construct a structurally complex narrative that rotates between past and present, and that can highlight the ordinariness of life but also the emotions and feelings involved in coping with life’s struggles and challenges. I display myself on the page and allow myself to be honest and vulnerable, authentic and emotionally credible. I allow things to appear as they are, contingent, unfinished, ambivalent and subjective and I examine how that is represented in the cultural scripts. I present and express a ‘tale of two selves’ and reveal the trajectory between who I was to who I have become, how my life has been transformed by tragedy or reimagined because of it. I want to be ethical in my portraying and move the reader ‘head and heart’ into their own becoming and towards action and social justice (Bochner 2000: 270-271).

Ethical considerations

Ethical approval for the study was granted by the Social Research Ethics Sub-Committee at Maynooth University. In this thesis I understand evocative autoethnography to be both an ethical and moral venture (Bochner 2018: 359). The evolving solitary nature of my life as portrayed in my narratives contributed to the fact that no individuals were exposed or compromised in anyway. While other characters appear in the narratives, I have used pseudonyms, disguised or obscured personal details and on occasion creatively modified attributes such as age, gender and family relations to ensure that no character in the narrative can be identified as corresponding directly to any actual individual. Any potential ethical issues around the subject of my divorce did not arise as, due to a relapse in my illness, I did not keep a journal in that timeframe from which to draw memories or write a narrative. In embracing highly sensitive topics and by self-exposing weaknesses, struggles, ambiguity and physical and emotional issues, evocative autoethnographers in particular can leave themselves vulnerable as ‘the telling, reading, enacting and listening of evocative autoethnographic inquiry, does not come easy’ (Smith 1999: 277). It can also come at a personal price for many autoethnographers but most, including this one, are willing to pay it. I prefer to view writing this autoethnographic thesis as ‘a courageous act, requiring the patience, persistence and resilience to convey painful memories and insights over time'(Hughes & Pennington 2017)

Conclusion

My research interest in ME stems from having lived with the illness for sixteen years. Having identified a significant gap in the ME literature, where no autoethnographic accounts were detected, I have chosen to write an evocative autoethnographic account of my lived experience of the illness. Being both the researcher and the researched informs both my ontological and epistemological approaches. The existing biomedical and social research findings were contested and pessimistic in nature. In opposition to this I posed the research questions: how can one imagine a 'self' living alone with a chronic, invisible, contested illness? Can such a reimagined life be considered a good life? In employing my own journal entries, photographs and poetry, I present narrative accounts that capture my lived experience with the illness from 2002-2018, with stated timeframe absences due to severe illness. This constitutes the data for the evocative autoethnographic narratives. These narratives are divided into four different time and content classifications or chapters, and put under analysis where the most prominent and salient themes and concepts are extracted. The themes identified include: voluntary simplicity and authenticity, enoughness, compassion, harmless living (ahimsa), reverence for nature, reciprocal gratitude and Zen mind. I then examine these themes within social science and interdisciplinary knowledge domains (Buddhist psychology, ecopsychology, literature) in order to answer my research questions.

CHAPTER 4

‘STRUGGLE’

ME anniversary

I am managing a seminar at the university. All the tutors whom I coordinate are in various capacities resisting or opposing the speaker, a psychologist who has not researched her audience or her subject’s application well. I did not book her, I would not have chosen her. Eventually I get everyone on the same page and the seminar is completed successfully. Henry Kissenger himself would have been impressed.

I am both drained and in a strange and familiar way, fulfilled.

I navigate the traffic and make the near two hour journey home to the hills. Lately, I am never quite sure what awaits me there. Exhausted, I yearned for what I sometimes get, a hug, a cuppa, the fire lit, dinner sorted. This day, none of that. Competing with the sound of the TV, I tried to debrief a little. I was told in no uncertain terms that I was a fool and that I should have got the seven hundred euro the speaker got etc. etc. Coat still on, I sat in the sitting room and cried. Something inside me split open. Once again, pleasing everyone and pleasing no one. A flu like illness began to brew. Two mornings later I awoke feeling rotten with what I thought was flu but my neck was very stiff and for a fleeting few moments my legs would not move at all. It morphed into yet another chest infection that three antibiotics did not shift and lingered for weeks. Usually I could push through but this one had me flattened.

A locum GP, a disinterested but informed South African man, wrote ‘Post Viral Fatigue’ on the first of many sick certs that would after a year read, ME.

I knew deep down even then that it was ME. In a way I had been expecting it.

Today is the sixteenth anniversary of that date. Sixteen years later I remain sick.

In the beginning: the blur that is ME and keeping a record

The events of the first two years of ME, 2002-2004, are all merged, particularly in terms of journal entries with a lengthy and painful revelatory process that my marriage was irrevocably breaking down. I had no idea I was as sick as I was, being too busy trying to have the kind of ME that did not inconvenience anyone. For the first several months I could sleep most of the day and all of the night and I thought that was going to heal me. As the symptoms began to manifest as brain fog, pain, headaches, sensitivities and intolerances and some degree of flu like symptoms daily, the ability to sleep or rest left me. I thought years of bad decisions such as over work, over training, over ambition and over involvement in other peoples' lives had burned me out and made me sick. I had caused this. I was not unused to hearing that everything was my fault. Consequently I felt it was my responsibility to fix it or find a way out. I researched ME to the best of my abilities given my severely altered cognitive abilities and subsequently put a regimen of diet, exercise, treatments and herbs and supplements in place. Nothing made much of a difference. I was unable to go anywhere, the lights noises and busyness of places I found painfully overwhelming. I was also alone a lot. I tried to quieten my increasingly worried and frightened mind by following a spiritual path and the Zen Buddhist message of 'no mind' and 'present moment living' resonated with me, but I was a complete novice.

I survived financially for the first year on adequate sick pay from work and my savings. The second year and subsequently I was reliant on disability payments from Social Welfare. I had always been the main earner and subscriber to the system. By the end of the first year it became clear that I was not going to be in the more fortunate statistical cohort of ME patients who regain their former health status and ability. Things were going from bad to worse. It was very difficult for me to have company and I had become isolated in a marriage that was in the final and very difficult throes of implosion. I do not know whether to bless or to blame the Buddhist teachings that kept me present and kept me from losing my mind during those final few months. Ironically, in the end I did lose my mind in Buddhist terms – I lost my mind and came to my senses and was finally able to truly 'see'.

The only ME tailored programme available in Ireland at that time was 'reverse therapy'. One woman came from the UK to the west of Ireland sporadically and saw ME patients for therapy sessions. At the time if I wanted to go I had to drive myself there, stay the night and drive back. I remember driving to the second session and having to pull in half way there to a hotel car park and sleep on the backseat of my car for a few hours just so that I could make it. I was dangerously outside my ability zone in every way but I was desperate for help. The 'reverse therapy' was a form of cognitive behavioural therapy. I was encouraged to rate my effort and energy expenditure and correlated symptoms and then consider the wisdom of the choices and decisions I made. I knew even then that you could not think or talk yourself out of ME. However what it did do for me was to highlight the dysfunctional dynamic of my relationship and how I would never be able to get well within it.

On the way home from that session I pulled my car over to the side of the road and cried for an hour into my then small brick of a mobile phone and in between sobs I ended my 20 year relationship. I was heartbroken but felt the beginnings of relief. The next day to my surprise I was handed a typed sheet of what household belongings I should keep. Five years and many court appearances later, I kept the house.

The impact of the ME cognitively meant that I had no real ability to read or write or retain new information for the first ten years of my illness. I could not use or watch screens without getting migraines. Radio was sometimes a welcomed possibility. I was light sensitive and always in dark glasses. My memory was very poor and everything got written on my calendar or it did not happen. However, even though my abilities were severely limited, some of my old intellectual curiosity persisted, if at a very different level. Things seemed to emanate from my heart now rather than my head. I would write down observations from outside and the feelings they invoked, or capture small moments of beauty in a photograph. Short poems came easily.

It was not until 2007 that I began to keep a sporadic journal again for a couple of years. I could feel the daily struggle waning a little. I was finding a new way of ‘being’ with my illness and of ‘being’ in the world. After the divorce in early 2009 I became ill again and for the next five years or so would find myself in various stages of relapse and respite. A lot of people returned into my life also in those years and that would prove to be physically difficult. I began to build a little farm and providing shelter for my expanding flock would be the main work of those years. I wrote the occasional poem and took photos but I had no appetite or ability to document much. My good friend Holly who was a successful academic, and herself going through divorce, suggested we make a radio documentary about our experiences, which we did later that year. We subsequently co-wrote and published an autoethnography chapter on it a few years later. Both experiences were momentous in their own way but I was once again dangerously outside my ability zone and would pay the price.

Everything seemed like one long blur of illness. In 2014 I began keeping a journal again. If I did not keep some kind of account I found that I was completely unaware of time or what state of relapse or respite I was in. Reconnecting with the journals was not unrelated to the reality that I was now, in order to not relapse so badly and so frequently, having to be a lot more solitary. My world was to shrink even more of necessity and would mostly consist of the happenings of inside my gate on my little property. I had known long years of struggle, had just recently found shelter for me and my animals and now it seemed that I would need to create some kind of safety and sanctuary in order to be able to stay well enough to have some form of ‘good life’. The journals from 2014 intermittently to 2018 document that process.

Sitting Duck

I was a sitting duck.
ten years in America
and ten years in this house
trying to keep it paid
working in nursing homes
teaching and full time study.
I ran marathons
drove a hundred miles a day or more
juggled money worries
and an imploding babyless marriage.
But I could make it alright
if I just worked more
pushed harder
acted braver.
Yea, that’s it –
focus on others more
give more
forgive more
believe more
and paper the ever widening cracks with optimism
Until I just couldn’t anymore.
I was a sitting duck
that just couldn’t stand it any longer
that had no strength left to duck what was coming.
So I ‘collided with a pathogen’*
and never got back up.

*Peggy Munson, *Stricken* (2000).

Three Vignettes

1. The Neuropsychologist

I drive twenty miles to meet my mother who will then drive me to a part of the city that I don’t know and that I would not be able to negotiate safely these days. The twenty miles is already way past my ability but my mother is in her seventies and I won’t ask her to come and get me it’s just too much. I brought the packed lunch and the thermos for us both. Going in anywhere for lunch would finish me.

My appointment is for one o’clock. Am I being squeezed in? We arrive at close to one. It is a general hospital but it specialises in Neurology. It is old, huge and teeming with people. The front desk is unoccupied but signs everywhere remind us to use the antiseptic sprays provided. MRSA is a known problem there. We follow the signs to the Neuropsychology Department which turns out to be a portacabin. En route my stomach heaves as yellow toxic signs surround a public bathroom door from which the worst smell I have ever experienced emanates. By now I am completely out of my body but trying to focus. In the waiting room Mom suggests we have a cuppa and a sandwich while we are waiting. There is no one around, she is starving. I just wrap my hands around a cup of green tea.

A guy in his late thirties comes out to greet us, he is extremely jocose and informal. He is the neuropsychologist. I go with him, bring my tea. He said that he had had my chart ‘walked over’ earlier so he could read it before I came but someone took it back before he had the chance so why didn’t I just tell him my story in my own words... from the beginning. Really I think?? From the fucking beginning?? I am already exhausted from just getting here, totally out of body, vague, overwhelmed and very close to tears. Why didn’t I just say that I would rather if he went and got the chart? Why? Because, as usual I am on the back foot. Because, the burden of proof and belief is firmly on me. Because maybe (and I am desperate enough) this guy can help me?

So I go into to teacher mode.

I explain ME, what it is, how it affects me.

I explain my career path, how I cannot work.

I remind him nobody chooses ME as a career.

He asks me about my qualifications

I tell him I have a first class honours Masters Degree.

He becomes less jocose, leans back in his chair, fingers linked behind his head, full man spread.

A series of neurological tests follow – over an hour's worth. I am given a binder with plastic covered sheets full of shapes and colours and diagrams. I am to identify progressions, know what comes next in a sequence, draw shapes inside other shapes.

Everything moves around the pages. My eyes twitch, I desperately need him to lower the lights. The migraines start, I think I am going to be sick. I do my best.

He tests my memory. He reads short paragraphs, I am to repeat them. I tell him I have not been able to read or retain information since I got sick. I listen to him read his tests. He asks me to repeat the first sentence. Everything has fallen into what I call the black hole in my mind. I suggest he asks me questions about what he has read that perhaps I can recall that way? It proves to be so. He reads me words, some quite cryptic and I am to explain them or put them into a sentence. I seem to do quite well.

Out of nowhere I start to cry.

Exhaustion...from just getting there?....from trying so hard to think and do at his request?....from the hostility I do not imagine?

He asks me in passing, how I think I will be in five years?

I am already eight years into this illness. I know the research and the statistics and they are not stacked in my favour. I say, probably not a lot different, I am realistic but that I manage well and have learned to cope and I have a lot to be grateful for etc.

His face tells me that I have not given the right answer. He tells me there are holes in my memory but that I am not helping myself. I still have myself on an academic pedestal that I am no longer on. I am aiming too high, I want to read Dostoevsky, when I should be reading the

Beano comic. Why don’t I read his favourite book *The Catcher in The Rye*? He has read it eight times. He gives me his card, I see his name and BSc in Psychology.

He is done.

I am completely undone.

As my mother negotiated her way back into the traffic she said ‘he seemed like a nice guy and very helpful’.

When his report came back to my GP I asked for a copy. In a lot of the memory stuff I had tested as remedial. In some of the language stuff I was in the 90th percentile. I *had* told him that everything pre-ME was still accessible to me depending on my level of exhaustion but that everything post-ME I was unable to retain.

His comment to my answer regarding where I saw myself in five years read:

‘Her own mental set with regard to her condition suggests that she will continue to experience difficulties for up to the next five years. She has a view that her current difficulties will be life lasting and that she knows herself through her own research and therapies that this is her life from now on. It was difficult for the examiner to shift with regard to any of her expectations and certainly I am willing to meet with her again to do some further assessment or for further counselling however at this point in time it may be difficult to shift her expectations as regards to her current position’.

It would be another four years (twelve since I got sick) until I could read and retain information.

2. Social welfare and the medical examiner

In general the system has been nothing but kind to me. I think of how it would be if I was still living in the States and sick with ME. I could not have survived. My experience there was that if you worked hard and paid hard and ticked all their boxes you were safe, for a while at least. But there is no safety net there and a lot less compassion. Everyone I worked with, mostly professional people in hospitals, owned houses and trucks and even boats, but they were all at any time, one paycheck away from the street. They ascribed, in those days whole evenings to balancing their check books, having to keep a constant eye on their credit ratings, one strike and you were out. No, I would be living in my car a long time ago if I still lived there.

I never thought I would even need social welfare. I had worked as a nurse solidly since my training at seventeen until my mid-thirties. In order to try and get out of nursing I availed of a ‘Back to Education’ Scheme with the Social Welfare system which gave me a basic payment and I could study and work part-time. I also qualified for help with the interest payment on my mortgage which at the time was 15%, the rate is about 3% these days. So when I needed disability payment I was already on board with my Community Welfare Officer. It never sat easy with me going to see him in the village in the early years. He always reminded me that he was only giving me what I was entitled to but I used to have to fight back the tears and often brought small homemade gifts when appropriate. He was a profoundly kind and gentle man and when he retired my dad, who is a lovely wood turner, turned him a walnut wood lamp for me to give him. As it happened I had exactly enough payments made to qualify for Invalidity Pension, which I did not know but which Kevin applied for on my behalf. This meant that I could benefit from a household package which paid my telephone line rental every month and paid a portion of my electricity bill. It also paid the television licence. Today after financial crashes and recessions most of those benefits have either well decreased or ceased altogether but I have always felt financially supported by the State. I also have a medical card which entitles me to almost everything medical free. I no longer have to submit any kind of medical verification or go anywhere to sign on and my weekly payment is paid directly into my bank account.

Over the years, varying circumstances and budget changes have meant that I either do or do not get a full or partial extra payment as a Christmas bonus. For six winter months I get a weekly fuel allowance. There are hardship or exceptional needs payments available through the health board. In the early years I got help with a fridge and a washing machine. Mostly I can manage and I never pursue things just because I might be entitled but only out of severe need. I have always been used to providing for myself and others, I have never been provided for.

About two years into my illness I was called before the medical examiner’s panel to monitor my level of illness and assess my suitability for work. I made it to the first meeting myself. I was only recently separated. The doctor was young and kind and I tried to explain my situation but I basically just sobbed. The nurse I remember locked the door as others sat outside waiting. The doctor apologised for having to ‘drag me in here’ and the nurse let me out a side door. The second medical examiner’s meeting a couple of years later went much the same minus the sobbing. The doctor, an older man, was also kind and wished me well.

The third meeting I wasn’t well enough to drive myself to. My mother and sister met me along the way and drove me through the traffic. I, true to form brought the picnic lunch and the flask. They were delighted with the visit and went shopping while I went to the meeting. Because of the planning and the picnic and the chatting and the prospect of more visiting after the meeting, I was tired but wired and completely out of my body. This was very common in those days. In order to achieve anything out of the ordinary I had to push very hard and I over compensated by acting way beyond my ability. The doctor was cool and detached and said he did not know anything about ME and could I tell him about it? I went into full lecturer mode and informed him and he ticked a few things on his page. Then he asked to examine me. I got up too quickly being wired and he told me I had a very athletic body. The examination was over. I left and a week later I got a letter saying I was fit for work and that my invalidity pension was cancelled of immediate effect.

The appeal took three months. In the meantime, I had to go every week to the Community welfare officer for a hardship payment cheque which I could cash in the post office. I had to get testimonial letters from my GP and any other kind of character witness could muster and put together an appeal portfolio of sorts. Finally I had to go before another medical examiner. This time my mother brought, me as I was a wreck. I sat in the next door Garda station for a while before I even realised that I was sitting in the wrong building entirely. It was a humiliating experience. Being dependent on the State, though grateful for it I find both humiliating and humbling. However being thought of as a possible fraud or a malingerer was an unnecessary burden. Nobody chooses ME as a career path.

My biggest fear when I hear the postman’s van skidding to a halt on the gravel at my gate is that he is delivering an appointment for the medical examiner’s board. If I was this unwell, sick and unable with any other comparable, recognisable, uncontested illness I would not have these fears. But from my experiences, my fears are not unfounded.

3. Catch 22

NOTE

In a 2016 study conducted by ME Research UK (www.meresearch.org.uk), adults with ME were interviewed in an effort to identify and prioritise some of the main issues of concern to the group. Along with loss of identity and independence, anxiety about the future and feeling invisible socially, the respondents also identified often being caught in a 'Catch 22' as a major theme.

For months I agonised over the shabby state of the outside of the house. The paint was faded. At some points where the animals rubbed off it, it was down to a green which was two paintings ago. The paint on the wooden eaves had flaked off. Six years ago my family had come down and stayed overnight and given it two coats of the deep purple that is now looking in need of an update. My family are wonderful and their stay involved a lot of kindness and love and special moments but it took me ages to recover from it all. More than they ever needed to know. Now, on the tail end of this latest relapse, I simply cannot imagine being able for any of that. 'That' would only be seen as normal stuff by a well person: hospitality, making up beds, lots of extra meals, chatting, sitting around at night socialising. All 'that' would have been considered lovely in my old life, but totally beyond me now, never mind trying to co-ordinate and 'mind' people getting up ladders and scaffolds etc. My funds do not allow for paying a professional to do it or paying a neighbour to do it, who will understandably come only when and as they can which will wear me down entirely as I never know from one day to the next how I will be.

I made some enquiries about paint and it needs a very deep base for the damson colour I had been considering, as it would be a few shades deeper than what is on it now and only need one coat. I do not know what madness or determination took me to the local hardware store that afternoon but I walked out of it carrying two 5 litre cans of paint and an extendable roller which was a total cost of 135 euros.

These mornings were sunny by 6.30 am so the next morning I got up early and said I would chance a bit of a wall and see just how doable it all was. I threw down a couple of old drop sheets under the gable wall and moved the car close by and left the hatchback up so the dogs could sit in it. I had forgotten to buy a roller tray so I used my neighbour's dear departed cat, Riley Love's old litter tray. The paint went on well. The high points of the gable wall took the fullest extension of the roller plus me on a chair jumping up and down. I made it up 99% of the way. It would not be necessary to get to the other 1% as it was very close in colour to the old paint. A full hour later I had the whole wall done. Sometimes the dogs got too close and got a bit of paint on them especially the pup Ely but all in all the four of them were brilliant once I kept a good eye on their whereabouts.

I moved round to the front of the house which was a smaller expanse because of the windows. Again I did not have to be that particular because of the existing colour. That is what saved me, I did not have to be constantly on and off the chair with the cut in brush which burns the leg muscles off me. I finished the front, the porch was fiddly and then with cushions under my knees I did the base boards by brush. It was 1.30 and I had the shakes and considered the couch for a few hours. The dogs needed a snack, so I went inside. I had my flask full as always and made several mugs of green tea which were so good, the quickest fix food I could rustle up for myself was banana and jam on spelt toast. My hands were so stiff I could hardly hold the sandwich and it shook on the way up to my mouth. I was completely hypo so I ate several chocolate digestive biscuits and drank the rest of the flask. I sat back in my rocker my legs crossed under me and my eyes closed and rocked, self soothing like either a baby or a demented person, I wasn't sure which. The dogs were crashed out in the kitchen and it was silent except for the ticking clock. I was wrecked and a bit incredulous of what I had already done. The only incentive that lured me away from the very strong pull of the couch was the notion or was it the dream of getting the house completely painted so that I would not have to think about it again for years.

I went straight back out. The second gable end was my biggest dread so I went for it immediately. First I had to pull out some bags of coal and empty gas cylinders and sweep years of dirt from the base boards re-homing critters as I went. I started with the extended pole at the highest point of the wall and me on the chair. The sun was in my eyes. I started to feel nauseous and the extension pole already felt ten times heavier than before so it wobbled on and off the wall as opposed to rolled. I had to dig really deeply so I just closed my eyes and aimed high and put in 20 minutes of hardship. It was the 'wall' of my current marathon and I knew it but I just had to push through. The pole got stuck on the old satellite dish and I had to jump up and down on the chair several times to free it. Eventually the wall was done. I fed the animals and sat in the garden chair surveying my work. My neck and shoulders were so sore and when I went to move one of the cylinders my back went out and thankfully immediately back in again. I started to turn cold with the fear of what tomorrow might be like or next week or next month? I would have only myself to blame. I am not a wet day out of one of the worst relapses in years and yet look at what I was doing? But this is all part of the relentless ME ‘catch 22’ dilemma. Last year I just could not face this task. This year I am sick of looking at how decrepit the house has become but I cannot face the even less manageable price or cost of well meaning family help nor the cost of paying for the whole job to be done or the fall out from having strangers around. So I take the chance and go for it, go into that deep determined minute by minute Zen place that sometimes enables me to get things done. But God is it hard? It reminds me of the hard training runs I used to do. The 12 miles of hill running, head down, pushing through pain and breathlessness, sometimes repeating mantras just to get to the top. The greatest reward was finishing, standing there with your hands on your hips grinning and then later those few moments of deepest fulfilment and pleasure when your exhausted body sinks into the hot lavender bath and you lie there reflecting on your achievement and feeling truly part of the game of life.

With one wall left to paint, the finish line is in sight. I could not stomach leaving it and having to wake up to it tomorrow. I am very low on paint so I work that last bit of paint like you wouldn’t believe. In the end I had to do the last bit of the baseboard with the old paint. I didn’t care, only the sheep up the back hill would see it. It also points out the damson, blueberry richness of the new paint. It is seven thirty in the evening. The donkeys are at their gate over the road honking for their evening bucket of feed and treats. The hens need to get supper and go in their run. There is very little clean up for me to do. The paint roller head is almost bald and is only good for burning, the brush I soak. I water the vegetables in the tunnel and tend to everyone. The immersion tank is on for a bath. By 8.30 I was dizzy and cold and happy enough to warm up mushroom soup from the fridge and bang a couple of potato waffles under the grill and put them with salt between two slices of bread. It was crap and it was divine. I sat in the rocker with the dogs around me and drank several cups of tea. It was a little surreal. I could not believe I had done it and that more importantly it was ‘over’. I felt like I could not tell anyone. I knew there would be terrible payback and how could I expect anyone to understand and not think me irresponsible?

An hour later I was in the fullest bath I had had in years as I am usually quite sparing of the hot water. The only pleasure of the whole long day was those first few moments when the warm sudsy water reaches all those places of pain that you ignore and override and deny. Relief and mild triumph give way to silent laughter. Whatever happens next, you made it! Plus you did it on your own with as little hassle as possible, peacefully, with not a word spoken and no sound except for the birds and the company of watching dogs. I rubbed arnica into my dodgy back and got into bed. The moon shone in, Peggy was at my side. Sleep was not an expectation, but sleep came.

JOURNALS

28 May 2007

The almost full moon on
the tunnel makes the plastic
taut and transparent.
Dishes wait in the sink
beside rhubarb defrosting pink.
I catch my face in the lit window
it is high boned, clear
and exhausted.

31 July 2007

Today was a lovely summer’s day and now I sit outside on the old armchair. I can hear all the machinery noises as farmers catch up after all the rain. The animals have had a great day. The baby goats snoozed for hours on the grass in the sunshine. That is a new development for them as they usually return to their little base camp. Last night I stood outside late and watched the full moon appear. I prayed out loud although the words and thoughts were difficult to formulate, but I felt the connection and the gratitude and the awe. I hoped to raise the level of my being and consciousness from one of endless doing and struggle to something higher. Still I cannot rest but there is a space if I do not mindlessly fill it or if I can override my conditioned message.

Yesterday I went to visit my neighbours with a gift for one of their three girls who is sick. She is a beautiful child, they all are but there is something very special about her. She was reading the latest Harry Potter book, I couldn't help but wonder why which was stupid of me, as she is only expected to live a few more weeks. There was such a sense of unreality about the whole household. Her older sister was making spaghetti Bolognese and kept handing her carrot slices. The mother was her usual kind of full-on self but I noticed her sending furtive glances at her precious girl with the scarf on her head and the brilliant smile.

(Afterword: I would be at that beautiful child's wake within the month.)

13 August 2007

Another bad flare up, I am doing all the 'right' things; soup, fluid herbs. My joints are very bad, I go to bed for a while but cannot rest. It occurred to me while I was thinking about my 'lot' and trying to practice gratitude that I might be a farmer or I might be a writer or I might not need to be anything at all.

14 August 2007

I know this summer never really got going but today it feels like it is definitely gone! Yes I have a nasty head and chest cold but it feel so Autumnal to me. Five fleece parkas – I can't ever remember ever needing that many clothes in Winter. I lit the stove really early and already the kettle is boiling away on it and the house feels more relaxed. I have gotten so many wettings out bottle feeding these baby goats and sheep several times a day and it was hard to dry everything out. The dogs are in the back kitchen, I have them on newspapers and old towels. The worktop is covered with feeding bottles and lamlac mixed up in jugs for the next feed. The floor is taken up with 25kg bags of feed and baskets of turf and logs and an array of boots and jackets. Last night as I sat in my rocker I saw the first small truck of logs going down the road – someone is preparing for Winter. It is a lovely feeling walking around my little plot with a lamb and two baby goats and three hens following you. Pippy hen is clocking so she is in her new clean bed with regular room service, setting on three fertilised Bantum eggs. Bless her I'd say I have as much chance of hatching those eggs as she does.

1 September 2007

In present moment living everything is absolutely fine but I have no certainty about anything now nor does anything seem worthwhile in the old familiar sense. At the moment I do feel sad and an unusual amount of self pity, considering I don't usually feel any. When I withdraw from the old external striving, instead of feeling relaxed or relieved I feel kind of lost. I am lost in that place between attachment to the old and the newer connection to something greater.

25 September 2007

I am touched by today's reading in the Zen calendar: 'It takes a long time to understand nothing'. The little prayer flags Mary sent me are on the wall, I say 'Om Mani Padme Hum' for each one of them. That little mantra sustains me and my growing Buddhist practice is gentler than my old disciplined drive. The power of breaking out from within, versus trying to break in from without. Now it is time to fill the bird feeders.

4 October 2007

Today is an Indian summer day. I had to go to bed between 10am and 1pm but then I was able to potter outside with the animals and put a bit of weather treatment on the side of a woodshed. Yesterday was vet day with Flora, she had to get her horns done under anaesthetic. It should have been done before I got her which would have been easier on her but the guy didn't do it. Margo does not have horns. It was a tough day, in and back twice to Tullow which is a good two hours of driving altogether. I had her in the hatchback of my little car and she whinged the whole way home. I was totally undone by the time she settled finally in her shed by 9.30 that night. She was shivering so I brought her into the spare room and settled her beside the radiator on a hot water bottle, all her little goat current poos flying out of her, and under the spare bed. Her wounds bandaged and tied under her chin like an old lady's scarf. She has always been high maintenance, but she is devoted to me and can make sounds that are scarily human. On the way home yesterday from picking her up we must have looked a sight. I pulled in off the road to try her with a bottle to see if it would calm her roaring. There we were for all to see, her with her scarf under her chin, me sitting in the hatch back with the door up feeding her a bottle. Looking around me I noticed this amazing apple tree laden with yellow and gold apples and it suddenly struck me that it was Autumn, Fall time and it is so beautiful. As I made the last turn up to my house and saw all the colours of the changing trees against the blue sky I thought even through my feeling ill and stressed and sad, it is just all so beautiful. What would I do without the anchor of nature and Mother Earth to remind me that there is always joy and sadness, birth and death, beauty and change. It is all part of it. Otherwise all our prompts would come from the media and corporate worlds, just trying to mould us or sell us something. Bernie really saved me last night. I was vulnerable and sad on the phone to her, bereft at coming up to being 5 years sick and confused about how I actually am and how things might pan out. She gently told me to put Flora out into her house that she'd be fine. Exhausted, I hadn't the wit left to see that for myself.

21 October 2007

I can hardly hold the pen after a few very difficult days. I am unable for anything, spun out, sore, scary headaches and nausea. It is very hard not to keep wondering how to make sense of it all, even trying to make something 'of it', using all the old redundant ways of measurement. Unusually for me I have managed to keep away from everyone and everything which actually does tend to build me back up a bit. When I am this low I can, at least for a while, let go of that sense of duty towards everyone and everything that can so easily dictate my life.

On the back of that, last night, a beautiful, frosty, increasingly moonlit night saw trouble with the deer lampers. Not unusually I caught them going past my house towards the forestry, so I did my usual and quickly switched on the bright outside lights and flashed them with my torch. A couple of hours later their vehicle crawled at a slow speed past my place and lamped all around. Then they stopped for a while which was a bit sinister, so I put the outside lights back on, hung out my kitchen window and flashed them with my torch. They turned their incredibly strong lamp in my face. I cursed them out of it, they roared back something unintelligible. I told them that they were bad bastards, that I had their number and that I was calling the Garda. They lit me up again, I held my lamp on them before they finally took off slowly down the road, eventually turning right on to the little bridge in the valley right below my house. Then they sat there with their lamp blaring right up at me. I called the police in Baltinglass, the Garda was familiar with my location and said he would try and send a car out, but to call them in future and not to engage with the lampers.

I was awake a long time thinking about that. I am wrecked from going through this intermittently, every winter for years now. The cops will never get out here in time while the lampers are flashing and if they get the chance, taking a shot from the road. Yet, I am so very weary from the ME payback of it all. I rattle and shake afterwards but not from fear. My voice goes weak and my chest aches and my breathing goes way down from the adrenaline/ cortisol release. I just feel so loyal to the deer who don’t stand a chance, paralysed by fear in the lampers’ lights.

I think the next time I am in Baltinglass I will go into the Garda Station, explain it all and hand it over to them.

28 October 2007

The concept of first world pain came to me tonight when I was in the bath. I had been watching a documentary on anorexia. The young woman really struggled with self esteem, self loathing and pain. I thought of my own struggles and being so sensitive and how I undermine that ’pain’ because it seems ridiculous when I have so much in comparison to those struggling to survive real pain in the developing world?

20 November 2007

Up at 7am, I awakened with that heavy dread feeling that I wish I did not have. It is that ‘here we go again thing’ that mostly is not true of life for me but at times I am so wiped yet wired that I am just not tuned in. The rain is lashing down and the farmyard is one big sludge. I need to sort it out so as it is more manageable. Of course it is probably as bad as it can get after this incredibly wet season and yet I am managing so that is not so bad. If and when the budget allows, I will probably put down a few slabs to walk on, and fence in the front garden to keep the dogs clean. For now I must make the best of things and manage. I have neither the drive nor the resources to make it happen and it would make me very sick. It is more appropriate to focus on the gratitude versus the striving as everyone has been so generous towards my every material need and that need can so easily become insatiable if I do not keep an eye on those who have so much less than me.

23 November 2007

What a night! It is 11pm and it looks like daylight. It is still and white with frost and completely silent. The dark sky is sparkling with stars. Nan is sleeping peacefully on the ground outside not choosing her cosy bed. Mu, after a day inside, is puffed up surveying it all from the high kitchen window ledge. The goats and hens are silent in their houses under glistening roofs.

Earlier today the full moon peeped up from behind the back hill and forestry at about 4.30pm – it was a vision. Nan did one of her ‘dances’, pouncing on all fours and charging and head butting whoever got in her path. Flora grabbed and chewed the MBMA gold card application I had just picked up from the mailbox, truly she got more use out of it then me! Exhausted as I was and eyes twitching with headaches, I still had to be part of such a glorious evening. The dogs were happy with sticks always around my legs, me as their centre. I am still a bit of a mess, unable to focus or get much together but fundamentally all is well. My animals and their comfort and happiness is at the centre of my days and is the source of my contentment and that for now is fine.

4 December 2007

I have lots of errands to do; stocking up on animal feeds and supplies for the house, bill paying but I cannot manage any of it. I am lying here thinking this will be my 3rd Christmas alone.

People often say I was ‘gutted’ but I feel like using the term ‘mollusc-ed’’ like a little shell creature prized off a rock, half dead and half alive. I have no idea once again how I will manage Christmas on so many levels. Always the challenge for me is to do less, to keep it small, to allow myself to be humble enough to recognise that just enough can be plenty.

10 December 2007

A fabulous blue, dry, cold day today at last, after a good spell of wind and rain, that has lead to too much muck, sludge and filthy animals, and a subsequent filthy house. I am a little worried about the water pump, it keeps switching off and not coming back on. It probably needs a service, more money! Luckily I have a bit left from my birthday fund so I will have to prioritise the pump along with the missing roof tile. I had a Radionics (energy healing) treatment this morning. I really hope that it does me some good, it seems to. Interesting that ‘disappointed’ came up as an issue. I had a lovely moment with Nan this evening. She really looked at me and then came over to me and allowed herself to be stroked. She is here 5 months now. I made her a cosy bed for lying out on. Like all sheep she loves to be out on a cold dry night.

Mu was with me most of the morning when I was trying to clean a bit. She was very unsettled and was making unusual chatty noises but would not go out as the dogs were out. She came out with me once I put the dogs in and toileted outside and then looked to go back in. They all have their own personalities and precious lives and even though most of them did not get a great start in life before they came here they trust me, and that is my privilege.

12 December 2007

I came to lie on the bed for a few restorative moments. I have to laugh at how the dogs tiptoe down to join me, Credence quick to claim the rug beside my bed. Wei is happy to lie across the doorway. What a journey he has come from terrible anxiety and fear, to trust and relaxation and belonging. I almost cried yesterday when he came when I called him, ears back but laid down to have his skin treated. When he lies down to rest he lets out a big sigh and puts his head on his paws, his wagging tail thumping the floor with happiness, even when I am talking to Credence.

In the kitchen a large pot of rice is simmering, it is for them. I like this time of evening when all the work is done and the animals are tucked up, the cooking is over and the house is cosy while outside is dark and cold. These days I am pushing through immense tiredness and weariness and soreness just to try and keep things ticking over. We are in the mouth of Christmas and I survive by lists and by keeping a very strict eye on my tiny budget. I have something very small for everyone, I have stretched it out well. But it is all without enthusiasm and it is the worst year yet in terms of creativity. Sometimes when I feel this sick and weak I wonder 'when did I last feel like this?' What is the pattern? Is this just winter? Is it always this hard to hold the pen? Everything merges, the whole timeline is such a blur. Yet there is so much discovery. This weary anger that has plagued me the last few weeks is subsiding. I definitely do better alone. I am thinking of Pema Chodron's 'hold your seat', that definitely helps me as everybody's drama comes flashing in and out. Maybe that too is why I like this time of evening. I fool myself that I am safe, I can wind down even hide if necessary and it is often necessary. I don't feel so empty when I can just be empty here quietly.

29 December 2007

These days go by so slowly. I am feeling so unwell yet I am lost without my chores. I literally cannot relax. Sadness over Credence is welling up inside me. He is not well, he cannot sit and seems to be in a lot of pain. I took him to Caroline the vet who has given him medication and will neuter him next week. She is not sure how bad things are yet. He was so good, I fell in love with him all over again. I am undone at the thoughts of losing him. A big rat, bold as you like was up on his back legs in the hen run today. I blocked in all his tunnels in and out.

31 December 2007

A rare visit today with Eilis and Connie. They are the two gentlest most artistic souls I know. I was unusually candid with them about how things are for me and why I can rarely visit. It was really weird for me to hear myself being so honest. The girls had only left when my neighbour Kevin came in for a cuppa then my other neighbour Lila came. She fancied a hot whiskey as it was New Year’s Eve and she stayed for ages. I was out of my body from trying to facilitate everyone, but things like this seem to happen me, when I say yes to one person it is a flood of people. I was feeling drained and a bit resentful as I took care of the animals in the dark. Next thing a car was at the gate, my heart totally sank but it was Lila who had driven 25 miles round trip to get me Chinese food with tofu as a surprise, and for me to celebrate New Year’s eve in some small way.

4 January 2008

What a difference a few days can make? Beloved Credence does not have cancer and is home with me now after his surgery with no great ill effects. Lyn the vet had taken him home with her the night of his surgery and he spent that night sitting with her and her husband. She is so understanding and respectful of my situation. Now he is lying beside me here snoring away. A couple of days ago water started spraying out of the pipes in my hot press. I was waiting for hours for someone to come and fix it, in the end it was not anything too major. Now everything is fine with the water and with Credie. I heard today John O’Donoghue died suddenly. What a huge loss to the world. He has been such an inspiration and a comfort to me. There is very little that is truly worth worrying about in life but we all fall into the same old stress traps and yet we can be gone in a second and it is all over for us. I am in a bit of trouble with my left arm. It is really tight with burning pain, probably a fibromyalgia flare up. My poor old body is packing in. I give it so little attention. Ironically when I was well and really fit I was really into my body, now it seems like we have abandoned each other.

19 January 2008

It is a very stormy morning. I have the candle lit and I am sitting here thinking how it feels like I am constantly switched on and how it is impossible for me to ever get any real rest. I am switched on yet there is no power coming through. I read about people with ME who are constantly in bed, are they switched off? Every day, I wake up beaten up yet wound up like a toy. Only I know this.

5 March 2008

Yesterday, I gave a leftover dish of mashed potatoes with roasted garlic to some very delighted hens. The dogs got the bowl of steamed Brussels sprouts, the goats got the net bag of raw ones. The turnip whose destiny was to be creamed with fresh nutmeg now sits in the scrap bucket. Nausea, my current companion is only friendly with steamed broccoli and I am not too sure how she will fare with the yellow split pea soup bubbling away in the crock pot. In a strange dream last night, a huge crack opened up in the earth. I tried to push it back together again apologising. I realised that at some very deep level I apologise too much. I am always apologising for my symptoms and try to gloss over them. I am sorry when I cannot absorb what other people are saying because I am drained. I apologise when I am not well enough to visit, sorry when I couldn't wash my hair or 'get dressed up'. Yet 'normal' people constantly tell me as they yawn repeatedly and unapologetically down the phone, how exhausted they are.

8 May 2008

The gorse is scenting the air. I stood by a big yellow bush yesterday and breathed it in. It is my favourite smell in the world followed by the smell of my dogs' heads and that big old bunch of dried lavender that hangs in the polytunnel. I am so done in from my recent flurry of activity; a visitor, a trip for groceries, a few phone calls and some chores. Nothing to a 'normal' person, but impossible for me. For such an energy spend there will be payback and it is now. My neck is so stiff and sore, my throat and chest are sore and tightening. It is becoming increasing difficult to get a full breath. My voice is a whisper. My limbs are leaden. The frontal headaches are bad, my right eye twitches all the time and it is hard for me to summon my words. My memory has left the building.

9 May 2008

Some days, it seems like the further you get from your old life, the easier it is to live with this or like this. There is not so much need for explaining or needing others to understand.

10 May 2008

Credence and Wei-Paddy slept late so up and at it very late for us this morning. I didn't mind as the heavens had opened and I lay in bed listening to it. Feeding the animals in the warm soft rain was lovely even though we all got soaked. Now inside, the window is open and the dogs are licking themselves dry. Flora is finally quiet, she stood in the open shed earlier crying and complaining to me about the rain. Then she made the short bolt for the tunnel and now all is well as the three big girls and the hens potter around what has become their summer house. I just heard the soft thud of Mu the cat land on the study floor – now the boys whine at the kitchen door as she stands there hoping for in. Outside the window two perfect snails, antennae up, are making their way over the coal bag's humps and bumps, it must be like a Himalayan expedition to them. Stasia is now down the ladder from the lay spot looking relieved and sounding it. Yesterday I hoped the tiredness would lift enough so I could get over the hills for my organic vegetables. In the end I never got there, after a nap I sat in the rocker trying to think how I could manage until next week with what I have. Yesterday evening I cooked a big shepherd -less pie with lentils and mint pea puree for Mom and Dad who are to come tomorrow. Mu is now in the kitchen. She faces the two dogs easily enough now although it still seems acceptable on all sides to have a fierce chase when she is outside. She just got up on the big old dresser and with her claw removed a dog cookie from the wide mouthed jar. She dropped the first one and Wei got it gleefully, they were like a pair of scam artists.

As I write, some swallows dive splay winged past the window. It is like formation flying, a twittering, aerodynamic display.

17 May 2008

I worked myself into a wired state, way too many visits. It is so easy to lose my inner focus with all this outer focus. This inner journey and trying to live by your ideals is quite a brave and solitary experience. This is possibly why the counselling work with Colum is so valuable as is his gentle validation. As he says there is no validation 'out there', I must constantly give it to myself. That can be a challenge when you are constantly exhausted.

5 June 2008

I couldn't save the tiny field mouse in the end. Mu had him down in my bedroom, she must have brought him in the window. It was like Tom and Jerry, the mouse was up the side of presses under the futon, Mu one side me the other. Then he got into the unmade bed. I had to pull all the clothes off and shake them, Mu got him with her paw, I yelled and got him into a glass with my hand over the top and put him out the window . He ran down the outside wall and down the shore, by the time I got out to him he had drowned. I shook; the poor little thing, such needless suffering.

6 June 2008

Thelma and Louise hen came today. They are in the composter and have their own separate run till they settle in a bit. They are so timid and afraid yet already they make little noises when I talk to them. Wei and Margo, the two gentlest souls on the plot check them out.

8 June 2008

The fox was here again this morning at 5.15. He/she was pacing up and down outside the run scaring the hens. I was feeling very low anyway and it took till about 3pm till I could function with the nausea, so the hens had to stay in to be safe. Every time the dogs barked I thought the fox was back so I dragged myself out and fixed up a safer temporary run for them to pick in. That evening I saw three little deer just standing at the back fence staring at us. They had the sweetest, most innocent faces and I felt they were engaging me as if to say thank you for taking the dead baby deer off the road the other day and burying it.

10 June 2008

When Nan and the goats try and come into the back kitchen Wei Paddy gets upset. He will pretend to bark a half-cross bark and put Flora's head gently in his mouth, that is about as mean as he can get. Even in the rescue place, when I saw him being attacked by stronger dogs he ran over to me with his punctured leg and licked me. When he first came to me, he needed so many treatments and baths and ear washes, and even though he was a nervous wreck, he never gave out. I love that now he is so happy and feels loved and secure and part of something, it is his just reward.

10 July 2008

It is raining outside. I am sitting here in the rocker listening to the birds. The dogs are here with me filthy and dozing. The cat is on the window. I am still in my pyjamas, I have had my porridge but am completely out of it with exhaustion. It is probably payback for trying to read a little the last few days. I was already low with lots of symptoms. I was trying to think back to uncover a pattern to this illness. Was I like this last summer too? I know I had a rough winter. It is all so blurry, I can remember so little in terms of time and details. My mind is all over the place, replaying scenes from the past, worrying about survival, fretting about my losses, confused about this awful illness. Sometimes I do have some insight and I think I am fine and things are as they 'should be' in the spiritual sense. More times I get bashed around in the wake of everyone else's happenings with no direction of my own. Is that because I still measure success in terms of doing, accomplishing, giving, participating, earning? For years I dreamed of 'stepping off the world', of living without commercialism or materialism to any great extent. I dreamed of getting to know my spirit, of being in nature, maybe creating something worthwhile. I often dreamed of living lightly, gently in the presence of animals and of keeping things simple. Mostly I have those things now, granted I am alone and ill and unable. Yet when I can own all of this I am fine. When I am with others who are different from me (and that is pretty much everybody that I know) I begin striving. Striving to be able to do more, provide more – lots of old ego stuff. I become very easily influenced. I visualise myself doing or becoming allsorts again, losing my clarity and becoming very ill again. Is the purpose to learn compassion, especially self compassion? Simone Weil says that compassion directed towards oneself is true humility. Is the purpose to just let go and to have no agenda of my own and to empty myself of self? Should I aspire to shine out joy, love and peace? But to shine it out surely you must first 'be' it, so that others can just witness your life and consider it exemplary or not. Because of how things turned out, I am divorced with no children, I am without paying work, I am ill and because of that illness can rarely leave my property. I am ‘blank’ to everyone else’s ‘full’ canvas.

25 August 2008

I watched Dinah hen today repeatedly seeing off a magpie who kept returning to pinch the hen food. She was so determined, shoulders forward, head down charging intently at the magpie.

20 September 2008

I am sitting here with beetroot stained fingers sipping anti-viral herbs. Last night turned into a very bad night with violent IBS. I ended up on the couch at 3.30 am. However it is a gorgeous morning, blue and sunny though quite cool. The birds are singing away. I have not heard them sing in ages. They too must love this long awaited fine weather. I lay there early this morning staring at my bookshelves and all the inspirational spiritual books that have helped me, and I wondered how come I cannot live more from that place? Instead, I seem to battle through the worlds of form daily, and it really does seem to wear me out.

19 November 2008

As I awake this morning to another day of crushing headaches, racing mind, soreness tiredness etc., and I lament what I am no longer able to do, I just need to think of last night’s incredible starry sky and let go, because none of it really matters. Just let go of all striving and planning, because the universe will remember none of that, I am not sure it even recognises it.

Sitting on the door step
light fading.
Birdsong
deerwhistle
cat companion.
Nothing left for me to achieve
just be part of it all
I am on my way
back now
to Source.

The missing years and a narrative gap (2009-2013).

As previously mentioned, after the difficulties of the divorce I relapsed badly and with the exception of photographs and poems and some notes, I did not keep a journal or much of a record of that ‘missing years’ timeframe. As also mentioned, with a long spanning illness such as ME, time and things can so easily merge into one long blur. However, I have included a further four vignettes and a poem here, which are memories of events which are true to this timeframe and describe both struggle and loss (‘Court’ and ‘Credence’) and the beginning of rethinking or reimagining struggle (‘Equanimity’, ‘Rescued’, ‘Every Day’). My predominant memories of that timeframe are of rescuing the animals and building the little farm, which overtime would become a kind of sanctuary.....for us all.

Court

Over a four year period I was scheduled for court many times. Because my jurisdiction was rural the family law courts sat for two days three times a year maximum. The case lists were huge and even if you were listed you could sit around all day and never be called. Often I found out just before 5pm the previous evening that the ‘other side’ had got an adjournment – another three month wait. Because of the ME in particular, each court visit took days to prepare for and weeks to recover from. My sister always took me and P would often be there as at times were other very supportive friends. I would have all my documents which I had gathered and frequently updated, mostly of my own volition, in a wicker basket which was really heavy. By the end of the four years its handles had completely worn. I wore a long black coat with a silver angel broach and my hair pinned up and always on my wrist either blue or orange prayer beads. At times I of necessity withdrew completely from the group conversation as we waited. I prayed that I would have the strength to just not pass out from weakness and that if I was called to be heard my stressed out brain would not completely turn to fog. For my loyal supporters I always brought a car picnic lunch of egg salad sandwiches and homemade rocky road. All I could ever swallow was the green tea as I tried to smile and hold on to what bit of dignity I could. In my wicker basket was every receipt, statement, letter and piece of history that I thought could help my case. My legal team were often quite dismissive of my ‘over preparedness’. Yet eight or nine appearances later, when my case was finally heard it was every one of those pieces of paper that ultimately kept a roof over my head.

Credence ~ Soulmates

Through all my struggles my older German Shepherd, Credence, never left my side. He was always protective but since I became ill wherever I lay he lay, for hours and hours when necessary. When the sadness overwhelmed me and I'd slide down the wall into the 'sitting cry' (yes it could be a yoga pose) he was there in front of me staring his wordless love. When my second shepherd came to us from dreadful circumstances, skeletal and a nervous wreck, my older dog was tolerant and when he finally realized he was here to stay, began to teach him and essentially raised him into the peaceful loyal creature he has become. When I would come home from the many non-event or adjourned court hearings those dogs were there for me, through every bout of illness they were there. When the symptoms were so bad that all I could do was sit quietly in the rocker, often it was enough of a healing to just watch them. It took almost a year after the divorce settlement to get the house transferred into my sole name. It was mid-winter and there was a terrible snow. The postman struggled to deliver my mail and the paperwork declaring me finally sole owner of the property was the last mail he could deliver to me for weeks. Credence's hips had been deteriorating fast and that same night as he ambled down to my bedroom where he always slept, his back legs went completely and he never stood again. How he looked at me said everything and next morning with the help of wonderful friends and neighbours and 4-wheel drives we got to the vets. My neighbours, both big strong men, carried him to the first jeep, tears running unashamedly down their faces. Another jeep with another neighbour in it awaited us down in the valley. I feigned strength and calmness for Credence. When we finally returned with his body wrapped in his favourite quilt a third neighbour hacked through frozen ground to lay him to rest above my bedroom window. How I wished the ground had not been so cold for him. That night I had to push on my heart with my hand to hold in the pain and just let the overflow come out my eyes. Surely this was the last thing to lose? Through the darkness of that snowy winter night I lay there and through my sobs tried to let him go on his final journey, unable to thank him enough for his unwavering loyalty and real actual love. At 5.30am a ball of yellow light flew in and past my bedroom window. It was over in an instant. I let myself believe it was him on his way. After a couple of weeks of grieving, real physical grieving (where he would not even eat) my younger shepherd Wei-Paddy stepped into the breach and continues to do so today. I thought my 20 year relationship and all that it entailed was the stuff of soulmates, but I wonder if we humans don't over credit ourselves?

Equanimity

It is a while since I tried a top up shop in Hacketstown. There had been snow at the weekend and even though it is now March it is too soon to let the supplies drop down too low. I have been caught like that in the early years. I wasn't really well or steady enough to go but I needed to get it done so I could drop it energetically. When I finally reached the store with my list I tried to cover all bases for another few weeks. When I got to the check out, I noticed the large steel shutters were down on the windows and I was the only shopper in the place. The internet had gone down, and nothing could function. I looked at my full trolley crest fallen. The staff offered to ring me when it was back up, it might only be an hour or two? My face must have said it all, as they said that if I had cash and could choose the important items from my shop, they could check me out using the calculator on a mobile phone. Most things that I had in the trolley were important but I could not overwhelm their kindness so I chose carefully. Ironically, being just used to swiping the items they did not know the prices for anything. I on the other hand knew the price for everything – I have always had to. I was let out a side door. I was just so pleased that I got enough that I wouldn't have to think about it for a while. When I got home I tended the critters and finally got to warm up some soup. The spoon shook on its way from the bowl to my mouth. The last bit of strength left me and I was freezing cold. The overriding feeling was one of delight that I made it all happen.

My delight was short lived as for the first time in all my years here, the toilet backed up when I flushed it. I rang Edgar as my tank is on his land across the little road and he has the digger and tank to empty it. He is busy lambing and calving and he suggested that I find the shore behind the bathroom and 'rod it' through. My septic tank is lost in an overgrown wilderness and will not be easy to find but if I am stuck he will try and get up in a week or so. I dig around outside to see if I can locate the shore. It is hard as a rock, there are years of compacted stone chippings and a layer of plastic to be dug through. It is entirely beyond me. I go over the road to see if I can find the tank. Gloved, I pull at briars and overgrowth for an hour. Nothing is obvious but it could be under a couple of feet of earth by now. I am freezing. I ramble up the road with little hope of finding Harry who I know is at a funeral in the village. Just as I get to his yard I hear his low whistle and the familiar dragging sound of his wellies. I could have cried. I told him my tale of woe – ‘sure I’ll get the pitch fork and come down with you and see what we can do’ he said.

We spend another hour digging for the shore, Harry concentrating on one spot looking for a pipe to follow, me clearing the overgrowth, the chippings and the plastic with my shovel and my hands. I rarely ask God directly for anything ever, but I was just so low and overwhelmed and I knew the trouble, work and worry that lay ahead if this could not be easily found now, so I basically begged.

Nothing.

We went inside to try the flush again. Harry in his socks, plunger-ed down my toilet bowl. It was a vulnerable moment, who knows what might surface? There goes the very last bit of my ego I thought. We flushed, it worked fine

‘She might have cleared now’, Harry said. I could not believe it!

It was 4 pm. Harry still had his foddering to do before he set off for the ten mile trip home to Aughrim. He often gets a lift from his son since he can no longer use his quad bike. Now he will have missed any chance of a lift and even though he often walks it, I insisted on bringing him home, which I did. I didn’t manage a dinner that night, nor did I flush the toilet again until five the following morning. I just needed to sit there with several cups of tea by the range in the belief that everything was okay, even if it really wasn’t. I had managed not to indulge in catastrophic thinking, the true enemy of equanimity .

All the plumbing seemed fine and the next day I saw Edgar on the road and gave him some eggs and said how reluctant I was to have had to bother him during lambing. I manage most things myself. Over the years I have had terrible problems with my water. Years ago my well hit iron and the water turned a milky coffee colour and was unusable. Neighbours would come and try and get it going, I could be without water for weeks. The neighbours who came to help and other lads that they knew who came to help, wouldn’t take any money despite my insistence, so finding ways to thank them was difficult. It was often a prolonged and difficult dynamic as I would have to hover around them outside for hours as they peered down the well, offering tea, running around for things that might help. I would be cold and unwell and unable for their cigarette smoke. None of them could countenance how with each passing hour I was falling deeper and deeper into negative health equity. Even now, though I do have some help to call on, when something like the septic tank goes wrong I have to dig deep not to remind myself not to fall apart. It will all get sorted eventually, I can manage. I do not have to go back physically or emotionally to that very vulnerable place of the past. Equanimity, in Buddhist terms, is the steady conscious realisation of reality's transience. I must constantly remind myself of it.

Like now.

The toilet backed up again. I dig around again outside to see if I could find that manhole with the shore. No joy. I wondered if Finn was up with Harry as he had offered to find it. Such joy to see his truck in the yard up there. He came down a while later with his little nephew, Ben, who is four and had brought his little plastic shovel to help. Finn who is a horse of a man went at the place with a pickaxe and found the shore in minutes. With all my hours of digging I had only been inches away from it. The shore is completely full. I have Greta's chimney rods and we connect them and Finn rods through as far as he can but nothing changes. The sky turns black and hail stones batter us. I have to take Ben inside. He is the gentlest little soul with blue plastic Harry Potter glasses. He is afraid of the dog so I keep them separate. We look out the window at Finn who is pick axing his way to the source of a pipe. Now it is chucking down big wet snow flakes. Finn with long plastic lambing gloves feels down the man hole – small bits of pooh float up. I apologise awkwardly. I try and stay present and out of my head which is busy writing a horror movie.

The snow stops and I bring Ben out. I help Finn although we are running out of options. The wind picks up and it snows again. I put Ben in the woodshed sitting on a box with the door closed, he is still holding his plastic shovel. I tell Finn that there is nothing more he can do now. He says that I may need Arklow Jet to blow through the pipes, which costs about 300 euros. He will come back next weekend and see what he can do. This is Sunday. I give Ben his own box of chocolate biscuits, he is charmed. At the gate I give Finn eggs and 50 euros. He argues, I insist. Out of nowhere the squall ends and the sun comes out. Finn hops the fence onto Edgar's land to 'have a quick shufty to see if I can spot the septic'. I stand in the road with the very dated house plans trying to figure them out, Ben holds my hand. I am frozen to the bone, it is 2.30, Finn came down at noon. As if sent by the Gods, Edgar drives up in the jeep to check the sheep. He hops the fence but there is no evidence of the tank. It is agreed that he will come in a few days, as soon as he can get a break in between lambing, and dig to find and empty the septic tank. Two trucks and two and a half men drive away.

I come inside to the heat just in time, everything goes a bit numb and I feel faint. The wind and the snow are back. The donkey's door blew over just before Finn came and they got spooked and wouldn't go back in so I had to close them out of it. I go back up with their feed and close them in, it is hard now to stand up in the wind. In the kitchen my laptop and journals sit untouched. I had set aside yesterday and today to type. All I can manage is to light the woodstove, close all the critters in early as it is still snowing and roast a few potatoes to go with some freezer food. Sitting by the stove with a plate of food and the dogs stretched around me I contemplated the nature of so-called progress. I couldn't shop a few days ago because the store's internet was down. When indoor plumbing goes wrong it goes horribly wrong. When the power goes we can do nothing. It makes me reconsider the virtues of a candle and a chamber pot. What stressors accompany progress? How free has it really made us? I am more self reliant than the average woman but I am severely compromised, more so by poor health than by poor means, and therefore limited in my independence. If I cannot find an easier solution to living simply and lightly, then I may just have to learn how to care less and let go more. Something along the lines of a metaphysical chamber pot perhaps?

All these years of illness have rubbed a lot of the shine off my exterior. Yet every struggle has led to learning, and some way of coping and the constant lesson that one almost always survives. Not a lot really matters. The initial 'heart sink' response to a mini crisis still needs work but that is often contingent on how low my health baseline is at the time. Unfortunately for the last five years or so it has been a pretty low place to start coping from energetically. The Buddhist equanimity message of not being bounced around by your thoughts has taught me a lot. Before the toilet blocked I was 'fine', after it blocked I was 'not fine'. When I thought the problem was fixed I was 'fine', when it wasn't actually fixed I was 'not fine'. Equanimity teaches us to be 'fine' either way and this is my constant learning. It seems I get plenty of occasions to practice!

A shower squalls up as I write this and I stand up to let the dogs in. I see the donkeys quietly move towards a fence for shelter. They turn their arses to the rain, put their ears back, lower their eyes and let it pass. Now that is equanimity.

It would be another two weeks before the septic tank was fixed. The job as it turned out was always going to be way beyond the kindness or abilities of Finn and his shovel and rods.

The septic tank proved to be illusive. Edgar with his JCB digger dug trenches about four feet deep across from my house on his land. He eventually found a pipe but it just lead into a percolation area. He phoned the original builder who he knew and he said that it was on my land. Egdar had to get back to his farm as twin lambs were coming two heads together according to his wife and it would be another several days before he could get back. I would have to manage with a bucket for the loo and a basin for a wash for another while. In preparation for Edgar's return I had to take down fencing so the digger and tank could fit on my land.

When eventually Edgar did return with the digger it seemed to swallow up what was very wet land. Without putting the pods down underneath it, the digger would have sank. We located the tank fairly easily, as we could follow the line of the percolation pipe from across the road. It was a huge old fashioned tank with a four foot wide cement lid that had to be lifted by chains by the digger. The tank was full. Edgar had to leave with the digger to exchange it for the slurry tank, the place got cut up even more. I closed in all the animals including the cats as the open tank was toxic and dangerous. When the slurry tank returned, the suction pipe would not reach the septic. Another neighbour had a longer one and Edgar had to go out again with the tank and go get it and fit it. Finally, the tank was being emptied, however the full shore still would not go down. It was way beyond Edgar's ability with the slurry tank but we devised a method to suction out the pipes which required me to get a ladder and climb down into the tank, put a device under the pipe and hold it while Edgar ran the tank and blew through the pipes. I held on to the ladder, held on to the device, put up my hood and turned my face away as sewage spewed out of the pipe and into the tank. The shore went down. The lid went back on. Sorted.

Edgar finally agreed to let me pay him as that was way over and above our usual neighbourly barter. I had made him two apple tarts which are his favourite. When he finally manoeuvred his way off my swampy land there was a wall of muck up against the hen run which jammed it shut and all the heavy three feet paving slabs I had made a path around the land with, were either up on their sides or broken in half. I could not let it overwhelm me. Edgar had done his very best for me. That evening I had a small bath, flushed the loo and felt the beginnings of the shakes, but mostly I felt relief and gratitude.

It was short lived. The next morning the shore was full again. That was when my equanimity packed its bag and fled. It was St Patrick’s Day. I walked up the road to ask Dan, Harry’s other son who is a builder who I should call or what I should do next. His little kids had their green hats on and their faces painted and were heading off to the local parade. He said he would drop down the next day to have a look. As I walked home, I felt old and alone.

When Dan did come down, he brought long turbo type rods and the shore cleared. As we ran water through it, it started to fill slowly again. He said he would get back when he could and would bring help as he thought it could be a collapsed pipe. When he did return several days later with another guy, they dug out the pipe at the septic and could see that it had caved in. Edgar came up yet again with the digger and pulled out the offending pipe. It was dented in the middle from years of weight and work. The three lads worked away as if it was nothing to them. They would regularly throw kind supportive remarks my way, ‘that’s her now Orlagh, (everything is female in the country here) she’ll give you no more trouble now, that’s the end of it’. I was so grateful and all attempts at payment were refused, point blank. I will find another way to thank them that will probably include apple tarts.

The land remains churned up but dries a little every day. It should bother me more than it does. Somehow it doesn’t seem that important when full sewage service is restored. After they all left and darkness was falling, I thought I saw a small shape at the gate with a suitcase.

Ah, it is my equanimity returned home.

Rescued

New animals have come over the last several years, mostly rescued, but who is rescuing who? Little Gracie, a long haired collie-cross, was dumped in a forest at nine weeks old, weighing just four pounds. Now she is happy, healthy and looks like a dog from a Disney movie. Zebulon, a

German shepherd pup, was the only surviving pup in a litter that came unexpectedly during last winter's fierce snow. A dream was fulfilled when two donkeys, a mother, who would have been bred year-in and year-out, came to me last Halloween with her three week old son. I called them Ike and Corabeth as a nod to *The Waltons.* You could say that they are rescued, but that suggests that I rescued them while really we rescued each other. Besides a non-bullying policy here, it is a rule-less environment, mostly non-hierarchical and peaceful. My dogs, though loving and gentle, would defend and at night they become my ears. When like me, you have no particular partner, no child or career, it is wonderful to have such a purpose and a cause that is valid and worthwhile. A dear friend calls it my ' little ministry in the mountains'. I believe very few spiritual teachers compare with the gentle teaching of animals. They have an amazing ability to forgive, to live in the present, to give love and to be ecstatic with joy and to trust despite the hardship they have previously known. They are truly content with little.

Every Day

This is not a story of suffering or transcendence.
Every day is quite an effort.
There is certain lack of ability
uncertain pain
and a variety of symptoms.
That is all there is to be said about that.

There are billions of sentient beings
way worse off than me.
Yes my life that I had painstakingly created
crashed and overtime burned
but I unlike many of the other billions
had options.

It is not for everybody to see life as a gift.
For many understandably
that is an impossibility.
Mostly I can
and it is from this place that I choose to live.

No? Not Buying it?

Not hearing the trumpets
or seeing flashing lights?
That is because there are none.

Every day is quite an effort
There is certain lack of ability
uncertain pain
and a variety of symptoms.
This is not a story of suffering or transcendence.
Mostly now
I just don’t
‘mind’.

CHAPTER 5

‘SURRENDER’

5 May 2014

Sentences, glimpses come into my head on a daily basis, hourly sometimes, and I think they are locked into memory but they are not. They could even be gone without a trace. It is no small thing that recently, very recently I have come to love the pace of my life, or should that just read as ‘life’? The warm long lit days help of course, no need for a fire or foddering animals. The donkeys are out to graze, Ike sometimes tearing around the meadow with his tiny short gallop of joy. The four new hens are with me a full week and are no trouble at all. In fact they are quite devoted, coming to the sound of my voice which they already know means food. Junebug made herself a tiny nest in the goat house and laid her first egg, so small it falls through the egg stand. I brought my young shepherd Zeb to the lower trail with the bog holes for swimming. One side of the trail is alive with bright yellow, coconut gorse – easily one of my favourite things about being in the world. He is fairly responsive to commands now and if he does attempt a solo mission he re-tracks quickly to my referee’s whistle and a food reward. That whistle has become a godsend as my voice has become so weak I could never be heard. I write this in my polytunnel and it is New Mexican in its heat. The lower quarter nearest the door is fenced off and that is where my big chair is and where the hens doze or make dust hollows for baths. Every now and then a spray of bath dirt lands on the page. The cat barely stirs. On the way back to the car from the trail I already felt the costs to my legs of the walk. Tonight if I were to press even lightly on them the pain would nauseate me. Silence again, the ride on mower though more than a mile away as the crow flies is finally switched off. Peace. I am mostly just used to the odd cry of a displaced lamb and its mother’s bellowed response. Now, too, the chatter of swallows. They have returned to the donkey house and have revamped their nest with muck and moss. Growing up we had a holy water font shaped just like it at the hall door and self blessing before any departure was mandatory

12-20 June 2014

Nan my ewe has her head down and her lungs are heaving. My good neighbour Harry came to look and said ‘pneumonia, you need Baetrol from the vets’. A trip to Baltinglass! I’m already so tired and sore and was only there yesterday but I flew in for it anyway and gave her her first shot subcutaneously. I blocked her in with pallets and feed and water buckets. She was a bit better next morning, but weak so I kept her in. The goats would not leave ‘Montana’ (their paddock) without her and cried outside her door when I was giving her a second shot. At 7pm Finn arrived down with the tractor and very rickety trailer (you could see the road through it traveling). I barely fitted in beside her she is so enormous with that fleece. As always, even turned half upside down for shearing, Nan kept looking for me. I chatted away to reassure her. Harry, as always says, ‘Jesus Christ Orlagh, you’ll have to ease back on the goodies, she’s three times the size she should be!’ I reply ‘I know Harry – but if I don’t give her a gingernut cookie at night she’ll put my back door in!’As I rode home in the trailer with a shorn and subdued Nan, nobody saw me dot lavender oil on the tiny nicks on her skin.

25-30 June 2014

Holly, Sarah and Rose were all here to visit within only days of each other. Holly was here first for breakfast, I made scrambled eggs and blueberry pancakes, date bread and chocolate beetroot cake. As always she is so inspiring and encouraging about the ‘work’. I sent lemon, blueberry cake home with her. It was a lovely visit with Sarah. It was sunny and we had a small walk over with the donkeys – I didn’t find it hard at the time, but afterwards, as with all three visits I had terrible paybacks. I had made hummus and spelt bread, and we had purple potatoes and salad from the tunnel for dinner, with chick pea and bean cakes, plus chocolate beetroot cake for dessert. I sent a homemade bread and lemon pound cake, eggs and salad plants home with Sarah, who really appreciates my cooking. Rose had a lovely well deserved break here. She came laden with tofu and little gifts from her holiday in Portugal (a gorgeous little Buddhist tapestry). It was the hottest day of the year yet, I couldn’t stand to be outside much. Rose loved her dinner of caramelized red onion and gruyere quiche with all the bits from the tunnel. She always cooks for everyone else. She had her wine and was chatting away. She insisted (I never would have even thought I needed one) that we take a break from talking. She went into the sitting room and was mortified that she fell asleep on my couch. I rested in the rocking chair with the dogs but then beep beep!!...Rhea was at the gate with a bag of her home grown broccoli. She didn’t come in thankfully. The evening Rose left I got three huge blood blisters on the roof of my mouth and the next day terrible IBS which lasted for a couple of days. I couldn’t function and everything went through me. My legs wouldn’t move till evening I was so low and drained. I knew I had pushed it, mostly to try to see a few special people, as the list was building and building and that is so draining for me as I never know how I am going to manage it all? In a few days my beloved godmother who I hadn’t seen in seven or eight years was going to be passing through a nearby town. My parents would be with her and it would be a rare chance to see her. I was so flared up I was incapable of making the decision to go or not, that happens me all the time. I was in no doubt that I didn’t feel well enough to go, but I felt I should go. When would I get the chance again? So I strategized for a few days, baked the evening before, pulled vegetables from the tunnel and made a gift basket and cleaned myself up a bit. I got parking outside the venue and stood for 20 minutes trying to hold a parking spot for them, I was out of my body altogether, weak and shaking and I nearly caused two accidents. The meeting was special, I laughed and joked and acted like it was all no problem. That night was raining and I was so wrecked, I could hardly walk or eat. I had to spend most of the next two days in bed. None of this is unusual, what hit me most was how worried I was about my parents and aunt who were in their eighties and the toll the travel and the outing might take on them. Later that same night my mother went out to bridge and to meet a friend the next morning. My dad went to his club to work out the next morning. They would never know the toll it took on me as I never would tell them. Another reminder of how ME is like nothing else, and you go it completely alone often making one bad decision after another for all the right reasons, especially if you live alone and there is no one there to protect you from yourself.

25 July 2014

The weather lately has been really hot and dry. My greatest concern is the donkeys, their little stream is dry, it is caked mud like a dessert. Several times and in several different ways I have lugged/driven/carried five litre cans of water (up to 18 in instalments) in order to fill the half blue barrel which the seven bullocks also in the field, are drinking dry. I have to wait till the bullocks are not around and fill small metal buckets in front of the donkeys and watch them drink it down in one long draft. Today Harry helped me (nothing like a bit of gentle help) to move the barrel to another gate and I led the donkeys up to show them.

Larry brought the delivery of logs today and I thought as I threw them into the shed in 27 degree weather, who else is preparing for winter? Who else needs to so early? Larry tried my elderberry syrup and popped some baby carrots from the tunnel into his mouth, after giving them a quick splash under the outside tap. He is going to bring me topsoil but will only barter for tomatoes not money. The book Holly and I co-wrote a chapter in arrived by courier – it is interesting to flick through it and feel pride however fleeting. Between my inflamed/ locked jaw (no more long phone chats) and lightning recently blowing up the TV satellite box, I think the universe might be saying ‘do another bit of work’.

8 August 2014

The rain today is very peaceful – everything is bursting with green-ness and seems very relaxed. I am pleased with my idea to fence in a patch of garden to contain the goats, sheep and chickens more. It’ll save a lot of cleaning up and supervision and maybe give me a little more time to focus on other things. I have bought all the posts and wire and Finn has agreed to do it along with seriously cutting back old trees before the Fall. I have put some money by to pay him. I am winding things down in the polytunnel. A large crop of tomatoes is just coming plus some baby salad leaves but the onions and potatoes are up and saved. The herbs are potted and besides chillies and peppers there isn’t much else left. A load of topsoil and manure will make a big difference to it for next year and I’ll keep the hens out. I have a shed full of logs and one full of turf and a stack of coal nuggets all collected and stored in dribs and drabs all summer. It is the best way for me to work both energetically and financially. Yesterday and last night I wasn’t well at all, so leaden and sore and drained, all food going right through me. Even today I am slow and sore and tired. Mind you, I did have a lovely rest outside in between the clouds.

29 August 2014

It has been a few weeks since I have written. Last week Finn did the fencing and clearing over two days. He is thirty two now, he was nine when I first came here. Each day for the last couple of weeks or so I set myself a target of picking one pound of blackberries (for the freezer till I'm ready to make jelly) every dry day. I mostly pick in the donkeys' field with the dogs with me and Ike and Corabeth following behind, mooching for blackberries, one for the bucket, one for each of their mouths!

I try and fill two bags of well rotten manure anytime I can so I can drag it down to the tunnel later. Six big aubergines have grown in the tunnel this year, each one needs the support of an old vegetable net. Seven mangos are ripening on the kitchen window ledge, they will go in with the blackberries to make jelly. Lots done, I know about it every evening.

10 October 2014

Yesterday was a beautiful blue cool Autumn morning. I was doing my usual chores outside when I spotted a flying ant struggling in a water bucket that I was just about to empty into the hot ashes bucket to cool it. I thought how unfortunate that creature could have been, how much extra suffering it could have endured it I hadn't 'noticed' it. I thought of my head filled with its agenda and the 'ten thousand things', and how none of them were as important as the well-being of that little ant.

Trip to the rain barrel.
A small black beetle
is clinging to a thin blade
of grass.
How long were you there?
Did you hope that I would come?
Or were you just there
clinging to a thin blade of grass
when I thought
I had rescued you?

12 November 2014

The weather has really turned, it is so wet the place has gone really soft and muddy. Darkness falls so fast and so early now. I am ready for bed by 9pm (old 10pm). All the winter aches and pains are back unbidden. A new dimension is the walks with the three dogs, having Wei, Peggy and Gracie up the forestry trails, it is lovely to be in the woods again. I take Zeb separately a lot of the time, plus he minds the place which is his thing. Before ME I walked or ran those trails most days, now getting up there is a rare event. The dogs have a blast and are no trouble. The flow of the day here is lovely. It seems to entail lots of getting wet and mucky as I muck out animal houses and empty fires, feed and fodder stock, the dogs always at my heels. But I enjoy it and find it very satisfying. I have plotted, planned and scrimped and managed to get all the necessary repairs and projects done and the supplies in. It all worked out well and is timely as it is getting very difficult to do anything over the basics at all now. Road trips and towns and visits are almost impossible now between soreness and tiredness and brain fog. It is almost unsafe now to drive much further than the nearest store in Hacketstown which is itself a ten mile round trip. Still the gratitude pervades all. Things are fundamentally good for me. I am happy the animals are well as are my family (I probably should have put them in the other order) and I can manage well with my limited resources. I am always reviewing and revising and simplifying of necessity, and it does make things easier. I have withdrawn even more from even trying to be able to do much for anyone. I try to manage a little for everyone through the year (birthdays etc) but this year I will not succumb (as I have in the past) to the madness of trying to do something for everyone at the same time, Christmas, when I find myself moving humble little gifts around like chess pieces. That new resolution is making this winter's physical downturn a lot easier to deal with.

2 December 2014

It is an amazing blue, cold day. It takes a couple of hours now to do the litany of morning chores, especially if it is raining as it makes sense to only get wet once, put all your gear in front of the stove or straight into the washing machine if I'm truly soaked. Before I light the range I decide to take the dogs for a run up the trail. Wei Paddy was charging about like a two year old though he is eleven and a long way off from a few months ago when I nearly lost him to liver disease. He is on food now that is 70 euros a bag! Later as I sit writing this at the front of my house, fully togged out in hats and coats, Gracie's head is on my knee, 'her deepest place' as Kerry Hardie writes. Little Peggy is inside my jacket. My hands are frozen but the wild birds are flitting about the trees and then hens are huddled like gossips. Zeb is up with the donkeys, him and Ike are like two dudes. Flora, my high maintenance goat, who whined a lot at the cold fog of the last couple of days, is finally content with the sun on her face and the hay feeder for a back rest. The cold has penetrated all my layers and boots and will rise me now for more waiting chores.

22 January 2015

The mountains are covered in snow. The ground is frozen solid as are the water buckets. Yet the sun is out and at 1pm. I am sitting in the now torn tunnel, fully togged out writing this. It is a while since I have written. I lost half the plastic in the tunnel to a bad storm several nights ago. I was out with the flashlight, fighting the wind so the dogs could have their last pee before bed, when I noticed a huge rip in the roof of the tunnel and the plastic blowing furiously. So at 10pm and with only a flashlight I had to drag the twenty or so bales that were now exposed to the pelting sleet, down the tunnel to where there still was shelter. Peggy thought it was hilarious, jumping from bale to bale. By 11pm I had pinned up a tarp as best I could and spent the rest of the night awake, plotting and planning how I could save my hay and move it to dry storage. Between 8am and 2pm the next day I barrowed each individual bale to any space I could find, goat house, sheds, pump house etc and I left the damp ones wrapped in the tarp in the dry end of the tunnel. I was so drained to begin with and annoyed, but as I saw that between me and the barrow I could actually manage it all myself, I just got into the zone and made it happen, grateful that I wouldn’t lose my winter feed. The dogs thought it was all great fun but were wary of my bad humour, but luckily I became aware of it myself and became more upbeat as they ran happily beside the barrow. By 2pm just before the next band of sleet hit, the hay was saved and stored and the flapping plastic weighted down. As often is the case I have no idea how I actually persevered to get that done. Of course as I write this I can account for the payback, but the great thing was my back held up. Beside me here is little hen Madge, all puffed up and heaving and alone here in my little ‘hen hospice’. I have been carrying her back and forth at night so she can sleep with her sisters – Junebug, her pal has been minding her. Even this morning Junebug stayed in the doorway of the hen house, turning back towards her until I tended to Madge. I am giving Madge sips by tiny syringe of electrolyte fluids left over from Wei’s last illness. I have had real hassle with the deer lampers again this winter, but finally the police are more on board and they have encouraged me not to challenge them anymore (I had been flashing them back with my torch and shouting at them to quit). It is a relief to opt out of that a bit

2 February 2015

Clouds race across
a blue sky.
A bird swoops by.
Seedlings stretch towards
the sun.
A dog kicks in his sleep
I just sit and watch.

I feel so vague today that I could not figure out the boot jack, which foot to lift which to keep on the ground! As I collected the eggs later today I leaned over the hay bales and the warm smell was lovely, somewhere in between talc and tobacco.

15 April 2015

I made it down the gorse trail for a short walk today with Zeb. It is my first time out in a while. I am just coming out of a few very bad days of flare up. I got drained last week, then a ton of the usual symptoms hit, IBS, migraines, no sleep, no appetite, lead limbed, back on the couch for hours at a time waiting for a bit of strength. The only creative ability I have these days is to write from where I am. Anne Tyler says that how she lives is where she writes from. I think of John Mc Gahern pottering about on his farm, always thinking. He only wrote a few sentences a day. His favourite days were the days when nothing much happens. I share his sentiments.

9 June 2015

I have not written for several weeks as the migraines came with a vengeance, I got new medicine from the doctor but it was really powerful stuff and you had to take it at the first hint of a migraine and it had loads of risks. I just reverted to my safe old mild stuff that helps with the nausea too. It all wipes me out so it is swings and roundabouts. I am already getting lettuce and rocket from the tunnel! Finn fenced in ‘Montana’ (the goat paddock) where it fronts the road with old pallets last week. I stained them dark and they give me much longed for extra privacy. All the hill walkers could see in to my plot before, and I was weary from all the small chat and waving. I vaccinated three dogs today and did the goats’ feet. As I write this, there is more pecking at my wellies by Patsy and Annie hen. They do it whether the boots are on me or at the back step – I think they might think the oats comes out of them? Rose gave me her old iphone, I have resisted all that screen stuff for so long as it kills my head and drains me but it is working out great if I don’t use it to much. My introduction to Google! The donkeys are very happy over in the field. I can’t get to them so easily or bring the dogs over as there are a few cows with calves over there and they charged me the other day, I fell, but they were after the dog in order to protect their young. Little hen Pearl died, she only lingered a short time and is buried with the rest in ‘henven’. The new girls, who have been sleeping in the old compost maker have mastered the art (I showed them several times) of going up the plank into the hen house at dark. It is still a race between me and the magpies for the eggs, some years they are really pushy. The weather has been very mixed but parts of most days are pleasant enough to potter about in shorts or dungarees, often till after 9pm. All the beasts love it, and for miles around you see them laying down, chewing. It really is so much easier for them than winter, but they probably don’t over-think it like us. Across from me now Edgar is baling his first cut of silage. All day yesterday it lay in heaped trails drying, like hair waiting to be braided. Greta was down for the weekend in her holiday cottage, she was looking for a home for her old wooden shepherd’s chair. I happily took it to put beside the woodstove, it looks like a little church pew.

17 July 2015

I have so gotten into the way of living this life that I sometimes don’t see it anymore, the magic of it, the dream come true. The many tiny moments of beauty to be found in each day. And what of the human tendency to strive for something over years and then not really notice it when you get it? In truth, I notice more than I don’t notice, and sometimes I cannot actually believe my dream, a small enough one, actually came true. I love being over with the donkeys by myself for a few minutes and looking over at my little homestead. I get a rare ‘glimpse’ at my life and my heart is filled with gratitude. Even though I have not had much of a break physically, I am constantly aware of all the advantages of the summer season. The produce this year is great. The green shading brassica tunnel that I sat outside for two days stitching together like a fisher woman, has worked out great for the broccoli and rainbow chard which are amazing. The polytunnel has produced lots of yellow zucchini and the deepest purple beets. A couple of days ago I harvested the little calendula patch and last night in the full moon light, I distilled the oil from them for my skin. I am over run with nettles all round the plot, in Montana they are up to my neck. I looked up how I might remove them organically but it involves digging up the roots – never going to happen!

7 August 2015

I am sitting outside in sweatshirt and pants. The sun is hazy and the wind is trying to be summery for August but it is more like early Fall. The polytunnel flaps a little too much under its pressure. Nan the sheep is propped against the nearby wheelbarrow chewing. The goat girls hog the warm walls of the front of the house. Gracie is stretched with full view of the road. Peggy watches her beloved hens who are preening under my bed sheets drying over the fence. Across the fields Edward's windmill is fairly flying it. I am re-reading Richard Rohr's *The Naked Now*. 'Prayer happened and I was there' (p.102). It seems and feels to me like these moments I find myself in are prayers – I have always sensed that prayer is resonance. He suggests that non dualistic or non-polarity thinking (as opposed to dualistic thinking where something is either good or bad, right or wrong etc) is actually contemplative seeing. The two main paths of transformation are love and suffering, they break down our ego defenses, crush our dual thinking and open us up to mystery. They are the primary spiritual teachers, opening up the mind space and the heart space. When you are inside of great love and great suffering you have a stronger possibility of surrendering your ego control, you are being led. Great suffering brings loss of control (one of the reasons we struggle so much), things happen against your will, you learn to give up your defended state. Suffering can make you better and close you down or it can soften you and make you compassionate, it takes you to the edge of your inner resolves where you have nothing left to lose.

6 October 2015

I saw Cara for a lovely catch up visit in the farm shop yesterday. I was low before I went and as soon as I got home I turned to cement and I am not much different this morning. Today is my 13th anniversary of ME. It dictates everything so I cannot ignore is as much as I might try. I live alongside it. There may be some fundamental change I'm missing that it requires. Less doing of the wrong kind? My little life struggles (little compared to billions who are starving or tortured) confuse me. When I try not to acknowledge them and 'plough on' I get sick, so I have to self obsess a little to stay well and on some sort of even keel. Going out gets overwhelmingly difficult in these coming months, what with my own viral flare ups and the risk of picking up other viruses. I'm trying to have it so that I can stay very local for my supplies and I will have to say no to visits.

14 November 2015

Days and days of terrible wind and rain requires constant farming to keep everyone dry, but thankfully all is well. I am predictably tired and sore, but one day is really bad and then the next I can manage. I made it to Baltinglass yesterday for the organic hen food and a few final winter supplies. Last night turned out to be a dreadful night for Paris with a terrorist attack, lives ended so terribly.

I had made beetroot chutney to use up a glut, it is shining jewel like out of its jars on the dresser. Holly called as I was finishing farming, she reminded me of my commitment to write the 'work'. I was waxing lyrical on the notion of Mary Oliver's 'thousand days', and the Buddhist notion of the 'ten thousand things'. Holly reminded me to do ten minutes! Tiny, purple faced violas that I had grown then dried, sit in the window grinning. The wind has been so strong the last few days, my chest and breathing are weak by evening and my legs have turned to lead. I am so glad I dragged those slabs up to the donkeys when I could, it gives them a dry place to stand. Mu the puss keeps coming and scratching at the kitchen door as I write, she wants me to come and sit with her on the couch. She has given up her summer 'glamping' in the tunnel in favour of sleeping on my bed with Peggy. When all the animals are closed in I had to sit and finish this outside. It is almost darkness, except for the reds and oranges and yellows of the skyline to the west. That beauty, in combination with the quiet and the dogs beside me is my idea of sacred, of knowing for that moment that you are *here.* I recognize, and am grateful that this is my reality now - not being a victim in a terrorist attack in Paris, or not being buried under a mudslide on a jade mine like in Burma today, where the poorest scratch out an existence.

16 December 2015

It is usually pointless but I made an appointment with the GP. My symptoms are bad enough to go but mostly I have to put myself in the frame with the new practice since my GP of many years retired. My mouth (top right) has been really sore, it is hard to eat or drink with the blisters. I just checked it out with the flashlight and it looks nasty. I have a lot of bone tenderness especially in my face and head and I cannot put my elbows down on anything, fibromyalgia time again. My breathing is shallow and my glands are untouchable under my armpits. Also, I had a bad episode of inflammatory bowel, with lingering abdominal tenderness that lasted for several days. I have not been to the shops in ten days. When I am tired and virus-ey it is too easy to be cross with the dogs, especially at Gracie's high pitched, relentless barking at a distant deer. Thankfully, I have learned to be aware of it, it certainly is not their fault.

18 December 2015

The new doctor's office is the brightest place I have ever been in. White paint, bright lights, blaring radio. The chairs just keep filling up, the time says I should be next, I have the second appointment but it is almost ten and I didn't even have breakfast to be here for ten past nine. All around me people are coughing and sniffling, what is this going to do to me? I use the medicated handwash again. It is a bigger shock to the system then I had anticipated. The sensory overload is all the worse because I am so physically low at the moment. When I hear of people being 'housebound' with ME, I think, I am 'property bound'. If I didn't have the little home farm that I can manage on my own terms and just had the house, then ME would limit me to being housebound. The new GP was kind. I had asked for a woman this time. She was only 30, the same age as my niece and had one thin line of silver braces on her teeth. She had a beautiful large square diamond engagement ring and gave me a two-finger handshake when I extended my hand in greeting. She asked me a few leading questions. All the preparations to get there, the waiting, the sensory assaults, and now her heavy perfume and the plug in air freshener (when it puffed out fragrance I leap with the fright) meant I could not remember dates or symptoms and I had to apologize as I put my dark glasses on as my eyes began to twitch with a waiting migraine. She was very understanding and said ‘so you have been through a lot then?’ I said I had but I couldn’t talk about it right now for fear of crying. Next question was, did I live alone? I said that my marriage did not survive the illness. She said that that happens a lot with this sort of illness. She checked my mouth (which by now is way better) and gave a sharp intake of breath. Then she identified my painful lymph glands. Then funnily enough as no phones had rung, excused herself saying the other GP needed her for a minute. Did she need to run me by another doctor? When she returned I said it was difficult to explain everything especially when for so long you were not always believed. She said she had a friend with ME who found going through dental school very difficult. She asked me if I was working. These kinds of questions are so surreal to me. I answered that I had just begun reading again two years ago and I am lucky to make it in to town here once a week for groceries. I said I have learned to manage things well but I wanted to make myself known to them as my new GP service and just needed to know that medically somebody had my back. I continued emphatically that I was not depressed and did not tolerate medication well. I left realizing that I had forgotten to mention most of my symptoms and was just so relieved that she had a friend with ME and that I hadn’t broken down completely in front of her from the physical toll of it all. As I was leaving she gave me a full warm handshake and a knowing look. Imagine, that for me would be considered a fairly successful GP visit and still, I leave with all the symptoms I went in with largely un-discussed and certainly un-helped. I had to be mindful of that sadness and vulnerability for the rest of that day. It was hard to regain my peace. I did not cook dinner. I went to that place of ‘hovering over’ my life for a while. A lovely, timely care package from Cara arrived in the post. She had made a contribution on my behalf to the donkey sanctuary. I started to recognize myself again.

29 December 2015

The cosy red chair I was undecided about taking from my neighbour has been moved about the kitchen, it is mostly for the dogs and they love it. I put my rocker between it and the range and now my place is starting to look like a little old lady's house. But they have always been the places that resonate with me the most. Molly, up the road would always sit by the range. She would lean her house coated arm on the warm edge of the Rayburn, kettle steaming, the enormous Bizzie Lizzie in the deep window, the coloured vinyl table cloth that was always getting the swift wipe of a J cloth. Maggie's kitchen was the same, couches and chairs beside the range in a tiny square kitchen, two cupboards over and under the sink that held everything. No granite worktops or spot lighting or islands but both were places you felt the better for being in. It is exactly a year since with Holly's encouragement and belief, I opened up to the reality of some kind of 'work'. She never gives up on me and always tries to understand, when it must be very hard to understand, as I don't often fully understand myself. Still, if it was not for her I would not have written anything down and everything would just be a blur now. As this year ends, the 'work' has turned into and dear and silent companion.

13 January 2016

I realise I have not written in weeks. I think it must be storm exhaustion, we have had six storms in six weeks. I struggled with spot flooding around the animal's houses, particularly in the donkey house due to the poor standard of the door. I made it to Baltinglass on January 6th for some health store provisions, and Peggy got a much needed half trim from the groomers. It was only when I went to walk along the main street, I realised how weak and sore I was. I have been slugging through muck and afraid of slipping for weeks, it was strange to walk normally again. Sometimes when I am in a flare up and venture out in the car I panic that there is something wrong with the power in the engine until I realize that although my leg is pressing on the accelerator there is no power in my leg!

I chanced the dentist in the town on the 8th, it was a Friday so you don't need an appointment. I thought I needed an x-ray as I was losing the fight with nerve pain in my top right tooth and it was setting off my already sore jaw. I ended up getting a lot of work done on the bottom right and the top right. I had to get injections which locked my unhinged jaw and scared both me and the dentist. He said he had never seen anything like it and didn't know how I managed. I was just so glad to have got it done on the day, holding up my strength in anticipation of an appointment like that is draining. There was considerable payback and even now it is tender and puffy. I was lucky my medical card covered it, so some pain spared! I met Mom and Dad in Aughrim for breakfast yesterday. I had not seen them over Christmas. They are in fantastic form. I was not well enough to wash my hair etc but they were just glad of a visit. I managed to bring some veggie dishes I had in the freezer that I thought they might enjoy and some eggs and a soda bread I had made Dad. I had to be humble enough to admit that that was the best I could do, even though they deserved so much more. They both enjoyed a full Irish breakfast and the chat was lovely even though I was pushing through fog. Dad leaned across the table with 200 euros and said I had to accept it, that if he was a younger man he would be down doing things around the place for me. My vulnerability got the better of me and I wobbled. I said I wished I was not *that* daughter, the poor one and wished things were the other way around. Dad's eyes filled up and he said I was not that daughter and that I would do more with 'that few bob' than anyone else. Today is a blue morning but there is an icy frost on the ground. I am completely drained but managing the basics. It is very cold so the range is on from early. Dad and Mom are still on my mind since our visit. I get so used to so little contact or maybe I forget what it is to be around such human love? My love for them almost hurts my heart. My prayer at night is always a thank you, the only thing I ever actually ask for is that they will never have to suffer or be afraid.

10 February 2016

I am about to meet Rose in Aughrim. Cara just sent a text to see if I could meet later or tomorrow morning? I have not seen either of them in ages. My hands shake, my head races. Should I? Could I? That ME indecision, the Catch 22 between wanting to and not really being able to.

24 February 2016

I did push to see both Rose and Cara. Right afterwards I came down with a terrible flu which I am slowly starting to recover from. It was the worst one in many years, the nausea made it difficult to eat or drink. My chest got infected and I was so weak that for several days I dreaded the little hill up to feed the donkeys. Last week, for the first time in the 13 years of ME, I asked for help with shopping. Rose brought down my supplies and had a breakfast visit. It has taken discipline to try to cook and eat (I still feel like neither) but I am getting there slowly. There is only me to do it and no other way back to better health. For several days I really wondered how I would manage much longer, but then gratefully, things started to improve. I had a truly rotten gunk filled chest and if it was not for the old Chinese herbal antibiotics that Helen had sent me from the States, I would have been in trouble. Antibiotics would have been a crap shoot and then the recovery from them… Yesterday was my beloved shepherd Wei Paddy's first anniversary of his passing. A year since he was euthanized, his head in my lap by the lit stove. I miss him still. It snowed all day but did not stick. Today however the mountains are white with snow, and it is a calm sunny cold day. I sit all bundled up outside to write this before 4pm. The donkeys are outside picking, the hens are lying down, birds sing. Although it is to be -2 degrees again tonight this is a welcome respite. The place is still a mucky mess but Spring cannot be too far off. The sun is turning white and the temperature is dropping now. It was so lovely to sit here with the dogs and write this to birdsong and bamboo chimes. There have been nine wind or rain storms since November. A lot of this winter was spent 'coping and hoping' everything would stay intact. I have lots to be grateful for even if it totally required keeping my head down and just getting through. A day like today reminds me of the other side of why and how I live here. It is the special side of things and it fills me right back up. More than any medicine or tonic or super food, this fills my spirit and reignites my optimism. Nan stands right beside me as I write, delighted with a scratch on her head.

6 March 2016

Elijah Jack, 'Ely' came a couple of days ago. Abe, the neighbour I got him from, popped him over the gate on a snowy day. A three month old German Shepherd. This is the morning of his second day here but it feels like he belongs. There is that immediate bond there between us that took so much longer with Zeb because of his personality and the difficult start he had in life. The bond between Zeb and I now is deep and he is being wonderful to Ely. The girls are facing him with curled lips and terms and conditions, he takes no offence. I gave him a much needed bath yesterday and he even lay down in it. I had wondered at taking on another dog but he was definitely the right thing to do.

15 April 2016

I have just recovered from a bad back I earned from trying to dig the dreadful winter muck from the driveway last week and barrow it away. So stupid really and I paid big time, so much for trying to save some money. It made me realize yet again the realities of the physical work here and the financial realities of what is required to pay for help. As soon as my back is stronger I will try and get the spuds and onions into the tunnel. The car failed the NCT, nothing too major. The clocks changed a couple of nights ago, it is bright until 8pm already. The birds are singing away, I am still feeding them. I am still in the winter habit of not cooking for myself until all the animals are in for the night. Earlier I made a pot of organic sweet potato soup and a pot of creamed cabbage which I will have with smoked tofu cutlets. I feel so much gratitude. Yesterday I could not get off the couch and get going till around five, today I couldn't accomplish much but I was able to be 'in it' more – and that is so often how it goes.

26-30 April 2016

The enormous forestry cutting machine finally arrived today. Coillte had been prepping the forestry areas on either side of my house for weeks, putting in roadways and turnabouts etc. I had left several messages for the Ranger regarding the unidentified birds of prey I had seen carrying large sticks in their beaks and doing lots of diving and making 'mewing' type sounds. They even hovered over the machine. I walked up to the driver and pointed them out to him, and he said 'Jesus I never saw them, I will keep an eye out for their nest'. The Ranger finally came on the 27th, she saw the birds and identified them as buzzards and said it was nesting season, and she would get on to the harvesting manager in Coillte. Of course, nothing seemed to be happening on the buzzards' behalf so I walked along the edge of all the forestry way up high with my binoculars, looking for any signs of a nest, because the forestry people said they would work around nests. There was no sign of the Ranger making a return visit. I found a spot I thought they seemed to be flying in and out of and I marked it with a stag's antler I found. It was a freezing cold day with blue sun in between hail and snow showers. I was way up the hill behind my house, up with the sheep and the silence, looking way down on my little plot which has been my entire universe for so long now. I talked to Helen on the phone in the States, her holistic medical support has saved me so many times. I seem to be so low for I don’t know how long. It is all such a blur. Helen suggested Ashwaganda, an adaptagenic herb which I can get online. I made another visit to the GP. She seems to understand that I am a positive type doing my best to manage this illness. She wants a thyroid blood test, she actually wanted me to start low dose thyroxin straight away. I said I would wait for the test results. I took the rare step of asking her how she thought my prognosis might go. She said at best, relapse and respite. She obviously read my notes and asked if I was doing any research or study at the moment? I said I had fleeting notions and was not giving up hope. She kindly commented that because of my experience and my nursing background, I would have a lot to offer. Another nudge from the universe?

11 May 2016

It was all go in the forestry today. The guys with the chainsaws are here (Latvian guys who live in a caravan owned by their boss, just over the mountains), and by 7pm there wasn’t a tree standing. I could not bear to watch or listen. I felt a sadness for their loss of life, they were probably there thirty or forty years. There was an eerie stillness tonight. The landscape is so different. Now I feel even more ‘hewn out of the hill’. The sadness I feel for the trees reminds me of Mary Beth in the States and how her healing group travelled to Alaska some years ago when an ancient hard wood forest was felled by loggers. They sat for nine days and nine nights grieving with the tree stumps. God, I could cry. I wonder at the guys here driving those huge machines, and all that grabbing and ripping and stripping. Does it never sadden them?

10 June 2016

On the way to the supermarket earlier not far past Abe’s farm something small on the road caught my eye by its small movement. I stopped. It was a tiny rabbit and it was very badly hurt, sort of splayed in to the road. It was missing an eye, its socket bleeding freshly. I picked it up with a small plastic bag. One eye and one hip had injuries, and looked like they had been pecked at. It looked at me and was very warm. I soothed it and told it not to worry, and positioned it as comfortably as I could hidden in some long grass, inside an old gate and covered it up, hopefully to hide it from further birds. Nature can seem so cruel. I thought about ending its life if it was suffering and frightened but it had movement, and maybe with all its reserves and a bit of time and safety it could have some kind of life. I felt that kind of shaky, sick sadness inside, the near crying that seems to affect me when I see some little creature suffer, particularly at the hands of humans. Somebody was most likely going too fast in a car, their minds racing or far away. A little further down the road another little rabbit was squashed completely into the road. It always makes me think that we the humans in our mad, metal machines are the invaders of nature's privacy; going too far, too fast, often unnecessarily. Why can't we just simplify? Why can't we all just need less and stay put more?

The blood tests started off an interesting journey. They did reveal a slightly low thyroid but it was borderline. Again my GP wanted me to start the thyroxine drug. When I researched it (and it was complex, with T3 and T4 and antibodies etc) there was a case for it being autoimmune. I asked for a retest and eventually it came back resolved, it had just been part of a flare up. Once you get on that medication, you rarely get off it. Once again, my nursing background had saved me from a wrong move that could have been lengthy to get over. What about those lost in the ME wilderness, without any medical background?

17 July 2016

Mom's 80th party in my sister's house in Dublin was a lovely success for her and all the family. It was in truth way beyond me and I paid a huge price for it. But who better to pay a price for? I had tried to cook and freeze for the buffet any good day I had and my contributions turned out ok. I came to hate the cake I insisted on making. My own fault entirely. Nobody asked for, expected or even noticed the five different frostings. A couple of frostings less and I might even have managed to wash my hair which would have stood to me better. I didn't realize how dreadful I looked until I saw myself in a mirror, upstairs in my sister's house. I really struggled with that and I just wanted to make a bolt for her front door and head for the hills. It was a real wake up call. Usually I could pull it out of the bag and not look so bad. I had only made it as far as the community thrift shop, and bought a dress for the princely sum of four euros which just looked plain wrong on me. Also, the house was full of relatives I had not seen since I got sick and as lovely as they were, between the noise and their perfumes, I completely shut down and shook. I hid it all with a smile but something inside me broke. I had not mentioned to anyone at all that I had submitted my PhD proposal just the week before. It was like a secret that sustained me, like a very early, much longed for pregnancy.

29 September 2016

A week ago I made it for a couple of hours to the 35th year reunion of my hospital nursing group. I had never gone to any of the others but they had tried to pick a place close to me and they didn't expect me to go for the dinner and the overnight, just breakfast the next morning if I could. I struggled with it, but as my dear friend Una, the first of our group to pass on, was a year dead and had always wanted me to go, I went. The usual strategizing ensued, trying to clean up and travel etc. 'Near me' turned out to be an hour and forty minutes each way! I am still in touch with four of the women. The only person in the remaining five that I had not seen in years that I could relate to was Maeve, who I had been friendly with when we both lived in California. She still lives there. Everyone said I looked and sounded like 'my old self'! However, driving home, utterly wrecked, the skin started to blister and fall off the roof of my mouth. Things deteriorated, and I got a dreadful sore throat, rotten chest and all the usual suspects. Emotionally, I felt very open and vulnerable, these women and I went way back and had very strong connections. I had not revealed or had the chance to reveal to them who I was now. I am not sure they were even interested. The chat seemed to be on the level of married children, pending grandchildren, holidays and husbands etc. When I got home and had tended the animals I sat with a cup of tea and called two of the women I knew best. They spoke to me from their car phones, both going clothes shopping with their daughters, already! I could not move. Should I have even gone?

I am reminded of a verse from a Naomi Nye poem

If they say, 'We should get together''
Say, 'Why?
It's not that you don't love them anymore.
You're trying to remember something
too important to forget.

Trees. The monastery bell at twilight.
Tell them you have a new project.
It will never be finished.

8 October 2016

For weeks and weeks in the middle to late part of the summer, I could get nothing done. I started to worry about how I would line things up for winter. I learned a very valuable lesson when, in just a few long awaited good days I got it all sorted easily enough.

So, just because I could not do it how and when I wanted, did not mean that it did not all get done in its own way. Hannah Hauxwell's books *Seasons of My Life* and *Daughter of the Dales* have calmed me a lot. She got by happily on much less that me and with a place way more remote than mine. It has been a long wait for the SUSI funding decision. A lot is riding on it as any hope of doing the PhD is based on getting it. It became a huge issue a few weeks ago, and I had become way too attached to it, so, I had to let it go and get in touch with what it would be like to be refused. I knew fundamentally that I would be okay.

News of the SUSI funding came on the 4th. They will pay my full fees and some maintenance. I shook with excitement at the mailbox. I had been watching and waiting since July and certainly I had the post man stalked since September. I would phone the SUSI hotline almost daily to see where I was in their process. I thought I had another bit to wait so I truly had no idea it would be there that day. What joy and relief, I had not had anything so good happen to or for me in many a year. I could not wait to tell Holly, she was my first call. I just walked around my house, head up to the sky saying, thank you, thank you. I was seen and heard and said 'yes' to. It was a bit like the final divorce hearing. Over the last several weeks I had to relearn 'letting go and trusting'. I had become obsessed with needing to know the outcome. Waiting and uncertainty takes a huge toll physically and energetically with ME. None of it was helped by this dreadful dose I have had since the nursing reunion. Trying to get ready for winter over the last several weeks, and feeling the energy draining and knowing what is coming physically with the onset of bad weather, I yearned to know if I would have the whole new chapter that is the PhD to carry with me, to help me have a new dimension to living. Underpinning everything is genuine and permanent gratitude. I think that that is the spiritual legacy from having known constant worry and lack, and what it is to be overwhelmed and undermined. I have had to have the range going a lot since I got this dose. I seem to feel the cold increasingly. I am expecting two more tons of turf and two of logs. I have also ordered 400kgs of coal nuggets and two gas cylinders and kindling. A lot of my funds go on fuel but I need to stay warm to stay well. When I am this low, the cold literally frightens me.

23 December 2016

I have not written much in weeks. The last several weeks has been filled with water struggles. The pump packed in, I thought the pipes had frozen. Then after the pump was replaced and the water was still like coffee, it transpired that the backwash/filter system needed changing. It all went on for weeks, waiting for plumbers, who gave definite appointments and never showed up or phoned back. In the meantime I had no water, and had to buy it in and not flush etc. It was all so worrying and draining but I managed. I had to contact the County Council about grant coverage and they were really kind but I had to pay the plumber and then when I could submit a clean water test, I could apply for a seventy five percent refund. I had to pay out a thousand euros, pretty much the only money I had. Now I have to wait till after Christmas to get the water test done which is another 180 euros. Then the chimney started to leak smoke so I had to get that done. Luckily Barry came the next day so I did not have to live without the fire for long. All the guys that came to help me were kind. Still the physical cost was only known to me; facial migraines, inflammatory bowel etc. I was too low to cook or eat, I would find myself nodding on the couch in between caring for the animals.

I did my best to rustle up a few gifts and bits for Christmas for the family and for the immediate neighbours. I had baked a load of chocolate things, pimped them up in plastic and ribbons and delivered them. I checked in with who I could by mail or by phone. Two days ago, SUSI phoned to say they had awarded me maintenance money in error and I would need to pay it back. I am emotionally drained, sick and weary but I try not to rain on everyone else’s Christmas which seems to be in full flight. Next year, will I be able to disengage even more? I certainly hope to be so engrossed in my work that I can be more true to myself.

CHAPTER 6

'SEEING'

23 January 2017

It is midmorning and I am sitting outside in the cool but sunny weather. My legs are tired and weak and heavy and I thought I would never get the chores done so I could put them up on this chair, which Peggy now shares. Of course as soon as I sit all the other dogs want up on my lap or to mooch in my pocket for a stick or a treat. My fingers are sore to the touch and I could not get much sleep last night with neck and shoulder nerve type pain. Too much time spent with the computer and typing. I didn't speak to anyone trying to conserve energy and stay in the work zone. I have made some ground with the work lately but it takes everything I have got and then some. I have decided it doesn't really matter because I am happy to do it anyway and no one else is really that interested or impacted by if or how it affects me so I am just trying to stay in my own lane and to adjust. Everything hurts today and nobody knows, nothing new there then. Still, and more importantly, peace pervades the plot as I sit here, dogs now stretched, Nan rummaging at hay, Flora softly groaning in pleasure from her hay cushioned spot in Montana, Margo chewing and looking out from the doorway of her house. Ike and Corabeth are standing ears back looking into the sun and Mu is under the trees bird watching. The birdsong is beautiful. I have just filled all their feeders. My latest creation is an old twelve foot guttering that sits among the trees. It feeds loads of them especially the bigger birds.

I know the dogs would love a stretch in Edgar's field but my legs won't allow it. I am chasing the results of my water analysis which is delaying the paperwork for my grant to be paid out. The house insurance renewal just landed in the post (they are really kind to me in the brokers) otherwise thankfully there is nothing to drain my energy or my attention. I romanced the notion of asking Mom and Dad to visit tomorrow as the weather is kind at the moment for them to travel but I cannot really imagine being able to do it or worse, how long it would take me to pick back up again, so I will have to leave it for now.

What a privilege this life is in so many ways even with all the physical symptoms today, and I have not mentioned all of them. Still it is a beautiful life. I know only too well what big worries feel like so I know the absolute blessing of having none at the minute and am deeply grateful. Junebug has jumped up on to the old armchair that the hens love so much. It is in the sun and they love to pick away at the old lining on its base. Now the birdsong is really loud! When I think of the struggle of so many humans and non-humans in the world today, I think I am quite fortunate and if there is a price tag attached to living this way, I must be willing to pay it.

11 February 2017

I have been making progress with the work but I lost some time with it because of other things going on and the resultant paybacks. Money has been tight. If it wasn't for the maintenance grant money which has to go back but for the moment is acting as temporary cushion, I would be wiped out now while waiting for the water refund. Topping up the fuel, fodder and feed took my last few bob. I have been very resourceful around my own needs, and good with my diet and cooking which takes a lot of time and focus but you can still eat well for less that way. Today was another very cold day with sleet showers but it is on these types of days in particular that I am most grateful for my set up here when everyone has shelter and comfort. That has been a long road and probably at the heart of my days for the last several years. It gives me the greatest satisfaction above all else that everyone on this little plot is dry and safe and not stressed. All is well in my little world behind my gate, in my little 'dominion'.

I write this by two candles in a warm kitchen. The range has been lit since midmorning because of the cold. The dogs are in various beds around me. I have eaten a lovely dinner of the vegan meatless loaf, mashed potatoes and creamed turnip that I have made in instalments between yesterday and today. I also managed to make a pot of vegetable soup, a mango and coconut cake, a spelt loaf and hummus with olives, most of which are already stashed in the freezer in one person servings.

I have had to check out from mainstream radio again. I had got back into it again listening to Trump and all his antics. It is hard to remain anyway happy and fearless when you listen to all the man-made suffering in the world at the moment. When I reduce things down to what works for me it is no surprise (if my guilty secret) that I take so much comfort from watching the Waltons. For me comfort demands a certain amount of living in a 'simpler time'. It helps me get through. This is no great surprise I suppose as my illness, and lack of belonging to the ‘mainstream’ anymore, has nudged me further that way. I think of Grandpa Zeb (though fictional, totally representative of that era) and his deep love of nature and lack of ownership of anything material. His feet were on and of the earth. Even in those American depression era times when you still needed money for taxes and cars and electricity, they had the means and the time to provide most other things for themselves. I suppose I don’t do too badly for the times we are in. I have not bought anything besides food, fuel and farm supplies for a few years now and it is the final year of my mortgage.

Hopefully this year I can grow and preserve more. I am going to use up all the seeds I have and try and extend the growing season and maybe put in some long term soft fruits in the green tunnel. Maybe a few more hens so I can share and barter eggs? Such thoughts to be having when it is cold and icy and windy outside and me wrecked! But I do think when my financial cushion is depleted, like now when the water repairs has cost me 1180 euros, how very hard it is to re-accumulate money. I can manage well but it is hard to have anything left over to save for contingencies such as repairs or vet bills etc. That is why I must always consider ways to conserve and cut down and simplify so I can put a little by.

15 February 2017

The blisters are bad on my lips and in my mouth. My chest is so sore and my arms are burning. I am pushing through tiredness and painful legs. It is very hard to get back up after an hour on the couch and tons of green tea. It is a bad viral flare up. I try and trace it back. Is it from chores in the cold wind, a brief trip to Hacketstown for provisions or a few consecutive days of hard thinking and reading? I am drained when I get back up and cranky. If I am this depleted I am sure the animals can feel it the same way they can feel the authentic love from me when it comes naturally. Try as I might to fake it when I am drained and low and less patient they still know but in true animal spirit, never hold it against you. I hang another hay bag in the donkey house for the night and give each of them a rub under their head collars and a slice of bread. In front of their house the sky catches my eye, for that second the beauty was divine and in no need of description. I locked it into my memory as shades of grey and lavender, with the smoke from my turf fire heading up to mingle. I thought of Pablo Neruda, ‘when did smoke learn to fly?’ The last two straggler hens were heading home, Mu on the gate of the hen house observing. I spoke to no one today, despite the symptoms it was a peaceful, contented day. The blisters are throbbing. I had considered roasting some spuds that need using but it is safer when I am this viral to stick to soft food in case I get that dreadful ‘glass throat’. So it is rice, broccoli and tofu for dinner and glory for it.

1 March 2017

I have been at the books it seems constantly for days, pushing through. I am running in and out from storms farming, eating anything easy, and shaking from the effort. Sometimes I would look down at myself in smelly clothes, at my muddy farming hands, dirt engrained and embedded under my finger nails. I would not stop until I really had to, pushing on to the next chore or the next chapter. Short tempered at times from tiredness and unable to move, I would resent the short trek up to the donkeys. Finally finished outside I would change wet trousers into pyjamas, finish my chores indoors and dream of a bowl of food and a flask of tea then push on until 8 or 9pm. It can seem a bit surreal, I never thought but always hoped I would find myself at my table with books in the evening. I have finally pushed through some kind of old barrier more towards myself now and I have the work to thank for it. Today I met Holly to return a really useful book she had got me. I was so wiped and a bit overawed by being out and in company or just unsure of myself that I don’t think I explained myself very well. I think it might be that I have forgotten how to talk easily as I am both quiet and alone for so much of the time. The glass throat that came on so quickly after the visit is closing in on me now.

8-15 March 2017

It is a week since I met Holly. I have snuffled, hacked, blown and spat green phlegm since, and it has turned into a really rotten flare up. I find myself in gasping paroxysms of coughing with tears rolling down my face, clutching my chest with the soreness. Now after a full week of it, the right side of my head has to be held while coughing because of the pain. At one stage there was blood in my nasal mucous and now my mouth is blistered on the roof from the viral outbreak. Heat courses through me and I wake up with no power in my hands or legs. Almost out of coping

I talked to Helen in the States and she thinks it could be from working so hard. She believes that because I have such low Chi, when I work that hard, I go into a severe negative balance. She is rarely wrong. I will have to try and find another way.

I spent most of today trying to download the form to apply to the hardship fund at the university. I am so weak, and cranky and I am falling a lot and banging into everything. I have a myriad of small stupid injuries, stubbed toes, minor burns, sticks in the eye, grated knuckles, scrapes at the side of my head. I managed to get the dogs up the back for a short stretch and am going to burn some rubbish now. I could crawl into a ball somewhere and just opt out but that is not an option and I have to get back to trying to type up my notes and plug on.

30 April 2017

It is ages since I have written and I cannot remember the exact sequence of events but I got that huge chapter on autoethnography finished and juggled a lot of stuff with the animals and vegetables! Zeb developed a severe allergy and I had to go to the vets a few times for stuff and then bathe him with oats and basically take him off his food and cook for him. Then Margo got some really serious udder issue and almost died and the vet had to come here a few times. She still has a partial paralysis and needs help to stand up all the time. I spent over 200 euros on vet bills. All the vegetable seedlings I have been carrying in and out daily for weeks to harden off are ready for the ground The farrier was here to do the donkeys' feet before they go out for the summer. I have started looking at some of the ME stuff for the next chapter. I am reluctant, I have looked at it before though not in as much detail. What works for me is living alongside the illness, not spending all my time trying to beat it which I know you cannot. What is the message? What is the gift if there is one? How can I live in peace and happiness when so much has been lost? What can I keep or replace?

18 May 2017

I keep this green journal on the dresser now. It reminds me to put stuff from my head on to the page. It is 9.30am and I am sitting in the rocker by the open window, a cool breeze blows in even though the place is lit by sunshine. I see the recovered Margo ambling about by the door to her house. She still doesn't venture too far in case she falls. Zeb is by the chair, he looks up at me, his ears back. He is very bonded since all the itching and treatment stuff and since I have allowed him down to sleep by my bed. Something in him wanted that further connection with me more than with Ely the pup. He adores Ely and has raised him into the gem he is but he was becoming part of a 'duo' and I thought he was up for that but it seemed not because he made an issue of it through the behavioural changes and the itching. Thankfully I noticed and have fussed over him and reinstated his position as leader in the pack and he is no trouble again. I agree with Temple Grandin (2010), animals do make us human.

28 May 2017

Yesterday was a very wet day, the first in ages. It suited me as I could barely move. The blood blister that had erupted at the back of my mouth a few nights ago has turned herpetic and is sore and tight and the viral outbreak explains my exhaustion. It is hard to eat and drink even though I crave fluids. I had to surrender to the couch for a few hours although no sleep came but with the dogs beside me and the sounds of the rain through the open window it was restful. The donkeys across the road had found shelter in a hollow of gorse. I found the new version of Anne of Green Gables on Netflix, it is beautifully done. It is probably the viral flare up but I find I am moved to cry very easily these days. All the hurt and the humanity around the Manchester bomb at the kids' concert was so sad, but it was the poor young father from Tipperary who forgot about his child in the car in the heat wave that undid me.

6 June 2017

It is great to see the goats up the donkey plot again. I did their feet earlier and sprayed them. They are so trusting but it is so hard on the old back. I hung up the homemade hanging baskets, just nasturtiums and night stock this year but that smell at night will be worth it. Where has my interest in baking gone? I just cannot seem to rise up to it even though I have butter to use and a ton of eggs.

13 June 2017

It only took a week to get those cookies made. I finally used up that butter and they turned out well along with some peanut butter and dark chocolate. I froze the dough uncooked in logs so I can bake them off over time or have them on standby if somebody visits. Nan got shorn a few days ago. Finn just landed down with the trailer for her. There wasn't room for me to go with her and that was the first time I wasn't there with her. He trimmed her feet and dropped her back down. I made a rhubarb tart and had it ready all warm and sugary and wrapped in a red cloth for when he came back with her. It was sweet to see him manoeuvre the tractor out the gate with one hand on the wheel, the other hand holding up the tart like a treasure. All the vegetables are flying up in the polytunnel. There is still a bit of slug damage in the green tunnel. I am out with my flashlight removing them at night and putting them down the end of the plot.

13 July 2017

I have started the walks up to and into the woods again. Out of the last 14 days I have walked 12. It has been a push but I have been determined to make it happen and the dogs are thrilled. I have to lie down a lot afterward but it reminds me of the old post-run feeling and that former sense of possibility. Who knows how long I will be able to keep it up for? There are about ten visits in the pipeline but none of them may happen. I am not going to plot and plan and drain myself over it. My old neighbour was back from Scotland and there was the usual drama around her visit. It reminded me of how it was for me here a few years ago. You would never know who was at the gate or what they wanted, even though they were very good to me in return. At one stage I had four sets of keys to four neighbours' properties and I always seemed to be minding somebody's place and animals while they went away sometimes for weeks at a time. It wore me out and I was in a dreadful loop I never asked to be in. Things became so difficult I had to draw back and even though I repeatedly tried to explain the effects on my health, some of those neighbours barely wave now. It is a necessary price for my survival.

23 August 2017

In the end I did manage a few meaningful visits and helped my neighbours with their sheep and attacked my giant nettle invasion. I managed a second planting in the green tunnel, lifted my little potato harvest and bagged some manure. The walks had to go.

15 September 2017

The last few weeks weren't great. I had been struggling with some kind of reflux and pain. I eventually saw my GP Ellie, and she said it was oesophageal ulceration which she put down to the prolonged bending cutting he nettles. Because of the ME the muscle in my sphincter had loosened and allowed acid to travel up and into my lungs. I had to take a proton inhibitor for 10 days and to eat small and often etc. At the same time Mu my cat had difficulty swallowing and she was losing a lot of weight. I tempted her with everything she usually loved. Eventually I took her to the vets, she cried and drooled all the way there as she was only ever in a car once before over 11 years ago, when I took her to the vet to be spayed. The first visit she got bloods taken and we had to wait a week for results. Nothing showed so she had to back for an x-ray under sedation. I sat in the vet's car park hoping I could take her home and not have to drive the 24 miles return again later. She needed fluid drawn off her chest to ease her breathing which had become laboured, so she had to stay with the vet for a few days. Then a drain had to be put in. I was so sad for Mu, so out of her comfort zone, used only to pottering around the farm with us here. By 7.30 on the following evening Freya the vet rang to say that when the fluid was cleared a scan revealed a tumour in Mu's mediastinum that was inaccessible. She was still under anaesthetic so I said to Freya to put her to sleep. I drove to Baltinglass to pick her up at 9pm. She was wrapped in her blanket and closed into a little brown box. I didn't open it up to see her. It was so sad driving home with her and surreal as I had never been out driving at night in all the years since I got sick. I don't know how I made it. I let her rest in her favourite chair in the spare room and the next morning buried her just in front of the tunnel which was her favourite spot. I put a little solar light over her. She seemed to be sick and then gone in a matter of a couple of weeks but she didn't have to stress or suffer. Freya the vet is a beautiful young woman of not much more than 30 with three little girls and she was lovely to us. Yet, I felt old and pitiful for some reason. It cost me 240 euro but I would do it for her again in a heartbeat. It was

12 years since I had found her, tiny and crying in a ditch and twelve years together wasn't too bad.

The swallows are gone about a week. All summer they made their way in and out of the little gap in the pump house, raised two families and chattered and hunted insects all evening. Now as I clean all their droppings from the walls and floors I can only hope they made it safely and will make it back next year. Mu is gone but the circle continues just like someday it will continue without me.

20 September 2017

Yesterday turned very wet and I was worried about poor old Ike and Corabeth in the field, but today is mild and sunny again and I always have to remind myself of the long winter when they will not have all that space and freedom. Despite a lot of physical stuff at the moment I continue to try and sort through all the ME research. I neither want to dwell there too long nor be the poster girl for it.

23 September 2017

I am sitting outside this glorious evening. The donkeys came home two mornings ago, Harry helped me. I think they were keen to come, it had gotten wet and they were scootched arseways into a gap in the gorse for shelter and where they could see the road and the house. Corabeth is a bit lame on her bad leg. They ambled home and up the plot and into their house. Today they lie in the long grass and are delighted to see me coming with their buckets. I have been very tired and sore and hoped for a quiet day to potter yesterday when Harry came to the gate to apologetically ask me to go to Baltinglass to his vet for medicine for his ewes. He doesn't drive and it would be a big deal for him to ask me so I just went straight in and out, which is a good hour's driving. Today I made the second batch of blackberry butter and some chocolate beetroot cupcakes and two loaves of zucchini bread for the freezer. I listened to an interview with Laura Hillenbrand the successful author and probably the most famous person with ME. She talked about the price she pays for pushing past her 'red lines' and how even still she avoids music as she has to mind her sense of sadness and loss. I could relate, my life used to be one long soundtrack but I have no relationship with music or movies anymore as I am unable for the emotional uncovering they can produce. She also discussed her appreciation of the minutia in life and her sense of all pervading gratitude. She is often asked why she doesn't write about ME and her answer is that she knows all that already and prefers to research and write about new subjects. Truthfully I think nobody, including myself, really wants to write about ME but prefers to distance themselves from it in an effort to try just to find a way to live with it in peace. I think you struggle with it, then try to fix it, then learn to cope or manage it, then accept or embrace it whichever feels right and then forget about it! Many would disagree as lots of people seem to either stay or get stuck at some other point along the way.

5 October 2017

Jim the farrier came today. Things went quite smoothly and the donkeys stood well for me as he did their feet. Jim is a bit of a rough diamond and employs fervent and oblivious use of the 'c' word. It jars me as an old feminist but I missed my opportunity to address it when he first came here. He would mean no insult, it is part of the vernacular with a lot of country lads. Like most people I have dealings with here, Jim's kindness outweighs all. He tells me about a lot of wealthy farmers who let their donkeys' feet go too long rather than pay him to do them. Today he came from one such farmer and he told me 'I said to him, I'm on me way now to a woman that has nothin' and she has me twice a year to do her asses feet'! He also tells people to use my trick of bribing the donkeys in with a gingernut biscuit. He insists on charging me 10 euro less than his going rate and I always give him eggs or jam or baked goods. Last year when he was here and we were chatting about the deer lampers, I told him that I worried about the donkeys when they were over the road and told him I had tried luminous tape on their halters but that it would not stay on. A week later he was back at my gate with a pair of children's neon armbands that would Velcro on to their halters and that I could write my number on in case a gate was ever left open accidentally and they wandered.

I see every nettle I killed myself hand cutting is back up again.

26 October 2017

I jumped one of my most difficult hurdles yesterday - the dentist. I had a bath the night before in case it worked out that I could go. When I called for an appointment they said just come on over and gratefully, when I got there they took me in straight away. That is no small thing as despite my deep breathing and praying in the waiting room, the lights and the smell and the whirring of drills and the thoughts of what is to come, marks the start of the decline. ‘Ah yes I remember you’, said the dentist, ‘you always bring us biscuits and tell us to brush our teeth after them’ he laughed. ‘I hope I don’t have to do too much to you’, he said, referring I suppose to my nervous behaviour and increasing pallor. I flew around my prayer beads ready for all sorts of pain but it wasn’t too bad. I always have to remind them about frequent suctioning as that saves me from chest problems afterwards. Today the gargle liquid is navy blue. The bit that had broken off my tooth didn’t need repairing. ‘That old amalgam is great, it never moves’, he said. ‘Even if it is poisoning me’ I offer. He puts zero store by the mercury poisoning theory. I do, but would not be well enough to go through having most of my back teeth refilled. In general they are kind to me and increasingly respectful, but I have worked hard for that. I would explain about the ME, and apologise for being so nervous and jumpy. I would say that I never used to be like that, saying ‘hell in California I had dental work without any injections’, trying to convince them. How do you keep explaining that drills whizzing and implements scraping and blowing air in your mouth, felt like they were going straight up into your already frazzled brain and that it felt like a nuclear attack? That the fear before and during the visit and the effects afterwards would usurp your whole week? Could I tell them that every night for the last six months or more I questioned the possibility of maybe making it to the dentist the next morning? Could I pull it all off, the drive, the work, making it back out of the traffic safely? Today their gift for tolerating me was a pot of blackberry butter all gussied up. I could not believe as I walked down the dingy stairs back onto the main street that it was all over. The depth of my feeling of accomplishment is probably unfathomable to any normal soul, but for me it is now off the table, out of the budget, off the anxiety radar, one less spinning plate to manage. There were lots of things I could have done on such a very rare visit to a big town, I even had a list. I just headed straight for the hills.

Today, the morning after, I lumber around the plot like poor old Margo the goat. Everything is heavy and sore and hard to move. I am chesty and coughing and feel nauseated. I guess that navy blue gargling shit wasn't a winner. Still, as I roll my tongue around my mouth, I know that sharp chipped bit of tooth is gone and cannot get me in the dead of winter. It all seems like a fair trade.

29 October 2017

Well things did go from bad to worse after the dentist. I only managed to get the basics done since. Standing up and setting off was like trying to launch out of concrete, it was a zombie-like tiredness with no hope of sleep. Everything ached, when the dogs touched off my legs it felt like an assault. I was good for nothing and briary. My new little freezer arrived, Brian from the hardware store set it up and took all the packaging away with him. He also went home with some eggs. I hope with this extra freezer space to only have to go out every month or more and lower my risk of picking anything up as there is an Australian flu outbreak. Barry came to do the chimney and offered me his young cat who he said stands up well to his two ridgeback dogs. I couldn't even get my words out right to explain that winter would be a bad time for me to try and settle her in with the dogs. The clocks have just gone back so there is even less daylight. He was lovely about it and left with some eggs. It troubled me all day, that bloody ME indecision, maybe missing out now on the perfect cat for here? My head just could not process it.

The dogs were unsettled during the night, and as I stood at the back step at 1.30 am waiting for them to come back in, there was a loud bang and a flashing light. Hunters? Maybe it is just as well I don't have a new cat to settle in. I spent the rest of the night awake with the radio on low.

30 October 2017

Some sleep finally came last night and a dream to go with it. For some reason I had my own little baby girl. Then an earthworm came out of her mouth, I pulled it out and put it back in the earth. Next I was in Supervalu's bakery section with my parents. We all thought the baby might be cold as she only had a vest and a nappy on. I was very relaxed with her so I just put her inside my big pink Himalayan cardigan. Then she shrivelled into a tiny blue thing. I gave her mouth to mouth, I could feel myself breathing into her. Then a young handsome doctor was there with oxygen and an ambu bag and she came back to normal. I was so happy and I hugged him and he clung to me. Suddenly the baby was about 12 years old and I was still pleased to have her but I woke up deeply missing my baby. I can still feel it.

All of that chapter is well behind me now. Some mornings I pick Peggy up off my bed and she snuggles into my neck, she is warm and smells like buttery toast. Those times I wonder for a moment, what it must be like to pick your baby out of her cot in the morning, breathe her in and have her all day? I think the world might be divided simply by those who have children and those who do not, not a hierarchical division, just some sort of a biological one.

6 November 2017

Vinnie finally came to cut the trees fronting the road. I was not wrong to dread it. Demolition man. He drove off with his 120 euros and left carnage behind him. I stood in despair looking at the branches and boughs left on the road. ‘Sure just take your time, go ‘ah hih’ slow’, he drawled. I pulled and dragged and stacked and sorted trees bits for two hours after he left just to clear the road frontage. There was nobody passing to help. It was just head down, in the Zen zone, one branch at a time. No surprise I paid the price, for a whole week. Every old familiar symptom made a guest appearance. The overriding joy is that with a good eight feet lopped off the trees I can see the whole countryside again, and the view, and my sense of place in it all is wonderful.

14 November 2017

I am going through something. The ‘gap’ seems wide again. That is the gap between me and my beloved ‘normos’. Unusually, I am a bit silently cross with them which is pointless, as they are all just on their own track and do not need to be on mine. I am glad to have recently found YouTube and my bunch of homesteading types and my Buddhist and vegan humans. I enjoy the philosophy and creativity and resourcefulness. I ‘saw’ myself reflected a little and it has had a powerful and peaceful effect on me. I can see my little homestead and myself, both a little the worse for wear, as good enough in every way. Though a bit one sided, it was the kind of communication that I have been missing. Nobody that I know is interested in living as I do. I realised recently that my situation doesn’t really have any true impact on anyone else’s reality.

They are all very busy and as much as I know that I am loved, I would not be near the top of anyone else's agenda. The truth of the matter is that nobody owes me that, it is just a difficult habit to drop when you have lived with a partner for 20 years. I think it is one of the reasons I take so many photographs, I used to turn around and say 'look at this', now I click and capture it for…what? Evidence that I was here, I saw it, it happened, it matters.

21 November 2017 – (56 today!)

I have spent the last while immersed in the ME literature. It surprised me how much personal content was available on line and on YouTube in particular. Their stories and struggles are very similar to my own. The ME profile has really risen since I last looked into it when I first got sick 15 years ago. The amount of medical research has grown. It is not that much has improved but it does seem like it is its own 'entity' now. The research content along with the screen exposure has thrown me back into my old migraine clusters. I am seeing Mom and Dad and my sister Rose in the hotel in Macreddin later. Mom especially loves to see me on my birthday, and tell me how I was born on a Tuesday at 3am and didn't hang about too much. She sneaks her cake slicer that sings happy birthday in, in her handbag. They are fabulous for their years and full of love. Before I left for the hotel, after the farming chores and before I cleaned myself up, I sat in the rocker with my head throbbing and my eyes closed and wondered how I was going to be able to make it happen. I yearned to just stay in that chair. But the reality is that there will be too many years when there will be no chance to see them, so I counted my blessings and got up.

26 November 2017

I am full of inflammation. I made vegetable and lentil curry in the crockpot and mushroom and pesto soup on the stovetop and before I even got to eat anything I had violent cramps and the runs. Later that night in bed heat, not any kind of sweat or fever, was coursing through my arms and hands and my guts. I must be really depleted. I know I push it.

The next day I managed porridge and just when I was about to chance plain rice and vegetables for lunch Harry was at my gate. His son had been assaulted outside the village pub. Harry is a shy and nervous man. He came in, he sat in my sitting room as he is afraid of my shepherds and had a mug of elderberry syrup and some chocolate biscuits. He saw all the logs beside the woodstove and said ‘be gor you’re grand and cosy here Orlagh’. Sitting with his boots off, his head back and his hand on Peggy’s back he let his worries out. Before he left he offered to do ‘the bit of fodderin’’ for me ‘any cold day next week that might save me going out.’ I must look as bad as I feel!

30 November 2017

I have just finished farming at 4.30 which is 5.30 old time so it is almost dark. The moon which is not quite full yet was already up from behind the hill. The frost was already making every breath icy. Gracie was up on the big rock up the back yipping madly. It must be that lame old brazen fox that has been up the back for days. The poor old thing, dragging across the fields, looking for something to eat. A few days ago it kept coming towards the back fence even though the dogs went mad barking at it. It just stood and looked at us and I could see every bit of its face and I could feel its need. There was no barrier between us. I did not know how to help it without it ending up badly for my old lady chickens. As it happened it wasn’t the fox causing the excitement. In the very last of the daylight but directly under a line of moonlight, head down grazing were two deer. Just for that brief second before recognition kicked in I could feel the moment as sacred, then it felt beautiful and elemental. I quietened the dogs. That moment and those deer deserved silence and stillness. Later walking back up the already crunching driveway, the animals checked for the last time, the smell of turf on the night air, I pass my kitchen window with the candle lit and see the laptop and books still on the kitchen table. I have spent so many hours trying to cut a wedge through all the ME denseness and sadness. When I read all the studies it is hard not to recognise that the future might get even harder for me here. Without sounding like Pollyanna, how do I explain that moments like seeing the deer grazing in the moonlight behind my little house here in the hills, balance everything difficult out?

1 December 2017

It is a dazzling frozen blue day. Everything is out picking, plenty of action on the bird feeders. Larry dropped up a ton of turf and logs, a gas cylinder and firelighters and kindling (160 euros), so throwing all that in the shed was the morning's work along with burning some rubbish. I was enjoying my soup in the company of the Waltons when Harry was at the gate. I expected an update on the lamb I had been helping him mind for the last few months. Something had bitten or injured the side of this ram lamb's face and it was raw to the bone and huge and hard. The eye on the same side was completely closed and the other eye was partially closed. We had been giving him antibiotics and I mixed up a hibiscrub wash for the face and a camomile wash to help the eyes to open. I brought up lavender oil for the stall to keep the pesky bluebottles away. He was a cooperative little creature and over time the hard face softened and both eyes opened. He was in the company of another pet lamb that was motherless and came from another farm. He was black and adorable. He was handed over in Dublin to Harry's son, from one tradesman's van to another and then down to this stall. He used to nudge my legs when I was in with the injured lamb. What Harry had come to tell me was that he had fetched a good price for both lambs at the factory, the injured lamb had fetched 109 euros. My heart sank. Harry is a very kind farmer and still, I cannot reconcile that kind of dominion over other sentient beings. Also, people have no idea what they are eating, there was a lot of infection and antibiotics in that 'premium' young lamb.

10 December 2017

As forecast there was snow and sleet from 2am, driving in at a 45 degree angle from the North East. Though it had lain overnight it was full of sleet so it was just cold and slippery as I farmed. Everyone needed a bit extra and it seemed like in no time at all I was closing everyone in again for the night as the temperatures fell to -8 C and darkness was down at 4.30pm. I put the infra red light on in the pump house. I suppose people could think that I just 'cosy up' on such days but in fact I need to be out every few hours at least, checking, topping up food, rummaging up snacks for the critters, opening and closing doors to facilitate their shelter. The hens were fed in their sleeping house this morning, and then, heads down and wings out they ran towards the goat house and spent the day in there with the door closed. I left plenty out for the birds, there were lots of blackbirds picking the ground, actually they had been around for days, my lovely old neighbour Molly's sure and certain sign that snow was coming.

I write this by the large woodstove in the sitting room which is roaring with flame. Peggy and Gracie are stretched on the couch beside me. Poor old Gracie has always been slightly reluctant to include herself, staying by the range in her familiar bed. Her part Lurcher personality makes her timid and her bad start in life has given her low expectations.

I have been through a few disastrous snows when doors and locks froze and I had to climb in and out of windows, when power went and water froze and animal houses leaked, or emergencies such as Credie needing the vet meant I had to travel on treacherous roads. So, being out and about in snow and keeping everything right is no problem to me. Most people I know would not put their nose out in such weather. I cannot imagine not being part of it all.

22 December 2017

It is impossible it seems to escape this dreaded Christmas season unscathed. I am just plodding, taking care of the farm and the finances, and studying with what is left. For the last while, days, maybe a couple of weeks, I have had the mouth blisters and swollen glands and the chondriatis, the rib muscle pain and the breathlessness is particularly bad by evening. I am trying to acknowledge friends and family in some small way. I wasn't going to send cards but I up-cycled some old ones and got them and some little gifts off in the post. I have some chocolates for the neighbours' children and then I tried to detach from the commercial drive and panic that despite my best efforts can still permeate through. That commercial Christmas push can be very hard to resist. I cop myself on and send what I can to Concern instead.

The morning chores these days take about two hours from farming to building fires and tidying up. I am hardly ever sleeping these nights so I get up nauseated but the porridge restores a bit of life.

I wasn't able for the planned Solstice meeting with Holly yesterday. I really laboured over it and held out till the very end, but with how I was feeling I just couldn't imagine being 'out there', or even being able to talk. I was really disappointed as Holly is always so full of life and ideas. She understood. She said she was exhausted anyway. I am reminded of what I read recently in the ME work; telling a person with ME you understand because you are exhausted too is like telling a patient with cancer you understand because you recently stubbed your toe. That is so true, but everybody would take offence although it is only intended to educate. The ME work is slow and constant and I am on a major learning curve; not just in terms of content but in terms of my cognitive limitations. Increasingly my brain struggles to process and retain. Each day back at the books can seem like groundhog day.

Christmas Day 2017

The farming chores are the same everyday Christmas or not. Afterwards I checked in briefly with family then I lit the range, lit the candle and....silence.

The bubble has burst. I resist the emotional pulls and prods as best I can but I have had a pain in my heart and a need to cry for days. Yesterday when I saw on the news those people in the dreadful floods in the Philippines, walking in brown water almost to their chins, holding on to a rope, everything lost, the tears came. The tears weren’t for me just in me.

I was at the sink when I got one of my rare flashes of recognition; I really do live a solitary life and yet I feel deeply connected to life, and the natural world. My deep bond and my deep love is for animals and nature. I understand it more than the world of people, although the first part of my life was all about people. Animals may need from you but they want very little ‘of’ you, and are mostly present, joyous and silent and never overburdened or dissatisfied. I learn a lot from them.

At the end of another Christmas day, I sit with the candles and the radio on. I listen to a documentary on William Trevor, and then to the South Wind Blows, an hour of gentle folk music and poetry. It has taken me a long time to be able to step over that line towards ‘being’ by myself. It was a matter of a lot of small steps and it feels good to be at that point. Yes I am sick and sore, and it is hard to find a comfortable position in the chair, but I am aware and grateful that I am in my cosy kitchen in the hills, peaceful with my four dogs who love each other and me. We are safe and sound with enough in the pot and the purse for now. That is Christmas enough for me.

31 December 2017

It is chucking down ice and sleet from the east all day. This morning I set everybody up outside for a bad afternoon. There was a fox lurking up the back hill earlier. They must be starving and possibly desperate enough to find a way in for a chicken so I blocked the hens in the goat house with a dragged pallet just in case. I topped up all the bird feeders – yesterday a sparrow hawk swooped in but got nothing. I have positioned the feeders as best I can but any that are not being fully emptied I move further in as the birds must not be confident enough to stay on them long enough to feed safely.

As I throw my leg over the chicken fence to get into the trees where I hang the feeders my second leg does not follow easily. Several times my wellied foot has gotten hooked on the wire and I have spun and slipped and been scraped by trees and brambles. It is only by evening I notice all the little tears and scrapes. Up till recently my second leg followed over quite naturally, maybe even spritely. But it just will not go up and over now. Note to self: ‘do some stretches - you cannot afford to lose that kind of movement’. I am only back inside when I notice a thrush, some robins and a female blackbird all on the ground looking for food. I go back outside and scatter oats for them.

Poor old Nan the ewe did the splits on the icy path this morning as she was walking up to greet me. I got her up quite easily and she made her way back to her house via the mucky grass. It is truly freezing, the cold actually hurts – I’ll know all about its physical effects later.

Bad weather requires vigilance. At noon I had to disconnect the pipe from the backwash system in the pump house in case it was frozen and the water couldn’t get away. Then I had to attach it again and rewrap it. The wood stove in the sitting room rarely needs to be lit as well as the range but it is a day for both today. I sit by it now as I write and it is comforting and cosy but I need to remain vigilant for another couple of hours so I must resist its lull to doze. Outside, the sky has whited out and the sleet is turning into huge flakes of snow. Time to rise and farm.

As I farmed the snow came down hard. The hens wouldn’t leave the goat house to make the tiny journey to their run. I lifted each one and put them straight into their beds with their supper and closed the door. The donkeys needed no encouragement to be closed in with feed and fodder and a little light left on. Oliver was on his way with my organic veg box so while waiting for him with the flashlight I plugged the infra red light on in the pump house. My hands were damp – at the best of times I get a small dart from that plug.

I fed Flora and Margo in the goat house and closed them in with the light and the radio on. Nan hovers outside waiting. I can never take my eye off her as when she was younger she slid the bolt closed and I had no way of getting out of the goat house only Helen was visiting from the States. Once bitten?

Everywhere is already covered with snow and the dogs are high, playing and barking with joy. Snow and wind chill takes on a more sinister feel when darkness falls and the temperatures drop. At least every creature I have is safe and cosy and secure tonight, everything else I can endure. I saw the days when their houses were not right and roofs and floors would leak or blow off and I would be out alone with a only a flashlight trying to make do and mend. My heart breaks for any poor creature that is left to stand out in that weather. Around here the cattle are all in for winter. Some sheep are in for lambing but unless there are drifts sheep can cope with snow if they can lean into a wall that blocks the wind.

A car has just chanced it up my road and got stalled on the slight incline near my gate. It finally gets going again and puts up a bit of speed to gather momentum but does a complete spin.

On the news it showed four young men being buried in neighbouring Donegal parishes today. Tiny churches at the foot of snowy mountains welcomed their coffins in, processions of ashen faced frozen young people following behind. My tears fell.

Here tonight all the snow is coming from the east, straight down off the hill right behind me. Luckily I had helped Harry take his sheep down off it yesterday as they are well in lamb. I took the shovel inside with me earlier. A lovely old neighbour years ago told me to always take the shovel inside with drifting snow so you could always dig your way out if it came over the door. I have charged the phone and the torch in case the power goes out, stored water and filled the flasks with boiling water in case I have to thaw the frozen gas cylinder hose in the morning. It is up to me to take care of these details. No matter how unwell I might feel it seems I can always rise to a challenge or situation. That is never the problem, the problem is the payback, the extent of which I can never predict.

Barefoot by the stove later not long before bed my little dog Peggy licks my feet – I remember I have a body.

The next morning blue sky causes deep snow to sparkle. As I let the donkeys out they gallop all round their plot. The hens will not come down their plank so must once again be lifted one by one into the goat house. My goats quite simply do not do snow! The dogs go crazy in it, I have to keep them in my sights at all times because I will not be in theirs and could easy be knocked down. Peggy has a collar on with lights that flash or else I cannot see her. Several times that day I will have to stand her in warm water to defrost the tennis ball sized snowballs from her under carriage.

Thankfully the power and the water have stayed on but I did need my flasks to open frozen bolts on doors and to thaw the gas hose to make my porridge.

A heavy freeze on what had been a light thaw made the next morning treacherous. Mindfulness was definitely required. Each step for me had to be slow and I needed a stick. The council with their makeshift snow plough had been through the road but only tractors and jeeps would chance it. Everywhere else is deep snow. I am feeling the beginnings of the lead limbed exhaustion that often comes from pushing it. The sky is deep blue and everywhere is magnificent and still. I walk up the road with eggs for a few neighbours.

As the hill behind the house is sheep free I brought the dogs up. They run free – literally free, I envy them. With the depth of the snow I cannot tell where the usual streams and rocks are so I have to move like a really old frail person but their joy becomes mine. These are the moments that I store in my heart; precious magic moments of truly being here, of oneness, of doing exactly what you want in life if even for only a speck of time. These moments balance everything else out, the shoulds, the must dos, the duties and the obligations, the inability and the pain.

I live in the hills and I take what comes. I am part of all of it from morning to night, season in and season out. I am mind-blown by people who do not notice the weather except when it inconveniences them. At most we are only a few breeze blocks and a roof away from the elements, elements that we came from, elements that have always balanced themselves out in the end until now because we have upset that balance by our greed and dominion. This little patch of boggy hill that shelters and sustains me, body and soul and that I share with my own animals and the deer, fox, buzzards, pheasants and birds and vermin of every variety, I can only hope will remain as it is now, slow and mostly forgotten about for my lifetime. I have indeed become what the philosopher Alan Watts calls a ‘forest dweller’.

By day three I am like cement, heavy and stuck. The freezing nights make any good thaw impossible and partial thaws get frozen over and become very slippery. Each step I take must be slow and deliberate, every little route premeditated. Previously a marathon runner now I must be humble enough to be content with staying upright. The slope up to the donkeys is the greatest challenge, especially when I must carry hay. My trusty stick goes everywhere, it has saved me many times. The most common fracture I recall from nursing school is the Colles fracture of the wrist, or ‘falling onto the outstretched hand’, a trusty stick will save you from that common mistake. My legs are full of lactic acid, way more than if I had actually run a marathon! Last night a cold sore blew up on my lip and its equivalent erupted deep in my throat. That is a sure sign that I have crossed the ‘overdone it’ line. It will be soft food and only lukewarm tea for a few days. The soreness in my ribs makes breathing a chore by nightfall.

The many tiny but necessary chores that consume most days here are multiplied and magnified in snow or storm. Forget to check on one shed door and it can flap and blow and damage its contents. Forget to start the car regularly and the battery runs flat. Leave the kitchen door open and a wet dog or two will happily get on your bed. Don’t put the heat lamp in the pump house and risk the pump freezing. Vigilance, though exhausting, pays dividends.

Welcome rain, and the rise in temperatures that preceded it, turns everything on the fourth morning a familiar green. The sun then brings all the creatures out of their houses and sees them picking contentedly. Already there is less for me to think about. Maybe tonight I can manage a bath? A few days’ snow on a tiny hill farm is not difficult – often I have been snowed in for weeks, power off, water frozen.

I live in the hills and I take what comes…Life here sustains my spirit and my soul and reminds me that all sense of adventure is not yet gone even if physical strength slips away.

Wintering

I have taken Peggy’s chair.
She was stretched on my small armchair
face buried into the thick red rug.
I scootch in beside her
we barely fit.
I read
she licks my arm from fingers to elbow.
Now she has no place to put her head
she lets it hang over the chair’s edge
uncomplaining.
I slot a furry slipper under the cushion to
make a shelf for her face
she stares up at me in gratitude
we see each other.
Ely is at my feet
as usual
he cradles his face with his upturned paw.
Silence except for the boiler clicking on and off.
Before the chair theft
I had just checked the pump house,
through the tiny broken slate
the infra red of the heat lamp
shines into the darkness.
Out for just a few seconds
I am shocked by the blue cold of the freezing mist.
The sky is low with stars
collecting together in all shapes and sizes.

A fox screeches nearby
sounds otherworldly.
The mountains are covered in snow
all day the sun on them made them look Alpine
a bit too exotic for here.
Cats everywhere are hollowed into straw bales,
chickens a sleeping mosaic in their galvanized box.
My bigger creatures are in houses
with low lights and low music
altogether
a kind
wintering.

CHAPTER 7

‘SANCTUARY’

6 January 2018

The last few weeks have been tough. That increasing pressure in my chest, then the palpitations and the difficulty getting a full breath up are a bit concerning. The struggle with the ME chapter continues, I am pushing through the dense detail, the lack of agreement over almost everything, the negative outcomes and the sad stories. It is almost impossible not to over-identify with it and I find myself thinking ‘that’s why I feel like that or that’s why it is so difficult or why I am sick so long’ etc. It didn’t help that I wasn’t connecting with anyone as everyone is on the Christmas track and I am just pushing very hard between two very narrow life tracks. When I finally spoke to Helen she thought it was all stress related and I was probably just finding it difficult to process the difficult content of the work. I knew it was most likely so but ME is a gateway illness and I live alone and remotely and I couldn’t afford to gamble with chest pain, so I went to see the GP. The Australian flu epidemic was still serious, there were ads on the radio advising you to avoid the doctor’s office where possible. I was ready to do my usual standing at the door till my turn came but in fact the waiting room was empty. The reason it was empty was that my usual GP was not there, instead a locum called me in, a woman from Eastern Europe. My heart sank but I stuck with it. From the beginning she was glued to the computer screen. I explained my symptoms, she typed away. I continued with a bit of my back story, she put her hand up until I stopped talking. She never heard of ME, she knew fibromyalgia. She didn’t like the sound of the pressure on my heart so I should have an EKG. The practice nurse, also not the usual woman, did an EKG. She pulled up both my thermal vests and had my breasts exposed all the time. The treatment bed faced the door where the waiting patients sat. What am I doing here I thought? The EKG was normal, that was really all I needed to know, as clued in as I am, that was not a call I could make from my kitchen. The doctor said I had angina and I needed to use a nitroglycerin spray. She saw the look of disbelief on my face. I asked her what might cause this angina? She replied ‘your age, atherosclerosis’. I am 56 and 8 stone and vegan. I said ‘it can happen with long term ME that the constant inflammation can cause cardiac muscle damage or cardiomyopathy’. ‘Yes, yes, cardiomyopathy’ she says, ‘you have fibromyalgia of heart’! I could have cried, I chose in that instant to wonder what ‘for fucks sake’ was in her language! She started to type a letter for a cardiologist, I said no, I would wait and see how things went. The EKG was negative that was all I really needed to know. I play down a lot of my symptoms and give things time to resolve on their own. I had waited for this to pass for a couple of weeks, I just needed to be sure there wasn’t a cardiac problem. But what if I was of a different personality type and or had no medical knowledge? I would be living under the diagnosis of angina and what that could lead to. I would return the nitroglycerin spray to my regular GP.

20 January 2018

My jaw locked in a risky yawn last night. I had a lucky escape. Today, even though it is tender and a bit swollen from the near dislocation, at least it is still attached. I am just back from the cottage field across the road with Ely and Gracie. They were off lead and joyfully played in every stream and bit of muck they could find. I love it myself over there, looking over at the smoke from my chimney. The field is bordered by native hedgerows and amazing old gnarled tree trunks which are covered in ancient moss with ferns growing out of them like blossoms. I found a tiny lichen covered twig and wore it home in my hair. Ike can see me from home and honks hoarsely, his voice breaking like a teenage boy’s.

Last night as I sat in my sitting room it occurred to me to wonder, what if this room, this house, this hill, this life was all there would ever be and nothing more until I die? It didn’t seem so bad. I thought of all the people who lived on this hill fifty or a hundred years ago. Where did they ever go? How stressful were their lives? When I first came here I took care of some of the very old neighbours who ended up in the district hospital/nursing home. They would tell me stories about how they lived and farmed here. In the early years here, when I ran everyday around the roads, I would meet old men in wellingtons and soft caps and suit type jackets over knitted jerseys. They would be leaning on gates and staring into fields at livestock. That was the nature of their day. Then, I was still very much in the way of, go more, know more, have more. Now, I know for myself the value of stillness and staring into fields. When I used to visit Molly my beloved elderly neighbour, she would tell me how, early in her marriage, they would go a couple of times a year on the ass and cart to Hacketstown to the old grocery store there. They would only buy tea and sugar and salt and flour and a few other bits. They would be taken in to the back of the store for tea and the children would be given sweets. It was a ten mile round trip but it would take them all day. In the years just before Molly died she would go into Hacketstown on a Friday with the bachelor neighbours to do her shopping. I was there once just as she got back, her headscarf tied under her chin, her purse clutched to her, an air of exhaustion about her. She was in severe need of a cup of tea and had a terrible headache from the 'road'. She would say 'thanks be to God I am home'. It would seem though 30 years younger than her, I have become her.

1 February 2018

I finished the ME chapter last night really late. It is very scientific and it took incredible perseverance. Even though it nearly killed me, I actually wonder how I was able to do that kind of work with all my cognitive difficulties? And then it hit me, another contested illness legacy, another 'catch 22' where people might say, but you couldn't be that bad if you are able to write that? So in one brief sitting I wrote this 'epilogue' to the work. I was not letting this one pass.

I am writing this short epilogue because as a person living with ME, I often receive the comment: 'but you don't look sick!' I expect I will now receive the comment: 'And you're doing a PhD, aren't you great ? I couldn't do that and I don't have ME!'

Let me explain.

Two months into this piece on ME, I thought I would have to change tack completely. Maybe what I wanted to say could be made relevant to all chronic illnesses, not just ME? Or maybe I should just broaden it to include all invisible illnesses? I was looking for a way out. I was finding it hard to get a foothold. Yes, the information was vast, widely dispersed and I was hacking my way through dense medical reports. There was so much disagreement, about everything, that nothing was easy to get in and out of, grab a good quote and move on.

But that wasn't the problem. The problem was twofold. One, the black hole in my memory was back, that void that everything on the previous page would fall into. Two, I desperately did not *want to have to associate so intensely with ME and its unavoidable reality – well actually it was avoidable, I had been doing it for years. Who were these people? They were just so depressing.*

For months, each day became the same. I was willing to allow that. I chose it over having to give up. The only gun to my head was my own starter pistol. It became increasingly difficult to physically get out of the bed. There was always a couple of hours farming work before porridge. I tried to hurry my usually leisurely chores of letting the farm animals out, filling their buckets and hay feeders, shoveling poop, and feeding dogs. Then have porridge and tea. Then set the range, fill the turf and log baskets, feed the birds, tidy a little, pull soup out of the freezer for lunch (I would be quite weak by then). Set something up for dinner, so that later when I am truly exhausted, I don't fall into the 'tea and toast' trap, just so I can get back to 'work'.

Usually I can take all morning to do this, be a lot more 'present', take the 'push' out of it. That way of working costs me a lot less physically. But for the last few months I have been trying to save energy, strength and time every day, anyway I can so I can factor in the work. The work has had to be central for me to get to it. I have had to shave off any little thing I can from everything else in a day to make it happen.

This I do willingly.

Walks with the dogs have gone. I rarely call anyone, or listen to radio or use screens other than for the work. I do crock pot cooking, which is minimal effort and it lasts for days. I have been to the supermarket twice since Christmas, with a mask on under my scarf, in case I got the flu which would finish me for months. Everything else I get delivered. My hair gets washed every few weeks. In ten weeks I have seen two people. These adjustments I make willingly.

Late December, things became very difficult. I had found my way in to the work, I was in the thick of it, so much information was now uncovered, assimilated, spread on a page somewhere on the floor. I was watching too many lost ME souls on YouTube. My chest caved in, everything hurt, my breath became even shallower, something was pressing on my heart area and I had real palpitations.

I hate 'these people'.

Don't panic I said, it will pass, it's nothing, it's ME. Wait.

I waited.

I got worse.

I braved the flu epidemic to go to my doctor. She wasn't there. A locum saw me, typed instead of listened, she had no clue about ME. One normal EKG later, she told me I had angina and sent me home with nitroglycerine spray.

I never took it.

I waited more.

It went.

I re-emerged from some kind of physical and emotional despair, from an over-immersion in the swamp that ME can be. If I was going to be able to continue this work, I was going to have to do it from the shallows, and with a binoculars if necessary.

I did.

It worked.

I came to understand 'these people'

January, I just existed, willingly. I gave the days and nights over to the work. There wasn't much left to shave off the everyday to facilitate more 'work'. The everyday was now fairly bald. So I would have to push harder, harder than I knew, to find my way to the end. I kept us all alive on the farm but that was about it. Gone were the extra little moments of care, treats, cuddles and kindness. If you barked or honked when my frayed nerves weren't expecting it, I might shout at you. My cement legs resented the little hill up to the donkeys.

I tried every room in the house to find somewhere or somehow to sit and work where it might not hurt so much. The pain followed me everywhere. Despite the freezing weather my arms burned off me. I wore a woollen poncho instead of a fleece because the fleece hurt. My hands, swollen from writing and typing made it too sore to chop vegetables. I put them into the crock pot whole.

I pushed on.

I was coming to love 'these people'.

I would work too long into the night. My blistered mouth and irritable bowel both tired of the crock pot. I cannot yawn in case my stiff jaw pops out. I type by candlelight, I used to be a decent touch typist, now I am down to using one finger. I forget how to spell everything. I stare at that red corrector line, clueless as to what it wants from me.

I do it willingly. I get 'these people'.

And they would get why I do this.

To everyone else who might pass the comment: 'Aren't you great. I couldn't do a PhD and I don't have ME', those of you who (and bless your fortune) can run around all day every day. To those who have careers and families and partners, who go on holidays and airplanes, and go to movies and restaurants and weddings and meetings and mini-breaks and book clubs and choirs and sports events. To those of you who do sports, or do lunch or do your nails or hair, who eat where and when and what you want. Those who can walk through a shopping centre unscathed, and who can cough your way out of a flu in a week (even if you might think you're dying!) To those of you who can use phones and devices and screens without a second thought, or who can leave your property more than once a week.

To you all I say, I am doing a PhD instead *of any or all of that, and I am doing it because it has to be done.*

I am doing it willingly.

I am doing it because I am 'these people'.

7 March 2018

For days we were being warned by the media about a huge storm. It was being named the beast from the east or Storm Emma. It was a level red warning, the highest meteorological warning available in Ireland. It was to be a blizzard, the worst in 50 years. The country was in lockdown. I was as prepared as possible in terms of supplies and back up plans but certainly, it was hard not to be frightened by the messages from the national preparedness committees so I limited my viewing. When Storm Emma did hit you could not have been ready for the nature of blizzard snow. It was unlike any other snow storm I had experienced. The winds and the snow coming high off the ground and into your face made it very difficult to be outside at all. The snow came flying down from the easterly back hill and sat in huge seven foot high drifts against any kind of resistance it met, be it house, tree or fence. The wind roared and did not let up for two days. The wind blew the snow under every door outside and in between every crack or join in any structure. The animals were all well-bedded and closed in, yet when I opened their houses with great difficulty to feed and check them before nightfall, the houses were full of snow. I had to shovel out what I could, lay fresh straw and stuff old feed sacks under doors and in between cracks to try and prevent them from filling up again. The snow was so deep the driveway was cut off completely and there were drifts up to my thighs to get up to the donkeys. I had to put flashing collars on the dogs and keep Peggy on a lead in case they went down into a drift. Of course the dogs adored it and had great fun. All the time the wind was blowing snow into my face and it was hard to walk. I only went out to check the animals, otherwise I stayed in. The actual blizzard only lasted two days but it was exhausting. I needed to use two sticks to be able to get around the plot. When I went up to the donkeys I had to strap their hay onto my back. Two people sadly lost their lives in the storm despite all the warnings. All the time miraculously the power stayed on. The water wouldn't backwash but I had enough to manage. The neighbours phoned to see of I was ok. Luckily we had just got Edgar's ewes and lambs down from the hills the day before. Some of Harry's ewes had to be dug out of the snow. Edgar had a difficult calving, the vet couldn't get through and the cow and calf died.

Dramatically, the snow was also piled up on the inside window ledges of all the windows at the back of the house, which faced due east. As I was cleaning off the snow from the spare room with the window open just a little the wind was so strong that the door which has a dodgy lock slammed shut and I was completely locked in. I only had slippers on but had to manage to climb out a partially open window into a drift with nothing for leverage. It hurt but I managed and the second blessing was that the back door was unlocked so I could get back in. Though exhausting by the end of the second night when the storm was abating I allowed myself to breathe out a sigh of relief. Too soon, when I went into bed the bed was wet in the middle and water was dripping down the light switch. It was 11pm. That was my heart sink moment. I was afraid it was a burst tank in the attic, I tried to get up but couldn’t hear anything. Reluctantly I rang my neighbour Dan, he was asleep but bless him, pretended not to be. He couldn’t physically get down I knew but I just needed to know what to do in case the tank was to come through the ceiling. There was nothing I could do except sleep on the couch and wait until Dan could try and get down in the morning. The drifts were so high that Dan had to walk over the tops of fences in fields to get down to me the next morning. He had to climb my gate and find a way around the drift to get up the drive. Up in the attic he found snow that the blizzard snow, which was the height of my roof had blown in under the tiles. Together we bucketed out the snow and that was the end of my problem. Still I could not face sleeping in that room so I made up a bed in the sitting room.

Some of the neighbours cleared the roads with their diggers and pushed the snow up against the ditches to give seven foot snow walls but the roads were drivable if you had the courage. A couple of days later Edgar came up with his digger and cleared my driveway but it would be another week before I would have either the courage or the strength to venture out. After the blizzard had passed I watched the weather report on the television. The reporter said ‘after what we have had tomorrow will be positively balmy!’ My eyes fill with tears and they spill down my face. Tears of what, relief, gratitude? Some sort of internal tension or pressure I had not let register until now was dissipating. The roof of my mouth blistered over.

9 April 2018

No matter what way I go about it, visits with people, even my closest few, have become increasingly difficult. That list of pending visits that no matter what I did never got cleared anyway has pretty much had to go. The plotting and the planning and the pushing to make it all happen was a constant stress. The price of closing that list as it were is that you rarely see anyone. Is that a big price to pay? No, it seems like the more time passes the easier it gets. Plus people just go on to the next thing.

As I write this one of Con’s cows down the road is really bellowing, he is not a kind farmer which is rare around here. However as kind as my other neighbours are to their animals, they are totally at the behest of mankind. They do not have much of a life really. I honestly think if people saw the reality of it all not to mention the chemicals that they are dosed with, they would not be so quick to eat it! It is all about domination. The animals’ lives are filled with lots of tiny moments where humans make them scared, uncertain or threatened. You can see the ewes panicking to find their lambs when they have been moved from field to field or worse crying when they are weaned from them. When you see large flocks of sheep being herded on the road, a dog often hassling them or jumping over their backs in agitation, you can see their panic, their chests heaving in terror. Harry does not use a dog and when he walks his herd to the village for dipping there is scarcely a sound. The younger, less patient farmers herd their sheep from their jeeps, honking their horns and banging the sides and shouting. All totally unnecessary.

I used to hate seeing those huge trucks carrying the sheep into the factory. Some of them looked at me once, I could never look again, too much fear and suffering and domination. It is all a form of violence and harm.

I have to be aware not to be short tempered with the dogs when I am totally drained and they are giddy or demanding in some small way. I rarely get cross but when I do, there is a fleeting look of uncertainty on their faces, their ears go back and their tails go down. I feel in that moment that I have caused that unnecessary violence and I am remorseful. My aspiration in life for many years now has been what the Hindus call ‘ahimsa’, harmlessness. We are all capable of many tiny moments of mindless harming.

19 April 2018

I have had fierce symptoms the last while, yet I continue to plot and plan with my lists and my agendas. I was lucky to make it to Hacketstown yesterday to post off Sarah’s 60th birthday gift and pick up a few things. When will I ever crack this going out thing? I don’t need much but still it seems to take all my energy trying to keep all the boxes ticked. I yearn to let go completely but I fear that if I stopped I might never get going again. I needed to go within a bit, and to try and get in touch with what might move me on a bit from just continually pushing to get stuff done. It was warm and sunny so I put Gracie and Peggy into the car and headed over to Rhea’s place which is about five miles away. She was delighted to see us. Her place is a little heaven. At 82, Rhea is a peaceful, free spirit. She plods bout her six acre plot on two sticks and has put in a huge bog pond on her land and planted hundreds of native trees. She grows all her own fruit and vegetables. At the bottom of her land sits a wide rushing river with sporadic miniscule beaches where you can stand or launch in to swim. The dogs adore it there, as I do myself. When Peggy first came to us as a very nervous rescue dog she did not sleep much for the first two days and would howl when I left the room. On the third day, I brought her with me to Rhea's and I sat with Peggy on a huge rock in the middle of the fast moving river. After a while Peggy just completely crashed out, she let go, decided to trust and I had to carry her sleeping body back to the car. She slept for another 24 hours straight.

Rhea's thing is no air miles. She just could not be doing with rice or pasta, preferring the native spud. She freezes the surplus from her garden in late summer and eats from that or what is left in the plot in Winter. If someone gave her a pheasant, she would pluck it and eat it. She bakes and preserves. Her father died at 103 and she wears some of his cozy old clothes. A retired doctor, she has a heart condition and carries a do-not-resuscitate order.

It was the right thing to go there today. I needed to stretch my legs and my soul and to remember to do less and just be more. I am considerably younger than Rhea and I choose to take on a lot more than her in terms of the animals etc. but there is a lot to be learned from watching her gentle, peaceful way. I leave her place re-minded.

25 April 2018

It is a month since I made my final mortgage payment, 25 years of payments, the last 15 on my own. I finally made it to Tullow yesterday to the bank, to sort out an electronic payment transfer so I can get the deeds. I struggled with the interaction at the bank. It is all machines there now and they are beyond me. A young woman helps me, I fight back the tears, she doesn't notice. I find myself apologizing, explaining that I have a chronic illness and that I rarely get out. I do this all the time in shops. I am so out of my element and overwhelmed by the lights and the noises, the speed with which they want you to pack and move on, that I make self deprecating comments about being 'just down from the hills', as I shake and drop things or get confused with my laser card. The people just smile politely at me, they are mostly oblivious to what I am saying, it is I who am continuously saddened by my demise. I usually bring a flask on such outings, as I need a few restorative minutes and a cup of green tea, before my jelly legs and muddled brain can attempt the drive home.

The SUSI grant letter was in the post when I got home, I have funding for another year. I apply early so I can put my mind at rest. I am so grateful, and back on the couch by 2pm.

28 April 2018

It was a few days before I could get going again, but yesterday at 5pm I put Gracie and Peggy in the car and went up to the lower trail just to see the little waterfall that has sustained me for years. When I look at it I am reminded that it is always just ‘there’, clear water running over stones and ferns, day in and day out, before me and after me. I am, like everybody else, just a speck in the grand scheme of things. It was lovely just to be out and to see the dogs having such fun. When I got home I planted the blueberry bushes with the ericaceous earth and the raspberry canes in the green tunnel. It is still a sodden mess in there but maybe someday it will turn into a fruit cage.

Earlier today Harry was at the gate. He needed a hand moving a few ewes and their lambs which I gladly did. He walked back down with me and stood the goats while I gave their feet a much needed trim. It make such a difference when I get help like that, especially with their back feet, otherwise it can turn into a bit of a rodeo. Now at 6.30 as I write this sitting on the front step, the sun is out again after huge hailstones fell. I had to make a dash into the tunnel with the vegetable seedlings or they would have been flattened. Typical for April. There is silence now except for birdsong and one of the hens picking at an empty bucket. And now the cuckoo who is back with us since yesterday. I have had to close the doors on both of the animals’ houses in order to force Flora out for a pick. She is grazing now on all fours, she might need medication for stiffness. She is turning eleven. I rummaged out my old mitochondria supplements earlier, I am hoping they might help to build myself up or I will soon be on all fours like Flora!

The sun has just gone in and the mountain silhouettes look incredibly dark. The gorse is just starting to bloom yellow. The swallows flit about for insects and tiny birds jump in and out of a feed bucket. The smell of the turf smoke from my chimney is a bit nauseating to me as I am feeling so low. The dogs are stretched beside me. Suddenly down in the valley, Iggy starts up his tractor and that is the end of everybody’s peace. The dogs hate his dog, who always comes with him and snarls at them through my gate. They are down there now poised and ready.

7 May 2018

It is a bank holiday Monday today and like all other holidays makes absolutely no difference to my life here. The coconut smell of the gorse is unprecedented. I am surrounded by it usually at this time of year but with the exception of down by the little river trail where I walk Zeb, where for a couple of weeks every year the gorse scent engulfs you, I usually have to inhale the blossoms up close. Today, I suppose because of the recent hot days and the gentle breeze, the smell surrounds me as I sit outside with John O'Donoghue's book *Beauty*. I am grateful this 'season of being' has finally arrived after the longest old winter of 'inside-ness'. I remember this 'outside-ness' so intensely and I often carry it with me through the short winter days but feeling it again is beautiful. All the animals are doing their thing. Nan has emerged from her shady house and is picking about the place, bedding straw hanging from her too dirty bottom. She needs to be shorn. The hens are picking the turned over manure heap and the goats are back in their house with fresh straw and a good shake of baby powder to freshen things up. Zeb is dozing in the open hatchback, Peggy is under my chair with Ely beside it. Gracie is on the front step. Swallows chatter, some small birds are still working away at the feeders in the trees. Big grey and black crows negotiate the shorn boughs shaking and pulling at the fat ball feeders. Yesterday's burning heat has been replaced by sun through cloud, which is so welcome. That burning on skin sensation I can no longer tolerate, nor the oppressive, draining feeling it produces. It makes being outside on such days not only unpleasant but unwise. I think of all my loved ones' impending trips to Spain and Croatia and the Canary Islands, and I wonder how they can do it? Yet, I remember the joy it used to give me years ago and how running in 100% humidity in Florida used to take nothing out of me.

Ike and Corabeth don't even hear me when I call to them with treats at the cottage field gate where the hedgerows and the sweet grass and the warmth on their backs more than compensates for any possible loss of my company or shelter here. It is wonderful to see them settling in so well. It is to be wet tomorrow but they will find shelter in their familiar places over there.

A young couple have just walked up my road with a small dog and my lads go cracked at the gate. It is a holiday so the 'Wicklow Way' can attract all sorts from literally all over the world. In recent years, more local running and cycling clubs and walking groups pass by sporadically through the summer. Families park their cars at random forestry entrances and walk. City people are running out of open spaces and are having to travel further around the country on their scheduled off times, perhaps inspired by favourable write-ups in glossy weekend newspaper supplements. Sometimes, with the Irish walking groups in particular, you can hear them long before you can see them coming down my road. They are broken up into little subgroups, talking loudly at each other, not looking at anything around them. Their overpowering mixture of laundry and cosmetic scents lingers long after they pass. I try really hard to feel universal love for them but usually fail.

16 May 2018

Poor old Margo is not well again. Harry helped me to put ointment up her huge udder. He milked the teat a bit first and some nasty looking liquid came out. Then Edgar phoned from up the back hill to see if I could help him bring down his sheep. They really ran him all directions so I went up to try and get behind them for him. Last night in bed as I closed my eyes for sleep I saw such flashes of light that I got up to see if it was lampers or a car. Then it happened again but this time it was like a load of stars, so I knew it was migraine. My reward for doing too much, I had done a lot of cooking yesterday evening. I made roast butternut squash and cashew nut pasta sauce. I made pancake batter and 18 little fairy cakes with pink frosting and sprinkles. They would be a little thank you for all the waste vegetables for the animals that the organic grower keeps for me. This month is the final payment from the SUSI grant this year. That money has been such a godsend. I was able to buy some decent thank you gifts for people who are always so good to me. I bought a stepladder for here so next time I can get up into the attic myself and I bought some fruit trees and berry bushes and a tablet and a decent printer. I stocked up on fuel and provisions and still managed to save 80% of the money.

Through it all the last few days the whole top of my mouth is raw and now the gums at my back teeth are stiff and sore. My glands are up and I have very little power to walk, so I am just doing the basics here. I watched three episodes the other night of James Herriot's *All Creatures Great and Small.* Why do I hanker constantly after those simpler times?

2 June 2018

The last week has been a total heat wave. It has also been a week of rats! I saw one in the goat house, then late at night I saw two scurrying away in the goat house. Then three literally were flying around the goat house including over the goats' backs. Then I saw one in the hen run and another run scurrying from a hen bucket back into the hen run. I had been reluctant to replace Mu for a bunch of reasons but now I was going to need a hunting farm cat and soon. I asked around the neighbour farmers but they don't keep cats as they reckon the cat pee can abort pregnant ewes. One neighbour left a message with an older couple across the fields who have cats and they will get back to me. I went to a rescue centre across the mountain and they had adult cats but I would have to keep the cat indoors for a few months or they would run away. I spent hours trying to clear behind the goat house and hen run and block up any holes or spaces. The next morning there would be fresh dug up soil and a new tunnel way in! It has me bunched.

So I brought some baked goods from the freezer and went to find the cat couple, I had an idea where they lived. As I drove down my driveway two Jehovah's witnesses waited at the gate. I smiled and told them that I was a Zen Buddhist and that my belief was to try to live happily in the moment. They didn't resist that! Ironically, the cat couple's house ended up being a house of prayer! The sacred heart picture was lit up everywhere in the country kitchen where the range was also lit on the hottest day of the year, 'for the hot water'! The elderly man was lying on a comfy old couch watching a match on a flat wide screen television that was the width of the wall. He told me he got it from a guy he knew that had a hotel and when he delivered it he thought he was bringing a door! The cat woman was reading *Ireland's Eye*. Nobody heard me at the door for ages. Eventually, a middle-aged daughter opened it and asked was I here for prayers? Apparently her Mammy has 70 people on her list, mostly with cancer or depression. After some chat the cat woman donned the gardening gloves and got two cats in the crate outside but they were not the two brothers that were assigned to me but two rather sick looking females who tried to kill each other. I suggested we let them out and try again when possible. They were such lovely gentle people, and prayer was included in the conversation at every opportunity. I tried to explain my spiritual way when asked, careful not to alienate them in case I wasn't considered to be a suitable home for the cats. They would try to catch the cats as soon as possible and would drop them over.

I prepared a crate for the cats in the goat house and set up litter trays and bought in food. I waited. The heat wave continued. The vegetables were leaping up in the tunnel and it needed a lot of watering. The guy who sell the hens will be in Hacketstown at the monument on next

Monday so I have decided to get four new hens. The older girls only give a couple of eggs between them now and eggs are great for barter and thanks. I have prepared a temporary area for them as I always do for new hens, it minimizes the bullying by the old hens. I had not planned to get either cats or hens but things change. The tablet I ordered online was delivered and I surprised myself by being able to set it up.

18 June 2018

I got tired waiting for the cats to come. There was a fat rat bold as you like sitting in the hens' food last night. Armed with a warm soda bread I swung by the cat couple's place a couple of days ago and there was nobody there. The weather was still roasting, I was full of blisters and tired from trying to outwit the rats so I wrote them a nice note of thanks and told them not to worry I could now get cats from a friend. It was not the truth but I was just so bunched from it all. I had just taken to the couch when I got home when Edgar rang from the back hill to see would I help him by opening the gates and standing on the road while he drove the sheep down. As I was standing on the road, four Canadian hill walkers from Alberta filmed us with their phones and asked me a million questions about sheep farming. Surprisingly I knew the answers.

I knew my sister had homes for all her new kittens but when I spoke to her yesterday she was happy to re home the new mother cat and her female kitten with me if I wanted them. So this morning with a cardboard box and no real memory of how to get to my sister's town (I had never been to her current house) I set off. After a visit we got the mother and kitten into the box and into my hatchback. I hadn't pulled out of her estate until the cats were loose in the back but the lid was on the hatchback and they stayed very quiet. It was a good hour's drive home. Gloved, I got the mother into the crate in the goat house first and then the kitten. They ate and slept. To the day I die I will not forget the shaking tiredness I felt from the heat and the travel and the plotting and planning to make that all happen. Still, the cats were here now and maybe soon the rats would go.

21 June 2018

The cats are settling in well. I give them time out of the crate in the goat house with the door closed so they can run around together for a while. Then I bring the crate out into the sunshine and then into the shade. The mother cat, I have called her Esther, can be out of the crate during the day but not the kitten Sadie yet. That way Esther won't wander far from the crate. I brought the dogs down one by one on the leash to see if we could all be friends but Esther went feral. Too soon.

Yesterday Harry came with the trailer for Nan, she is to be shorn. She kept trying to jump out so I had to ride up with her. They said they would call me when it was her turn so I could go up and be with her when she was being shorn but I never heard anything and at 8pm they brought her back down all shorn. She doesn't know herself in this heat without that huge heavy fleece. All good things are happening here yet I really do feel rotten.

22 June 2018

I found a dodgy rash under my left breast area and the doctor confirmed today it is shingles. I will have to take the anti-viral medicine. I had to take it before about eight years ago for an outbreak in my mouth and it wiped me out for a month. I could do without that now.

29 June 2018

The cats are so sweet. I can let the kitten Sadie out a bit now and she flies around the place playing. I think I should have called her Joy. Esther is a wonderful mother to her but she hates the dogs and hisses if they come near her gate. Zeb is stressing over them and whining all the time when he sees them. It will take time. In the meantime I just have to be vigilant.

Yesterday I had to go to Baltinglass to the vet to get Esther spayed. I had an awful feeling she was in kitten again and she was. She had the startings of five more kittens in her and Sadie is only about seven weeks old. Luckily we repealed the 8th amendment last month! I was in no fit state to go twice to Baltinglass as that is an hour round trip driving both morning and evening but the next appointment wasn’t for three weeks and Esther would either have given birth or at least be pregnant again if I didn’t go. She was a real little trooper, and didn’t need the plastic collar they sent her home in. All shaved and stupefied she just rolled into the crate and slept it off.

By now as well as the shingles on my body I have a whopper of a painful cold sore on my lip. It makes eating and drinking difficult. I wrote down all the things I had done in the last while including all the people I had helped with medical and emotional problems, the heat wave and the rats and the cats and the research work and I thought, especially with my low baseline and chronic viruses, it was no wonder I got shingles. Hopefully it won’t be too bad for too long.

1 July 2018

I sit here in the gentle breeze and the most tolerable temperatures in ages. Chimes are ringing and all the animals are well and happy. There is food growing in the tunnel and more than enough money to live on. Everywhere I look there are mountains. I have no oppressive agendas or responsibilities, I am truly happy. This is my gift of a life, my trade-off for all the other drama, necessary and unnecessary, the stuff that can fill all the time that is your brief little life.

I have lost my sense of healthy detachment again. I know way more than I need to know about everybody else’s stuff. I have fallen into my old pattern of advising and fixing and everybody has come to rely on it again. I used to spend all of my life tending and giving to others.

I am not self compassionate enough. I love my lot in life but I am going to have to stop listening to others for a while and go back on my own path. I used to think self preservation was selfish but for me now, at 56, it is essential.

6 July 2018

The heat wave continues. The cats are doing great, Esther is out at night now and Sadie has to sleep in the crate until she is old enough to be spayed. I am wiped from the shingles virus and the medication. I need a couple of hours on the couch every afternoon just to keep going. I brought all the dogs to the river for a cool down today. It is a bit of a circus with them all in the car and then the state of it after their four wet bodies. I could hardly walk but I am thrilled I did it.

It is very late these very hot nights when I eventually get all the critters to bed. The goats can pick until 9.30 as it is cooler for them then, but I cannot just leave them to their own devices as Margo still needs help getting up and down. The new chickens haven't fully got the hang of going up the plank into their house yet so they need help. All the in house fighting seems to have calmed. The older hens are in the minority now as poor old Mona died last week and Junebug is still very weak. Kate is the matriarch now. As I watered the tunnel and picked some zucchini and salad leaves I decided to manure the ground well at the end of this growing season and let it rest for next year which will allow me more time at the work. Also I will put more strawberry raspberry and rhubarb plants in the green tunnel, mulch it well and just let it come on also until I am finished the work.

12 July 2018

I was feeling so wrecked I could not get off the couch. I let the hens pick an hour longer than usual. I heard squawking and when I ran out I saw a hen flying back over the wire fence terrified. When I jumped the fence I saw a trail of feathers almost back to the forestry boundary. When I came back and did a headcount I realized the fox had got Amy, one of the new hens. I had just missed him by minutes. I was disproportionately distraught and began to cry. I so rarely take my eye off the ball here and try and keep them all safe. The cement like tiredness that kept me on the couch today that hour too long, I usually just push through. I feel such remorse for the suffering of that little hen. I walked up the road to catch Finn and he has agreed to put up a pallet fence tomorrow to keep the new hens away from the boundary.

18 July 2018

I think the encephalitis must be flared up from the shingles. I have headaches all the time, my spine and neck are sore. I am dizzy and kind of head over toward my left a lot. I am extremely fatigued and nauseated. It is hard to eat much besides porridge.

Zeb made a run at Sadie who slid back down a big cardboard box and into the yard. She got away fine but Esther got up on her hind legs and boxed the nose off him. He took off with a whimper.

It is a huge effort to get up these mornings, I am so tired and sore, but I cannot give it a second thought as Sadie is in the crate and needs to get out and the hens need to be let out of their house which is too hot in this heatwave. I need to set everybody up with shade these mornings. Edgar's cows are at my back fence roaring, they definitely need something, possibly water. He has just gone up to them. It is unheard of for the streams up the hill to dry up but this heat wave is bringing a drought. The grass has stopped growing. Most unusually for this time of year I am bringing a slice of hay bale over to the donkeys in the evenings to supplement their grazing. All around me the neighbours are moving stock around to be closer to water troughs.

With this awful tiredness reading and retaining information has become very difficult again. I am exploring theories and looking for teachers and pioneers to inspire me. Maybe I am looking for it all to be reflected at me rather than me just gazing at my own reflection for a bit.

This post shingles cave-in has been humbling. I have had to lie there for hours lamenting that I am doing nothing. Yet, enough gets done. Most things get taken care of and there is incredible peace. I had one of my long rare chats with Brigid on the phone and as always felt better.

23 July 2018

I am bunched, I stayed on the couch and then when I went into the spare room for something I had to lay down on the bed again! Zeb did something to one of his back toenails the other day and it is very bent now and he is constantly at it. When I got up, I put him in the car and brought him to the river hoping the nail might just fall off. It didn't so when I put him back in the hatch back I quickly clipped it off with the goat's clippers. I got the shakes as my usual courage reserves are drained by the prolonged exhaustion. I made coffee and walnut cake to share with Larry who had insisted on bringing my turf and logs delivery in instalments, so I wouldn't tire myself out trying to get it all into the sheds. Who else fills their sheds for Winter in July? I kept some cake for when I drop down to see Greta who is down for a week in her holiday cottage nearby. Greta rarely passes my gate without leaving some treat or act of kindness at it.

Since the shingles and the relapse it has caused, I have had to rethink things again. I have had to learn to slow and simplify even more and to try and still my agenda based thinking. There has been a shift, because as I look at the overgrowth and shabbiness around me here, I have come to realize that it is really unimportant. If the animals have a good day and I am not too ‘chore driven’ then there is peace. For peace it seems to me, there is if not a price to be paid, then at least a bargain to be made, a trade-off of sorts. Less must get done, things must get shabby, there must be less accomplishing and more rest. I realised that what I thought was simple living still had a ways to go to reach easy living. There must be more letting go.

I looked around me last night and saw all the ‘wilderness’ aspects of my life and the ease that it offered. I finally saw the value in allowing things to be just good enough.

31 July 2018

I am finally able to stay off the couch!

Margo cannot stand up. Her udder is huge again and rock hard but there are no signs of infection. She was out picking till late last night even though she had to constantly rock to keep her balance. I called the vet who suggested an anti-inflammatory which I gave her but I think it is a tumour and it is pressing on her spine. Her back legs are already so weak, she hasn’t a chance of getting over this one. Harry came down to have a look at her and he thinks her time is up too. I rang back the vet to organize a euthanasia visit. It all makes me very sad. It is the downside of farming. Still, Margo came to me at three weeks old with Flora and is eleven now and has had a great life here and she will not suffer. Yet, I cannot stop looking at her. I picked all sorts of brambles and leaves for her and have given her her favorite treats, ginger nuts and rice cakes. She is content and oblivious. I closed them in a little early with hay but just put the pallet across the door. Sometime afterwards I thought I saw her in her usual place, rummaging head down on the compost pile. Sadly, I realized I would never see her do that again. It is the end of an era here, herself, Flora and Nan out mooching and grazing together.

After I had closed in the hens I heard Junebug have one of her turns. When I got to her she had her wings outstretched and her head all the way back wheezing. I had to whip her out of the hen house and dunk her beak into the water bowl until she came round. Who would ever believe all the little ‘ways’ of all the creatures here and how much care I gladly give them? I would hate it to be a chapter in my life that was over. I am aware of how fortunate I am to live with these animals.

It is full darkness tonight by 10pm, we are already moving away from the light.

2 August 2018

Paul, one of the vets finally came today at eleven am to put Margo to sleep. He was to come yesterday but I didn’t find out until 4pm that he couldn’t make it. Waiting is one of the worst energetic drains on an ill person. Well people don’t realize what it does to us, how we try and hold ourselves ‘up’ for a scheduled event, even a social visit, how we have to budget so strategically to make something happen. The emotional and energetic drain of this waiting I can already feel.

Margo was lying down when Paul came, I put Flora out of the shed. I knelt down and put her head on my lap, she was restful and not worried, she is used to injections. I chatted away to her and soothed her, my head buried into hers and she was gone in seconds. Afterwards, I tried to fit her into one of the ton-sized canvas bags that the turf comes in as it is so hot and I didn’t want flies at her. An hour later Harry came down and we fitted her into a second bag and dragged her out of Montana, the little goat paddock, and up the few steps on to the driveway where it will be accessible for Edgar with the digger later. Harry came in for a cold drink of sparkling elderflower water and told me kindly that I could not have done more for her. I had to fight back the tears.

It was 7pm when Edgar came up with the digger and hooked the canvas bag with Margo’s body on to the digger bucket and brought her just across the road on to his land where my donkeys summer. He dug her a fine grave in a lovely spot within full view of my house. He would not take any money saying that I would offend him if I insisted and reminded me of the ongoing help I was to him with herding. I gave him a dozen of eggs and chocolate biscuits for the kids.

I was bunched. I finally checked the post as I waved Edgar off. A letter from SUSI, they are withdrawing all fees and funding. It seems that I am too educated already.

4 August 2018

No sign of a break in this heat wave. Harry and his sons and tiny grandsons were out very early this morning walking the sheep into the village to be dipped. It is lovely to see the three generations being gentle with the sheep. I spent most of the day and evening cooking with some of my harvest, then cleaning up. I peeled and steamed my baby beets, made blueberry and lemon zest muffins and spelt buttermilk scones. I made two types of pasta sauce, roast zucchini and tomato and roast butternut and cashew. I used up the glut of basil and made vegan pesto with sunflower seeds and nutritional yeast. With the sauces and the pesto I made and froze small lasagnes. I sometimes wonder if it is worth all the work, but I still seem to do it.

It is almost 9pm as I sit outside and write this and the sun is only just gone down. I had hoped to get the dogs out for a walk but I have already pushed it to get the cooking and the farming done. They are beside me now and are stretched and content. Animals do not run lists or agendas like us, nor linger long under disappointment.

5 August 2018

Rose came as a surprise this morning. She phoned to say she was 20 minutes away and to put the kettle on! It is hard for my family to know what to do around visits. Since I have had to stop the invites and the plans, they try and come very occasionally at short notice and only stay a couple of hours. I always make Rose her favourite breakfast of scrambled eggs on toast. She comes with all sorts of useful groceries and treats. Mom sends tons of stuff with her too. I was fairly together and had eggs and a few baked goods I could send home with her. I took the opportunity to take her over the mountain to a little hotel that my parents wanted to have their 60th wedding anniversary lunch at so I would be able to go. The place is rustic and homely and seems suitable but I think it is too far for the rest of the family. We will see.

The chat with Rose is easy, since we were tiny we have always been close. I think the company did me good. I have been in my own head a lot for months. Still, as I write this hours later, I can hardly see.

The weather is finally set to change and become more seasonal. This heat wave was the hottest in fifty years and lasted seven weeks. That will have serious farming repercussions later in terms of crop production and crop prices. I always welcome the seasons changing. I have lived in climates where it was hot and dry most of the year and although that seems to be celebrated by humanity I have always felt it to be more of a concern. I like the more gentle temperate nature of seasonal living.

10 August 2018

It has cooled considerably and I try and sit outside but I am just so sore that I cannot stay long in the rocker or out in the sunlight with the headaches. I don't know how to shift this oppressive, drained, sick, sore feeling. I have done the least maybe I have ever done for weeks now, trying to rest my way out of this post shingles fatigue. Yet I get very little true rest and sometimes I think I might consider actively doing less as actually resting. Plus I am so depleted I am unbelievably cross, a bark can go right through me at the minute. I need to constantly remind myself of what I truly believe in and how I aspire to live, and remember the Source more.

It is 9pm and I had a merciful doze. As the sun sets now the dogs are stretched beside me on the front step, they are exhausted from some serious barking at cows activity earlier. It is lovely to hear the pulling and grazing and chewing noises of Flora who hasn't suffered too much from Margo's loss. The cats are on the pallet fencing waiting for supper, I delay it as long as possible as Sadie has to be put in the crate with hers and it is a long night for her. The hens I also leave out as long as possible. Junebug is on her last legs, she is still taking her funny turns in the hen house some nights. Last night when all the other hens were in bed she was by the door of the house with her head down and her backside completely up in the air, she looked like a gonner! There is not much left to pick in the tunnel. I picked the organic calendula flower heads and put them out to dry earlier. Then I can immerse them to make calendula oil for my skin.

Despite my drained grumpiness, there is so much to be grateful for and peaceful about.

12 August 2018

Today is really humid and silent. I have been taking medication to see if I can break the migraine cycle that I have been in and I have gone back on the supplements to see if I cannot build myself up a bit again. I did a winter stock up shop a few weeks ago, for myself and the animals and I thought I might get another one done before the kids go back to school in a couple of weeks, but I must abandon all notions of going near a town, I just would not be able for it. I stocked up on porridge and rice milk, basmati rice and wheat free pastas, green and chamomile tea, lentils and beans, spelt flour, baking stuff, peanut butter, soy butter, frozen vegetables, coconut milk, spices, rapeseed oil, pink salt, rice cakes and pitta breads. That is what my culinary world consists of. That plus the organic vegetables, tofu and vegan cheese I get from Sam across the fields as I need it. I have stocked up on a lot of wet dog and cat food and their treats. Their dry food I can get delivered with the oats and stock mix. It can be unnerving spending so much money in one go, but that is what it takes to be prepared for winter. I have it pretty much down pat by now. If I was a small business, all my funds would be tied up in stock at the moment!

18 August 2018

I am just back from giving the donkeys their evening bucket and some apples for a treat. They were standing right where Margo is buried. Every day I end up rescuing bumblebees from the donkey’s water barrel. For some I am too late, the baby ones rarely survive, but if there is a blade of grass or a piece of fern floating in the barrel the sodden bees will cling to it, and revive very quickly when returned to the grass. These days, I pick a pound or more of blackberries every time I go over as they are at their peak now. Because of the heat this summer there is a bumper crop and they are huge and bursting with juice. I will freeze them until I am ready to make the jelly. It was Zeb’s turn to go today, he loves to get out by himself with me. He is an anxious dog and with that goes the skin rashes and the allergies. Still, we manage with the oatmeal baths, the supplements and the special diet. He is definitely mellowing with age and is completely devoted to me and all the creatures on the farm. To a stranger at the gate he looks and acts quite fierce but that serves its own purpose here.

Big drama yesterday when Edgar's cattle busted out through a hole in the forestry boundary and were travelling the roads. I phoned him only to find out he was away on holidays. He contacted Joe, a farmer who sometimes helps him and between us we got them back up the hill. Joe felled a few trees to block the gap. However it did not stop there, for the next few days they were down at my back fence roaring and they trampled a low fence and broke into my green tunnel. I spent my time trying to herd them back up the hill. None of us knew that Simon, the farmer down the road had put a bull on his land and Edgar's female cows were mad to get to him! It wasn't until the bull was removed that things calmed down. When Edgar returned he and Jim re-fenced the whole back of my land. I insisted on paying for the wire but Edgar did a job that would have cost me hundreds. I made apple tarts for them both and dropped them to them the next day. For some cultural reason I do not understand, there is nothing an Irish man likes better than an apple tart. I have had very shy bachelor neighbours texting me notes of enthusiastic thanks for my apple tarts.

29 August 2018

It has taken the last few weeks to sort out what my academic options are since SUSI pulled the plug on the funding. More waiting and all that goes with that. I am desperate to know where I stand. I have had a good look at the finances, and although friends and family have offered to lend me the fees, that is not an option. I have only just finished the mortgage. It took me years to tidy up financially after the marriage, I do not want any more money worries or debt. I live on very little but I do not owe anything and I prefer it that way. I can manage the fees paid over nine months, that wipes out all the money I saved from last year's grant and will be supplemented by the money I used to pay monthly on the mortgage. It leaves nothing in reserve but I have promised to ask for help if something crops up.

I will keep going.

15 September 2018

Autumn has finally crept in. I thought my thyroid was waning again as I felt so cold in myself but after I lit the range I realized that it was just natural for the time of year. The heat wave summer had gone on so long I had forgotten where I ‘was in the year’!

I have to remember to withhold my winter panic and ‘be’ in the fall of the year which has all its own beauty. There is a whole other season before I need to feel the restraints of winter. This is usually a time of preparedness for me, but now, fifteen days into September, I have all that preparation done. Sheds and shelves are filled with every anticipated need that my mind and my money can allow. Soon, it will not be safe for me to venture out at all and I must retreat even further into survival mode. Only I can understand how necessary if undesired that is, as the consequences will be mine alone to deal with. I have had to learn over the years how to live in retreat and remain on the borders of sanity. This year more than any other I must self preserve in order to be able to do the work.

Many things punctuate the year here, but bringing the donkeys on and off my land divides it. They went over to Edgar’s field just opposite my gate on the 4th of May, the beginning of summer when the nights have finally warmed up and any rain will not be cold rain. They came home again five days ago after there had been a few nights cold enough for starry skies and dark early enough for errant deer shooters on the far hill. They had had a particularly good summer despite the streambed going as dry and cracked as Eritrea. The mountain springs above it had dried up completely, a thing almost unheard of around here, I have a huge water tank over there that Finn keeps filled up for me so they were not under pressure unlike so many other animals around me who had never known thirst before this. Stock everywhere were being moved to wherever there was even a trickle of a stream or to where they could be reached by a tractor pulling a tank.

The neighbours suggested I leave the donkeys out until Christmas, that I should leave them with the pick and the stretch until then. But when I put my hand on Corabeth’s halter five days ago she took off for home, Ike at her heels, without the usual encouragement from Harry at her rear. Out the gate they went, down the short stretch of road, in my gate and straight up the slope into their little patch. That night they slept in the back of their house. Last night as ex-tropical storm

Helena passed through they were safe and dry in their house. I will feed, fodder and muck them out at least twice a day every day now until early May next when the year will divide once again.

18 September 2018

It is extremely blustery today but warm, sunny and blue. It is a lovely day for the critters and these types of days are bonuses at this time of the year. I just gave the animals diatomaceous earth and jam sandwiches, a natural preventative treatment for parasites. They all licked their lips. This unseasonable warmth penetrates my limbs as I sit in the rocker. I have forgotten how sore my limbs are from mending the donkey house and other beyond me chores. I turn my face up to the sun and surrender to rare feelings of comfort. My brain breathes out, there is the chance of a nap, a quick grab at sleep that dodged me all last night and several before it. Other than the wind that rustles drying leaves and billows polytunnel plastic, it is silent. These are the moments that are un-news-worthy, un-reportable when anyone asks me, 'what's new with you?' Yet they mean everything to me. On an aware day there are many such moments, it is the 'way' I live, the way I go through life. It is what sustains me, amazes me, bursts my heart open with love. I rarely think in terms of loss anymore. My life instead has become a fair trade. As I sit in the windblown, early Autumn, four dogs' heads on my lap, I do not have hands big enough for the love. The clouds that are to bring heavy rain and gales later are blackening the blue sky, yet the hot sun still defies them. With my eyes closed I am trying to still my mind, override the many practical thoughts, the plots and the plans that have become so frequent they have become a habit. I am trying to dig deeper than 'have I got brown rice made for the dogs', or running the mental movie of farm chores still necessary before dark. I am trying to get into the place where the work lives, to let it out and speak for itself. I am trying to remember what I have learned from living alongside this illness and to stay in that place so I can work and resist the worldly pulls that no longer serve me well. I try to put gratitude between me and that world so it can no longer bounce me around like its toy.

People close to me are either in or about to go to Sri Lanka, the Greek Islands, the Canary Islands, Florida or the El Camino for holidays. Envy or desire do not even enter my mind. My thoughts are with someone I remotely know whose already operated-on tumour is so rare and so incomprehensible that ten specialists sat together in a room cannot fathom it. I am so grateful that that is not being asked of me in this lifetime (and I have no sense of entitlement to believe that it should not be) that I never consider much above and beyond what I have now and how I live now. Suffering is such a shared consciousness.

24 September 2018

Last night was the first slight, white ground frost. I moved the strawberry plant baskets from the green tunnel and hung them in the plastic tunnel. JD had arrived at the gate with more crates of apples for the animals. I have sorted through them and today my house smells of apples as I have stored the better ones in the spare room. The rest I have put in the tunnel. It is warm in there today and the cats have finally discovered it as a heat trap. Esther sits all puffed up on the wicker chair, while Sadie stalks something imaginary under the plastic that covers the manure. The recent storm put a split in the plastic on the top of the tunnel and as I splayed myself over it earlier in a fruitless effort to tape it up Sadie, ricocheted off the sides in an effort to get up to me. I would be doubtful that the twenty plus year old patchwork plastic will survive this winter. In fairness it owes me nothing. It will cost a lot to replace, too much for the foreseeable future. Nan just came around the corner and head butted Zeb out of the spot along the house wall that she wanted for herself. A hen clucks loudly in the goat house, I think I am losing eggs since the new hay bales came. They lay in every hidey hole and gap in the bales, their wild instincts to lay secretly and privately surfacing. A buzzard cries overhead, crows in its wake are circling something. Small birds twitter. I think the swallows must be gone. I did not witness their leaving this year as in other years, when they line up on the wires for their group departure. It nearly breaks my heart, the thought of that long journey and all they need to ‘know’ to get there safely. I wonder which of them will make it and who will not, things that would never enter their minds as they just fly.

The autumn equinox has passed. Within the last couple of weeks darkness has already moved from 8.30pm to 7.30pm and from now on the light will just shrink and shrink as the earth turns further from the sun.

My nephew WhatsApps from Sri Lanka, he is resting in a hammock in a tea plantation.

Across the valley cut grass lies in rows waiting to be baled, this dry cold week makes such a late cut possible. Fodder is to be incredibly scarce this winter. A couple of hens scratch in the dung heap, while the others lay fanned out in a sun-stripe.

All the dogs are crashed out beside me now as I write. These short days I try and facilitate them being out as much as possible as they are inside so much during the long evenings and nights. I try and give the donkeys a stretch too by letting them roam around the plot even though there isn't much left for them to pick. They will ramble back up to their house when it rains. Flora the goat has recovered from her colic and now I leave the little radio on in her house day and night. The cats and hens keep her company, Sadie in particular loves her. Nan has struggled with rapid onset lameness, I have checked her for foot rot but her feet are okay. She is completely off her feed. I have been able to treat her myself with antibiotic shots and the dogs' anti-inflammatory syrup. She cannot outrun me now because of the lameness.

The only time I leave the property lately is to walk up and down to Harry's farm. I have been helping him to treat two sick ewes up there. One has a swollen face and one is lame. Mostly I just help him to work out the antibiotic dosage. Walking down the road towards my little purple house which blends in now with the fall colours, I wonder at my life and how it has turned out. Nursing and farming have taught me so much that is both useful and meaningful. I love to share all the beauty but I find it hard to explain the underlying daily physical cost. Why? Am I afraid it will sound negative or that I am complaining? Or worse, that people will criticise me for doing it even though I am sick? Will they think I am causing my own problems? How could they know that without it all I would have nothing, I literally would just sit here looking out at life.

Sometimes people who care suggest I give up the animals and focus more on myself. They are well intentioned but are viewing it all from well, busy working and family lives. They can do, see and speak more in one day than I could most months. The caring for and company of the animals that live with and around me punctuates and lends purpose to not only my day but to most of the sixteen years since I have been sick. And what more focus can I put on myself? I have been down every road and thought about this illness from every angle and decided that the best way not to go under with it completely was to fight to keep some kind of life around me. A quiet safe place where I could at worst survive, maybe just wait it out until I or somebody else had cracked it, or at best create some kind of good life for myself. What I have come to know so well but find it hard to convince others of, is that there would be a similar price to pay for any other way of living with ME and a lot less independence with it, and fewer if any moments of self recognition, peace or fulfilment.

Sanctuary

Who would believe the myriad of tiny chores
sequenced and consistent every morning
when the first peep of even half light
gets me straight out of bed
into farm clothes
and out the back door
which only ever closes for wind and rain.
I begin the work of tending
responding to needs and nods and neighs
ushering in and ushering out
until the light is gone
when farm clothes off and loose clothes on
and candles lit
I make tea and vegan food
(Oh the joy when it is leftovers)
and sit at the window and
certain that everyone had the best day possible
I breathe bless and thank.

Most people I know would hate my life
even I think pity me
my solitude

poor health
small means
limitations.
They would be horrified if their days consisted mostly
of repetitious chores
out in all the elements
in muck
shit on your boots or worse
in your hair or under your nails
despite hat and gloves.

But now
there is just the hum of the range
the ticking of the clock
the odd dog snore
restorative silence
my sustenance.

Nothing much happened today.
I spoke to no one.
A neighbour left apples for the donkeys at the gate.

Two cock pheasants were at one of the feeders in the trees.
Four eggs in the lay spot.
Nan sick in herself earlier
asleep now in her bed of borrowed time.

I consider myself blessed for
despite illness and loss
things are easier now
easier because I have found
sanctuary
or maybe I even created it.

Figure 1 The Precious Full Moon

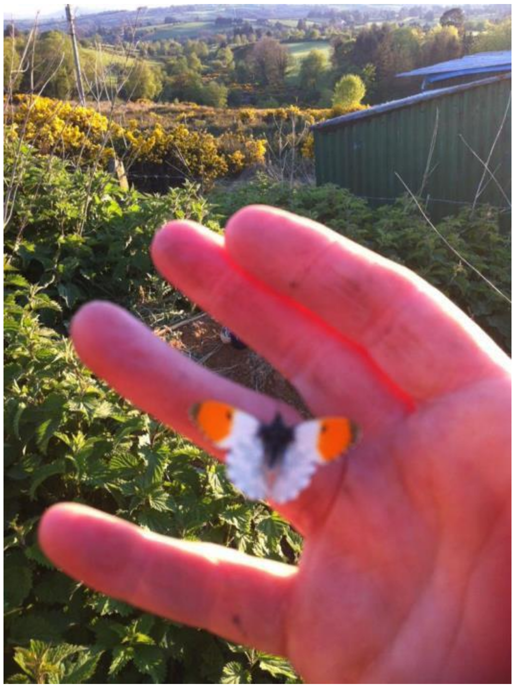

Figure 2 Surrender

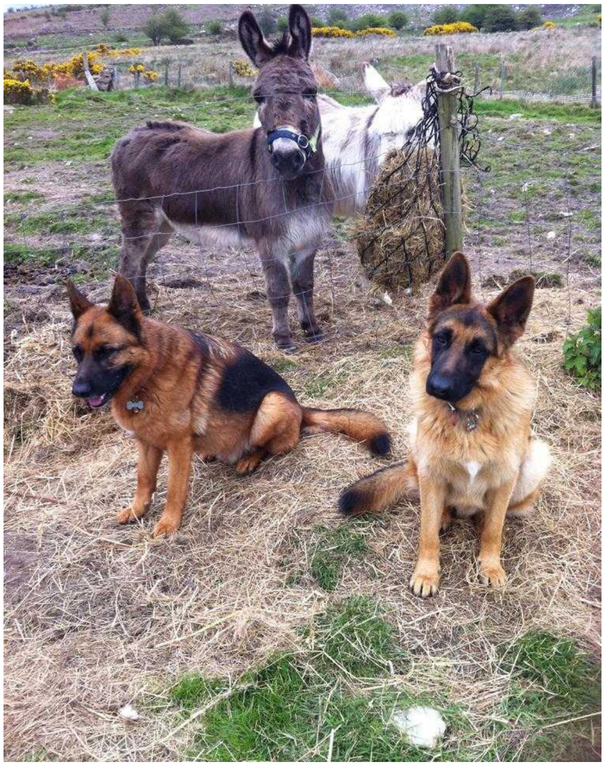

Figure 3 The family

Figure 4 Wei among the produce in the polytunnel

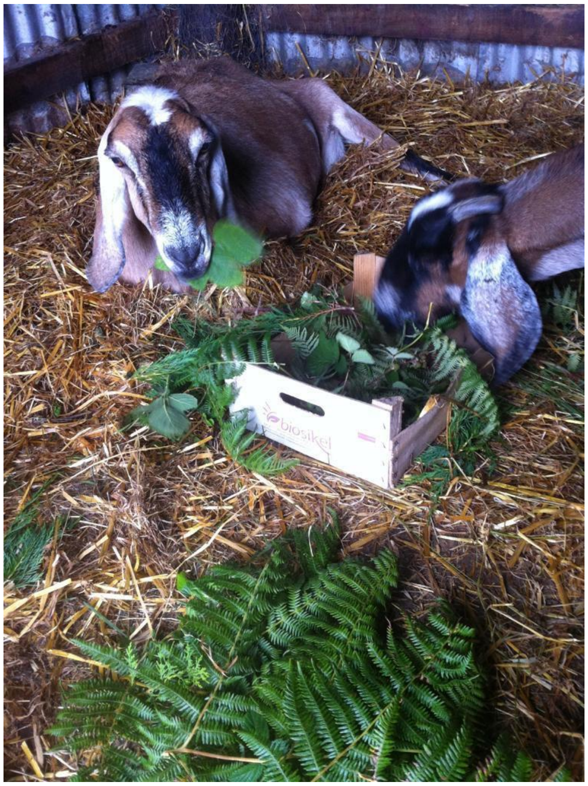

Figure 5 Margo (left), Flora (right)

Figure 6 Gracie (on wall), Zeb (left), Ely (right)

Figure 7 Christmas gifts- Bramble Jelly

Figure 8 Elderflower cordial

Figure 9 Dust bath

Figure 10 View of my little sanctuary from the hill behind

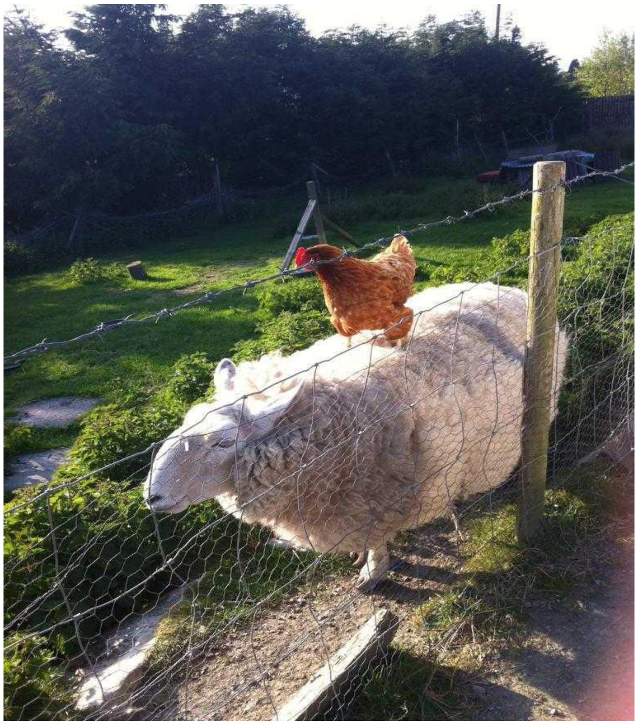

Figure 11 Nan and hen pal

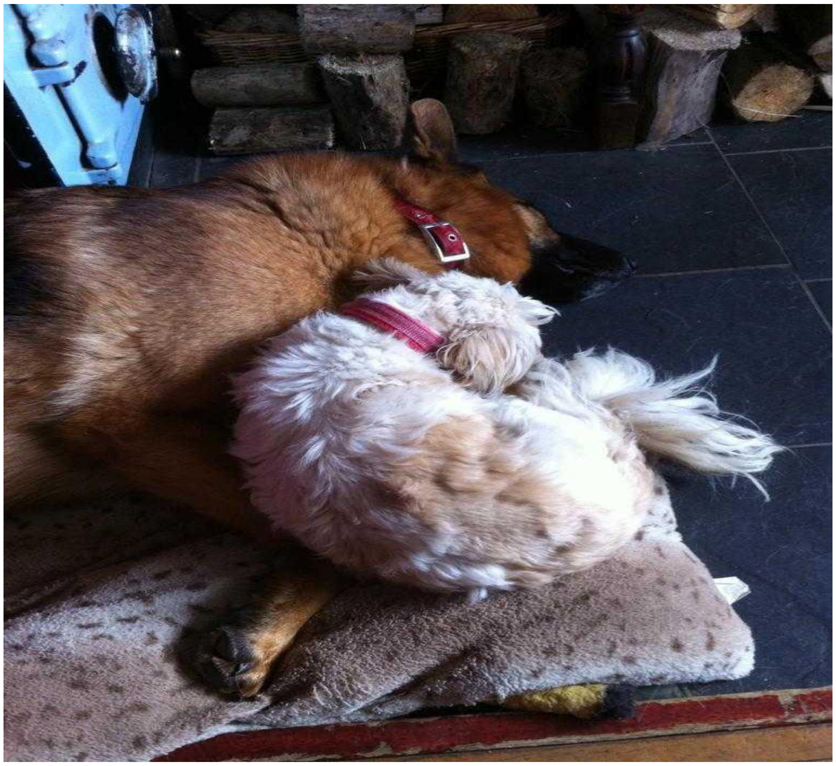

Figure 12 Zeb and Peggy by the range

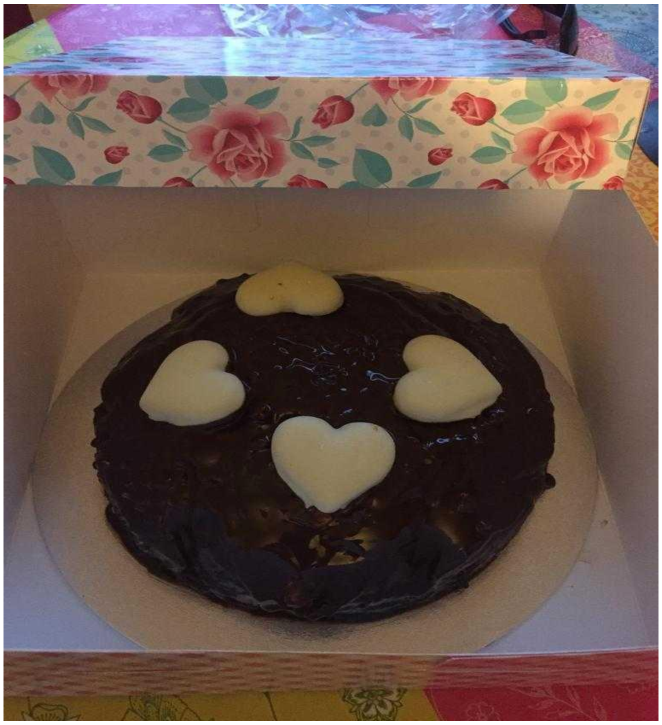

Figure 13 My ways of thanking

Figure 14 Gift of Thanks

Figure 15 Harvest

Figure 16 Home made

Figure 17 Peace on the plot

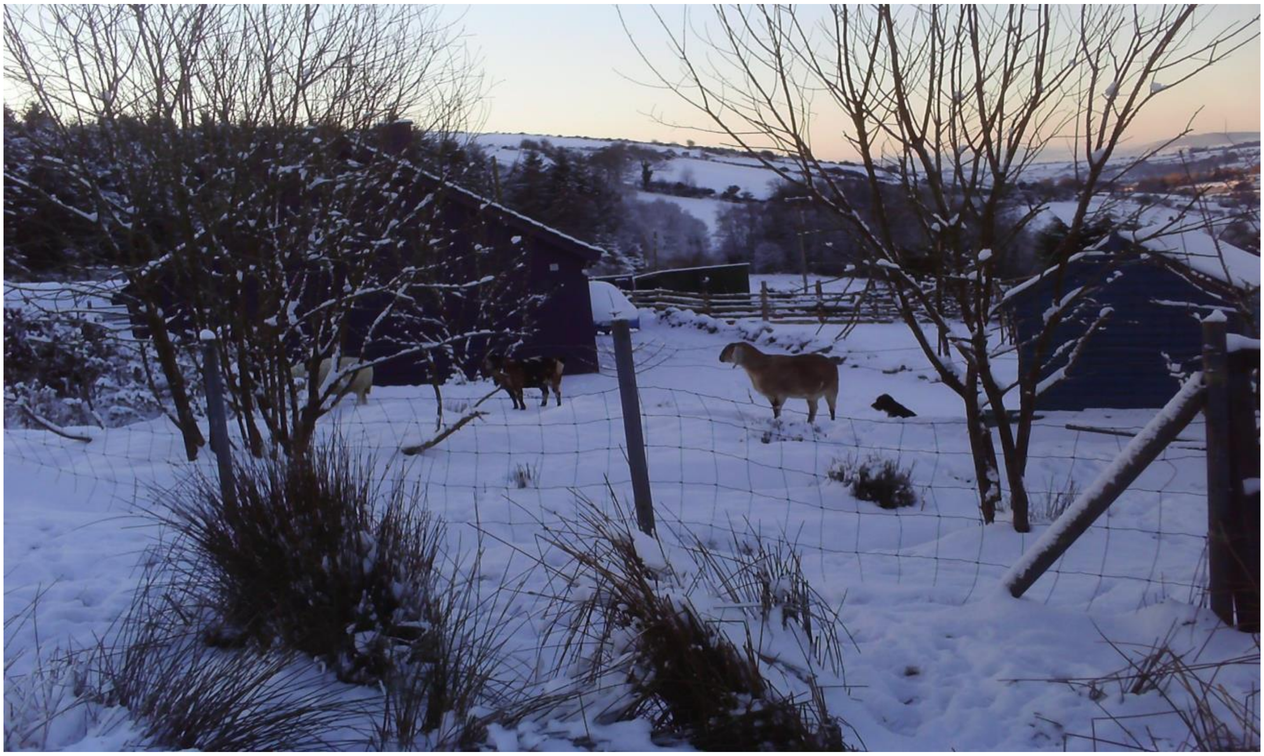

Figure 18 Pottering in the snow

Figure 19 Septic tank issues

Figure 20 Prior to felling - forestry behind the donkey house

Figure 21 Little blind Junebug

Figure 22 Winter in 'Montana'

Figure 23 Snow Patrol

Figure 24 Credence and Wei in the bog hole

Figure 25 Flora

Figure 26 Mu

Figure 27 Home grown

Figure 28 Zeb, Peggy, Gracie and Wei

Figure 29 Ike with mother Corabeth following, across the field for summer

Figure 30 Four eggs in the lay spot

Figure 31 Esther and Sadie - ‘The Rat Pack’

Figure 32 Free Range

Figure 33 Evening

Figure 34 Struggle

Figure 35 Sanctuary

CHAPTER 8

‘STRUGGLE’ UNDER ANALYSIS

The habit of struggle

Struggle can so easily become a habit, even a way of life. A struggle with a health issue if acute, then fixable, can be short term. A chronic illness, by definition, is long term and generally un-fixable. A chronic illness may be manageable, recognisable, treatable and containable although it might impact you to a greater or lesser degree physically. However it can leave your family, work and social lives relatively unscathed.

In Chapter 3, ‘ Struggle’, I write of my experience in the earlier years of living with ME. I live mostly at the moderately affected point of the continuum that is ME, I can tip towards the severely affected point at times but never the very severely affected point, where the person can rarely get out of bed and needs help and care. If you are affected to a moderate or severe degree by ME then, depending on your circumstances, your life does not remain unscathed. The illness can end your ability to have or continue your career or to work for any income, which will have a ripple effect on your material quality of life. It can damage or end your marriage and relationships and it can limit or even isolate you socially. It can essentially draw a finish line under your old life, your old way of being, your old self.

In my case, as my story reveals in the ‘Struggle’ chapter, all of the above came to pass. The struggle was not just about coping with a physical chronic illness which was invisible, contested and largely un-help-able. The struggle was coping with the fall-out from the illness which saw me with an ended marriage, a lost career, and having to battle for medical supports, benefits and to keep a home, while constantly trawling for anything that might help my physical health improve. Ironically it was the reality of struggle itself that I believe put me in the pathway of ME. I was a sitting duck while acting like a swan, gliding gracefully on the surface while paddling furiously under water, just to stay afloat. And then I ‘collided with a pathogen’ (Munson 2000).

An ‘unhomelike being in the world’: the fallout from chronic, invisible illness

Whether you subscribe to the naturalist view of health (which is the primary conceptual model in Western medicine) where you describe health and disease in biological and statistical terms (Boorse 1975), or whether you are in the normativist camp, where you deny that health can be defined in purely biological terms and take a holistic overview (Nordenfelt 2007), as an individual with an invisible, contested, chronic illness, you are probably not going to fare well, or have welfare. Either way, the Western medical pathogenic view sees ‘the human organism as a marvel of mechanical organisation [which] is now and then attacked by a pathogen, and damaged acutely, chronically or fatally’ (Antonovsky 1996: 13).

Within the philosophy of medicine, theories begin with either the concept of disease or the concept of health and then analyze the other concept in terms of the first, which has the effect of making them seem like polar opposites and therefore incompatible (Bluhm 2012: 158). Also within philosophy, phenomenology argues that neither the naturalist nor the normative approach takes into account the lived experience of the illness itself, its meaning for and impact on the individual. It argues for an embodied approach versus a biological, bodily account of illness. It does not reject the bodily account, but argues for the inclusion of the lived body, ‘embodiment’, with the mind within it, not separate from it, as embodied, consciousness (Merleau Ponty 1962). Our embodied consciousness is our way of ‘being in the world’ (Heidegger 1962) and in chronic illness the fall-out is extensively more than physiological. Therefore when discussing chronic illness, rather than focussing solely on the physiological, what is important is to focus on the possible reduction of the impact of the illness on the person’s life – the ‘fall-out’. In order to do this a full account is required of the lived experience of the chronically ill individual, her daily activities, goals, her social and environmental interactions and how they have been compromised (Charmaz 1983). This account can demonstrate just how altered an individual’s agency, not just physically but spatially, temporally and socially, might have become (Carel 2007). Change at any or all of these levels can be profound, and transformation, depending on the individual, can manifest either as a practical requirement for coping or as a desire to create an improvement in one’s conditions. Either way an improved quality of life or way of being is sought. This corresponds to the first stage of Witkin’s (2014) conditions facilitative of change, where the desire for something better outweighs the uncertainty or fear associated with change. The nature and means of this transformative process is as individual as each person's lived experience. Society, that same society from which the chronically ill person is potentially becoming increasingly distanced, has limited prescriptive powers or options to offer.

Many excellent qualitative studies have been done on the nature of chronic illness and understandably there is a wide variety of findings. Qualitative enquiries using interviews do reveal subjective first person reports which can explicate themes and commonalities (Michael 1996; Charmaz 1983). These themes can range from struggle to loss and grieving, guilt, and anger, to a sense of honouring the self, celebrating life and transcending the self (Lindsey 1996; Thorne et al 2002). Philosopher Kay S. Toombs, who lives with MS, distils down what she considers to be the essential characteristics that constitute the lived reality of chronic illness. The five main features Toombs identifies are: loss of wholeness, loss of certainty, loss of control, loss of freedom to act and loss of the familiar world (Toombs 1987: 229). More recent research examines the concepts of health or well-being within chronic illness, concepts developed in nursing studies in the 1990s and later within the phenomenology of illness (Carel, 2007, 2008). These are concepts I will return to later in the work.

My preferred view of chronic illness from within the experience of living with it, particularly in the stage of struggle, is as a sense of 'unhomelike being in the world', of 'a constant sense of obtrusive unhomelikeness in one's being in the world' (Svenaeus 2000: 10) where one's previous sense of embodiment and meaning have become unrecognisable. Svenaeus, in his description of medicine as an 'interpretive practice' sees it as the art of providing a way home for the patient (2001). This, as both a person with and a researcher of chronic illness, I find deeply insightful and touching, but unfortunately my experience as both suggests we are a long way from such a thing yet.

An unwinnable war: battling ME's contested, invisible nature

As discussed in Chapter 2, one of the most distinguishing features of ME as a chronic, invisible illness is its contested nature. Certainly as the vignettes within the chapter 'Struggle' show, this continual contested nature of the illness is the most difficult to manage and in the early years, I would suggest, to endure. It can seem like a succession of battles (when you are least able) big and small, from neuropsychologists and medical examiners to the neighbour in the supermarket who insists you look ‘fantastic’.

> If your neighbour sees you at the grocery store, she assumes you’re always well enough to shop. She doesn’t celebrate the fact that you have managed to dress, put the car into gear and find your way to the dairy case; nor does she rue the fact that when you return home, you may lack the strength to take the groceries out of their bags and put them away. This matter is beyond her realm of experience and education. (Bell, 2000: 29)

Over time, the battles become less worthwhile as you realise it is an unwinnable war. I found myself in situations such as with the social welfare medical examiner, when I was asked to ‘explain’ ME to him, defensively stating that I was not a malingerer, a term frequently found in the earlier ME literature (Wuytack & Miller 2011) and one I found the most ill-descriptive and offensive. I would be as a thief in the night, mal-lingering around Parsons’ sick role, ‘claiming the privileges, social benefits and responsibilities that come from having a medically recognised illness’ (Nowakowski 2016: 1620) without me actually having a medically recognised and accepted illness.

The invisible nature of ME (I think my gravestone might read ‘but she looked great!’) does not resonate with the impression management (Goffman, 1959) that would be understandable with some chronic illnesses. Mostly, as a person who is moderately affected with ME, I am unable to be out at all. If I have ventured out at all, I have embarked on the endeavour feeling okay, but I will not end up that way. Ron Davis, Professor of Biochemistry and Genetics at Stanford University, whose son is severely affected by ME, says in an online video:

> One of the problems ME patients have is that they don’t look sick. If they overexert themselves they look really bad. But you never see them like that because they’re in bed. Years from now the medical community will look back on the dearth of research and the absence of answers for people like this and think, what a stupid tragedy. (Davis 2016)

This ‘Catch 22’ motif is actually present through all the stages of this autoethnography, particularly in relation to going out to complete necessary errands or for any type of social event, or even getting anything accomplished In my ‘struggle’ years I tended to override this reality out of optimism and necessity, but many years later it has not become easier despite all types of ‘proactive coping’ (Ouwehand et al 2007). I would need to transform my way of being.

The first journal entry in ‘Struggle’ on 28/5/2007 sees me catching my reflection on a moonlit night and seeing it as clear, high boned (more from being drawn by illness rather than any genetic type of beauty) and exhausted. Exhaustion will be another motif that threads through all the stages of the autoethnography. Exhaustion is the mother ship to all other forms of tiredness and is either ever present with ME, or just one small activity away. Many illness narratives purposely and effectively dedicate a lot of description to the symptoms of the illnesses they write about. They explain the medical realities of their conditions as they pertain to the revelations they make, in order to increase the reader’s level of understanding (Defenbaugh 2013; McKiernan 2018; Nowakowski 2016; Birk 2013). In my journals I frequently mention (particularly in the earlier stages) the presence of the variety of symptoms that occur regularly, but rarely expound on their detail. The term ‘flare up’ is often used as it covers a multitude and is sufficient for the purpose of this work which seeks to track the reimagining of the self living alongside such an illness, as opposed to coping with it or endlessly trying to cure it. Having outlined the aetiology and clinical and research realities under which ME still labours in Chapter 2, I showed in the four narrative chapters how those realities might play out in lived experience. Now, in putting my narrative under analysis, I contribute an amount of telling to the showing, by excavating the meaning of those experiences and how they contributed to the need to transition around them, highlighting the possibility of transformation rather than transcendence.

Beyond tired: discussing the reality of exhaustion

The motif of exhaustion is worthy of further discussion here as it is central to the ME lived experience and it is not unrelated to the negative impact the contested nature of the illness has on people who live long term with the illness. It is just one more story of misunderstanding. The voices of those living with fatigue are minimal in the literature. It is rarely called exhaustion. It is widely accepted that it is difficult to articulate and describe (Adinolfi 2000). As a symptom of many chronic physical diseases, fatigue has been described as complex, subjective, poorly defined and encompassing cognitive, emotional and physical components (Darko et al 1992; Glacken et al 2003). Fatigue is twice as common in women as it is in men (Sharpe & Wilks 2002). Kralik et al (2005: 375-376), in a qualitative study of 30 women with ME and other chronic illnesses, reported the following descriptions of how some of the participants gave meaning to their experiences of fatigue.

> I definitely feel a crash coming on when I have overdone it. I have a debilitating level of fatigue. It feels like my eyes are being dragged out of my head and all you can do is lay down, as the fatigue is all consuming. It is definitely not just a sensation of ‘feeling tired’ but is extremely debilitating and I don’t think that anyone who has not experienced it could imagine what it is like.
>
> Before the fatigue hits you feel as if you are physically being drained. Like someone has pulled a plug on you somewhere and your entire ‘life force’ is being drained off. Also, often a feeling of utter despair comes at the same time. It is an awful, and often frightening experience.
>
> Fatigue for me is a wiped out feeling...there is no energy or interest in life, just what I call existing...without any interest in what is happening around me, or thoughts going through my brain...as if there is not enough strength in my body for anything. It is a very final feeling.

Laura Hillenbrand, author of *Seabiscuit* and *Unbroken* and one of the most famous people with ME since her groundbreaking essay ‘A Sudden Illness’ was published in *The New Yorker* in 2003, suggests that ME is to fatigue what a nuclear bomb is to a match, that it is an absurd mischaracterisation. I know extreme fatigue intimately and I frequently visit absolute exhaustion, for me they do not live very far apart. Either can be extremely difficult to elucidate for others, as everybody thinks they know tired well. The extreme fatigue of ME I liken to a combination of the bone weary tiredness of ‘proper’ flu, along with the ‘out of it’ vagueness of jet lag, in combination with the bleary eyed, stimuli sensitive, sick feeling that is a hangover.

> *I am in surgical scrubs and running shoes, hair scooped up with my pen through it, stethoscope round my neck and chewing a sugar free Dentyne, I push through the Intensive Care Unit doors at Doctor’s Hospital, Miami at 6.55 a.m.*

> *I am flying down the freeway from Palo Alto, a bagel in one hand, gear stick in the other, my long hair is drying out the rolled down window, ready for a double shift in Labour & Delivery.*
>
> *With my chunky old Walkman in hand I run from home to Hacketstown to Tinahely to home again, 23 miles, marathon prep.*

I can barely remember that person, that self. Now, I would settle for a glimpse again of what it feels like to have energy, to feel somewhat well, able, like I could do something, and then something else after that, without even thinking about it. A person walks mostly without considering it, without conscious effort until they break a foot and then every step must be planned, afforded effort and aided. Can I tell you what it is like to live completely drained or must I wait for you to break a foot?

In 'Struggle' I was still living from that old familiar place of 'push' which had morphed into the 'boom and bust' pattern all too familiar to ME. Despite all my acquired health literacy about and personal research into ME, I remained deeply conflicted about accepting its reality for me and the course of my everyday life. The way was not littered with useful road signs. I was affected by the stigma attached to the illness, and the social response it cultivated (Conrad 1987). I was discreditable, having a deviant attribute that was not visible, and that rendered me 'no longer a whole and usual person [but] a tainted and discounted one' (Goffman 1963: 3). I was undone from the drip-by-drip diminishment by the raised brows and the 'but you don't look sick' (Butler 1999) and the constant need to explain and defend. I was surrounded by lack of understanding, even by those who knew me (Kralik et al 2005). It seemed like nobody was open to releasing me from some of the social roles (Garfinkel 1967) that had always identified me and fulfilled needs in others, friends, family and neighbours (Barroso et al 2002; Small & Lamb 1999). I had not yet learned true self care (Kralich 2002) or strategic management (Bury 1991), nor did I want to be banished into a chronically ill world (Defenbaugh 2008), certainly not the 'hope-breaking' sickness world of ME.

Becoming one: the transition into solitude

As mentioned in the introductory piece to ‘Struggle’, ‘The Blur that is ME’, I was still married in the very early stages of the illness. It is not alone for ethical reasons that I have neither written in nor written out my ex husband. It is also because it is only relevant in this autoethnography in the context that I ended up alone or single, having lived with someone, or been half of a double act for 20 years. In the complicated, complex, contested contemporary world of first world diet and nutrition, the activist and journalist Micheal Pollan, is celebrated for his commonsense take on nutritional advice, distilling his wisdom down into a seven word Haiku:

Eat food
Not too much
Mostly plants

For the purpose of this autoethnography, and to respectfully address my reality of how illness can signal the breaking point of a marriage, I follow Pollan’s Haiku approach:

Twenty years
There was love
Not enough

Becoming single, and being alone over time transitions into a theme of solitude which is examined later in the work.

In the piece ‘Court’, I allude to the prolonged struggle I had in the lengthy and complicated process of getting divorced and trying to maintain my home. Five years of what became adversarial proceedings took a severe toll on my health and I found myself in a prolonged state of relapse from about 2010-2014. I kept no real record or journal entries during that time period and I can only remember it now in terms of new animals found, rescued and loved.

In ‘Struggle’, the animals and the joy they bring is evident and un-requiring at this stage of any analysis. They bring meaning and purpose to an ever-shrinking reality, themes that will emerge later. Overtime, chronic illness can ‘beat people down, exhaust and frighten them’ (Birk 2013: 393). In ‘Struggle’, I had needed to self-advocate too much and it took everything I had. It left me, in this stage of my embodied story, ‘wounded not just in body but in voice’ (Frank 1995: xii). But that is not the whole story, if we can in fact ever tell a whole story in autoethnography.

Through reflexivity, one can only attempt to ‘make meaning of the story retrospectively and to communicate something of the chaos with enough fluency to break its silence but not so much as to dishonour its ineffability’ (Birk 2013: 397). In putting ‘Struggle’ under analysis, I write not ‘from the voice of the confident theorist offering rigorously produced knowledge, but in the voice of the vulnerable storyteller with moral imagination in pursuit of social justice’ (Bochner 2018: 363), and I would add in pursuit of a peaceful self.

An emerging Buddhist practice: recognising the First Noble Truth

My search for a peaceful self had begun before illness. Buddhism had become part of my exploratory path since the late 1990s. I was drawn to it in wellness and it came to sustain me in illness:

> *My growing Buddhist practice is gentler than my old disciplined drive.*

I slowly came to recognise the ease of more present moment living, and the value of equanimity as a more peaceful way rather than reacting constantly to life’s dramas, big and small, and the toll such reactions extracted from me physically. The central message of Buddhist philosophy is that in life there is suffering and in life there are ways to end suffering. If suffering cannot be recognised, it cannot be alleviated (Suzuki 1971). The First Noble truth in Buddhist philosophy is that there is suffering. In recognising that there is suffering, Buddhist philosophy teaches that one should turn *towards* suffering as opposed to away from it (Moon 2004). As we turn towards the struggle or suffering we are letting go of the desire or the grasping for things to be different, which is the true cause of suffering (Gauthier 2016: 134). Accepting things as they are, the *suchness*, the true essence or characteristics of a thing or person (Nhat Hahn 1992: 69) or as-it-is-ness of the life situation, diminishes suffering.

For the purpose of this autoethnography, it was necessary to highlight the nature of the struggles that as a person living alone with ME I contended with, particularly in the early years. These struggles were of a particular type because the nature of ME is controversial, contested and invisible, however they would be similar for many people living with chronic illness. My experiences of the fall-out from the illness, divorce, financial and bureaucratic challenges, is also not uncommon. However, because of how Buddhist philosophy resonated with me, I came to view the fall-out/struggle/suffering, differently. I could have seen the struggle solely in terms of disillusionment, disappointment and disempowerment and, so far in this work, by framing it in terms of conceptual knowledge, that is the view I have portrayed. I had become conceptually ‘conflicted’ about ME’s reality for me, felt burdened by the stigma attached to the illness by both medicine and society. I considered myself ‘tainted and discounted’, misunderstood and trapped in old social roles, ‘banished into sickness’ and ‘wounded in both body and voice’. My old patterns and templates had become increasingly redundant and possibly harmful. However this old, familiar conceptual, constructed knowledge framework/perspective that had been at the foundation of my social, cultural and academic life was shifting. I was starting to see the need for change, some kind of transformation, as a better option.

Central to Buddhism is a radical deconstruction of beliefs (Moore 1995) and a ‘radical reflexivity’ that facilitates the individual’s examination of their embodied knowledge and their phenomenological realities. It allows the individual insight into the nature of suffering and the possibility of liberation from suffering or struggle. With this deconstruction, common also in postmodernism, comes the need for a ‘mindful reconstruction’ (O’Brien 2006) to the extent that we need to be able to live in the world. How did I start to reconstruct or ‘reimagine’ myself living alone with a chronic contested illness? I began to, in Buddhist terms, change my ‘mind’, my way of ‘seeing’ of being, of living in the world.

It is very important here to differentiate between changing one’s mind and changing one’s thinking. It is actually vital given the nature of this illness and, as discussed in Chapter 2, how patients can so easily be psychologised and how they have to linger under the ignorance that still surrounds the illness. You will not ‘think’ your way out of ME, no matter how much CBT (Cognitive Behavioural Therapy) you are advised or choose to have, anymore than you will think your way out of Parkinson’s Disease or cancer. The purpose of writing ‘Struggle’ was to show the lived reality of ME and to endorse the myriad of ways it can effect and change a life. Many people living with ME choose to dedicate their time to a continuous, personal excavation for answers, options, remedies even cures. Many attach to the nature of the illness, advocate for its recognition and validation and an escalation in the improvement of entitlements and benefits.

Many people wait it out in beds and on couches, others suspend their lives in hope. Some cannot cope and some cannot stay.

Conclusion: arriving at the 'wild space'

In putting this narrative under analysis, and on reflecting on 'Struggle' I realised that a turning point had been reached. Everything had been tried medically, from Western to Eastern to alternative approaches. All possible life style changes had been installed including the weird and wonderful. Yet the long term vista seemed to be more of the same. I knew I needed to find a way to 'stay', to live, or better yet to create some kind of a 'good life'. I had begun that shift by adopting the animals and caring for them. However, I had also come to realise that few, if any of the ways, constructs and concepts that had gotten me to this point of my life were going to get me through. It is in this context that I write of changing my 'mind' or reimagining my 'self', transforming into a self that could get me to 'see' struggle/suffering (or at least my sense of identification with it) differently. The struggles I faced could not be eliminated through the usual quick fix society (Ritzer 2010) and possibly would always remain as realities, but in order for me to find an easier way of life, that could contain some sort of meaning and purpose, I had to surrender and stand in the courage to change. I had to stand in the 'in-between spaces of relationality, beingness, chaos, pain and a desire to flourish' (Marshall, 2016). This space, Zen teacher Roshi Egyoku Nakao calls the 'Wild Space' in *The Blessing of the Wild Space.*

> When you arrive at the wild space,
> May you simply be, breathe, and listen - nothing more.

CHAPTER 9

'SURRENDER' UNDER ANALYSIS

> It seems quite beside the point from where I am sitting to argue for this or that point of theory: the arguments have been made and won and lost. We have through their use learned our skills, and no one need now be shocked or shaken, bumped or bruised. What we are dealing with is simply survival, and the simple human need for a language in which to convey a vision upon which survival depends. (Fischer 2016: 65).

Surrendering old self identities

The work of putting this narrative under analysis is to through 'right' language convey the vision upon which this writer's transformation in order to survive depended. How, by reimagining a self it is possible to live alongside a chronic, contested illness, and maybe even consider it a good life? In the losses of chronic illness, particularly in the earlier years of struggle, I had to question my own concepts of myself as a person. In truth they were not actually my own concepts of myself, but social constructs that I had knowingly and unknowingly subscribed to. As a consequence of illness, society tossed them back up at me to view as I began increasingly to deviate from its norms. I may never have considered myself traditional but I lived in a traditional society with traditional social and cultural forms that are repeated over and over again. Fischer proposes that there is a self concept which our society, language and family creates for us and that 'we live almost completely through the filter of this concept' (2016: 59).

Sociologist Anne Byrne writes that it is difficult to extricate social identities from self identity in lived life (2003). As an Irish woman born in 1961, I am not unaware of the 'consequences of dominant social identities for the composition of self-identities' (Byrne 2003: 9). As a woman this is particularly true in terms of the 'holy trinity' of heterosexuality, marriage and motherhood. As a childless woman (involuntarily at the time and as a result of infertility issues) and a divorced woman (definitely voluntarily) I am also not unaware of the reality of 'stigmatized identities' (Byrne 2003: 9). Previous research and lived opportunities have allowed me to explore social identities within women's experiences of infertility/involuntary childlessness through a feminist lens (Delaney 2004). I have also in a collaborative autoethnography explored the experience of the divorce process in Ireland (Farrell-Delaney & Kennedy 2014). Now, in exploring yet another ‘stigmatized identity’, that of chronic, contested illness, my research commitment is to the examination of self identity rather than social identity as a possible locus of change (Byrne 2003). Self identity unlike social identity is less concerned with an examination of roles and stereotypes than it is with values and choices and ‘re-imaginings of self’. Just as the aim of this autoethnography or micro-sociological account of chronic illness is to ultimately connect and contribute to the macro-sociological picture, similarly, the outcome of reimagining or ‘recomposing’ self identities can be consequential for effecting transformation in social identities, which can be beneficial to both the individual and their society.

On reflecting on the early journal entries in ‘Surrender’, I am among the animals and the smell of gorse, the chattering of the swallows is the only sound to alter the silence. There is no sign of the legacy of struggle. However in the years that had passed since the end of the ‘Struggle’ narrative, I had relapsed from the prolonged effects of it and as a result the ‘Surrender’ narrative sees me living in a different way. This change came about both from necessity and desire. In reflexively reconsidering the move from struggle to surrender in terms of Witkins’ (2014) second set of conditions for facilitative change, there needs to be some reflection on what perceptions and understandings might have contributed to the ‘state of affairs’ or lengthy period of struggle and how they could no longer serve me well.

Similarly, in terms of the Second Noble Truth, it would be necessary to identify the causes of the struggle or the suffering. Not the direct cause or reason for the struggle, i.e. ME and the fallout from it, but rather the attachment to the struggle (beliefs and perceptions) which causes the actual suffering itself. Suffering is the add-on to pain or struggle, a social construction that most often takes the form of chronic dissatisfaction with life as it is (Loy 2000).

On analysis of the ‘Surrender’ narrative the key perception or conceptual understanding that I would extrapolate would have to be the belief that striving for and after success and accomplishment was both a self sustaining and social requirement. Under such an umbrella concept of the need to strive and succeed, one might also consider the notions of being good enough, authenticity and happiness. When ME or a similar type of illness hits and remains to become chronic, the old ‘drive to strive’ is slow to leave. It is widely accepted in the ME literature that it is the ‘type A’ personalities that are more susceptible to ME from ‘pushing the envelope' and 'burning out' and then colliding with a pathogen and never getting back up. More relevant is the statistic mentioned in the earlier chapter on ME that the ratio of women to men getting ME can be as high as 6:1. Women are the multi-taskers and the kin-keepers and the plate spinners of the contemporary culture, it is not a surprise that they represent the majority of people with chronic and inflammatory illnesses.

It became clear from the 'Struggle' narrative, there was a deep need for surrender, for letting go in order to slow and stop long enough to consider the 'troubling state of affairs' and its causes. Buddhist priest and writer Norman Fischer teaches that 'in order to solve the problems that we are in, to solve the problems that are us, a taking apart of everything personally and socially is necessary'. This must be done in conjunction with Buddhist philosophy's basic humane tenet that 'the self be clarified and therefore liberated from the grip of wrongheaded views that create suffering' (Fischer 2016: 23-24).

Re-examining feminist expectations

I was sidelined completely from the 'old game of life' at forty one. The belief or assumption that I had based the previous twenty years of my life on, was that I could have it all and that I could do it all. I think I may have even been born feminist and it was central to my sense of direction and ambition. But, in examining my ill serving beliefs, I too needed to ask Donna King's (2012) research question: does feminism provide theoretical supports for women who [must] slow down, grow quiet and let go? Can one be simultaneously feminist and 'nothing special'? (King 2012: 53). King goes on to situate the term 'nothing special' in terms of the cultural contradictions she accuses 'free market feminism' of. By its promoting the relentless pursuit of personal and professional achievement by women, does it consider that such female empowerment can so easily, without intention, subscribe to consumerism, individualism, inequality of life chances and environmental damage (Eisenstein, 2009: 14)? Eisenstein points also to the contradictions in the cultural and feminist messages feminist women received about productivity, fast pace, pushing past limits and denying the body (2009: vii, 220). There is no doubt but that those cultural and feminist messages impacted me and that I most definitely pushed past limits and unwittingly denied my body. Frequently in the literature where the feminist researcher is herself chronically ill often with an invisible illness, the writer is still working in the academic world in some capacity. They often reveal that they are tenured and full time and constantly have to balance the ‘flare up’ nature of their illnesses with the stressful demands of academic work (Defenbaugh 2008; Nowakowski 2016; Birk, 2013; Mc Kiernan, 2018). However, their illness experiences have caused them to put the dominant cultural dictates around the relentless pursuit of personal and professional achievement under the feminist lens. They are largely in agreement that feminism in its subscription to the social and capitalist priorities of success and progression (and what Virginia Wolf describes as the social view of the ill as defectors from the army of the upright) has not led the way in advocating the very real ‘human’ need for ‘retreat, reflection and rest’ (King 2012: 57). Feminism does indeed seem to favour ‘strong, highly productive politically active roles for women in society’ but it also needs to acknowledge that ‘human beings are limited, [and] that some losses cannot be repaired and that above all female strengths and weaknesses must be integrated’ (Hillyer 1993: 15). When as a feminist I did strive to have it all (become special) and yet through chronic illness lost it all (became nothing special to use King’s term) I had to come to know myself in a deeply embodied way and accept over time that as King writes ‘this is my body, these are my limits, these are my priorities, there is only this moment and I can let go of everything else’ (King 2012: 68). Being sidelined for years by a chronic invisible incurable illness, I had plenty of time to examine and subsequently reject the social norms and expectations that I had subscribed to and that had endorsed my pushing past my limits and into exhaustion. This would be the kind of exhaustion whereby if you do collide with a pathogen, you generally do not get back up.

Eisenstein discounts feminist postmodernist analyses that focus on individual and private acts of resistance. However, I argue that listening to women who live with invisible chronic illnesses, and who because of physical and mental disabilities must find ways to renegotiate expectations in terms of achievement or worth, is a very valuable act that has a very public and societal application. In reimagining a self that in order to survive must let go or surrender the old patterns and beliefs that through struggle led to suffering and illness, then surely a gentler, slower, simple more caring and compassionate way of being must be considered? Any society based on striving and success and strength alone, is not accommodating to a body that breaks down, and any body can break down, particularly when ‘there is no clear line of demarcation between working to maintain a reasonably normal and healthy life and the fairly common phenomenon of overcompensation, defying limits at some risk to your health' (Register 1987: 98-99).

Detaching from suffering: the Second Noble Truth and stabbing ourselves with the 'second arrow'

The Second Noble Truth in Buddhist philosophy is that there are causes of suffering and that it is necessary to gain awareness into the nature of suffering for it to have the potential to cease. As mentioned briefly, Buddhist philosophy differentiates between pain and suffering. Pain is inevitable in some form at some stage in life, it is the 'first arrow' that stabs us, but suffering is optional, it is an add-on. Suffering is how we stab *ourselves* with the 'second arrow' (Sallatha Sutta SN36.6). Arrows of physical and emotional pain will stab us at any stage of our lives. However, when we suffer or add on our thinking about the pain or attach ideas around the experience of the pain; (e.g. this is dreadful, I can't believe this is happening to me, when will this end?) we stab ourselves with the second arrow. Trying to escape pain by constantly seeking temporary pleasures and behaviours also causes us more if not so obvious jabs of the second arrow (Schipper 2012: 208). Stopping to see and stay with the experience of the pain (the first arrow) does not cause resistance, or attachment to the desire that things should be otherwise. Direct observation of the pain allows us to detach from the pain, the pain is happening now to me, I am observing the pain, I am not the pain, the pain is not me.

No carpenter
Will build a
Wagon-on-fire,
We make it for ourselves
And ride on it.

Zen Harvest, p. 114.

In the 'Surrender' narrative this sense of detachment had come to serve me well. I had stopped long enough to observe my experiences and although I could still on occasion jab myself with the second arrow, it was no longer a constant jabbing. My mind set was becoming less attached to the old thinking and concepts. Surrender, Eckhart Tolle advises, 'is not weakness, in fact it requires great courage. Through surrender it is possible to be free internally from the situation' (1999: 69). This did not happen for me by just sitting in meditation. It also happened through replacing striving and the 'extrinsic' drive with a slower, simpler way of living, and by discovering a more authentic self. Sitting quietly in Beginner's mind, as an observer with the swinging portal that was my breath, I began the process of detachment.

A process of transformation versus transcendence

On reflecting on the narrative of 'Surrender', there are flare-ups of the illness quite consistently even after I have reduced the exteriority of my life socially and in terms of any acceptable notion of achievement or success. But that is another motif throughout the work, I constantly live alongside this illness. This is not a story of transcendence but of gradual transformation. However in the 'Surrender' narrative, packed around any single sentence of pain is a paragraph of simplicity and beauty, written from a different place, a place of gratitude and contentment and of awareness of a deepening love for the natural world around me.

> *If I didn't have the little home farm that I can manage on my own terms and just had the house, then ME would limit me to being housebound.*
>
> *Underpinning everything is genuine and permanent gratitude. I think that is the legacy from having known constant worry and lack, and what it is to feel overwhelmed and undermined.*

Rohr (2009) names the two main paths of transformation as love and suffering. They break down our ego defences, end our dual thinking and open our hearts to mystery. Suffering was my path to transformation. I was tired of struggle and striving, literally exhausted and I was open to finding an easier, simpler way. Simplicity is central to this autoethnographic narrative. In Chapter 2 I identified the contested nature of the illness as being the worst aspect of the illness in both medical and sociological terms. I identified the extent and nature of the exhaustion as being the most difficult physiological aspect to deal with. I have just now identified striving as the central concept or ideology that lead to what Witkins calls the 'state of affairs' or struggle or suffering. As I reflect on the 'Surrender' narrative, I can identify 'simplicity' as the antithesis of striving. Simplicity as a way of thinking and living underpins ‘Surrender’, it facilitates mindful or I prefer intentional living, the coming to recognise that one can both have enough and be enough without striving. Voluntary simplicity is a slow growing social and cultural movement and is about much more than just living with less ‘stuff’.

The concept of voluntary simplicity

> The life of voluntary simplicity is a life lived consciously, a decision to live in harmony with life, to show reverence for life, to sustain life. It is a life of creativity and celebration, a life of community and participatory democracy, a life in touch with nature and the universal life force. It is a life that has a soul, it is a life that allows the individual’s soul to awaken. (Andrews 1997: 22)

In the ‘Surrender’ narrative, most of my life happened ‘behind my gate’. This was born of necessity, in order to minimise the fall-out from ME, but increasingly, it was born also out of desire and the belief that I was detaching from an older ‘extrinsic view’ of living, and moving towards a simpler ‘intrinsic’ way of living. Monopolis (2010) defines extrinsic pursuits in terms of the need for acceptance, reliance on a consumerist culture, acquisition of possessions and concern with image or status. Intrinsic pursuits include personal growth, autonomy, mindfulness, affiliation, meaningful work and volunteerism. In my life before ME I would have been aware of the extrinsic nature of my pursuits and would have aspired towards a foothold on the intrinsic continuum. However, I could not seem to get there until I was ‘kicked to the curb’ by illness. Voluntary simplicity is achieved by ‘deliberately and mindfully reducing one’s consumption of goods and services, living with fewer possessions, cultivating non materialistic sources of satisfaction and meaning, and developing deeper connections with one’s social and ecological community’ (Monopolis 2010: 14).

One of the greatest initial contributions simplicity made to my efforts to transform my life was that it involved a deliberate organisation of a life for a purpose (Gregg 1977) and my life, drastically altered by illness and therefore up for negotiation by society in terms of worth, began to take on new meaning, ‘of greater purpose, fulfilment and satisfaction’ (Elgin 1993: 25). In ‘Surrender’, I had on occasion found myself in the familiar ‘Catch 22’ situations, particularly in regards to visiting with other ‘humans’. I had reduced all the running around I used to do for and with others. I had shopping down to a weekly or bi-weekly event and much less in the deep winter months. Still, family occasions and red letter days were a conflict of interest, my interest in them versus my self interest. I still became ill after anything that required a change of pace or location, or when I had reverted to that cheery, ’can do’ woman that was by now inauthentic. When I lived a simple, slow life on the plot with the animals, growing food, cooking, pottering in and out of all weathers, fully aware of my surroundings I did not get as sick as when I had to rise up and out and beyond all my actual capabilities, to connect in with a way of life that was considered socially normal and even expected. The trajectory of a normal, energetic life is horizontal, progressing easily from one thing to the next. The trajectory of my life had become what Eckhart Tolle (1999) calls ‘vertical’. I was remaining in the same place with a downward deeper trajectory with little sense of the past behind me or the future ahead. My life was ‘becoming more deliberate’ (Luhrs 1997: xiv) and subsequently more authentic, which, with an energy depletion illness such as ME proved beneficial. It proved beneficial in so far as I was constantly being ‘catch 22-ed’ and wasting energy I did not have by still ‘pretending to be someone other than who I was’ (St James 1994: 184).

Simple living is a lifelong process where the choice is to turn away from the search for power and status and achievement and the constant need to acquire, and to ‘move towards an authentic life where one might find peace and meaning’ (Pierce 2000: 25). Without an authentic self we are always in search of a ‘pre-packaged self’, usually supplied by the high street and which is rarely concerned with an ecological footprint (Andrews 1997: 73). The value of simplicity and the refining of the authentic self does not stop with the individual and any benefits are not confined to the individual’s life. There is a profound social justice component to a life lived in voluntary simplicity as the benefits ripple out into society and the planet. It can lead to a paradigm shift from a society of conspicuous consumption to a society of sufficiency and enoughness (Monopolis 2010: xviii). In choosing to live lightly and to consume less, we greatly reduce energy use, resource depletion and habitat destruction (Burch 2000: 81). However it must be mentioned that alongside those of us who are in a way privileged enough to choose to live in voluntary simplicity, there are the many millions of humans who must live in involuntary simplicity or poverty (de Graaf, 2003). The individual is the ultimate arbiter of the reasons and way one lives a voluntary simple life, but within its intrinsic pursuits abides the greater concerns and considerations of social justice. How we live our lives either ‘symbolises, validates and facilitates our concern for the hungry' (Sider 1997: 187) or it does not. In simple, intentional and conscious living we try to position our way of living so that:

> Never again can one make a decision about buying and using without thinking about the poor. They lurk in the new car lot and behind the rack of fall outfits. They sit beside you in the restaurant and wait for you in the polling booth (Longacre 1980: 26).

The voluntary simplicity movement is not an organised movement as such but more of an alternative cultural movement that seeks to change aspects of individual behaviour in terms of how they partake in consumerist and materialistic pursuits and what the consequences of their behaviour might mean for society and the environment. How each individual lives serves as a possible example (or they could be an exemplar) of another way. There is no appetite for indoctrination of others. A 'way' of life is proposed, as opposed to a 'style' of life. As befitting a 'slow life' practice, it is preferred that the invitation for change comes from within the individual and that any following spreads slowly, as it is more likely to stand the test of time (Monopolis 2010: 210). Living simply takes longer, and it takes into account the 'vital need of [all] other creatures' (Devall 1988: 84). Living simply is not about scarcity or self deprivation. It simply offers an alternative to the dominant consumerist philosophy that 'ever expanding material consumption is the best way to meet one's needs, enhance one's life and seek one's identity' (Monopolis 2010: 16). Living lightly can mean living frugally but not necessarily cheaply. The idea is to purchase and consume goods that were made in ways that do not damage the planet by people who were not exploited in their making.

Hannah Hauxwell: an exemplar of simplicity

In the narrative 'Surrender', I refer to Hannah Hauxwell and the inspirational effect she has had on my life; both of us in various ways running a small holding, alone in remote locations. Hannah died in 2017 at the age of 91. She came to the attention of the public after she featured in a Yorkshire television documentary made by Barry Cockcroft in 1973, *Too Long a Winter*. It featured a forty six year old white haired woman trying to pull a large uncooperative cow through the snow. Hannah lived on a dilapidated small holding, in the most northerly tip of the Yorkshire Pennines. She captivated the audience by her gentle manner of speaking that was from an earlier century, and by her wrinkleless face and piercing blue eyes. She spoke almost poetically about her love for her farm and its surrounding countryside. Her animals were her only companions. Hannah had a stream for water forty yards from her cottage, and no electricity or bathroom facilities. The winters there, were extremely harsh and they came early and stayed late. She maintained that 'in Summer I live, in Winter I exist'. She only had a coal fire in her kitchen on which she cooked, and an oil lamp for light. She depended on the cow calving and very small rent from her fields to generate and annual income of £280. Her shopping/grocery bill was £5 per month, her provisions were left by the grocer on a wall that was a long and difficult walk away. Life and goodness shone out from Hannah and she had a simple philosophy of gratitude and contentment.

> My favourite place is here, down the road through the iron gate. I stand here and watch the seasons come and go. At night moonlight plays on Hunter Beck...and the waters sing a song for me. I know this place will always be loyal to me. If I have nothing in my pocket I have this'. (Hauxwell & Cockcroft 1991: preface.)

Hannah was more than an 'exemplar' for me, she was a kindred spirit. Somehow, she managed by her gentle ways, to take the last bit of 'striving 'and worry out of me. Although my circumstances would not have been as deprived as hers, I would still be considered to live below the poverty line. In 2018 in Ireland, the average industrial wage was 745 euros per week, I live on 29% of that. However Hannah confirmed for me that I had enough. When the water or electricity would go in a storm, or when the septic tank was broken and I had to avail of a bucket, I would always think of Hannah and how she managed gently and peacefully, rather than focus on the 'lack' of the service. As I moved around my little farm, often in pain like her and often in old torn farm gear like her and always alone like her, I would think about how far away from the prescriptive 'norm' I lived. I too consider my animals to be my family and I deeply love where I live, and when I too have very little in my pocket, I think about where and how I live, and it always seems like more than enough.

The concept of 'enoughness'

'Enoughness' as a first world concept is recent. Enoughness, as a First Nations or indigenous peoples' concept is ancient. Western economic thought for centuries now has not concerned itself with enoughness but has instead only concerned itself with growth. Indigenous societies conversely have only ever been concerned with enoughness, sufficiency and sustainability. Rebecca Adamson, an indigenous economist and founder of First Peoples Worldwide, argues that the contemporary Western edict of sustainable growth is a fallacy. There can only be either sustainability or growth (2016). A contemporary Western, and in particular North American notion of not-enoughness (as in not being or having enough) or the recovery from the same, is addressed by Weisberger online (www.enoughnesssessions.com).

In the narratives I often mention having enough and being genuinely content with enough, in the awareness that I had more than many millions of others did. I considered the concept of 'enoughness' without knowing whether it actually existed as a concept or for that matter, even a word. Outside of indigenous economics or commentary on the 'way' of indigenous peoples, little discussion of enoughness could be found. The indigenous world view and subsequently its economy, include the concepts of interdependence, decentralised production, responsible resource management, abundance, kinship and of most relevance here, a belief in enoughness (www.ajlinks.ca/enoughness). Enoughness and the notions of sufficiency and sustainability are born out of the notions of interconnectedness and interdependence, which are central to the way of life of indigenous nation and first world peoples. Indigenous peoples' territories span 24% of the earth's land surface yet they are home to 80% of the world's biodiversity. This is not coincidence and Adamson argues is not a result of indigenous people's lack of technology and means to destroy the land, but moreover, their genius stewardship of the land. European and American economics is founded and built on domination, individualism, the notion of private property, accumulation and growth. Indigenous economics is founded on tribalism, kinship, balance, sustainability, communal usage and spirituality (Adamson 2016).

Sachs (1999) quotes the Worldwatch Institute assertion that the amount of fossil fuel used in one year took a million years to produce. An economic world view in which society 'puts production highest on its list of values and seeks "the good life" through the expansion and acceleration of their economies' by default considers 'less commodity-intensive, less professionalised, less speedy societies' inherently deficient (Sachs 1999: 2). Yet, these same societies preserve for all of 'us', 80% of global biodiversity. In simplifying my life, becoming more authentic and aware of just my own ecological footprint, I had come to recognise a sense of enoughness in my own life: a sense of having enough and of things being good enough. This ultimately would lead to me answering in the affirmative that it was possible to live alongside an illness such as ME and to consider it a good enough life.

Becoming embedded in nature

In the surrender narrative, I write of the forestry department cutting down large areas of softwood pine forests where buzzards were nesting. I write of rabbits flattened by fast cars and insects drowning in buckets. Mountains are covered in snow, storms pass through, hens die, silage harvests are cut, seasons come and go with full moons, birdsong, and cats and dogs at my feet. Slower, simpler living can facilitate the time and the mindset to consider deeply ‘the vital needs of all other creatures’. The old conceptual view of standards of living can give way to the notion of ‘quality of life’ which deep ecology measures in terms of ‘wellbeing....of the whole community, not just human beings’ (Devall 1988: 85).

In reflecting on the ‘Surrender’ narrative it becomes clear that my universe is largely behind my gate and consists of the hills behind me, the valley in front of me, the mountains all around me, and fields and growth and trees as far as the eye can see. Above me are vast expanses of sky where buzzards and red kite and myriads of other birds soar and where night is black enough to see millions of stars and the occasional planet. The seasons and all the ways that they change, impact me on a daily basis. I have become embedded in nature. My personal happiness, my embodied reality, my sense of well-being, my ‘self’ has become deeply entwined with the well-being of my environment, of life around me, seen and unseen.

Voluntary simplicity endorses a sustainable lifestyle, a lifestyle of ecologically responsible behaviour (ERB) aimed at minimising the use of resources, reducing emissions of waste and pollutants and not jeopardising the needs of future generations (Monopolis 2010). When I am living on the time line of nature, concerned for its well-being, immersed in its seasons, surrounded by its creatures, I have no thoughts of being a ‘tainted or discounted one’, no thoughts of stigma or role or wounded body or voice. I am not attached to the illness of ME, I am not labelling exhaustion or pain or inability. I am aware instead of a sense of authentic happiness, of a more sustained underlying sense of satisfaction with [my] life circumstances, which have become much more about meaning and engagement (Seligman 2002). Research proves that the focus on intrinsic values and goals produces greater well-being and happiness than those who focus on extrinsic goals (Kasser 2002; 2004).

The lived experience of chronic illness had brought me to understand my own sense of embodiment; how my behaviours and motivations thoughts and feelings can be both generated and constrained by my physical nature (Stevens 2010). But in the ‘Surrender’ narrative and from that point on, I had willingly become embedded in my surroundings. I saw nature and the environment as ‘real’ life and as such a different ‘self’ understanding came. The environment ‘is not a scene through which we move but the medium with which we are embedded’ (Stevens 2010: 266). By accepting mind as a physical manifestation of a physical system (embodiment) which is itself embedded in a physical environment (embedment) then our location or environment can fundamentally change us, our minds, our selves. In my case, as evidenced in the narratives, the effects of the landscape and natural environment in which I found myself fortunately embedded, were fortuitous. My earlier experiences of chronic illness had always seemed like an ‘unhomelike feeling in the world’ (Svenaeus 2000: 10). Ecology comes from the Greek ‘oikos’, which means ‘in my house’. When a deep connection with place (in my case my home-place and its surroundings) can engender feelings of ‘love, reverence, awe [and]....of kinship’ it becomes possible that we can feel ‘like we are merging with or becoming one with ....a place’ (Stevens 2010: 267). My tiny plot was to me, always about more than just property, it was about ‘place, and at-home-ness’, and living in ways that made sense…‘being [myself] in a place that was somehow as much in me as I was in it, it was about belonging’ (Godlewska 2013: 226).

My deep connection to my environment and to place resonates with Chalquist’s (2007) notion of ‘terrapsychology’, or the deep study of the healing presence or soul of a place including the ‘things and creatures within its ambit’. Walter (1988) argues that our places cannot heal us until we learn to experience them more deeply or until we can ‘weave our personal stories into the larger story of place’ (Chalquist 2009).

Conclusion: embraced by the ‘wild space’. Nothing is not the path

With the stillness and slowness of simplicity and the sense of oneness with nature, my rational mind, the small I, the relative mind (which sets itself in relation to other things) my former trained, dualistic, conceptual mind, was yielding. It was yielding to the Beginner’s mind, the non-dualistic ‘original mind’ of early zazen or sitting in gentle Zen practice. A practice of trying to empty the mind of self-centred thoughts of achievement, in order to find a more compassionate mind which is true to ourselves and in sympathy with all beings (Suzuki 1971). In attentiveness, stillness, awareness and sitting in zazen practice, the mind is observed rather than analysed. In ‘sitting’ I increasingly began to ‘develop more wisdom, a seeing more deeply ‘in’ to cause and effect and the interconnectedness of things’ (Kabat-Zinn 1994: xv). There were, as Witkins’ theory advised, better options and new ways of being. As the Second Noble Truth teaches, suffering can cease. ‘Suffering is necessary until you realise it is unnecessary’ (Tolle 2003: 118). It is possible for the mind through present moment living to empty and rest in non-judgemental and non-dualistic thinking. In non-dualistic thinking the mind sees things as they are, without the constant commentary and categorisation into right or wrong or good or bad.

I was beginning to connect with my own deepest nature and original mind through ‘the gentle, appreciative nurturing way of mindfulness or heartfulness’ (Kabat-Zinn 1994: 7). I was trying to see everything as the path, for ‘nothing is not the path’ (LIAO-AN).

> May the wild space be a threshold
> Beyond your habitual tendencies-
> The need to understand or control,
> The fear of self–doubt,
>
> The thicket of opinion and belief-
> May the wild space hold you to its bosom.
>
> *The Blessing of the Wild Space*
> Roshi Egyoku Nakao.

CHAPTER 10

‘SEEING’ UNDER ANALYSIS

Seeing that ‘suffering can cease’

Witkin’s third condition facilitative of transformative change is the recognition (seeing) and availability of a constructive alternative to the ‘state of affairs’ or the struggle or suffering. Alternative positions can ‘help us make sense out of a situation in ways that the previous ones did not and they enable us to move forward’ (2014: 310). In Buddhist philosophy and the Third Noble Truth ‘suffering can cease’, we learn to ‘drop our attachments’, stop stabbing ourselves with the second arrows and ‘open our hearts’ (Schipper 2012: 222). True happiness is possible and we can develop wisdom and compassion for our self and for others.

On reflecting on the narrative in ‘Seeing’, it is evident to me that the transformative process was in ways ‘held back’ by the necessary ‘looking’ that I had to do once again, at the nature and reality of ME as a chronic contested illness in order to do this research work. I had distanced myself, or ‘detached’ from the personal struggle I had had with the illness in the early years which has been discussed in the earlier analysis. However, the deep research brought up again the conflict between:

1. Me having somewhat successfully distanced myself from the illness and managing to live alongside it:
   …truthfully I think nobody, myself included really wants to write about ME but prefers to distance themselves from it in an effort to try to just find a way to live with it in peace.

2. Me not wanting to be the poster girl for ME:
   I am struggling with this ME research. I neither want to dwell there too long nor be the poster girl for it.

3. Me trying to distance myself from the ME ‘world’ yet realising in the epilogue that:
   I am these people.

Vulnerability and invulnerability

Mcintyre (1999:8) criticises Western philosophical tendencies to valorise what he calls ‘independent rational agency’ or an agent who is considered active, autonomous, confident and in pursuit of goals. He argues that this approach ignores a fundamental reality that human life is punctuated by affliction, dependence and vulnerability, and that this trio of truths are particularly true for the very young, the very old and the very ill. However Carel (2016) and Kidd (2017) argue that this trio of truths is in fact the concern of all self-reflective human beings. Kidd (2018: 391) refers to affliction, dependence and vulnerability as ‘experiences of adversity’ and argues that such experiences are ignored or downplayed in favour of the potentiality of the independent rational agent who is healthy in body and mind and is the best representation of the ‘flourishing life’. Mcintyre agrees that this representation is at best incomplete and at worst a distortion. It is akin to Ehrenreich’s (2009) warning about ‘bright siding’ (which is particularly relevant to chronic illness narrative) where the desired emphasis is on uplifting stories of inspiring people where no mention is made of the ‘dark sides’ of an illness or problem, due to the ideology of positive thinking, which is strongly culturally endorsed, certainly since the turn of this century.

In ‘Struggle’ I began to see myself as vulnerable, and to view my state of ‘separateness’ from other humans as a difficulty. In ‘Surrender’ I had come, through my spiritual learning and transformative process, to see everyone in life as vulnerable. I had come to recognise that ‘independent rational agency’ was itself in fact a vulnerable condition and that all sentient beings suffer. But those realisations had been somewhat subsumed again by the rational mind work and conceptual thinking that the research work required. I had previously seen through the social illusion that invulnerability was our human default setting and it was illness that took that away to leave us vulnerable. I needed to remind myself of that in ‘Seeing’.

Bluhm’s (2012) research reworks Gilson’s (2011) work on vulnerability and social oppression to expose the binary opposition between vulnerability as being ‘weak and subject to harm’ versus invulnerability being ‘the only way to be strong and competent’. Gilson argues that social structures and practices encourage us to ‘learn the habits of invulnerability’ as society only takes us seriously if ‘we demonstrate that we are in control and self-possessed’ (Gilson 2011: 314). Invulnerability however is fearful of change whereas vulnerability facilitates ‘a kind of openness to being affected and affecting in both positive and negative ways' (Gilson 2011: 310). Vulnerability facilitates the gap between the thoughts that Tolle (1999) argues permits present moment living, or, to borrow from Leonard Cohen, provides the crack where the light can get in and facilitate change. To be born is to be vulnerable, and anything at any time can knock the scaffold of invulnerability that we build around our lives. When illness comes, particularly lengthy chronic, invisible illness, the invulnerable state of health which is perceived as the normal desirable state is replaced ideologically by the abnormal, vulnerable state which is highly undesirable (Bluhm 2012: 150) as it can frighten the masses by shaking the scaffold that protects the preferred societal illusion of invulnerability. The legacy of the ME research effort in 'Seeing' sees me asking: how can I live in peace and happiness when so much has been lost?

Can you be ill and happy? Discussing creativity, adaptability and a sense of coherence

I was born with the happiness gene. According to the father of positive psychology, Martin Seligman, we all have a set range for happiness that is particularly situated or pre-determined. Possibly half of your happiness score is determined by the score your biological parents would achieve. Our set range is a fixed and inherited level of happiness, a set point on the 'happiness thermostat' that we will instinctively revert to after a period of unusual sadness or joy (Seligman 2002). I am fortunate to have come from fundamentally happy folk. In the measurement of subjective wellbeing (SWB) the research shows that only the individual can experience their emotions or feelings and therefore judge whether they are happy or if their life seems worthwhile to them. Within (SWB), if an individual believes that they are happy then they are (Diener et al 1997). Long multi-questioned surveys are not carried out, the volunteer is generally just asked, at this point in time are you happy in your life and does it seem worthwhile? (Monopolis 2010).

Positive psychology defines itself as 'the scientific study of the strengths and virtues that enable individuals and communities to thrive' (Seligman 2002). It is founded on the belief that people want to lead meaningful lives. Its formula for happiness is:

$$H= S+C+V$$

H or health equals S (your set range) + C (your life's circumstances) + V (factors under your voluntary control.

One of positive psychology's central concerns is the individual's positive emotions. They advocate for contentment with the past, happiness with the present and hope for the future. As I reflect on the 'Seeing' narrative, I can find no discussion of contentment with the past and hope for the future. Most things described happen, and are experienced and considered in the present, in the now.

The phenomenologists ask, can you be ill and happy? (Carel 2007, 2008; Kidd 2012). Their answer is yes. However Carel argues that such an endeavour requires adaptability and creativity. Carel chooses adaptability as a term in deference to the term adaptation which is used in evolutionary biology. She describes adaptability as the 'behavioural plasticity of ill or disabled people who need to adjust their behaviour in response to their condition' (Carel 2007: 105). Adaptability occurs on physical, psychological, social and temporal levels, often simultaneously. It is understood but rarely acknowledged that changes occur in the negative realm, you rarely have to adapt to anything novel or good in illness. There must be a new narrative for the person because of 'biographical disruption' (Williams 1999, 2003) so new meanings, explanations and approaches must be found. This biographical disruption can be portrayed in the research in either negative terms, such as struggling or enduring hardship; or in more positive terms such as the reformulation of the self or showing courage in adversity (Ohman et al 2005; Michael 1996). Carel's notion of creativity is actively portrayed in terms of creative responses, such as gaining control of an altered life, and recreating meaning in an altered life. She also suggests finding new activities to replace lost ability and living in the present moment (2008: 258). The literature identifies 'health within illness' (Lindsey 1996) and 'well-being within illness' (Carel 2007) as options within the broader context of chronic illness. Many if not most people find ways to adapt to the negative effects of chronic illness (Brennan 2012; Frank 2002). The negative effects, Carel writes, 'may be temporary and can be mitigated by life's other goods such as good relationships, intimacy, and finding joy and solace in new activities' (2008: 264). It is worth remembering here that chronic illness is on a continuum ranging from migraines to MS. I cannot identify my experience of chronic illness in terms of either health or wellbeing in illness, but I do experience authentic happiness and peace. Whereas I subscribe to Carel's philosophy that adaptability and creativity are required in illness, in answering the question I pose in ‘Seeing’, can I live in peace and happiness when so much has been lost?’, I would see the concept of creativity employed differently in my situation.

In creating or reimagining a self living with an illness like ME, I needed to push past or perhaps dig below (in a vertical life) just the creative ways to adapt, such as new intimacy or dancing instead of running. I find it difficult to place myself on the continuum of chronic illness and nobody wants to be in the position of claiming the lower end as theirs: argue for your limitations and sure enough they are yours. If my illness was a car it would look to be in good shape, in workable order. If you ‘popped the hood’ everything would check out, however if you were to turn the key, nothing would happen. I live with a continuous flat battery, that if on occasion does take a charge it will not hold it for long. If you keep turning the key relentlessly to check for a start then other parts start to break down. Others, with more visible chronic illness and considered by society and medicine to be much worse than me (and I do not argue to contradict anyone else’s plight) are still capable of being out and about, some can still work, are able to have families and social lives through the use of creative adaptations and devices and medications and treatments. As previously explained, that is not the reality for anyone who is moderately or severely affected by ME or by some other forms of invisible chronic illnesses. All earlier attempts to live in some way alongside my old life were unsuccessful. Ironically, as shown in the narratives, any small attempt at ‘old normal’ exacts a high payback price and over time there is less and less in the bank to meet the payment. In fact you start most days in negative equity. To complete my earlier vehicular analogy, I have been living with ME for over sixteen years, that is six thousand mornings when I turn the key and the battery is flat.

I have what medical sociology terms a strong ‘sense of coherence’ (SOC). I can, largely down to my nursing background and health literacy, ‘understand’ ME and its realities. Therefore, I have the first tenet of (SOC) which is ‘comprehensibility’. Secondly, I avail of any resources available (which are not many) and that is considered to be ‘manageability’. Thirdly I wish to be motivated to cope and to find meaning, which is considered ‘meaningfulness’. However Antonovsky’s (1996) salutogenic model, similar to the coping concepts of optimism, hardiness and resilience, all of which I have employed over time, still are not sufficient to equip or buffer me against ‘old normal’. My sense of coherence and my adaptability and creativity in coping all only seemed to work or be effective in the ‘sanctuary-like’ circumstances of the little world behind my gate. I had slowed and simplified my life and was trying to reimagine a self where my old rational and conceptual and dualistic mind, could, by dropping the habit of compulsive thinking and over identification with those compulsive thoughts, ‘shift deeper into consciousness and into presence’ (Tolle 1999: 42).

I had not in any way heroically transcended my illness, I was merely trying to detach from it. I was detaching from suffering and the second arrow of dualistic thinking, and ‘any notion of a separate fixed self’ (Gauthier 2016: 135). The ‘self’ Yup (1980) proposes is never concrete, but is instead only ‘a result of the temporary assemblies of consciousness, feelings and perceptions’, a proposition which subscribes to the importance of the Zen practice of observing one’s thoughts. Mine was a transformational path aided by a spiritual practice. Such a path did not require anymore striving or pushing or doing things to ‘become’. It was not a self improvement or a fixer-upper project, it was a letting go into the belief that whatever was here and now was enough. I could stop the simultaneous spinning of the many plates or what the Buddhists call the ‘ten thousand things’. This new way of ‘seeing’ made sense out of the changes chronic illness required and life although circumstantially similar was already feeling lighter and more authentic. I felt no need to shave my head or join a temple, but I had been drawn to Zen initially by the example of a young Irish woman who had.

The contribution of the exemplar to the reimagining of a self

The role of the exemplar in the consideration of the good life is to be found within virtue ethics. Exemplars are persons who ‘exemplify or manifest a moral quality or role or even a whole ‘way of life’ to an advanced or superlative degree’ (Kidd 2017: 330). Exemplars are most commonly heroic type moral heroes such as Jesus or Buddha or Ghandi or Martin Luther King, but they can be found in everyday ordinary contemporary life. Kidd offers the example of his grandmother, whose level of selflessness and kindness was to such a degree that it was an outstanding example of the virtue of selflessness. The characteristics of an exemplar according to Kidd who has expounded on Zagzebski’s (2017a, 2017b) moral theory, are that they are charismatic, or captivating to the point that they induce the emotion of attraction or admiration in the other. Such admiration in turn inspires emulation where the other (not in a parroting fashion) tries to introduce aspects of the exemplar’s way of thinking or being into their own lives. This emulation is based on a reflective understanding on what Aristotle called the exemplar's 'second nature', which he considered to be genuine goodness (Kidd 2017: 331). It is possible to encounter an exemplar by personal encounter or by a testimonial or narrative encounter. Some are recognised as theoretical sophisticates engaged in philosophy or moral teaching and many are not. In either case it is through their lived experiences of adversity and the wisdom it produces that we, the 'other', are drawn to their lives. Much of the content of exemplarist narratives would describe the ordinary, everyday feelings, thoughts and actions in the rhythmical living of a human life (Kidd 2018: 387). The sequence of these events is rarely orderly or linear, but proves to be generally courageous, altruistic and authentic.

Maura O'Halloran: an Irish Zen Buddhist exemplar

I encountered Maura O' Halloran in the mid 1990s. I was driving home from the university from a night class and was just turning up into the woods when a documentary came of the car radio. Maura would have already been dead ten years by this time, and would have been born only six years before me. She was born in America and lived as a small child for seven years in Ireland, her father was Irish. When her father was killed in a car accident the family returned to Ireland. In 1979 Maura entered a Zen monastery in Japan and became Soshin-san (warm open heart, enlightened mind) and three years of intensive training later she received the transmission of her teacher in 1983. Six months later in Thailand, on her way home to Ireland she was killed in a bus accident. Her life and her work and her compassionate heart were held in such regard that she was considered to be identified with the bodhisattva Kanon, the Buddhist saint of compassion. Much of her writing was lost or stolen from the crash site but in 1994, the Zen journal of Maura Soshin O'Halloran was published as *Pure Heart Enlightened Mind, The Life and Letters of An Irish Saint*. I read Maura's book in one sitting. I was alone in the house with just Credence the dog and Zen the cat for company. A thunderstorm came and blew out the fuse box, I just lit two candles and kept reading to the final page. Tears came and something broke open in my heart that has not closed since. I started to sit in meditation and to read the teachings. I later called my second cat Mu or 'nothingness' which was Maura's koan (a Zen teaching paradox) and which she roared until she lost her voice, during the many long nights of sitting zazen, as she emptied her mind and achieved no-mind.

What follows are excerpts from *Pure Heart Enlightened Mind*:

March 11 1980

Holding my soup chawen [bowl; also soup], steam curling, all of us giving thanks, the miracle became apparent, the daily alchemy. This had been life, killed and now made me, made my life. Humble beans and onions passing into me, supporting me, becoming me and I in turn passing into nourishing beans or maybe onions. Endless magical stream, not really of creation and destruction, only flow. Funny how in front of seventeen people, most of whom I don't know, I can, as alter boy, make mistakes, be corrected and feel no blush. The notion of a nation is to a country what ego is to a body.

Mid May 1980

I stood in the rain for the longest time without getting wet. Nobody knew. It was my koan. The rain noises were on cement, on stone, on my plastic mac. The bird in the apple blossoms shook the moisture from its feathers and sang. I, in sympathy shook in my mac and was silent.....How can one be Buddhist and not be socialist? How accept and allow the perpetration of a system based on desire? A system that functions as trigger and effect of the desire for money and commodities? A system that, to feed itself, must resort to crass commercialism and ever spiralling desire.

1980 Tokyo

Mu
My skin is raw from the biting cold
My skin burns from my tears' salt
It drops onto my chest
Runs wet down my breast
I think
Nothingness

(O'Halloran 2007: 54-55, 82, 217)

Cultivating Beginner's Mind: compassionate and harmless living (ahimsa)

Maura Soshin O'Halloran opened my heart and shone a light on to a way of seeing that I was going to need to facilitate transformation. Maura's experience; 'spoke to me not only as a woman but as a Westerner. In her simple down to earth way, she describes the lived Zen experience that is much more human that it is Eastern or Western' (Loundon 2002). This transformative process *away* from being 'stuck with' invisible, chronic, unsupported illness, would facilitate the development of compassion, not just *towards* others but *towards* my 'self', a way of being that was non-striving and could find ease with the is-ness and suchness of whatever was happening. Pierre Hadot (1995) called on twentieth century Anglophone philosophy to re-embrace philosophy as a 'way of life' and that philosophical practice or wisdom be put in the 'service of life'. Undoubtedly, the Buddha would be considered one of Kidd's (2016) famous moral heroes and his writings would be considered exemplarist, but I was not engaged in an effort to emulate the Buddha (even if I or anyone really could). In my efforts at transformation, I was studying Buddhist teachings not to study Buddhism but to study myself (Suzuki 1971: 76). I was attempting to cultivate Beginner's mind through silence, sitting and seeing. Beginner's mind is the 'open mind, the attitude that includes both doubt and possibility, the ability to see things as fresh and new, Beginner's mind is the practice of Zen mind' (Suzuki 1971: 13-14). I could not know what Zen mind was, it was enough for me to grasp that the true purpose of Zen was 'to see things as they are, to observe things as they are, and to let everything go as it goes' (Suzuki 1971: 33).

I was moved into action by the teachings on compassion and 'ahimsa' or harmlessness. In reflecting on the narrative 'Seeing' and to a later degree in 'Sanctuary', the notions of compassion and harmlessness are frequent motifs.

> *Seeing the deer grazing in the moonlight behind my house here in the hills balances everything difficult out.*
>
> *I am moved to cry very easily these days.*
>
> *Mu is gone but the circle continues just like someday it will continue without me.*
>
> *I cannot reconcile that kind of dominion over other sentient beings.*

It is through the lens of non-harming that I reflect on the presence of compassion in the narrative analysis. Compassion can be defined in terms of ‘a state of mind that is nonviolent, non harming and nonaggressive’. It is a mental attitude based on the wish for others to be ‘free of their suffering and is associated with a sense of commitment , responsibility and respect towards others’ (Dalai Lama & Cutler 1999: 91). Genuine compassion is free from attachment and based on the sentiment that all sentient beings have an innate desire to be happy and to overcome suffering just as ‘I’ do. If you see a fish writhing at the end of a fishing hook, you may spontaneously experience a feeling of ‘not being able to bear the fish’s pain’. That feeling is not based upon a special connection to that fish in terms of knowing that particular animal as a friend, but based on the fact that that fish/sentient being has feeling, can fully experience pain and has the right no to have to suffer like that (Dalai Lama and Cutler 1999: 93).

Compassion means to suffer with. Compassion is a mind that removes the suffering present in the ‘other’. It is the ability to recognise the physical, material and psychological suffering of the other by putting ourselves ‘inside the skin’ of the other (Nhat Hanh 1992: 81-82). The practice of compassion, even at a distance through loving kindness meditation, is based on the effect our thoughts and feelings and actions have on the world around us. Each of us lives ‘with the ten thousand joys and the ten thousand sorrows’ (Kornfield 2005: 63). Empathy is a vital component in compassion. To feel empathy for humans or other sentient beings, one only has to imagine the situation they might be going through (perhaps a human’s physical pain or a sheep’s fear awaiting slaughter) to truly understand. This may require a temporary suspension of a previously held viewpoint.

Ahimsa or harmlessness is a concept precious to Hinduism, Buddhism and Jainism. It has become central to my life, and as is evidenced in the narratives, adds meaning and purpose and peace and a sense of a fair-trade for all the other perceived losses through chronic illness. Perhaps as a result of having been sidelined from the ‘old normal’ game of life, space has been provided to give attention to and ‘see’ such things. However, I subscribe to the opinions voiced in other women’s narratives concerning chronic illness, that although illness has given me ‘time’ (Register 1987: 104), I do not believe that I ‘became ill *because* I needed to learn what illness has taught me, nor that I will get well when I have learned everything I need to know from it’ (Wendell 1996: 175).

Ahimsa is a Sanskrit word which means non-harming or nonviolence. All living beings have the 'spark of divine spiritual energy and as such should not be harmed' (Krishna Consciousness Society 2009: 33). In Jainist ethics, ahimsa is paramount. Animals are never injured for food, and plants are only harvested under certain conditions for food. Very strict Jains do not go out at night in case they step on an unseen insect (Laidlow 1995). Ghandi applied the principle of ahimsa to politics. The yogic path encourages non-violence towards ourselves on a daily basis. Watching our thoughts as they form (they come, recognise them, they go, no reaction) fosters self compassion which brings non-violence into our lives. Violent or stressful thoughts produce the stress hormone cortisol whereas loving thoughts produce dopamine, a chemical that helps the body to relax. Non-violence, ahimsa and self compassion mean not pushing yourself over the edge, or at least being aware when you do, and recognising the possibility for change (Djenab 2016).

Buddhists across Asia have long presupposed that all sentient beings down to the smallest insect, experience suffering and seek release from it (Kieschnick 2005). What underlies non-ahimsa and the related manmade environmental issues is anthropocentrism, where humans see themselves as the centre of the universe. If anything or anybody else has value, it has so in an instrumental sense. Anthropocentrism is based not on biology but on moral assumptions. As early as 1967, Lynn White argued that the Judeo Christian metaphysical claim of dualism between humans and the rest of the planet, was one of the root causes of the environmental crisis. Taylor (1986:60) argues that each animal is a 'teleological centre of life and pursues its own good in its own way', and the claim that humans are inherently superior to other animals is incorrectly based on 'a criterion established only for human excellence, i.e. rationality'.

Reverence and reciprocal gratitude

John Muir was one of the founding fathers and earliest exemplars of the ecological movement in California in the early 1900s. He was one of the earliest defenders of non-human centred ethics. In his travels, his wilderness living and his journals he espoused a theory and a lived life of non-anthropocentrism. Muir's observations and experience in nature led him away from the centuries old philosophy of domination and dominion, and towards an ethical holism. He argued that rejecting anthropocentrism was essential in order to live the good life, as was the need to be attentive (to beauty and to one's instincts) and a sense of reverence.

> A numerous class of men are painfully astonished whenever they find anything, living or dead, in all God's universe, which they cannot eat or render in some way what they call useful to themselves...the sheep...food and clothing for 'us'...whales are storehouses of oil for us, to help out the stars in lighting our dark ways...Hemp is a case of evident distinction for ships' rigging, wrapping packages and hanging the wicked...Now it never seems to occur to these far seeing teachers that Nature's object in making animals and plants might possibly be first of all for the happiness of each one of them, not the creation of all for the happiness of one...Why should man value himself as more than a small part of the one great unit of creation? (Muir 1917: 54)

Muir's life lived in attentiveness and reverence for nature and all her creatures resonates with my reflection and analysis on the narratives. Even on my 'sickest' of days, animals and nature are central to my life.

> *I live in the hills and I take what comes. I am a part of all of it from morning to night, season in and season out.*
>
> *I have indeed become a 'forest dweller'!*
>
> *Life here sustains my spirit and my soul and reminds me that all sense of adventure is not yet gone even if physical strength slips away.*

Muir argues that attentiveness to beauty, reverence, a reciprocal sense of gratitude and recognising animals as exemplars, are all considerations for any attempt to live the good life, something I examine next in 'Sanctuary'.

Conclusion: from head space to heart space to 'wild space'

In reimagining and recreating myself in order to find ways to live a good life alongside chronic illness I had turned to the exemplars and the exemplarist teachings. Zen and the Beginner's mind, Tolle and the *Power of Now* might be necessary theoretical sophisticates, but other contemporary exemplars such as Maura O'Halloran, Hannah Hauxwell and John Muir through their examples of compassion, harmlessness, kindness and 'whole ways of life' have inspired and helped me ‘make sense out of situations in ways that the previous ones (feeling vulnerable and a failed ‘independent rational agent’) could not’ (Witkin 2014).

In reflexively examining the narrative and putting it under analysis, I can recognise or ‘see’ reflected back at me how dropping old conceptual, dualistic thinking and living more simply from a ‘heart space’ rather than a ‘head space’ (yet still alongside illness) had facilitated a transformative process from the old habit of struggle, and that in fact I had found a way to live that had meaning and purpose, even if it was a small and silent existence that had to mostly happen behind my gate, which had become a sanctuary.

May the wild space bestow silence
And unknowing upon you
May these faithful companions
Reveal the mysterious and subtle presences of life.
When the unexpected is distressing,
May you receive it as the gift that awakens

The Blessings of the Wild Space
Roshi Egyoku Nakao

CHAPTER 11

'SANCTUARY' UNDER ANALYSIS

> May the wild space be a refuge
> Where the untamed heart awaits you-
> Where the unseen and informed dance
> To the wisdom of their own darkness.
> Life wounds and heals itself-
> May wholeness and unity be your heartbeat
> Go! Go! To the wild space-
> May the tree shelter and the earth sustain you
> May your journey be blessed.
>
> *The Blessing of the Wild Space*
> Roshi Egyoku Nakao

The concept of sanctuary

The notion of sanctuary, even in modern anthropological terms (with sanctuary cities founded on the Quaker movement of providing asylum) always has some act of conscience, following some higher law or religious association (Rabben 2018). Animal sanctuaries provide permanent shelter for neglected or homeless animals. It is a historical principle and as a concept, sanctuary has been sacrosanct in all cultures and spans all times. All definitions of sanctuary include the terms shelter and protection or safety (Chase 2011: 29). It is because of these meanings within sanctuary - shelter, safety with an element of the sacred - that I chose sanctuary for the final 'concept' or aspect of the thematic framework for both writing the narrative and then analysing it. Sanctuary in essence and by definition is some kind of endpoint or destination, usually after some kind of struggle. Following on from the Third Noble Truth that suffering can cease, the Fourth Noble Truth states that there is a path that leads to the cessation of suffering. This path is the Noble Eightfold Path and it concerns itself with 'right' or a more contemporary term would be 'wise' understanding, intention, speech, action, livelihood, effort, mindfulness and concentration. However the Noble Eightfold Path is not a pathway of prescribed steps of 'becoming', but rather a 'way' of being in the world. Grouped under morality, wisdom and mind, the pathway leads to a holistic approach to living a liberated life that is in support of the good life (Schipper 2012: 222).

Sanctuary is created and provided or gifted by others to others, or by self to others or by self to self. It can be geographical, physical, internal or imagined or all of the above. On reflecting on the narrative ‘Sanctuary’ it became clear to me that all the threads of transformation (from all the years of struggle; from attempts at surrendering old thinking, from efforts at seeing and new ways of being, from stopping and simplifying, from looking and listening at and to guiding exemplary others) had finally put me in the ‘way’ of sanctuary. As will be clear from my narrative ‘Sanctuary’, my sanctuary is not Nirvana or heaven or perfection of any sort. My sanctuary is a humble enough creative effort. I find myself in agreement with Freeman (1996) who states that our job is not to hunt down perfection and live within it, it is instead, to take whatever broken pieces we have found and sew them together as best we can. Sanctuary for me is simply a safe place sheltered from a world that I can no longer function in easily with an element of the sacred that I find healing and restorative. The importance of those same elements could be weighted differently for another. As a woman who lives alone with a chronic illness such as ME, the importance of retreating into sanctuary has made life workable for me. As mentioned earlier, people who live with chronic, invisible, contested illness can choose to manage their lives in many ways. Some continue to search for answers, some fight for rights and change, some cannot cope. This autoethnography is *a* story of living long term with such an illness and the attempt to reimagine a self, a life, that despite all or perhaps because of all, may still be able to be a good life.

Stillness, silence and solitude

Sanctuary is not impervious to struggle, but it views it differently and therefore struggle does not have to last too long. As I reflect on the narrative ‘Sanctuary’, I see there were storms and blizzards, flying rats, dying goats and hens, chest pain, shingles and viruses, cattle trampling fences, the loss of financial aid, while every morning, still waking up with a flat battery. Yet, there were creative ways to manage. There were always good neighbours to help, as the old Connemara saying goes: a good neighbour is better than a bag of money. There was also the sustenance of the silence and the stillness, and the beauty of the environment around me in which

I had become embedded. I mention silence and stillness as sustaining and in fact with the exhaustive nature of ME, they are restorative. This is not an essential truth for everyone, but it is evidenced across most of the narrative chapters. Solitude could be considered the birth mother to silence and stillness, and it did in fact start off as a distinguishing feature to the research work: 'reimagining a self living *alone* with a long term invisible chronic illness'. However, in analysing the narrative, solitude has not really emerged as a major theme. So far it has only been relevant in terms of addressing the necessary changes that I have had to make with regard to relationships, visits and negotiating 'outings' etc. Christmas does seem to put solitude under the limelight, but the resolve of much greater humans than me, has been shaken by the mammoth collaborative forces of materialism, consumerism and society during the holiday season. On reflecting on the narratives, I did recognise fleeting moments of profound aloneness, such as; when the remnants from blizzard snow was pouring through the ceiling light fixture at eleven o'clock at night, or when two weeks later there is still no remedy for a broken septic tank, or when your goat is put to sleep on your lap, or seven weeks later and you still can only barely function after shingles in a heat wave. However, something that I have discovered anew from reflecting deeply on the narrative is that being alone is central to the story, and that while it is often a consideration, it does not naturally lead to loneliness. Solitude is not the same as isolation, a fear that many observers would have on my behalf. It seems that in changing my 'mind' from a busy conceptual, striving mind, to Beginner's, non-dualistic, more present mind, that I have 'met' myself , that 'inner self who holds the key to intuition' and I have become my own 'healing companion' (Leibrich 2016: 216).

Another motif through the narrative is my trying to reconcile the desire to see people and/or their desire to see me, with the payback or negative physical consequences that all of that has come to entail. The reality of my circumstances, such as my very rural location, adds grist to that mill. It is at least 100 miles or 160 kilometres round trip for most people to visit me. It is 300 miles or 480 kilometres round trip for my best friend to get here. The kind of visit that I can handle well, an hour's chat over a cuppa, is not a possibility for most people I know currently. My old pattern, particularly in 'Struggle', was to 'boom' in order to still try to facilitate all the old relationship dynamics, and then to 'bust' or collapse, and try to recover on my own 'sanctuary terms'. I do the 'boom and bust' less and less in 'Sanctuary' and I am grateful that most people who have remained in my life (and many have not) understand. If they cannot understand, and it is not easy to understand, they accept. One of the aspirations of this research work was to try and explain or close the gap in the understanding of the realities of ME, so that people might understand more, and things might change, or become easier in terms of the practicalities of relationships for me and the millions of people like me. However, another unexpected finding from analysing the narrative, was that that gap is in fact unclose-able because the only change I can make is to change my way of ‘seeing’ and of valuing and living my life. I am ‘sick’ and still and solitary, while the beloved ‘others’ are well, very busy and (as is the norm) have partners and/or children and grandchildren. That, on reflection, does not constitute a gap, but two distinct realities. Society might put those realities in a hierarchy, but I no longer subscribe to that concept or thinking, and therein lies my sanctuary. The sitting and stillness and the seeing of solitude, has brought me to that understanding. Solitude can in fact ‘take care of existential loneliness’ (Leibrich, 2016: 216).

According to Tolle in *The Power of Now,* it is ‘inner stillness that will save and transform this world’ (2003: xii). Outer stillness can be thought of as a space between the doings and the goings. How much space is there on any day between the doings and the goings? Inner stillness is not dependent on silence but I seem to need silence on a neurological and on a spiritual level.

> *In writing this I had to take the battery out of the ticking clock.*

Stillness and silence and solitude do not require the backdrop of illness, or life on a small farm in the remote hills in order to provide sanctuary. The old Chinese proverb says: ‘A minor hermit needs to reside in the mountains. A major hermit resides in the heart of the city’ (Phap Hai Tich 2019: 439). I am at best a ‘micro hermit’ with a micro sociological story, sharing my particular story of what is not universally uncommon.

My sanctuary needed to comprise of both an external, physical place like my tiny homestead, and an internal sense of sanctuary, where stillness, solitude and silence could find a home.

> *Now I know for myself the value of stillness and staring into fields.*
>
> *There is silence now except for birdsong and one of the hens picking at an empty bucket.*
>
> *Other than the wind that rustles the drying leaves and billows the polytunnel plastic, it is silent.*

> *I love my lot in life but I am going to have to stop listening to others for a while and go back on to my own path.*
>
> *I have had to lie here for hours lamenting that I am doing nothing. Yet enough gets done. Most things get taken care of and there is incredible peace.*
>
> *I have over the years, had to learn how to live in retreat and remain on the borders of sanity.*

Animals as exemplars: correcting our anthropocentric culture

Witkin's (2014) fourth condition facilitative of transformative change suggests that 'there are role models or experienced others [exemplars] who can facilitate the articulation of ideals, allay fears of isolation or "craziness" and provide living proof that "it" can be done', transformation is possible. Across the narrative chapters the animals feature but I have largely reserved mentioning them until now. They belong in the analysis of the 'Sanctuary' narrative. They certainly, as per Witkins' conditions, allay any fears of isolation or craziness. The animals are exemplars to me, and have been central to my reimagining a self and a life with chronic illness. At the time of writing I live with four dogs, two cats, two donkeys one goat one sheep and five hens (yes Junebug the epileptic hen is still with us!). I also live in connection with all the wild birds including pheasant, buzzards and one red-kite, foxes, deer, squirrels, rabbits, hedgehogs, sheep, cows and horses. They have taught me stillness, acceptance, dignity, reverence, patience and how to just go with things, such as severe weather and unexpected events, injuries and illness and how to live in the now and to accept what is, without yearning after what cannot be right now. Despite our anthropocentric culture, many people can recognise the virtues that animals teach. Tolle (2003: 82) urges us to 'watch an animal, a flower, a tree and see how it rests in Being. It *is* itself. It has enormous dignity, innocence and holiness'. Again, Tolle asks:

> Have you come across a depressed dolphin, a frog that has a problem with self-esteem, a cat that cannot relax or a bird that carries hatred and resentment?...watch any plant or animal and let it teach you acceptance of what *is* and how to surrender to the now. Let it teach you Being. Let it teach you integrity – which means to be one, to be yourself, to be real. (Tolle 1999: 157)

I spend most of my waking time caring for animals in some shape or form, not continuously, but with only having a very small plot for so many, there is always a need to keep an eye out for them. The day is punctuated by feeding times and by multiple letting ins and letting outs. Nobody feels any stress or fear and they contribute in their own ways and show concern for each other. The dogs protect, little Peggy goes in the car and sleeps with me, the cats hunt, the hens lay and the goat and the sheep and the donkeys all eat the wild growth. There is always an accepted matriarchy amongst the hen flock, yet it is more peaceful without a rooster (Danaan 2010). Some hens really bond as pairs. I have seen a hen Gladys, who was badly injured by a mink (in the only attack I have ever had) and whose companion Julia sat by her side, in the little recovery area I had made for her. Gladys died from her injuries and Julia sat in her vacated spot and died three days later. Other hens can be bossy and fussy. Their variety of behaviours could, Lennox (2010) argues, 'be the forerunner of psychology, sociology and management theory' and have made great contributions to common parlance, including 'pecking order', 'taking someone under your wing', and 'ruffling someone's feathers' to name just a few.

Many of the animals that I live with came from very bad beginnings but they have sanctuary now. My two donkeys are a mother who was ten years old when she came here and her son who was just three weeks old. Once Ike, the son was old enough he was gelded so they could spend their lives together. Corabeth was used as a brood mare and every one of her offspring had been sold on. If I had not bought her she was about to be put in foal again. Donkeys need a constant companion although they are often left to stand alone in remote fields. These two can finish out their lives together, with their 'unfathomable donkey gazes...their stoic tranquillity and peaceful spirits' (Merrifield 2009: 253). It is often suggested that I give up the animals and focus more on myself and caring for them does take a lot in every way. I have written in the earlier narratives about the dogs and their constant and devoted companionship. Tolle (1999) has written that one of his greatest spiritual teachers was a cat. I have no need to brush the tiny white gravel stones on the driveway of a Zen monastery all day long to learn the meaning of impermanence. I only have to wash the kitchen floor, and open the door again to four muddy dogs – that is impermanence.

Stiff and sore I stand up
a million times to let you in and out
I try not to be cross

but to do this simple act
of repetitive service
in love.

The caring for and company of the animals that live with and around me punctuates and lends purpose to not only each day, but most of the sixteen years since I have been ill. Animals are, as John O'Donoghue (2015: 64) suggests, 'our older brothers and sisters...and carry a huge ministry of witness to the silence of time and to the depth of nature'. Animals have made me human, my deepest wish is that they could all find sanctuary.

> Animals hold us to what is present: to who we are at the time, not to who we've been or how our bank accounts describe us. What is obvious to an animal is not the embellishment that fattens our emotional resumes but what's bedrock and current in us: aggression, fear, insecurity, happiness or equanimity. Because they have the ability to read our involuntary tics and scents, we're transparent to them and thus exposed – we're finally ourselves. (Ehrlich 1985)

Landscape and the contribution to health of restorative environments

A nature motif reveals itself in all the narrative chapters, but the sanctuary narrative reveals a life embedded in nature and in nature's own sense of time. Leibrich (2016: 214) writes: 'think about what happens when you let go of "time" as a *concept* or measurement and simply become part of it...then time is timeless and this is one of the deepest sanctuaries I know'. When I reflect on the sanctuary narrative, I see clearly what I know to be true. I have reimagined a self that has slowed and settled into a rhythmical life. The seasonal changes really matter here to the landscape and the light and to every wild creature. I write in 'Sanctuary' of the year being divided in half by the coming and going of the donkeys on and off the plot, and by the coming and going of the swallows from their wattle font nests. I write of my small harvests and blackberry picking and of the stocking and storing of fuel and provisions for the enforced Winter hibernation. I write of the daily feeding of the wild birds for half of the year, and the equinoxes, where the light is either shrinking or growing, as this earth turns either towards or away from the sun. The interaction with landscape and its sense of elemental wildness has healing potential in that as humans we must 'slow down to the level of attention where [we] begin to come into the rhythm of the landscape' (O'Donoghue 2015: 66). Animals and nature, as I found reflected in the narratives, have taught me attentiveness and reverence. Attentiveness takes a stilling of the self.

Attentiveness helps us to be aware of how nature 'carries out its miraculous work quietly, under the veil of the ordinary' (O'Donoghue 1998: 33). I was trained to be observant as a nurse which has stood to me in caring for the animals. However, attentiveness requires us to be 'as fully engaged as possible with the unfolding of both the inner and the outer world' (Larson 2011: 35). Both the poets and the scientists endorse the blessings and the benefits respectively, of time spent in nature in sickness or in health. John O'Donoghue writes:

> The more attentive you are and the longer you remain in a landscape the more you will be embraced by its presence. Though you may be completely alone there, you know that you are not on your own. In our relentless quest for human contact, we have forgotten the solace and friendship of nature (O'Donoghue 1998: 53).

According to the National Research Council (1981) those who live in highly industrialised nations have begun since the 1980s to spend more than 90% of their lives indoors. That has since risen to 95-99%. This has impacted on personal and social well-being and on mental health (Evans 2003). Environmental psychology, ecopsychology and its practice of ecotherapy are all coming to explore the concept of restorative environments; natural places which have inherent properties that help us feel better, more attentive, and increase our abilities to cope with life's physiological and psychological challenges (Hartig and Staats 2003). Reconnecting with the natural world, according to ecotherapy acts as a 'reset' for exhausted and or ill bodies and minds and can increase the individual's perceptions of health, self relatedness, social connection and joy (Chalquist 2009; Bedard et al 2003).

Living a 'good enough life' alongside illness

There is both meaning and mystery (non-knowing) in internal and external sanctuary. I can relate to Leibrich when she writes that 'sanctuary is a miracle which renews life...the physical signs of instinct – gooseflesh, shivers, catching of breath, sudden tears – point to something deep within ourselves' (2016: 219). When we are truly present in our lives we 'understand one-ness, the *I am* becomes the *we are*. These deep experiences often bring tears' (Rohr 2009: 104).

> *Tiny moments of beauty often reduce me to tears.*

> *The sun has just gone in and the mountain silhouettes look incredibly dark. The gorse is just starting to bloom yellow. The swallows flit about for insects and tiny birds jump in and out of a feed bucket.*

Early in the sanctuary narrative I ask:

> *What if this house, this hill, this life was all there would ever be and nothing more until I die? It didn't seem so bad.*

Later in the narrative I answer myself when I consider all the little un-news-worthy moments of my life which:

> *...mean everything to me. On an aware day there are many such moments, it is the 'way' that I go through life. It is what sustains me, amazes me, bursts my heart open with love. I rarely think in terms of loss anymore. My life instead has become a fair trade.*

If one considers everything in life to be a gift, then 'the degree to which we are awake to this truth is a measure of our gratefulness, and gratefulness is a measure of our aliveness' (Steindl-Rest 1984: 12). Founding ecologist John Muir was celebrated for his sense of gratitude and reverence with reciprocity. He was concerned with what he could give back to nature and life for all the beauty and gifts that he received from them. A desire to give back is an essential feature of gratitude, distinguishing it from appreciation or thankfulness and in this sense gratitude is an activity (Fromm 1956). To be reverent is to be grounded in each moment and the truth it reveals about our situation and ourselves, and most importantly our proportionate place in the world. From this place, Muir (1919) writes, a good life can flourish. Not unlike Muir, my own sense of gratitude has a reciprocal element to it, in that my ecological self became more vigilant. On reflecting on the narratives, it is clear that I am aware of my ecological footprint. A useful question for us to ask is: how many hectares of natural resources would be needed to support my level of consumption? Or put another way; how many planet earths would be required if the entire global population adopted my lifestyle? (Monopolis 2010). The circle has been drawn around my small life by illness yet I can still put my mouth where my life is. I am vegan, I make, bake, sew or grow as much as possible. I drive about ten miles once a week or sometimes once a month. I have been on an airplane once in fifteen years. I buy second hand or recycled goods, I burn timber or turf and use very little electricity. I buy organic and fair-trade goods as often as I can, and I refuse to use anything that has been tested on animals or that is toxic. I write this with no intention of self aggrandisement because as Monopolis (2010) highlights, it is a fallacy to frame environmental responsibility as self sacrifice or restraint, or diminishment of personal happiness. As the research shows, the pursuit of personal happiness, 'does not appear to require consumption based environmentally damaging activities' (Brown & Kasser 2005: 350). And so, from putting this 'Sanctuary' narrative under analysis I pose the question again: is it possible living alone with a chronic invisible contested illness to live a good life?

In a similar vein, Kidd (2012) asks: can illness be edifying? Carel (2008) in her phenomenological account of her severe chronic illness (that has a very poor prognosis in terms of longevity) reflects on the virtues of humility and self learning or education while ill. In other writings Carel (2007: 109) proposes the virtues of adaptability and creativity as positive responses, that 'can enable a good life even within illness'. Kidd (2012: 501) suggests that adaptability and creativity can be understood as virtues in the 'classical Aristotelian sense of excellence of character'. However widely I read within the world of virtue ethics and moral reasoning, I could not find a home for this work there. It did not seem to belong amongst the solely rational, dualistic accounts, that employ a mainly inferentialist or argumentative style, that prescribes a code of conduct for an abstract situation, particularly when it seems to be devoid of real understanding of lived experience, and devoid of compassion. I chose instead the world of exemplarism, where any role of ethics can be considered as a guide to life or as an agreeable option (Kidd 2016). However, even before I became ill and when I still held my 'rational independent agent' card, I was more drawn to Eastern philosophy than the legacy of the ancient Greeks, on which the patriarchal society in which I was raised was built. I cannot imagine a good life for myself without compassion for self and for others as a foundation. I found the exemplars within the Buddhist teachings and Buddhist philosophy, that showed me a 'way' that did not require me to label myself a Buddhist. The Four Noble Truths (there is suffering, there is a cause of suffering, suffering can cease and there is a pathway that leads to the cessation of suffering) had led me to conditions that were facilitative of change. In relinquishing or surrendering the habit of struggle, and in seeing and being affected by the example and teachings of others, both ancients and contemporaries, I had ultimately found a sense of sanctuary, a way of being ‘at home in the world’, even if that world was small and largely behind my own gate.

> Home. There, I am utterly myself, no best behaviour, no putting on a face. I am just who I am. Authentic, safe and sacred. That is sanctuary to me. (Leibrich 2016: 210)

In Western thought, the idea of moral or ‘self’ cultivation promises personal fulfilment and happiness, compassion is an achievement of the self. In Eastern thought, one can never consider personal happiness as a goal, because it is impossible to separate ‘one’s own personal happiness from the happiness of all sentient beings...I am not a separate being but part of the stream of life’ (White 2017: 180).

It became clear as I reflexively analysed the narrative that I had overtime reimagined a self, a life, where simplicity and gratitude and compassion for all sentient beings had created a good *enough* life, a life where I could live alongside illness, without being attached to it. It was a life alongside which ‘old normal’ could run in a parallel, fairly peacefully. I had downshifted materially but I had also downshifted from my head to my heart, from a preoccupation with myself, to a preoccupation with all sentient beings (White 2017: 183). The analysis of this autoethnography helped me to realise that my effort at reimagining a ‘self’ so that I could find a better way to live alongside an illness like ME had actually saved me.

Conclusion: becoming a poetic observer

Illness had sidelined me from the game of ‘normal’ life but in the stillness and silence and simplicity and solitude that ensued, I had become a willing observer, recognising in glimpses that ‘there is not a petal of a flower or a blade of grass that does not configure the way’ (Bassui, Zen Master). In emptying my mind of old ways of thinking I had become ‘mind-full’, if mindfulness is defined as: ‘knowledge or wisdom that pulls the whole mind and heart of the knower toward a connection with the way things are in all their exciting particularity’ (Goodenough & Woodruff 2001: 586). And then came a universal gift in that I gradually became a poetic observer. The value of prose according to Norman Fischer, a Zen priest and poet is that it ‘explains, makes a point, persuades and fulfils a purpose...often reading prose you have the idea that you know more that you did when you started', whereas the usefulness of a poem is that 'you will occasionally be brought up short by something that suddenly seems quite true, even though you can't tell why' (Fischer 2016: 30). My reimagined self that had travelled the circle, clockwise from struggle to sanctuary, now sat permanently in sanctuary and perceived things, particularly the everyday ordinary moments provided by a life embedded in nature, in an intuitive way. It seemed that the 'scent of Zen' (Lam 2017: 106) that had come to infuse my life, was manifesting in poems which seemed to come, fully formed, not good, not bad, just there. The self in 'Zen scented' poetry is only a strategic position through which the world and other humans are acknowledged, 'the poet is not the knower, or the analyser that subsumes the non humans' (Lam 2017: 109).

In the post-struggle years of this autoethnographic trajectory of illness, the poet Mary Oliver spoke to me when she asked: 'Tell me, what is it you plan to do with your one wild and precious life?' (Oliver 2010: 54). I knew then that my one wild and precious life would be in some ways like hers, up every morning, outside with eyes and heart wide open, a pen and paper near to hand. In noticing the smallest thing, I would stand like her and 'put my lips to the world and live my life' (Oliver 2008: 57). Even if it would be alongside illness, it would be a good enough life. And so, in conclusion, I still follow Mary Oliver's exemplary instructions for living:

Pay attention
Be astonished
Tell about it.

Sometimes, 2008, p. 37.

SIT

SIT

I can barely remember the constant distraction of busy-ness
something always happening next.
I have had to adjust to the not accomplishing anything
and the no one to tell it all to.
I am in the loosing light of my kitchen window
writing this by a flickering candle.
The kitchen smells of pine smoke
yet another mug of black herbs downed.
On the radio Kate Bush sings of her son.
Reports of traffic on the M50 mean nothing to me.
I will not send out for food in foil dishes later
or pick up laundry or children.
I don’t know who hates who on the soaps.
There is just me
and the wind
and Whoever thought
all of this was a good idea.

RESCUE

The sad rescue mare
first day in the new field
walked up to me
as if I had the answer to her question.
She stood staring over the ancient stone wall
into and across fields she had never seen before
unable to ask
where her foal was.
Humans with their throw away cruelty
never stopping to consider
the depth of her loss
her cosmic loneliness
her expected resignation
and servitude.
Yet if their child was out of sight
behind a supermarket aisle
for even mere seconds
how
dry mouthed
and lead limbed
would they wait?

THERE

Trip to the rain barrel
a small black beetle
is clinging to a thin
blade of grass.
How long were you there?
Did you hope that I would come?
Or were you just there
clinging to a thin blade of grass
when I thought
that I had rescued you?

SKY CRY

This evening my farming
is stopped by fraught child like
cries from the sky.
I can see nothing.
Then from behind my head
a single cry
a wing span sound.
I look up to see
a big pale bird with
a long extended neck.
A Hooper swan?
A Brent goose?
Is it time?
From under distant cloud
two more appear
cry and beckon
and wait
until my backward friend reaches them.
The cries stop.
The three of them fly
upwards into some point
of joy and knowing
that I recognise
that is the same for all of us.

MINDLESS

I am mindlessly banging pots.
Little rescued Peggy leaves her breakfast
and hides behind the rocker.
I stop
remember
soothe and coax
position her and me
beside her bowl.
I squat
and breathe into the downward dining dog.

CHOSEN

My visiting swallows are on
their second family.
At start of summer
they return and tweak
their font like wattle nest.
At dusk they sing
and swoop their sky ballet.
Each one capable of
eating two thousand
insects a day.

As summer stretches
they must brave
me and the dogs
on our late night
potterings near the donkey house
now their home.

They dive and call
over our heads.
When they are away hunting
I peep in and see
three fat faced bug eyed babies waiting.
In no length
those babies

swoop and call
and join the sky.

When the house martins
come and chatter
hanging seemingly upside down
from the eaves
often needing to be rescued from
the kitchen in cupped hands
I think how like the swallow they look
yet giddier.
Vital in their way
if perhaps a little less endowed by nature.
No second comings there.
No second sittings
unlike now
in mid August
action in the wattle font.
I creep in to see a downy
head with a silent open mouth.
In absence of sky warnings
I stand in awe mighty love.
Grateful to have been chosen.

MORNING RITUALS

I let out the hens.
Disliking the frost
they hesitate
then follow their leader
Pearl
down the plank.

Nestled in the straw
already
two warm eggs
one for each pocket.

Buckets in both hands
I knee open half doors
feed goats and donkeys
calling over shoulder
to the sheep who watches and waits.

Bending with the pitchfork
I sieve through straw
then hip carry
the hot dung bucket
to the heap.
Dogs at my heels
I arse through a gap

ducking old briars
and top up bird feeders
buried deep in trees
to guard from the sparrow hawk
whose single swoop can silence the whole plot.

Head bent I clean stoves
empty ash
fill log and turf baskets.

The kettle is steaming
I eye it
sore and yearning.
Not quite my turn yet.

Four dogs eat peacefully in a row.

I watch from my rocker.
Boots splayed.
Hat off.

In my pockets
two warm eggs
still.
I have become
Yogi of the yolk.

HOLY

Out with the flashlight
though there is no true darkness
every night you have beaten me
so far
nibbled broccoli
devoured cauliflowers and cabbages
in their infancy
leaving lacy holes
and silver trails.
I find your relatives
transport them
stuck fast to my fingers
way down the plot.
Slug, snail, sentient being
you are leaving bite sized holes
in my compassion.

HUG

Eating porridge
the outside animals fed
just the wild birds waiting in the trees.
The sun gradually de-shades the fields
and creeps up to the neighbour’s windmill.
Beside me as always the dogs
Shih Tzu and young shepherd pulling and dragging in play
little one’s head in big one’s mouth
he nibbling
she snuffling her cardiac laughter.
Old shepherd watches from his basket
collie gives a high pitch yip if things get rough.
Two cars pass for early mass
my picking hens briefly look up.
My day began hugging the necks of two donkeys
oats falling in foggy breath.
Then back into a steaming kettle
a ticking clock
and whatever the day holds.

ENOUGH

This is enough,
sitting here
ten in the morning
the chores done
the porridge eaten.
Everyone fed and out
picking or grazing.
The cat is back on my bed
the dogs stretched
Gracie upside down in her bed
legs splayed
blankie bunched the way she likes it.
Wei Paddy, head buried in the biggest bed
Zeb, head under the dresser
bum against the door
so nothing gets by him.
The kitchen clock ticks.
Outside small birds chirp in
dying trees under wet misty skies.
I have taken herbs that silt in the mug.
My chest is tight and sore
my body aches
but the headaches that followed me for days
have eased
which makes writing this possible.

The day stretches out
I am unclear what to do
or what I am capable of doing.
I am trying to keep going in optimism
and always gratitude.
So much of the day
seems to glide past me
unparticipated in.
As I approach fifty I am
trying to find a way to claim them back.
I am out of the habit of happiness and joy
having replaced them with
peace and contentment.
Time now maybe to remember old dreams
or find a few new ones.

SIMPLE

Now
who will smell of apple blossom?
Have homemade cakes in tins?
Be relied on for peppermints
use hat pins
and cold cream?
Who will know how to preserve ginger
or turn the heel in a sock?

SUMMERTIME

In the valley the water is rushing
a donkey brays what sounds like loneliness.
Nan my sheep lays protectively
in front of the goat house.
When I stand long enough she bleats
to acknowledge me.
Soft talk of mine draws sleepy cries
from my goat babies.
The moon is rising behind the forestry peaks
I am thrilled by its precious light
and lock it in like a secret.
There is no full darkness
the gift of summer we so easily forget
in winter.
In front the mountain silhouettes
are shapely as women.
My dogs bark their warnings at no one.
I stand in night clothes and slippers
and wonder at my sheer good fortune.

FALL

I sit mid chore on the front step
one dog stretched at my feet
the other sitting in the open doorway behind.
It is September with
warm sun in between showers.
Mountain rescue just flew overhead
can they see the wild haired woman
in purple clothes
carrying a blue milk carton and yellow pack cat food?
I am just up from three hours of necessary sleep
the kind that you want more of.
I am so grateful for it
even if it was fuelled by migraine medicine.
In the distance I hear the rattle and drone of harvest machines
closer the meditative sound of the wood pigeon.
How quickly the wind has whipped up
soon a shower will rise me
and drop the crab apples.
The tattered prayer flag
beaten but enduring rises to greet
another Fall.
September
when husbands leave however they must.

GIFT

Late summer in winter
red and orange trees
stand unshed
under warm blue skies.
Even flies still buzz
and birds sing
 as yet unpanicked about food.
It takes a jacket but I sit outside.
I cannot be anywhere else
or bear to miss a moment of this.
Beside me hens chatter and hum.
The donkeys lie unseasonably contented
in their brown earth clearing
faces to the sun
ears back
dozing with lowered eyes.
Blink and it will all be muck
and they will be back
peering out from their shed.

The dogs surround my chair.
Gracie’s soft jaw on my writing hand
Zeb watching the road
Peggy asleep on her side
her short lame leg stretched.

There is a bit left to pick for the goats and sheep
every bramble and thistle long ago devoured
nettles left as the last resort.

Plenty needs doing
I truly barely care.
On such a late gift of a day
I simply sit and stare.

STRUGGLE

Who turned out the swallows' nest?
And why am I so bereft?
That old familiar struggle with other's suffering.
White feathers hang out of their nest.
The swallows now tentatively check out the pump-house
for a new home.
A little strawed box in hand
I try to think like a swallow
and choose a place to tack it up.
This swallow pair flew back from Africa
and landed here on April 12th
way ahead
industrious and loyal
maybe it just doesn't pay
to be the early bird
only to have struggled in vain.

PLANS

All around me the world is spinning
everybody I know has first world plans
places to be
people to see
things to buy.
Unless you are in the other 80%
where your plan for today is to survive
maybe to stay safe
stay alive
eat and drink a little
if not watch your child's belly swell
brush the flies off their eyes
stop their crying
hide them from soldiers.
I have become separate from the
first world planners
yet am way more privileged
than the 80%.
Convention suggests that I have lost everything
health
marriage
unborn children
career and income
all sorts of social belonging.
Yet I have everything.

I sit outside on a blue October day
on a quiet hill in a peaceful country.
I can care for myself and fifteen farm animals.
There is always enough
without much left over.
I am not persecuted in any way.
I live mostly in silence
embedded in nature
out of sight
out of mind.
This is the place I live from
as I waken to each day.
Each same day the pain kicks in
the exhaustion
the sickness
the inability.
All constant shadows that can never darken
the light of gratitude.
Whatever has been taken
has been over compensated for
by nature and spirit and the Divine.
It is a world I would much rather inhabit
just could never seem to reach.

THE SCENT OF ZEN

i.

Grounded
to a stop
by the smell
of night stock
in a hanging basket.

ii.

Mist rising
a goat chewing cud
two hens on her back.

iii.

Clouds race across
a blue sky
 a bird swoops by
seedlings stretch towards
the sun
a dog kicks in his sleep
I just sit and watch.

iv.

Bird sings

clock ticks

tea steams

that is all for now.

v.

Hens in the morning

checking pots

for sleeping snails.

vi.

A dog chews a bone

breath steaming

a magpie watches.

vii.

Early autumn rain

cows still graze

not lifting their heads.

CHAPTER 12

DISCUSSION

Introduction

This final chapter presents a short reflection on this autoethnographical account of reimagining a self while living alongside Myalgic Encephalomyelitis (ME). It also discusses the original contribution to knowledge of this thesis.

I am privileged to have had a medical background and research experience and a strong sense of coherence (SOC) (Antonovsky 1996) so that I could sift through my individual options as an ME patient, choose or refuse treatment that might help or harm me, maintain some independence and eventually gain autonomy. I could easily have lost my home, and be back living with family or in uncertain social housing, like so many people with ME who may not have had my fortunate tools. I could be on antidepressants, pain pills, thyroid and heart medications to name a few interventions that I ultimately did not need, such is the level of ignorance that surrounds ME. In highlighting the medical, social and political uncertainty that surrounds ME I have identified ME as a contested illness that creates negative stereotypes for ME patients. Both these features are the greatest burden for ME patients to bear (Blease et al 2017). The controversial and contested nature of ME also puts ME patients on the receiving end of epistemic and testimonial injustices, where their credibility and capacity as a ‘knower’ and valid contributor to conversations regarding their own health is undermined and undervalued (Fricker 2007). Also with the absence of hermeneutical resources (concepts, ideas and narratives) it is not possible for patients to turn bewildering and challenging symptoms into an understandable or self manageable illness. Hermeneutical injustice in this instance finds its roots in medical schools where training and education in regards to ME is sparse or non-existent (Stenhoff et al 2015). It is hoped that this research thesis will contribute to redressing this situation as much work is required in this area. On an optimistic note, Professor Nancy Klimas, a leader in the field of ME research and treatment, recognises ME as a complex and multisystem illness and now advocates the use of integrative medicine for the management of ME. Integrative medicine advocates for clinicians to provide, in partnership with their patients, care for mind, spirit, community and body using medical and natural and less invasive interventions where possible and embracing diet, supplements, sleep management, appropriate exercise and pain relief and emotional support (Klimas 2019).

However, in reality, the thirty year web of confusion that has surrounded ME since its earliest days - or what Dimmock & Lazell-Farnon (2015) have called the thirty years of disdain - have contributed to the notion that ME is a pessimistic and hopeless chronic illness and an unchanging reality. Faced with such a personal reality I posed the research questions: is it possible to reimagine a self living alone with a chronic, invisible, contested illness? Could such a reimagined life be a good life? I return to the privilege of my medical background, research skills and strong sense of coherence here, as they facilitated (alongside illness) my using autoethnography as both method and methodology to seek to answer those research questions and to make a significant contribution to the field of ME and other contested and invisible illnesses.

Authoethnography, as has been widely discussed and demonstrated in this work, is an approach to research and writing that seeks to describe and systematically analyse ('graphy') personal experience ('auto') in order to understand cultural experience ('ethno') (Ellis 2004; Holman Jones 2005). My choice to use an evocative autoethnography allowed me to express the consciousness and subjectivity of my own position as author/researcher through using a 'personal vulnerable, reflective, self conscious, self narrative voice' (Ellis & Bochner 2016: 174). Sixteen years of lived experience living alongside ME was presented in four narratives (struggle, surrender, seeing and sanctuary) comprising journal entries, vignettes, my own poetry and photographs. Evocative autoethnography allowed me to use a writing style that is emotional, vulnerable and heartfelt (Ellis & Bochner 2016: 57). It also facilitated this research thesis as it allows for the inclusion of stories alongside theories and for referring to literature as well as science. I particularly welcomed it as it as a suitable method as it bridges passion and intellect, analysis and subjectivity, ethnography and autobiography and art and life (Behar 1996: 174).

Martha Nussbaum (1996) argues that one of the greatest benefits of literature and the arts is that narrative, by presenting us with the lived experience of another person, helps to inspire compassion in us to a level that we would not achieve alone. I hope that the narratives in my autoethnography would resonate with Bochner's description of 'a poetic blending and bending of science, literature, poetics and politics through which a self- conscious and reflexive writer or performance artist, expresses the beauty and tragedy of a lived life' (2018: 365).

Whereas there is the view within autoethnography that evocative, concrete texts should be considered to be as important as abstract analyses (Ronai 1995, 1996), which is a view I share, I chose for the purpose of this thesis to put my four personal narratives 'under analyses'. Using an original conceptual framework which I titled 'the struggle cycle' in conjunction with Stanley Witkin's Conditions Facilitative of Transformative Change (2014) and The Four Noble Truths (which deal with suffering) taken from Buddhist philosophy, I explained my personal transformative trajectory from 'attached', dualistic, conceptual, suffering mind to more of a non-attachment to suffering (suffering is always present in life) and to a Beginner's mind, which in Zen terms is able to accept or at least to be aware of the 'such-ness' and the 'as-it-is-ness' of the world.

A summary of the 'Struggle Cycle', an original conceptual framework

To summarise the trajectory of the narratives, from 'Struggle' to 'Surrender' to 'Seeing' to 'Sanctuary', I visualise a circle with 'Struggle' at the top and an arrow (the second arrow of suffering) moving in a clockwise direction to 'Surrender' (visualise three o'clock) to 'Seeing' (at six o'clock) and the arrow concluding at 'Sanctuary' (at nine o'clock). The clockwise second arrow would not close the circle back up to 'Struggle ' (at twelve o'clock) because I visualise the struggle/suffering to have ended in 'Sanctuary'. Although there will always be suffering in life, and to an extent it is present on a daily basis with chronic illness, non-attachment to it means one does not have to return to struggle as a 'self'. Also I visualise an arrow going in a counter clockwise direction from 'Struggle' to 'Sanctuary', for as Richard Rohr (2009) teaches, the two greatest paths to transformation are suffering and love. Those few higher beings whose transformation comes about through love, need only to follow the counter clockwise arrow from 'Struggle' to 'Sanctuary'. That was not my story. Suffering had changed my 'mind', and transformed my view from the rational, dualistic, conceptual mind to a Beginner's mind, seeing the suchness, and 'as-it-is-ness' of things. 'Dualism is rejected, emptiness is welcomed, material life is experienced in the now and what arises is compassion' (Davidson 2018: 85). My rational self had become a more intuitive self, a more relational self that facilitated a more harmonious and respectful ‘seeing’ and affinity between my ‘self’ and the other, particularly the non-human other. By emptying my mind of ‘self’ as the centre of all things, I had come to find my ‘proportionate’ place within the ‘interconnected and interdependent structure in the universe’ (de Silva 1998: 4) and to be increasingly aware of the impermanence of all things. I was happy to live in the non-knowing, and the as-it-isness of the world, which is Zen reality (Milstead 1998: 29).

An interdisciplinary approach.

To excavate and discuss the themes which emerged from putting my narratives under analysis, I benefited from the synthesis of ideas provided by an interdisciplinary approach. Autoethnography as a methodology opposes the ‘binary of science and art’ (Ellis et al 2011). An interdisciplinary approach therefore allowed me to examine my research questions by borrowing from both disciplinary worlds while creating new knowledge and ideas that would ultimately contribute to answering those research questions. I found such knowledge and ideas in the hard sciences (medicine and nursing), in sociology and the social sciences, in psychology, spirituality, literature and the arts and in the humanities (philosophy and social justice). This also provided the creative space to reflect on knowledge while creating it. Having either studied, worked or taught in these areas, an interdisciplinary approach, as Professor Tara Brabazon from Flinders University posits, suited my ‘wild wandering intellectual spirit’. It also unearthed some emerging concepts and schools of thought which not alone provided insight and answers to my research questions but whose broader applications academically and societally warrant mention here. I refer firstly to the concept of enoughness. Enoughness and the notion of sufficiency I had identified in my own life. I was aware that globally many had more than me and many had less than me. I preferred the idea of enoughness to the 1990s new age concept of abundance, and the idea that the universe was standing by waiting to provide for your every desire if you could just ‘trust’. I questioned how that might work for the billions of humans who survive this world on two dollars a day. Enoughness seemed relevant to the notion of voluntary simplicity which I explored in this thesis and the notion of interconnectedness and interdependence and ecologically responsible behaviour (ERB) which now has a global relevance in these immediate days of ‘Extinction Rebellion’ and the climate emergency. However, to date there remains a poverty of research with regards to enoughness.

Ecopsychology and terrapsychology as emerging fields

Not unrelated to these findings is the discussion of ecopsychology and terrapsychology in this work. In my narratives I frequently referred to the silence and stillness and restorative nature of my environment which sustained me, living alongside an illness like ME. However the restorative nature of environments is not confined to those with either physical or mental illnesses. In an era where in industrialised nations we spend over 95% of our time indoors (Evans 2003), environmental psychology and its practice of ecotherapy are coming to explore the concept of restorative environments or natural places, which help us feel better and help us to cope with life’s physiological and psychological problems (Hartig & Staats 2003). Allied to this is the emerging theory within ecopsychology of terrapsychology, which is the deep study of the healing presence or soul of a place, including the ‘things and creatures within its ambit’ (Chalquist 2007, 2009). This subscribes to John Muir’s early twentieth century environmental views and his notion of reciprocal gratitude, where one cares for the earth out of deep gratitude for its beauty and its bounty, rather than the modern view of the need for self sacrifice in the name of sustainability (Monopolis 2010).

Using exemplarism as a research tool

In this thesis I introduced the philosophical notion of exemplarism. My admiration for it as a research tool is manifold and it proved very beneficial to my research particularly when I was putting my narratives under analysis as often there was a lack of availability of useful cultural scripts. Exemplarism deviates from the more common inferentialist style of moral reasoning, which is a process of *only* argumentation in order to persuade. An exemplarist style of moral reasoning is based on encounters (personal or narrative or literary) with exemplars or individuals who exemplify some quality, role or way of life to such a degree that it engenders admiration to the extent that the exemplified behaviour or way of being is emulated by the admirer (Kidd 2017, 2018). As previously mentioned in Chapter 3 of this thesis, the epistemological contribution to this research of exemplarism as a concept is that it allowed me to examine my autoethnographic narratives, not alone in terms of what I learned but how I learned it and uniquely, who might have taught or influenced that learning or becoming. Also the non-inferentialist style of persuasion found within exemplarism resonated with the 'showing' inherent in evocative autoethnography versus the 'telling' in more traditional research. Although exemplarist moral reasoning does use argumentation, it is always sequentially and conceptually secondary to the stages of admiration and emulation and experience (Kidd 2017). Exemplars do not need to be moral heroes or iconic figures, and exemplarist narratives are often descriptions of ordinary everyday feelings, thoughts and actions in the 'rhythmical living of a human life' (Kidd 2018: 387). Therefore, as researchers and perhaps particularly as autoethnographers, in revealing our narratives of adversity and the wisdom they produce, we have the potential for our work to be exemplarist, to be useful and to invite comfort or invoke beneficial change on the part of the reader.

Autoethnography and the call to social justice

Allied to this autoethnographic call to change and transformation is its call to social justice. Productive autoethnography and autoethnographers who reveal their social and dialogical selves have the potential to promote social justice (Toyosaki & Pensoneau-Conway 2013). In addressing the concepts of compassion, empathy, ahimsa (harmlessness) and non-anthropocentrism (where humans do *not* see themselves as the centre of the universe) I seek to defend non-human centred ethics, advocating away from human domination and dominion and towards an ethical holism. I, like Muir, consider this central to living a good life. Highlighting in this thesis the contested nature of ME and the epistemic injustices that surround it, I consider to be social justice work, for the burden of constant corrective, persuasive and credibility work should not fall directly on the shoulders of the already sick and exhausted.

Autoethnography, generalizability and validity

Ironically, the act of writing autoethnography, particularly evocative autoethnography, is also not without its own need for persuasive and credibility work. I share the autoethnographic commitment that research can be rigorous, theoretical and analytical *and* emotional, therapeutic and inclusive of personal and social phenomena (Ellis et al 2011). I have availed of very little literary license in writing the narratives in this thesis and I hope I am considered to be a credible narrator by those who read it, for the questions most important to autoethnographers are: Who reads my work? How are they affected by it? How useful is it? Can it change the world for the better? (Holman Jones 2005; Bochner 2002). These questions are related to the notions of generalizability and validity in auoethnographic writing. I write in Chapter 3 of this thesis that the degree of reflexivity employed in my micro-sociological research (my story, my autoethnography) contributes to knowledge by considering the ‘micro and macro linkages’ (Laslett 1992: 392) necessary for social change. My original conceptual framework ‘the struggle cycle’ can be applied to many forms of transformational change and to reimagining a self, and not just to my experience of chronic, contested illness. Epistemic injustices lurk silently in many walks of life. Exemplarism is a viable alternative for many in a world of diminishing cultural scripts. The best measure of generalizability in autoethnography is determined by the reader as they decide whether a story resonates with them and their experience or the experience of someone they know (Ellis & Bochner 2000). They decide also if a story is valid by comparing their lives to the life on the page, by questioning the differences and similarities portrayed in the story, particularly when the stories told are about unfamiliar experiences and lives (Ellis 2004).

Creativity and originality

Autoethnography, in its blending and blurring of science and art allows for a level of creativity and authenticity that would not be located in other more traditional forms of research. Prosaic language is welcome in what Bochner (2005) calls ‘poetic social science’. The solitude and the silence and the stillness evident in the narratives presented of my life living alone (in the company of animals) alongside long term illness facilitated my insight into the transformative process from struggle through surrender through seeing to sanctuary. I had become a willing observer of life, if no longer an active participant in it in social terms. Embedded in nature, with a sense of reverence for beauty, gratitude for enough, and awareness of the scent of Zen I had become a poetic observer, and as such I include a collection of poems after the narrative analysis section of this thesis, that captures the essence of both the narratives and their analysis. Adding another creative strand, I included a selection of photographs I had taken overtime and I included them directly after the sequence of four narratives. Their photographic content resonated with the content of the narratives and added another layer of reality to the story for the reader. This level of creativity contributes to the originality of this thesis and increases the level of shared witnessing on the parts of both the researcher/author and the reader. As witnesses, autoethnographers allow readers to feel validated and better able to cope with or seek to change their circumstances (Ellis et al 2011).

The usefulness of this thesis

As an autoethnographic research work comes to an end, an autoethnographer asks (as does this one now) how useful is this story and to what use might this story be put? (Bochner 2000). The aim of this final reflective chapter in this thesis was to identify some of its uses both general and specific. The harsh reality remains that globally, chronically and invisibly ill patients living long term with ME lose partners, friends, jobs, careers and financial security (Dimmock & Lazell-Farnen 2015: 11). The #millionsmissing campaign (www.#millionsmissing.meaction.net) addresses the fact that millions of people worldwide are missing from their old lives. They rarely find any kind of validation or shared witnessing. In Ireland, 12,000 people who live with ME have experienced very little validation or seen themselves mirrored in any autoethnographic research. I view the writing of this autoethnographic research thesis as a socially-just-act (Holman Jones 2005) that seeks to reduce the prejudice (Ellis 2004) and misinformation that traps ME within the confines of a contested illness, that encourages personal responsibility and agency (Pelias 2007) and that raises consciousness and promotes cultural change (Goodall 2006). In writing both an accessible and an analytical text it allows for resonance, for a story to ring true for the reader and for the reader to be moved from ‘aboutness to withness’ (Shotter 2010). This in turn poses another major autoethnographic question for the reader: ‘What if this was true for me, what then?' (Bochner 2000). In this evocative autoethnographical research thesis, through a mindful attempt at a 'poetic blending and bending of science, literature, poetics and politics [this] self –conscious and reflexive writer has expressed the [loss and the beauty] of a lived life in a form that enables the reader to bring their own mindful attention to other people's experiences of love, hate, joy, injustice and deep pain' (Bochner 2018).

SEEN

Not sick enough to be seen to need help?
Not well enough to live your old lifestyle?
Invisibly and interminably ill?
Dearest
I would leave lasagne
or a small crate of oranges
at your locked gate.

CHAPTER 13

CONCLUSION

Using an autoethnographical method, this thesis describes the lived experiences of Myalgic Encephalomyelitis (ME) a chronic, invisible and contested illness. The research asks if it is possible to reimagine a ‘self’ that could find a way to live a good life living alongside such an illness? This autoethnography shows that with assisted transformative processes it is possible to do so.

In Chapter 2, ME is described as an acquired, complex disorder characterised by a variety of symptoms, principally extreme fatigue or malaise following exertion lasting six months or longer (Caruthers et al. 2011). ME is revealed as a chronic, invisible, contested illness (Blease et al, 2016) with a global prevalence of 17-24 million sufferers (www.meaction.net). To date there are no laboratory or diagnostic tests to identify ME, and no cures or treatments (Green et al 2015). However of greatest relevance to this thesis is that ME is considered a contested illness. A contested illness is a disorder that is considered medically suspect because it is not associated with any known physical abnormality (Conrad & Barker 2010). The legacy of this contested nature is that the ME patient’s credibility is undermined and as a result diagnosis and adequate treatment and support are delayed. It is the contested and unsupported nature of the illness that is most burdensome to the ME population. The literature review reveals that the majority of research into ME is biomedical in origin and that there is a dearth of research into the actual long term lived reality of this illness.

Chapter 3 reveals the methodological design of this thesis to be an autoethnography. Utilising an evocative autoethnogaphical method proved to be the most beneficial method for my research questions which sought to examine the physical and emotional challenges faced daily while living alone with a chronic and unsupported illness, yet trying to stay well, maintain dignity and find a sense of purpose. As my personal journal entries were the main data source in the writing of this autoethnography, I consciously used my identity and my experience as my epistemology (Hermann-Wilmarth & Bills 2010). As added creative strands, I included my own photography at the end of the narrative section to serve as small capturings of my daily life. The evolution of the narratives when put under analysis revealed a ‘poetic dimensionality’ (Bochner, 2005) so it proved effective to include my own poems as they related to the narratives. The narratives, photographs and poetry contributed in this autoethnography to the exploration of the ‘two selves’ that Bochner advises should be included in an autoethnography: the ‘self’ the writer was then and the ‘self’ the writer has become as a result of the transformative ‘crisis’ (2000).

An original conceptual framework, the ‘Struggle Cycle’ traced the circular movement the transformative process took, moving from struggle through surrender through seeing to sanctuary, where the old attachments to struggle ended. Witkin’s (2014) Four Conditions Facilitative of Transformative Change, and the Buddhist philosophy of The Four Noble Truths were also employed as conceptual frameworks. The three frameworks were successful companions in identifying and mapping the trajectory of the transformative process and explicating the emergent concepts and exemplars that were instrumental in that transformation, or reimagining of a self.

The data in this autoethnography is presented as four highly evocative narratives that span the length of the illness (16 years) and document the daily experiences and challenges of living alone with a chronic, invisible contested illness such as ME, that tips repeatedly from relapse to respite. The narratives simultaneously reveal a solitary life in a remote rural environment living alongside rescued animals and guided by a Buddhist philosophy.

Analysing these narratives reflexively, resulted in the identification of the recurrent themes of voluntary simplicity and authenticity, enoughness, compassion, harmless living (ahimsa) reverence for nature, reciprocal gratitude and Zen mind. The further exploration of these concepts in parallel with the utilisation of the aforementioned theoretical frameworks and the autoethnographical methodology used, mapped out the trajectory of the transformative process and answered in the affirmative the research questions. It *was* possible to reimagine a self living alone alongside a chronic invisible contested illness, and such a life could be considered a good life.

This autoethnographical research thesis was reliant on the study of my ‘self’ and my own lived experience of ME, with the aim of bringing previously silenced perspectives to the forefront. It was necessary therefore that my autoethnography be a critically reflexive self-study and narrative inquiry, systematically constructed and reviewed to allow for the findings of a ‘single case’ to be transferable to similar contexts (Bochner, 2000) and to have utility and social relevance. It also provided an opportunity to ‘write to right’ or to write to highlight the misunderstandings that have been attached to ME as a contested illness, which I view as a social injustice.

The original contribution to knowledge of this thesis was the writing of an evocative autoethnographic account of living with moderate ME, which spanned the length of the illness (16 years), and despite the contested and pessimistic nature of the illness, sought to reimagine and transform a ‘self’ that without the need to transcend the illness, endeavoured to find a way to live a good life. To date there have been no such autoethnographic accounts written about ME.

Consequently in increasing awareness of the realities of ME at an academic level there is the potential for discussion and change. This work can inform medical professional and other support services dealing with ME sufferers. This work can inform the general public and those who share their lives with people who live with ME. It is hoped that this work will help others who live with ME to reflect on and understand their own experiences. In ‘writing to right’ in this thesis and to correct the injurious effects of the contested nature of ME, I hope to reduce the burden of the ‘credibility work’ that exhausts an already exhausted minority.

An original contribution to knowledge was also made at a methodological level by submitting an evocative autoethnography that included original poetry and photography at a doctoral dissertational level.

Completing this evocative autoethnography afforded me the added benefit of turning an extremely difficult set of experiences and circumstances to creative and constructive purposes for my own benefit and it is hoped for the benefit of others. The vulnerability of revealing oneself in this thesis to such a degree and the expectation of criticism of one’s deepest being (Ellis 1999) has been a reality in the writing of this research. An element of courage and commitment to the cause was required. It is in the spirit of resourcefulness, helpfulness and usefulness that this autoethnography has been written and in the desire, as Audre Lorde suggests, not to waste the pain.

EPILOGUE

No matter how weary we get
no one of us is without embers
to kindle a light.
Each of us can be bringers of light
and together we can make a radiance.
Mark Belletini

I began this PhD research as a woman who, although I was living a life affected and impacted by ME, had become purposefully detached from it. This research thesis required that I surrender any such detachment and immerse myself once again in the world of ME, re-examine it, un-earth it, question it, try to explain it. As with all worthwhile endeavours, such experiences incur both costs and benefits. Before illuminating such costs or benefits, but not unrelated to either, is the issue of the intention of this thesis. The research questions and methods and findings have already been concluded, however in an autoethnographic work such as this that has intentionally included an unusual degree of originality and creativity, reviewing what was intended and, by default, not intended is of consequence. My thesis highlighted the contested nature of ME and the lack of agreement within medicine and science, and how it has been the ME patient who has borne both the burden and the brunt of what medical history will not review favourably. In highlighting this, my intention has been to increase awareness of the depth of ignorance and misinformation that surrounds ME and to contribute to any potential for positive change. Women make up 75% of those with autoimmune and inflammatory disorders about which little is yet understood. Consequently, they find themselves falling repeatedly into medical 'knowledge and trust gaps' (Dusenbery 2017). Although this offends deeply my feminist sensibilities, I did not intend in this thesis (past highlighting it) to 'take that on'. My intention was to find and later describe and share 'a way' or one woman's way, to live her one short 'wild and precious life' alongside such a contested and disputed illness, an illness that lives embedded deeply in both the knowledge and trust gaps. My intention was to share the idea of really living alongside illness, versus waiting, waiting to be believed or understood or helped or supported. I wanted to share the idea of reimagining or transforming a self or a life, versus losing or shrinking that life because of illness. Added to this was the intention that such ideas might be found useful or replicable in some way by others who found themselves caught overtime in a similar 'troubling state of affairs'. I hope that these ideas can translate into derived benefits from this work.

The experience of completing this research PhD has been profound. This is probably true for all PhD candidates. My pre-ME academic fluency never returned so I had to work twice as hard to accomplish half as much in double the time. If I spent much time away from the work all my carefully synthesised thoughts would disappear – a touch of groundhog day. My solution was to stay attached to it always, awake and asleep and as such the work became a constant and intimate companion. Together, over the years, whether at my kitchen table or out farming we would form hundreds maybe thousands of threads of thoughts and though I could not see it happening, every one of those threads got sewn into its rightful place in the work. This is what touches me the most deeply, and recently as the work draws to its conclusion can bring tears to my eyes. Tears of what? Gratitude? Relief? Yes, both of those. But mostly I am moved that all the benevolent universal forces conspired to allow it all to happen and that despite everything I could send this story from behind a locked gate out into the world where it might be of some use and some beauty.

However, I must mention that the cost to me of doing this work is also the final 'Catch 22'. I have been both inspired and affirmed by this research while simultaneously being overwhelmed by it physically and emotionally. I continued to work away silently and willingly. Yet often, ringing in my ears were the voices who might say and the minds who might think: 'how bad could she *really* be, to be able to write that thesis?' To these voices I must say:

> I have inflamed myself
>
> ulcerated myself
>
> flared up

burned out

merely existed

and lost precious ground

for this precious cause.

Twenty percent of people with ME have limped back to work to some degree. 20% are being cared for by others around the clock. The 60% in the ‘moderate middle’ are what Cheri Register calls the ‘interminably ill’ (1987), or those who are more recently considered as the “#millions missing” invisible from their old lives (www.millionsmissing.meaction.net). Anais Nin writes that a life can shrink or expand according to one’s courage. Many people with chronic illness find courageous ways to live with their illnesses. A personal benefit from writing this autoethnography was that I began to see myself as quietly courageous and subsequently became more self-compassionate. Overtime, I went from being ‘driven to being drawn’ (Rohr & Claiborne 2010) which is an easier, gentler way of being and another benefit I hope that by being ‘shown’ to be so in this autoethnography, can also be useful to others.

Autoethnography reveals both the power and the vulnerability of the personal voice, telling one story at a time. Yet if creatively used, the personal voice can, as anthropologist Ruth Behar suggests, ‘lead the reader not into the miniature bubbles of navel gazing, but into the enormous sea of serious social issues’ (Behar 1996: 14). In telling the vulnerable story of illness you can be reduced down to the floor of who you are (Charon 2006). I hope in this autoethnography I have also told a story of who you can become.

Summer is sliding into Fall for yet another year as I conclude this work. The donkeys will soon be home as the light once more turns away from the sun. The swallows have left for Africa. The wood pigeons, who had lost their home in the tree felling have returned and now sing their song as Kate Bush captured it....*A sea of honey....A sky of honey.....* Junebug, the little epileptic hen has given up her struggle and passed, along with two other sister hens. The rest of us other ‘good life’ critters remain. Thoughts must now shift not alone to the approach of Winter and the stocking up once again of food, fuel, fodder and feed, but also to the shortening of the days and the need for me to remain behind the sanctuary of my gate in order to prevent further illness. I have asked, ‘what if this house, this hill, this life was all there ever would be?’ I have answered that I would consider it to be a ‘good enough life’. A good enough life, a happy life, a successful life is one that is loved by the person living it.

As I wrote this, lost in the thoughts and the words, a baby bird flew into the kitchen. Stiff and sore, I was too slow to get to it before one of the dogs caught it in his mouth. I retrieved it, it was unmarked but gasping with its little beak open. It closed its eyes. No, I begged it, please, live. I breathed into its tiny beak, stroked its downy chest but it was gone. I wanted to cry, I wanted to bring it back.

I breathe...

....remember Zen mind,

and the suchness and as-it-is-ness of things.

> You arrive in the village broken open
> Carrying the story of suffering
> Study the rupture, then apply the balm – intention is medicine.
> Learn to
>   Eat the autumn air
>   Make an Offering of Gratitude
>   Translate everything
>
>   *Joy, sorrow, struggle shame*
>   Into acts of art and love.

(Excerpt from Ann Filemyr 2015)

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APPENDIX 1: INTERNATIONAL CRITERIA CONSENSUS 2011

Because of the more recent research findings that had become available since 2003 when the Canadian Criteria was written, The International Consensus Criteria (ICC) evolved . They argued that the research had strongly pointed to widespread inflammation and multi-systemic neuropathology, that indicated a specific underlying pathophysiology peculiar *only* to ME. Therefore ME having its own identifiable pathophysiology suggested the need for a refinement of patient stratification. The panel represented 13 countries internationally and included clinicians, researchers teaching faculty and this time, an independent patient advocate was included. Several members had previously been involved in the development of the Canadian Criteria.

One of the major outcome changes recommended by the panel was that the illness once again be called ME. It suggested it was the most accurate term as it reflected the underlying multi system pathophysiology of the disease. It considered ME and CFS to be two widely diverse conditions. It rejected the interchangeable uses of the terms ME and CFS and it rejected their combined uses as ME/CFS or CFS/ME. It suggests again that a disease entity should have only one name consistent with the WHO classification rule that a disease cannot be classified under more than one rubric.

THE PRINCIPAL DIFFERENCES IN THE INTERNATIONAL CONSENSUS CRITERIA

According to the ICC, for a diagnosis of ME to be accurate, symptom severity must result in a significant reduction of a patient’s pre-morbid activity levels. Activity levels must be reduced by 50% or more. It further categorizes activity reduction levels into :

Mild: activity/ability reduced by 50%

Moderate: patient is essentially housebound.

Severe: patient is bed bound requiring care.

Fluctuations, (in each category) can vary on an hourly or daily basis with variations in recovery time.

The major criteria in the ICC definition is post exertional neuroimmune exhaustion, (PENE) previously referred to as post exertional fatigue or malaise which is category (A). This is a pathological inability to produce sufficient energy on demand and symptoms post exertionally becoming evident in the neurological and immunological areas. In fact according to the ICC this is a mandatory requirement for a diagnosis of ME.

It also requires at least one symptom from three of the four neurological categories, category (B)

1. Neurocognitive impairments
2. Pain
3. Sleep disturbance
4. Neurosensory perceptual and motor disturbances.

It requires at least one symptom from each of the three categories in Category (C)

1.Immune impairments

2. Gastro-intestinal impairments

3. Genito-urinary impairments

Finally, at least one symptom from Category (D) which is energy production and transformation impairments.

The symptoms themselves do not vary from those in the Canadian criteria so in the interest of brevity have not been repeated here.