From Me to Ill:
An autoethnographic illness narrative

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Unless otherwise acknowledged in the text, this thesis represents the original research of the author.

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Signed: _______________________________
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To my parents, for the support you offer now, and then, and forever, and my family for not killing me.

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And to all the people who make up my story, and let me be part of theirs:

Stories you read when you're the right age never quite leave you. You may forget who wrote them or what the story was called. Sometimes you'll forget precisely what happened, but if a story touches you it will stay with you, haunting the places in your mind that you rarely ever visit.

—Neil Gaiman. ‘M is for Magic’
Contents Page

Introduction p.4

Chapter One: Medicine p.18

Chapter Two: Work p.33

Chapter Three: University p.48

Chapter Four: Relationships p.61

Conclusion p.79

Bibliography p.89
INTRODUCTION

*If you don’t turn your life into a story, you just become part of someone else’s story*

—Terry Pratchett

When I think of being ill, my mind still, instinctively, draws forth an image of bed and warmth: my mother’s cool hand pressing against my warm forehead, a sense of sleepiness overlaying a burning throat and aching muscles. This is probably the first memory I have of ‘being ill’, and yet it is not the symptoms I recall clearly, but the bedclothes and my mother. I most firmly remember that it was *okay* to be ill, *it’s okay, you’re going to be fine, it’s okay*. It is reasonable to assume that a lot of people have similar first experiences and memories of illness as a child, that they also bring forth such images when thinking of illness. It is odd for me, because for the last nine years I have lived with an undiagnosed chronic illness- a seizure disorder without name, and without medical validation. When I think of having a *disease*, that is when I am seized (aptly) by images of convulsing limbs and twisting muscles, of a tableau of emotions so strong my mind naturally shies away from it. I think of doctors visits and medical tests, of blood and questions. I think of doubt, in myself, in my doctors’ faces, in my reality. I feel ill when I have a seizure. I feel ill after I have a seizure, and sometimes even before. I
have acute and irrefutable symptoms; a seizure is harder to disguise than cancer. But I do not have a ‘disease’ or an ‘illness’ in the medical sense, and this means I am often forced to forfeit it in the social.

One does not have to fight to explain a named or diagnosed illness, but will inevitably have to fight stigmas, prejudices, assumptions and discriminations. People living with an undiagnosed chronic illness experience this differently; as Joseph Dumit put it, it is ‘illness you have to fight to get’ (Dumit 2006). Fighting intimately implies conflict, and conflict lies at the heart of constructing my condition. In the four major spheres of my life – work, relationships, medicine, and university – I construct my illness differently, and am afforded different recognitions and validations. I have used these spheres as the topics of each chapter. Each speaks of the social construction of a condition, told through rich, descriptive text, composite accounts of lived experiences, creative and visual auto ethnographic methods, and theoretical analysis.

There are so many questions to be asked about illness, disease, disability, and society. What do these words mean, and why do they mean so many different things to so many people, cultures, and societies? What is the role of illness in everyday life? How much of it
should be mediated through medical lenses? Through cultural ones, or personal? Why do we struggle to reconcile the experience of illness with living a moral life? Many a brilliant writer or researcher has posed these questions, and more. But of interest to me is how the day-to-day experience of the chronically ill is routinely defined by stigma, by otherness, by a fractured and immoral life. I have had the interesting fortune of experiencing a chronic, undiagnosed illness, one that started in my late teens and has framed most of my life since then. In choosing to document it for my honours thesis, I was influenced by two factors. First, a desire to understand my own existence in a more active sociological sense, and secondly, to explore why the world positions illness as so removed from a ‘normal’ life, when our medical, technological, social and cultural progressions clearly indicate differentness is in fact the ‘norm’. Is it merely a bone-deep and atavistic fear of death? A lesson taught to us socially by a culture obsessed with progression of the human state? Answering these questions is not the goal so much as the driving force: I instead intend to explore how illness construction is mediated by different spaces.

Important to the structure of this thesis is the construct of my sense of self. I exist in a liminal space between disability and illness, belonging to neither, and often relegated to the status of a healthy
person. It is in this liminality that the spirit of my analysis can be found. To be ill, to be forever presently sick, is a burden in our current world. We can best appreciate liminality through Victor Turner’s (1970) description:

The attributes of liminality, or of liminal personae (“threshold people”) are necessarily ambiguous, since this condition and these people elude or slip through the network of classifications that normally locate states or positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial (Turner 1970:95).

Betwixt and between we are, and therefore difficult to theoretically analyse. How best to capture the illness experience without sacrificing the true meaning of living it? The very first question was to reconcile what other subject must be analysed in hand with illness: namely, the body. Is the body just a container for the self? Cultural dialogue would certainly suggest so. We view our bodies as separate, as an Other, a thing with limits and borders which hold us apart from the world. The dialogue of illness expresses this conceptualisation perfectly, when we describe stroke patients as trapped inside their bodies, when we say illness changes a person, or that one suffers from illness. Unspoken is that illness—and chronic illness specifically—often ‘includes metaphor and meaning, moral judgments and ethical dilemmas, identity questions and reconstruction of self, daily struggles and persistent troubles’
(Charmaz 2000:277). The body is not just a container for the self, but it is the vessel through which we connect with the world, how we protect ourselves, and holds our identity as a stable construct. In illness, ‘the self has become vulnerable, and thus problematic (Charmaz 2000:277). My self-construction is wrapped around my illness, and my illness is undefined and fragile.

One thing became apparent as I dug deeper into the research for this thesis: that every single experience I had of illness had been referenced and dissected by dozens of other writers. My doing away with heels and difficult clothing? Kelleher 1988. My struggle with organising my illness into experiences shared with others so doctors might listen to me? Dumit 1997. The annoyance from those same doctors as I commandeered their power? Charmaz 2005. Stigma in the workplace, relationship breakdown, feelings of alienation, exclusion from social contacts? Bury, Conrad, Nettleton, Pinder, Pierret, Little- the list was endless. I became uncertain that I had anything to add to the discussion, until I started reading Arthur Frank’s body of work.

Before the preface of his book ‘Letting Stories Breathe’, Frank selected a short quote from a mythological-historical story by Barry Unsworth: ‘We are all the victims of stories in one way or another,
even if we are not in them, even if we are not born yet’. Iphigenia, daughter of King Agamemnon, is the speaker, and it is hard to think of a person who more embodies that idea than she. Those who know the myth would know her death was decided upon before she was even born, that she is relegated to a footnote in the history of Greek mythology. It is a poignant thought to begin any narrative, especially for the sociologist who sees how much of an individual life is controlled by the society to which they are born. We are all the victims of stories. The chronically ill, in literature and culture, are so often reduced to victim narratives, or to subjects in medical studies, or the respondents of a sociological survey. We are the many, nameless, objects around which other people write their stories, but our stories do not end when their narrative does or in the conclusion of the study. The most disappointing eulogy is the one that reduces the entire story of a person to some sad summary of their illness. I wanted to speak out through my story to provide research and analysis into lived experiences of chronic illness, and chose the method of autoethnography, and illness narratives to do so.

Autoethnography as a method for sociological research occupies a tense threshold between groups affording it different definitions. The competing forms of autoethnography would (and indeed have)
require a whole book to describe, so I am settling for offering an explanation of the form I chose to utilise – analytic autoethnography, so coined by Leon Anderson (2006). Broadly, autoethnography can be defined as “research, writing, story, and method that connect the autobiographical and personal to the cultural, social, and political” (Ellis 2004:xix). It is, however, Anderson’s (2006) call for ‘distinctively grounded opportunities to pursue the connections between biography and social structure that are central to C. Wright Mills’s conception of the sociological imagination’ that drew me to the method (390). Anderson sets the parameters of analytic autoethnography within three rules: ‘ethnographic work in which the researcher is (1) a full member in the research group or setting, (2) visible as such a member in the researcher’s published texts, and (3) committed to an analytic research agenda focused on improving theoretical understandings of broader social phenomena’ (375). I fulfil the first, am presenting as the second, and am committed to the third. It is the third point to which I now turn my attention, to discuss the theoretical concerns I use to analyse chronic illness, as well as my justification for studying my own narrative.

Autoethnography has detractors the same as any method, raising many legitimate concerns. Sara Delamont (2006), Paul Atkinson (1997), and more have written extensively on the inclination of autoethnography to generate self-indulgent or lazy research useful
to only a privileged few. This is entirely possible, but it also ignores the potential to create research that delves deeper and produces stronger knowledges of under-privileged areas. I see the need for the author in the text. When Gatson writes of her experience of being biracial, she highlights the need for the subject to speak out in the text by offering a subjective opinion not easily accessible for those ‘outside’ her own self: ‘As I both research racial and ethnic definitions comparatively and historically as well as move myself about the world, I find a less definite, yet more connected, identity’ (2003:21). Gatson tells her reader, and sociology at large, more about the complex experience of bi-raciality in one paper than a dozen formal participant-observation ethnographies ever could. Analytic autoethnography tied with illness narratives (as defined by both Charmaz 2000 and Kleinman and Seeman 2000) provide a similar outcome.

In hand in hand with analytic autoethnography are the key concepts for this thesis- Michael Bury’s (1982) biographical disruption, Miles Little’s (1998) liminality, and Arthur Frank’s (2004) sociology of witness, or call for storytelling. Bury’s concept needs little introduction, given its seminal status in the study of chronic illness. It is from Bury’s ‘disruptive event’ that I draw my focus: my seizures are the epicentre of my disrupted biography, but how do I –or
anyone afflicted with a disruptive illness—construct a ‘stable’ reality around them? Furthering this, Miles Little (1998) conceptualises the lived experience of illness as a category called ‘liminality’, which incorporates a process ‘in which each patient constructs and reconstructs meaning for their experience by means of narrative’ (1485). It is Little’s inclusion of narrative analysis that leads us to Arthur Frank’s call for ‘wounded storytellers’ (2013).

It is as the wounded storyteller I write this thesis. Often I am hurting: these words were written not just at desks, or on lawns, but in beds and the many waiting rooms of medical professionals. My world before committing these words to paper seemed as Arthur Frank describes the chaos narrative:

‘those living in chaos are least able to tell a story because they lack any sense of a viable future. Life is reduced to a series of present-tense assaults. If a narrative involves temporal progression, chaos is anti-narrative’ (2013:xv).

Stringing together disparate threads of experience feels like searching for meaning in a kaleidoscope: the interconnectedness of the parts is apparent, but there is no big picture. I do not disagree with Frank’s (2013) assertion, on the topic of narratives, that ‘to turn the chaos into a verbal story is to have some reflective grasp of it’ (98). Yet chaos is inherent to my narrative, and writing it out had not diminished that. I try to weave it into words, but it is like clutching at grains of sand: the harder I try, the faster they fall. I
focus on the least chaotic elements, and my story becomes a summary in no way reflective of my lived experience. To balance this, I include thematic vignettes, experimental writing sections, and my own informal speaking tone. I do this to convey a living sense of the ‘me’ in my story; where I fall shy of deeper analysis is where I am physically incapable of reflection, as ‘the story traces the edges of a wound that can only be told around’ (Frank 2013:98, my emphasis).

Being able to capture the past in any linear sense is difficult for persons with chronic illness. Events of acute and non-acute episodes bracket the recollection of life history, and the world seems as if wholly composed of immediate pain. If chronic illness unfolds as Michael Bury (1982) suggests, ‘first, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries’ (169). The next is crucial to even an outsider understanding of chronic illness: chronic illness ‘involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others’ (Bury 1982:169). Constructing a linear autoethnography was therefore impossible, but the potential of recounting specific events—as done by Huang Zhenji in Kleinman and Kleinman (1994)—seemed possible. It is this illness narrative aspect that I
found pivotal to this research. Worrying that I would lack distance and self-reflexivity to produce meaningful research, I thought of Oliver Sacks’ words: how could one know that one had shrunk if one’s frame of reference had shrunk?” (2012:156). Could I know who I was enough to write of illness experience if I struggled with time and boundaries? Was it true when people told me ‘aren’t you brave’, like there is something active about my approach to illness? Like somehow I’ve chosen this existence, instead of simply reacting constantly to each day? If I think there is no action in my actions, only reaction and response, can I honestly produce anything worthwhile? Such doubts, however, are very much important for the wounded storyteller. We are working from a place less stable, a place defined by its reduced bonds. It is in this place that our stories become critical, that they become ‘about recognising how much we as fellow-humans have to do with each other’ (Frank 2013:163).

To begin this thesis, I outlined my main researcher question (how do I construct my illness?) and separated it into four broad areas that define my life: work, relationships, medicine, and university. While there are thematic overlaps in some of these categories (work and university had the potential to be identical), I soon realised the construction work I do in each area differs to degrees of which I had not been consciously aware. In ‘Medicine’ I analyse power
relationships in the medical world, using my own experience to explore the basis of illness construction as socially—and not biologically—framed. In my chapter ‘Work’, I dissect power and culturally normative responses to illness. I consider how my illness frames my working identity and ability, and how the failing morality of the ill body is shunned, contained, or hidden in the workplace. ‘University’ covers the role of knowledge in illness production, the lived experience of pain and medication, and the emergence of my ill identity acceptance. In ‘Relationships’, I question the right to the ill experience, and analyse how others respond to my illness, and why holding oneself apart is problematic. For all of these chapters, I contend that ‘illness is not simply present in nature, waiting to be discovered by scientists or physicians’, but an evolving and fluid experience that stretches from body to body, in and out of social organisations and frameworks (Conrad and Barker 2010:S68).

I want to convey not only the sociological implications of chronic illness, but also the lived experience, and this autoethnographic illness narrative gives me the freedom to do both. If we accept that female writers are needed for insight into the female perspective, as we do with feminist literature, or that the inclusion of ethnic writers will dismantle the ‘white’ hegemony of sociology, then I believe we need writers from inside the chronic illness experience to usefully
engage with theories, and develop a better sociology of health and illness. One way to engage this process is the use of storytelling, a concept espoused by Frank (2013) as being ‘a sociology of witness’ (24). The story of the ill person is that ‘they seek not to provide a map that can guide others – each must create his own – but rather to witness the experience of reconstructing one’s own map’ (Frank 2013:17). I need not to impress or sadden, to elicit empathy or pity with my personal story, but rather to call forth connections between myself and others.

When I have a seizure, I am alone. It is only me who knows the strange, hollow ache in my left arm, who slides towards the floor and feels my muscles becoming stiff, unresponsive and painful; only I know the alienating sensation of watching and feeling my body contracting and convulsing without my control. Only I know the exquisite pain deep in my bones when I go limp. Yet, I am never alone in my illness. Others see me in these states: doctors and nurses, my mother and father, my family, my friends, co-workers and complete strangers. They too carry stories of my illness, bear the weight of it, and share in the inexorable change of life with a chronic illness. This thesis is my story, but it is made up of their stories too. This is the role and responsibility of the wounded storyteller: to be trusted with, and trust in, the stories with which
we construct our lives; to find the many meanings and grant them a voice.
CHAPTER ONE: MEDICINE

What then does one seek? Not a hidden power, but a source of kinship for mature persons. And also the assurance that it is not totally absurd to have suffered.

—Emmanuel Levinas ‘Is it righteous to be?’

This chair is uncomfortable. It is my first thought as I settle into the room the nurse has led me. I shift and twist, give up. Standing, I look around at the faded walls, the usual array of medical posters, and trays of medical supplies. I wonder briefly if I could have use for a handful of whatever those plastic-wrapped tubes are. Probably not, but I am irritated by the multiple delays this morning. Three and a half hours drive, two more in the waiting room, and now a cheery ‘the doctor will be just a moment’. A ten-minute moment, so far, and the impulse to filch random things is my poor attempt at empowering my position. I console myself by flicking all the pamphlets out of order, pause, and re-tidy them. My stomach is twisted up, and my hands are shaking slightly.

The door opens, startling me. The doctor—who will soon tell me these are all indicative of his diagnosis—is a tall, smiling man who I have met three times before. A neuro-psychiatrist, he has a kind expression, and makes me feel at ease. At least, until he informs me I am not suffering from an undiagnosed seizure condition.
“It’s purely psychological. We didn’t find any evidence of a biological basis.”

“But I was told you didn’t find any evidence of a psychological basis, either? And the neurologist here said I was definitely having seizures.”

“Well, our final group decision is that it’s in your head. It’s a good thing- epilepsy or any chronic illness is a terrible thing to live with.”

I’m quite shocked. Weeks of back and forth tests, driving interstate, being strapped into beds and wires and headgear, a reiteration of the last 7 years of my hometown medical induction, and... what? All leading to a dismissal even my long-term doctors never reached.

For some reason, I fixate on one point.

“I have disability status at uni.”

“Cancel it. You need to get on with it. You’ll probably never have another little turn again.”

I am convinced I must be angry, but I can’t access my emotions. I wonder if this man has read my medical file. I have 7 years of seizures to prove him wrong. But I can’t form an intelligent reply. I am suddenly incapable of arguing my defence. I sit and agree, nod along, anxious to escape this room. I am consciously aware that I’m playing the role of the patient, to my own detriment. It does not matter what I know. Doctor knows best. He’s seen a hundred girls like me- girls, a slip of the tongue, or were all the patients female? Is
that why I’m effectively been given a modern day diagnosis of hysteria? He basically confirms it: I don’t have the usual trauma background for a psychosomatic illness; it must be my disposition. Never mind that the five previous psychiatrists and psychologists have said I am intelligent and well adjusted. There’s no biological evidence, I must be crazy.

I stand, and I’m nauseous and shaking. I don’t let him see. It is very important that he sees me, this last time, as calm and accepting. I want to yell at him, but I am firmly behind my wall of icy politeness.

Medicine Analysis

Issues of identity, authenticity, and conflict frame my relationship with the medical world. I am, as Michael Bury (1982) theorised, caught in a ‘disruptive experience’ of cultural frameworks that allow limited or no recognition of the effects of chronic illness (p.169). My status is further complicated by my lack of diagnosis. Doctors regularly see me as unusual but not critical; I am allowed a certain percentage of medical time, but without the essential commitment of future. Sometimes I am dismissed outright, sometimes humoured, rarely authenticated by attention or action. My experience in the medical community is hardly unique- the patients in Bury’s rheumatoid arthritis study, Sarah Nettleton’s Medically
Undiagnosed Symptoms, Little’s cancer patients, and more, all describe a sort of alienation between patient and doctor. As White (2009) indicates, our medical profession is designed not to cure illness, but as ‘the social control function...in enforcing compliance with social roles in modern society’ (6). This results in a certain problem of expectation between doctor and patient. We, as patients, implicitly assume the doctor can, if not cure us, at least contextualise our ill self. When we fit into a recognisable category of medicine, the doctor can prescribe both treatment and our social role. When we do not, it is a failing of two kinds: no medical treatment, no social role.

These failings are best expressed through the approach of Little et al (1998), for it is the ‘adaptive, enduring phase of suspended liminality’ in which the undiagnosed chronic illness experience is located (1485). My illness lives in a liminal space, easily apparent in a physical sense, yet hidden from conventional medical testing. When I have a seizure -and my use of the term is controversial in the strictest definition- I fall to the ground, my muscles contract and stiffen, my cognitive function lessens, I am without control of my own body. Yet, monitoring from MRI, CAT-scan, EEG, EKG, etc., indicates no discernible aberration. According to these tests, I have no illness. According to the hundreds of seizures I have had, I clearly
have a illness. A lack of diagnosis extends much further than the doctor’s office, it permeates every space of my life, leaving me ‘neither here nor there’ (Turner 1970:95). The space I cannot enter, that of authenticity, is the one I most need to occupy in order to facilitate my cultural positioning. My lack of diagnosis is not a rare occurrence- in one UK study, 51% of new patients were identified as having ‘medically unexplained symptoms’, and of the neurology patients, 27% of those presenting with seizures were considered to have this same lack (Reid et al 2000). In Australia, up to one in four primary care patients experience these symptoms (‘Health Report’ 2012). Over time, my illness has been referred to as ‘atypical seizure disorder’, ‘tonic-clonic seizure-like activity’, ‘undiagnosed muscle spasms’ and ‘myoclonus’, a descriptive, symptomatic term. I usually describe it as a seizure disorder, for ease of understanding, and to lessen questioning responses. In a medical context, I cling to myoclonus, as it is a recognisable term. But it is also in response to the diagnostic uncertainty of waiting to find a disease with which to label my symptoms (Timmermans and Buchbinder 2010).

Uncertainty is the key to this diagnostic wait, and while Turner (1990) points this out as ‘compliance in the sick role’ (201), Timmermans and Buchbinder (2010) stress the long-term impact this has on the patient. Terming us ‘patients-in-waiting’, the authors offer a succinct explanation for my liminal state: without diagnosis,
where a ‘cognitive schema that offers a plan of action for both patient and clinician’ is lacking, there develops a ‘pressure to fold an incomplete characterisation back into more conventional categories’ (409/410). We—as patient, clinician, or other—crave categorisation and label.

The reality of living with an undiagnosed illness repositions the medical world as a daily construct in my life. I have medicalised routines of medicine-taking and pathological monitoring. I record bodily symptoms and events across an array of technological devices. My calendar is littered with appointments and follow-ups with medical professionals. I debate and defend my treatment plan with personal friends and professionals alike. I check online sources and consult medical dictionaries for information. I keep folders of documentation on my bookshelves, propped up by decorative bookends. Medicine and my body are visible to me in ways I would not recognise if I were healthy. Yet for all the medicalisation of my daily life, I am ‘outside’ the medical realm, looking in. The impact of this is two-fold: I am not authentically ill, yet I am ill, and thus my identity is fractured. Sarah Nettleton (2006) suggests my experience is ‘emblematic of contemporary society, hallmarks of ‘a demise of social classification and social categories, and a concurrent rise in perpetual insecurity, risk and anxiety’, making my identity struggle
the outcome of a skewed power imbalance between medicine and the individual (1167).

Constructing my illness in a medical space becomes a high-stakes negotiation between myself, my doctor, and the medicalised world. I am expected, as the patient, to act uncertain, as ‘an essential component of patient compliance in the sick role’, to remain ignorant in the face of the doctor’s knowledge (Turner 1990:201). The doctor in turn must imbue confidence in me, fulfilling his role as gatekeeper to protected knowledge, and authentication of a social state. Yet it is crucial to note that the chronic illness sufferer is not afforded the luxury of remaining ignorant nor uncertain. In order to manage the day to day of our lives, we must take up an active state of being in both medical and non-medical spaces. This puts us in conflict with medicalisation, as Charmaz notes, ‘People with chronic illness can and do become knowledgeable about their conditions; these individuals are not always the unsophisticated passive patients the medical model assumes’ (2000:288). We fight constantly to know more about our illness, to better construct our lives, but are frequently forced back into passive roles.

In my vignette, I focus on this imbalance of power in doctor-patient interactions, and the role of authoritative validation. That moment
remains a defining one in my conceptualisation of the medical community, because it highlights the underlying issue of being undiagnosed in a world regulated by labels, names, and positions. I am at all times *proving myself ill* to the medical world, and from the medical world. I turn myself again and again to the medical world in an effort to legitimise my experience, an act that Gareth Williams correctly asserts will ‘assault an individual’s sense of identity’ (1984:175). Identity frameworks are reinterpreted as belonging to medical value systems. The naming of illness ‘allows an opportunity to conceptualise disease as separate from self’ (Bury 1982:172).

Do I even want to be labelled ‘ill’? Ann, the subject of Ron Iphofen’s ‘Coping with a perforated life’ (1990) speaks of her reaction to diagnosis, ‘I would now never be free from the fear of being powerlessly subjected to a violent public exhibition’ (456). The pathologisation of life problems is in itself a cage. The problem is, when I respond with dismay or anger towards the medical world refusing to legitimate me, I am not expressing a desire to *have* a disease (as the psychosomatic model would suggest). What I am doing is ceding to social forces that insist that my irregularities are only valid if they are medicalised. Take for example our understanding of public speaking. My inability to talk confidently in large groups is no longer ‘social reticence...(that is) typically
considered characterological...part of the normal range of human personality’, but a medicalised problem named ‘social anxiety disorder (Conrad 2007:150). It is not natural, it is pathological. My seizures and other abnormalities are not ‘natural’ parts of my physiology, but without biological basis, they are problematic. The medical world would rather they (and I) went away, because they sit outside of our cultural and social understandings of pathological models. This view is echoed by other sufferers of chronic illness, in Nettleton’s ‘Understanding the narratives of people who live with medically unexplained illness’ (2005), respondents spoke of ‘...the implication I got from one doctor was that there was no problem’ and ‘what I can’t accept is them saying, ‘look we don’t know what it is, go away and leave us alone and stop bothering us’ (207/208). These narratives could be the template for most interactions MUS sufferers have with doctors. Opposing this paradigm are a few doctors intent on providing treatment, or at least being understanding, to the undiagnosed in their care. Considering the negative effects of liminality, Louise Stone offers ‘strategies for the management of medically unexplained symptoms, including the importance of an empathetic therapeutic relationship’ (2014:192). Included in her suggestions are:

• ‘Validating the patient’s experience by acknowledging that the symptoms are real and distressing. It is also important to validate the frustration and uncertainty experienced when
there is no concrete diagnosis.
• Offering a detailed biopsychosocial explanation of symptoms using language and imagery that the patient understands.
• Naming the illness appropriately. This may involve diagnostic terms, or explanatory metaphors.
  (Stone 2014: Table 1. Managing the patient with medically unexplained symptoms)

Such an approach offers a bridge towards a more ideal patient–doctor relationship, but there is little spread or acknowledgment of such thinking in the broader medical community. Additionally, this strategy lacks solutions for social legitimacy, including welfare or workplace support, and interpersonal relationship management. While we continue to live in a society that privileges medical knowledge, we need these aspects of the illness experience to be acknowledged. Medicalisation is best seen as a form of social power—we privilege its knowledge due to ‘the alliance between hospitals, universities and the medical profession’ (Turner 1990:157). As we are trained to defer to the judgements of these groups, we are asked to assume the knowledge imparted is empirical. To question this, or in Conrad’s (1992) words, to ‘emphasise the darker side’ means the ‘assumption of medical moral neutrality, domination by experts, individualisation of social problems’ (223) is flawed, uncritical and dangerous, or as Nettleton (2006) puts it, proof of the ‘postmodern world bracing itself for life under a condition of uncertainty which is permanent and irreducible’ (1169). We, in the micro sense, cling uncritically to the knowledge of the medical world to prevent chaos
in ourselves; dismissal from this world thus necessarily invites chaos into us. There is some suggestion of challenge to the hegemony of biomedical knowledge (Kelly and Field 1998, Williams 2000, 2003), particularly in the rise of complementary medicine used by chronic illness sufferers (Thorpe 2009), reiterating Nettleton’s (2006) stance on the postmodern state of uncertainty. While these links are undoubtable, the power of ‘the biomedical system, despite acknowledgement of its flaws, (is) seen as a source of relative certainty amidst the uncertainties’ (Thorpe 2009:387). Continually medical spaces and power are the centre against which to construct the illness experience.

In a way, my dismissal of the physician’s ‘diagnosis’ was validated by, and negotiated through, my knowledge of sociological theories of illness. This knowledge elicited a response that spoke to a core belief in my illness (that I have an illness), and my tendency to ‘differentiate’ as a valid person who also happens to have an illness (Clair et al 2005:83). My thought process and conceptual understanding of the medical world still renders me an inarticulate patient because the model requires compliancy pre-diagnosis. Articulating a differentiation challenges the systemic prejudice that would constrict the ‘patient’ to a homogenous template. Crucially, ‘the great danger here is that transforming all difference into
pathology diminishes our tolerance for and appreciation of the
diversity of human life’, a resultant dystopian affect which impacts
all of society (Conrad 2007:148)

In contrast to my experience in the vignette, I currently see a
neurologist who attempts to transcend this paradigm. At my latest
bi-annual review, appointments were running late, as is standard,
and I was acutely aware of two things: the laminated sign reading ‘if
you have been waiting for more than an hour, please approach
reception desk’, and the filtered conversations behind the desk,
‘we’ve got a hold up in pathology’, ‘neuro registrar’s darted off to ED’,
‘any word on imaging backup?’, ‘did you hear that woman? No, of
course we can’t issue medical leave until five if your appointment
finished at 11’. As the clock ticked over to 11:45, almost two hours
since I had arrived, I pointedly ignored the laminated directions.
The stress of the staff was tangible and I recognised the truth in my
appointment notification:

Every effort will be made to see you at the allocated time however
individual patients appointment needs may vary. We recommend you
allow flexibility when planning your day, as your allocated
appointment time may not be the exact time you are seen.

The neurologist fetched me, a look of harried apology on his face.
The well-practised yet sincere explanations on his lips quickly gave
way to his easy friendliness. This neurologist is the one you want for
long-term complex care: happy to explain but never ‘dumb down’,
gentle flaunting of the bureaucratic rules (sessions carry on as long
as you need to feel comfortable with your treatment, without a hint
of exasperation), a genuine or well-faked interest in you outside your
symptoms (‘How’s that thesis going?’ ‘Quit that awful job yet?’), and
an oddly holistic approach to illness management. We had barely sat
down when he queried how I was: not medically, but in the same
way an old friend might after a period of absence. Another in a long
run of medical students sat with us, the doctor routinely pausing to
volley medical jargon at her, but more often to fill in narrative
history. This act resulted in what Radley, Mayberry and Pearce
(2008) describe as ‘medico-presentational’. My doctor represents our
consultations as an active narrative event in my illness, and himself
an actor in it.

This experience offers two points. First, I frame the interaction as
positive because there is a recognisable sense of authentication in
being cared for in a humanised way. Authentication is a concept
repeated here because while my doctor is unable to award me a
legitimate ‘named illness’, he does grant me it in the social form.
Authentication, outside of being ‘passage’ to ill status, needs to be
unpacked in its relationship to living a good life, one composed of
‘moral acts’ that position illness as an acceptable mode of being. We
need to be able to work with medicine to find ‘the assurance that it is not totally absurd to have suffered’ (Levinas, quoted in Frank 2004:141). Second, it demonstrates consolation, what Frank (2004) considers a viable solution to the shortcomings of modern medicine: the offering of consolation between patient and physician. Conrad (2007) asks ‘What are the limits to medicine’s role in reducing suffering?’, a question startlingly relevant in this medicalised age (156). My interaction is evocative of this reciprocal consolation. My doctor offered consolation to me through the recognition of these limits. We shared in a paradigm of generosity that humanises both our roles, and returns the story to the body and the body to a peaceful identity.

There is a pervading sense of failure against which we measure experience in the medical world. The failure as patients to get well, the failure of medicine to provide cures, the failure of the physician to help us. What I respond to in this interaction is Frank’s (2004) call for consolation, to ‘render loss more bearable by inviting some shift in belief about the point of living a life that includes suffering’ (2). We should invite suffering into our lives, instead of denying its reality, and decrying its impact. In place of the simplistic narrative about hope that is so lauded by cure-oriented medical narratives, we as beings inevitably faced with suffering need a medicine that
recognises and shares in our bodies and our stories. In place of a 
*hopeful future* we need a *present of generosity*. In experiencing 
chronic illness, I may have to live in a world where pain is 
interminable, where categorisation is unfeasible, but it could also be 
a world that is connected to me by generosity.
CHAPTER TWO: WORK

You’re wandered all over and finally realised that you never found what you were after: how to live.

—Marcus Aurelius

I screw my eyes shut. It is not because of my pain levels, or even the unbearable lightness in my bones, the constant threat lying dormant in my muscles (do you feel us, do you trust us yet). No, it is because of the watchful eye of my audience. I am the unwilling performer in a distorted side show, the proverbial freak to marvel over. This is not a sentiment expressed through the lips of my observer, but it is what I read in their eyes. Show us your trick, they sing silently, prove to us your value- make this worth our while.

Am I worthy?

I cannot tell. Behind the black-red of my eyelid shield, I am hyperaware of my body, the room, the people. I feel hate and shame; at my unworthiness; at my vulnerability. At the curve of my stomach, pinched over the edge of my jeans. At the tingling of nerves in my hip, caught between fat and skin and the uneven surface of the rough carpet. At the deadening sensation in my left arm, as my weight bears down on it, and the sparking inside me- the warning, the prequel of what is to come.

While all these thoughts and sensations flow through my mind and
body, my colleague watches on from a distance, unaware of my silent tension. She stands more than a metre from my location on the first aid bed, hovering between taking a step closer, and retreating to the chair positioned against the far wall. There is genuine concern in her eyes, the same concern that held her hand against my shoulder as we walked to the room, that sent her around the small space seeking out glasses of water and temperature controls, and that is now central to the incessant chattering she offers in my direction. I have tuned this dialogue out by now, the same contraction of work-related gossip and suggestions of medical advice that always leads with, ‘my cousin’s wife had the exact same thing, and…’ because this is the same recycling of communication I hear every time a new person witnesses my transformation into Sick Person. Amongst the concern for me lies her other, dominant, worries; the eye flicker towards the door shows me her desire to not be part of this transformation, her own pressures and responsibilities mount up between her words, and the low gurgle from her stomach indicates that I have interrupted her scheduled lunch break.

I fight the aggressive anger that wants to shout shut the fuck up, can’t you see I’m suffering? and give into the submissive desire to still look intelligent and engaged to my superior by answering her questions routinely and repetitively. I veer between assuring her my work is completed and saved appropriately, with notes for whomever
will finish it (*oh, we’re not worried about that, our only concern is your health* says the organisation from the mouthpiece of the individual), and patiently explaining that, yes, I have heard of hypnotism being used on ‘people like me’, and of course I will consider it, right after I get through this iteration of my illness. The careful balancing act we have constructed falls down the second my leg begins to shake, and her composed face fractures into horror as my body arches and falls, contracts and thrusts.

**Work Analysis**

*I was good at work until I was bad at health.*

Constructing my condition in a workplace is always a challenge. I have vacillated from non-disclosure through to systematic description involving ‘living documents’, to glib shorthand and angry, defensive confrontation. I cannot say which has ‘worked’ the most, but each approach has been mediated by the broader landscape of my life. My first adult job was at 18, and came seven months after the initial onset of my illness. The preceding months had been constructed entirely around my physical state- monitoring my symptoms, alleviating my pain, recovering from my exhaustion, going to check ups and follow ups, awaiting test results, deciding on new treatment. As the months wore on, the hectic activity wound down, leaving me adrift in the summer months, sleeping and
generally not considering any plans for the future. Then, in February, my parents politely but pointedly told me to get a job. My health was stabilised, we believed, but I was caught in that post-graduate haze of new adulthood, amplified by the disruptive launch from child-at-school to grownup I had experienced primarily through medical induction. I do not much remember how I got the job, but I found myself employed more or less full-time in a bookshop within the month. In my familiar, naive manner, I babbled childishly to my new co-workers about my medical experience, chalking it up to a one-off viral occurrence. I spoke more of my time in the medical world as a form of capital— I had experiences my colleagues did not, exciting ones that involved brushes with ‘death’, pain, and entry into a community that was restricted to a members-only pass. I was, in that tiny bubble community, the privileged survivor of The Sick Role.

What I failed to recognise, in my small, selfish youth, was the fact that basically everyone else had had equally important events happen in their own lives, and in my obsession with discussing myself in such a light, I was positioning myself as not only a victim, but also minimising its impact on my emotional and mental growth. I framed it as a brief aberration in my life trajectory, not a significantly traumatising event that I needed to process as a brush
with mortality. Kathy Charmaz generalises my experience saying that ‘a crisis can be long talked about, but kept contained in time and place’ (Charmaz 2000:281). She problematises this framing as ‘such stories must be carefully constructed lest negative meanings from the past seep in… patients may concentrate on past crises and thereby avoid dealing with present uncertainty, impaired bodies, and changed lives’ (2000:281). Regulating my ‘crisis’ as an acute episode meant, as Charmaz predicts, I was unprepared for the reoccurrence of my symptoms. In the context of my working self, this had several, important, consequences.

Firstly, I had lost the biographical assumption of a ‘working life’- the ability to perform material resource collection, limited only by skills, capital accumulation and ability. Second, my way of working would be forever mediated by the lens of illness- I would have to construct my work identity through physicality, emotionality, and complex negotiations in employer-employee/teammate-teammate relations. A co-worker once likened my workplace participation to a battle, ‘it’s like you come in here charging, striking down all foes, before your injuries slow you down or cut you out’. He meant that I would start each day intensely attempting to complete all my daily tasks, before my illness had a chance to stop me. His enthusiasm for historical-fantasy might have framed his analogy, but he did manage to expose
a pattern of behaviour spoken about by many sufferers of chronic illness. It is a defensiveness that often permeates all areas of life, but focuses in the work paradigm as over-compensation. A ‘well’ colleague might be pressured to complete their work in a 8-hour shift, and thus structure their day around the usual limits of hunger, focus, interest, and ability. Someone living with a chronic illness, however, must mediate these concerns with the ever-present threat of symptom onset.

A typical workday for me starts when I wake up. I perform a mental checklist in bed- what are my pain levels? How do my muscles feel? Do I feel weakness in my arms? Am I experiencing any signs of symptoms- dizziness, distraction, and aches, mood swings? Next, I plan my outfit, but it is not appearance with which I concern myself. If it has been several days since a seizure, I like to choose pants, or some other restrictive clothing. Otherwise, I dress myself in lightweight, moveable clothing- a loose dress, well-worn stockings with slouchy waist, flat shoes I can kick off. I used to love heels, but between weight gain and increased seizures, I avoid them. If I have the energy, I do makeup and hair- more and more a mask for puffy, bruised eyes, pallid skin and limp hair, worn out from medication. I wonder when clothes stopped being fun ways to express myself and merely protective draping for my body. When makeup ceased to be
about fun lipstick colours, and instead about painting myself into a ‘healthy person’ veil. With my false face in place, I am ready to put my false persona on. When Hochschild wrote that ‘emotional labour is the silent work of evoking and suppressing feeling- in ourselves and in others’, she managed to encapsulate the position of the chronic illness sufferer in the workplace, but there is a rapid cycling between our ‘surface’ and ‘deep’ acting (1993:333-4). In place of the consumer in Hochschild’s model are our employers and co-workers, and we must sell our emotions continuously to enact the proper social model of a worker. The moment when we falter, when we shed our healthy skin and slip into the sick role, we cease to be the worker.

Once at work, there is a pattern of back-and-forth role performance, worker and sick person, sick person and worker. Perform tasks competently; remind others about limitations (‘I’ve finished with this, I need a break, I can do that in ten minutes, I can’t stay late tonight’). It is a primarily hidden process, held to gratefully by co-workers who do not wish to disrupt the structural presumptions of the ‘morally competent actor’ (Pinder 1995:624). These covert processes are the result of ‘the tacit rules of organisational behaviour (which) define the working self’ (Sennett 2005:131). We hold to these patterns because we still innately see health as good and sickness as bad. I have been in situations where I have been
informed of changed responsibilities ‘not because of your work, but we don’t want to risk your health’. I am the immorally incompetent actor, regardless of the acuteness of my illness. This is problematic not only in the immediate sense (the biomedical happening of illness serves to repeatedly fracture any status quo), but in the deeper structure of work-place existence. By bringing chronic illness into the workplace, I at the least disrupt the ‘tacit rules’ on an unconscious level.

The chronic illness sufferer is responsible for bringing to light the transparent phenomena of embodied work. Our bodies cannot be regulated to the background of the workspace, but exist in a spotlight in the foreground. Taboos are disregarded by self and other; I discuss and consciously refer to bodily functions daily, others take hold of my body in ways otherwise unacceptable. As indicated in the vignette, the boundary between private and public blurs in the context of illness. It is a daily occurrence to have someone direct my body into their perspective, to claim an ownership of my physical existence, and my autonomous decisions. Is it not a normal occurrence to offer someone advice, especially if you have experience in the topic? Say, your colleague has a cold, and you offer a lemon-and-honey-tea recipe. This is kind, a sharing of knowledge, and concern for another human being. It is also an assumption that they
are not capable of caring for themselves, that they are not participating in the ‘getting well’ process. It should be redundant to say that an employer telling an employee, in the midst of a acute episode, that they ought to try this-or-that, is a horrible abuse of power, an unfortunate reflection of the moral ‘righteousness’ of the healthy over the ill. Yet, such incursions are a daily part of any chronically ill person’s life, an attribute of the masked nature of embodied work.

In this sort of event, there are two factors at work. In the first, the way in which the ‘disruptive event’ mandates a sort of marginalisation; resettling a situation is often the expected response to disruption, a need to maintain the status quo. Second is how responses to contested illness, especially a disruptive one, are more overtly stigmatised. The person depicted in my vignette felt authorised to comment on my illness management (not only in general, but during a seizure) because I am afforded very little legitimacy due to the stigmatised nature of my illness. As stigma is normalised and embedded in the workplace, each seizure event ‘increases the susceptibility of a person with epilepsy to further stigma—thus setting up a vicious, difficult to interrupt cycle of medical and socioeconomic morbidity’ (Fiest et al 2014:443). Any attempt to deconstruct workplace behaviours like this would require
for one much more structural power than I have had access to, and
for a second, an articulated awareness of systemic inequality. Such
an articulation would necessitate a pedagogical overhaul of the
‘diversity’ programs found in most workplaces.

Work has both tangible and intangible affects, which serve to create
a participatory experience for the common worker—superannuation,
housing, capital both financial, and social, stability, social
connectedness, etc. The less work is an option for an individual, the
more the deleterious effects of what Little (1998) calls ‘boundedness’
become apparent to the chronically ill. Boundedness, described by
Little as ‘the particular ways in which the world ‘contracts’ for the
patient, through an awareness of limits to space, available time and
empowerment’, is a theme easily apparent in the narrative of
working while ill (1998:1486). In both acute and non-acute phases,
the chronically ill experience heightened awareness of the limitation
of working, and begin the ‘surrender of social and working roles’
(Little 1998:1488). Time becomes measured in health and illness,
not days or weeks. Spaces are restricted in new ways—in one
instance, I was moved from my office team to a separate desk closer
to the first aid area. Space suddenly highlighted my differentness,
and limited my working interactions. These forms of hidden
disability discrimination are spoken of by Little’s patients, and in
every anecdotal story I have heard (1998:1488).

Little further expresses the concern in these issues, stating that 'limitations of choice and power are particularly important for those whose social role is to a significant extent defined by their work’ (1998:1489). Work affords meaning to a life, and the sudden, ongoing exclusion of the chronically ill from employment reduces a person to less than whole, ‘a life that is diminished’ (Frank 2013:xvii). This diminishment, contraction, or boundedness, creates a new form of suffering that is at once tied up in, and separate to, the specifics of chronic illness. When I consider my relation to the working world, I feel resentment equally towards my illness and my past jobs/employers. I can recognise, as an educated person, how complex a situation this is, and acknowledge misplaced blame in my reaction. What I cannot reconcile is how this knowledge can assist me, and in that disenchantment, what is there is in attempting to reconcile it. I find myself incapable of thinking of my future stability. When I do, my stress levels rapidly rise, and I fixate on these limitations, the manifestations of stigma in the workplace. It would seem difficult to resolve this, to stop these stigmas making me ‘not quite human' and reinstate myself as acceptable with my illness (Goffman 1990:15).
Relational interactions in the workplace are only relevant when actually employed. The feasibility of working full-time or long term with a chronic illness is heavily impacted by type of work, workplace support, acute phases, familial support, and individual value systems. There is a pervading sense of uncertainty, of living in Little et al’s (1998) constant liminal space. Restructuring processes and narratives as an individual moves in and out of acute periods of illness often means setting career or employment goals to the side, by choice or circumstance. The effects of variable employment are manifold and long reaching. The affect of employment on recovery or increased management of chronic illness is well documented. Simpson et al (2013) note statistical increases in its positive affect (173), while Brooks et al (2015) points to the benefits of participating in socially valued activities. Despite this, chronic illness is mostly incompatible within workplace structures. The follow-on effects of variable employment reach into superannuation, housing, identity and social judgement, and stability. These are not abstract concepts for a person living with a chronic illness. I have lost jobs. I have less than half the super of my friends. Living outside of home is compounded by my inability to safely live alone, the infeasibility of renting, and my long-term ability to pay a mortgage. I can hide most of these, which affords me successful social ‘performance’ but heightens my alienation. It is one of the most stressful sides to my
relationship with employment. Ignoring the personal desire to work, or social capital it creates, I struggle most with the alienation of non-employment. I cannot communicate to even my closest friends how not working is an extension of my illness, and not an active choice. It separates us from the smallest issues—affording a meal out, shared stresses about working life—to the largest—the successful adherence to the social model of a ‘good’ person. This separation, described by Little (1998) as ‘communicative alienation’, invariably means I negotiate a framework other than ‘illness’ to explain my employment status. Whatever that framework is, it is a necessary misdirection I use to validate my social participation. When we recognise that ‘people take for granted that their views reflect the true, objective reality, and build ‘shoulds’ and ‘oughts’ into them’, (Charmaz 2000:279) we can understand why people with illness work so hard to ‘explain distress in ways other than a disease process’ (Charmaz 2000:282).

The conjoining of work and illness always draw images of Dickensian suffering to my mind; a wrecked and coal-dusted body on an equally wrecked and coal-dusted street, where even the snow falls dirty, and the work day is never over. Perhaps I relate strongly to this image because in the narrative of chronic illness, ‘work’ is often as unattainable, incomplete, and physically wearing as it is for
Oliver Twist or Bob Cratchit. The intrinsic imbalance of power in the working structure is exasperated by the way illness is always visible to the ill. What I see as I enter a workspace is not what others may see. I note the distances from desk to exit to sick room, and the strangers seated between them. I do not want to complain about this place being too crowded to have a seizure, or that person making me uncomfortable during an event (complaining, after all, is bad), but, actually, I do want to complain. The body must be acknowledged in the structure of work, as moral competency is governed by factors not overtly recognised (yet intrinsic to) the production of the workplace.

What this all adds up to is constant uncertainty about the future. The relationship I have to work is as often about earning money or having a ‘purpose’ as it is about ‘proving myself healthy’. Being employed, and able to participate fully in my ‘worker’ role lets me ‘own’ the identity I want to portray. I am responding to a need to ‘establish a sense of coherence’ against the incoherence of illness. (Radley 2002:3). Employment is a critical component in our social value-system; not working is deviance, immorality, and acceptable exile (Pinder, Clair, Fiest). It is a struggle to express the framework of undiagnosed chronic illness in a world set up to deliberately hide illness narratives. The specificity of the workplace framework is
almost epistemologically incompatible with the inconsistency of chronic illness. The stigma of contested illness is manifested in the very space of the workplace, and in how access and time are mediated through ‘concern’ for health. Being *undiagnosed* essentially acts as a legitimising dismissal of my altered state, I cannot be sick if I do not have a name, and if I am not sick- well, why aren’t I working?
CHAPTER THREE: UNIVERSITY

There is no greater agony than bearing an untold story inside you
—Maya Angelou

What to do about pain? As I am writing this, I sit twisted on a hard chair, upper body supported on forearms against the desk, legs curled beneath my torso. I shift regularly, pain from my lower pain extending up through my shoulders, and down my upper arms. I stretch and pull against tense muscles, rub the stinging tendon in my neck. I ignore the light jerking of my fingers, a remnant of yesterday’s seizures. Today is what I categorise as a ‘bad day’, as I am on my third set of painkillers, and still feel uncomfortable. This influences my writing; flicking through reference books, I cannot engage with the text. My mind shifts and wanders, jerking back into focus as the pain spikes. Perhaps more so than the seizures themselves, this situation impacts my ability to perform research. I resist the urge to lie my head against the cool desk, and turn back to Arthur Frank’s Wounded Storyteller: Body, Illness and Ethics. He is speaking of dyadic and monadic bodies; the body that experiences illness in of itself and in the other, or the body that is alienated and separate in its experience. I wonder what my parents experience when they see me in pain. I wonder, as Frank does, if ‘cultural
perceptions of where medicine places the body on the continuum from monadic to dyadic’ mean I exclude them from my pain, if I refuse them legitimacy of experiencing the pain alongside me (Frank 2013:??). This leads me to broader implications. How much of my illness is mine, in the sense that I am the one most impacted by it, most limited or changed, most hurt by it? Right now, bone-weary, resentful, and more than a little angry, I do not want to cede any of my illness to others. I do not want to see my pain reflected in their eyes, or share in it with them. I want to be alone in it. Yet, illness truthfully cannot be experienced alone, and I have never ‘been alone’ in it. I have yet to have a relationship of any type that has not been impacted or informed by my illness in some way. Constructing my condition with my intimate others has from the first instance been my most difficult task. Pondering this as I rest the book on my hands grows more difficult, in the physical sense. The next line in the book fades in and out of focus, and my attention drifts. There is a familiar frustration to this. I cannot think of a single essay I have written in my university career that has not been impacted by illness. A day studying without pain is an oasis (scratch that, a day without pain is an oasis) in the unending, terrible desert of chronic illness. Today such an oasis is not even a glimmer in the distance. My writing is muddied, my thoughts undeveloped, my analysis infantile. I stretch my legs out from underneath me, slam the book
shut. Standing, I feel a wave of dizziness. As it passes, I gather my book and bag, walking slowly outside. There will be no more studying today and I wish I hadn’t made the drive to campus. I will nap in my car, seat extended almost flat, tinted windows protecting me from querying eyes. I will let the flickering shadows of the trees lull me away from the pain and the stress, and pass a few hours unnoticed among the bustle and movement of university life. When the pain fades, I will be a student again.

University Analysis

The dying summer light hits low across the classroom, reflecting off the metallic edges of my table. I am correctly answering my tutors’ question, but there is a nagging sensation in the back of my head. I am staring at the light and not my class as I realise I am about to have a seizure. I get up to leave, but my tutor misunderstands, and somehow we end up crashing bodily in the middle of the room. I am shaking and frantic as I half-shout, ‘Seizure, have to leave’, and bolt from the room. A friend from that tutorial later tells me I actually seemed calm (and not as insane as I feared), but this does not stop the sour acid of embarrassment every time I recall that day. As an unplanned breaching experiment, it quite accurately reflects on how people react to my illness at university. Empathy, certainly, but
pity, fear, disgust, and even irritation, are the predominant responses. Chronic illness functions as a border at university, separating me into a different category of student. This border operates on bureaucratic, academic, and social levels. My construction of my ill student identity is challenged and framed by two key areas. In the first, the state of my physical and mental health acts as a regulator to the limits of my academic participation. My body dictates where I move on campus, when I study or attend class, how well I can perform assessments, when I complete tasks, or how I interact with others. The second lies in the response of others to the legitimacy of my illness. To be found ill is one challenge, but to be found healthy is equally important. It requires a delicate balancing of perceptions, disclosure, and concealment. I must be ‘ill’ to disrupt a class, but ‘healthy’ to earn a mark. These are the central conflicts of being chronically ill at university.

I first decided to go to university while sitting atop a Scottish cliff, being battered by wind and snow. It was a lot less dramatic than it sounds, less a ‘eureka’ moment and more ‘well, I was healthy enough to climb up here and be ludicrously uncomfortable, I can be ludicrously uncomfortable while learning’. I have to admit, that was the entirety of my though process, including and all the way though my bridging course, testing, and acceptance into my Arts degree. I,
like many students, had no idea what I actually wanted to do once there, but I felt it could lead to something important. Forensic anthropology? I could work for the UN and uncover graves of genocide victims. Archaeology? I love history, and playing in the dirt. English literature, and write the next Great Australian Novel? Or sociology, which had suddenly introduced me to ways of viewing the world I had never considered? My transcript after first year resembled a sampling menu, and I was floating in excitement over the possibilities of the future. Eventually, my health hit another low, and I had to make serious decisions about my degree. Could I ever really be healthy enough to work as a forensic anthropologist, or any high-intensity career? I chose initially to ignore these questions, and my health steadily declined, mentally and physically. This head burying, as Charmaz (2000) suggests, is typical of chronic illness sufferers, especially considering ‘they seldom want to be invalids; they want to be accepted as valid adults’ (282). At 21, I desperately wanted to be validly adult, to have an adult identity separate to my illness.

It is a negotiation of moral discourses that the chronically ill enters into with social others. The interrelation of students – the competition, the networking, and the support – is underscored by emerging moralities of maturity (be they formed by new knowledges
found in the classroom or the bar). The microcosm of society found on campus brings about moral assumptions of academic behaviour. There are varying rules about this morality, as if on a spectrum, and the ill person is subject to certain expectations – related to when and where our bodies become ill, for how long, and in what way – and these expectations, if breached, have complex repercussions. The stigmatised body may be intellectualised on campus, but it is far from free of cultural taboos. It is not the threat of discovery, nor of associated relationship affects, but of academic viability: to be essentially accused of ‘cheating’ each time illness alters our academic participation. Once, I messaged a friend to say that I had received a HD on an assessment in a class we shared. His reply was instant- ‘wow, that extra time sure did benefit’. Referring to a week’s extension I had received as part of my disability plan – granted automatically in times of illness – I was dismayed to think he saw my grade as a reflection of ‘bonus’ time, instead of a necessary step to reinstate fairness, in light of my health.

Perhaps he was right: if I did not have special consideration, would I still have done as well? Would I have done better, or worse? The problem with this line of thought is that it assumes a situation that did not happen, and could not happen. Yet, it is constantly asked of the chronically ill. We are expected to apologise for the moral
transgressions of a life we are not capable of living. To be judged by co-workers is one thing, but the judgment of academic peers has specifically troubling connotations. I naively assumed prior to my degree that there would be a greater acceptance of ‘differentness’, especially in studying sociology, with classes like ‘health and illness’. There is, however, rarely intellectual enlightenment over disability culture, even among groups studying it. I was shocked to be told (by a person identifying as ‘disabled’) that I had no right to claim disability status at university, and then immediately ashamed- why do I get to chose their definition of disability when they so clearly share the same internal struggles I face? Should I not show compassion and generosity to those who share in my experiences, even if they refuse to grant me access to their authentic states? How are we to even consider ways of stepping outside this paradigm? Nirmala Erevelles writes of finding ‘no easy way of drawing boundaries between who should be in and who should be out’, and that is one of the most complex understandings I have reached about chronic illness (2014:para 2).

Presuming access to the ersatz title, I am recipient to the legal obligations of the Disability Act, and the accompanying support services. These rules and regulations, support programs (Access & Equity, ETC), etc., are all in service to the declared aims to ‘raise
awareness and understanding of disability issues with all students and staff (and) enable students with disability to participate fully in University life’ (‘Welcome to Access and Equity’ 2015). The intention is clear, but what universities lack is a culture of care, or to return to Frank (2004), consolation and generosity. When I have a seizure in a classroom, I do not want pity, panic, or the peculiarly belittling prattle (‘Oh, you poor thing! What should I do, do you know what to do now? Should someone call her parents?’). I do not want the judgemental reaction, where the normalised routine is to assume my infantilism. What I want, and I draw this from Frank, is to be allowed to remain fully human in this moment. To see neither averted eyes or fixated ones. To not have tears or nervous laughter. To, instead –keeping with necessary medical routines– be included in the event. I recognise the criticisms of this position, but I would consider them to be the product of socially shaped responses to illness. I have experienced the non-disruptive seizure, and what I see as absent in that situation are what Pierret (2003) conceives as central to the stigmatising force: ‘to assess the impact of the social structure on the illness experience, the factors (such as ignorance and fear) motivating stigmatisation must be analysed; and the effort made the better to understand the ‘stigmatisers’ (15). I should like to engage with my own stigmatisers and work together to create a new narrative in which we can accept each other. Drawn together by our
shared status as students, with a commitment to rising above the
unchallenged stigmas of society, we could work towards a state in
which my illness need not create isolation, but connection.

**Writing on medication:**

Note to future sober self: This was a really bad idea. You’re literally seeing the walls
move right now. I mean, I’m seeing the walls move, and I kinda wanna dance with
them (take that out, totally take that out). What did we want to write about? I’ve got
this hand written note here, but your notes are stupid, ‘write about being on meds
WHILE ON MEDS’. Super useful. So much help. Self, how did you get a degree?
I’m laughing so hard right now. I’ve got this paper, (MOST of the paper, I lost at least
three pages to the floor demons) and the author’s going ‘ they also signal possible
hegemonies, with economic rents from creative capital ownership appropriated by
controllers of financial capital, the encroachment of soft power and the loss of unique
identities in cultural products as ‘global’/western forms dominate.’

Like, what does this even mean? Why do we write like that? Do people actually read
this shit? I think even Beckett would laugh at the incomprehensibility of these words.
Oh, Beckett. How weird is it that I can still quote him, years after that one course, ‘at
me too someone is looking, of me too someone is saying, He is sleeping, he knows
nothing, let him sleep on’. Maybe we should use that somewhere? Oh, this is
distraction. Let’s regroup, self. Where are we? What have I said?

Wait, is this the paper I’m meant to read? Where did I get this?

It is however true that these conflicts—between authentic and
inauthentic status, intent and result, obligation and anticipation—
currently affect every aspect of university life. The body is rarely
‘brought forth’ in the academic environment, and this often means
the affects of bodily experience are reduced by virtue of being
unrecognised. A lecturer once called me into a meeting. He was
concerned, holding a copy of my disability plan. In response to my
explanation that I had been experiencing a long period of intense
seizures, he told me (not without sympathy) that ‘my class isn’t
designed as a distance course- you would better learn the content if you attended the tutorials regularly’. He was completely correct. Another once exclaimed ‘what do they expect, that I install an elevator for you?’. The governance of student-teacher power relations is upset by the construction of chronic illness in the bureaucratic system. The system may be in place to support these changes, but the cultural and social stigmas remain. This is evident when other lecturers have been supportive. They offer alterations. They are empathetic without pity lacing their words. They work with me. But I am uncomfortable with my experiences. If my work environment is mediated through complex moral evaluations, then my university career is even more so. I feel immense discomfort, a strong sense of shame, when I reflect upon the alterations of my courses, regardless of how they were medically and bureaucratically authenticated. These responses are described by Kleinman and Seeman (2000) as ‘the link between culturally patterned and personally contingent elements of experience as they impose themselves on people’s lives’ (235). The reductionist approach to understanding illness renders perceptive and compassionate interpretation of the illness experience impossible.

**Writing in pain:**
Half a day ago, I had a seizure. That is just enough time for the medications to wear off, and the pain to kick in. I am typing slowly, hunched over, while my right leg bounces to an erratic beat. I cannot focus on the screen of my laptop. I want to say something smart about this experience, but I cannot think past the pain, cannot
process how to- how to, um, something. I should probably lie down now. That lady, the one who wrote that book on pain, (fill in the reference later, self) said something like ‘pain is disbelief’, and she is certainly right. I don’t believe how much pain I’m in. Although I think she was referring to other people’s ‘disbelief’. I’m getting seasick staring at this page. But, what’s really hard, is this fog in my head. It slows everything down, pushing against thoughts, blocking connection and understanding. I feel stupid, so I stupidly test myself. Read two lines from an article, try to interpret:

“neither sick nor healthy, or they are as much healthy as sick; an ambiguous dilemma. Taken-for-granted, everyday methods for accomplishing and managing this condition – in categories of sickness or healthiness – appear to be breached”

I sound it out, ‘Or. They. Are. As. Much. Healthy. As. Sick…’. The words are like molasses, slow and sticky, sliding into each other. I have no idea what the sentence is saying. I read it again: ‘for accomplishing and managing this… condition… appear to be breached’. It is just words. No meaning. I am so so stupid. I really don’t want to write this, but there is a bubble of hysteria crawling up my throat, and I’m either going to cry or throw things.

To a certain extent cultural assumptions of bordered bodies and the pain experience contribute to these conflicts. The effective invisibility of bodily experience in any social arena reduces the capacity to empathise with pained and altered bodies. This is never clearer than in Scarry’s (1985) words: ‘The events happening within the interior of that person’s body may seem to have the remote character of some deep subterranean fact, belonging to an invisible geography that, however portentous, has no reality because it has not yet manifested itself on the visible surface of the earth’ (3). Being in pain, or to make broader application, being in an altered physicality, is to be constantly in a different world. In an academic location, the pained body straddles intellectual, articulated assumptions of understanding, and covert reproductions of societal
prejudices. The resultant experience is unlike the transparently similar working world. To participate inside this heightened environment (in which the implicit assumption is that you are obliged to develop critical thinking skills) as an ill body, you must learn to defend your identity. The outcome of such defence is often that the chronically ill person begins creating a testimonial narrative, one ‘that seeks to bear witness, or to give voice to, those who suffer’ (Kleinman and Seeman 2006:238). These reflexive and articulated stories are seen most prominently on campus through disability advocacy groups. The central tenant of these groups is that negativity-surrounding disability is emblematic of what is described as ‘ableist culture’ (see Cherney 2011, Linton 2006). While they seek to destabilise the bordered body and monadic pain experience, the effect is often that of another border. I struggle to connect the many rules of these groups with their objective goals, and my lived experience. In one instance, I recall a fight breaking out over the creation of ‘safe spaces’ for disabled students. How to construct them, where to construct, for whom would access be granted? Many long hours devoted to discussions, and the whole time I was thinking- ‘but aren’t we ignoring the issue? Shouldn’t everywhere be a safe space?’ It is not that my thoughts were ‘better’ or more important. Engagement with a bureaucratic model to alter systemic assumptions of bodies will inevitably invite in complex and
meandering pathways to change. Is my desire to be authentically ill outside of these groups problematic? Is their perspective less so?

Then again, these are not the questions that need asking. We should be less concerned with how much than with what sort of help.

Illness narratives in academic settings are moderated by assumed and actual modes of acceptance, expressed through conditions of authenticity and conflict. We are confronted by discourse hinting at better ways of thinking, of knowing, of being, but we as ill bodies as still subject to broader societal controls. In the heightened atmosphere of universities, the chronically ill are both presented with modes of understanding their illnesses –ways that carry certain academic legitimacy– and with intense reproductions of the biases we will confront in the social world. Disability status allows me some authenticity among select groups, not others. The ability to utilise critical thinking and academic theory to construct my ill identity offers expansive benefits for my future. Conversely, university also teaches me the limitations of this type of knowledge. The critically absent representation of illness at university is the ‘somato-moral dimension where the expression of illness’ is acknowledged as subjective, as plural, and as malleable (Kleinman and Seeman 2006:239). Without these, the ill experience at university remains a state of conflict.
CHAPTER FOUR: RELATIONSHIPS

The fix is right in front of us, but we can’t imagine a big change like that. We can’t imagine being agents of a change that big.
— Jacob Clifton, ‘While you were over there’

We are reclining, backs against a tree, legs loped comfortably over each other. The water of the lake is hypnotic, and I watch as reeds sway slightly in the soft wind. We have not seen each other in three months. Busy summers for both of us, but we are in the last month of the season, preparing for the new semester and have finally caught up. I am comfortable in the silence, content to watch the little birds on the grass and smile at the passersby. He speaks suddenly, interrupting the peace. Says that he ‘just needed a break— not from you, just the constant illness. It was too much, too often. I felt like I was forgetting why we were friends, it was all so draining’. God, that hurts. Partly the fact that he needed a break, that friendship had become burdensome to him, but more acutely that he was able to walk away and recover. I wanted that too. To walk away from my illness and come back refreshed. I stay silent because if I get angry, he might walk away, again. It’s not the first time someone has. It’s not even close to the first time, and I sit, trying to count how many friendships, relationships, have ended over my illness. No
one really says it’s because of the seizures and the mood swings, the hospital visits and the medication comedowns, but I know. I see it in their eyes, like his eyes right now, wary and not quite making contact. He, they, wait to see how I’ll react, if I’ll be normal. I say, coolly, that I understand. I make a joke that I don’t hear, and my mind goes very, very still as we discuss our summers. I feel intensely guilty, for relying too much on him the previous year. For letting him (for letting anyone) see too much of ‘sick me’ when I should be protecting myself and them from that. I need to change that this year, I resolve. I will go to classes and parties, with exit plans that don’t involve my friends driving me home. I could put a foam mattress on my back car seat, sneak away when I feel a seizure coming on. I could do this alone, which is what I want- away from the flitting eyes and unspoken words, the repressed annoyance. I will do this, and my friends will be happier. I will be happier. Most importantly, I will not be repeating this moment with yet another friend or boyfriend. I won’t have to watch anyone else walk away. He is talking easily now, a story I don’t take in. He invites me to a party. It will be two weeks before I will injure my arm during a seizure in my car, alone. Not the best plan, and we revert to our old status quo. Three weeks later I have a seizure in a shared tutorial, and he drives me home, smiling and gently telling me it’s ok, he is happy to help, joking about getting him out of class. Months later,
we’ll have a screaming match, when I finally get angry that he
makes me feel guilty for my illness, and our friendship will actually
be over. When I think of that moment by the lake, I realise all I
remember is the water and the wind in the reeds, our legs tangled,
and the quiet warmth of friendship as we sat silently.

Relationships Analysis

There is a line in Jacob Clifton’s *While You Were Over There* that
reads ‘Or how far: While you were over there, I am yet still
entangled’ (2014:80). How entangled we are, with our mothers, our
fathers, with siblings and friends. These entanglements stretch
across time and place, bound by memory and convention.

Friendship, as defined by Tillman-Healy (2003) is ‘an interpersonal
bond characterised by ongoing communicative management of
dialectical tensions, such as those between idealisation and
realisation, affection and instrumentality, and judgement and
acceptance’ (730). The tension of an undiagnosed chronic illness
disrupts such management, positioning new (often transparent)
power imbalances at the centre of all relationships. I have seizures
that make me physically dependent on others for my wellbeing. As
discussed in my Work chapter, my financial status makes me
dependent on family and friends for housing, and other financial
needs. I am emotionally dependent on these relationships, to trust them with my safety, to keep me sane, in ways that differ from (or stretch) culturally normative rules of relationships. These imbalances stretch the other way, with dyadic and monadic assumptions of bodies and health controlling their participation in my illness (see Frank 2013). The ‘dialectical tensions’ become not a give-and-take between equals, but something closer to child-caring. It is easy to fall into this paradigm, and hard to slip out. The stress of chronic illness on families and friendships is well documented (Little 1998, Knafl and Deatrick 1987), the lived experience of altered expectation which moves and defines interpersonal bonds.

The central tension to my relationships, with family or friends, is the constant threat of suffering. Such ‘suffering occurs...when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed, or until the integrity of the person can be restored in some other manner’ (Eric Cassell, quoted in Frank 2013:169). This suffering can be of the body (the act of the seizure, the pain, the medication or hospitalisation), or around the body (emotional or social suffering between me and them). This tension can never fade, integrity never be restored, because the illness state is boundless. Everything changes in relationships when chronic illness is a factor. The acute periods disrupt and restructure
daily motions, but perhaps the most important change is found during the non-acute. This is when the disruption of illness fades into the background of conscious thought, and the constancy of daily life dulls the awareness of ‘chronic’. Here, when the threat of suffering is distorted, is the source of most conflict. While I constantly experience a ‘heightened and alien state of bodily awareness’, those surrounding me do not operate within this same state (Charmaz and Rosenfeld 2010:4). Suffering becomes muted and invisible, and those on the outside ‘may hear the words but be powerless to penetrate the experience’ (Pinder 1995:624).

These hidden illness traits (contested or otherwise) offer a challenge to generosity shared among relationships. How often can the non-ill respond compassionately to imprecise depictions of pain and suffering? How often can the chronically ill, the chronically pained, articulate their suffering? When Scarry (1985) writes of pain ‘belonging to an invisible geography that, however portentous, has no reality’, it is an articulation of the chasm between pained and non-pained bodies (3). I live in this ‘invisible geography’ for which I have no more descriptive words than the non-pained. To converse with someone else who see this landscape is to recognise its incommunicable truth: no one can know my pain except me, no one can know your pain except you. The resulting segregated realities
enhance the divide between my lived experience, and my family and friends’ understanding of it. It frustrates me to experience the world this way: while we sit in this cafe, let’s say, I am with you, but I am also in this other place, the one that measures time in pain and analgesics and restrictions. Perhaps you also reside simultaneously in another world, one as invisible and silent as mine. Perhaps you are just as incapable of articulating it as I. Either way, my wounded body remains silent in all my relationships, not yet able ‘to give voice to an experience that medicine cannot describe’ though those dialectic tensions I want so badly to reinstate (Frank 2013:18). Be it family or friend, each relationship is held apart: my chronic illness sits between us.

My relationship with my family changed forever the day I first had seizures. Just 18, I was thrown back into the role of child as we passed in and out of medical spaces, learning new languages and new ways of being together. I remember being cradled by my mother, for the first time in years, remade into an infant as a nurse extracted spinal fluid from my lower back. I was in agony and the only thing I could cry was ‘mummy, mummy, mummy’. In many ways, I have not left that bed, or my mother’s arms, since that day. This infant state frames my relationships, every time I seize I become beholden to a carer. The weight this brings to a relationship
is not insubstantial. For my family members, it is an added layer to the care-giving inherent to the family unit, and an elevation of myself above my siblings. Discord and empathy abound in these dynamics; as I ‘win’ extra time and energy, yet stagnate in my biographical progression, slipping further behind as they race off into their futures. It is true that ‘the family undoubtedly represents the first line of affective and material support, essential to helping the patient cope with disruptions’, but what does it mean for the health of those families (Pierret 2003:13)? These relationships become fractured, seemingly without hope of repair if the chronic illness cannot be ‘cured’.

In the vignette, I purposefully chose to depict a short-term friendship (and short-term response) to avoid attempting to unpack the complexities of long relationships and chronic illness in short narrative form. How do you reconcile the behaviour of family members with chronic illness? Is my aunt’s response, for example, one born from our lifelong relationship, or her social understandings of seizures? When she suggests asking about this new treatment, or stares uncertainly when I move past her child, are her responses about me, or her? I hesitantly brought this up once, questioning if she would only be happy if I were ‘fixed’. I hurt her with those words. The same tensions are in place with my every interaction
with my parents. When we fight, I am convinced they structure everything around how my illness stops me from doing things; they are equally convinced this is not true. I think about what a strange existence this must be for my little brother, to only know me this way. If I say I feel a seizure approaching at the dinner table, he will only sometimes stop eating to check if I need help, but is always happy to take from my plate. I spend time plotting out text messages, projecting an image of self that does not reflect my internal state:

*Hi! God, I am SO SORRY, I had seizures, can we reschedule? I am the worst.*
*Argh, seizures again. So sore. So, so sore. Next time, I'll just organise a truck to run over me, hey? Would you mind if we cancelled? Can we do my house? I'll cook! :) Can't drive right now, is all, seizures rahrahrah, but I do have wine...*

Apologetic and humorous, self-effacing and silly, every word is carefully selected and structured to fit the right image, one which is ‘to blame’ yet not at fault. All of these small parts of relationships are curated to distract from the real effects of illness and dispel burden- upon me and upon them.

These are some of the distinct patterns and behaviours located temporally in every relationship in which I participate. The initial building of an interpersonal bond is irreducibly based upon disclosure: when do I disclose, how do I disclose? Pierret (2003) observes that ‘the disclosure of epilepsy might be made to ‘close
friends’ and future spouses in carefully thought-out and staged circumstances, such as during trips or long moments spent with friends (12). The issue here is always, ‘but what if I disclose unintentionally’? Seizure-illness is only ‘hidden’, the sufferers only ‘pass’, until the moment of incapacity. Then you are violently, forcefully, made sick, making managed disclosure a tenuous, fragile claim to autonomic power. I tend to the up-front divulgence. Not quite ‘Hi, I’m Giv, I have seizures, please don’t panic or put a spoon in my mouth’, but very near to it. The next step of disclosure is harder- when I say that my seizures are ‘atypical’ or so forth, I am met with resistance. ‘You don’t lose consciousness?’, they ask sceptically. There is little social recognition, even today, of the umbrella-term nature of seizures, of focal, generalised, unknown, absent, tonic-clonic, myoclonic. We expect to see the dramatic, and if our expectations are not met, ‘we can apparently handle the differentness of others so long as it is fairly obvious and does not catch us entirely by surprise’ (Iphofen 1990:458). Relationships begin and end with my illness, it is hard to consider structuring anything a relationship if I have not disclosed; it is fundamentally impossible to understand a relationship without first considering my illness.

Disclosure might seem to be the most vulnerable step in a
relationship, but it is far out-weighed by the relentless, effacing, never-ceasing period of justification. Familiarity breeds not just contempt, but contemptuous habituation. At some point in the chronic illness trajectory, every body (including the ill person) will become compassion fatigued. There are streams of disconnect and resentment, my little brother says ‘oh, that’s just what Giv does’, my sister sometimes spits ‘I can’t help it if you’re sick again’. These moments pass in and out of on-going relationships, building up then dissipating in relation to each own circumstance. And then there is the person who remains (it seems) wilfully ignorant, questioning over and over again ‘just what’s wrong with you?’. This is the person who most struggles with the invisibility of pain, of illness that does not fit into socially prescribed boxes. They ask me, ‘aren’t the doctors going to do something?’, or my personal favourite, ‘have you tried *inset alternative medical practise here*?’. In my ‘on’ moments, ill health is forgotten, and the tone changes, ‘are you considering going back to work?’. It does not matter when I patiently explain my medical management plan, or tearfully inform them of my physical pain, or angrily point out I have somewhat of an investment in my own self, thank you very much. What matters are the cultural dialogue of health and illness accounts that ‘articulate a person's situation in the world and, indeed, articulate that world, in which the individual will be held accountable to others’ (Radley and Billig
1996:221). My health account fails to connect to their own accounts; indeed the stories are so incompatible as to be considered entirely different genres of discussion. My attempts at constructing ‘valid’ accounts for these people are stymied by uncertainty in my own illness beliefs, and threatened by, as Frank writes, the ‘chaos...in the claustrophobia of confronting others’ inability to see what I so clearly felt’ (2013:xv). I want to relieve them of these burdens, but I also want the right to live my story, ill or otherwise.

In the account construction, there is an element of resentment, of anger at the experience of the other in my body. I do not want to participate in the response of others to my body, it generates immediate emotions of anger, frustration, even rage. This reaction is the monadic body, taught to hold itself alone, to know itself as ‘existentially separate’ (Frank 2013:36). The opposite state, the dyadic body, as Frank (2013) continues,

Represent an ethical choice to place oneself in a different relationship to others. This choice is to be a body for other bodies. Living for others means placing one’s self and body within the “community of pain” to render Schweitzer’s phrase contemporary. (37)

To be capable of becoming a dyadic body requires a fundamental, ethical shift in my understanding of my illness and its connection to my relationships. Part of writing this thesis, this chapter, is to edge
towards an active and evolving reality wherein I participate in my illness with others. Can I learn to cease being the ‘domineering body’ that ‘displays rage against the contingency (of illness) onto other people’ and allow family and friends in (Frank 2013:47)? It is problematic to consider as the body exists in reciprocal motions with the other: my changing self cannot happen without equal change in those others. What is crucial here is recognition of the other in constructing my illness. I have heard family members and close friends describing my illness, ‘She starts to shake, but first there’s a bit of vagueness or anger, and then she drops. Her whole body shakes, it’s like, it’s- you know, a seizure. Her arms and her back. And you have to see it’ ‘Well, Giverney had one of her turns the other day’. These words anger me. Their language is not my language, not my experience. I do not have ‘turns’, a term that brings to my mind a meaning that is not relevant to my experience of my body. Yet this is their experience. There are exceptions, like my best friend, who has more than once slept on strange, plastic chairs in hospital rooms, and unfailingly refuses to differentiate between healthy-me and ill-me (with both grace and a sense of gallows humour that might read cruel to outsiders). She is few and far between, however, and I wonder how I would respond if these many interactions broke free of the cyclical nature of relationship performance.
These interactions are characterised by justification and authentication processes, irresolvable and limiting to everyone involved. Dependency is a source of conflict in most interpersonal bonds, a debate conscious and unconscious for balance. The stress of over-dependence of the chronically ill on their close friends and families is well established as negative, encompassing, and constant (Iphofen 1990, Frank 2004, Pinder 1995). In hoping for removal of the ‘domineering body’ I am seeking a continuity of relationship performance and of relieving dependence- as Charmaz (2000) recognises, ‘maintaining control over life derives from concrete daily actions and regaining continuity and coherence of self and one’s world’ (280). What Frank (2013) suggests is the ‘communicative body’, a body which when it ‘associates with its own contingency turns outward in dyadic relatedness, it sees reflections of its own suffering in the bodies of others’ (49). In adopting the communicative body, the chronically ill are better able to engage with relationships. We can share our story and see it reflected back in their stories, much like standing in a hall of mirrors. It is quite simply a way of bringing back a kindness lacking in modern relationships; a way to acknowledge pain and differentness without reduction or burden. Becoming a communicative body involves accepting illness as part of the human experience. It recognises illness as complex, as separate to being immoral, and as being situational- as much as health.
Yet, while they are ‘over there’ we are still entangled. No matter how separate my experiences are to theirs, we still move through recognisable frameworks of friendship and society together. It may be an imbued response to cling to the self as ‘we confront the fear of dying, of pain, of decline and degradation, and the dread of the nothing into which we apparently go’ (Little 1998:1491). Guilt may war with anger in the dialectic tensions between my relationships, and myself but I am still a part of a social group that more or less supports me. The constant state of conflict, within my body and surrounding it is exhausting: I want to acknowledge the privilege of my situation, but am brought down by the inexorable effacement of each day. I am bone-weary facing my interpersonal bonds. The mere thought of romantic attachment causes my mind to shy away. I look at my family and close friends, at my academic commitments and work life, and think even this is too much effort. Yet while there is resentment, there is underlying hope- hope that by engaging in stories I am reimagining the context of the illness experience. That by bearing witness to my own ill narrative, I am setting forth on a path towards a life lived better with illness. And that in this emerging path, I am able to meet those others I share my life with, and share my narrative better with them. The act of engaging in any
type of relationship while living with a chronic illness is invariably fraught with imbalanced tensions. It may be that a reimagining of self, story, and body could open up new ways of being together.
Conclusion

We all dress ourselves in stories. Then you start to spill, and for a little while afterwards you don’t know what you’re really saying anymore. And finally, the thing that is most shocking about spilling is you yourself.

—Pasi Ilmari Jaaskelainen, “The Black Rabbit Literature Society”

Sometimes I wake from sleep and wonder who I am. There is the me inside my mind, and the me I see in others faces, the me who stretches out on strange ground and shakes herself incorporeal, and the me who watches all her other selves fracturing and resetting, over and over. I wonder if I would think this way if I did not have a chronic illness, or if everyone feels this way, or if I was healthy, would I only know one me? I divided this thesis into four parts not just for ease of analysis, but because I construct my illness so differently in each sphere. It is an angry and rigidly structured condition in my work life. I am more uncertain and fragile about it at university. My relationships flow backwards and forwards through changing lenses of illness and health, dialectics of responsibility and consideration. I am constantly liminal in the medical space, not quite ‘here nor there’. Sometimes I feel as though my entire world is constructed around my illness, operating as the central force in my life. There is a sense that there is no me without illness, as one of William’s (1984) interviewees put it ‘where have I got to? There’s nothing of me left’ (88). I am constantly waiting for
Chronic illness defies description. It is a state of being that is too heterogeneous and too readily disguised for definition. It is at its heart chaotic. When Bury (1982) states ‘chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death’, he evokes a meaning that resonates perfectly with my lived experience (169). To be chronically ill is to be constantly aware, of our selves, of our bodies, of living in ‘an altered situation’ from which you cannot emerge (Bury 1984:170). What is lacking in this awareness is a sense of understanding or of stability. We the chronically ill are transformed into fractured bodies and minds, disrupted biographies, and problematic others. In describing my own story, I hope to have connected with other chronically ill persons stories, to have helped in some small way to achieve Frank’s desire ‘to shift the dominant cultural conception of illness away from passivity —the ill person as “victim of” disease and then recipient of care—toward activity’ (2013:xix). Compounding any degree of success is the chaos of non-diagnosis, of living in liminal spaces, of being eternally disrupted. To exist permanently in these spaces renders comprehension of ability quite low: it is not a fragile ego that displaces confidence but a entrenched condition of unfastened reality. What is true of my illness construction today will be
plausibly untrue tomorrow. There is no constancy, and therefore no measurement for success. Additionally, what may be true for my experience may be foreign to another. The other day, a customer stopped me in my parents’ cafe. ‘Your mother told my colleague about your thesis topic’ she announced, eyes bright as she lightly touched my wrist. ‘I just wanted to say, it’s such a good choice- I was undiagnosed for 10 years, I have arthritis. I know what it’s like’. She wanted to read my finished copy, but I demurred, claiming it too unfinished to share just yet. She did not let up, reminding me again the next time I saw her, ‘I’d just love to read your work’. I am afraid to share it with her, because what if my story does not match hers? Will ‘my’ people, other sufferers of chronic illnesses that struggled to gain acceptance, reject me? Or worse, what if my words trigger something in her that she has not dealt with? I think it is my own insecurities about my writing, about my illness, that precipitate these thoughts, but I have not brought it up with her again.

Writing this autoethnography of my illness offered an unusual opportunity to witness—via analytic reflection of biographical experience—my own story-becoming progress. The events I recalled as central to my illness, and the ones I found myself incapable of writing about, drew forth themes I expected—liminality, biographical disruption, variable alienation—and ones I did not:
acute loneliness and rigid self-segregation, familial tension, and how acceptance of my ill-self causes the most conflict. Drawing lines between aspects of my life brought forth what I have come to realise is an autoethnographic illness narrative. Incorporating the very real need ‘to avoid (the) dehumanisation – of clinician, researcher, or patient – that comes from treating those who suffer as if they have nothing to say of any relevance to their own lived context’ with the tenants of illness narratives and analytic autoethnography to create a story (Kleinman and Seeman 2000:239). My analysis sought both to find the meaning in my own life, and to join in the ‘web of all stories’ (Frank 2013:220).

A curious artefact of this analysis is my own recognition of where I place my body in my illness. I do not, as Kelly and Field (1996) suggest, consider the ‘management of physical problems’ the epicentre of my experience (247). In fact, I vehemently disagree with their statement that ‘coping with the physical body has to precede coping with relationships, with disruptions and indeed with any social reconstruction of events’ (Kelly and Field 1996:247). The body is central, always, but the chronically ill body becomes normalised in its own way; it is ‘social reconstruction’ which is constant and requiring primary focus. Perhaps this is because of social reluctance to notice the body, a refusal to ‘bring forth’ the body and thus lessen
its social ramifications (the disruptions and breaches, the unclean and immoral). But it is not ‘eating, bathing, or going to the toilet’ which take central importance in daily life, but the reactions and responses to differing physical ability (Kelly and Field 1996:247). The chronic illness sufferer learns how to cope, ‘perhaps best seen as a cognitive process whereby the individual learns how to tolerate or put up with the effects of chronic illness’ (Williams 2000:44). It is not the personal struggle of pain or disruption or seizure that construct my life. It is the limitations of sharing in those bodily and mental experiences with others.

Primary to the construction of these limitations is my inclusion in the medical world. To become and remain ill is both requirement of the chronic illness experience, and failure of the social self. We are punished by the cultural paradigms framing medicine that refuse ill health as an authentic way of being. To be chronically ill with a disputed illness pushes authenticity further away. Seeking to rectify this, Kleinman and Seeman (2000) call for a illness narrative to ‘improve the quality of care’ (239). Frank (2004) sees resolution in generosity and wants from us a simple maxim: ‘To be generous, first feel grateful’ (142). In any of these research papers which seek to bring into focus the ill experience, I see what I have voicelessly called for: someone saying I am grateful for your story. Medical
professionals share their stories with me when they impart their knowledge and advice, their consolation and empathy. I should like to hear that generosity, and in turn show them my gratitude, through my story and my consolation.

I touched on the way chronic illness is consumed by the day-to-day of life, and the dialectic tensions produced by this state of being in ‘Relationships’. When Little (1998) acknowledges that ‘there is little wonder that the experience of liminality is so unsettling, nor that families and friendships are so important and so deeply challenged by liminality’, he touches a profoundly raw element of the chronic illness experience (1491). Everyone is drawn into the chronic illness experience. In this way, all impacted are forced to negotiate the liminality of the illness experience, an enduring state of being which constructs and reconstructs their own narratives (Little 1998). It is impossible to untangle the threads of experience as it forms, and informs, the narratives of everyone involved in ‘illness’, to measure the extent of how ‘illness is not bounded by the bodies or consciousness of those who are ill’ (Kleinman and Seeman 2000:231, original emphasis). This in turn pushes monadic and dyadic bodily assumptions into the foreground of lived experience, creating tensions between the ill body and its associates. The predominant question here is one of ethics- ‘who has a right to my body?’.
were simply the case of receiving medical treatments – which are themselves outcomes of monadic assumptions – then there would be clear ethical pathways for a decision. However, to include conditions of a ‘good life’ muddles the delineation of ethical expectation. Our lives involve other bodies, to which we have access and which in turn have access to ours. A good life need acknowledge that illness does not happen in isolation. We are all affected by illness, and we will all remain in those liminal spaces until ill health is brought forth.

The bringing forth of ill health is problematic to conceptualise in the real world. The nature of the workplace is a pertinent example. The ill person in a working environment undertakes a specific set of moral quests: to engage with work, to lessen the impact of illness on others, and to ‘act well’. Few working environments are capable of providing an alteration because the central premise of labour has no position for the actual body. Successful integration of ill persons into working environments requires a shift in thinking about labour. It is easy to fixate on surface level rejections of such change, like incompatible physicality for a job, or fiscal expenditure for altered equipment. Much like previous arguments against women in the workforce, these arguments are arbitrary and inconstant. Yet, they remain as vocalisations of entrenched moral conceptions,
highlighting ‘anxieties about maintaining existing body boundaries and body purity’ which govern rightful access to worker roles (Pinder 1995:624-625). As a chronically ill person in the workplace, I have repeatedly faced these anxieties and the discriminations they bring about. We who are ill are left without appropriate dialogues with which to frame these experiences. Illness is made invisible to whatever cost, producing tensions the ill can rarely articulate as discriminatory. Our limitations become moral transgressions, and our access to workplaces becomes fractured.

Likewise, in negotiating access to university (from academic and social standpoints), the ill person must navigate prior assumptions of ability and constant threat of moral misstep. To be found a competent and viable student, I have at times rejected or repressed my ill self, to mine and others’ detriment. I have highlighted and fixated upon my illness, and received ostracism and vilification. It would be a jejune conclusion to lay blame at any specific circumstance here. Rather, the academic environment draws its discomfiture with illness from its own, awkward juxtaposition as both learning centre and labour workforce. Students are presented with new modes of knowledges just as quickly as they are trained into specific social roles; approaches to and understandings of illness are necessarily shaped just as quickly. My personal experience of
being ill on campus has been about straddling the intellectual and labour roles. The inherent conflict in this situation may be irresolvable if we do not consider the broader social paradigms: illness will remain an inauthentic excuse for differentiation while society believes it so, while definitions of normality mean ‘we are no longer in a mood where normal means average; we are in an era of amelioration, enhancement, and progress through increasing intervention into the ‘mistakes’ of nature’ (Lock 2000:273).

I remember reading Emmanuelle Labroit’s ‘Selections from The Cry of the Gull’ as she speaks of discovering her ‘I’ after learning sign language, and her joy of self-identity, ‘I had discovered the world around me, and myself in the midst of it’ (Labroit 2006:433). She, born with a condition that set her apart, alienated by cultural and medical practises, had to wait until age 7 to discover her own identity. I, on the other hand, was inducted into the normlessness of disability at 18. I reflected on her joy, and contrasted it with how painful her existence must have been up until that point. In reading her words, I felt a degree of recognition that confused me. I shared her experience in no meaningful way, and yet I was drawn to her. What I had realised is that I do not remember a time before I was a patient. I do not remember not being ill. I know, objectively, that I was not ‘ill’ prior to being 18, but those past memories are viewed
through present lenses. They seem as though belonging to a different self. I have wrested every sentence from the chaotic heart of my illness experience, onto paper, and assembled something I did not expect: the same world Labroit so joyfully received. My illness—however much maligned, however much feared, in so many ways desired gone—is a part of my identity. It is no more possible to assemble a ‘healthy’ identity than it would be to consider myself male, or a duck, or a tree.

The act of looking at the lived experience of chronic illness, through the lens of autoethnography and illness narrative, ought to produce descriptive and illuminating text situated inside the perspective of the chronically ill. The value of such research is that the resultant text highlights both what the chronically ill consciously consider important, and the unconscious lapses in their narrative. The themes that I privilege in my narrative are ones I consciously consider important, yet those absent tell their own tale. There is an undercurrent of sadness, even with acceptance. I did not speak of my failed relationships, or the weight of illness upon them. I did speak of my inability to speak authoritatively to physicians, but not of yelling at them. I had to reflect on these absences to recognise them. Our stories—our memories—are always chaotic and fragmented, even without chronic illness. We assemble truths from thoughts
made hazy by time, by recollections distorted by emotion and interpretation. We call up memory gifted to us by those we share our stories with: mothers and fathers, brothers and sisters, friends and foes. Our experiences do not happen in isolation, but in constant movement with our pasts, presents, and futures. We do not naturally assemble our life stories into analysis and identify themes—but we do tell stories. The stories I have constructed and written down here were consciously chosen, but revealed things I had not planned. The sadness, loneliness, and anger were things I thought belonging to other chronically ill persons. Belonging, as it were, to other stories not a part of mine.

I opened this thesis with a quote from the British author Terry Pratchett: ‘If you don’t turn your life into a story, you just become part of someone else’s story’. His words were particularly apt, for a man who would be diagnosed with early-onset Alzheimer’s, yet whose vocation was imagining stories. They were equally apt for me, because they highlight the very real need to be become more than just a statistic in a medical journal, or a Medicare number claiming benefits, or the anecdotal ‘I had a friend who…’. Illness deserves a platform to be a credible story, and not simply in the victim narrative that so proliferates biographies in bargain bookstores. There is a need to sociologically examine the role of illness, of ill
health, of chronic illness, of suffering, as stories that benefit our understanding of the world. The value of stories, of why we write for each other, is so ingrained in the cultural psyche that it has become the very fabric of connection to other experiences, and in that ‘everything that is said carries the resonance of previous stories, because every indignation and aspiration, every expression of despair and act of courage has been told before’ (Frank 2013:220). We use stories to see into the past, to be connected to our present, to live beyond our deaths, and to invite others into our bodies and step into theirs. Stories become ‘about witness and testimony, as wounded storytellers seek to provide different imaginative conceptions of illness’ (Frank 2013:187). We can seek—as I have sought here—to highlight illness conceptions, and imagine different ones. Our identities are tied up in and made up of stories. We can and should use these stories to write illness narratives, to be Frank’s wounded storyteller. In doing so, we open up the possibility to sustain hopeful imaginations, to extend generosity to others, to bring forth a need for an ethics of illness. Most importantly, we need to offer to others the same courage and hope I found in Arthur Frank’s (2013) questions: ‘What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it?’ (159).
To this end, I have shaped my illness and my story the way I have *needed* it to be shaped. Without holding back negative analysis, but without deliberate hurtfulness. Without victimising myself, but not without self-empathy. It is not the story I expected. It is not a story that is finished, but it is my illness, constructed and deconstructed. I play a game. I flex my hand and think, this is *my* hand. This is *my* leg. This is *my* arm. I move through my body, reclaiming it as inherent and interconnected, as part of the me who chooses when to move, how to feel. The game ends, and I am short of breath. My eyes sting. I stare at my left hand, the one I write with, paint with, and draw with. It is still, hanging in the air, foreign and familiar. I wonder when it will pass from me to ill. I watch it some more. It remains still.
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