# Reclaiming the Docile Body: An Autoethnography of Illness and Adult Education

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I would also like to thank my son James for this unbelievable patience with me, and for busying himself while I had work to do.

#### Abstract

I am presenting an autoethnography on my experiences of illness and my return to education, in an adult education context. I first became ill with acute kidney failure in January 2011, a few months after giving birth to my son. It happened so suddenly and unexpectedly. I was thrown into a completely different world, questioning and reflecting on my life up to that point. In this thesis, I will show how my experiences of illness led me to return to education and how adult education enabled me to reclaim myself through agency. I have used the work of Foucault to help me interpret my experiences. I chose to do this topic for other to gain insight into the experiences of those with illness and how adult education can be used as a catalyst for change.

# **Table of Contents**

Chapter 1: Introduction
Chapter 2: Methodology
Chapter 3: Illness and the docile body
Chapter 4: Existential crisis and return to education
Chapter 5: Adult education as a catalyst for change
Chapter 6: Agency over the body
Chapter 7: Conclusion
Bibliography50

#### **Chapter 1: Introduction**

At the beginning of the academic year, I had many ideas for a thesis. I knew that I wanted it to be based on my own experience, and I was drawn to disability and illness in higher education and the experiences of a single parent in higher education. For my undergraduate thesis, I looked at barriers for adults in higher education. Many different themes came from this and I wanted to explore one of them in detail. As I met with my supervisor and with the aid of our group supervision sessions, I decided to focus on the area of illness and disability in higher education. I began by writing out a summary of my own experiences. I had initially intended to do an in-depth interview with students in university who had a chronic illness, but I found that my own experiences were so vast and unusual that I was drawn to composing an autoethnography. I had not attempted anything like this before. The more I read about this type of research the more I was drawn to it. I became excited at the prospect of having more control and input into the research. What involved was a look at my illness and experiences of adult education.

In the first chapter, I have a methodology section, in which I explain what exactly autoethnography is and how I came to the rationale of that research method for my topic. I have also included ethical issues I encountered during my thesis.

In the second chapter, I will show how my experiences of illness and hospitalisation are representative of Foucault's concept of docile bodies from his text *Discipline and Punish*. The third chapter details questions and reflections I had when I first became ill, and to a decision to return to education. The fourth chapter will show examples of my experience of adult education as a catalyst for changes in my life and most notably to reclaim my body. The fifth chapter contains examples of my reclamation of my body.

At the beginning of each chapter I have included a song. When I first went to university I studied music. Music is something that evokes emotions in me. When I hear a song being

played on the radio, it reminds me of what I felt the last time I heard it. I associate songs with events. For this reason, I have chosen to include a song that I associate with the content of the chapter.

#### **Chapter 2: Methodology**

#### Autoethnography as Method

I have viewed the term autoethnography into three interconnected parts (Fig. 2.1) Autoresearch subject being myself, ethno relating the research to culture and graphy being the skill of writing. As opposed to autobiography, autoethnography must make some sort of contribution to "scholarly work", contribution to knowledge, so it should have some sort of concept or theory behind

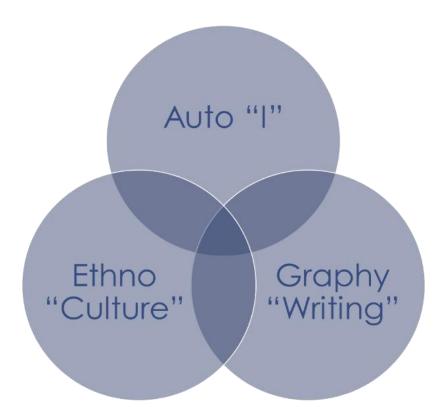
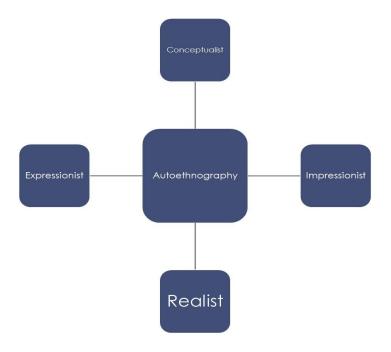


Fig 2.1

In reading autoethnographic methods, I came across a variety of definitions as to what exactly autoethnography is. The definition seems to take into consideration the approach and style of the autoethnography, so I wanted to choose an approach that fitting in with both my ontological and epistemological position as well as my research topic. Whilst all agree that autoethnography is a writing of the self, what differs is how the experience is analysed, if at

all. The definition that most spoke to me was a combined definition of some authors of autoethnography I had been reading Stacy Holman Jones, Carolyn Ellis and Tony Adams "Autoethnography is the use of personal experience and personal writing to (1) purposefully comment on / critique cultural practices; (2) make contributions to existing research; (3) embrace vulnerability with purpose; and (4) create a reciprocal relationship with audiences in order to compel a response". (Denzin p.20) Perhaps because this is a combination of their techniques for autoethnography, it fitted within what I perceived to be autoethnography. Other definitions left me feeling too vague, such as Carolyn Ellis' definition "As an auto ethnographer, I am both author and the focus of the story, the one who tells and the one who experiences, the observer and the observed...I am the person at the intersection of the personal and the cultural, thinking and observing as an ethnographer and writing and describing as a storyteller" (Denzin, p.19) I wanted to portray numerous things by using this method not just my own experience, but to be vulnerable in my writing and critical in my approach to the vignettes using social theory to interpret my experiences.

There are numerous distinct types of autoethnography, each with their own set of characteristics. (Fig. 2.2)



Below is a summary of the distinct types of autoethnographic styles adapted from *Autoethnography* by Tony Adams.

# Realist



- Experiences, analysis, stories and interpretation
- Research reports
- Analytic autoethnography
- Ethno-drama
- Layered accounts

Fig. 2.3 Characterisites of a realist autoethnography featuring a picture of myself from 2011 when my hair was falling out and cut short due to chemotherapy

# **Impressionist**



- Creating an experience to draw in the reader
- Sensory and physical accounts
- Narratives of space and place
- Interactive interviews
- Co-constructed narratives/collaborative autoethnographies

Fig. 2.4 Characteristics of an impressionist autoethnography



Fig. 2.5 Characteristics of an expressionist autoethnography

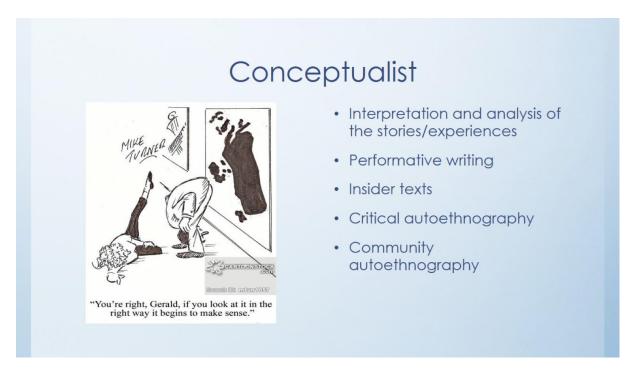


Fig. 2.6 Characteristics of a conceptualist autoethnography

For my own approach, I borrowed from each of these styles. I felt that I did not fit into one particular set of characterisits so I used a combination of realist, impressionst and conceptualist ideas. I used layered accounts: writing, analysis, reflection and accounts from the Realist style, the use of sensory accounts of my experience from the Impressionist style

and use of interpretation, analysis and some critical theory from the conceptualist style. I felt that using this combination matched well wit my writing style and also made it approachable for others to read.

#### **Research Paradigm**

I have approached my research from an interpretivist point of view. As I am drawing on my own experience, it is important that my research reflects that I have a subjective stance. My experience of being ill was a life changing one for me, that enabled me to make changes in my life, reflect on past experiences and using adult education make meaning and transformation in my life. It is a set of circumstances that people will experience and interpret in diverse ways, therefore not measurable by the scientific methods of research. I have met many different people on dialysis, each with their own unique experience of what it means to be ill. I think a substantial difference was that many of the other patients on dialysis had chronic kidney disease, they knew they had a progressive illness and were prepared for dialysis when the time came. They did they not have the sudden "on my death bed" existential crisis experience that I had. And for others who have been on their death bed, they might have interpreted it completely different. It is not a measurable data.

I was once asked to complete a survey by the hospital on my experience of doing dialysis at home, a type called peritoneal dialysis. It was a tick the box type of survey, data to be gathered and quantified into tables and graphs. I remember it asking me about how I felt being on dialysis, to tick a box and quantify my feelings into one-word answers. I ticked that yes, I was in pain, yes, I was depressed, no I did not feel like I had enough support. But it did not portray the whole picture for me, my experience, my interpretation of what it was really like on dialysis. This experience influenced my decision of an interpretivist paradigm, to be

able to say how I really felt, and relay my subjective experience rather than reduce it to a set of statistics.

I have also been influenced by critical theory, in my reflection on theory as part of my undergraduate and masters. I believe that social constructs exist and that these must be critically reflected on to bring social change. I have drawn from this in my use of Foucault, to help explain my experiences.

#### **Research Procedure**

My experience of writing an autoethnography was not a linear approach unlike my previous research which had the traditional thesis structure of a literature review, research via interviews, findings, discussion's, and adding to my literature review. Doing autoethnography was a challenge as it does not follow the structure that I was used to. My peers were using the linear structure, and I found many of my research classes geared towards the tradition structure which made it more difficult for me to understand and work through. I sometimes felt as though as I was searching in the dark. I remember my classmates excitedly coming back from the resource room which copies of previous theses they had found and following the structure, having examples of outlines on how their thesis 'should be'. I had no such example. I found this made my research more complicated but also gave me the creativity to structure it as I wanted, and let the research subject, and my readings into autoethnography to direct the methodology and layout.

When I first decided to take this approach, I was basing it on an experience, that of my illness and returning to education. I already had an idea of memories/experiences I wanted to use, so in gathering data, I used circular approach of reading, thinking about my experiences, writing about them and then analysing them. I used this approach throughout writing my thesis, and then drawing themes that became apparent as time went on. (Fig. 2.7) I connected theory to my writing by making connections between the narrative experience and theory I

had explored as different themes of my journey. "Theory asks about and explains the nuances of an experience and the happenings of a culture; story is the mechanism that illustrates and embodies these nuances and happenings" (Adams, Tony p. 90)

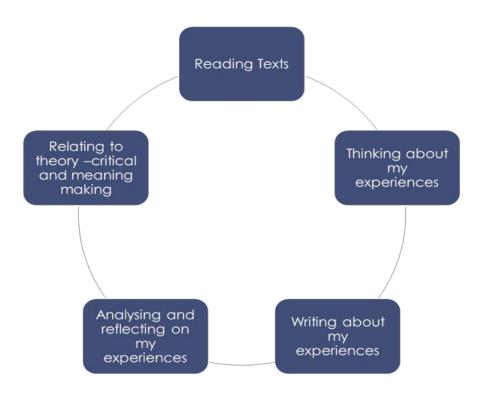


Fig. 2.7

I used a few different techniques for my writing. During my course, I learned a technique in my reflective practice module which involved meditation followed by free writing. When reading through my texts, I would link it to past experiences and reflect on this, to write vignettes. After a brief meditation to clear my mind, I would explore some free writing, which would usually end up drawing from the themes I had read in my literature.

In gathering these texts, made of notes from reading literature, free writing, reflective experiences and parts of essays completed during my course, a technique known as spiralising. In coding this data, I bought a scrapbook for each theme, and cut and pasted parts of essays, notes, anything I thought I might use and divided it up into mini-themes. I had a scrapbook for

each major theme. It made it much easier to write and structure my writing having my scrapbooks and themes in easy to read sections. (Fig. 2.8) (Fig.2.9)

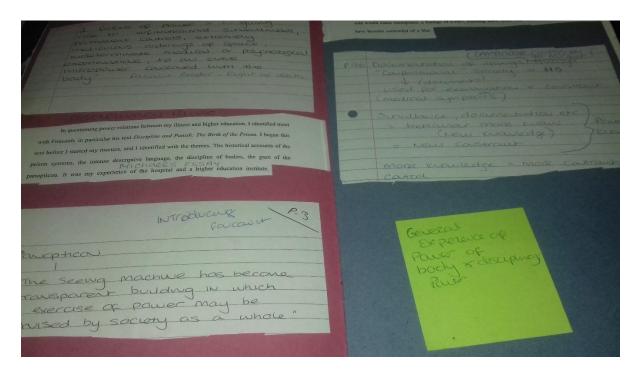


Fig. 2.8

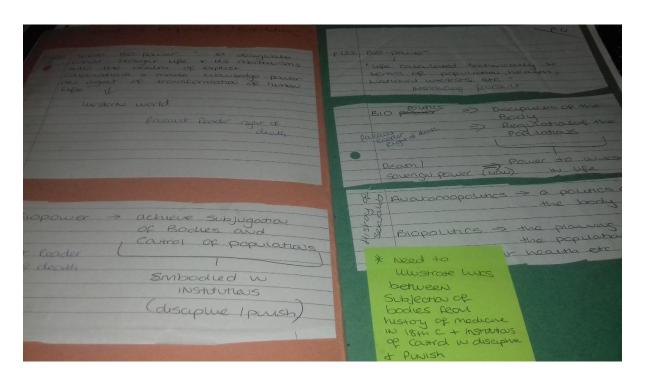


Fig. 2.9

#### **Ethics**

I was particularly worried about the ethics of doing this type of thesis. It is obvious who I am, and that others will read my experiences. I had to consider which experiences I could put in that I would be comfortable with people knowing, while at the same time ensuring that I was making an honest representation for others to read. I wanted it to be a real representation of an experience of illness and questioning, so I have included stories that I have never told before. It is important for others experiencing illness to have the courage to speak out about their experiences, the good, the bad and the ugly, so I had to do both them and myself justice by opening up about things that I had not shared before. In doing this, I felt a duty of self-care towards myself. There were times when writing was difficult. When revisiting the past took an emotional toll on me. I tried to balance my life by making sure I also took time to do things that had nothing to do with my thesis. One of the ways I did this was by reading. I took a half hour every day to read a book, that was not on Foucault, illness, social research. It helped as form of escapism and relaxation so I was not completely immersed in a world of recalling painful experiences.

For others who were identifiable in the Thesis, I asked their permission. My brother Rory, was only too happy to allow me to use a photograph of us. In fact, he posted it on his Facebook page. When I saw it, I felt a rush of love that I had for the little boy in the picture, the little boy that I looked after throughout my teenage years. I wanted to include that love. I also asked permission from my son James. At six years old, he has grown up with my illness, it is normal for him. He has also seen me doing college work for the last six years. I sat him down and explained "You know all the work mam is doing? It's for a thing called a thesis. It's kind of like a book and it's about me being sick and going to college. Would you mind if I talk about you in it?" "Yeah ok mam. You should write about our trip to the zoo!"

What I really wanted for this thesis, especially for showing how Foucault's *Discipline and Punish* applies to my hospital experiences, was a copy of my hospital charts. Under freedom of information I applied to get a copy of my charts from Tullamore and Beaumont Hospital. I wanted to use the information that was held about me, to show how patients are assessed in hospitals. I got a copy of my chart from Tullamore, but not from Beaumont. I was disappointed by this, as my chart from Beaumont is considerably large. Although I have read it, I was unable to show copies in my thesis. I received an email from Beaumont hospital that they were currently only processing November's requests in May.

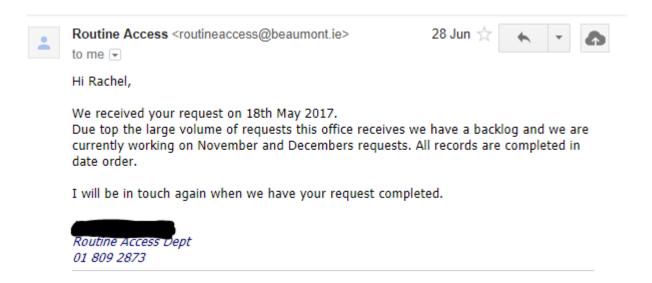


Fig. 2.10

### **Chapter 3 Illness and The Docile Body**

## Bruce Springsteen, "The Streets of Philadelphia"

I was bruised and battered, I couldn't tell what I felt
I was unrecognizable to myself
I saw my reflection in a window, I didn't know my own face
Oh brother are you gonna leave me wastin' away
On the Streets of Philadelphia

I walked the avenue, 'til my legs felt like stone
I heard the voices of friends vanished and gone
At night I could hear the blood in my veins
Just as black and whispering as the rain
On the Streets of Philadelphia

Ain't no angel gonna greet me
It's just you and I my friend
And my clothes don't fit me no more
I walked a thousand miles
Just to slip this skin

The night has fallen, I'm lyin' awake

I can feel myself fading away

So receive me brother with your faithless kiss

Or will we leave each other alone like this

On the Streets of Philadelphia

I lay in the bed in the bottom corner, opposite the nurse's station. It was pitch black. I did not care about my moans, louder than the others stifled breathing, heavy snoring, quiet chatter and the rolling of the blood pressure machines from bed to bed. Beside me was a cardboard kidney dish, it was for me to be sick in. I thought it was funny that they called it a kidney dish, here on a nephrology ward, even though it was round. I later brought one home and put it on my son as a hat. It fitted perfectly...he looked like a cowboy.... the nurses laughed at the picture I took when I brought it in for my next dialysis session. The bile kept creeping up my throat, my stomach clenched...the kidney dish filled bright red. The rolling of the blood pressure machine was coming closer. She was coming. Exhaustion from trying to lift my head to the bowl, to rid myself of the clot that had overtaken my lungs, tears rolled down my face at the thought of lifting my arm for her to check. "Rrrrrachel! Time to check blood pressure now". My eyelids half opened a saw the white top and the black hair as she roughly opened the curtains exposing the bright lights and smell of chips from the nurse's station. It was a Friday night...that was the night they ordered Chinese. "Rachel! You have not taken these tablets!. Sit up... you have to take these now!" I had been vomiting so much...I couldn't swallow them. The thought of so many different coloured shaped and sizes sliding down my throat...I moved my head to the bowl, my throat burned...more blood. "I can't...I can't...I can't stop...I don't want to take them anymore....I can't stop getting sick...tears rolling down my face. "It doesn't matter. Dr. Said you must take these. So, take these now. You be in big trouble with Dr. In the morning." She walked away, her footsteps louder and faster than usual. I closed my eyes. A time later...time was very difficult to track then...a felt something cold in my arm...I opened my eyes and saw a new clear bag on the drip stand, the tube pumping a cold mixture into the cannula I tried so hard not to break...for fear of the doctor trying to find a vein amongst my blue and red poked arms. There was a young doctor, one of the interns dressed in blue scrubs..."I have given you the cyclophosphamide in an IV. You have to take this one, this is the important one."

I first became ill in January 2010. I gave birth in September 2010 and had very bad joint pain afterwards. I went to my GP. He was a new GP for me, as we had moved late in my pregnancy due to a reduction in the amount of rent allowance. "Well, you've just had a baby! Of course you are going to be sore!" I continued through the pain, but it became worse and worse. It came to a head the evening of my son's christening. It was St. Stephens Day. I remember standing up from the table to go to the reception to pay for the meal. I could barely walk but I gritted my teeth and hid it from everyone. It took 40 minutes to walk to walk the usual 5-minute journey from the train station to the apartment that night. I spent the next few nights in bed, resting. I remember the fireworks and cheering at midnight on New Year's Eve, as I lay in bed crying. I went back to the same GP. "Oh, I think you have a blood clot". This time he looked worried. "You need to go to the hospital."

I went to the emergency room. I was eventually seen by a young doctor. He told me he thought it was a blood clot but there was something else wrong. He didn't know what. "This kind of thing....it's something you would see on someone who has climbed Everest or something!" Despite not being able to walk, I was sent home and told to return the following day for a scan. I did what I was told. Who was I to object to what the Dr. said? I knew no different. I returned the next day, it was decided for me that I would stay over the weekend as the swelling was so bad. I was given Warfarin for the blood clot. I took them. I spent the night in a state of dizziness and vomiting. The ward was very short staffed. The bell by my bed was ignored for prolonged periods of time. The Dr. and pharmacist came to see me. They concluded that I was allergic to the Warfarin and was told to take a different medication. Then came a rash. The nurses ran a glass over my skin. They were perplexed. "I've never seen anything like this before have you?" one said to the other. I went to the bathroom, and there was blood. I told the nurse. "Are you sure you don't have your period?" "No..." I had no idea what was going on. I was told nothing. A nurse arrived in the middle of the night, on my second night there...."

the Dr. from downstairs is going to come up and talk to you. It will be a while, mind, they are very busy down in A and E" The doctor sat in the chair beside me. Only on reflection of what he said do I realise now, how difficult it must have been. "We looked at your blood results and there may be a problem with your kidneys. If you go to the toilet before the morning, you will be fine." Oh grand, I thought. I did not understand what he was saying. The word kidney failure was never mentioned to me. I had no idea of the severity of the situation. I went to the toilet after he had gone and thought to myself, oh that's all right, everything is grand now. The next morning, I met my consultant. I had never met her before then. With her was a team of about ten, surrounding my bed. I didn't like the look of this... "There is a problem with your kidneys...so we are going to move you to intensive care so we can look after you there." I still didn't quite understand what was happening. I was very confused. I phoned my mother. She used to be a nurse. It was when she came, she explained what was happening. I felt a fool, being kept in the dark with no idea what was going on. I overheard someone say, "I hope she makes it through the night."

My first experiences of illness were surrounded by secrecy. I later learned that my consultant had told my mother than life support was the next step. I was never told. I did not feel like a person. Doctors talked about me in the third person, while at my bed. They talked about me when they thought I was out of earshot. I was sometimes informed of what tests or medication I was going to be subjected to next. Most of the time, I received a little plastic cup full of assorted colours and shapes and I took them, without question. I felt powerless. I felt I had no control over what was happening. I was shocked, confused, giddy, drowsy from the different medications. My experiences of the hospital, dialysis units and medical staff where can be explained using Foucault's *Discipline and Punish*. I first read *Discipline and Punish*, in the August prior to beginning my Master's degree. It was a recommended book on one of those lists of 20 books to read before you die, that type of thing. Whilst I didn't finish the book at that

Foucault during my master's degree, and I became interested more interested in Foucault and how his theory related to my experiences. Recalling memories from my many times in the hospital, my feeling of a loss of control was explained by this. Foucault uses history as a basis for his theories. Foucault's traces power over the body beginning at the 17<sup>th</sup> century when public displays of torture were the form of punishment by the sovereign. If you did not follow the rules that were set out by the sovereign in charge, a public display would ensure that others followed. In the 18<sup>th</sup> century, attitudes to punishment changed and it was decided to become a private event, in case of sympathy from the public. This led to the development of the prison system, as we know today. Two concepts from the development of the prison system are particularly relevant to my experiences: Docile Bodies and the Panopticon.

Docile Bodies is about the discipline of the physical body itself. Foucault describes it as "One that may be subjected, used, transformed, and improved. And that this docile body can only be achieved through strict regimen of disciplinary acts." The example he gives is the solider. A solider is coerced to obey a particular set of rules, he is disciplined, he works to a set timetable. Foucault states that the discipline is achieved by the art of distributions, the control of activity, the organisation of geneses, and the composition of forces. That is that discipline requires a closed space, a timetable, dividing time and activities into units and that we are all a small part of a larger unit. The body achieves its docility through this discipline. I apply this concept to my experiences of illness within the hospital institution. My body was one of many. I had been coerced to accept a particular set of rules, that doctors hold power and should therefore be obeyed. They have been trained and know what is best for the patient. I followed the rules, the timetable of the hospital. My body had been conditioned to be a part of the machine of society, where those in a position of power held a higher ranking and should therefore be obeyed. The institutions function as a type of machine in which to control and produce these docile bodies. "The human body was entering a machinery of power that explores it, breaks it down and rearranges it...it defined how one may

have a hold over other bodies, not only so that they may do what one wishes, but so that they may operate as one wishes, with the techniques, the speed and the efficiency that one determines. Thus, discipline produces subjected and practiced bodies, "docile" bodies" (Discipline and Punish p.138)

The institutions provide two functions according to Foucault, to observe and control, the use of the panopticon and when this control and regulation becomes ingrained in docile bodies, the use of self-regulation. The panopticon is a concept designed by Jeremy Bentham, in which prison staff can observe inmates, without inmates being aware of whether they are being observed. This is called the 'gaze'. "The seeing machine has become a transparent building in which the exercise of power may be supervised as a whole." (Introducing Foucault, p.118)

My experience of the panopticon is in the layout of the hospital. In my ward, there is an open section nearest the nurse's station, in full view of all who come into that ward. There are also two bed wards, segregated by gender and two private room, reserved for those willing to pay or who are infectious. Each room's door is always open, there are transparent glass panels. There is the feeling that a staff member can enter at any giving time, so I must therefore follow the rules, I am not sure when they are watching. During my first stay in hospital, I was a patient for about one month. I began to miss the simplest of things, a choice of food, to choose when I wanted to eat, what time I wanted to eat at, when I wanted to wash or get dressed. I became institutionalised, as I had set times to adhere to certain things. My mother visited one day, I was so hungry. I was on a huge dose of steroids and I would say to her "The first thing I want to do when I leave is go to Eddie Rockets". I used to plan what I would eat, every day I would have a conversation with someone as to what I should order.

Should I get a burger and a milkshake? Or chips? Or will I get a hot-dog? I never had one of those there before. I think I will get the swiss cheese on the burger and maybe the onion rings? They come on a spindle type thing, with garlic dip! I relished the thought of the freedom to eat what I wanted. It was so exciting, my eyes lit up when I told people of my plan.

My mother felt sorry for me, she turned up one day with a McDonalds double cheeseburger. She hid it in her bag. She waited until the nurse was gone, drew the curtains around the bed. I could smell it before I opened it. I smelled of melted cheese and grease. I peeled away the wax paper. It had two sad little corners of cheese sticking out the side of the bun, drooping down. I bit into it. My mouth watered. It tasted smoky, the texture like something entirely new. I may have even closed my eyes.....it would have made a great advert. A smile formed across my pale face, I felt so happy, it was so delicious. It felt illicit, exciting, tasty. The curtain suddenly whipped back, I instinctively pushed the burger under the sheets of the narrow bed. "Well Rachel, just doing another blood pressure check for you there..." She rolled the machine over, ripped the Velcro cuff and placed it on my arm. My heart was racing. All I could think about was the burger, hidden in my bed. Can she smell it?.... Surely, she can smell it?.... What if she finds it under the sheets?.... Oh, please just go away... go away... I know I am not allowed cheese.... or salty things.... I just wanted a burger....I just want to go home....Where I am not being interrupted every few minutes....poked at....prodded at....asked questions....Beep, beep, beep...aaahhh "Hmmm, it seems a bit high there....I'll come back and check it in a few minutes" She smiled as she walked back up to the nurse's desk, she had a soft face, she always treated me as I thought a mammy should. A real mammy. The curtain was left open. I felt around the mess of blankets for the burger...It left a lukewarm patch on the sheet. "I shouldn't have done that....I should have known better than to bring it in....you're not allowed" My mother set in the large green high-backed chair stuck in the corner... "Sure, no wonder you had high blood pressure"

My bed was situated opposite the nurse's station, I always had the same bed when I was admitted, I was under the "gaze" of the nurses, an observation of control. I longed for privacy within such a public space, I often drew my curtains, or unable to move asked a willing staff

member to close them, but the never remained closed for long. The nurse who took my blood pressure, by drawing open the curtains I felt exposed, my body and all its symptoms there for observation and recording. The blood pressure was taken at hourly intervals, meticulously recorded in my chart, which held a wealth of observations about my body, my mind, my demeanour. Through this system of knowledge, more control is gained by medical staff. I had always had great difficulty swallowing tablets. They would sit on my tongue and as I felt them moved down my throat, my reflexes caused me to gag, my eyes would water and I would focus my mind on not throwing up. I was still in the process of learning to swallow medication at that time. The taste and smell of some of the pills made me nauseous. I had on occasion swallowed tablets only for them to appear partially disintegrated in my vomit minutes later. I had to watch as the nursing staff debated whether I had ingested enough or would require another dose. In the opening story, I could not face attempting to swallow them. I was expected to do as I was told. The nurses uniform was a symbol of power of my body, I was expected to obey. I remember having to fight to not take that medication. I realise now, though maybe not to the same extent at the time, that it was necessary for me to take it to survive. The staff in the hospital are trained to extend my life expectancy, a form of the self-regulation of power. My body was subjected to medical intervention, whether I requested it or not. I was not given a choice or control over my own body, I was not aware that the specific medication they were concerned about could be taken in an IV form, only as a last resort was that step taken. I did not feel I had any control or say over my own body.



Fig. 4.1 Northern Cross Dialysis Unit: This was a private dialysis unit contracted by the HSE, I preferred being here, it was quick and efficient and the atmosphere was different from the dialysis units in Beaumont. I did not feel under constant monitoring in such a Foucauldian way, as it was a private business. They also had WIFI!

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HEALTH S	SERVICE EXECUTIVE	
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CONSENT FORM		
	MIDLAND REGIONAL HOSPITAL AT TULLAMORE	
(A) Insert Name	Patient ID: 229253 DOB:18/04/1986	
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hereby consent to undergo	Dr. Eoin Bergin Nephrology	
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Insert Name or Brief Acco	ount of Operation or Treatment, the nature and	
effect of which has been ex	planted to me	
A		
I also consent to such further or alternative operative measures or treatment as		
may be found necessary during the course of the operation or treatment, and to the administration of general or other anaesthetic for any of these purposes.		
No assurance has been given to me that the operation/treatment will be performed		
or administered by any particular	ar practitioner.	
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Fig. 4.2 Foucault at work in the hospital: A consent form with the operation or treatment unidentified, I don't recall signing it, the first signature is not mine or any a relative

Another experience of being a docile body was when my consultant decided to conduct his own research project on me. After a couple of weeks in hospital, I had been given a diagnosis of Ancavasculitis, a type of autoimmune disorder. However, they were never sure whether this was the case or not. Most autoimmune disorders have the same symptoms and it can be difficult to differentiate between them. My consultant approached me and told me that for his own interest, he would like to run some test for autoimmune disorders, to see which one I might have. "Although it makes no difference, they are all treated the same, so we would have given you the plasmapheresis and the cyclophosphamide anyway. Do your eyes ever feel dry?" "Em...yes I suppose" "Ok, we will send you for a biopsy for Sjogren's syndrome then. They biopsy the lip for that." I was told that the consultant who would be doing the biopsy was in a smaller satellite hospital. I went in as day patient. I had a local Anasethic, but I remember feeling the blood running down my chin onto my neck. My lip was so swollen I found it difficult to eat or drink for days. I got a call that the sample had been 'inconclusive' so they would need another one. I had another day trip to the same surgeon, and another swollen lip. I asked while on dialysis a couple of weeks later. "So what were the results of that lip biopsy?" "Oh it wasn't Sjogren's after all. I think it is the Anca-vasculitis." I still have the scar on my lip.

My age and the fact that I had so many different procedures led me to become an excellent test subject any time I was admitted into hospital. At times, I felt like a guinea pig. I did not feel I had any right to refuse the dozens of medical students that would surround my bed. There was one time when they were having exams. These exams consisted of several medical students observing and attempting to identify what my scars where. The most 'interesting' ones are on my stomach and chest. So, this involved lying in the bed with my nightdress rolled up, while stared at by a group of people, and those who wanted to examine me were also allowed. Being touched by strangers on a regular basis is not why I was in hospital in the first place. I was there to rest, awaiting test results, waiting for operations. I wanted to be left alone, but I did not feel it was my place to say this. The medical students had to do a presentation once, a very excited young man

was delighted to be the first to approach me as they each had to have a different patient. I was apparently top of the list. It felt disconcerting to know I had being talked about and identified by senior doctors as 'a great study'. I did not feel like a person but an object to be observed and recorded.

#### **Chapter 4: Existential Crisis and Return to Education**

#### Pink Floyd, "Time"

Ticking away the moments that make up a dull day

Fritter and waste the hours in an off-hand way

Kicking around on a piece of ground in your home town

Waiting for someone or something to show you the way

Tired of lying in the sunshine staying home to watch the rain You are young and life is long and there is time to kill today And then one day you find ten years have got behind you No one told you when to run, you missed the starting gun

And you run and you run to catch up with the sun but it's sinking Racing around to come up behind you again

The sun is the same in a relative way, but you're older Shorter of breath and one day closer to death

Every year is getting shorter, never seem to find the time

Plans that either come to naught or half a page of scribbled

lines Hanging on in quiet desperation is the English way

The time is gone, the song is over, thought I'd something more to say

Home, home again

I like to be here when I can

When I come home cold and tired

It's good to warm my bones beside the fire

Far away, across the field

The tolling of the iron bell

Calls the faithful to their knees

To hear the softly spoken magic spell

As I lay in my bed every day, my mind ran with thoughts and regrets of what I had achieved in my life up to the point of when I was first admitted to hospital. I had feelings of guilt and shame of a life I felt I wasted. I had responsibility from an early age. I remembered first attending college, and watching the freedom of other students. They were involved in societies, big groups of friends, sexual freedom. They drank, they laughed, they studied, they had experiences. I was in a committed relationship from an early age, I had a different life. My brother was the same age as my son is now, I would drop him to school at 930 in my red Toyota starlet, worrying if the fiveeuro petrol I had filled it with would last for my round trip to Maynooth. I can still picture his smiling face as he hopped out of the car. "See you at 3 Fafa". I went to lectures between 10 and 3. I found it difficult to maintain friendships. I was lonely, and jealous of the others with their freedoms I could not have. My mother and brother moved down the country the year after. I moved in with my boyfriend at the time. My life now consisted of working, and trying to pay bills. I was 19. The pressure to keep working and studying became too much, I left college, I worked, I paid every bill that came into that shitty converted garage we lived in. I watched my boyfriend get a first-class honours degree and masters. I waited patiently for my turn, but it never came. I watched the money I earnt get paid into rent and bills, I never had a chance to spend money on myself. It was never there. I watched the other girls dress up, their hair in GHD curls fresh from a trip to the hairdressers. I felt like a frump. I didn't have the money to look nice, have nice clothes, things that normal girls in their late teens and early twenties have. My boyfriend began to neglect me. He spent hours in front of his computer calculating premier league statistics to see what bets he would place at lunch time. He worked, but still we never had money. I watched as old friends began careers, went abroad, I longed for those things, and I still do. I was excellent at my job in

retail. I loved going to work, I loved the people, I felt I had a place to belong, a family. It was nice to feel wanted. I got a promotion to a new store. I commuted from Maynooth to Dun Laoghaire every day, I had no friends in my new position. I was lonely. Things were bad at home. My boyfriend's gambling was getting out of control. My alarm clock went off one morning, and I lay there. I felt numb. I didn't move. I didn't move for days. I stayed there alone all day and then ate until I couldn't move every night. I didn't know what was wrong with me. The father of my son came to visit us one day, I went from one relationship to another. I decided to go back to college, finish that degree, try and achieved something in my life, but then I became pregnant, and shortly after the birth I became ill. Lying in that narrow hospital bed, clicking of nurse's shoes all around, I reviewed my life so far. I had achieved nothing. It was a miserable life. I had an unhappy childhood and adulthood. I had not been abroad in 11 years. I had one person who ever visited me while I was there. She came with her husband to be, her face screwed up with disgust at another patient vomiting. I felt the need to constantly apologise. She never visited again. Had I wasted my life, my opportunities? All I had ever known was being responsible for others? What about me? What do I want from life?

Whilst I was writing this, I attended some English lectures for work, supporting undergraduate students with disabilities. One lecture was on *The Bell Jar* by Silvia Plath. I had studied her poetry in school. There is one famous passage in this book, that reflects how I felt back then. The story of the fig tree.

"I saw my life branching out before me like the green fig tree in the story. From the tip of every branch, like a fat purple fig, a wonderful future beckoned and winked. One fig was a husband and a happy home and children, and another fig was a famous poet and another fig was a brilliant professor, and another fig was Ee Gee, the amazing editor, and another fig was Europe and Africa and South America, and another fig was Constantin and Socrates and Attila and a pack of other lovers with queer names and offbeat professions, and another fig

was an Olympic lady crew champion, and beyond and above these figs were many more figs I couldn't quite make out. I saw myself sitting in the crotch of this fig tree, starving to death, just because I couldn't make up my mind which of the figs I would choose. I wanted each and every one of them, but choosing one meant losing all the rest, and, as I sat there, unable to decide, the figs began to wrinkle and go black, and, one by one, they plopped to the ground at my feet."

I felt I lay there in that bed surrounded by black figs, wasted opportunities, and wanting more than that.

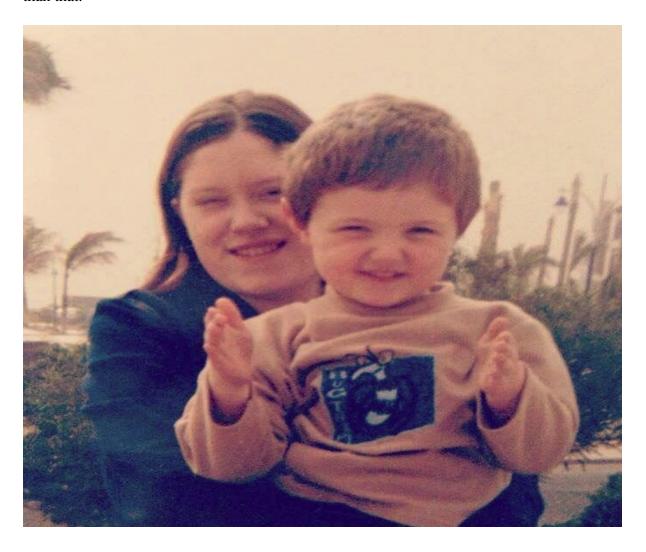


Fig. 3.1 My Brother Rory and I on holiday...strangers presumed he was my son. I remember a woman in the bank once who told me I was doing a wonderful job. Age 14-15 and 2-3 apx.

I related some of these experiences to Foucault's *History of Sexuality*. I can see that a large part of my regrets come from my place as a woman. In a History of Sexuality, Foucault uses his historical style to show how in the nineteenth century women were reduced to their ability to control population, "The good woman was fulfilled through her reproductive capacities and through the nurturing of children" (McNay, 1992, p.31) For me, this is a belief still held in today's society. I was expected by others to be satisfied with my life as a woman, I had a wonderful child, I was told numerous times how lucky I was. The identity of mother alone was not enough for me, although perfectly acceptable for others to tell me it was enough for me. Foucault identifies that as women are perceived as being reproductive beings, the idea of pleasure and sexuality of a woman was deemed perverse, the concept of the hygienisation of women. I interpret this as a metaphor related to my experience of constantly providing for others. My mother became a single parent with full responsibility for two different children and was ostracised by her family and society for engaging in pleasure. I as a woman, fulfilling my societal obligation as a reproductive vessel, took care of my brother. I denied my own pleasure by conforming to the expectations of having one long term partner after another. I gave up my freedoms to support the men in my life, looking to a stable future to provide children.

Before my illness, I was a strong woman. I was confident. At the time, I was sure of myself, who I was. I was a wife to be, a mother, I was content with my life, although I still had ambition. I had a high paying job, a career. The illness changed my perspective on things. I was no longer content with the life I had. I felt things were missing, I wanted to make memories, I felt trapped. When I first became ill, I was in hospital for about a month. During this time, I was mostly bed ridden, each day brought unfamiliar terms "Anca vasculitis" "creatinine" I was given numerous updates daily on the theory of what caused my kidney failure, what tests I would be receiving that day, how efficiently the dialysis was working. I adjusted to the language with ease, I would find myself

going through my chart analysing my own bloods, I constantly asked questions, I became somewhat of an expert in my own illness. I became frustrated with others who did not understand. They could not feel the exhaustion, the loneliness. I didn't know who I was anymore. I was now Rachel, "the one on dialysis". I hated the pity, the texts, the phone calls, the visits. People became awkward, they didn't know what to say. I could see the pity in their eyes. I hate being pitied. I hated that all people would talk about was my illness. "How *are* you?" They would say. "How are you feeling *today*?" I felt like a burden. I wanted to talk about other things. I wanted to escape from the endless cycle of going to hospital, going home, going to bed. I wanted to reclaim my identity. I decided to go back to college, as a means of escaping the life I now had. I wanted something else in my life. I was no longer satisfied.

Foucault talks about the 'Arts of Existence', attaching significance to day to day activities. "What I mean by the phrase are those intentional and voluntary actions by which men not only set themselves rules of conduct, but also seek to transform themselves, to change themselves in their singular being, and to make their life into the oeuvre that carries certain aesthetic values and meets certain stylistic criteria" (Foucault, P.10-11) This is what I realised in the hospital bed. I did not have control over my illness and but I could choose to change other things in my life. I decided to make a mental list of all the things that I wanted to do but I never did. It was a simple brief list. I wanted to go on a holiday. I had never been abroad without my mother, and not in about ten years. I wanted to get married, I didn't want to die without having experienced that. And I wanted to go back to college.

#### **Chapter 5: Adult Education as a catalyst for change**

#### Bob Dylan "Times They are a Changing"

Come gather 'round people
Wherever you roam
And admit that the waters
Around you have grown
And accept it that soon
You'll be drenched to the bone
If your time to you is worth savin'
Then you better start swimmin' or you'll sink like a stone
For the times they are a-changin'

Come writers and critics
Who prophesize with your pen
And keep your eyes wide
The chance won't come again
And don't speak too soon
For the wheel's still in spin
And there's no tellin' who that it's namin'
For the loser now will be later to win
For the times they are a-changin'

Come senators, congressmen
Please heed the call
Don't stand in the doorway
Don't block up the hall
For he that gets hurt
Will be he who has stalled
There's a battle outside and it is ragin'
It'll soon shake your windows and rattle your walls
For the times they are a-changin'

Come mothers and fathers
Throughout the land
And don't criticize
What you can't understand
Your sons and your daughters
Are beyond your command
Your old road is rapidly agin'
Please get out of the new one if you can't lend your hand
For the times they are a-changin'

The line it is drawn
The curse it is cast
The slow one now
Will later be fast
As the present now
Will later be past
The order is rapidly fadin'
And the first one now will later be last
For the times they are a-changin'

I had managed to convince the council that I was in dire need of housing and due to my illness, I got a place in Maynooth. I was extremely happy to be back home and not having to make the two-hour journey for dialysis three times a week. I was often very ill on the drive home, vomiting, exhausted. It was a relief to be nearer to the hospital. I looked for a part-time course, as I knew that with my illness I could not manage to go back to college full time. I found one in Maynooth, I was very excited about. The modules on adult education and sociology looked fascinating. I had loved the training part of my previous work. I attended an interview for which I was extremely nervous. I was very honest about my condition. It was great to be supported and not pitied about being ill. I had not experienced that before. I remember during the interview, one of the interviewers told me that she admired my determination to get a degree, by being in college before, and returning previously and now returning. I had never looked at my educational experience in that light before. It was always something I had regret over, I was a failure, a college drop-out. Her remarks stayed with me throughout my degree. I found the adult education experience completely different to my other college experience. When I first went to college after school, I was doing a degree in music and Irish. The Irish was a huge problem for me. I was expected to be fluent and I was far from it. Lectures had a few hundred people in one room, with the lecturer on an elevated platform talking down to us. Few of the lecturers knew my name, there was little or no interaction between staff and students. The concept of adult education had lecturers and students on the same level. Our life experience was valued. We were encouraged to participate in class, to question norms, and to develop our own opinions.



Fig. 5.1 My diploma parchment I received half way through my degree...I finally had a qualification!

I was a couple of years into my degree when I first heard of transformative learning. It was something that I was already experiencing long before I heard of it. In my class, my mind was opened to concepts I had realised were here all along and offered some explanation as to how I now perceived the world. I met like-minded people. I finally felt a connection to other, who shared the same beliefs and outlooks. It was something I had been searching for a long time. Mezirow speaks of recognition that you are discontent and the process of transformation is shared by others. Not only could I see the change in me but I observed it in others. One classmate, who I felt an enormous connection to, enabled me to observe that others go through transformative change, and although we did not have the same 'disorientating dilemma', we found much in common. I found relief in the knowledge that someone had shared similar experiences to mine. I admired her greatly, we often discussed how we were going to change our lives, different directions we would take after our degree, what a profound impact this degree that had on our confidence and to address the issue of power that men had over our lives. This friendship, along with the content of my weekly classes formed a basis for my own critical reflection.

Some social theory modules opened my eyes to issues of gender, verifying that in my personal relationships, we were assuming gender roles, and I was no longer content with this. My husband expected me to be a homemaker. When I became pregnant, I was forbidden to work, it made me uncomfortable at the time, but learning social theory and applying it to my own life circumstances, enabled me to reflect on my personal relationships, and what needed to change.

In one module on counselling skills, we were required to do an essay on a text of our own choosing. I chose *Man's Search for Meaning* by Victor Frankl. That text came at a time when I was attempting to leave my husband. It had taken me years to gain the confidence that I could leave, to get over the fear of being alone and to realise that I deserved better. I was seeing two

different counsellors at the time, learning about Carl Rogers, enabled me to interact better during my counselling sessions. It was as if I knew what was expected of me, and I knew to what capacity counselling could help me. It was up to me to take charge and change my own life, the counsellor as an enabler. Through years of depression, there was a specific part of *Man's Search for Meaning* that spoke to me. We are socialised into believing that we should be happy all the time, that when we are unhappy we believe that is a fundamental flaw within us. Victor Frankl spoke of finding meaning in one's life in several ways work, love. I began to find meaning in my own life by studying. I studied during every dialysis session, the nurse would lay the table exactly how I wanted it, in anticipation for my laptop and bundle of books that always arrived with me. I found meaning by changing my role, my position. I planned what I wanted from my life: to carry on with my education, to leave my husband.



Fig. 5.2 My Undergraduate thesis. I became interested in barriers to education, as I had experienced this myself.

"Look...there's your man Johnny Adare's house!" she blurted out. It was a house plastered in Union Jack flags. I mean the garden, the walls, the windows, the porch, the separating wall between the houses. The bus erupted with laughter. I could feel the blood rise to my cheeks, my eyes watered. I had not felt this good in a long time. My body felt alive, my eyes danced, I laughed with excitement and expression again. "You're a mad yoke!" I roared back at her, my eyes still fixed on a house in a council estate we were driving through, dressed head to toe in Union Jacks. It was summer school time, the second for me, and we were in Belfast staying overnight for a module on communities after conflict. The excitement and anticipation of the trip bubbled inside me for weeks beforehand. I was going away! I could escape, a trip with all my college friends, no husband, no child, no hospital.

The summer school trip to Belfast was a fantastic experience. People still mention it to me today. We were doing a module on communities after conflict, and we visited and interviewed both loyalists and nationalist in Belfast who now worked in partnership together involved in community projects. The people we met we extremely honest in their love for violence in previous years and readily admitted that they would never have thought of being in the same room as someone from the opposing camp and would have thought nothing of killing them. The change that these people made in their lives was inspirational for me. On a personal level, this trip was the first time I had taken a trip away with friends. To me it was a taste of freedom from my illness. At that stage, I was doing dialysis at home. It enabled me to begin to take control over my illness. I went for a week's training at the hospital and then my equipment was delivered to my home every fortnight, where I would set up my machine for ten hours per night or alternatively, do it manually every four hours during the day. I felt this as a turning point is taking control of my body. I had built up confidence through my degree, and requested to do peritoneal dialysis. The trip to Belfast was evidence to me that I could take

responsibility for my own body, that I perhaps knew my body best. I now measured my own weight, calculating my fluid intake. I quickly figured out how my body coped with dosages and if I could drink more than what the doctor recommended fluid intake was. I discovered that if I ate food such as chocolate, which I was not allowed on my extremely restrictive diet, whilst on dialysis that the phosphates cleared out before I was finished. The little things I picked up during this time contributed to my viewing my body as something I should have control over, not others.



Fig. 5.1 Me beside a door from the H block at Belfast Summer School



Fig. 5.2 Murals on The Falls Road in Belfast



Fig. 5.3 Murals on The Falls Road in Belfast



Fig. 5.4 Murals on The Shankhill Road in Belfast



Fig. 5.5 Murals on The Shankhill Road in Belfast

## Chapter 6: Agency over the body

## The Doors "Riders on the Storm"

Riders on the storm
Riders on the storm
Into this house we're born
Into this world we're thrown
Like a dog without a bone
An actor out on loan
Riders on the storm

There's a killer on the road
His brain is squirmin' like a toad
Take a long holiday
Let your children play
If you give this man a ride
Sweet family will die
Killer on the road, yeah

Girl, you gotta love your man Girl, you gotta love your man Take him by the hand Make him understand The world on you depends Our life will never end Gotta love your man, yeah

Riders on the storm
Riders on the storm
Into this house we're born
Into this world we're thrown
Like a dog without a bone
An actor out on loan.
Riders on the storm

Riders on the storm Riders on the storm Riders on the storm Riders on the storm Riders on the storm Through adult education, I had the agency to reclaim my body. I no longer see my body as something which is out of my control, a docile body. I use my knowledge to take what I need from the hospital and medical staff: blood results, check-ups, medication to prevent my kidney transplant from rejecting but I exercise control over what happens to my body.

I go to hospital for my check-up clinic approximately every three months. I find it a necessary frustration. The clinic starts at 11.30 am, however the blood tests that I need for clinic take two hours to come back. As a single parent, I have no one to mind my son, so I drop him to school at 9.30 am and then take a train and a bus to reach the hospital at about 11.00am. As a result, I only have my blood work done just before clinic. I am often asked to stay for blood results when I go in to see the doctor. As part of my reclamation I take control and tell them that I will not stay, if there are any issues they can contact me. It is not something that I would have done when I was first ill. I now have knowledge of what they are looking for in the blood results, what the figures mean in relation to my kidney function and medication adjustment, so I feel empowered to make my own choices in this situation.

Another way I have reclaimed my body, is through tattoos. When I got transplanted, I wanted to take back control over the physical aspects of my body. I have many scars on my chest, my stomach, both arms and my legs. I did not choose to have these scars. They were the result of operations for several types of lines to enable dialysis. My left arm has a large scar due to an attempt to make a fistula. This would allow safer and more permanent access for dialysis to take place. However, when I woke up from a general anaesthetic I was told that when they cut open the arm, the vein was not where it was supposed to be. Despite having been sent for a scan to make the vein prior to the operation. It was a wasted operation. A second fistula was attempted on my right arm. That time they managed to find the right vein, however shortly after waking up, my arm felt numb and I could not move my fingers. They did not know what was wrong. I was sent back down the following day where

my arm was recut open, and when I woke I was informed that they could not find what had happened. I then went for numerous scans and they decided it was possibly a clot. For the third day in a row, fasting, I went down to theatre. This time when I woke, I realised I had no underwear on. I was wearing underwear and a hospital gown when I was put under. The surgeon came to see me. "Oh, it was a blood clot. So, we took a bit of a vein from your groin and put it in your arm. With a few months of physio, you should be grand. We thought the arm was gone there for a while!" I had two months of physio exercises to be able to use my right hand again. I found it so shocking that I never consented to having surgery on my groin, and to wake up feeling so exposed. That is why I chose to tattoo my right arm, the arm that isn't supposed to be there. For me, it is a way of choosing to scar myself, in a place that I want, with a design that I want.



Fig. 6.1 My first tattoo...on my right arm



Fig. 6.2 More tattoos...I will eventually cover the whole right arm

## **Chapter 7: Conclusion**

I found it a difficult experience using autoethnography as a method. As it was such a personal topic and required reflection and writing skills, I sometimes wondered if I should have chosen to do research similar to my undergraduate thesis. I did want a challenge, and I am glad that I took it on. I feel it is important to explore new methods of research. Although challenging, I thoroughly enjoyed the creative freedom that autoethnography allowed. I enjoyed using images as part of the story and the freedom to create my own structure. I have found that I now use the process of reflection from my thesis in my personal life. I have learned from writing this thesis how to use reflexivity in ways other than my academic work.

During the year, I bought and kept a journal in which I wrote reflections on topics covered in class, meeting with my thesis supervisor and anytime a thought would pop into my head. I would often by watching television late at night and something would trigger, I felt the need to write down all of these things. Despite most of the writing not being used in the thesis itself, I found reflecting in this way enabled me to get thoughts out of my head and not be a constant distraction. I had very bad trouble sleeping, my mind would be racing with thoughts, especially when I was deep in my work. It settled my mind to get them out on paper. I could look through my journal when I felt some writers block, and see whether the ideas I had at the time (and always thought were genius in the moment) were actually any good, relevant or even make sense. When faced with writing for my thesis itself, I used a technique I had learnt during the reflective practice module which involved meditation followed by free writing. When reading through my texts, I would link it to past experiences and reflect on this, to write a vignette. I also had epiphany moments from my educational and illness experience that I wanted to include in my thesis, so I would reflect on these experiences by first writing everything I could recall, and then editing at a later stage for inclusion.

My reflective experiences did not always match what I set out to do. I was often trying to recall experiences for my thesis and my free writing ended up being about my present, nothing to do with my thesis topic. I found it a useful outlet for other things happening in my life. At times,

I didn't want to write anything at all, so I would write how I felt. All the things that I was worrying about, the pressure I felt, my struggles, my hopes. This experience taught me that reflective practice is not necessarily about trying to get your work done. Through reflection on other experiences, outside of the thesis "world", it enabled me to gain perspective on things, let out feelings that had been bouncing around my head, and then make room from the work itself. During the year I began another journal, separate from my thesis work for my personal reflections. I have found that the use of reflective practice in my personal life to be very beneficial to managing my emotions.

Recalling experiences from previous years for my thesis came with a variety of emotions. Until this year, I had still felt like a little girl at times, while others around me were grown up. I think a part of that was spending most of my twenties in hospital, I somehow seemed to skip them. It felt like my life was on pause for nearly five years, while medical staff and my own mind were kept waiting for the transplant for things to go back to "normal". I wrote a summary of my life up to the point where I became ill for an assignment during the year, to show how I had wanted to change things. Looking back now, I see a lot of decisions made in naivety and innocence. A part of me feels ashamed for having been taken advantage of for a long time, through my kindness and wiliness to always put others before me. Seeing it out as a summary on paper, I realised that it had been happening for a long time, from my teenage years up through my twenties. Through our feminism module and the reading of Foucault's History of Sexuality, I realised that some of this naivety, finding it difficult to say no and being ladled with responsibility for household and children from my early teens came from the fact that I was female. I had expected myself to do all this as a female, I felt it was my duty to "take care" of others up to the point where I no longer did what was best for me or took care of myself, and I put up with things that I should not have. I feel that the use of reflective practice in this way, has changed a part of my identity, where I would now consider

myself a feminist. Although I understood the term and done modules on feminism in my degree, it was not until I began to analyse my own experiences through this lens that I found a blatant disregard and prejudice against women throughout my life. I now find myself standing up for myself a little bit more, saying no to people, and trying to put myself first. I am very conscious of being treated differently due to my gender and I have found a great interest in feminist literature.

The main difficulty I experienced with reflective practice and my thesis in general was the will to write. From this point, looking back on the year, I wonder how I actually managed to get through it. I had depression, I struggled to manage my house, to shower, to mind my son and then began to have problems at home towards the end of the year. Weeks went by where I wrote absolutely nothing, then things began to get a little easier. I was swallowed up with guilt, when listening to some music one night, I took out the notebook that was gathering dust by this stage and wrote:

"At times, I found writing this thesis extremely difficult. I fell into another black hole of depression. My world seemed to be falling around me. I lay down, struggling to get up in the morning. My motivation was at its lowest peak. Part of me wanted to just throw it in, not bother finishing. Another part of me knew that this would be a decision I would regret in the future. Amid depression, it feels like you will never climb out of that hole. Everything becomes an enormous chore. I couldn't even wash myself. My hair was matted. And then from nowhere, when I had given up hope of being able to write anymore, having listened to the same songs over and over and over, I stopped crying. Instead I sang the words out, at the top of my voice, I felt every beat, every breath, every syllable. Suddenly, I felt a weight lifted. The impossible seemed to be possible again."

I experienced a variety of emotional responses writing this year, up and down often numerous times a day. Some days I was walking on cloud nine, I felt proud and excited and inspired and could not wait to write. Other days I could not lift a pen, I felt useless, that my writing was pure bullshit, ashamed to let anyone see anything, never mind submitting something. My emotions were so all over the place that I began googling symptoms of bi-polar at three in the morning one night. It was only when I began to relax about the thought of my thesis that emotions settled. Some days I think I would overthink and overcomplicate things, instead of just clearing my mind and writing from there. I found it very difficult at times to clear to mind, to write. I checked out a book on overcoming depression from my local library. It uses CBT as a way of reprogramming your thoughts. I found it very useful for me, I tend to have spiralling thoughts quite frequently. Many of the exercise in the book were like the whole concept of reflective practice. Using mindfulness to stay in the present, keeping a journal. I allowed myself to feel my emotions, but not dwell on them. When I found myself getting distracted by dragging up unwanted thoughts, I focused my mind on the present. I am continuing to do this, and I find it very useful in controlling my emotions and enabling me to write. I found at the beginning of the year that whether happy or sad my emotions were very overwhelming and made it difficult for me to calm down and concentrate. By the end of the thesis, I was content in my work. It was important for me to represent an accurate portrayal of illness, and I feel I have achieved this.

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