# **Chapter Five**

Privilege Site/Self

# **Privilege**

# Site/Self

In this chapter auto ethnographic techniques are interrupted to include other voices and stories. I enter into a process of finding ways to express the in between and inhabiting the invisible space that occurs in the disjunctions. From this space the 'data' is recast as stories, poems and other textual devices. I use the strategy of 'writing across the divide' to explore the relationship of power, privilege and knowledge.

This chapter links the individual, and the individual stories with the global. The global here refers to power and privilege operating on a global level and its ties to how individuals exclude and include other people and themselves. I make visible how global power is enacted at the individual level and how individuals resist that.



I write an email to Ken Cox, author of *Doctor & Patient* explaining that the area that I am looking at now is the interrelationship between the training of doctors (and indeed all health professionals) and the way in which the medical site is named, its boundaries drawn, and its borders protected. He replies that: "You've made contact successfully! Well, with me and my address, but not necessarily with my mind because I'm not quite sure where you're coming from or going to". (Cox, K. 2003, pers.comm. 17 September)

I struggle to reply in a couple of paragraphs. To find the simplicity in this overwhelming collection of thoughts, of readings, I write pages and pages, it is as if the words are flowing out of my mouth my nose. Suffocated by the flow of words. Later I am choked as words cease to flow and become lodged in my throat. A knowing that comes up from my belly, my chest, my heart, which I try to force through the sieve of language.

I am drawn to quotes, through which I [re]read my statements, and worry about how to organise this for the reader.

In contrast to structuralism, which considers language as having a fixed structure, post structuralism destabilises this view. Thus, post-structuralism tends to 'stress the shifting, fragmented complexity of meaning (and relatedly of power), rather than a notion of its centralised order' (Beasley in Hughes 2002: 16)

Tight knot, into which I try to prise my finger nails under the individual strands of rough string. Trying to pull one out enough to then be able to loosen another strand. The more I try, the tighter the knot. I can't get into it, there is no access, no way to loosen it, no entry. "Sorry," I say to Viv, "we'll have to cut this knot." His earnest five year old face watches intently as I cut the wool away. This is a skill he knows he'll need if he is ever to conquer finger knitting and bow and arrow making.

Privilege, like Foucault's notion of power (1980:141-142), exists at many levels, in many places, and in many forms. Privilege can be defined as access to limited goods and privileging is the way that we include certain people and exclude others from that access. Those who co-inhabit, or reside within a site of privilege share a hegemonic view. Privilege is not continuous but rather is discontinuous, fractured although its effects radiate out, undulate and ripple across the spaces and connections creating lines that are simultaneously barriers and pathways.

In *Cartographies*, Diprose (1991:viii) uses the analogy of a net. In a net the knots of rope are sites in which many things come together, and the spaces in between the knots of rope are as essential to the concept of "net" as the rope itself. The purpose of a fishing net is to allow the water to flow through in order to sift *out* the fish. The very concept of out here is important as it alludes to the fact that the net itself is encompassed by "other". This other is the unseen but vast undifferentiated flows and essence in which the net is suspended.

I let my mind wander through images of oceans and universes. Birke (1999:63-84) traces the tendency to atomise the body in part to the images of space, and hence see organs as separate enabling them to become decontextualised. She talks instead of connection and connectivity. With this I return to my original image of the net suspended in an ocean of other, of essence.

Within this ocean, there are other nets, and crayfish pots, and nets like wind socks, all through which the water flows, and jolts some against each other. Yet each is separate and different from each other. If one net moves, it is not its movement that moves the crayfish pot, rather it is the water that flows throughout.

Perhaps it is not too fanciful to say that the intersection of power and privilege form the knots of the sifting net, and hold the tension and shape of the net. In my mind the knots are the sites, the fixed places in which various constructions and forces come together momentarily to hold and fix the discourses that shape our world.

#### Site

What is a site? I have often used the word/concept in conversation in the postgraduate group as I refer to moving in and out of say the medical site. I am comfortable in my use of it and assume my understanding is shared by the group. Then one day Fran asks: "What is a site?" The question, innocent enough, floors me. I try to capture the meaning I wish to signify. I think of the places and spaces of site.

A site is place. A material space. It generally is, was or will be inhabited and has a particular purpose. A space becomes a site when those that inhabit it are part of a group, defined as such through a set of common practices, rituals and symbols; or when occupation of it by an individual or a group produces a set of common practices, rituals and symbols. The naming of a site occurs through an act of dominance or resistance. It is the intersection of the place and the people who designate it for a particular purpose that define it, and consequently name it, as a particular site. The place is interchangeable. A site, in other words, is moveable and can encompass one or many places, can be permanent and/or transient but always involves materiality.

The entry of a group of people into a place can bring about a change of site. For example a local school hall can be changed into a medical site if it hosts a medical conference, or even simply if two nurses walk in in uniform, and co-opt the space by making a speech, and declaring themselves the experts. The materiality of their uniforms, the inscription of their roles in /on their bodies, and the philosophical underpinnings of their frames of reference as nurses, their assumption that medical knowledge is the dominant world view, all act to co-opt the space.

Similarly the inhabitants of a place may leave – but leave material traces of their practices – and this is enough to declare it as a site. As in a hospital. The equipment, the paper records, the smell and so forth all serve to change the building into a medical site. That same building, however years later, may be co-opted into a museum and become a site for say, The Academy.

The medical site is in fact a series of sites. There is the public hospital research, and teaching hospital site(s), the pharmaceutical site, the chemist shop, the GP's office, the public health site as it blares its messages over radio interviews and television ads, momentarily existing in peoples homes, the health portfolio at Federal and State level, the community health site, with outreach programs, aged care institutions, and baby health centres. The list goes on.

The lines of power and privilege that radiate out from each of these knots or collections of power/privilege form the whole net. And throughout this net, flows the water, that is the stuff of life. The fish, well, they are the very reason for the existence of the net, and swim with the water. The patients, the clients, the selves, that we all are.

What I had wanted to do in this chapter is to take one site, the medical site, and to examine it as a site. To look at how its boundaries are created, what they might be. The medical site is defined by invisible boundaries created through its naming. One can enter into that site without being a constitutive member of that site. Mohanty's

comment on the world of "The Academy", that of universities, reminds me of those halls of mirrors in side shows, reflecting back the same image, endlessly – and it seems that this can apply to any site:

Again, questions of power, difference, knowledge, and democratic struggles dominate this analysis of my own primary place of work and struggle for the last two decades: questions about potential solidarities, and about borders and their underlying relations of power preoccupy me here as well, questions about where the unseen borders in the academy lie and how we can make them visible, about who crosses these borders and who cannot, about the kinds of passports/ credentials needed to cross borders, and the building of communities of dialogue and dissent that democratise and decolonise these borders so that all constituencies can access and utilize the knowledges each need for autonomy and self-definition. (Mohanty, 2003:171)

The constitution of a site requires the naming of it and the protection of its boundaries. This work is not mutually exclusive and there are those within that site, who are empowered to name it and others who do the work of boundary guard, and the work of both may overlap, be discontinuous, or be separate.

#### Men's conference at Wee Waa

Just eight words

hanging in the room

declares the expert.

Like a cotton gag stuffed into the mouths of those who were waiting to speak

The others resume their places on the wooden benches, patiently waiting for someone else to speak for them.

Easier that way.
disempowerment and familiar silence.<sup>1</sup>

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<sup>&</sup>lt;sup>1</sup> People often ask what the eight words in this poem were. They were: "Vitalcall you can hang it around your neck ". The situation: The local community nurse had stayed to watch a scenario presented for a group of men on men's issues. The audience was all male with the exception of the conference convenor and this nurse. A healthy discussion amongst the men followed the scenario, during which someone wasn't sure of the name vitalcall, The nurse then interrupted the conversation, and the discussion ceased. It took some deliberate strategies, and time, to re-establish the conversation amongst the men.

So looking at site also required that I look at what it means for 'that group' to exist, the inhabitants that is who are privileged within that site, and being so, are empowered to name it, and be named by it. But through doing this I found that the nature of this chapter was changed. I couldn't untangle the who from the where as easily as I had thought. It seemed that the creation of site and the creation of self were intertwined. A tight knot that when cut away or even untangled becomes strands of disconnected meaning, fragments in the wind. St Pierre (1994:260) quotes Braidotti saying:

Since identity is retrospective one must be placed for a time in order to remap one's cartography. If we wish to practice identity improvisation, attention to places may be required.

The chapter is changed. I struggle with Who and Where, with Power and Privilege. I take them out to tea with me. Power and Privilege are easily relegated to the abstract, but I struggle with the materiality of site, with place, with space and with Who. In her examination of 'who is the self' that teaches in adult education, Valerie-Lee Chapman (2003:37) argues about how power relations work to produce people and actions saying:

Power is productive – for as it is applied to our bodies and souls, it produces us [as 'adult learners and teachers']; so too, are simultaneously socially moulded through techniques. Techniques conflate power with discourses and practices within political and social institutions, such as the school, the college, the department, the graduate class or seminar. Thus we are disciplined into our discipline. Practices are diverse; they can include the socialising, communicating, and eating patterns of our daily work places, instructional strategies (didactic or interactive – or whatever the norm that's been established in our institution), the establishment of daily transportation practices (walking, biking, driving to college, and who's therefore green, and who's not), personal grooming, wearing the right kind of clothes and shoes and makeup and hairstyling, all these practices are normed and acceptable in our institution – and making us acceptable too.

Similarly the training that health professionals undergo, initial, preparatory and work based, constructs the self, just as the positioning of the patient/client/other as in, but not of, the medical site acts as one of the mechanisms by which that constructed self is maintained. This interaction between the protection of the site and the maintenance of the constructed self manifests as an ongoing dance between place and subjectivity, story line and agency (Davies 1997a; 1997b; 2001; 2004; Davies & Dormer 2001; Davies & Law 2000).

#### Becoming...

She said she had been a good butcher, won lots of awards, she thought she'd make a good nurse.

Not that she liked people, mind you. But maybe she could work on that by selling Avon products.

Her garden was always tidy. And they had put themselves into hock for a Vexby vacuum cleaner. Super cleaner. Cleanliness is next to ... Incessantly mowing. Washing on the line. She hated the way her sister-in-law's place was always neat controlled and clean. His parents always favoured the sister in law. Treated those children better than hers. Poor Tammy, having to come second to Mary's kids.

No one ever listened to her. Not the in-laws. Her Nan old now and Pa dead. Mum doesn't really care. Thinks I'm no good.

They'd never believe that she had been accepted to university. First university student in the family. Well they didn't much notice. Noticed the third pregnancy though, Her mother told her not to be competitive with Mary. Still, she had three to Mary's two.

Trust Mary to decide to get into the nursing course at TAFE. But she was at Uni. And they all might think Mary was great now. But one day, when she graduated, when she was an RN, she would be the expert.

They would have to listen to her then.

There are many inhabitants within the medical site, or perhaps many dwellers, many unseen and fleeting, shadows of the other, some with passports, some with visas some with birthrights others visitors, passing through.

I don't really know the medical site, as an insider. That is I haven't undergone medical training. I don't know what it must be like to spend 7 years of my life immersed in the medical world, belonging, that is, to the group who go to work there.

And yet there is something most familiar about hospitals. Their corridors superimposed on the corridors of the high school I went to. Must be the lino.

When I was a child I used to play teachers. I liked the sound of the stick tapping on the blackboard as I pointed out the words to my docile students – dolls and teddies all lined up.

Worlds of clearly defined hierarchies. Worlds where roles and training click in together to respond ... When I grow up I want to be a ...

Bourdieu (1990:75) asks "has any one ever asked what it means, for a group to exist?" In reply I ask what does it mean for me to exist? What does it mean for someone with diabetes to be "grouped"?

Diabetes is a global affair, a global pandemic, a global business. The positioning of people with diabetes is necessary in order to promulgate the diabetes industry; an industry that is comprised of academics, doctors, pharmaceuticals, allied health workers, specialists, generalists, food manufacturers, sports industry and so forth. Diabetes is big business. Diabetes funds many research grants – and not only those directly connected with diabetes.

Globalization is a slogan, an overused and underunderstood concept, and it characterizes real shifts of power around the world. Institutions, and people in power, rule and maintain inequality in part by hiding or mystifying the workings of power. (Mohanty, 2003:171)

John Le Carre's 'fictional' book *The Constant Gardener* (2001)is a book about the extremes that pharmaceutical companies will go to protect their interests. It is a story of intrigue and murder and, as I have noted in an earlier chapter, foretells the legal battle between the pharmaceutical companies and countries, over the development and distribution of cheap generic drugs to combat AIDS in Africa. I read his dedication:

For Yvette Pierpaoli Who lived and died giving a damn

And I shudder.

# **International Diabetes Federation Congress: Poster presentations**

#### First Act

Clutching pins
For the carefully prepared
Information poster

"Voices of experience: Ethnographic Film as a Research tool in the field of diabetes."

Earnest Serious. Heartfelt.

Lost amid all this money

Dwarfed by advertising posters

The size of my house.

#### **Second Act**

Chrome and space Glittering display stands And hype Lots of hype

The poster display sits somewhere in this cavernous hall So large we need a map

Here are the big boys
The big end of business
Slick pamphlets, and glamorous people

Pharmaceutical companies flex And have cocktails with the researchers, The professors, the politically placed

I can smell the power.

Some practitioners file in, Audience to this opera, this exuberant seduction.

#### Third Act

Moleskins and akubras costume one stand of impossibly beautiful young things

Flashing their smiles
Flaunting their perfect bodies
And laughing

As they start a competition: "How fast can you inject *this* orange. With our new pen".

#### **Epilogue**

No space here for someone with diabetes.

# Change the lens

The initial step of deconstruction, as Spivak outlines in the 'Preface' to Of Grammatology, is to locate the points at which discourses undo themselves (Derrida 1976:1xxvii), to uncover the operation of hierarchy, to show how the valuations of positive and negative – itself of course a fundamental binary opposition – attach themselves to the primary and marked word respectively. Now although a seemingly infinite number of concepts lend themselves to this type of positioning, what is apparent is that many pairs are simply subsets of generic terms, or have been ascribed to them. What evolves is a functional set of pairs which consistently privilege all concepts linked with one generic term over those linked with its pair. And clearly one of the most striking examples of such an extensive division though gender is by no means the only axis of difference/difference – is that associated with the signifiers 'male' and 'female' (Shildrick 1997:106)

The notion of the underlying hierarchical binary structure of language which reflects the dualism of Western philosophy is interesting when looking at the boundaries of a site. In this analysis of language the marked term, is the suppressed term, and is the feminised term. Woman/man; moon/sun; earth/sun; mother/father and so on.

In looking at the medical site I take three words nurse doctor and patient.

Doctor

Nurse

**Patient** 

And then combine them in three sets of binaries

Doctor/Patient

Doctor/Nurse

Patient /Nurse

When the term nurse is the binary opposite to Doctor it is the marked or feminine term however in the binary patient / nurse, the term nurse shifts from the feminised position to the masculine position.

As Foucault (1980:119;140;142) points out, power is neither good or bad – however it is all too easy to fall into the trap of assuming that resistance must be the resistance to oppression rather than as evidence of the existence of power in a particular site. And I would argue that it is at the boundaries of that site that the evidence of resistance struggles are most evident. And that conversely it serves to mark the boundaries. This is the place of the border guards, and whoever approaches this nebulous edge of site, this permeable edge, may be co-opted into the role of border guard.

Something elusive about lying on a doctor's examination 'bed' waiting for female GPs to come in and practice using a new speculum. They will be using my body as the object on which to gaze, and into which to put their new instrument, while I use the situation to gaze upon them.

Silent room, medical equipment everywhere, an excuse for a pillow and to read Leder's "The Absent Body".

Juxtaposition of conversation and examination by these GPs – these women. One was relaxed about her own physicality. During her conversation with me before experimenting with the new equipment, she touched me. Placed her hand on my abdomen, firmly, sharing body space, including body to body contact as a part of a communication that was about an exchange from her to me. Felt like a sharing of power, a recognition of my power to physically contact her as well as her asking a physical permission to invade my body with an instrument and view my cervix.

There was an interesting reaction from a group of these doctors when, after they asked if the new instrument was more comfortable than a traditional speculum, I replied that for me it was, but thought that it would be good if they could each have a turn being the patient. There was some considerable awkwardness. Seemed like a good idea to me if they themselves could experience the sensation then they could form an opinion of the comfort level that was based in their own bodily experience as well as the related experience of the women who had volunteered to participate in the training.

#### Ante Natal Ward – Diabetes complications

The professor sweeps into the room, his presence creating a slip stream that catches and holds the attention of all. Students, registrars, other doctors, and the sister follow. Some moving closer to be noticed, others safely hanging back, joining in with the others. After a brief dialogue exploring the case history, he (it was always a he) turns his attention to the patient. She is huge with child. Chinese and smiling, nodding her head politely. Relieved to have his attention, to perhaps be given some knowledge,

some fixed point to help her orientate herself in this unknown land, this journey that has taken a detour, this 'complication' of pregnancy.

Unfortunately she does not speak English, and the professor does not speak Chinese. He turns to the sister: What dialect does the patient speak?

The notes are consulted.

Has an interpreter been called? How are they communicating with her? Has an appropriate Chinese diet been organised? He asks.

Titters and laughter – surely this is a joke. The professor frowns. What is the point, he asks, of giving her a foreign diet? What are the future implications? he asks the students

The sister reclaims her position. Efficiently, briskly, replying that it will be done.

Thy will be done and I will bask in your glow.

As a private patient in a public ward I had a unique view of the workings of a teaching hospital. A close link to my doctor, access to his home number, left me outside the sole control of the nursing staff, resident doctors and teaching professors. A shortage of private rooms, and I was sharing a ward with three other patients – all of whom were public patients, having little or no say in who their treating doctor was. I was in the ward for five weeks and saw many patients rotate through the beds.

The specialist doctors, all involved in the research end of their areas, talked about each case as a unique case. Context was important. Cultural issues were included in the treatment. They took time to talk kindly, to reassure, to order that the educators, the translators, the support networks were involved. They invited questions and took time to answer them well. I did not once in the time there witness any of the specialists, the professors, speak arrogantly, dismissively or in an offhand way to their patients. They came in on their days off to deal with emergencies.

What fascinated, frightened and angered me was the way that this was not enacted through the system.

Years later I heard an interview about the movement involved in 'taking research out of the research context' and seeing how it 'rolls out in the mainstream.'

In a teaching/research hospital, at the heart of the most clearly delineated medical site categories are held as Shildrick says, clear and distinct:

It is quite clear that both the 'ideal' of rationality and the allied medical model of health privilege the unity and clarity of categories, and demand detached judgement. But in so far as each of those discourses relies on suppressing the diversity and connectedness of everyday experience, it will be inappropriate in certain contexts, notably in many and perhaps most medical encounters. (Shildrick, 1997:120)

This is the research context – the teaching/research hospital, and here the patient is easily identified as the one in bed, or with equipment attached to her/his body, or walking hands clutched over belly, face drawn. The doctors, robed with stethoscopes, uniformed nurses, cleaners are easily distinguished from the patients and one from the other. They are the ones with access. Some behind the counters, some to the notes, some to the keys of the drug trolley. Everyone identified. Food arriving at specified mealtimes, in specified quantities, urine and water matched, input with output. But in the outside world, the world without, the categories blur, unable to be held so separately, the construct falters.

#### Just need help getting back on the wagon.

Sometimes I hate this body. I hate the awkwardness and heaviness as I limp up the stairs to work. Tripped yesterday on my way out from the Laundromat. Scattering clean clothes in the gutter, sitting in the gutter, ankle swelling, sobbing, not prettily.

I hate the smelly demands, as I cook greasy strong eggs and bacon, or tuna, which leaves little bits clinging to the rim of the tin. Sure, this diet has worked miraculously in the past. I felt great. Had energy. Lost weight. But most of all had normal blood glucose levels. Gave up insulin – threw away the syringes, the jelly beans, the accourtements of diabetes.

*Intervention point*. I might cook eggs and bacon, stick to the tuna lunch but every night is an exception. If I think honestly, the diet is now just a theoretical memory.

I've lost control. I feel dreadful. My glucose levels creep up till I just know I have to measure them and confirm my horror. Depression, irritation, spiralling anger, bind together like strands of DNA, double helix climbing with the glucose levels. Makes it so hard to get back on the diet. So hard to see a way out. So hard to be in this body, these rolls of flesh, this unfathomable interior. Sometimes I hate this body, it feels alien.

Hate the way this body brings me back to here, to my materiality. I stop. A momentary flash, a breath. A voice amongst many in my head. Voices of doctors, of readings, of my mother, of my father, of authors of endless books, of *my* advice to others. A story. An intervention point.

I remember the feeling in my body when the diet worked.

I remember the cravings that I get when my glucose levels are high.

I remember the hunger when I eat lots of carbohydrate.

Just need help getting back on the wagon.(cont).

I put a hand over my stomach – not my belly – my stomach. Remember how distended it felt the other night. Hard. Full. Over full. But not satisfied.

Stuffed. Hungry. Ill at ease.

Embodied knowledge.

My body now so hungry. This flipping into this flipping diet which once I have got through the first few days will bring sanity satiation and ease. Just so hard to do when I am in this state.

*Intervention point.* I want some help to get me through these days. I want warm hands and comfort. Massages. And walks on the beach. Calm, protection from any stress, even the stress of boredom. Lots of things to entertain me. Food, the right food, prepared for me. Glasses and glasses of water and hot drinks prepared to wash away the hunger.

How much I wonder would that cost? How does it compare against the cost of complications from unmanaged diabetes? Against the cost of insulin and medication?

I don't object to medication. But this diet which I can stick to for long periods of time, had better results. Just need help getting back on the wagon.

The end		
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The team approach to diabetes is the current terminology used in the health care sector, Essentially this means, that when the resources are available, once a person is diagnosed with diabetes they visit an educator, a dietician, a podiatrist, an ophthalmologist, and their GP. This team may be enlarged to include an endocrinologist and a cardiologist. If the patient/client (as they are now categorised) is on medication they will also be visiting (in most cases) a pharmacy. They may attend a specialist clinic (outpatients clinic at a public hospital) or their treatment may be coordinated by their GP. It is recommended that pathology tests are done, and it is not uncommonly at 3 monthly intervals. Diabetes is also a complicating factor in other illnesses so patients/clients/ people are advised to be in contact with 'their doctor' for advice regarding flu vaccines, or minor infections. Along then, with diagnoses of diabetes there is an expectation that the person will enter, various different medical sites, and interact with a series of health professionals on a continuous basis.

One of the Divisions of General Practice in northern NSW, in an attempt to coordinate this team approach designed a form with room for each member of the team to comment on the 'management plan' on a yearly basis. (Interview General Practicioner, 2003). The current design means that the patient/client can read these comments but there is no room for them to participate in the exercise by adding their own comments.

In the interim the patient must pass relevant information to different members of the team. The fine details of treatment and approaches and their effect is often not recorded in letters or referral and their replies. And in the case of allied professionals there may not even be a reply to the GP. If the patient moves doctors, or geographic areas, specialist etc the history of the treatment, resides with the patient.

The language of health care associated with diabetes is revealing:

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Diabetes management

Management of blood glucose levels

Blood glucose control

Blood glucose monitoring

Compliant

Non-compliant

I've had good control

Her management has been

Diet

Portions

Management plans

Team

Complications.
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"The management of diabetes requires daily monitoring with the aim of achieving good blood glucose control in order to prevent or reduce the onset and severity of complications."

The Whitehall Study (Marmot et al.1995) shows that the greatest stress is produced in workers where there is a disproportionate relationship between levels of responsibility to authority/control/status. If there is either high responsibility matched with high authority/control, or low responsibility with low authority/control/status there is a correlated decrease in stress levels, The greatest stress is correlated to high levels of responsibility with low levels of authority. In diabetes management and other team managed chronic illness (cancer) the patient/client/other has a high level of responsibility but little authority/control/status. Although it is nominally expected that the GP be the co-ordinator of a client's treatment the situation of GPs is complicated by their simultaneous occupation of the medical site and that of small business.

It's not just something that you just see for 10 mins on one day and forget about but unfortunately that often is the- I mean you constantly going in your mind- 'Oh I wonder how Mrs so and so is going?' but because -just of the number - you don't really have a chance to consider it every day ... one of the perennial problems with General Practice is you know we have a full day and no one - you book your day full - and then no one's - people complain that they can't get in to see you.

But you can't run a business when you're empty the whole time waiting for people to come in. Interview General Practitioner 2003



#### The doctor's surgery.

The line always strikes me first as I walk into this space ushered in by the doctor—"Just wait inside I won't be a minute". The line. It is light with a polished sheen to it and curves up against the wall—no sharp right angles or skirting boards. A hospital cleaner once told me that this was because when it is curved it can be cleaned better. Images of "germs" huddled in the space of the right angle shying away from the big grey strands of the ubiquitous cleaner's mop.

There are always at least two chairs to choose between, and I am always conscious of the choice. To sit nearer to the doctor's chair or leave an empty chair between? I never think to rearrange the space. And of course it is always very clear that one of the chairs is the doctors chair. So I sit.

So here I sit. In silence. In the doctor's room. Trying to accommodate, trying to feel comfortable in this space. Feeling awkward, bumpy and clumsy. I arrange my bag neatly at my feet. Rehearsing what I want to say. Clinging on to my sense of self, to my life and place and body through a rehearsed script.

I have come here today to get the result of pathology tests. These are routine tests to measure the degree of 'control' of blood glucose levels, Triglycerides, cholesterol, and to check kidney function and liver function. A week ago I went over to the pathology lab. Held out my arm while they took blood and put it into three little vials — each with a different coloured band — the blood deep deep red pumped into the glass vials with each pump of my heart. There I left this part of me to be analysed and sent to other laboratories further away for the more complex analysis. I left with a flutter of gauze wrapped around my arm and a small purple flower on the inside of my arm.



Now I sit, in the doctor's surgery, next to his desk waiting and I do not as yet realise the significance of his computer. Once the doctor arrives and sits on his chair my view of the computer screen is blocked. When he turns his back to me in order to work on the computer I am blocked out and he reads the results from the screen. Is he talking to me, the body in the chair, or the bits of my body on the computer? We discuss these results, the health of the decontextualised body that now exists in the computer. Both of us discussing another body, that belongs more to the doctor than to me. He even turns from time to time to refer to the computer when referring to the body.

In fact legally, the parts of my body that have leaked out into the vials in the pathology lab now belong to the lab and to the doctor and I have no right to reclaim either the blood or the results. Which body do we need to learn in diabetes education? I can discuss this other body in the doctor's surgery that falls neatly into measured numbers. The doctor and I have a language of numbers and instances that we can discuss. But in doing so we silence this roiling changing being that I am, that is a meeting between the inside/outside, that is always a being and a becoming, an exchange and a taking in of the world and a part of it and a constituting force of/in the world. This body that leaves bits, sheds rafts of skin that pile up if I stand still, that leaks breast milk, and urine and faeces, that objects to the sudden introduction of poisons by depositing them back, on/to the outside that savours food and laughs and cries and talks and loves and tries to meld flesh to other flesh.

# Change the lens

These are stories of difference, of struggle against the annihilation of self through the erasure of diversity, of material situatedness in a contextualised life. All stories collected through the past few years. There is a disjointedness as I write. I collect my material and try to place it in a logical order. Finding a movement between site, between bodies, contextualisation, I look for the linking logic to move from site to

site. Instead the material jumps out. Poems, stories each complete moments in themselves. Frozen moments that can be fixed and pinpointed in time and in place. The silences and blankness in between is important. As Grosz says:

In a sense the field of differences, the trajectories of becoming, do not lend themselves readily to representation, to handy models. (Grosz.1994:210)

These stories need to be read first through one lens, then another. And the fissures the gaps are represented in the white spaces. The blank spaces. These stories, either in their writing or in their storylines, are stories of resistance.

When respected, this difference implies distance, division an interval: it involves each relating to the other without being engulfed or overwhelmed. In other words it involves a remainder, an indigestible residue, which remains unconsumed in any relation between them. More commonly, though, this gulf, this irremediable distance, is what remains intolerable to the masculinist regimes bent on the disavowal of difference and the insistence on sameness and identity: these regimes make the other over into a (lesser) version of the same. While sexual difference entails its own forms of violence, the insistence on sameness, identity, equivalence, formalised exchange, exerts a different kind of violence, a violence that occurs to a group whose difference is effaced. The former is a constitutive, formative, incliminable violence, the violence of existence and becoming; the latter is a wanton, gratuitous violence, a violence that undergoes historical and cultural transformation, a violence capable of being transformed, rewritten, even reversed, through the counter-violence of resistance. (Grosz 1994:208)

#### **Intersections**

I am carrying the distress of last night's conversation in my chest, the tops of my arms, a tight knot above my belly button. My arms. I look on them now, large and pale, sagging slightly with age and weight. Arms even though it was 17 years ago I still see the head of my newborn babe in the crook of my arm, can feel his weight there and the glow of loving that floods through me. I remember that well in my body. This contrasts with the despair and distress that wells up also within my body.

Edges of hysteria dragged at our conversation, making the sentences all ragged. He needed to sleep or his brain wouldn't grow, would no one ever consider there was something physiologically wrong. Terror of brain damaged, non perfect, babies staying forever dependant. "He turned from a settled baby into a crying baby and that's not what I want" wound through the disjointed conversation. One moment I heard about a baby not wanting to suck, another about a baby too tired to eat, another about a baby too hungry to sleep, bodies unable to produce milk, breast pumps - emptiness

Her unexpected pregnancy was a gift and the baby was born into arms of awe and joy and delight. She had wanted to breastfeed.

The day following his birth, the nurse said Comp.

Then something must have happened. The email read "all fine now that dummies accepted and sleeping 4 hours".

I worried about the dummy. A nipple is a wonderful dummy I thought. Something tickled at me, but I ignored it and sent supportive emails.

Two days ago the nurses arrived, at the home, and declared the baby was losing weight.

Comp they said.

By last night the specialist lactation expert had arrived at the house and observed. Comp she said.

I thought back to another mother I had interviewed, also older, also enmeshed in a world that privileges the intellectual. One mother an attorney, the other a researcher. Both used to using analysis, to a world in which the body is silenced. Both struggling alone, then going to the medical expert – but not to women who had successfully breastfed.

#### **RPAH- Cardiac- Pre-operative Ward**

She was crying, back turned to the others in the ward. Rolls of ageing flesh visible against the white hospital gown, tags uselessly dangling. White thick cotton sheet covering her vinyl armchair. But she was perched on the side of the metal framed steel glinting bed. The tears ran down her thickened cheeks. Slowly she started to brush her hair, down the side, brushing so that the strands untangled, white grey now glinting with the silver streaks.

Earlier that morning the staff discussed her hygiene, while she was in the bathroom. Loud enough for the others in the ward, starved of stimulus to listen in to. Yes, said one nurse, I tried to look, down there, to see if she was clean, down there.

She kept brushing, her hand trembling, breathing through the sobs, rhythm taking over – stroke, stroke, start brushing other side, then back to the start. Hair glinting and a curl at the bottom of one strand. She searches through her dilapidated shower bag, pulls out lipstick and small mirror. Concentrating to keep her lips still she smoothes the colour on, looks, takes up the brush once more, defiantly flipping her hair back. I glimpse the young girl preparing to greet her lover. Composed now, she waits.

The next day there is a great flutter, a drama. Preparing for cardiac surgery, the routine consent form is read out. Her age though is different to the admission form.

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"Is that her correct age?"
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Great consternation – the operation cannot proceed without her correct age filled in. She will not tell them – holding on to that one bit of control, that one bit of privacy. I willed her not to give in.

"How have we got the age wrong?" Asks one professional to another.

"I lied" she interrupts, proudly, defiantly. Her woman's right to silence intact. The girlish glint mischievously present.

I do not know how it all ended – but in my mind I see her still, flipping back her hair.

<sup>&</sup>quot;No"

<sup>&</sup>quot;Is the admission form her correct age?"

<sup>&</sup>quot;No"

<sup>&</sup>quot;Is this the age she told them?"

<sup>&</sup>quot;Yes"

<sup>&</sup>quot;But it is wrong?"

<sup>&</sup>quot;Yes"

<sup>&</sup>quot;What is your correct age?"

<sup>&</sup>quot;I'm not going to tell you."

If ... the real material differences between people are to be acknowledged, difference must be reconstructed as diverse, plural and in practical terms irreducible. It is not enough simply to avoid false homogeneity of sameness, for simple difference (black/white, young/old, heterosexual/homosexual) is conceptually organised in equally homogenous and oppressive binary opposites. The notion of diversity, by contrast, embraces heterogeneity, sidesteps the devices of dualistic hierarchy, and allows differences and sameness to coexist and mingle. It takes on in short something of the indeterminacy of *différance* without losing touch with material circumstances. (Shildrick, 1997:127)

#### Sonia

Well, she confessed I do miss, I used to like, just every so often, at about 4 o'clock in the afternoon, as a treat, now that I'm on my own, I do miss just a little glass of whisky. Just every so often, at that time, it was a little luxury...

Sonia is 67 years old. A tiny woman, who lives in a tiny house. Often in the afternoons, the house bulges with her grandchildren, some of whom she walks home from school to wait for their mother to pick them up.

She uses insulin now to control her blood glucose levels. Starting on it was worrying. Even worse was the three hour session first with the educator, and then with the dietician- two and a half hours *that* was. Sheets and sheets of paper. You see I can't have protein, because of my kidneys, and I can't have salt because of my high blood pressure, and I am on low fat low carbohydrate, low GI for the diabetes, but I have to eat at least 6 times a day – It was hard for the dietician to work out what I could have – there's not much really – it's very boring. I was exhausted after the session – Don't tell anyone, but I came home, had a cup of tea and two chocolate biscuits – *two*! I never normally have two.

There is not much evidence of money. Her dog Monty and cats are loved and attention lavished on them. Her one luxury, just every so often, a little glass of whisky, at four o'clock, on the days when the grandchildren weren't there. And a chocolate biscuit every now and then.

"I wish I was like you", she once said to me, "able to tell the doctors what I want. Do you think they really could adjust the medication, just so I could...? I wish I could ask them but I'm not like you, I don't know enough..."

#### Ode to a Tim Tam

No one home Except for me. Go down to the darkened room The carpeted one

Prepared

Hot coffee And tim tams

TV on.

Settle back into the brown velvet couch From dad's place

Memories in the smell
Of Canberra winter days
And Elizabeth Barret Browning
Reading poetry curled up in this
couch
Cream walls books,
Leather, with fragile pages

Years later, I slowly savour the first bite, Chocolate, forbidden and mine.

I try out the trick the boys talk of Bite the biscuit, Use it Like a straw Suck up the hot Coffee.

Chocolate melts
Dissolves and fills me,
over tongue,
down throat
Like velvet inside
Sweet liquid.
Sliding

Oh sweet sweet sensation, Of body, And world And taste And being and living.

# **Entry**

#### Opening melody

Standing in front of the tall huge metal doors of the Mitchell Library Heroic figures cast in metal caught in battle I stand awaiting entrance Dwarfed.

Then warmed by the musty smell of old books And calm and beauty

The light that falls just so, the silence and the turning pages Hard wooden bench and soft thick paper.
All that knowledge in those books, up the stairs Hidden in the stacks
Years and years and years
And librarians that magically guide me.

I cross the threshold Am invited in To stay a little while

# Second melody

The white white limewashed walls Thick and flowing, lumpy Shaped over the straw bales Marshmallow walls I want to bite into them.

Perfectly placed in the landscape, Routine and harmony on the outskirts of town Pure water, children running free

"No don't eat that, its bad for you"

Controlled domesticity
Mother in control
Centre of the home,
Nature loving worshipping

Homebirthing in the hot tub

The midwife has taken away the hot tub Someone else is using it And the baby is breach.

Surely the baby can still turn

# Counter point

Hospital carpet coloured
To hide the stains and silence the footfall
Clinical wards and delivery rooms are clinical. Echo.
Instruments and bare surfaces
Hard unyielding
smelling of disinfectant.

HE asks the midwife for the case history No names Just images of torn placentas and strangled babies Impartial violence

The other doctor doesn't deliver Breech Just cuts them up. The mothers that is.

The lines are drawn The knives are out.

#### **Threshold**

Enormous doors Silently slide shut When the doctor Turned hope away

# Climax, denouement, and echoes of a melody

The messages of love shaped by cupping the mud oozing through fingers, moulding and crafting caught in the ghostly glow of flame and delirium

flicker red on the white white walls, Marshmallow walls

the home teeters

screaming woman, dying babe, blood and placenta

No help

Nature rears and roars and grinds and rips the fabric of comfortable notions

#### A woman's prayer

Let my baby be born into love Into arms that gentle And wonder

Let the doctors stand in awe and honour me

And save me as I slip and hover Blood pooling under me Warm wet

let me in let me in let me in let me in let me in

Over the years I had confided in the doctor. I had taken him my children, entrusted them to him. I had let him see my body unclothed. Invade it even with his hands. I had permitted him an intimacy of self and body that only doctors and mortuary attendants have. He had seen me in intense pain, migraine and incoherent in the mess of my house, in my bedroom, vomit bowl next to unmarked essays. In an effort to maintain a genuine dialogue with him, I offered him my trust:

Precious
shards of glass
fragments of thoughts
glimmering,
dipped in
Amethyst shafts of emotion
Private self
hesitantly and bravely shared
An offering
to one who would tread this path with me.

In entrusting my private self/my body I trusted that I would be met, with respect, as an equal and valid partner in this dialogue. That we had differences of knowledge, of opinion. were a part of the dialogue. To be negotiated, mediated.

I had been seeing that GP for the past 7 years. Throughout pregnancy I had been linked in to a specialist diabetes unit in Sydney, and seeing an obstetrician in Sydney. The obstetrician here, in the regional town, had referred my case on. Pro-active in my learning of diabetes over the years I had discussed the idea of the GP and the diabetes unit being in a share care arrangement. On the surface, the agreement seemed to have worked. When the unit referred me to an endocrinologist in Brisbane, who specialised in obesity and diabetes, I thought another share care arrangement would work. The endocrinologist was supportive. The GP agreed.

I didn't keep on with the arrangement. I felt defeated when the GP read out a sentence from the letter to him from the endocrinologist – "she eats hot chips sometimes once a week". I squirmed at the tone of voice. Torn between feelings of self righteous and guilt.

We had no car. Little money. My husband had just had a heart attack. My teenagers were, well, teenagers.

The GP didn't like prescribing the appetite suppressants the endocrinologist had prescribed. They were expensive. I should be able to do it myself. I gave up trying to see the endocrinologist. The doctor told me I'd put the weight back on. I did.

Every time the GP took my blood pressure, checked my pathology results, he would weigh me. And say: "lose weight and exercise".

I took up soccer. Ruptured a tendon. Sprained an ankle. Had physio.

Walked. Obsessed about diet. Weighed myself. Seesawed from denial to obsession.

Felt guilty. One day...

The moment still, my entire focus on the doctor. Deliberately I ask:

"What if I can't lose weight?"

"Why not?" he asks – conservative shirt, and that private school male honeyed tone, with all those soothing, authoritative harmonic notes.

Breathe.

Steady myself.

"It doesn't matter why, what if I can't lose weight. What will we do then? (pause, eyes staring into eyes) What will you do to help me look after my health then?"

He prescribed tablets to help reduce my blood pressure, cholesterol. I had a car by then.

The educator had moved. I had lost any continuity with the specialist unit. I wasn't quite fat enough to get into the metabolic unit. I decided to link in to the specialist unit at St Vincent's where the educator was, where there was an endocrinologist who specialised in obesity and diabetes. And anyway, the last eye examination had shown the very first signs of complications from diabetes.

I was scared.

The practice and pedagogy of accommodation is profoundly different if not incommensurate with the practice and pedagogy of dissent and transformation (Mohanty, 2003: 178)

# First visit – St Vincent's Hospital

Collect the armour
Thick leather petals
Book bindings and paper
Curl up from pelvis to neck

Blood pumping heart beat Into the vial

Next stop

Surgery

Collect results Referrals Plane ticket

Ready Armed for battle.

I was in the car, warm, safe. Feeling that organised feeling I always get when the car keys jangle in my hand. All the bits collected and organised to go down to the new specialist. I had been waiting to see for 10 months. 10 months in limbo really. Seeing the GP for scripts for ongoing medication – just to hold everything till I got to the specialist. Blood pressure soaring up then plummeting. Unknown and unlearnt changes. The referral from the GP and results from last round of pathology in a brown sealed envelop addressed to the new specialist.

Ripped the top of the envelope – deep in my belly a squirming sense of breaking the rules. Deliberately ripped the envelope open – like breaking the silence in domestic violence.

Glance through the referral. Breath catches in my throat. Nausea erupts. Waves of emotion, blinding, anger, shattered. Trust ripped away.

Vulture talons pinning down the carcass Beak inserted tearing out the guts. through raw flesh.

#### REFERRAL

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bet own ideas on things.

"Her management over the years has been less than ideal as she likes to consult lots of people here, in Sydney & Brisbane & has her own ideas on things."

# In mly place

Ken Cox in *Doctor and Patient* (1999:145) alludes to the resistance he faced from other professionals to his teaching-learning event where medical students were admitted to hospital as patients. This move, designed to encourage the students to consider the effects of medicine on patients, is a move to get them to experience the "other", to for a while become "other". It is intriguing and noteworthy that this is a site of resistance. As Chapman points out Foucault's direction to look for the resistance struggles to power is a useful one.

A counter history looks for the way seemingly random events show power at work, looking not for power itself – a difficult and confusing task – but for the evidence of resistance struggles to it. Foucault, being useful rather than obfuscatory for a change, suggests this strategy: look for stories of resistance. (Chapman 2003:40)

Another story of resistance in Cox's work (1999:41) can be read in the following story and commentary. Cox starts by quoting Oliver Sacks<sup>2</sup> and then comments on the effect of incorporating this perspective into clinical practice:

"I saw that one must oneself be a patient, a patient amongst patients, that one must enter both the solitude and the community of patienthood, to have any real idea of what 'being a patient' means... because as a patient one's experience forces one to think." (41)

These insights into illness are precious (as is the symbolism of the act of seeking them). Teachers should ensure that students hear them and subsequently use them in their own practice. Associate Professor Leslie Schrieber, a student in my Master of Clinical education program, has recruited "Patient Partners" as co-teachers. (41)

#### However as he relates:

One of the senior academic rheumatologists was incensed at the idea that a Patient Partner, a patient with rheumatoid arthritis trained to teach musculoskeletal examination techniques, could be as effective as a consultant rheumatologist in teaching medical students. Truth is sometimes too painful to bear! (42)

<sup>&</sup>lt;sup>2</sup> For a more extensive reading refer to Sacks O (1991), A leg to Stand On, Picador, London p 132

Here what is being proposed is that the other is firstly understood as being valid through the single move of becoming "other". Then the validity of that knowledge is upheld through the incorporation of that "other" into the medical site. This then becomes a double move where "other" becomes akin to the professional self, and this too becomes a point of resistance. I shall explain this in greater detail. First by looking at the single move into the experience of "other" and then the double move of incorporating "the other" into (in this example) the medical site.

The third story of resistance is that of the women GPs recounted earlier in this chapter.

There is something that niggles at me here. A physical knowing of a pattern, a disjunction, a relatedness. I feel it in the front of my stomach, in the muscles there, in my knees. I wonder what it means this resistance that I sensed from the GPs and to those touched on by Cox.

Firstly the resistance that Cox refers to comes from others *within* the medical site and is expressed as the objection to the setting up of learning experiences for students who are perhaps still border dwellers, whereas the resistance from the women GPs is to the suggestion of an embodied approach to their own learning.

I want for a moment to reflect back on that moment, Leder's "Absent Body" still grasped in my hand, where I, for a fleeting minute in equal communication with the woman doctor. For a fleeting moment *her* body was present. I ask was the resistance of the women GPs to the idea of being cast as other? As patient? Or was the resistance to being bodily present? In the doctor/health professional scenario whose body is absent – the patient's or the health professional's?

Liz Grosz (1994:194) says body fluids "affront a subject's aspiration towards autonomy and self-identity ... They betray a certain irreducible materiality; they assert the priority of the body over subjectivity; they demonstrate the limits of subjectivity in the body'.

Shildrick (1997:100) notes that such threatening fluidity is characteristically assigned to female bodies. The sick, then must be differentiated from the well; they become the (feminised) other as in *Doctor/Patient*; *Nurse /Patient*.

It could be argued then, that in the case of the women GPs it is the *presence* of body, with its leaky boundaries, that is the signifier of hierarchical placement in the medical site- with the most extreme expression of body being the feminised patient and the most absent body being the signifier for the professionally constructed self.

So the embodied knowing of doctors and health professionals becomes as silenced as the embodied knowing of the patients / clients / other in an attempt to maintain the liberal account of an essential, autonomous self, necessary to define the boundaries of the medical site.

This is reflected in the hierarchical nature of the access to more and more complex technologies. So as the degree of specialisation of the doctor increases so too does the use of technologies – CAT scans, angiograms, and so on. So while these doctors may also be using their own embodied knowledge as a reference point, they justify their opinions through technologies, thereby absenting, and modelling an absenting of, their own bodies.

If one has the power to define who is in and who is out/other, who is ill and who is healthy, and by extension who/when one is a medical professional or a patient, then by definition it is impossible to be "out" or "other". That is the point of reference for "in" or "out" is the self, which is taken as a fixed referent. The power resides with that fixed referent – the medical professional. This is so even in the case of students who are beginning to construct themselves as medical professional through opposition to the position of patient. So as a medical student, and as such a fixed referent within the medical sphere, even though they are admitted into hospital and undergo the experiences of the patients (and thereby the experiences of the other) it is from the position of referent. Thereby this experience also serves to define the patient as other. Someone into whose self they have to more accurately imagine themselves in order to be able to empathise with the other.

Early in Cox's work he quotes Saedegh-Zadeh (1981) saying:

It is part of being a profession to be given the official power to define and therefore create the shape of problematic segments of social behaviour; the judge determines what is legal and who is guilty the priest what is holy and who is profane, the physician what is normal and who is sick. (Saedegh-Zadeh ın Cox K 1999:38)

I am not criticising the genuine motivation underpinning the attempt described above to increase the student's perceptions of what it is to be a patient. Within a liberal framework that seeks to establish equality between individuals it is a useful exercise to enhance communication and empathy. However the problem is not necessarily that those who enter the profession of medicine lack imagination, but rather that the process of becoming trained and working within that profession, the very act of defining the self as part of the profession reinforces an atomistic view of the world. Furthermore the liberal view is based on the assumption of autonomy and individual freedom. As Shildrick<sup>3</sup> (1997) explains / posits / uncovers the ethics of professional practice in medicine also relies on the assumption of autonomy, consent and moral agency, all of which are problematic in the feminist framework.

The definition of self as separate, essential and capable of objectivity relies on the existence of other as its definition. If we apply Derrida's notion that the reliance means that the other is always a shadow within the meaning, autonomy is deconstructed and collapses. In order then to maintain this construct of self, of the professional objectivity, any move to blur the boundaries between self and other becomes a point of resistance. (Weedon 1997, Shildrick 1997, Grosz 1994)



The yearning for a fixed essentialist self, and resistance to colonisation are held in tension within this chapter. The individual voices within this chapter express their

<sup>&</sup>lt;sup>3</sup> see particularly chapters 2 & 3 in Shildrick (1997)

resistance to global power, to exclusion, to colonisation. Juxtaposed with this is people's desire and subsequent quest for a fixed essentialist self.

I proposed that the desire for a fixed essentialist self is expressed through the fixing of sites, and the guarding of the arbitrary boundaries of those sites. The protection of privilege of those at the centre of a site was seen as a part of the quest for the fixing of self for those at the margins of that site. The resulting setting of rigid definitions and boundaries, and the exclusion of 'others' from that site, in this case patients with diabetes, serves to maintain patriarchal hierarchical systems of privilege. Furthermore the discontinuous and local nature of power, manifest in the regulatory state, means that both those within and without the site exercise these mechanisms of exclusion.