

**The story in the body:
narrative rememberings and the illness experience**

Submitted by

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Abstract

Through the stories of a woman whom I have called Anna this thesis explores the experiences of 'being ill' without a medical diagnosis. Anna suffered an extreme form of unexplained paralysis following what appeared to be an asthma attack a few years ago and has never recovered. Through Anna's illness narrative she identified her 'self' through the medical, scientific discourse as 'consciousness' and an 'object' body and described herself as being 'just a head'. This study reveals some of the consequences of 'being' a medicalised Cartesian body. The dominant scientific assumptions of the body in health care have resulted in some major theoretical tensions that both contradict and complicate theorising the body. In response to what Anna experienced I have drawn upon theorists who are committed to re-thinking the body to deepen my understandings of the experience of illness. The way that knowledge and meaning are constituted through language and the body are a feature of the analysis in this study.

Through the process of telling Anna's and my stories I have attempted to account for 'difference' and 'subject experience' through an analysis of the stories that we chose to tell about ourselves. These stories reveal something of the social and material conditions that shape our lives and opens up the possibilities that there are many 'truths'. Anna and I engaged in critical conversations that revealed many gaps, inconsistencies, and contradictions as our stories unfolded. This activity allowed us to make unique sense of our lives.

The stories in this thesis expose how both Anna's and my Cartesian understandings of the world so dramatically shaped, but at the same time concealed our stories and thus our experiences. Anna's stories challenge people to explore a range of different positions on the problematic of illness and the body as it becomes clearer how narrative may shape and construct our lives and thus our reality.

Statement of authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for another degree or diploma.

No other person's work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any other degree or diploma in any other tertiary institution.

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Denise Fassett

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Chapter one: Entering 'the kingdom of the sick'

Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place ' (Susan Sontag 1990:3).

Becoming friends

As a person I have, from time to time, identified myself as a 'citizen of the kingdom of the sick'. However, like many people my experiences of being ill have been transitory and I spend most of my time as a well person. I have spent all of my working life as a nurse, and it has been in this role that I have come to know illness through the experiences of others who live out their lives 'in that other place' as described by Sontag (1990:3). Living in the 'kingdom of the sick' is the subject of this thesis. Through the story of a young woman whom I have called Anna I explore the experiences of being ill. I was with Anna when she crossed that boundary that seems to exist, between illness and wellness, when her story of living in the 'kingdom of the sick' began. It seems appropriate then that I should begin this thesis with that story, of how Anna and I met and she became ill.

A few years ago I began to dislike my body. I think I had developed what Wolf (1990:186) refers to as a 'fear of fat'. In a determined effort to change my body, I succumbed to the stereotypical images of other women's bodies in order to be described as feminine and thin. It was not hard to find another woman whose body was, as Bordo (1989:28) would suggest, 'a site of struggle' like mine, someone caught in the same web of a cultural conspiracy which constrains and

regulates women's bodies; someone who would exercise and diet with me to change her body.

That is how I met Anna; we recognised in each other the same struggle that many women share, which is a desire to look a particular way.

This 'struggle' with our bodies was an important issue for both of us because it formed the basis of our friendship. Without that we were perhaps two unlikely friends because Anna is a scientist and I am a nurse and we did not have many shared understandings about the world. This was later to change, but at the time it was our absolute commitment to diet and exercise that brought us together. The irony of all of this was that neither of us ever imagined that Anna's body and her whole life were about to change dramatically and that her experiences would impact on and shape both of our lives so intensely.

We knew very little about each other when we first decided to walk before work, early every morning. I did know Anna had asthma and she seemed well informed on her condition and her treatment. Off we went, walking every day on cold frosty mornings in the dark. We sometimes welcomed the hills (and there were many) to warm us up and to burn up that excess fat. Yes, I admit we were obsessional. But we were caught in the 'tyranny of slenderness' and all of the 'normalising' self-disciplinary practices that go with that (Bordo 1990).

I think we became friends during this time because we had 'critical' conversations about our desire to change our bodies and the way each of us constructed being a woman. I was reading 'The Beauty Myth' savouring Naomi Wolf's every word of 'fear of fat' and we would intellectualise, theorise and analyse what we were doing. But still we relentlessly pursued that very myth. Nothing deterred us — even Anna's asthma. As she would say, she lived with asthma rather than she was an 'asthmatic'.

As we plunged into the depths of a very cold winter Anna began to use her inhaler more often and we discussed the possibility of her having an asthma attack while we were walking, but she insisted that she was well prepared. However, one morning Anna was hospitalised with acute asthma after one of our walks. I thought the walks would stop after that but Anna talked of getting out of hospital to get going again. It certainly gave us both a scare but Anna was not about to give up exercise. Her medications were reviewed and altered and we decided to walk after work when the air was much warmer. The time it took for Anna to recover gave the weather a chance to really warm up and we enjoyed many more walks where we endlessly chatted away unravelling the stories of our lives to each other.

One particularly warm afternoon we ventured out intending to take our time on a much longer walk. After about half an hour Anna seemed troubled, not short of breath, just uneasy. We stopped and Anna said she was experiencing difficulty in breathing and swallowing so we made the decision to get her to the hospital. For Anna, this was the last time she really ever walked, and her life as she knew it changed in that instant. We arrived at the hospital and within minutes she was lying on a trolley in accident and emergency having an intravenous line inserted. Anna seemed to get worse in the hospital and the staff quickly responded. Nurses were drawing up drugs, machines were plugged in and scanned for information. Doctors were examining her. It all seemed so unreal to me, one minute we had been walking and laughing, and now Anna was fighting for her every breath.

There was a sudden decision that Anna should be transferred to the intensive care unit (ICU) and one of the nurses handed me her shoes. I followed the trolley along the corridor and only had time to thrust the shoes under the trolley, and to give Anna what I hoped was an encouraging look, as she disappeared through some double doors. I was worried because I had not

expected her to go to ICU but I was quite confident that Anna would be stabilised very quickly and home in next to no time. She is a strong woman, I thought, she will bounce back! But she never did — or has not yet, I should say.

Anna travelled through an experience of acute asthma to become a person disabled with a chronic, unexplained illness that was eventually attributed by the medical profession to a 'psychosomatic state'. Briefly, she went from being a fit active woman to someone unable to care for herself, unable to walk or fully use her arms, confined to a bed and a wheelchair, without a 'proper' diagnosis.

Anna came to embody chronic illness as a thin, emaciated woman whose flesh seemed to be draped over her bones because there was little viable muscle. As her hair began to fall out she had asked the nurses to shave her head. With pale almost translucent skin she looked frail and cold. When she sat in her wheelchair her feet were twisted from 'foot drop' and her legs were clearly the legs of someone who did not walk. Unable to swallow, she relied upon a pump to artificially feed her. Hanging from the bed was a bag of thick blood stained urine. To be able to sit up Anna needed a neck brace and straps around her body to secure her in a wheel chair. Her hands were splinted so that she could use them and to move from the bed to the chair or shower Anna used a hoist.

In bed, Anna would lie upon large sheep skins with a variety of pillows supporting parts of her body. She seemed to disappear into the bedding. Despite all of this she was always ready to talk, her quick wit ever present. And, she was always the scientist ever vigilant in her belief that the 'real' diagnosis had been overlooked.

Since that eventful walk, Anna has spent most of her time in and out of health care institutions slowly losing more and more of her previous ways of having and being a body. Her experiences of 'being a patient' continue as she lies in a rehabilitation centre somewhere in Australia. Anna's world has been totally

transformed. Although her condition changes she is now living with all the potential infections and complications of having and being a body which no longer moves.

Why this story?

At the time I met Anna, I was a postgraduate student deeply immersed in a critique of science. Everything that I read moved me further and further away from the shackles of positivism that had constrained the health science degree I had undertaken previously. When I timidly dangled my toes into the critical social sciences, post structuralism and post modernism, it is true to say that I started to think about knowledge and meaning being constituted through language and the 'body' and I was drawn to more 'unconventional' ways of exploring nursing. Since then, when I read or write about nursing, Anna comes to mind. Her incredible chronicle of experience that comes to expression when I tell her story makes me aware that her life and her experiences are not only reflected in these stories but that they have actually been created through them (Walker 1995:157).

Through Anna's experiences of being ill, I found that I was confronted with 'the body' and how the body is theoretically approached in nursing. My interest in the body led me to Jocalyn Lawler's book 'Behind the Screens: Nursing, Somology, and the Problem of the Body' (1991). Her work has had a profound impact on the way I now think about nursing and on how I was to interrogate nursing as a postgraduate student. I can best describe this experience as 'freeing'. It provided me with the intellectual stimulus to explore aspects of nursing I had previously avoided or chosen to ignore.

Lawler (1991:vi) proposes that 'the body [is] the pivotal construct which [has] the capacity to explain lots of things about nursing as an occupation'. In

explicating a theory of the body she suggests that 'nursing practice is fundamentally about people's experiences of embodied existence, particularly at those times when the body fails to function normally' (Lawler 1991:vi). This spoke to me through the connections I had made between Anna's experiences of her body and my experiences of nursing. I wanted to know more about her experiences of her embodied existence as an ill woman over the last few years. It seemed a natural progression to formalise this inquiry in the form of a thesis.

I spoke with Anna about my interest in exploring her story for my thesis. Initially she misunderstood my interest because as a researcher and scientist she thought I wanted to examine possible 'causes' to explain her illness. I discussed how I was interested in her story and narrative as a method to engage us both in critical conversations around her illness experiences. I knew that Anna was familiar with the work of Oliver Sacks and we had conversations around some of his ideas that helped motivate us both to explore the notion of narrative and the experiences of illness. Anna clearly wanted to tell her story and she said that no one had ever really asked her to do that before, not even me.

Anna knew that I had become interested in her experiences of embodiment, (more specifically, as it seemed to me), that Anna thought of herself as a mind and a body. I had actually heard her describe herself as 'just a head'. I wondered how nurses went about caring for someone who saw themselves as 'just a head' and what it might be like to abandon your own body. It was the next few sentences that Anna spoke that profoundly influenced and shaped this study.

Denise: *So how would you describe yourself now?*

Anna: *I guess I am really 'just a head'.*

Denise: *How do nurses go about caring for someone who sees themselves 'just as a head'?*

Anna: *I guess I care for my head and every one cares for everything else.*

Denise: *So are you saying that you care for your mind and others care for your body?*

Anna: *Yes, I'm not saying that nurses picked me out to treat me either **not** as a person or as a person but some nurses seem to treat all of their patients as people and a lot of nurses treat **none** of their patients as people. Before I was ill I was very aware of my body, but being ill has forced me to split my body and mind and I've given up my body to be cared for because I have no control over it but I feel like I have absolute control over my mind.*

The Cartesian body

Clearly, Anna is talking about her body as an object. A body aware of itself because it does not function and aware of itself because of having things done to the body. According to Leder (1984:33) the process of objectifying the body is often begun by the illness itself. Referring to Strauss, Leder (1984:33) argues that 'when suffering the body can come to appear as Other' to the self. It is the Cartesian body, the mechanical body, the body which houses biological processes, that becomes ill. Once a person presents his or her body for physical examination the task at hand is to search for the disease and this forces a person like Anna to experience her body as a scientific object. In wellness, bodies are usually taken for granted and as a result embodiment is taken for granted.

Anna makes sense of her body as if she was a scientific object to be understood, and this was clearly evident in the way Anna spoke of the duality of her mind and body. The language through which Anna made sense of her body constitutes the nature of her illness and the illness experience itself. Anna, as we heard, talked about 'having' to become dualistic about herself as a response to being ill. In her words '*being ill has forced me to split my mind from my body*'.

The medical profession had also successfully separated Anna into a mind and a body. When they had exhausted all of the possible scientific explanations searching for a diagnosis they said that her condition was 'psycho-somatic' in origin. 'Psycho-somatic' is a term used in medicine to imply there is a mind and a body and that a problem in or with the mind can 'cause' a problem in the body. There is nothing unusual about this, considering we know that the epistemological tradition of Cartesian dualism has dominated the way the body has been understood in medicine and nursing (Scheper Hughes & Lock 1987). But what do we know about what this might mean to a person living through an illness? How legitimate does a person feel if their illness is attributed to a psychosomatic state? Listening to Anna describe herself, in terms that forced her mind and body apart, was confronting for me as a nurse because it forced me to think about how significant language was in shaping peoples experiences of their bodies. Moreover, it was the ease in which Anna separated mind from matter, that so unsettled me.

Illness is a time when people experience the profound consequences of 'being' a 'medicalised Cartesian' body. Indeed it is extremely difficult to move beyond notions of the 'medicalised' body because of the way illness is constructed through Cartesian understandings. Frank (1990:136) argues that 'our capacity to experience the body directly, or theorise it indirectly, is inextricably medicalised' and that 'science' and the way it influences our understandings of the body, both contradict and complicate theorising the body (Frank 1990:132).

Parker (1991a:304) points out however, that the consequences of the widespread acceptance of these science -based assumptions has 'resulted in an understanding of the body as an object of medical scrutiny and of technical intervention and of health as the absence of disease'. Nursing scholars are now beginning to critique such dominant scientific assumptions of the body and to recognise how scientific attitudes are problematic for nursing and health care

because they are not congruent with notions of the human world of nursing and health care (Parker 1991a, Taylor 1994).

I believe that the difficulty nurses have in terms of re-thinking the body is that they continue to reinforce a dualistic and mechanistic approach in their practices. Hand-overs, nursing notes, nursing rituals and routines, ward rounds, and more recently the Australian Nursing Council Incorporated (ANCI) competencies are all a testimony to the objectification of the body in nursing (see Parker & Gardner 1991/1992, 1992; Parker, Gardner & Wiltshire 1992; Street 1992a & b; Walker 1993, 1994a, 1994b, 1995). This creates a paradox if you believe as I do that the body is central to nursing as a discipline. It is surely then an imperative for nursing to re-think the 'body' or as Lawler (1991:227) suggests to 'build a theory of the body' if nursing is ever to be part of the challenge to move beyond mechanistic reductionist views of health.

In response to what Anna was experiencing I wanted to find a way to re-think the body to deepen my understandings of the lived experiences of illness and suffering to enable me to translate these understandings in the way I teach the problem of the body to nurses. The experience of illness is the 'stuff' of nursing. Nurses listen to and share the intimate life stories of the people with whom they interact with every day. As Walker (1993:173) reminds us, nurses 'must listen to and share the stories of outrage and disbelief, the tales of abjection and torture, the narratives of disquietude and despair, and the histories of struggles with pain and impending death'. It is through these stories that I believe that nurses discover what for me has always been 'intuitively clear and now is becoming formally clear, that we are in no sense machines or impersonal automata' (Sacks 1984:188).

Through my experiences as a postgraduate student and this friendship I began to search through narrative techniques for a legitimate space to bring to the surface what I believe has always been known but hidden in the oral culture of

nursing. I was challenged with finding a way to give Anna voice to her experiences. Following Judy Lumby (1992) I came to the conclusion that the method to drive this thesis should be narrative and story telling. Lumby (1992) spent almost two and a half years sharing stories with one woman who had a life-threatening illness and who, like Anna and I, were friends and co-researchers. In 1993 Lumby spent some time with our Master of Nursing class and I was inspired when she spoke to her research—mainly because it was accessible to me as a nurse, as a woman, and as an academic. As a woman it appeared to me that story telling was a familiar way through which I communicated with other women every day. As a nurse I was familiar with story telling because of the oral culture that exists in nursing. As an academic it was an exciting possibility as a mode of research moving away from the boundaries of conventional research (Lumby 1992).

The story of one

Lumby's work was indeed as she suggests a 'new space' in which to explore women's experiences and thoughts (Lumby 1992:12). When I began this study people would ask 'how many participants were in the study?' Lumby gave me the courage, then the pleasure, to be able to say, 'one'. I thought that story telling as an approach had some exciting possibilities for the production of knowledge because it cuts across the traditional nature of objective research. Story telling could be 'interactive, contextualised and humanely compelling through the recognition that, 'knowledge is socially constituted, historically embedded, and valuationally based' (Lather 1991:52).

So as I begin to reveal Anna's story through the pages of this thesis I feel I should make explicit some of the complexity of such an endeavour because there is not just one story to tell. There are many stories, and as they run along side each other, twist and turn, intersect and join, they are sometimes me,

sometimes Anna, and sometimes 'other' to both of us. Frank (1991:50) writes 'How medicine treats the body is an essential part of the story of illness, but it is never more than half of the story. The other half is the body itself'. In this thesis I have attempted to bring together these stories to make the body central through Anna's experiences.

When I talk of Anna's experiences I am not implying that her experiences can be generalised but rather that her 'unique' experiences may speak to others through a certain and necessary celebration of 'difference'. Anna's story has challenged me to 'write the body'. I hope that the people who read this thesis will be provoked into telling their stories of embodiment, and that in time there will be stories which offer a range of different positions on the problematic of illness and the body as it becomes clearer how narrative may shape and construct our lives and thus our reality.

Chapter two: Writing the body

In the next two chapters I spend time problematising the body and making connections with and between narrative and notions of 'body' thus revealing something new about our understandings of the body generally. Benoist and Cathebras (1993:861) argue that the concepts and notions of the body in the literature are so diverse that an analysis of the literature is almost impossible. This was reassuring to read because as I travel through the theorists writing the body, there are many 'bodies' to consider from the pre-scientific body, to the post/modern body. And, as more theorists attempt to re-situate the body, they have created an endless maze of typologies. McLaren (1988:57) argues that the term 'the body' is problematic by his following remarks. 'The term the 'body' is a promiscuous term that ranges from being understood as a warehouse of archaic instinctual drives, to a cauldron of seething libidinal impulses, to a phallogentric economy waging war on women, to a lump of perishable matter, to a fiction of discourse' (McLaren 1988:57).

The body

Much of the theoretical work around the body, that I have read, follows McLaren's (1988) view that the body can be constructed as 'a fiction of discourse' (see Bordo 1989, 1990; Foucault 1975, 1980, 1985, 1990; Frank 1991; McLaren 1988; Scheper-Hughes & Lock 1987; Wilcox et al 1990; and Butler 1993) or as a 'phallogentric economy waging war on women' (see Grosz 1992, 1994; Cixous 1981). Bryan Turner, a sociologist (1992:16), who has produced some of the major studies on the body talks about 'having a body', 'being a body', and 'doing a body'. Using a comparative and historical approach, the body is conceived by Turner (1984) as a potentiality which is elaborated by culture and developed in social relations. Turner (1992:18) has been interested

in the concept of the body as a target of many diverse social practices which aim at regulating the body and in particular, the regulation of female sexuality. Frank (1990:134) argues that to date Turner provides the most coherent sociological theory of the body but adds that Turner has become 'less sure of what a body is' as his work has progressed. Foucault (1975, 1985, 1991) analysed medicine, psychiatry and criminal justice to examine how 'bodies' are produced by discourses which were to produce power/knowledge over bodies. This analysis has been particularly relevant to nursing because it highlights the tension that exists when one 'acknowledges that we are both victims and agents within systems of domination' (Sawicki 1991:10).

As contemporary scholars are engaging with the term 'the body', it would seem there are many debates emerging as to which discipline best accommodates the body. As Frank (1990:131) comments, 'bodies are in, in academia as well as in popular culture'. There is an academic scramble to theorise the body and to thus lay claim to particular truths that will, in time, construct different experiences for people and their bodies. It is an exciting time in that respect. But also it is a time when I cannot help but be concerned that in the rush to theoretically accommodate bodies, the relationship between 'real bodies' and the body as constructed in discourses may be lost (McLaren 1988). Moreover, even though there is an endless array of categories that classify the body, I do not believe that we, as yet, have adequately theorised what it means to be 'a lump of perishable matter' (McLaren 1988:57) or that which I call the Cartesian body, to begin to understand the concept of 'real bodies' explicated by Silverman (1983, in McLaren 1988).

Embodiment in nursing through the rhetoric of illness

In nursing scholarship Lawler (1991:3) argues that the body's presence has been 'implicit, subsumed and privatised' which is interesting because in nursing practice the body is very explicit. All disciplines it would seem, are faced with the 'problem of the body'. But Lawler (1991:3) argues that 'nursing can, and does necessarily and inevitably accommodate the body and corporeal existence' in ways that most other disciplines do not. Lawler (1991) argues that nursing is in a prime position to theorise the body because of the knowledges nurses can generate through their sustained intimate contact with people and their bodies.

However, nurses are predominantly women and in theorising the 'body', they are challenged with writing a theory that does not obscure gender and 'provides women with non patriarchal terms for representing themselves' (Grosz 1994:188). Grosz (1994:3) remarks that 'feminism has uncritically adopted many philosophical assumptions regarding the role of the body which are complicit in the misogyny which characterises Western thought'.

Nurses' constructions of the body have been reviewed more recently by Colin Holmes (1994). Holmes (1994:116) argues that 'current scholarship on the body in nursing signals recognition that the body, and the discourses which it invokes, have been recognised as a central concern to nursing'. He continues by saying that he considers the 'field relatively untouched' (Holmes 1994:116). Holmes discusses Lawler's work and makes the comment that 'the most valuable aspect of Lawler's doctoral study has been to expose the various regimes of the body as they affect both the clinical practices and the discourses of nursing' (Holmes 1994:116). Many nurse clinicians speak of the alienation and distance they feel when they are exposed to nursing scholarship. By making the body explicit Lawler's (1991) work does seem to engage these

nurses with a certain interest as they recognise the centrality of the body to their nursing practice.

This was highlighted for me during a conversation with some clinical nurses. Many of these registered nurses had read Lawler's (1991) work as part of their university studies. Knowing these students who were registered nurses were thinking about the body, I was able to go into class and talk of my interest in the body through Anna's and my experiences. I remember their interest, the connections they all made between Lawler's work and their current nursing practice, and their enthusiasm to narrate their stories about embodiment in illness. As I talked about how Anna felt as a 'patient' there was a silence — but it was a knowing silence. The nurses were as uncomfortable as I was with the way Anna described herself through her story as 'just a head'.

Later as I reflected I realised that Anna's story exposed and confronted nurses with the full impact of how Cartesian reductive thinking shapes peoples' illness experiences. The nurses had difficulty with Anna's story because their rhetoric of holism collided with the mechanistic constructions of the body that dominated Anna's experience of illness. In fact from this discussion we critiqued Lawler's (1991) proposal that nurses integrate the object body and the lived body in nursing practice. Most nurses talked about 'being holistic' as if they had philosophically moved beyond mechanistic constructions of the body within nursing. It seems to me that nurses have prematurely credited themselves with a paradigm shift that has not yet begun in the Western world. There have been three hundred years of Cartesian constructions of what it might mean to have and be a body. Nursing seems altogether too keen to dismiss this under the rhetorical smoke screen of 'holism'.

Descartes's search for a world that can be treated scientifically, an external world which can be observed, led him to believe that we *have* bodies, but we are *not* bodies (Magee 1987:86, emphasis added). According to Magee (1987:86),

Descartes believed that the body is not part of the 'quintessential me' because he could conceive 'being' without a body. He could not, however, conceive 'being' without conscious awareness. This led him to postulate 'I must irreducibly be thought' (Magee 1987:86).

Williams, (in Magee 1987:92) argues 'that few people now assent to the absolute dualism between the mind and the body and that some distinction between subject and object, knower and known is essential and impossible to do without'. However as this study will reveal, while people may not assent to the dualism of the body in health care, they have little choice other than to ultimately objectify the body. Williams (in Magee 1987:95), believes that to work with this tension Descartes's original questions — what do I know? what can I doubt? what am I? need to be examined and re-examined until we arrive at an understanding of *what one might be*'. I think this is important because through the stories of Anna and others we are now beginning to have a clearer understanding of what 'we are not'.

Although Lawler (1991:55) argues that Descartes understood the body in more sophisticated terms than he is usually given credit for, he still none the less argued for the existence of both a palpable body and an intangible mind (Scheper-Hughes & Lock 1987:9). According to Scheper-Hughes & Lock (1987:9), Descartes described the soul as being located in the pineal gland where it governed the body. They argue that this separation then preserved 'the soul as the domain of theology' and the body the 'domain of biology' which allowed for a 'mechanistic conception of the body and it's functions, and a failure to conceptualise a 'mindful' causation of somatic states' (Scheper-Hughes & Lock 1987:9).

Although men, women and their bodies are fragmented, or reduced to body parts, when the body is theorised through biology and science this fragmentation has more significance to women. Martin (1987:21) argues that

women are not only fragmented into body parts through science but they are 'profoundly alienated from science itself'. Laqueur (1990:17) argues that 'science does not simply investigate, but itself constitutes, man from woman'. Martin's (1987) study tells us that women continue to fragment themselves because of the medical language they use to describe their experiences, but as this study will show there is, as yet, no other alternative. It seems that women are often reduced to the position of 'other' to male because of the pervasiveness of male representations of the body in Western society.

Illness stories of educated men of science

It is ironic that I will now examine the illness experiences of three people who are men and scientists, Oliver Sacks, Tony Moore and Arthur Frank. These men have been able to write successfully and publish their personal stories because it has been legitimate for them to do so as scientists and as males. Other illness narratives that I read were those of Kleinman (1988), a psychiatrist and an anthropologist who discusses 'patients' experiences of illness'. While his work is insightful, it differs from the work of Moore, Sacks and Frank in that it is not his own personal story of illness. Frank (1990:140-141) suggests that Kleinman's work offers 'an experience of what it is to be chronically ill in healthist, medicalised America'. Kleinman (1988) most certainly explicates the incompatibility of illness experiences and medical science, but his critique is more helpful for doctors rather than for 'patients' themselves.

Sacks (1984) attributes the incompatibility of 'the illness experience' with medical science to the Cartesian legacy of 'body' and 'soul'. His work, which incorporates what he refers to as neuropsychological and existential phenomena, clearly identifies some of the problems that confronted Anna. Sacks (1984:188) argues that the inability of neurology, and thus medicine, to describe his personal illness experience is that 'it excludes mental states,

'consciousness', because they are 'subjective' and 'private', and cannot be verified (or validated) in the conventional way'. Sacks (1984:189) believes that ultimately there will be a momentous revolution in medicine, as the 'classical' dualistic, mechanical model that underpins medicine is abandoned for more personal, self referential models. He may be right. However, long before such revolutions are likely to occur, people the world over continue to experience illness, silently, their stories never told. And, before any such revolutions, I think we should take the time to understand more fully the incompatibility of the present medical model and the experience of illness itself for both men and women.

People who have experienced an illness, especially if it is a chronic illness, have difficulty in describing the transition from 'being' well, in a state of healthy existence, to one of 'being' ill. The transition represents something of a crisis in their lives that is ontological in so much as it is about 'being' different. Arthur Frank (1991:12) describes illness as 'the experience of living through the disease' and goes on to say that 'if disease talk measures the body, illness talk tells of the fear and frustration of being inside a body that is breaking down'. What this is telling us, is that usually there is a medical diagnosis which labels the part or parts of the body as a disease and that 'patients' learn to objectify their body by using the language of medical science. Frank (1991) refers to medical language as 'disease talk', language that incorporates the medical treatment. 'Disease talk' is argued by Frank (1991:13) to be designed to make everyone believe that only the disease can be discussed. Exploring this notion further he argues that if you can only discuss the disease there is a gap between what a person feels and that which they feel allowed to say. As Frank's illness progressed, he began to feel as if he was in a wide, deep, gap which swallowed his voice, and with it, his story of being ill (Frank, 1991:13).

Tony Moore (1991) has also written his story of illness following a serious motor vehicle accident and he gives a very descriptive account of living through the language of disease. Moore, a medical practitioner, discusses giving up his body to be 'fixed' and how this caused him to experience being disembodied. He tells us 'when I looked down at my emotional self I saw something foreign. I was distressed by the feeling that the person I had been no longer existed' (Moore 1991:28). Moore had been so concerned with being a mass of broken bones that he accepted being treated as an 'object' because he wanted the staff to focus on his 'body' (Moore 1991:28).

Seven years later, however, Moore (1991:142) wrote 'my story attempts to reveal how a person, and not just a body, recovers following major injury. Where is the therapeutic equivalent of intensive care units for the emotional wounds that leech themselves onto a lacerated body?' Moore argues that while the technology coupled with physiological efficiency ensured his physical recovery, his spiritual and emotional contusions were often unrevealed, under diagnosed and remained untreated (Moore 1991:142-143). What Moore had obviously never considered until much later, if ever, was that 'the human body is a text, a sign, not just a piece of fleshy matter' (Dallery 1991:54).

What Moore's story does not reveal is a critique of the part he played in his own silencing that is reflected in the language through which he chooses to explore his experience. Based on his own understandings which infer a Cartesian logic he describes humans as physical, emotional and spiritual (Moore 1991). Sacks (1984), Frank (1991), and Moore (1991) theorise their own illness experiences but the significant difference between their experiences and Anna's is that they are all powerful, educated men of science who could bring their stories to expression. Being scientists and having a diagnosis meant they were 'legitimately' ill. Anna was told that the disabled body she became, resulted through a psycho-somatic state. What this actually suggests is that

'something' does not exist. Psycho-somatic, as an expression, preserves a mind body duality through implying mental as a control over a physical reality.

Being a body

According to Sontag (1990:131) the notion of psycho-somatic once belonged to psychology but 'with psychology's new credibility as science, it has returned to reinfluence medicine', extremely successfully. By locating the cause of Anna's illness in her mind, Anna was thought to be responsible in some way for her illness. Anna has always resisted this position but as my data analysis reveals, the alternative Anna longed for was to be healthy, as in the absence of disease, or if she could not escape being ill, to be 'really' ill with disease. To be anything else was to be uncertain and uncertainty, as I later discuss, is uncomfortable.

In summary then I have suggested that Cartesian understandings of the world are evident through the discourses of science and medicine and are discursively constructive of ways of being in the world (subjectivity). Within the context of health care there are a 'network of practices, institutions, and technologies that sustain positions of dominance, and subordination' that help us to construct the way we are in our bodies (Bordo 1989:15). It would seem Anna became enmeshed, at times, in collusion with forces that sustained her way of being that ultimately became oppressive (Bordo 1989:15).

To examine Cartesian understandings of the world of illness is also to confront the mechanisms by which ways of being an individual are often determined by these practices and technologies to which I refer, through the relationship between the social and the individual. I have chosen to explore this notion by way of an analysis of Anna's story. While Eagleton (in McLaren 1988:59) makes the point that the body can never be fully represented in discourse, he argues that discourses function to broaden and intensify the body and that 'discursive

bodies lean upon and mould real bodies'. McLaren (1988:60) argues that discourses are enfolded into the very structure of our desire, a process he refers to as the 'politics of enfleshment'. While this is a complex issue, the point he is making is that we do not simply exist within bodies, we actually are bodies (McLaren 1988:62). It is being a body which is largely ignored in medicine and nursing.

Chapter three: Reading the body through the narratives of illness.

Research approaches inherently reflect our beliefs about the world we live in and want to live in (Lather 1991:51).

Getting started

I was seventeen when I began nursing and I was totally unprepared for the experiences I had on the oncology unit where I was sent after preliminary training school. It was the first 'patient' I encountered, who influenced my decision to continue with nursing. This 'patient' was a young woman with cancer. I spent the last week of her life nursing her. It was conversations I had with this woman that fixed my interest on the experience of being ill. She told me her story, her pain, her suffering, in such a way that it became firmly etched upon my memory, and for reasons I do not remember, I wrote it down and often reflected on her story.

Years later, when I began to teach student nurses about nursing, it was this story and many more that guided my teaching. In the crowded lecture theatre the students become quiet as I unravelled my stories and those of the people I have nursed. These powerful narratives reveal something of the social and material conditions that shape people's lives, and something of what it might mean to be ill. However, all of the stories I tell are of people who have a diagnosis. Anna's story unsettled and confronted me because it forced me to think about the ways I had always constructed illness.

I have also had personal experiences of illness within my family which have influenced my methodological imperative to choose narrative. It became clear to me through keeping a journal that my understandings of the body were

mostly scientific and thus very limited. I became convinced that I needed to explore how people might experience illness and how these experiences have been shaped by science.

I wanted to situate myself in a space to take up the challenge of re-thinking illness, a space where I could tell both Anna's story and my story. I especially liked what bell hooks had to say about such spaces. hooks (1990:153) believes she has located herself in the margins of everyday life as a site of resistance, and that as people enter these spaces through suffering and pain, they are drawn to enter such spaces as a critical response to domination. I use the term 'space' because as hooks (1990:152) so eloquently suggests 'spaces can be real and imagined. Spaces can tell stories and unfold histories. Spaces can be interrupted, appropriated, and transformed through artistic and literary practice'. The space where stories can be told and histories unfolded is where I have positioned myself to explore Anna's experience of illness and I came to this space through my theorising of our experiences. hooks describes how one can come to such a space:

Our living depends on our ability to conceptualise alternatives, often impoverished. Theorising about this experience aesthetically, critically is an agenda for radical cultural practice. For me this space of radical openness is a margin — a profound edge. Locating oneself there is always difficult yet necessary. It is not a 'safe' place. One is always at risk. One needs a community of resistance (hooks 1990:149).

Speaking out : finding a critical voice through story telling

Yearning is the best word that describes a common psychological state (sic) shared by most of us, cutting across boundaries of race,

class, gender, and sexual practice. Specifically, in relation to the post-modernist deconstruction of "master" narratives, the yearning that wells in the hearts and minds of those whom such narratives have silenced is the longing for critical voice (hooks: 1990:27).

Interestingly the yearning to which hooks (1990) refers not only speaks to my desire to find a critical voice but also highlights the difficulty we all have, even hooks, in moving beyond mind/body dualism. She refers to yearning as 'a common psychological state'. In this thesis I have found it extremely difficult to escape the binary logic which underpins our world and account for 'difference' and 'subjective experience' without avoiding the tension of interrupting academic norms' (Lather 1991:8). I am referring here to Kramarae and Spender's (1992:1) notion, that the traditional acceptance of what constitutes knowledge, is that knowledge is 'objective, impartial, and neutrally discovered' and that knowledge makers have primarily been men.

Through the process of telling Anna's and my story, I position myself precariously by moving beyond the boundaries of what constitutes 'legitimate knowledge'. I believe that it is possible to account for 'difference' and 'subjective experience' through an analysis of the stories that we choose to tell about ourselves. These stories reveal something of the social and material conditions that shape our lives and they can open up the possibilities that there are many 'truths'. According to Weedon (1987:173) 'we have to assume subjectivity in order to make sense of society and ourselves'. Kramarae & Spender (1992:16) argue that the use of stories or biographies is a fertile ground for women to explore as researchers 'because it generates so many issues about the nature of knowledge and authority, about veracity and validity'. I have used a story telling process following Kramarae and Spender, and Weedon as a way for Anna and me to assume 'subjectivity'.

White (1992a) argues that we are shaped and constituted through the process of interpreting experience within the context of stories. Every time a story is told a person is in the process of re-authoring their life and according to White (1992a:80) 'there does not seem to be any other mechanism for the structuring of experience that so captures the sense of lived time, or that can adequately represent the sense of lived time'. It is through the story telling process that meaning is given to experience as people determine which aspects of experience they will select for expression in a story (White 1992b:123). White argues that stories are important since they provide structures for living rather than functioning as reflections of life which have no real effects (White 1992b:123).

Although stories provide structures we can live by, I am not suggesting that people live their lives as the stories of their experiences. Kelber (1990:75) argues that 'the art of telling stories has faithfully accompanied the human race from preliterate to post modern times'. However, Kelber (1990:75) referring to White says that 'that no one and nothing lives as story, for life itself does not narrate'. Indeed 'stories help to build a world of ontological security and continuity' (Revill 1993:129). De Certeau (in Revill 1993:130) describes stories as 'culturally creative acts' which create the world in which we live.

This is not a secure world, it only lasts as long as the story is remembered and every time it is retold the world is created a new. But it is a certain world because it is based on the narrative process by which we describe the world to ourselves in our own terms to our own satisfaction, enabling us both to manipulate that world and to move around in it (de Certeau in Revill 1993:130).

As we manipulate and move around the world through the narrative process many gaps, inconsistencies, and contradictions emerge as our stories unfold. White (1992b:125), asserts this activity is important since it provokes people

into 'meaning making' which involves making unique sense out of their lives as they try to resolve some of the gaps and inconsistencies. He also argues that our lives are constituted through a process of meaning making through story telling as we live and then re-tell the story of our experiences, in contrast to the view that the experiences or the 'lived' experiences are reality there to be uncovered or found (White 1992b:125). The process of re-telling a story can open up spaces and possibilities for alternative stories to emerge. People can become free to explore an alternative story when they can separate themselves from the dominant or 'totalising' stories that constitute their lives (White 1992b:127). 'Totalising' stories are those 'grand narratives' such as the one I have been discussing which is the Cartesian narrative of the mind and the body.

Grand totalising stories

One way of becoming aware of the implications 'totalising' stories have on people and their lives is to allow a story to emerge and stand by itself without it having to be compared to a normative structure. Lyotard (1984) has referred to the overarching philosophies of (his)tory as 'grand and totalising narratives' that attempt to speak for all of human kind all of the time. It is through these 'grand narratives' that we have come to engage with notions of the 'normal body'. Parry (1991:40) argues most convincingly that 'the very notion of the norm as applied to differences between people, the problems that arise, and of the difficulties in embracing those differences, is the source of the pathologising tendency'.

Anna as a marginalised 'other' revealed through my data could not and indeed has not found a way to have her experiences validated. She not only has no voice, she has no story. The voice of authority, in this case, medicine, has 'its voice sanctified by its sacred text and its story objectified as history' (Parry 1991:40). Anna was, in a sense, denied that because of the power of the medical

narrative. She was then also denied access to the length and breadth of her life and to her lived experiences through her story, and this affected her sense of personal identity. De Concini (1990:46) argues for an identity as 'persistence over time as continuously the same person' and this requires 'narrative remembering'. I am suggesting that stories are constitutive of our lives in contrast to the belief that experience is the reality.

Stories as being constitutive of our lives

My interest in story telling is also about me as a woman valuing the lived experiences of other women that come to expression through their stories (Campbell & Bunting 1991:7; Smith & Watson 1992; Gluck & Patai 1991). I believe that 'the deafening silence of women's voice and experience in western culture and history' discussed by Dallery (1991:53) is one of the main imperatives that should guide women doing research. According to Webster-Barbre et al (1989:4) 'Listening to women's voices, studying women's writings, and learning from women's experiences have been crucial to the feminist reconstruction of the world'. Assuming 'men have constructed the prevailing theories, written history, and set values that have become the guiding principles for men and women alike' this is a difficult and contentious issue for female scholars (Belenky et al 1986:5-6). The way that Anna and I assume the personal in this study represents what is a difficult journey for women in the academy who are generating knowledge, and at the same time coming to a critical voice.

I have argued so far that our lives can be shaped and understood through narratives (Cohler 1982) and the very act of story telling can illuminate, transform and reveal how a person's life can be understood (Sandelowski 1991). However, Kelber (1990:75) argues that we do not usually give critical attention

to our narrative impulses and performances and that which we mostly take for granted obviously eludes our full attention.

Nurses are immersed in the stories of others, yet Sandelowski (1991:1652) argues they have not explored directly, the storied nature of human interpretation and placed it at the centre of their scholarship and research. Nurses have certainly explored the 'lived experiences' of people through phenomenology. But they have not worked with stories and narratives within a more critical framework. Dickson (1990:60) suggests that when nurses entered the academic field they began to emulate other scholars and they primarily based their studies on the established 'scientific' way of knowing. The scientific research tradition has masked the knowledge nursing generates since it does not provide a frame-work to theorise the experiences of people, including nurses themselves. As 'other' to medicine, nurses have been searching for a 'space' from which to speak. The marginality and oppression embodied in nurses' experiences has silenced their stories and, simultaneously, those of the people they care for. And, because nursing is primarily an oral culture (Street 1992b), the stories of nursing are not captured in text. Most nurses resist any written practices because in general they are not actively attempting to change their taken for granted ways of being.

The enormous resistance for nurses not to participate in any written practices is discussed by Street (1992a). She found that clinical nurses argue their interests lie in providing quality care to 'patients', not in writing, which is seen as a waste of time for the 'busy nurse' (Street 1992a:18). Yet we know that nurses have intimate contact with people and being women involved in an oral culture of 'telling stories' we also know that story telling is central to nursing and these women. As Spreen Parker (1990) tells us, she has never met a nurse who does not have a story to tell because the art of story telling is practised in almost every facet of nursing. Spreen Parker (1990:39) argues that to maintain what she

calls 'personal integrity', or what I understand as confidentiality, most nurses' stories have been silenced and rendered unspeakable. Hays (1989:202), in Foucauldian tradition, argues that nurses have been silenced because they are constrained in practice by 'the fellowship of discourse'. Who should speak and what should be said is strictly regulated within a closed community. The stories that nurses tell stay within the oral culture of nursing.

Walker (1995) discusses the bureaucratic and clinical discourses that inform nursing and describes the tension in nursing between the former which values the written and the latter which values the spoken. He says that these discourses have remained largely untheorised and that this is why such contradictions continue to shape nursing culture (Walker 1995). Walker proposes that 'nurses' sense of themselves has been locked into modes of desire (after McLaren 1988) in which the 'other' is always white, male and endowed with certain knowledges; which inscribe authority, influence and privilege on the bodies of those who claim to possess them' (Walker 1995:161). A person's sense of self is captive to certain knowledges and dominant 'regimes of truth' (Foucault 1980) which I believe must be contested, challenged and deconstructed through the telling of narratives. Deconstructing authority is not to do away with it. Rather, it is to see how authority is constituted and constituting of our lives (Lather 1991:144).

The politics of writing the self and others

Anna and I had shared many stories together as friends but when I formalised this study and we began to tape the narratives for transcription, Anna became enthusiastic to the point that she seemed 'driven'. The study formalised a commitment from both of us to indulge in story telling, and we made sure we had the time to do it. Anna would look forward to my coming and described

our sessions as being therapeutic for her. Perhaps this was because Anna found a place to give voice to the privilege of speaking (Walker 1993:7). I chose not to involve any other participants in this study in order to give Anna a place of primacy from which to speak.

Walker (1993:235) argues that when theorists and participants jostle for space there are many voices to privilege and this creates a tension for the researcher. Reflecting on his doctoral study, Walker (1993:236), makes the point that 'one voice is necessarily privileged over the others' and in his thesis it was his because he had a question to answer. Although I have not escaped this tension, I believe that I have minimised it through a process of 'joint story telling' (after Lumby 1992) so that 'our individual reflections and our joint conversations formed the foundation of our meanings and of our journey together' (Lumby 1992:116).

I believe that the way I have approached the telling of both Anna and my stories 'disrupts' the received norms in research by a certain 'textual self-consciousness' referred to by Lather (1991:150) after van Manen. In this space in which I have situated myself, I hope to make a critical difference in taken for granted understandings of what it means to be ill.

Disallowing claims to certainty, totality and archimedean standpoints outside the flux and human interest, it is to tell a "story that retrieves inquiry as a 'way' that is always already beginning, always already 'on the way,' " a different story "that makes a critical difference not only at the site of thought but also at the site of sociocultural praxis" (Spanos in Lather 1991:151).

The meeting of friends

It had been my intention to meet with Anna every week in her home but when we began it became every night for the first week, several hours at a time. We were already friends and shared some history together so we escaped having to get to know each other to gain rapport and trust. We both enjoyed the sessions and the intensity and frequency seemed important. We chose evenings when Anna would be in bed after the evening nurse had visited. Initially we experienced an urgency to tell our stories through a chronological sequence of events and we both wanted to meet every night. It could be argued that the linear sequence of events we started with, allowed us to move into our stories. Kermode (in Sandelowski 1991:163) suggests 'the mind is put to rest by the illusion of sequence and order, the appearance of causality and the look of necessity'. As Anna and I became more at ease that we were not going to forget to tell a certain aspect of our stories, our story telling style seemed to change. Although our stories became non-linear, there was always sequence which De Concini (1990:115) argues is important, because in memory there has to be sequence for experience to be coherent.

The first time we met to share our stories we were both somewhat nervous having moved from being friends, to being friends and doing research. Almost as soon as our stories merged into conversation, Anna raised the issue that it appeared our rememberings for the same period of time we shared was different, and we discussed these differences at some length. We were beginning to discover as Weedon suggests, 'what an event means to an individual depends on the ways of interpreting the world, on the discourses available to them at any particular moment' (Weedon 1987:79). Our beginning conversations exposed the liberal humanistic assumptions that we both subscribed to concerning 'the transparency of language and the fixity of

subjectivity' (Weedon 1987:83). We were analysing the events as we both remembered them to decide on the 'truth'. At this time Anna and I assumed that there must be some certainty and that there was indeed a truth to *confirm our* experiences. From these conversations, Anna and I found that our experiences were 'open to contradictory and conflicting interpretation', since the plurality of language makes fixing meaning near impossible (Weedon 1987:85).

Anna was particularly interested in story telling as a method because as a scientist and a researcher she wondered if this was 'real' research and asked me questions about rigour, reliability, validity and so on. Initially she saw her story as a 'medical case history' and this affected the way she chose to talk about her experience. According to Sandelowski (1991:162) a case study is still a narrative, but not a story telling style that captures the depth of people's experiences. I was not comfortable with a case study approach because as Benner (1991:16) argues, 'stories — as opposed to case studies or analytic reports — engage persons in a learning dialogue with their own historical understanding and personal knowledge'.

It seemed Anna was more familiar and comfortable with 'all of those literary devices that separate authors from their text' such as writing in the third person (Sandelowski 1991:161). We discussed how it was only more recently, undertaking a postgraduate degree, that I had been taught by academics to situate the self in my work (Benhabib:1992, Walker 1994c). Along with many of the arguments that Webb (1992) puts forward supporting writing in the first person in academic work, I now avoid the methodological tension of writing in such a way that I become 'other' to myself. Initially, the way I used the 'I' was difficult for Anna, because her scientific training had taught her to make sure she was always 'other' to herself. She would have achieved this through the separation of method, results and interpretation in her own scientific work

(Sandelowski 1991:161). This approach that scientists use is considered to be 'anti-narrative' (Sandelowski 1991:161). These conversations became critical for Anna and I in so much as they became spaces for me to argue why I chose narrative as a methodology and for us to have some common understandings of my intent.

I was very grateful that Anna had read Oliver Sacks' 'A Leg to Stand On' (1984) and 'The Man who Mistook His Wife for a Hat' (1985). This was helpful because she loved his use of narrative and agreed that a case study may tell us nothing about the person. She particularly liked Sacks's work because he bridges the gulf between what he refers to (in a Cartesian way), as 'the psychical and the physical' and because, ironically, Sacks is a scientist using narrative (Sacks 1985:x). Anna commented that Sacks's stories spoke to her in ways through which she could understand some of her own experiences. Anna also liked the way Sacks states that he 'is equally interested in diseases and people' (Sacks 1985:preface). The very act of story telling then became important to Anna because it situated her and made possible the meanings she could give to her experiences. This dispelled Anna's concerns of being a mere statistic in 'my research'. She came to realise that her story would actually go some way to explaining the experience of illness and its meanings for her.

Reflections on narrative as a method

As in all research the politics and ethics of deciding to choose a particular method is of concern. In this study, (after Lather), I was concerned with the issues of how to tell a story that Anna and I share and how I would take the 'crisis of representation' into account (Lather 1993:5). Walker (1994a:46) argues that this crisis not only involves how to represent the voices of the research participants, but also the voices of the theorists drawn upon in the study. It is a struggle that he described as the difficulty of speaking for oneself and others.

I have wrestled with all of the uncertainties involved in how to represent myself and 'others' in this thesis. According to Probyn (1993:4) 'embodying a care of self in writing and speech' is a necessity to 'construct ways of thinking marked by 'me' but that do not efface actively or through omission the ways in which 'she' may see differently'. That is, I have clearly placed myself in the text but the tension for me became one of constantly making sure I have not spoken for Anna when she could speak for herself, and that I try to avoid obscuring her voice with mine. I have tried to emphasise the historical conditions involved in speaking, in this thesis, through a critical use of the self (Probyn 1993:28). Moreover my representations of Anna or myself are not innocent 'they always presuppose particular modes of understanding of which we may or may not be conscious at their moment of representation' (Walker 1993:49).

Engaging in the analysis of the data, I have worked with the tension of both Anna and I having many stories to tell. I believe that the empathy that Anna and I have for each other as friends allows a certain intersection of our stories that we became comfortable with. Probyn (1993:171) addresses this problem theoretically by suggesting 'because of the material conditions of our selves we cannot indulge in the fantasy of dialogism wherein 'you' can be 'me' and 'I' you. 'I' am not 'she' but articulating a working image of the self may allow for a movement of empathy between us'.

The theoretical considerations in situating the self are important to re-think since the process of story telling with Anna is not a process of self indulgent affirmation of our experiences (Probyn 1993:30). It is about creating spaces through narrative as a research technology that 'contests those 'received' understandings of what constitutes good research' (Walker 1995:157). I have appropriated narrative as a means to explore and speak the body through the text (Probyn 1993: 30-31). Probyn (1993) does this especially well by weaving

her narrative rememberings of living with anorexia, with dense theoretical arguments on situating the self a textual strategy.

The Politics of morality

The difficult, and perhaps insuperable, problem in situating Anna and I in this text, is addressed by Sacks (1991) in his work, 'Awakenings'. He asks, 'how do you convey detailed information without betraying professional and personal confidence, and still preserve what is important?' (Sacks 1991:preface). How ethical is it to tell this story?— whose is it?— and whose interests does it serve? I feel I need to make explicit some of the ethical issues that are the history of this thesis.

I believe that Anna and I had a unique opportunity to work as co-researchers not only because of our friendship but also because of our similar intellectual histories. Anna was familiar with universities and the nature of tertiary study. She has honours and a postgraduate degrees in science and has an arts degree in progress. With this background she was very aware of ethical considerations in research and the implications of possibly being identified in this thesis. She knew that the thesis was the final work towards a tertiary qualification that would be in my name. The benefits for Anna are varied and complex. She argued that it was therapeutic to tell her story and that a critique of her illness experience has been insightful for her. Anna is more determined now to write her autobiography using the transcribed data and this study as a basis for that project.

Our friendship was a critical ethical issue because I have had to consider such issues as: have I taken advantage of our friendship?— would this study affect our friendship detrimentally?— did Anna feel as a friend, that she could withdraw from the study if she wanted too?— would she regret the telling her

story for a thesis that I came to write to gain a qualification? I believe that these questions have made me extremely vigilant in always checking with Anna on these issues. And Anna would, I believe, have had no hesitation in withdrawing from the study if any of these issues were relevant or of concern to her.

Researchers often describe themselves as being 'immersed' in their data. I have been fully immersed in this story, as it was lived over the years by both of us. The ethics of 'closure' in any research is difficult, however this research process will finish. But Anna and I have a friendship that will continue long after this text is gathering dust on the shelves of the university. Van Manen (1990:71) discusses how 'between close friends there is usually a certain amount of sharing of one's life history' and that from these conversations people feel closer. Anna and I have had an opportunity to tell and re-tell our stories as we began the process of affirming my interpretation of our conversations from the time I started to write this thesis. This was a rigorous process that assured I believe a certain 'reliability' and 'validity'. Anna read everything I had written as preparation for this thesis and she read the transcripts as they were typed, and drafts of my work as I progressed.

The analysis of the data in this study was generated through the critical conversations that I had with Anna after we both read the transcripts. As I theorised the data using the literature, Anna had the opportunity to read and discuss the written text. I have found writing our stories difficult as I struggled to select which aspects of the stories should be told through the text. Throughout the writing phase I have had conversations with Anna. The first draft was read to Anna by me and I changed aspects that she felt were problematic to her since it was to become a public document. I have included her comments and reflections on this study in the closing chapter. I believe that

I have been scrupulous in my endeavour to work with Anna as a co-researcher and that the final draft does not contain any material that she has not approved.

Chapter four: A body of science: body as text

I have argued that the friendship Anna and I both share has been a critical issue in the writing of this thesis. The stories of our friendship I have already started to tell, continue as Anna's story of becoming ill is explored. My experiences of having critical conversations around Anna's illness, was that our understandings of each other as friends had deepened. We continued our journey as friends and as two people in the study. The complexity of juxtaposing the more formal research process, and the continuing narrative of our friendship, is evident by the way I have necessarily assumed the position of friend, theorist and self in the text. Anna has a story to tell and indeed, so do I. My own 'narrative rememberings' are interwoven within the analysis and they are problematic at times because, sometimes they are me, sometimes Anna, and sometimes 'other' to both of us.

I experienced a sense of discomfort as I began to position Anna, through our stories, as 'a body of science'. Somehow this story exposed how our Cartesian understandings of the world have so dramatically shaped but at the same time concealed our stories and thus our experiences. The rich descriptive stories of Anna's experiences, the tragic story of her despair, loneliness and grief are only to be glimpsed beneath the text. The stories that I, and perhaps you, would expect to hear and read are somehow seemingly trapped within Anna's body, and it is her 'body as text' that tells that story. In this chapter Anna's body becomes her most 'intimate' yet at the same time 'alienating possession' (Diprose 1991:67). The stories are a harsh reminder of the exclusion of 'consciousness' and 'being' from medical science. Diprose (1991:67) explains this by stating that 'we can only 'dwell' in a world, encounter objects within it and be encountered as an object (say by, science) if we are constituted by a set of relations with which we are, thereby, 'familiar'.

The Cartesian legacy that dominates the set of relations that constitutes 'being' for most people has cast the experiences of embodiment into an abyss of silence. Harth (1992:9) argues this point by proposing that Cartesian rationalism opened 'a discursive trap' with which women have struggled for centuries. Furthermore Harth (1992:6) argues that it is the Cartesian legacy which has 'contributed heavily to a totalising rational discourse of abstract universality and objectivity from which women by the historical contingencies of their gender became excluded'. I have emphasised this because Anna has struggled with 'exclusions' at many levels, professionally as a female scientist and personally as an ill woman without a diagnosis.

Being 'buried alive in our culture'

In a similar vein Whitford suggests that 'a danger of our times is that the knower has become split off from the embodied and social subject' (Whitford 1991:149). She argues that this split is far more significant for women because 'if women are cut off from their own becoming, then they are 'buried alive' in our culture' (Whitford 1991:149). This statement is a poignant suggestion of why Anna's experiences of being ill are only to be glimpsed beneath the text; in other words, I am suggesting that Anna is 'buried alive' resulting from the process of the objectification of her body as a woman (see also Diprose 1994) and from not having a diagnosis. The enigma of the body is captured by this process as Anna in her desperate attempt to 'be a body', some/body ultimately becomes no/body, 'just a head'.

Before Anna was to describe herself as abandoned, she travelled a journey that many people who have experienced illness may recognise. This is the traditional journey of 'becoming' a Cartesian body, a body for investigation by science. Residing in 'the kingdom of the sick', Anna lost more and more sense of her 'self' and eventually constructed 'her being', as 'just a head'. As Anna

objectifies her own body as a 'body of science' she appears to be lost or 'buried alive' within this chapter. This quote from the data is how Anna introduced herself through her narrative rememberings, before she travelled through her story to her experiences of being ill. What is interesting is how Anna chooses to position herself in the historical present (Probyn 1993:108).

A woman of science

Anna: Where in your life do you start...when you can say that things are relevant to how you are now? That's difficult isn't it. I guess for me...I don't really think I became a person until I left home, went to uni...was free to do what I wanted without my parents. So I don't think I became a person until I went to uni...I was seventeen then. My dad was married before so I've got a half brother and a sister and I had a brother who died in a motor bike accident in 1984...my mother died in 1988.

My mother's death was really bad timing because I had just completed my honours in science and the graduation was the next day...because I was removed from it, I think it took awhile for it to sink in. After my mother's funeral I went back to Uni. I had a commonwealth scholarship to do my Ph.D. I really enjoyed research because it was interesting to find out things that no-one else had ever found out before. It had a certain amount of tedium involved in it because you do repetitive things, obviously in scientific research, to get results. If you are doing quantitative research you've got to do a certain number of experiments to get your answers. I just found it really interesting — I enjoyed the work. I used to spend seven days a week on it I just loved it. But I also wanted to be an academic because that was a way I knew I could be in a university system with a permanent job and also be able to do independent research.

I have a sporting background and I loved skiing...snow skiing. I used to do it at every opportunity in the winter. We used to pop up to Mt. Buller and we always had our annual pilgrimage to Falls Creek. I use to love skiing. I also played state hockey and

intervarsity hockey — I loved hockey. I was also getting into triathlons. I was training...doing heaps of running, or riding my bike everywhere...and any time when I wasn't teaching or doing research I was training. So I had a pretty active full life, I was very happy then...it was a big decision to move interstate to a new job.

That is how I met you (Denise). The first time we met it was to discuss possible changes to the science course being taught to nursing students. We both got put on a committee of four and once we came together we found we had some pretty common goals. You and I were new staff members and there was a lot of pre-existing prejudices between nursing and science...a lot of old hostility between nursing and science...so it was a difficult thing we were doing...so basically we re-wrote the curriculum. We pioneered it...it was actually a good time...it was a watershed, wasn't it. It was a good time to be involved, and I feel quite proud of what we achieved. I'm quite sort of sad that I am not a part of that any more...I think we developed a friendship as co-conspirators...we had goals for nursing.

Do you remember I broke my ankle and had to have plaster on it for three months after walking around on it for ages after it was broken? But then after I got my plaster off I was really unfit and fat and I needed to indulge in some exercise...I think that's how we got started...I think you and I discussed that we both shared a common desire to get thinner...we started off walking almost immediately when I got out of plaster...we actually ended up doing some running...it was great. It was on one of our walks that I had an asthma attack. I have got a strong family history of asthma, but was not diagnosed as having asthma until the age of twenty. I must admit that I have been a very non compliant asthmatic, because I don't really believe in the medication. I do know, though, that asthma is a very insidious disease, in that you don't realise the damage you are doing by not treating it. I ended up in ICU with asthma after our walks...only I was too sick to remember an awful lot of what was going on at that time.

From Anna's story it becomes clear just how important 'being a scientist' is to her as she tells us how she values her life as a scientist. However, as a female

scientist in the academy there were many issues concerning the 'structural investments and patriarchal commitments in science' that undoubtedly affected her career (Grosz & de Lepervanche 1988:5). It is the exclusion of women in science that has contributed to gender being constitutively operative in science. Keller (1985:42) argues that this exclusion of women, and that which is known as feminine 'has been historically constitutive of a particular definition of science — as incontrovertibly objective, universal, impersonal — and masculine: a definition that serves to simultaneously demarcate masculine from feminine and scientists from non/scientists — even good science from bad'.

Namenwirth (1986:24) takes this point further by saying 'there is an excessive and destructive level of competition in academic science'. I recall that Anna was faced with this tension at work. Namenwirth (1986:23) argues that if women in science display competitive type behaviours it would invite criticism and conversely, if they behave as women are expected, that is supportive and docile, they are not seen as 'pursuing their careers with the appropriate level of vigour and drive' to be 'good scientists' (Namenwirth 1986:23).

Anna's background in science is in nutrition and this worked against her because, according to Hubbard (1990:44), women are said to be connected to this branch of science because of its links to 'home economics'. It must have been extremely difficult for Anna to belong in the world of science, but it was a world where she carved out a life for herself that she passionately embraced. This high level of tension is important when considering Anna's history as a female scientist because these same tensions surface and trouble Anna as she assumes the role of a sick 'patient'.

In Anna's story we hear that she was a very active person. She tells us about being involved in a variety of sports. She only touches on having 'asthma' briefly and describes herself as 'non compliant' by resisting medications, despite knowing 'that asthma is a very insidious disease'. Anna gives the

impression, from this story, that she is not someone familiar with being ill. She was a fit, active person living a full life at the time she entered the hospital as a 'patient'. I think this is an important point, since Anna was probably thrust or hurled into being ill rather than it ever being a transition. Both of our stories reveal the way Anna was thrust into being ill by the way she was walking with me one minute and then on her way to ICU within an hour. You will recall from my introductory story, that I left the hospital after Anna was admitted to ICU. Anna paused in her story at the same place saying 'I ended up in ICU', therefore it seems a logical place to re-enter both of *our* stories to continue the journey through the narrative.

A journey through Intensive Care: a space of privileges

Anna: In ICU I had to have adrenalin nebs and all of that stuff... anyway I can remember I thought I was going to die. I remember sitting...you know...the best position is to sit up and over...leaning over. I was sitting in that position and the physio was sitting behind me and she had her arms around my diaphragm...you know...around the side of me and she was saying, 'come on you can breathe'...and I remember I was breathing something like two times a minute — and I remember I just couldn't breathe...and I guess they called the doctors in...they were all around staring at me...one of them told me I couldn't breathe for myself and they were going to have to put me on a ventilator...that's all I remember. But I remember the physio sitting behind me and then I don't remember anything else until I had a sore throat...it was awful having a great big tube being pulled out...it was foul...this big thing coming out of your mouth...anyway, after I came off the ventilator I was very weak...I sort of couldn't move properly or swallow.

Anna had been ventilated for a few days until she could again breathe independently. I remember the day I went to see her after she had come off the ventilator. ICU was not a friendly place to visit. I stood outside some doors,

pressed a button and spoke to an anonymous nurse who, after some time, let me in. I was not comfortable visiting Anna in ICU. I found it to be an alienating environment. I will always remember seeing Anna lying limp in a bed. As I sat down beside her, tears had rolled down her cheeks and she held my hand. I remember this incident because it was one of the few times I had ever seen Anna cry—she rarely touched people, they usually touched her. She had looked absolutely exhausted from being ventilated and sedated.

Anna: I remember they watched me all of the time in ICU and I had a cardiac monitor on which went off all of the time...I felt really weak...and I felt really tired...I wasn't really getting any better and I thought they would find out what was wrong with me, so I wanted them to test everything. It's hard to explain how I felt...I just felt really unwell and the nurses started to worry that I was very flaccid...they kept a very close eye on me.

Anna makes it clear that 'she wanted them to test everything', she was prepared to let the doctors and nurses objectify her body, to carry out investigations 'on' her. Foucault's (1991) analysis of the body as an object and target of power in his work 'Discipline and Punish' helps make sense of this. Foucault (1991:136) makes reference to 'the army, school and hospital, as institutions that control or correct the operations of the body'. He argues that as the human body enters spaces such as those set aside for 'patients' in a hospital, it enters 'a machinery of power that explores it, breaks it down and rearranges it' (Foucault 1991:138). Anna had entered such a space and she expected and was indeed comfortable with, her body being 'broken down and rearranged' (Foucault 1991:138).

In hospitals, through the disciplines and practices of medicine and nursing, there is a 'mechanics of power' in play, that through 'a policy of coersions that act upon the body', then produces 'subjected and docile bodies' (Foucault 1991:138). Anna, in the role of a 'patient', allows this 'mechanics of power' to take place because, in the same way as an inmate in a prison or children in

schools, she is compromised. The notion of docility that results from being compromised allows Anna's body to be analysed and manipulated at the same time. This process is far more obvious in ICU because of the seriousness of peoples' illnesses when they become 'patients' and because there is more of an expectation to leave all of the decision making to the 'experts'. Walker takes this point further and argues that ICU, is in fact, a place where 'science has become institutionalised as *power* and the 'will to truth' is a key dimension of that historical process' (Walker 1993:134).

ICU in this sense becomes a panoptic space. By this I mean that the panopticon architectural design described and theorised by Foucault (1991) is evident in the ICU Anna found herself in. Foucault discusses the Panopticon as a mechanism of surveillance of inmates in the prison system (Foucault 1991:201). He claims that by organising people in such a way, observation or surveillance of many people can take place at one time. It can 'induce in the inmate, a state of conscious and permanent visibility that assures the automatic functioning of power' (Foucault 1991:202). In the centre of ICU was a raised platform from where doctors and nurses could see all of the 'patients'. Anna was able to say that the nursing staff were able to keep a 'close eye' on her partly by way of this architecture.

Under the inspecting gaze of the doctors and nurses I felt most uncomfortable being watched when I visited Anna in ICU. As Foucault has argued 'the panopticon is a marvellous machine that, whatever use one may wish to put it to, produces homogeneous effects of power', and this is what I was experiencing (Foucault, 1991:202). Power in ICU is not held by anyone in particular but there are positions of dominance because not everyone in the ICU space are equal. Rather for Anna it was the way she was positioned in ICU that is relevant here (Bordo 1993:191). Because of the hierarchical nature of

hospitals, the nurses and the doctors were able to exercise a certain power through the maintenance and surveillance of Anna's body.

Anna: The nurses would speak to the doctors about me when they were really worried...which was good because they didn't do that on the ward. They knew I had this strange feeling of being weak...if I moved around in the bed I would flop over to the side and I couldn't get back...when the specialist came the nurse told the doctor what was going on...you (Denise) were there when she did that.

I remember the ward round to which Anna refers. The specialist stood at the end of the bed, and it was the nurse who gave him a 'handover'. They had a conversation about Anna's medical status at the end of her bed. The nurse carefully threaded a little of 'oh and Anna is still very weak and we (the nurses) are concerned with how little she can move'. The doctor then turned his gaze towards Anna. He moved in closer to her. This was an interesting use of geographical space, with the nurse, a woman and smaller than the doctor (a male) gazing up at the doctor away from Anna the 'patient'. Then the nurse stood aside as the doctor gazed down at Anna, another woman, smaller than him and horizontal in bed. Foucault (in Bordo 1993:191) argues:

There is no need for arms, physical violence, material constraints.
Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he (sic) is his own overseer, each individual thus exercising this surveillance, over and against himself.

Anna had been grateful that the nurse had told the doctor that they were worried about her being weak which suggests that she was either not prepared to mention this herself or that she knew the doctor would take more notice of the nurse than her. Despite this however, after the round the nurse returned to Anna saying that the doctors had decided that she could go back to the ward

because her breathing was so much better now. There was no mention of the muscle weakness by the doctor at this time.

Anna : They decided to take me back to the ward...but really I was no better...worse in fact...I was a bit scared to go to sleep after being in ICU in case I stopped breathing. It took me months to get over that...because who would know if I stopped breathing at night on the ward? I didn't understand what was going on...at this point, I still thought I had asthma and that's what it was...and I didn't really understand.

Anna was scared to leave ICU because as a 'patient' and a scientist she most certainly saw ICU as a 'space of privileges', where she had access to the best and most sophisticated technology available, medical specialists and 'intelligent' nurses. Anna tells us that 'the ICU nurses were worried about her'. She has afforded these nurses with 'the intelligence' *to worry* which she does not do with the nurses on the ward. The ICU nurse could be seen as having a privileged position, because they work closely with doctors, and therefore science and 'truth'. Anna had come to 'trust' the ICU nurses over the ward nurse because of their positioning to the doctors and science.

On the ward, Anna describes being scared of not being able to see a nurse all of the time, and a doctor most of the time. She was no longer being technologically monitored. Being 'under surveillance' in ICU had meant placing her body in the care of 'others' and she was relying on the 'experts'. Leder (1984:35) argues that in doing this, 'there is an ironical fulfilment of Cartesian dualism — a mind (namely, that of the doctor) runs a passive and extrinsic body (that of the 'patient')'. The objectification of Anna's body achieved through a 'mechanics of power' in ICU is different on the ward where the docility of her body is assured rather more subtly through other disciplinary practices and codes of behaviour (Foucault 1991:137). Anna's remarks, about who would know if she stopped breathing on the ward, indicates how she felt the 'gaze'

was somewhat minimised on the ward in comparison to how she experienced the culture of ICU.

The body detective

The most worrying feature of Anna's experiences at this time was the lack of concern over her continuing muscle weakness. The transition back to the ward without any explanation about this was extremely difficult for her and she began to struggle to locate this 'thing' with no name herself. Anna had been led to believe that perhaps her asthma and muscle weakness were related since they had never been separated as different problems. This belief probably kept her remarkably calm as the obedient 'patient', patiently waiting to get better, even though she repeatedly was saying she was actually getting worse.

Anna: So there I was on the ward getting worse...I could not initiate movements with my arms and legs...or sustain the movement and carry it through to a completed action...swallowing was the same where the food would get stuck in my throat...and I coughed and spluttered. I started to get the breathing difficulty back...and one day I was trying to move in the bed and I fell out onto the floor. They were worried again so took me back to ICU because my blood gases had deteriorated again...this time while I was in ICU, I thought about the pathways...the pneumotaxic centre and the relationship between that and the respiratory centre and...you know...it didn't make sense...I must admit I did try and analyse...like I always wanted to know what my blood pressure was...and what everything was...I was very interested in that side of things, but I didn't understand what was going on. I remember it was really hard to move around in the bed...trying to move and sort of flopping over the side. I wanted to get out of there this time because people were so sick and the lady in the bed next to me had the ventilator turned off and her family were crying around her bed...it was awful...I said to the doctor 'get me out of here, get me back to the ward'.

Once again we hear Anna flag the point that she only went back to ICU because of her blood gases (her lungs) and her concerns about being unusually weak are still being ignored. Her faith in the doctors came into question and momentarily Anna describes moving out of the 'patient' role as she stood back from herself trying to understand her body as a scientist might. She puts herself into the uncomfortable position of investigating her own body. Anna acknowledges this tension by saying that it is not acceptable for 'patients' to analyse themselves scientifically. She was not prepared to be the passive 'patient', because the doctors had so far let her down. Their investigations had not acknowledged that asthma was far from being a diagnosis that encompassed all of the symptoms that she was experiencing. Indeed, they had not seemed to have listened to, or have heard, her concerns about the changes in her body. In these moments of resistance, Anna is able to bring to expression how on one level she was the 'docile body' biologically disempowered, and how on another level she was prepared to contest this.

This is a moment of resistance in as much as Anna objectifies herself. She has spoken of feeling guilty because she dared to suppose that she had the right or authority to think about her body scientifically. The only person in a hospital who claims this space is the undisputed voice of authority, the doctor, who speaks with the voice of science. This voice is legitimate as opposed to the voice of the 'patient' who possesses only local and untrained knowledges and skills (Foucault 1980). Usually the voice of the doctor diminishes and minimises the voice of the 'patient' often to the point that it is silenced.

Perhaps Anna as a scientist was not afraid to claim back some of the power that silences anyone 'other' than the doctor. Since the question of her muscle weakness was being ignored she began to ask questions at every opportunity of anyone who came into contact with her. The nurses, physiotherapists, and the pharmacists all echoed the same: *'You will have to ask your doctor'*. This is yet

another example of Anna's need to have a conversation about herself being denied to her. Each one of these qualified people would be unlikely to engage in talking to Anna about her illness because she had not got a diagnosis. These people disqualify their own knowledges by being as silent as the 'patient'. Foucault (1980:82) suggests that this happens because of the subjugation of knowledge, 'a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the level of cognition or scientificity'. I am arguing then that the silences that became a major part of Anna's experiences are partly because of the power/knowledge relations Foucault (1980) refers to.

Anna: As my asthma improved my muscle weakness got worse and the nurses moved me into a room with three really sick women...the doctors didn't come to see me as much...and I had a lot of time to think about what might be happening to me...that was when I used to want to read my medical history to check my results because no one seemed worried about how weak I was getting...I thought they must be missing something...surely something would show up.

Anna became concerned that the doctors may have overlooked some vital clues in her 'case' so she began to take a keen interest in what was, and what was not, 'being done' to her. When I visited her, she would talk very quietly to me, in case the other women in the ward heard. The screens were always drawn, and Anna would whisper to me her biochemistry results, her blood pressure readings, and all of the other data that she had 'secretly' collected. She would ask me to get her charts off the end of the bed and hold them up for her to read. I began to feel 'guilty' because I was complicit in the secrecy that began to shroud Anna's investigations. Moreover, I was worried that the nurses would see or hear me and despite all the rhetoric regarding advocacy and rights of 'patients', to read ones own medical charts, is transgressing a taken-for-granted boundary.

With Anna's focus now decidedly on her 'biological body' she only discussed herself mechanistically, reducing her body to a network of systems, examining it system by system. She reminded me of a detective, a body detective, searching for clues as to the cause of her illness. The problem was she was not officially recognised as being assigned to the 'case' so she had become secretive, concealing her intention from the official detectives, the doctors.

Anna: I was worried because I still couldn't breathe properly...and I couldn't swallow...I just couldn't...I had to make myself breathe ...the ladies in my room all had cancer and they kept talking about their illnesses...I just listened to them but couldn't really talk about what was happening to me...day after day I got sicker...no-one knew what was wrong with me and eventually they moved me to a single room again...I thought it was because they thought they might catch something from me.

Denise: Did they say that?

Anna: No.

Denise: But you had the feeling that they thought you were contagious?

Anna: Yes...or they were scared...I remember some of the nurses not wanting to nurse me because when I ate, I got mucous plugs stuck in my throat...and it was scary...they were frightened I was going to 'cark' it on them...not that they said.

Denise: How did you know that?

Anna: I don't know...I'm not sure...but I could tell that they were scared when I couldn't breathe properly...you can tell when someone is scared. Not long after that I got even sicker...I had a high temperature...and I got terrible bruises from them taking blood from me. My veins were wrecked...so they put a drip in my foot...and the only place they could get blood was my femoral artery...I just lay there...I thought I was going to die.

The nurses were probably threatened by Anna because she did not conceal her biological knowledge. She knew 'too much' to be a 'good patient'. Anna also had a way of exposing what the nurses did not know through her scientific questions, and this may have intimidated them. As Anna said, she thought they were 'scared she might cark it'. Everyone, it seemed, avoided asking questions, because there were no answers, it was a time when the unspoken became the problematic, a time of silences.

Watching and listening to nurses: being 'basic nursing care'

Anna came to be referred to by the nurses as someone who was 'basic nursing care' which as an expression denigrates simultaneously the body and nursing (Lawler 1991: 31). Since Anna could not move and she was confined to her bed or a chair, the focus of her days became watching and listening to the nurses. She offers some insights into these experiences.

Anna: Some nurses treated me as a person because I think some people just have an awareness of other people which translates in nursing to how they care for you. I have visions in my head of many nurses...especially of nurses feeding people...and you think...why did they bother to be come nurses...I liked Jane...a new graduate...she was pretty impressive. When you are in a hospital room with three other people there's not much to look at...so everyone knows what's going on in the room...and the way the nurse is interacting with all of the patients.

Benner and Wrubel (1988), and Lawler (1991) discuss how perhaps the experience of the nurse is crucial to how they might care for a person during illness. It is suggested that experienced nurses, referred to as 'experts' by Benner (1984), care for people in ways that are non-reductive which do not disembodify the person (see Parker 1988; Parker 1991b Gadow 1982; Colliere 1986; Wolf 1986; and Lawler 1991). Experienced nurses cared for Anna, but she

considered very few of them as part of her embodiment. It was far more than the 'experience' of the nurse that made them stand out for Anna as 'experts'.

The nurse who stood out for Anna, a new graduate, was sensitively negotiating the very public 'space' of a hospital ward. Through a process of enculturation many nurses, sadly, lose this sensitivity that Anna as a 'patient' noticed and appreciated. When the nurses referred to Anna as 'basic nursing care' they situated Anna discursively as being less important than some of the other 'patients'. This language suggests that there is a hierarchy of care and Anna as 'basic' is therefore on the bottom. To me, this language that some nurses use is far more denigrating and objectifying than some of the medical discourse because it is part of the discourse of nursing. Even though Melia (in Lawler 1991:31) states that 'basic nursing as a term has fallen into disrepute' it did not seem to be the case in relation to the nurses who cared for Anna.

Anna: Jane gave me great showers...she took the time and made sure that we weren't interrupted.

What Anna is referring to here is that she was often showered during the 'designated' morning tea period. Sometimes the nurses would relieve each other to take a 'tea break'. This complex time of body care was when Anna relied upon the nurse to 'be like extensions of her body'. I find it fascinating that nurses would think that it was appropriate to change over in the middle of what was such a personal intimate time for any person. Jane knew how important this time was for Anna from her everyday life, not from her experiences as a nurse. Anna suggests that some people have this awareness of others, which if they are nurses, they translate into their practice.

Eventually as the results came back, time and time again failing to reveal the cause of her illness, some nurses and other people avoided conversations with Anna. The nurses said Anna was 'in for investigations' but it was becoming

clear that the investigations were seemingly leading nowhere and this is how they came to refer to her as 'basic nursing care'. Even her regular flow of visitors slowed down and, as for many people who are chronically ill, she began to be an abandoned/neglected body. Anna eventually became silent and she stopped asking questions. She stopped examining her results and charts and, at the same time, stopped telling me what was happening to her. She tells us of her confusion and of all of the 'things' that were done to her, rather than how she was feeling.

Anna: I remember I was hypokalaemic at the time...that was one of the features...I was still having drips...and vitalographs every day...and peak flows...and my creatine phosphokinase...those levels went through the roof. There had been a flurry of tests because of my temperature and they put me on antibiotics...and I remember them saying 'you need these in case you get really sick with septicaemia'...I remember them saying that...I also remember the doctor asking me what I thought was wrong with me...I said 'you're the doctor'...in the end I said to him...'well maybe I've got an atypical viral myopathy'. The nurses didn't question any of it...and I kept telling them I couldn't swallow...I didn't know what was wrong with me...the breathing was a bother but things were crowding in on me...I got angry because I was so weak I couldn't do much at all...I started to get angry with the way my doctor just came and stared at me from the end of the bed every day without ever saying anything about what he thought...it was really weird ...it was as if I wasn't there.

Anna continues to objectify herself in relation to all of the tests she was having. She did not like the doctor suddenly asking her opinion on what might be wrong with her; as she says 'why ask me?' Until then she had been ignored, so she retorts 'you're the doctor', but later she seized the opportunity (and control) to offer him a possible diagnosis. Anna was placed in a difficult position by science and the doctor. Foucault has said 'Science...is literally a power that forces you to say certain things, if you are not to be disqualified not only as

being wrong, but, more seriously than that, as being a charlatan' (Foucault in Minh-Ha 1991:20). More importantly, science is a power which intimidates and silences. The difficulty for Anna here was that she had no 'proof' to substantiate any diagnosis she might put forward.

Anna also tells us that she was confused and angry with the doctor because all he did was stand at the end of the bed and look at her, without ever telling her what he saw or thought. This was the medical gaze to which Foucault (1975) refers. Foucault (1975:xix) argues that the silence between the 'patient' and the doctor is a 'clinical gaze', an observing gaze, that 'silently lets things surface without disturbing them with discourse'. Through the silence, Foucault (1975:xix) argues that thoughts are synthesised into a medical discourse, and a discourse of disease emerges so the doctor can articulate 'what is seen and what is said'. But some doctors do not articulate what they see and, if they do, it may not often be to the 'patient'. Anna describes being frustrated by the 'silence' of the doctor and, although this gaze is argued by Foucault as non-reductive for the doctor, it is most certainly exclusionary for the 'patient'.

Being nothing: no/body

Anna's experience tells us she was reduced to nothing; *'it was as if I wasn't there'*, because she was not acknowledged as being there. So, if medical discourse incorporates 'a perpetual and objectively based correlation of the visible and the expressible' as Foucault (1975:196) suggests, what did the doctors see, and what did they say about what they saw? The visible signs of a body losing tone and function were there, doctors could see the clinical changes on the surface of Anna's body. However if the diagnostic tests were sometimes 'abnormal' they could be explained away as a result of Anna's immobility, there was no 'pathology' to give language to Anna's illness.

As such the abyss beneath her illness, that is the illness itself, had no name and could not be revealed through language. Doctors had said nothing to Anna because they had nothing to say. The syntactical organisation of disease into language, that would render Anna an object of science through a discursive existence, could not occur. At this point it would seem that Anna was caught between the space of being enfleshed or disembodied, or as Laqueur (1990:12) puts it, between 'an extraordinary, fragile, feeling, transient mass of flesh that we are familiar with and the cultural meanings that we as bodies are so bound to'. As you will read in the next chapter, without a diagnosis, Anna began to experience being disembodied, describing herself as 'just a head'.

Chapter five: Being 'just a head'

Anna: I don't know what I believe any more about the mind and the body...sometimes I am really surprised by my body...it's hard to explain but I sort of think....oh it's me...is that part of me? It's very strange...so I guess for me my mind is separate to my body. I feel very detached and I didn't feel like this when I was well ...sometimes I was made to feel as if I wasn't a person.

Denise: So how would you describe yourself now?

Anna: I guess I am really 'just a head'.

Denise: How do nurses go about caring for someone who sees themselves 'just as a head'?

Anna: I guess I care for my head and everyone cares for everything else

Denise: So are you saying that you care for your mind and others care for your body?

Anna: Yes...I'm not saying that nurses picked me out to treat me either not as a person or as a person...but some nurses seem to treat all of their patients as people...and a lot of nurses treat none of their patients as people. Before I was ill I was very aware of my body...but being ill has forced me to split my body and mind...and I've given up my body to be cared for because I have no control over it...but I feel like I have absolute control over my mind.

I really get them to look after my body well...I get oil rubbed into my skin...I ask to be exercised...I make sure they use sterile techniques with catheters and that they do every thing properly —that they wash me properly. I have evolved how we do things...I hate it when I have new people because I have to train them...like the carers and nurses are like my arms and legs...the ones I have had for awhile just do everything automatically...they do all these things, so we can talk about other things.

Anna's story so far has been one of her desperately seeking an identity through a medical diagnosis. She had given over her body for investigation and to some extent had investigated her own body in the hope she would find answers to explain her illness. As time passed and neither she nor the doctors found any explanations she became silent and disembodied. As Anna lost her feeling for her body she indicates that she became re-embodied as 'just a head'. She argues that as she lost her body her illness forced her to make the split between mind and body in becoming 'just a head'. But as 'just a head' the nurses became extensions of her 'self' so she could be more than 'just the head'. She describes the nurses as part of her body when she says that they were 'like her arms and her legs'. In this sense she was re-embodied.

By constructing herself as 'just a head', Anna constructs the body as the 'negative other of mind' (Cranny-Francis 1995:3). According to Cranny-Francis (1995:3) 'the consequences of this negative valorisation of body are far reaching'. Anna dismisses bodily activity to become 'just a head'. As a result of this dualism Anna is limited or confined by her body, and her body can be thought of as trapping or imprisoning her mind (Cranny-Francis 1995:4). It is the process of the objectification of Anna's body that renders her as no/body that is so confronting. Anna has made explicit the mind/body dualism through her illness experience.

Nothingness and limbo

Anna's story is one of being ill within this reductive framework which she does not contest. Throughout this story, as Anna struggles to retain her identity, her despair and the harsh reality of the separation of her self into a mind and a body is revealed. Along with her struggle to be given a diagnosis to explain her muscle weakness, Anna had to eventually face what can only be described as a major crisis in her 'being' (an ontological crisis). This was when the full extent

of her muscle weakness was realised and she was ultimately dismissed by the medical and nursing staff for not having a diagnosis and pathology to explain her illness.

Anna: The doctor continued to see me and one day he came and he was actually nice to me...whereas he had been distant and abstract before...I'd just had a shower and I was really tired and breathless...he asked me if I was tired from the shower...I said 'everything makes me tired'...and he goes...'oh that's very interesting'...you know...it was sort of like he was starting to think again about the problem. And it was quite fortunate that I was sitting in the chair because he looked at my legs...and he goes...'oh look at your legs...they're very wasted'...He had never...not once...examined my legs...he had only been interested in my lungs. Anyway I said 'yes they've been like that for awhile now'...and I said, 'they went like this within a matter of days of me being in hospital'. I told him how I was someone who runs...who had quite muscly legs...and how they had become bloody sticks. He said 'oh that's strange'...then he took blood gases and did a vitalograph and started talking about my lungs...He had forgotten, I think, that I went beyond being an 'asthmatic'... anyway...he went then and didn't mention my legs again for awhile.

What stands out in Anna's story is the way that Anna articulates how the doctors constructed her as 'lungs'. The doctor had obviously only had conversations with Anna about her lungs, never about her legs, and certainly never about 'her'. Finally, by accident, the doctor was confronted by actually seeing her legs. For a moment, Anna began a conversation she had desperately waited for, only to be dismissed as 'lungs' again. As Anna says 'he had forgotten that she went beyond being an 'asthmatic'. This confusion in her being either 'lungs' or 'legs' exemplifies 'how people are understood to be separated from their bodies, their world and those around them' (Parker 1991a:295). Anna's body is an 'object' to her and others because of the reality of Cartesian understandings of what it means to have a body within our culture.

Sacks (1984:73) describes a similar experience how, when he mentioned to the doctor that he had lost sensation in his legs, he was ignored. He wondered 'what sort of doctor this man was, for clearly he had not heard him'. Anna like Sacks (1984:73) was totally frustrated in being cast in the know nothing role of 'patient'. Sacks (1984:77) describes being a 'patient' as a point where he entered 'nothingness and limbo'. As the organic foundation of reality was removed from his life, Sacks (1984:77) talks of falling into a hole:

This would be tolerable, or more tolerable, if it could be communicated to others, and become a subject of understanding and sympathy — like grief. This was denied me when the surgeon said 'Nothing', so that I was thrown into the further hell — the hell of communication denied' (Sacks 1984:77).

As Sacks later reflected, 'science and reason can not talk of nothingness' (Sacks 1984:81). Anna too seemed to turn inward as communication with medical science was denied her. She said little to the nurses now or to the doctors as she spiralled on her inward journey. Cixous (in Minh-ha 1991) who took seriously 'writing the body' and thereby made explicit links between power, discourse and the body, had the following words to say about the silence that inhabits women's writings. I believe her thoughts have particular relevance to the silencing of Anna through her experiences of embodiment:

...I who had been nothing but the expression of hope in a language which had become extinct, no-one spoke to me any more, not spoken myself I abandoned myself, I didn't believe myself any more, my voice was dying in my throat, silence submerged it, I no longer heard anything but the silence (Cixous in Minh-Ha 1991:138).

Anna: Eventually I stopped asking them what was going on...and I was sick of being treated as if I didn't know anything. One day the doctor mentioned my legs again...he said 'have you walked yet? Surely it was obvious I couldn't move let alone walk...then he said, 'we are not sure what is going on'...I think that is when he mentioned psychosomatic...and they all started to think it was psychogenic...and to think about whether I should see a psychiatrist...I was devastated...and this is when the nurses started to be different...I think their attitude to me was that I was a bit of a bother, because they had to do all these things with me. I remember how they made me sit out of bed in that chair...and I remember one day I slipped out and got caught in the hole...it was one of those Jason recliners...I was stuck there forever...without a buzzer... When they came in I swore at them and they got the attendants...I thought how horrible they were to me only...you know...now it doesn't seem so bad...but I was in that hole for an hour.

This account from Anna tells of how frustrated she had begun to feel. It must have been very strange to be asked by the doctor if she had walked yet. It was obvious, especially to those who cared for her, that she was unable to move let alone walk. In asking the question 'have you walked yet?' the doctor was dismissing Anna because he implied that Anna could walk if she wanted to. He then dismissed Anna yet again by saying that 'they' (the medical profession) could not explain Anna's condition. As soon as he said psychosomatic, Anna was re-positioned as having a condition, rather than an illness, where there was no disease and no diagnosis. It was not possible then for Anna to be afforded an illness that could be recognised as a 'real' illness.

Once the doctors had implied to Anna that her illness may not be 'real' she deteriorated rapidly. I found the experience of watching her get weaker almost by the hour very frightening. The medical staff once again reacted to her decline by re-investigating every system they could. When ever I visited Anna she had a new site of invasion on her body: bruises from venipuncture, sutures

from muscle biopsies, red marks from electrodes. She was referred from specialist to specialist including all of the allied health professionals. With every day, as she waited for a diagnosis, Anna seemed to slip further into her illness. She lost more weight and muscle tone to the point where her skin seemed to drape itself infolds around her bones.

Anna: Do you know I didn't have anything to eat for weeks and I was becoming bruised all over from having blood taken...One day they took blood from me ten times...I was very sick...I couldn't swallow or move very well and the nurses had to do nearly everything for me...I even had a lumbar puncture and then I had really bad headaches as well.

Anna's whole way of being was gradually changing and I began to notice subtle changes in the way nurses 'routinely' seemed to accept taking over more and more of her body care. Lawler (1991:158) comments on how nurses can create an 'environment of permission' that 'normalises the 'patient's' experience' but in this instance it was not helpful for Anna. For the nurses it was 'business as usual' as if this young woman, now in a quadriplegic state, was invisible to them (Lawler 1991:158). For Anna it was not helpful for the nurses to treat her experiences as 'normal'. She faced losing the function of her entire body and she desperately needed to talk with the people who cared for her about what was happening to her and then maybe she could have discussed what it felt like.

Nothing about Anna's way of being was untouched, everything about her was forced to change. No longer able to do anything for herself, in fact she could only talk, Anna lay motionless.

Anna: I began to lose the sensation of my legs, arms and hands... and the nurses and attendants turned me every two hours...I had to have a catheter...I hated that...if the nurses moved me and I couldn't see my legs I had no idea where they were in the

bed...I remember I asked you once to check on my legs and you found them stuck in the bed rails...I felt as if they were not connected to me.

As Anna lost her feeling for her legs she had to struggle to know her legs. Sacks (1984:49) tells of his experiences of not 'knowing his leg'. As he lost the feeling for his leg he described his leg as 'foreign' to his body. He discusses how this felt:

I turned at once to my leg, with a keen, startled and almost fierce attention. And in that instant, I no longer knew it. In that instant, that very first encounter, *I knew not my leg*. It was utterly strange, not-mine, unfamiliar. I gazed upon it with absolute non-recognition (Sacks 1984:47).

The loss of connectedness between Anna and her legs brought about a further dissolution of reality for her. The actual sensation of not having legs was somewhat metaphysical because it could not be explained scientifically.

Anna: It was really weird when I lost the sensation in my legs because I had no idea where they were in the bed...I wondered if I had a disturbance of proprioception because the atonia and muscle paralysis could not be explained by any of the doctors.

Once again Anna tries to explain the lost sensation in her legs scientifically. I remember her asking me on one occasion to look in the bed to see if her legs were in a good position. This gave me an opportunity to touch and look at her legs as I re-positioned them. She asked me to test her sensation responses and it was awful as I waited for her to tell me she could feel the sharpness upon her skin but she said nothing. I inspected her legs and massaged her feet for a while. It was in that moment standing there with Anna, confronted with her body, that I felt overwhelmingly sad and perhaps guilty that I had not massaged or exercised her legs before. I realised how I had struggled with being her friend and a nurse in a hospital where everyone knew me and how

this had silenced me into being the 'docile' visitor. That day as I massaged her feet I was scared by the cold unresponsive flesh that my hands touched. I could still feel the memory of her body in my sadness long after I left the hospital.

Being: 'a psych. consult'

Apart from the sensory losses that Anna was experiencing in her arms and legs there was sometimes the problem of her being unable to swallow. At times she even seemed to gag on her own saliva. One evening when I visited Anna she was choking. There was a nurse with her, but I noticed and was concerned that she seemed to be ignoring the choking. The nurse was calmly saying, 'nice deep breaths Anna'. I was scared because this was what Anna had done on our walk and she had the same distressed look. I asked the nurse if she could use the sucker but she said she had to go and get something and she left the room. For a few moments I was left with a very blue and petrified Anna. When the nurse finally came back, she casually and reluctantly used the sucker and Anna improved slightly. Something seemed to have changed. I sensed this in all of the nurses on the ward who were now different.

This particular nurse who sensed my shock took me aside and told me that all of the tests were negative and that Anna was 'for a psych. consult'. I felt absolute despair and disappointment with the nurses attitude and found myself feeling there was nothing to say to this nurse. From that time on I do not believe that Anna was ever cared for consistently in the same way again. Once the doctors had written 'for a Psych. consult' in her history, this appeared to impact upon some of the nurses and the care that they gave to Anna. The blurred boundaries of the somatic and the psych were now clearly demarcated; the rupture had occurred with the reductionist mind/body split, enforced and reinforced by medical discourse. I was as guilty as everyone else in that while

we were waiting for a diagnosis we had let Anna's whole way of being slip away.

Anna: The nurses stopped 'caring' for me from the time a doctor wrote in my history 'for a Psych. consult'.

No longer an 'asthmatic' Anna was resituated as someone who may have been responsible for her illness. When doctors appeared to 'give up' by handing over Anna to psychiatry it reinforced that the illness was not 'real' and that her illness was 'all in her head'. According to Leder (1984:40) to attribute the cause of an illness to be either in the body or the mind exposes the rigidity and the extremes of Cartesian dualism. The doctors could not diagnose an organic cause or disease process to explain Anna's illness. They could not explain the illness through pathologising Anna's body, so the alternative was to try and explain Anna's illness through her mind.

Although Anna never mentioned the notion of 'hysterical conversion reactions', the doctors most certainly had. Organic paralysis was observed by Freud to have 'neuro-anatomical' patterns while he argued that hysterical paralysis did not obey these patterns (Sacks 1991:176; see also Gatens 1988; Connors 1985; and White, 1991). According to Sacks (1991:176) Freud saw these two forms of paralysis as either mental or physical and these were the working definitions that all neurologists and psychiatrists came to use. The significance of this for Anna was enormous because the medical profession believe that if paralysis or anaesthesia cannot be explained anatomically through disease or trauma they must, by default, be 'hysterical' or 'mental' (Sacks 1991:176). Sacks argues that 'this [disallows] any investigation or understanding of *other* states of paralysis and [prevents] any exploration of the neuropsychological disturbances of body-image and 'self' (Sacks 1991:177). Anna's illness (paralysis) and the way she was or was not treated fits Sacks's observations. When Sacks was ill he realised that not even he as a neurologist could escape the rigid dualism of mind and body.

Taking on a diagnosis of 'it'

Initially Anna's body had been colonised by medicine as an object for the intervention of experts (Sawicki 1991:22). Then, as Sacks (1991) proposed, medicine abandoned her body and psychiatry prepared to colonise her mind as medical territory. At this point Anna had no alternative other than to conceive herself as 'just a head' because that was the way medicine and psychiatry constructed her. She was not, however, prepared to become a 'psychiatric patient'.

Anna: Some people didn't think that I was 'really ill' any more. The only people who looked to the future were the physiotherapists and they continued to work on my body...some nurses tried to trick me into doing things such as move my legs or arms. They needed proof that 'it' was in my head...I can't explain it...the nurses were just very different to me. Once when the nurse made me hold the tooth brush to clean my teeth my head fell in the sink...I nearly drowned...I knocked my head so many times because it was so floppy...I had a good primary nurse, but really I was too much for her...she used to have to drag me because if I wanted to use the commode she would persist in trying to get me to do some sort of transfer...I just couldn't help her...When she managed to get me on the commode chair I felt as if my head was going to explode...honestly I felt so sick...it was absolutely shocking...the pain was just horrible...it was really bad...I had a nasogastric tube down now...god I remember the trauma of that going down...I bled out of my nose and my mouth. I really did like my primary nurse, she was great. She had got really upset when they wanted to do tests on me...I think she cried...I said to her, 'look I know the doctors don't know what's going on with me...I don't understand all of this stuff either'...she admitted she was really worried. When I went for the tests, she actually came with me...she was checking it all out for me, like she was really concerned about it...know what I mean?

Anna refers to her unknown illness as 'it' when she says that the doctors and nurses needed proof that 'it' was 'real'. In the literature and in general conversation it becomes apparent that illnesses with no known cause, that collectively become psychosomatic states, are described as 'it'. With a diagnosis, 'it' becomes the cancer, the fractured leg, the tumour, the gall stone, the kidney condition, the heart condition, the ulcer and so on. Anna was 'devastated' because, semantically, the doctors had transformed her illness to 'it' and the possibilities of 'reality' became 'imaginary'. Anna who had become the innocent, passive 'patient' awaiting a diagnosis had been transformed into the 'culpable' (Kirmayer, in Benoist & Cathebras 1993:862). She was culpable because now it was possible to blame Anna for her own illness. Sontag (1990) argues that psycho-genic theories of disease blame the 'patient' for their own illness.

The widely held view that many or even most diseases are not "really" physical but mental (more conservatively, "psychosomatic") perpetuates the form of the miasmatic theory — with its surplus of causality, surplus of meaning — in a new version that has been extremely successful in the twentieth century (Sontag 1990:131).

Anna: I gradually felt out of control and I started to have really bad headaches...my head was really sore...I was floppy...I couldn't swallow properly...I wasn't getting any nutrition...my chest was hurting...I couldn't breath properly...and I just didn't know what was going on...I thought they were going to let me die. That's when I said, 'why don't you put me in rehabilitation?' I had it in my mind that I needed physiotherapy and that would be the thing to make me better. I don't think that some nurses liked touching me on the rehab ward...they just didn't do things like wash me properly...I didn't mention it to them...I honestly didn't...I don't know why...I didn't think I

should have to...so maybe it's part of my fault ...You have to do a certain amount of detachment for survival...maybe that's why?

I do not believe that what Anna is describing here is about the nurses not washing her properly. Because this was a rehabilitation ward the nurses were now trying to give back to Anna some of the 'body care' that they had been doing for her on other wards. Anna had decided that being detached was necessary for survival and now she was being confronted with her body and what it could and could not do. As a silent spectator to her own drama she often appeared to be quietly accepting all of what was being said or done to her. When the doctors she had invested so much hope in began to give up she momentarily found her voice and her will to survive (Frank 1991:56,57). By asking to go to the rehabilitation ward Anna was surely stating publicly that she wanted to improve. I didn't visit Anna as much while she was on the rehabilitation ward because I had difficulty with her sense of hopelessness as nothing seemed to change except that she became sicker. The big charts on the walls of Anna's hospital room displayed goals for her body, such as, by Monday I will be able to wiggle all of my toes. These charts were a stark reminder of what she could not do.

Anna: Nothing seemed to change, and you have to get better to stay on the re-hab ward. I remember that day...they told me, 'if you don't improve you will be sent to a nursing home'...I went out to see the home...I couldn't go there...not to a nursing home...so I decided to go to another hospital.

Re-investing in science

After being threatened by the staff with being sent to a nursing home, Anna was scared into reacting against such a suggestion. She organised her own transfer to a larger hospital. For a week, Anna seemed to come into focus again.

The doctors and nurses looked anxious because Anna was resituating herself again by giving up her body to another institution for scientific investigation. The doctor approached me about going with Anna, but when the nursing staff learnt of this they all said it should be one of them. The idea of going with Anna and doing some shopping in another state made Anna everyone's favourite 'patient' that week. It was a sad week as people came to wish her well, but she seemed to enjoy being 'legitimate', even if only for a week.

*Anna: I was relieved to go to the other hospital...it was a chance I thought, to find out what was going on and get better...it was good... I sort of felt like I was going to be in safer medical hands...It was a long day but finally I was put into bed four, in a room where no one, except me, spoke English...it was quite different. This was going to be my **medical salvation**...they chucked me in a bed and I waited for ages for them to do a round...The nurses came along and said 'in your own words why are you here?'...and I sort of said 'to have some tests and find out what's going on'...I wanted the latest ...really good physios and equipment...I had it in my mind they could come up with some sort of idea of what was wrong with me medically...a medical box. Anyway he came...the specialist...and they tested everything...bloods...lumbar punctures...nerve conduction studies...nerve velocity studies...an EMG...a MRI...that sort of thing...I spent hours having tests done...I was extremely floppy...I weighed 40kg and they fixed me up with a neck brace ...the physios worked on me twice a day. I was still having swallowing problems...nausea and stuff...my poor gut. That had been a feature the whole time but they never considered that... never really...it's the same sort of thing that they really can't concentrate on more than one thing at a time.*

Anna had gradually lost confidence with the local doctors and the nurses, but not with science, that is why she changed hospitals. Anna remembers the nurses asking her to use her own words to explain why she is in hospital. We discussed how this implies that the words of a 'patient' are not their own once they are in hospital, someone else controls their language and meaning. As

Anna talks of her 'medical salvation' science and religion seem to fuse together. Anna had thought she was in 'safe hands' but when no one gave her illness a name and it was suggested that 'it' was 'psychosomatic', she wanted to be in 'safer hands'. She also wanted a diagnosis, 'a medical box', but not a psychiatric box as she viewed the box of psychiatry with suspicion.

Anna: I had many investigations and eventually they said... 'we're not really sure what it is'. So they asked me all these questions... I was a very interesting case—very interesting they said. They sent a psychiatrist to see me... they said every one in neurology sees one... The doctor said many people with neurology problems can't be diagnosed like 65% of them which was comforting to hear... I mean it should not really matter whether they put you into a medical box, or not... but we are all brought up to believe you should be put in one... I didn't like the psychiatrist... I use to pretend to be asleep when she came... in the end she gave up coming. I became incredibly wasted... you know... I couldn't move to save my life. The ultimate experience for me was when they presented me at a grand round for the whole hospital... I had to be there... I was famous for a day—they were all extremely interested... I was wheeled in on the trolley.

Because it was explained that everyone in neurology sees a psychiatrist, Anna did not feel as though she was being cast aside so she agreed to see one. Relieved with the doctors' interest in her as a 'medical case' again, Anna had been told that they may not be able to diagnose her. For the first time, Anna expresses how the notion of being brought up to believe 'you should be in a medical box' has dominated her experience of being ill. This totalising 'truth' that ill people need to be medicalised through a diagnosis is also about being legitimately ill.

I would have to say that I was sad when Anna said that her ultimate experience was to be the star attraction of the grand round. I was sad because I was struck with how her narrative, her 'self' had been silenced — she had stopped asking

questions and had turned inward. Similarly, Frank (1990) refers to the experiences of Murphy who became paralysed with quadriplegia. Murphy said that 'thought, no longer capable of being embodied, turns inward as pure cognition...the thinking activity of the brain cannot be dissolved into motion' (Murphy in Frank 1990:85). Anna momentarily moves from this inward, marginal, position with an opportunity to be centred in the grand round, as a 'scientific body' and moreover a body worthy of such objectification.

Anna: The consultant said to me, 'we'd like to present your case at the grand round, because 'it' is such an interesting case and your diagnosis, while there are some aspects of it we know...we can say you've got such and such...and such and such, there are some inexplicable factors which we think would benefit from a grand round'. And he was quite good really because he was appreciative of my medical background, and he knew some things about me. He knew I had been an asthmatic and all of that stuff...he was quite nice. Anyway...I had no idea I had to be there...and in the morning all these nurses were getting me washed and dressed...the charge nurse came and told them to make sure I was ready for the grand round. Then I went on a huge epic journey.

Once again I draw attention to the 'it' in the quote from Anna. The illness, that is the interesting case, 'it', was going to be presented at the grand round, housed in the body of Anna. Anna recalls that the doctor was 'quite good' because he acknowledged that she has a bio-scientific background and he knew 'things about her'. And what of the nurses all bustling around Anna? Even the charge nurse visited her to hurry things along. I recall my own experiences of getting 'patients' ready for bedside grand rounds. Part of the rush is fear of the 'patient' not being in bed for the doctors or that the ward might have the tell tale signs of body care, such as a bowl still out or an unfortunate odour in the air. The bodies of the nurses reveal the ways they are disciplined in practice and the relationship that nursing has to science. Anna and the nurses endorse the exercise of power by medicine by such behaviour.

Anna did not usually have several nurses as well as the charge nurse concerned about her 'body care'. She was being groomed for a 'special occasion'. The practices and language of Anna and the nurses, positioned them as 'other' to medicine as they were silenced, subjugated, and marginalised. Walker (1993:105) argues 'that nurses constitute the colonised 'other', as *both a cause and an effect* of something of the conditions of their existence'. The doctor, closest to science, silently and effectively exercises power through the grand round, a time of medical worship. For one day Anna was no longer ignored and she made it quite clear that her body was there to be investigated and that the grand round was an excellent opportunity to objectify her body.

Anna: Anyway eventually they said to me, we're not sure what you have got'. I had every bloody medical specialist team in that hospital to visit me...you name it they came around to see me. They'd ask me had I ever been bitten by a tick or had I ever been to Germany...no-one was intimating psycho-somatic...well not to me anyway...no one was ever like they were to me in the other hospital...in the end, I was sent home because I was interesting but they never found a diagnosis...

Anna left this hospital having confronted some of the implications of the chronicity of her illness experience. She was obviously disappointed that she had no diagnosis or that she had not improved but she left believing that she was an 'interesting case' and that her illness was not psychosomatic and therefore not in her mind. I think that this point is very important because Anna was able to regain a certain sense of her self by feeling legitimate again. She was given back a position she was more comfortable to be in. Anna had succeeded, at least for awhile, in resisting being abandoned to the struggle of being 'just a head'.

Chapter six: Being an 'institutionalised body'

As this thesis draws to an end I struggle with what to say about a woman who has endured so much. I find I am left with all of the questions I started with and so many more, but I am left with some 'different' understandings of Anna, myself, nursing and 'being ill'. Being with Anna when she made that abrupt transition into the 'kingdom of the sick' will always haunt me. I doubt we will ever know what happened to her as she took her last steps before she became so ill. I remember the warm afternoon, the shimmer of light on the river, and the stillness of the bush that echoed our talking and laughter. And I remember the look on Anna's face as she went through the doors into ICU. These images for me are always together.

Even now, when I read the story that Anna has told and I have written, I am surprised. This is not the story I expected Anna to tell. I did not ever expect Anna to objectify her body to the extent that she does in this thesis. If Anna had been given a diagnosis her story would surely have been a different version of 'being a medicalised body'. I doubt I would be any more comfortable with that story but, from Anna's beliefs about 'medical boxes' and 'medical salvation', I'm sure she would be.

I had believed that I would have been able to write that, despite Cartesian constructions of the body in health care, Anna did not experience 'being a Cartesian body'— but she did and may have always, but never to the extent of 'being 'just a head'. Anna was forced into being Cartesian about herself if she was to remain legitimate as a 'patient' without a diagnosis. The consequences of this were that her story of herself helped shape a reality of Anna always being 'other' to her self. The reductionist mind/body split was reinforced for Anna by everyone — including me until she was cast aside to life in an institution.

Cartesian understandings of the body are a discursive trap for us all and these understandings are embedded in our culture through our language and thus our stories. This study reveals, if only partially, how the narrative structure of Anna's stories are shaped within the totalising narratives of modernity. The mechanistic constructions of the body shapes the way we nurse and the ways in which people experience illness. As Anna became ill it was evident that she was comfortable 'being' a Cartesian body. Later, however, she may have felt that science had turned its back on her — I certainly do.

Through Anna's illness narrative she identified her 'self' through the medical, scientific discourse as 'consciousness' and an 'object' body. She described herself as 'just a head' and argues that she gave up her body to be cared for. She also alluded to the ambiguity of such a statement by saying that some nurses did not look after 'just a body', they cared for 'her' and were described by Anna as part of her embodiment. This analysis touches only briefly on the complexity of theorising the body, the problem of the body, and the interactions that nurses have with people in their day-to-day work. When it was suggested that her illness was not 'real' many nurses and all of the doctors struggled with what to do with Anna's body. Others simply abandoned her. There were only a few nurses who continued to care for her despite her lack of a diagnosis.

The incompatibility of the experience of being ill and of receiving therapeutic health care is inscribed on the bodies of those who enter 'the kingdom of the sick'. Nurses know this. They live with this tension every day through the stories and experiences of those they care for but they seldom explore what it might mean. This narrative may help in raising some of these issues by illuminating the tensions that exist between embodiment and science. Other tensions that are evident in this thesis, such as how to speak for the self and others and how to theorise the body without losing 'real bodies', remain challenges for future scholarship.

Manipulating and moving around our stories through the narrative process of this thesis exposed many gaps, contradictions and inconsistencies. Both Anna and I immersed ourselves in these tensions to enable us to make meaning from our experiences through our stories. This was never a comfortable process as we ceaselessly positioned and re-positioned ourselves in this text, but it is a tension that provided a rich fertile ground for other stories to be told.

We are often led to believe that people, who have extreme changes in their lives through illness, somehow learn from them and become 'better' people than they were before. Anna disagrees — she says she was not a 'bad person' before she was ill. Perhaps it is as Sacks proposes that being ill forces us to 'scrutinise the deepest, darkest, and most fearful part of ourselves':

Force of habit, and resistance to change — so great in all realms of thought — reaches its maximum in medicine, in the study of our most complex sufferings and disorders of being; for we are here compelled to scrutinise the deepest, darkest, and most fearful parts of ourselves, the parts we all strive to deny or not to see. The thoughts which are most difficult to grasp or express are those which touch on this forbidden region and re-awaken in us our strongest denials and our most profound intuitions (Sacks, 1991:xix).

Through the telling of our stories some of my most profound intuitions have been reawakened by the strongest denials of both Anna and myself. These awakenings have led me through the questions that have guided and generated this thesis. Using narrative as a method to examine the experience of being ill, especially in an institution, I agree with Lawler that nurses are in a prime position to theorise the body.

I have not been able to come to a conclusion because I believe (after Weedon) that there is 'no monolithic truth' about our 'nature' or 'identity' to which we can or should subscribe and that in reality, as subjects in process' we 'ceaselessly position and reposition ourselves' (Weedon,1987:227). In ending this thesis I momentarily re-enter our story to leave Anna with the final words.

Reflections

Anna returned home for a while to a unit designed especially for a person confined to a wheel chair. However to live at her home, she relied upon a network of carers and nurses who visited her every few hours. Apart from some movement in her hands she could not move. She was still attached to a urinary catheter and a pump for feeding and nutrition. When she got home the realisation of the meaning of 'being' so ill gradually eroded some of the positive thoughts she had managed to feel before she had left the hospital. Totally dependent on her carers, Anna began to think she may not want to live as 'just a head' outside of her body for the rest of her life. The interest in her 'case' seemed to have ended and Anna knew that, even with the support she had, it would not be enough for her to regain any mobility. The nurses and carers could not provide the intensive physiotherapy she needed. Following many discussions with her general practitioner Anna decided to move to an interstate rehabilitation hospital with the aim of eventually being able to live more independently.

I visited Anna in her interstate rehabilitation unit with a draft of this study. It had been awhile since I had seen her and I had not been to this particular unit before. I was initially encouraged by the warm environment. It seemed as if there had been major renovations as evidenced by — fresh paint, new curtains and comfortable beds. But, as I found my way to Anna, the environment deteriorated markedly. It reminded me of the older parts of the hospital where

I had trained as a nurse and familiar sights and sounds greeted me. When I opened the door to the ward I set the alarm off and a loud sound hailed my arrival — everyone looked my way. The first person I saw was a scantily clad man in a wheelchair going for his bath. There was no privacy for anyone in architecture such as this. I scanned the rooms of beds for Anna. The people ('patients') I saw looked very disabled and some were calling out. I knew when I found Anna's room because I recognised her wheelchair and her belongings which seemed to spill out of her small designated area. The screens were closed and I could see the shape of the nurse as she moved around the bed half draped in the curtain. They were preparing for my visit.

The nurse gave me instructions on how to leave without the alarm going off and then said I could go in. Anna was lying on her side and she looked pale but better than the last time I had seen her. Her hair had grown and it was a beautiful golden colour. She had no catheter and no feeding pump but I could see that she could not move. We had a glass of champagne. Anna said it was on her medication chart, we giggled and I hid the bottle. I held her glass and the straw — it was good to see her. She had a view from her bed into a courtyard with trees and a water fountain. As we talked she would often stare outside. We talked for a while and then Anna wanted me to read what I had written.

She listened intently as I read to her and, as was our custom, she would interrupt to discuss what I was saying. She very quickly pointed out parts where she believed I had misrepresented her story and watched me write down her suggestions. Then she relaxed and smiled.

Anna: It is still the right story...even now, that's how it was...that's how I felt. It all seems like a bad dream...it's been so long — I've been so sick...I listen to my story and I think, why wasn't I more pro-active? But I was just not well enough...I remember a full life and suddenly it was taken away from me...I have felt loss and grief...I really

miss my legs...I remember the sound of my feet on the bridge where I lived...the sound of my feet walking...the wind in my hair.

I should have looked after myself better...not worked so hard.

I still know that something happened to me at that time...I couldn't control it and I can't explain it...

If I had gone to another hospital maybe I could have had earlier action...maybe if the medical profession weren't so narrow minded. Doctors are fallible and they may not always have the patients' best interests at heart. It puzzles me that doctors don't have the same curiosity that scientists have to find answers. The tests they have, are for tests of things that already exist. If they can't find the answer in the 'body' why do they think it's in the 'head'? And then why do they not consider that the 'head' is a valid thing to treat?

Pain is a big part of my life now and of course it can not be explained...I truly deeply believe something happened to me but at times now I question and doubt my own intuitive feelings about my body...I do know my body and I like to think I have always been honest about it to the doctors...I don't think they heard me.

I have been frustrated, angry, sad...and I grieve and I cry...I mainly cry for the other people I meet who are ill...people don't tend to leave here and I have witnessed some tragedies...I am not a better person for being ill...I wasn't a bad person before I was ill...and I am still basically the same person. I am becoming more aware of my body...my pain reminds me of my body. I don't think I will ever walk again...but my aim is to look after myself. People don't ask me what is wrong with me any more...they assume I have been in a car accident. But, if they ask, I say, 'I've got quadriplegic myopathy which is a condition of muscle weakness of unknown cause.'

In some ways I'm not comfortable listening to you read this but that's how I felt...it has captured lots of things...lots of things that happened...yes I like it...it's good...it says a lot...you know I still intend to write a book. I am beginning to feel a sense of time passing...I am worried I am missing what was going to have been the prime of my life. I

think about having children...I really like kids. I am going to look after myself...I am absolutely determined. I wonder, if I'm in a wheelchair will I find a man...desires are not knocked out of you because you are ill. I am different to most who are ill...it is very different having an illness that can not be attributed to anything...it makes the whole experience different and harder.

A diagnosis was not relevant at first...but as I became chronically ill it became more of an issue. There was the reality of a catheter...a feeding tube...not being able to walk...and no explanations. There is never a time when I don't want to get better...I have so much to gain from getting better...what sort of existence is this? Rules...regulations...I want to live...I want to do a Ph.D....I want to have children. ...I will get better but my legs won't...my body is the focus of my life...my future is guided by what I can achieve. Initially I expected to get better...now I doubt I will get better. It annoys me when people intimate that I may not want to get better...I am not always happy...the thing that stands out the most for me from this thesis is I would say the focus of your mind becomes your body in an institution...it is part of being institutionalised...something happened to me...I will never accept it was or is psychosomatic...what does that mean anyway? I think I was abandoned...yes...they abandoned me!!

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Appendix 1: Information sheet for Anna

STUDY TITLE:

The story in the body: narrative rememberings and the illness experience.

CHIEF INVESTIGATOR:

Denise Fassett, Lecturer in Clinical Nursing, Tasmanian School of Nursing

AIM OF THE STUDY:

Nurses have been working with the concepts of embodiment and the experience of being chronically ill for some time now. However, what I believe that they haven't done in this work is confront how female sexuality and gender are partially obscured through the ways in which nurses actually practice. This study is primarily aimed at prompting nurses to rethink those practices and understandings by interrogating the deeply embedded Cartesian notions of what it means to be ill which continue to pervade health care.

YOUR INVOLVEMENT

If you agree to participate in the study, you will be asked to be involved in approximately 10 conversations with Denise Fassett. It is intended that using narrative techniques you will be asked to describe your experience of illness. You will be asked to agree to have the conversations audio taped and transcribed, and will be returned summaries of each audio tape transcript. You will be expected to contribute only that information which you feel appropriate. You will be given the opportunity to be involved in discussions of the transcripts.

With your permission, data deemed suitable will be included in the thesis. All data collected during the course of the study will be regarded as confidential however as discussed you are happy to be identified as Anna in the study.

WHO DO I CONTACT IF I HAVE QUESTIONS OR CONCERNS ABOUT THE STUDY

If you have any questions about the study you may contact:
Denise Fassett.

Lecturer in Clinical Nursing, Tasmanian School Of Nursing, University of Tasmania,
PO Box 1214, Launceston 7250.

Appendix 2: The statement of informed consent for Anna

STUDY TITLE:

The story in the body: narrative rememberings and the illness experience.

CHIEF INVESTIGATOR:

Denise Fassett, Lecturer in Clinical Nursing, Tasmanian School of Nursing

STATEMENT BY THE: Subject Anna.

I have read and understood the 'Information Sheet' for this study and the nature and possible effects of the study have been explained to me. I understand that the study involves participating in a series of critical conversations and that the information contributed will be used and published in a Masters thesis to be submitted by Denise Fassett to the Tasmanian school of Nursing, University of Tasmania, in 1996. I understand that the thesis is to be written in a way that it is unlikely that I would be identified. Any questions that I have asked have been answered to my satisfaction. I agree that research data gathered for the study may be published provided that I cannot be identified as a subject. Any questions that I have asked have been answered to my satisfaction. I agree to participate in this investigation and understand that I may withdraw at any time without prejudice.

I agree that research data gathered for the study may be published.

Name of subject

Signature of subject Date

Witness Date

STATEMENT BY CHIEF INVESTIGATOR

I have explained this project and the implications of participation in it to Anna and I believe that the consent is informed and that she understands the implications of participation.

Name of investigator Denise Fassett

Signature of investigator Date.....