

# **Chapter Three**

**Three Readings**  
**Educational materials**

## Three Readings (Educational materials)

This chapter tells the story of my learning with and about diabetes. I trace the trajectory of my learning in a temporal sense. I then revisit my story and what I have learnt in a reflexive movement. Initially critical discourse is used as the analytic framework. This story is read through different lenses and what is learnt is changed by each lens. No reading is more true, but the truth of each is related to the context of its knowing. As the readings change the learning, so too the conceptual frame shifts, until the chapter is firmly positioned within post structural understandings. The essentialist autonomous self is disrupted and reconceptualized as multiple shifting and constructed subjectivities.



*I think through autobiography: that is to say, the chain of associations that I am pursuing in my reading passes through things that happen to me*

(Gallop 1988:4)

In 1997 three women, Alison Helen and Amanda, working out of a home based office, tried to raise funding to complete their film project. The project *Woman with Child* was to be a series of three ethnographic films on pregnancy with a variation of normal. At the heart of the project was a common aim to explore the positioning of women at the intersection between the medical, social, and individual expectations of mothering before birth; and the resulting ethical dilemmas. The first film in a series of three focused on maternal/gestational diabetes as the variation. Like boxes inside boxes, or stories sliding into each other, each step of the process involved learning. The project and the women shifting in a dance of creation that took up and responded to the forces outside the subversive and hidden space of their workspace/meeting place/office.

*We started off the submissions with seriously framed global statements about the state of diabetes in the world. Made heavy and fixed by the use of numbers.*

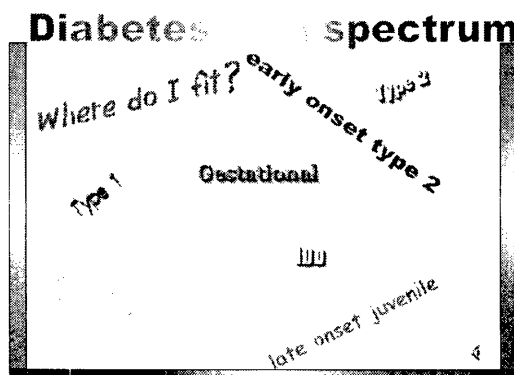
## Three Readings

Diabetes currently affects a significant number of people in Australia with the predicted number of people with Diabetes for the year 2010 being 1.2 million (McCarty et al.1996:v). The financial and human burden of Diabetes is considerable with huge costs associated with tertiary stage care and caring for those with complications (Songer in McCarty et al 1996:51; WHO 1994 in McCarty et al. 1996:6). Diabetes is recognised in Australia as the sixth major cause of death by disease (Diabetes Australia 1999:i). It is estimated that the direct annual health care costs for diabetes in Australia in 2010 will be in the vicinity of 2.3 billion dollars (McCarty et al. 1996:45). This does not include either the economic or other costs to our society that flow on from premature mortality.

*The submission writing process had been a learning one as we integrated what it was we already knew with how to present this to the large funding bodies, the pharmaceutical companies, the government departments and the philanthropic trusts. Each submission cost us \$100.00 Australian to produce and mail off. My writing style changed as I learnt to bullet, and produce the one page executive summary – short enough for an executive to glance through in a couple of minutes. With hints of interesting graphics and borders that had taken me hours to produce. My computer did not generate its own borders. I could draw straight lines and so joined four lines to make a box around the page. In the presentation of the submission it seemed very important to make sure that the lines met at exactly 90°, each line exactly the same thickness as the others. We were after all sending it out to the head offices of large multinational organisations. These submissions were to be mailed out from the small studio office in which we worked surrounded by the mess created by our young children, and the detritus of our daily morning teas, our testing strips, and disposable syringes.*

The findings of the DCCT (1994) and the UKPDS (1998) indicate that there is a correlation between intensive treatment of diabetes, reduced BSL's as measured by an HBA1C and the reduction of the severity and onset of complications. The control of BSLs needs daily management by the person living with diabetes. Daily management requires the consent and desire of the client to modify their behaviour eg take medication if necessary, exercise, control and change food intake, stress management and so on.  
(Presentation to the Federal Dept of Aged Care and Health, 1998)

Diabetes is a chronic systemic degenerative disease. Left untreated or unmanaged it has high levels of complications and mortality (Colagiuri et al, 1998). The mortality rate with diabetes is often hidden, as the mortality is associated with the complications that arise from the disease. In Indigenous people in Australia there is a high mortality rate associated with diabetes (Colagiuri et al 1998). Even in the case of treated diabetes there is a high level of complications- particularly in the case of Type 2 (mature onset) diabetes. Type 2 is often present for many years but undiagnosed until the onset of complications- for example problems with eyesight, blood pressure, or circulation.



*Narration for slide: The video is highly relevant for people with Insulin Dependent Diabetes, Non-Insulin Dependent Diabetes, Gestational Diabetes as well as those who are Glucose Intolerant. We feel that by categorising diabetes people tend to believe that they can get a mild form of diabetes or a more severe category rather than*

*understanding that serious diabetes is out of control diabetes. One of the findings of our research is people's belief that how their diabetes is treated is an indicator of how bad it is and they see that going on to more intensive forms of treatment is a bad thing – so that they go to extraordinary lengths to avoid receiving adequate treatment. So in the video what type of diabetes people have is treated as less important than making sure it is controlled.*

**FIGURE 1: Slide and narration from presentation to Federal Department of Health 1999**

The anecdotal evidence of health workers, educators and GPs supports the need for effective education for people with diabetes. There is a disproportionate ratio between people with diabetes and allied health professionals. (Alexander, 1998) Health resources are severely stretched so that “in many areas it is considered a good outcome if every client has 1 visit

with a diabetes educator” (Harris, 1999). In South Australia it is estimated that only 30% of people with diabetes see an allied health professional other than their GP (Alexander, 1998). This places a huge burden on GPs and people with diabetes (McConnell-Imbriotis, 2000) leading to a need for educational tools that assist in the effective self management of diabetes.

**FIGURE 2: Excerpt from script**

Graphic TV/DIC	Graphic Number	DESCRIPTION	SPECIAL NOTES	SCRIPT
V	1	Title on to foggy screen Title dissolves screen resolving into....		This video has been made for people with diabetes and their families
		Cold grey sky, rainy day in through window large room back of person working on a table. Large amount of things on table		Often when we are first diagnosed with diabetes it is difficult to take in and remember everything that we need to understand.
		Focus on large number of parts on table- jigsaw??		We hope this video will be useful as a starting point for you.
		Focus from collection of things to person hands in head		It is very easy to subject yourself to unnecessary guilt or make choices that will lead to unwanted consequences simply be ause you have the wrong idea about something that affects your body and diabetes.
		Cross to Daphne in garden working on mobile stay on this		So this video aims to full in the gaps for you, making sure that you

Gestational Diabetes is a complication of pregnancy. In Australia national guidelines recommend that women over the age of 30 are routinely tested for diabetes at 28 weeks gestation, or if there is a history of diabetes or large babies that they are tested between 13 and 16 weeks gestation. In 1991 the Australasian Diabetes in Pregnancy Society (ADIPS) recommended that all pregnant women should be tested for GDM in every pregnancy (Moses and Colagiuri 1997). Gestational diabetes develops with the development of the placenta and ceases at the birth of the child. Women who have had gestational diabetes are at increased risk of developing diabetes mellitus. It is suggested that women are tested for diabetes 1 year following the birth of the child. On diagnosis with gestational diabetes women are expected to comply with treatment for diabetes in order to achieve euglycemic levels (better than normal blood glucose levels) as there is a correlation between the blood glucose levels and the health of the baby. Moses (1999, pers. comm, August) has suggested that the high rates of gestational diabetes may be caused by undiagnosed diabetes prior to the pregnancy.



“I’m not too sure about this baby,” Alison had said to Helen, as they walked along the bike track. “Somehow I don’t feel connected, it’s all a bit traumatic”

Helen, had remained silent for a while, the rhythm of the walk taking over. The pram clunked along with young Eliza waving her fists up at the sky, eyes wide, three months old and delightful. The dog Penny, scruffy and restraining her desire to chase the magpies trotted next to the pram.

“When the baby gets bigger, when you can feel the weight of it in your belly, things will feel different then” said Helen.

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And for a fleeting second Alison remembered the delight she had felt when her older two babies, had first fluttered in her belly. Another baby at 40, and the diabetes so out of control before falling so unexpectedly pregnant.



For three months now Alison and Helen had gone walking together several times a week. Both had diabetes and this was a way of providing mutual support in their exercise routines. The relationship was to turn into a working partnership, along with another woman, Amanda. The three women set out to make a series of films on the complications of pregnancy, with the first film using diabetes as a complicating factor. The initial task was to secure funding for this project. The three women would meet, often bringing lunch or morning tea. Each had older children at school. Their conversations ranged from the practical aspects of developing budgets, contacts and filming resources, dealing with recalcitrant children at school, to the more intriguing and creative questions of the issues at the heart of the film.

The collection of statistics to support the funding application for the film *Woman with Child* was difficult. Diabetes is not a registrable disease. The only statistics available were the number of people registered with the National Diabetes Supply scheme (NDSS). Through this they were able to get an estimate of the number of women registered who were using insulin. Other estimates in Australia had been made by Moses (pers com 1999), and in the initial work of Zimmet in *The Rise and Rise of Diabetes* (McCarty et al 1996). The research which was later published as *The Australian Diabetes, Obesity and Lifestyle Study 2000 (AusDiab)* (Zimmet et al 2001) was being conducted at this time. In the search to collect relevant data the three women started to develop a network of people working in the diabetes field, the researcher for Diabetes Australia NSW, the outreach workers in South Australia, members of the Australian Diabetes Educators Association.

After a time Amanda was offered alternative work, with a guaranteed income, and she gave up the excitement of the film with its dubious materiality and took on the world

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of finance and accounting. Alison saw her again one year later in the supermarket, late at night, “The only time,” Amanda said “I can get away from my computer – I am into online trading now, stock market, doing quite well actually except its murder on the social network.”

The challenge for many women seems to be one to cease to be victims of patriarchy without becoming champions of capitalism even though patriarchy appears to be much more persistent than any economic model of production. The birth of democracy and capitalism, which are based on universal freedoms of choice have, historically demonstrated little freedom for women, especially in organisational life.  
(Vickers 2001:63)

Traces of Amanda remained in the artwork used as part of the submission.



***FIGURE 3: Front cover of submission Woman with Child***

Meanwhile Alison and Helen continued the work. But the film changed. In their tracking down of finance, it became clear that there was a gap in the educational material available for people with diabetes. That education was perceived to be central to the treatment and management of diabetes was clear in documents from practitioners' guidelines to the national strategy.



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For example in the guide developed by Alford, Baldwin, Colagiuri et al (NSW Health 1998:6) the starting point for the criteria for the principles of education states:

It is a fundamental right of all people with diabetes to have access *to appropriately tailored information and education* in order to acquire the knowledge and skills to participate in the management of their diabetes.

The National Diabetes Strategy and Implementation Plan (NDSIP) (Colagiuri, Colagiuri & Ward, 1998) outlines the task of implementing a national program to improve the quality of diabetes care as primarily to ensure that all people with diabetes have access to recommended standards of care, and to improve the metabolic control in people with diabetes in order to minimise diabetes complications. One of the key intervention points in known diabetes is the provision of education in self care at diagnosis (Colagiuri et al., 1998). Among the proposed indicators of the NDSIP is the proportion of people receiving diabetes education and nutrition advice. Consequently the dissemination of educational material by specialist units, GPs and other health professionals working at the client level is encouraged (Alford et al; American Diabetes Association 1995; Colagiuri 1998; Expert Committee of the Canadian Diabetes Advisory Board. 1992; U.K Clinical Standards Advisory Group 1994; World Health Organisation 1986).

The centrality of education was, and is, juxtaposed with the ‘accepted need for further research into the area of education and the self-management of diabetes’ (Berman et al 2000). At this time Alison wrote in her journal:

*Everywhere I go these days I hear stories of people with Diabetes, either stumbling through the dark, uninformed and out of control – the responsibility for their well being firmly in the hands of others, or more frighteningly feeling control taken away from them and handed over into a limbo of some sort. Others live frustratingly with their experiencing body ... The separation of disease from self, from experience, from body resonates throughout the stories of these people.*

Alison and Helen continued working together on an almost daily basis. As Helen's baby Eliza grew so did the baby in Alison's belly. The search for funding continued. The women experimented with different filming techniques. A draft of a video was written. This all happened casually intertwined with the real stuff of life. Helen stormed in one day, after having an appointment with her specialist. For months she had been worried about the numbness in her toes. For years she had been presented with images of "the diabetic foot". Alison's first search on the internet after being diagnosed with diabetes had yielded graphic pictures of "the diabetic foot". This took on a life of its own. Mention by Alison to educators of this, would always raise a knowing look, a laugh. Helen had finally spoken to her doctor about her numbness. Numbness is a symptom of the development of Neuropathy.

*FIGURE 4: Text from US government web site*

**What is Diabetic Neuropathy?**  
 Diabetic neuropathy is a peripheral nerve disorder caused by diabetes. The symptoms of diabetic neuropathy are often slight at first. In fact, some mild cases may go unnoticed for a long time. Numbness, pain, or tingling in the feet, or legs may, after several years, lead to weakness in the muscles of the feet. Occasionally, diabetic neuropathy can flare up suddenly and affect specific nerves so that an affected individual will develop double vision or drooping eyelids, or weakness and atrophy of the thigh muscles. Nerve damage caused by diabetes generally occurs over a period of years and may lead to problems with the digestive tract and sexual organs, which can cause indigestion, diarrhoea or constipation, dizziness, bladder infections, and impotence. The loss of sensation in the feet may increase the possibility for foot injuries to go unnoticed and develop into ulcers or lesions that become infected.  
 ([http://www.ninds.nih.gov/health\\_and\\_medical/disorders/diabetic\\_doc.htm?format=printable](http://www.ninds.nih.gov/health_and_medical/disorders/diabetic_doc.htm?format=printable))

So Helen had voiced her concern, had told of the symptoms. The doctor had confirmed that yes she probably did have some Neuropathy – but laughed, saying “Don't worry Helen, we're not going to cut your toes off yet” The real issue, the one that Helen and Alison pondered over, delved into, mined, turned every which way, was the movement from being able bodied to disabled, from having a healthy foot to *becoming* the diabetic foot. The reality of “living with complications”. The meaning

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and purpose of denial. The great divide between the living and lived life, and the safety of the doctors' perspective of expert. They began to look for signs.

As Charles S. Peirce once said, "A sign is something by knowing which we know something more". (Eco 1986:xi)

And so began the first reading.

## THE FIRST READING

*After a telephone conversation with the Australian representative for a pharmaceutical company, I came away with the instruction that the submission needed to show them “the information gap”.*

Specialist units in diabetes promote maximum drug intervention where appropriate, client education and support of GPs and other health professionals working at the client level (Alford et al; American Diabetes Association 1995; Colagiuri 1998; Expert Committee of the Canadian Diabetes Advisory Board. 1992; UK Clinical Standards Advisory Group.1994; World Health Organisation 1986).

Alison delivered a healthy baby, and moved from a pregnant woman with diabetes into taking up the rhythms of diabetes in her own life, adjusting again to breastfeeding and diabetes, and on weaning from being insulin dependent to attempting to adjust to different oral medications, diets, and various other medical regimes, delivered more casually with the removal of the ethical crises that occurs when a woman’s body both nurtures and threatens a baby growing within. With each of these steps, the women would talk, reflect and go out to research some more.

The conversation between the two women continued on for three years. Alison read through a manuscript of Helen in which she reported on interviews she had done with women with diabetes and their experiences of pregnancy. Alison was able to identify one of the women interviewed as a woman she had spent time with when they were both hospitalised in pregnancy, years before. They were able to talk about their own reactions to pregnancy, to this other woman. Together they had lived through Alison’s late pregnancy, the sudden Blood glucose swings, hypos, Helen’s brittle diabetes, they injected and ate together, pouring over the documents, the papers, the ever encompassing hoops required to justify the acquisition of seed funding.

They were approached to submit a paper for the International Diabetes Institute. They worked with three other women to produce a paper *Voices of Experience: Ethnographic Film as a Research Tool in the Field of Diabetes.* (Berman et al 2000)

By this time a whole production team had been developed with a marketing manager a project manager a visual graphics person etc etc. The two women held together the

content and used these others as their strengthening as they moved more and more into a world of business. Big business.

The Diabetes industry is worth billions of dollars world wide, with the WHO estimating in 2002 that diabetes costs between 2.5 – 20 % of annual national health budgets. The ongoing costs of managing and monitoring diabetes generates large profits for pharmaceutical companies. Anecdotal information from Roche and Bayer indicates that home testing kits to measure blood glucose meters are sold at cost price or a loss by pharmaceutical companies in Australia. The return of the investment comes in the form of the income generated by the sale of testing strips. These are currently available on the National Diabetes Supply scheme and are subsidised. The non subsidised price of a pack of 50 strips is approximately AUD \$28.00. The website for youth with diabetes – Reality Check – estimates that the cost of products for someone using insulin 4-5 times per day and monitoring 4 times a day will be in the vicinity of \$56.33 per month (<http://www.realitycheck.org.au/money.htm>). This does not include the costs of other medicines. In Australia the annual pharmaceutical benefits scheme (PBS) cost of the new drugs Actos and Avandia, for the treatment of glucose resistance in type 2 diabetes, is “about \$1,200 per patient per year and it is expected that some 50,000 diabetic patients will benefit from these listings each year.” (Dept. of Health, Media Release, Oct.2003)

Alison and Helen became immersed in figures and potential sponsors – researching philanthropic trusts and pharmaceutical company profits.

Meanwhile the Federal Department of Aged Care and Health launched their national initiative – the Defuse Diabetes Campaign. This was supported by a television advertisement. The sequence opened with a bomb with a prominent “wick”; the wick was lit and burning down. The sound image was of a ticking bomb. The voice-over detailed some of the complications of diabetes and urged people to go to their GPs for diagnosis, in case they were sitting on this time bomb.

The Federal Minister of Health, Dr Wooldridge, who came from a medical background and had diabetes himself, had supported the prioritisation of a national diabetes strategy. This had raised the profile of diabetes research. Not only was Diabetes big business, for a time it was almost sexy. The Federal Department became interested in the women's project. The women, the production team and the department entered into a dialogue.

The conversation changed the women, who, firmly positioned in the private sphere, the home, as the person with diabetes, found their perceived position change to one of representation.

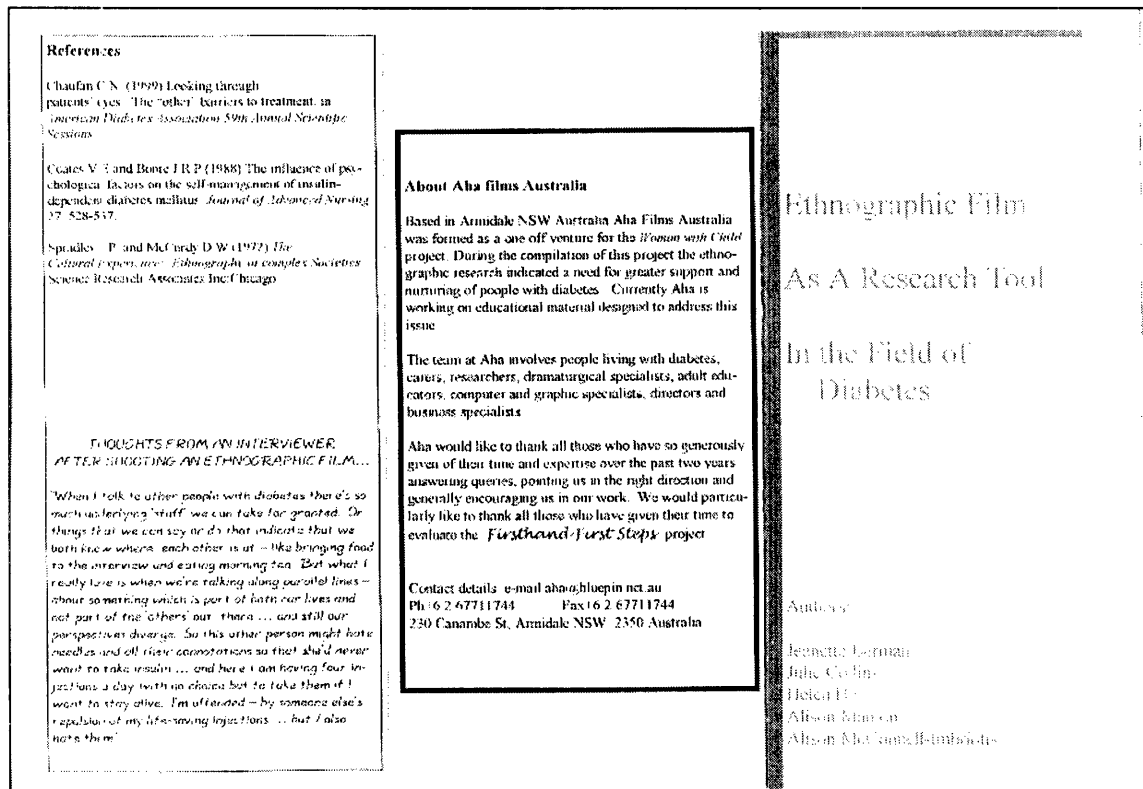
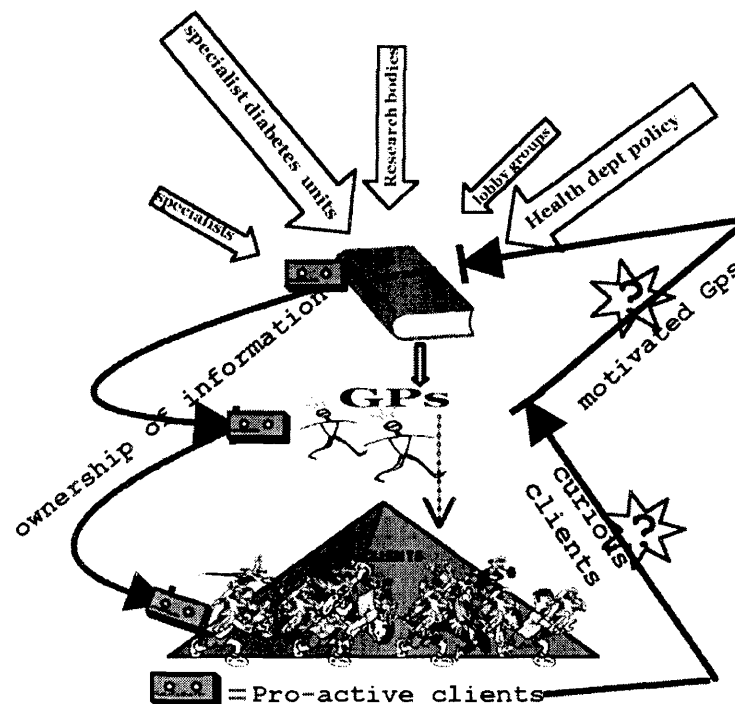


FIGURE 5: Brochure produced for IDF 4<sup>th</sup> Western Pacific Congress 2000

The bureaucratic arm of the Diabetes movement through the Federal Department of Health and Aged Care had endorsed the women's work. One of the most appealing facets for the Department was that their work was consumer driven. There was a

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mutuality between the desires of the women and the needs of the Department. The women desired to give a voice to the experience of those living with diabetes, and to acknowledge the possibility of the experience and expertise in that living being a valid contribution to the diabetes 'field'. The Department needed to find a diversity of educational materials, and to address the emerging realisation that despite the level of information available people were not changing their behaviours (NMHRC 2001). However despite recommendations from the Department the Ministerially appointed taskforce, comprising of three endocrinologists, while supporting the video in principle, did not see the funding of educational materials as a priority. (pers com. 2000)



**FIGURE 6: Presentation Federal Department of Health 1999.**

Eventually the pressures of maintaining a double positioning, within the world of work, the field of diabetes, the home, the private, as mothers, as wives as women needing to find a source of financial security grew too much and the conversation stopped. For a time. Both took a step backwards and picked up the threads of their earlier careers, Helen in writing, Alison in education and then the second reading began.

## THE SECOND READING

At the academic level I concern myself with the problems of language, communication, organization of the system of signs that we use to describe the world and to tell it to one another. The fact that what I do is called “semiotics” should not frighten anyone. (Eco 1986:xi)

A great deal of the discussion between Helen and myself had revolved around the information gap. There seemed to be a fissure between the idea of information and of knowledge, of the process of getting information and being educated, and in the purposes for that education.

While diabetes education is a main pillar of the Australian National Strategy on diabetes, and is heavily promoted in the current guidelines for treatment there is a disproportionate lack of diabetes educators to clients. (Alexander1998; Harris 2000; Interview General Practitioner 2003;Interview Diabetes Educator 2004;) GPs are not trained as educators nor do they have the resources with regards to time to take on an extensive educational role and where able they will refer their clients on to a diabetes educator. GPs, diabetes educators, dieticians all use pamphlets (booklets and fact sheets are included here as pamphlets) as a means of giving people information on diabetes. These information pamphlets by default assume the place of education, and become the signifiers for the concept of education. Print based material then is commonly available for people on first diagnosis which is regarded as a key intervention point.

Most educational materials produced as part of public health policy are primarily aimed at the whole community. This is very much the case when the materials are produced to support, or instigate, initial education on diagnosis of a condition such as diabetes. The sheer numbers of people affected by diabetes across the socio-economic and socio-cultural spectrum mean that the audience for these materials come from disparate locations across this spectrum. So even though the material is aimed at educating people about a particular disease or medical condition, it still needs to be framed in terms of a whole community spectrum. In other words, while the information regarding the disease is dealing with the commonalities of that disease the material itself needs to be flexible enough to be accessible to a broad range of readers.



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Patients in receipt of educational materials have often lived with diabetes – either diagnosed or undiagnosed – for many years. Educational materials are offered to patient/clients both on diagnosis and/or when they commence or change medication (Servier c. 1999). When people are diagnosed with diabetes they already have a bodily experience of living with diabetes. As Leder writes:

My body is always a field of immediately lived sensation... Its presence is fleshed out by a ceaseless stream of kinesthesias, cutaneous and visceral sensations, defining my body's space and extension, and yielding information about position, balance, state of tension, desire, and mood. (Leder 1990:23)

Furthermore as Type 2 Diabetes is most commonly diagnosed in people over 40 years of age, the recipients of the educational material will have had considerable life experience. This means that the material they receive will be read against a history of public health campaigns, popular media and advertising. A great number of people will have been aware of various health “fads” and campaigns revolving around diet, fitness and general health. These are an increasingly pervasive aspect of our lives.

Hancock et al (2000:3) comment that:

The fitness, health and dieting booms of the 1970s and 1980s supported the marketing of all sorts of commodities and techniques for bodily enhancement. For a significant number of women dieting can take on vocational proportions and one study [Ogden 1992] claims that only 10 per cent of women have never dieted.

In the light of this trend it becomes even more critical to acknowledge that educational materials intersect with prior information and [mis]conceptions. These three aspects alone, the socio-cultural background and positioning of the reader, the bodily experience of the individual and the exposure to other information are pre-existing conditions to any formal diabetes education. This means that the material needs to deal with the experiences of the people and supports the learning experience of the client. In educational terms it needs to be designed to encompass the whole spectrum of different learning styles and to address the needs of adult learners.

The majority of this material is presented to the clients as pamphlets, booklets and increasingly fact sheets and computer print outs. The means of distribution of this material is via GPs, Community Health Centres, educators or dieticians.

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Some of these materials are produced by the pharmaceutical and diagnostic companies that manufacture products for treatment of people with diabetes. Other material is produced by support organisations, research organisations and state and federal departments of health. In turn many of these organisations receive funding from the pharmaceutical companies specifically for the production of educational materials. (see Diabetes Australia, *putting diabetes first* . 1999). In Australia, the endorsement of these materials by organisations such as Diabetes Australia, or the Diabetes Educators Association is a mechanism of quality control. However this endorsement process is interesting in itself.

When Helen and Alison were negotiating for seed funding for the development of the video they approached Diabetes Australia for endorsement. The script for the video had been reviewed by people living with diabetes, as well as by a broad range of experts in the field, the majority with international standing. The script submitted to Diabetes Australia had addressed many of the concerns that had been raised through the review process, with regards to both form and content. All educational materials endorsed by Diabetes Australia are reviewed by the Health Care and Education committee (HCEC). The Australian Diabetes Educators Association were prepared to endorse the video if it was reviewed by the HCEC.

Members of the committee donate their time.

On the committee at the time were a number of people, including a legal representative, an endocrinologist, a general practitioner, a dietician and a diabetes educator. The educator originally came from a nursing background. There was some criticism by the dietician who felt that the guidelines that were used by one of the diabetes associations, authored by herself, should be included and used solely within the video. There was, and at the time of writing still is, no consensus in Australia, or worldwide, as to the most appropriate diet for people with diabetes.

*I also use a lot of computer print outs now - We have a resource of print outs from the computer so that's quite an easy way to access it rather than keeping mountains of paper in your cabinet- that's quite useful.* Interview with a General Practitioner 2003

The materials themselves are the end stage of a series of decisions. Form and content come together representing a variety of influences and representations. An analysis of various pamphlets, fact sheets and booklets materials used in diabetes education needs to consider aspects such as format graphics content and their links to education and learning. Furthermore, they need to be examined for what they don't say/reveal/represent as well as for what they do represent as "facts" or "truth"—for as Leder (1990:147) so simply puts it "Truth, understood in Heideggerian terms, is a process of simultaneous revealing-concealing. Aspects of the world are disclosed only by virtue of obscuring others. Within these materials are the traces of certain knowledges (Irigaray in Grosz1988:25), attitudes and assumptions, which are manifest in the decisions of presentation, in the making visible and explicit of some things, while absenting and making invisible others.

### **Format**

The benefits of print-based booklets and pamphlets are that they are relatively low cost to produce, easily distributed, and relatively non-labour intensive. The expertise for the information can be found within the specialist field and the expertise for the production of the formatted material is readily available.

However there are also several disadvantages with this form of information sharing and I detail these in the next section.

While the booklets, pamphlets and fact sheets had some graphical content they are predominantly print based. This format immediately discriminates against people who are vision impaired, non-literate or with low levels of literacy, and who speak English as a second language. Many people with diabetes suffer from complications with eyesight.

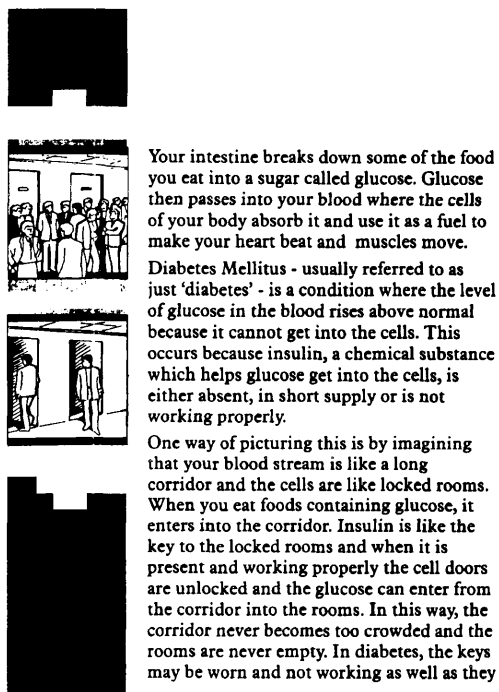


FIGURE 7: Servier brochure c.1999

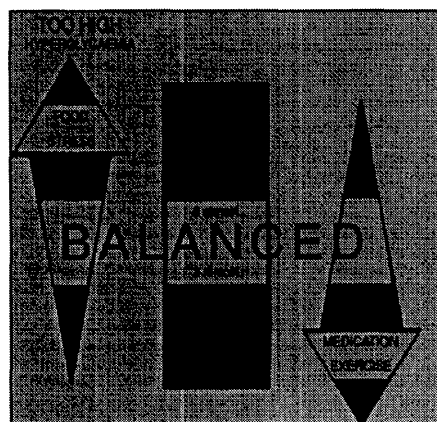


FIGURE 8: Diabetes Australia brochure 1996

Both these figures demonstrate the necessity of a high level of literacy in order for them to be understood. They are also underpinned by the assumption that information is conveyed simply by the literary expression of that information. The basic aim of education is to allow learning to take place. Current education theory accepts that there are different ways of knowing and multiple intelligences (Bloom 1956; Gardner 1983; 1990;). So even in the case of people who are highly literate, literature may not be the most effective tool to ensure that the information is accessible. (ABS 1997)

The physical format dictates the way in which information is expressed.

And the tool mediates the construction of knowledge, not in an unbiased way but through the traces of the knowledge that constructed it in the first place.

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[invented tools] turned from history into nature, they are invisible, unremarkable aspects of our experiential world...these tools literally carry intelligence in them, in that they represent some individual's or some community's decision that the means thus offered should be reified, made stable, as a quasi permanent form, for the use by others... as such tools become invisible, it becomes harder to see them as bearing intelligence; instead we see intelligence as residing in the individual mind using the tools. (Pea in Daniels 2001:17)

The fact sheets are often presented in a folder. Each page or sheet deals with a separate issue – for example: dietary guides; definition of diabetes; where to get help. The physical format therefore means that the different components of the folder are presented as discrete information.

Space constraints associated with pamphlets, booklets and fact sheets promote brevity. This directs the use of language. Consequently the language used tends to present a series of statements as concrete facts. By highlighting these facts and eliminating others (by virtue of not presenting them) it then ranks the presented aspects of diabetes as more important than the unmentioned aspects. (Reilly, 1997)

### **General Principles of Adult Education**

The general principles of adult education promote learners as autonomous self directing people who come to the learning situation with their own history, learning styles, experiences and expectations. (Beauchamp & Walters 1999, Brookfield, 1991, Mackeracher 1996; Merriam & Brockett 1997; Vella 1994). Effective adult education utilises the linking of examples to the experiences of the learner. (Knowles, 1990) The theorising around the need for learning to be applicable to the learner's life assumes a dialogue between ongoing experience and learning.

Aronson argues that in order for meaning to be extracted from new information the different elements of that information must be placed in a context. The way in which we link the different components is part of how we organise our knowledge, changing our understanding of a particular subject may involve finding different ways of linking the information and then re-examining the relationship to an overall framework. (Aronson et al 1995 see chapter 6).

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Manion examines this in light of her work on theories and models, and argues that interpreting (extracting understanding from) a diagram, (linguistic or otherwise) model or pictorial representation generally is a learnt, and therefore individually and culturally specific process. This process involves two main steps. The subject must be able to identify which parts of the representation are significant. Secondly the subject must be able to relate elements in the representation with elements of his or her understanding of the world (Manion 2002).

In much the way Billett (2002:1) theorises the affordance of the workplace- as its invitational qualities, so too can educational material be read. In what ways does the material afford the reader the opportunities to enter into learning through their body, in a participatory process between their experience and the practices made manifest through the representation(s) in these materials?

*We had worked in an iterative process between our experience, the stories of other people with diabetes, and the information booklets brochures and pamphlets. Looking through this lens, developed as it was out of the conversations between the two women, the second reading of materials developed further into a critical analysis revealing flaws like fault lines through which we could fall, and places into which we didn't fit. Later I was to develop a framework of analysis, a set of criteria for analysing educational materials, which drew on this experience and work in the adult education field:*

- Are the elements of the information presented in such a way as to allow the learner to [re]view the linking of the information to an overall framework?
- Is the new information placed in a context?
- Is the context expressed in ways that allows for cultural difference?
- Is the overall framework inclusive?
- Are different ways of knowing acknowledged and incorporated into the material?
- Is the autonomy of the learner fostered?

## Three Readings

The constraints of the pamphlets lead to very narrow and limited use of experiential examples. The predominant examples reflect the dominant middle class white heterosexual western stereotype. Again the unintended result is to rank the presented examples as more important or common (Fairclough 1989). By not presenting examples that are culturally important to some, it demeans the cultural identity of many people within the community.

A clear example of this is the photographic illustrations used in the Diabetes Australia (c.1999) "*putting diabetes first*" booklet. All the clients are white middle to upper-middle class, and with one exception are over 60 years old. The one exception (figure 9) is minimised by the weak positioning in the frame and the lighting. All the professionals depicted are also white and middle class and younger than the clients. They are depicted as being more powerful than the clients by their positioning in the frame (figure 10). Heterosexuality is implied through the pairings always being presented as male and female.



*FIGURE 9: Photo from Diabetes Australia brochure 1999*

Note larger and well lit positioning of the professional in figure 9. The clothing is authoritative and the body language is confident and focussed. She is dressed in a “power “uniform and her hair is controlled. The client’s body language is uncertain, her position on the furniture not balanced, she is badly lit and is in dark clothes. The point of focus is the folds in the clothing around the abdomen - which creates a marked contrast in the apparent body weight of the two women.



*FIGURE 10: Photo from Diabetes Australia brochure 1999*

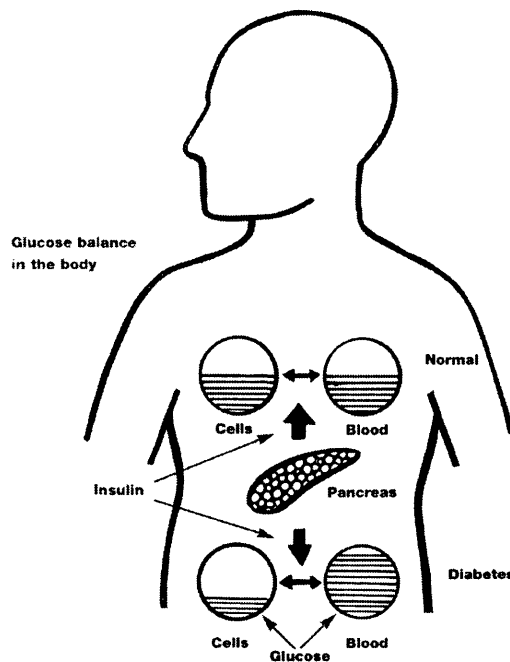
In figure 10 the client appears to be being held up by the authoritatively clothed professional. The professional is young, wearing jewellery and red nail polish- She is projecting her body forward into the frame. This presents an image of confidence, vitality and power. The client is moving away from the camera. Her body is angled in towards the professional and encased by the arm of the professional. She is dressed in soft wrinkled fabric- creating a softer more vulnerable image.



Other examples lie in the dietary guidelines, which do not take into account the different economic constraints or the ingredients that are the expression of different cultural and economic eating patterns. This removes the clients' ability to see themselves as a participant in the translation between reader and text.

## Graphics

The graphics use captions and literary based explanations. As with the written component the variety of graphics is limited by space availability. They are frequently two-dimensional and there is limited use of colour. Consequently they present as diagrammatic. They draw on limited models and analogies. Cultural and educational bias affect the information that is extracted from the pictorial representation. A comparison of say an Aboriginal dot painting and a urban road map clearly demonstrates the cultural differences in the representation of place yet such cultural sensitivity remains unobservable in the representations offered to readers of these pamphlets.



**FIGURE 11: Illustration from Amcal brochure**

As can be seen in figure 11 a prior knowledge of anatomy and physiology is required to extract meaningful information. It is also necessary to be able to read the captions.

## Three Readings

A pamphlet from Dubai, gives an indicator of the interconnection of funding, global pharmaceutical companies, cultural identity and the effect on educational materials. This was one of the only pamphlets for general distribution uncovered by a doctor working in Dubai. The pamphlet is carefully translated into Arabic. The graphics, however, instead of being reproduced to give a more accurate translation of cultural dietary values have obviously been lifted from an American publication with the brand names of the cereal still in English.



**Figure 12: Graphic in brochure from Dubai**

The role models used are all presented as coping with the disease and living a “normal” life. The caption to the photograph below (figure 13) makes many assumptions- such as access to a dietician, availability of food and a mutual definition of “delicious food”. As one educator interviewed commented:

## Three Readings

[W]e have a lot of homeless and sort of ... old guys, living in a single room in Kings Cross paying obscene rents so there's often no money for food and to say to them you have to eat three meals and three snacks a day and must eat the best quality and blah, blah, is totally unrealistic for that person when sometimes they don't know where the next meal is going to come from let alone that it's the best fruit and veg.

Interview with Diabetes Educator 2004



*FIGURE 13: Photo from Diabetes Australia brochure 1999*

“Normality” is assumed to be a desirable way of living, and it assumes all sorts of cultural biases. “Normal” assumes routine, time based models of life. It is also implied that this way of organising life is achievable for all people. Control of the aspects of living is seen to be a choice of the person with diabetes. Examples are: choices of food, time of eating, level of exercise, work routines and so forth. Statements like the following reinforce this:

“No-one can change their family history or age. It is possible however to control weight, diet and activity.” (Diabetes Australia 1996: 4)

## Three Readings

Quite clearly for several client groups this is not the case. As in the earlier example economic constraints may well affect the choices of food – sausage mince while high in fat is far cheaper than lean meat. Family structures or rotating shift work may dictate the ability to “stick to a routine”. Exercise regimes for, say, a single woman with very small children, no childcare and little access to finance can be unattainable without shifting whole structures of society.

Um. That really throws people because that's not what the book says and you're not supposed to question it, so - I think that's part of - it is a real tension between knowing what you should be aiming for, in some way, and what's achievable.

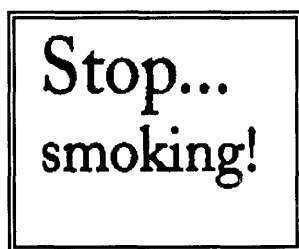
Interview with Diabetes Educator 2004

The progression and effect of the disease itself will also lead to variances in “normal” life patterns. Events such as the use or change of medications, onset and severity of complications, varying levels of symptoms and the interaction of other physical stressors will affect both the process and the outcomes of decision making.

She was a patient of one of the guys at PA not long after I started there so she was a sort'v periphery patient to begin with and then she moved on to someone else and we, over time, became friends apart from that, so I guess in the last 10 years or so when she was on dialysis and things [speaking very faintly as she did before when speaking of this person's death] and in the final years as well, would often go over and cook while she was hooked up to a machine while her husband was at work, and things like that, so it was - the diabetes was always there but I guess in many ways we didn't talk about it a huge amount.

Interview with Diabetes Educator, 2004

As the example in figure 14 illustrates the treatment of the disease is seen as an event rather than a process. This implies that once the decision to follow this advice is made it will not need to be revisited. People are constantly, day by day faced by choices for how they will behave. The elements that need to be balanced that lead to the choosing of a behaviour do vary on a daily basis. That people choose to follow the advice one day but not another, or may modify the degree to which they follow the advice is a natural manifestation of this. That this is not acknowledged by the ‘expert’ voice of the information pamphlet may diminish the efficacy of the advice because it sets up a situation similar to that found in “yo-yo” dieting: The option seems only that of “Doing it perfectly or not doing it at all”.



**FIGURE 14:** *graphic from Diabetes Australia brochure 1999*

Inferences such as these – that the desired behaviour is achievable, normal and adopted easily (Diabetes Australia 1996) can lead to a sense of failure and isolation when people experience problems in adopting the outlined behaviours. Much of the literature emphasises the need for the person to adopt new or different behaviours. The difficulty of doing this is not discussed. There is little acknowledgment of the vast evidence that suggests for example that changing eating patterns in people is an extremely difficult process (Goody 1982; Kaufman 1998). The result is often that people feel inadequate and guilty.

Much of the material can be interpreted as a series of directives. In chronic disease there is often anger and grief at the loss of control over one’s body and life. (Berman 1999) Respect for the individual’s control over self would be better emphasised if the educational material presented choices rather than directives.

## Content

There is very little focus on the level of shock, grief, and denial associated with chronic disease. Information in the pamphlets is presented as a series of facts, couched in terms of the medicalised body (Hancock et al.2000) and because of this the psychosocial aspects of the disease are rarely mentioned, acknowledged or dealt with. This happens in a variety of ways including: silencing such important psychological factors as the recurring nature of negative emotions; ignoring the social, physical and emotional differentiation of clients; the depiction of stereotypical normal lifestyles; and short-term over-simplistic focus on lifestyle changes which treats diabetes as a static disease.

Shock, grief, anger and denial are recurring aspects of chronic disease. (Berman 1999) People have to deal with recurring emotions that arise at different times, and that manifest in different ways. Acknowledging and flagging the emotional responses to chronic disease would encourage the use of metacognitive processes – so that the client can use, or seek help to use, a cognitive approach to interpreting their own behaviour (Freire, quoted in Taylor 1993:58) and approaches to decision making For example the emotional response of denial can cloud the self-management of the disease. Furthermore, giving clients the reflective tools by which to name the interiority of their world creates an emancipatory structure for the learner. (Freire 2000)

Many people are already living with complications of diabetes. However in this literature complications are treated as punitive. The material deals with complications of diabetes as end results of diabetes and as negative – and this can be interpreted as the complications being the result of people's behaviour as opposed to being a part of the progression of the disease.

I offer the following example:

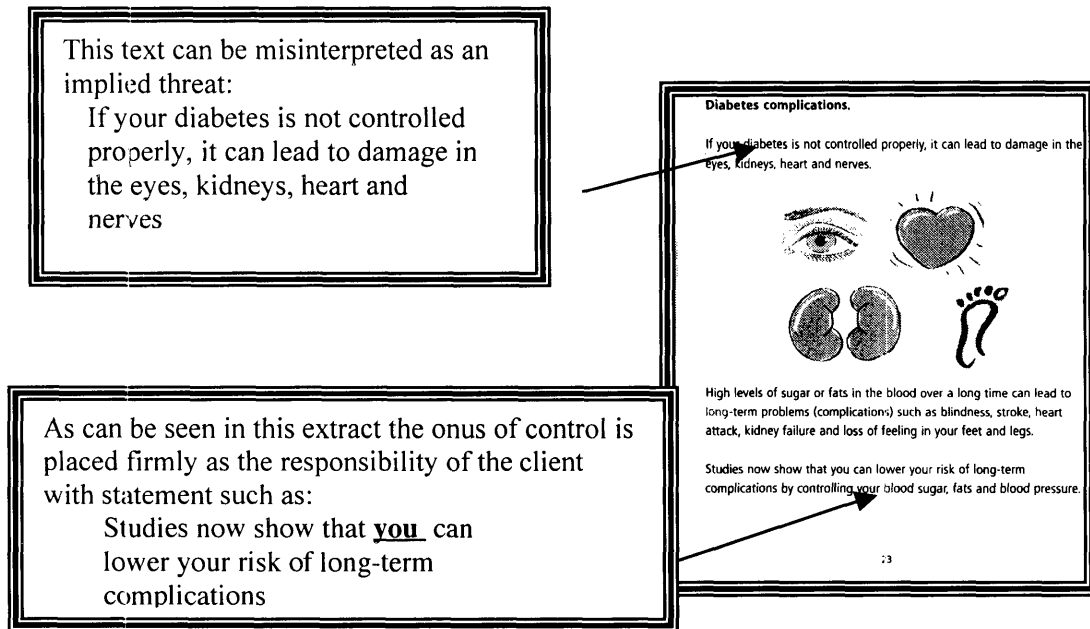


FIGURE 15: Novocare brochure c.1998

This sets up a fear response to the possibility of complications, while disempowering people already living with complications. By ignoring the realities of living with complications the material does not provide a framework that allows for a positive discourse. For people already living with complications the allocation of blame is both disrespectful and counterproductive.

Death is not mentioned or is euphemistically mentioned in the material. When it is mentioned it is done in a manner that sensationalises it or removes it from the arena of the reader. For example in the excellent introduction to Diabetes Australia's *putting diabetes first...* (c. 1999:i) the statement is made that:

“...diabetes is recognised as the sixth major cause of death.”

but on the following page this statement appears:

“However that doesn't mean that it's [diabetes] diagnosis is a death sentence.”

While the admirable intention may be to lessen the fear of people diagnosed, it also has some negative consequences. On one hand this undermines the client's need to deal with issues of mortality on diagnosis, and at various other points during the progression of the disease, while on the other hand minimising the degenerative nature of diabetes. This adds to the perception of diabetes being a static illness rather than a dynamic illness that has different manifestations at different stages and in differing circumstances. It also ignores that clients may have to deal with issues of mortality on diagnosis and at various other points during the progression of the disease.

While the progression of the disease is different for every person, and the severity and onset of complications vary widely, the lack of consideration of issues around mortality suggest that there is an element of denial in the material itself. By reinforcing the denial the responsibility for decisions regarding health is taken away from the client. Adult education learning theories (Freire in Taylor 1993; Knowles 1990) stress the importance for the motivation for learning lying within the control of the learner. The shifting of control over decisions from the client to the health professional then interferes with the learning process.

It is interesting to note that although the promotional material concerns the body there is an absence of reference to body experience in the literature. There is little to help reframe the bodily experience into positive/bodily framework. An example lies in the bodily experience of hunger. Rather than denying the urgency of the sensation of hunger, it may be more useful to reframe the meaning of hunger (Kaufman 1998) in much the way Cognitive Behaviour Therapy (Edelman 2002) reframes beliefs. Kaufman has had a significant degree of success in working with obese patients, through an approach in which they reflect on and reframe the concept of hunger. For people with diabetes this needs to acknowledge, as a valid biological feedback, the relationship between hunger, starvation and high blood glucose levels. For example the self-talk may need to become:

*When I feel hungry it is possible that my body is starving. This signal could be because I need to eat more food. It could also mean that I am in need of more*



## Three Readings

*medication or exercise so that my body can access the energy provided by the food I eat. I need to solve my body's need and then the hunger will be satisfied.*

The provision of such a tool in the material would serve as a link between the sensations and experience of the body with the medicalised information. Such a device was not apparent in any of the materials examined.

Management of diabetes is often referred to as a team approach (Colagiuri 1998:51-60). A team approach implies that the contribution of each member of that team is valued equally. The participatory involvement of the client in the management of diabetes assumes that they are a member of the team. Therefore their input is as valid as that of any other member and that needs to be genuinely acknowledged. Their experience and how they interpret it is something that only they have access to and this knowledge is a unique contribution to the management of their disease.

*B -- I think the team approach, so that... This is a report for example about a local person who is on our program, and so I've got this report here - this is from Pru, and this is from Gillian, and this report comes from me from the Educator's point of view saying, you know, he walks most days, and has a light beer and the HBA1C is up, and so we need to look at that, and then Gillian has gone through and looked at the - the, ah, the dietary side of things ... So yes, it's a team thing, and I think that's - yeah.*

*A Now, what if there was a section on that where the patient could put some stuff in, about how they're finding the team -*

*B Yeah, yeah. That's a very good thought. We tried - we did that to a degree by making sure that the report they get which - the annual report that goes to them - so that it's their report. It's got all the information on the back.*

*A .Mmm.*

*B There's educational - you know - there's a little brief paragraph - Why we measure that, why we check the eyes, why we check the kidneys, why we*

*check the pulses and the legs and all those sorts of things. Ah, and then they sign it, they sign the form - do you know all about our project here?*

Interview with GP 2003

It would seem that much of the print-based material currently available does not encourage clients to become self directed and pro-active learners. The brevity of the statements, and the discrete nature of the way in which topics were presented in the material, results in patchy information. There is a lack of elucidation with respect to diabetes as a systemic disease, which affects mood, emotional wellbeing, and body, as a whole system.

Without a whole overview of how the body works there is no context into which to place the new information about the body as it is affected by diabetes. Recipients interpret this as their own inability to understand, as they are unable to draw logical conclusions from the insufficient data. When material is reinforced by inappropriate analogy many clients feel alienated or alternatively believe it is too complicated to understand. This then diminishes their willingness to take a pro-active approach to the education. (1999 pers comm., Interviews 1998-2001)

If the aim of diabetes information booklets is to encourage clients to be pro-active in coming to understand their illness, and in making informed decisions regarding the management of their health, then it is necessary to ensure that their first contact with diabetes education is one that encourages them to continue to learn and empowers them as autonomous self directing people. This education needs to enable them – should they so decide – to take a co-ordinating or equal partnership in the health team that advises and assists in the management of their well being.

*B Yes, um, yes so they - they sign that, but maybe your idea of, actually, a space for a patient comment is a good one, yeah.*

Interview with GP 2003

Today Helen came in and we slipped back into that comfortable conversation that moved between and through the intensely personal remembering and retelling of

events – other people’s stories and how we were making sense of the gulf that we feel between the sanctioned and the unsanctioned voices in the diabetes stories and world. As the conversation flowed the phone rang and the policy advisor to a retired Health Minister rang. We found common ground, as she too had a ‘chequered’ academic career – moving in and out of research, with breaks for other parts of life and living. She was speaking on her mobile phone and in her car. And like our careers it cut in and out.

We talked about the best way to present evidence for my prior research, and she commented on the world of diabetes saying: ‘the politics and personalities of diabetes in this country are immense’ (pers com, 2002).

Helen, the ex-policy advisor and I exchanged gossip: Diabetes Australia has just wrested back the national Diabetes Supply Scheme (NDSS) from the Pharmaceutical Guild. They have won the contract and have another 4 years to prove themselves. Part of their strategy will be to fund education and research into education.

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*Diary entry 28<sup>th</sup> July, 2003*

*Have rung Diabetes Australia three times now and emailed them twice asking for a copy of the report evaluating the Defuse Diabetes Campaign. Still no reply.*

Later I was to ask whether I had colluded or was being enticed to collude in the shifting of responsibility, ethical, moral and financial, from the state to the individual in a reflection/doubling of Foucault’s (1980) ‘self policing’.

The bureaucratic arm of the Diabetes movement through the Federal Department of Health and Aged Care had endorsed [our] work. One of the most appealing facets for the department was that [our] work was consumer driven.  
(‘First Reading’ section of this chapter)

## Three Readings

The way in which desire and power were intertwined was that our desire for a voice, which would validate our empowerment, self-direction and individual outcomes, was the hook that co-opted our positioning into a legitimisation of the shifting of responsibility/regulation from the state to the individual. But we were unaware of this at the time.

And so began the third reading.

## THE THIRD READING

In her examination of the body in feminist poststructural research Margaret Somerville writes in reference to Elizabeth Grosz' work:

Because of her underlying intention to work across the binary divide, corporeality is always present in a dialectic relationship with the cultural. Just as we can theorise that language is always there, we can also theorise that body/matter is also always already there, and the body can intervene in discourse just as discourse can intervene into the body. (Somerville 2004:51)

In this third reading I reformulate my concept of the data of this research. I offer the movement between the educational materials, my body-at-the-scene-of-writing, and the reading of the materials as the data, the subject of my research.

I start by moving between different reading(s) of the material, locating the differences in the relative differences of my own shifting and discontinuous subjectivity. From a simple movement in which I attempt to bring my earlier readings into a discursive relationship with poststructural analysis, I start to disrupt the underlying assumptions of a 'liberal humanist self' (Davies, 1997b; 2001; 2004) that is the knower, the analyser, and the autonomous researcher.

My position cannot, and does not, remain fluid and connected as I move from a "sensory world [which] involves a constant reference to our possibilities of active response" to a visceral depth where "[t]he spatial ambiguity of the visceral depths is accentuated by the phenomenon of referred pain. A process taking place in one organ can experientially radiate to adjacent body areas or express itself in a distant location." (Leder 1990:18;47)

*When I first looked at the graphics in the educational materials I did so from the perspective of someone with diabetes, feeling very uncomfortable with the arrangements in the pictures. I felt angry and contemptuous – much safer that way.*

*I looked at each one in a way that made sense of the pictures and my feelings. When I glanced through them again today I looked at a series of pictures and found different meanings.*



*Each member of your health care team is specifically trained to provide the guidance you need to manage your diabetes and help you incorporate it into your lifestyle*

**FIGURE 16: Image and caption from Diabetes Australia brochure 1999**

*Looking at this particular picture and the text below the main emphasis is the acceptance of the medical model as a part of one's life, where that knowledge will take precedence over own ways of knowing. It is about moving into a particular acceptance of a particular construction and site of production of knowledge.*

Notes made during workshop with Bronwyn Davies (UNE 2001)

Shildrick (1997) writes that:

A proliferation of texts has appeared which go well beyond the fixed certainties of the past and posit a problematic in which the health-care encounter is seen as one which must be negotiated with as much ethical as technical acuity. It is not that the transactions of health care have entirely escaped moral scrutiny in the past, but that the issue was assumed to rest on the proper conduct of the practitioner. So long as she was seen to be exercising appropriate moral agency, according to parameters already laid down within implicit and explicit professional codes, then the moral requirement was satisfied. The position of the other participant – the patient – in the health-care encounter was of limited ethical interest in that she was characterised as a passive receiver of benefits rather than as an independent agent. The dichotomy between the two positions, that of morally active professional and

of the inactive patient, was most clearly evidenced in the traditional medical model of health care in which the two roles were clearly delineated on an institutional level. (7-8)

During the workshop I looked through the graphics and noticed the separation between the clients and the professionals. It is easy to distinguish who the medical personnel are and who the clients are. Even more interesting is the way the professional women are isolated and not in relationship with each other, their environment or their clients. The professional men, in contrast appear to be either able to directly look at their clients, and still maintain their authority. The women, who as professional workers in the medical sphere, doctors nurses or pathologists, it is difficult to distinguish which role they play, are in the main easily distinguished.

As I understand it, what is at stake in traditional health-care practices is that the material boundaries of the body should be securer and that otherness be excluded. (Shildrick 1997:11)

They are more formally constructed, tend to either be supporting the client physically, or to be in a world bounded by uniform and test tubes.

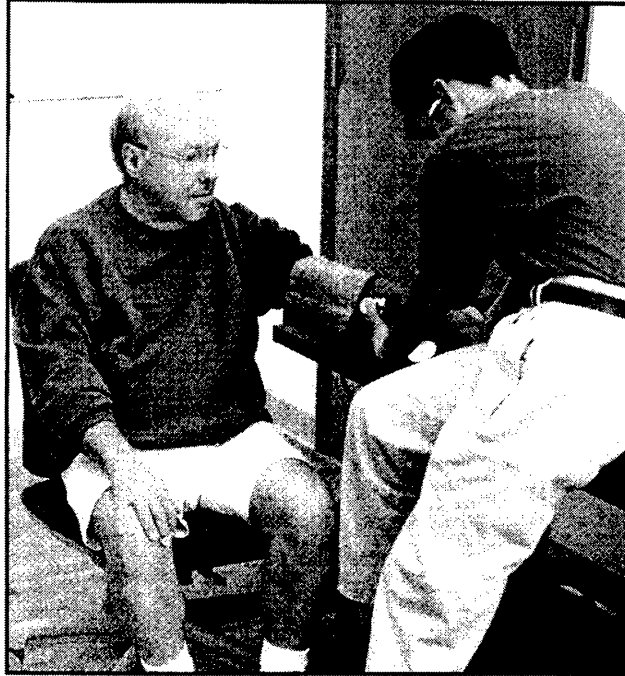
And I wonder how, if in the medical sphere man is in the centre, that woman may be used to define the edges:

Barbara Holloway, in her thesis on the inscription of land in the new colony, shows that woman provided both inner core (as home) and outer limit (as frontier). She refers to the work of Bachelard to theorise woman-as-home, to Kristeva (and the abject) for woman-as-limit and to Burgin's view of the pre-*oedipal* mother as the first object of abjection (Somerville 1999:192)

I am intrigued by the professional who is casually on a desk, turned away from the camera and the client, measuring blood pressure. Only their back is seen, hair short, casual clothes. Is this a woman? I think perhaps it is. And I ask what is it that makes me think so: Is it the curve of the cheek? Or the way the body awkwardly turns in towards both client and equipment, the placing of the body in relationship to the patient even at the expense of comfort? Or is it the precarious position, perched on the table, marginalised at the edge of the table balancing one leg reaching to the floor the other hitched up? Again, although not presented as the other women are, in total medical uniform, bearing the marks of belonging, the woman is isolated even from

## Three Readings

the viewer, no longer given a face. (Later I re-read this again, is that facial hair? Should I perhaps have realised that the lack of uniform was indeed a marker of gender?)



**FIGURE 17: Photo from Diabetes Australia brochure 1999**

Barbara Holloway consciously sets out to unravel the knot of woman as both home and envelope/limit. (Somerville 1999:191)

I have come down to the beach house to work. To get the final pieces of this work down re arranged. I have with me Vivian, who is five; Daniel who is thirteen and is sporting a huge pimple, shadows of a moustache yet to be shaved; Jacques who at 17 flexes his power as a male in an adult male world – knowing all in anticipation of living it. sure of his place in the world and his invitation to power; and Regina, a German exchange student who has had the misfortune of choosing this family at this time to spend 8 weeks with. Speaking with my sister after one day here I complained that I did not know if it was a cultural thing, a Germanic indoor thing that despite the glorious beach here, the relief from the cold of the Armidale winter, the banksias, the dolphins, the blue of the Australian sky, and the garage full of the equipment for outdoor living, canoes and kayaks bikes and balls, Regina chooses instead to find where I am sitting, with my books and notes, and sits directly opposite on the couch,



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with a book to read, or just sits. I feel responsible. I feel consumed. The children are needing to eat, I urge them to take responsibility for the house, be rostered on for lunch for dinner for washing up. The effort to discipline them is exhausting. I feel busy all the time, my writing some dream, hovering in the background hazy and insubstantial. I feel like I am giving bits of myself away. I am being consumed for lunch, for dinner.

*The two staple strategies for diabetes are exercise and diet. But what if you are the diet?*

The most frustrating thing of course is that when I am in the flow of writing, and wanting to keep the world out, the demands out, no one responds to my requests to entertain the 5 year old, leave me alone or whatever- but as soon as it suits them they go off and give me instructions to work hard. The determination as to whether the world invades my boundaries is entirely dependent on others.

My sister rings and tells me she has been awake, in the night, thinking. She needs to tell me the difference is not cultural, not German, but that Regina is a girl. A teenage girl; that I have only had boys. And that for a teenage girl the most important thing is to relate. That I should try to cultivate a generosity of spirit for this young girl, on her big adventure, her travel away from her home, her homeland. And I am trapped between my need to complete this work, a requirement for my work in the world my entree into the centre and into the paid workforce, to a sanctioned voice, my protection from the marginalisation of woman with dependant children without 'a room of her own' or 'independent means.' (Woolf 1945), and my need to fulfill my gendered role of mother, and be kind to this young girl, who is really doing her utmost to fit in.

I want to tell my sister in response to her gentle admonition to treat Regina as I would want my son treated if he were overseas, I want to say: But Jill, I need to cast out my sons, at least the older ones, I need to write, I need to relate only to myself, the writing, the world. I want the separation and distance that I can only get in retreat. Because as I am in the world, as mother, as woman, as gendered and boundaryless

## Three Readings

– merging and being merged and consumed and consuming and becoming. Never fixed, always in process.

Of course the most marked categorisation, and yet unmarked by virtue of its hegemony, is that of male and female, woman and man – all adult and sexed beings – their sex signified through those myriad of signs assigned to categorise gender, and sex.

Against that tradition, my own use of the concept of *différance*, like that of Diprose, serves to underline the ultimate instability of the biomedical task, and to claim that if bodies are not fixed, then nor are ethical relationships. Moreover, I am fully committed to the recuperation of embodied sexual difference as the certain co-instance of an ethic of intimate and irreducible differences. (Shildrick 1997:11)

And I consider that in all the material on diabetes I have read the only reference to sex and its relationship to diabetes lies in the definitions of gestational diabetes – which is often noted as a complication of pregnancy, and is something that occurs in pregnancy, and is never ever attributed as something that happens exclusively to women. Men do not get gestational diabetes. And I start to spiral into thoughts about the nature of gendering and diabetes. And then I remember another difference. Impotence is often cited as a complication of diabetes. Helen would often complain that there was no significant studies on the effect of diabetes on women's sexual life though plenty on impotence.

*I'm itchy again. deep disturbing itch of thrush. at the centre of my sex. sex. my libido hovers, flickers into a memory. I move in towards his body, at first only seeking affection, soft reassuring touch of another human, of belonging, too tired, and unaroused for lust. slowly emotion teases at my skin, as body warmth meets body warmth and excitement and desire build. only after do I remember the throbbing of tissues inflamed now not with desire, but with thrush and I say "My glucose levels must be up again".*

If we are to do work with bodies then is it indivisible from doing work on gender? If there is indeed a relationship between sex and diabetes, between the hormonal flows, production of hormones whether or not that is inscribed and produced on/in the body

### Three Readings

cultural y and historically, a changing of the biological interface with the world, then must we also look at how we gender the body and how that inscribes itself on the body- must we incorporate this in our manuals, our hands-on-bodies our 'how to' change the body? To change the body and make the world safe for our bodies, how can we overlook this most fundamental of categories, the sexing of our bodies?

But even more puzzling is why, in this essentialist sphere of medicine, out of which comes the sexual binary, which positions all 'knowers' as if they too stand at the very centre of the scientific construction of the world and share the scientific view, why is there no reference to the difference in the disease, the experience and the manifestation given the sex of the person with diabetes.

Significantly, the first object of abjection is the pre-oedipal mother prefiguring that position if the woman in society which Kristeva locates, in the patriarchal scheme, as perpetually at the boundary, the borderline, the edge, the outer limit, the place where order shades into chaos, light into darkness. (Holloway in Somerville 1999:192)

Unsolved in this, at the heart or the body of the puzzle, is the notion that bodies and the sexing of bodies are made invisible. The relationship between the sex of the body and diabetes is unspoken, the most gross difference is unremarked. Balanced against this is the issue of the socio historical and cultural inscription on the body that genders the body. And then propping up the dilemma is the refutation of essentialism within the feminist poststructural project.

"In so far as the deconstruction of boundaries and the recognition of radical differences is at the heart of postmodernist feminist enterprise, the very category of 'women' becomes difficult to appeal to in any unambiguous way. Where signification is acknowledged as slippery and treacherous, the issue becomes not the creation of new normative standards, but a persistent endeavor to forefront the instability and provisionality of the concepts with which one is dealing." (Shildrick 1997:2)

*I re-read Somerville's (1999:180-217) chapter on houses, and her question "What does a girl need to write?" resonates again. Echoes an earlier question I had asked Margaret. And here I am, feeling desperate because I have brought too much – I have packed up my thesis, my resource notes, they fit neatly into boxes, but the four children seep out, slither into my writing space, the boys yell and fight fists and*

*bodies everywhere while Regina sits, inside, reading, quiet but ever-demanding, a passive recipient waiting to be shaped, coming alive only when at her request we go for coffee and some boys wave at her.*



Coffee in a small coastal town, really an extension of the bakery, a few locals, not really tourist time. Further in the distance is the blurring of the view I have close hand from the house. The cars drive past and this girl, sitting with me suddenly comes alive, “They’re cool” she says.

“Who?” I ask peering around- there really isn’t much to see in this desolate, suburbanised shopping centre.

“Those boys there, they waved at me”.

And I contemplate the whole gender thing again. Woman made for man’s gaze. From the house we are staying in, on the very shores of the water, crystal clear water in which dolphins surf at dusk, native birds call, clean clear air swells in round the headland into the bay. I sat floating in a Kayak, drifting watching fish glide underneath, could see to the sand.

But it is not summer time, or tourist time and there are few people here. Certainly no young surfers, to gaze at Regina and so provide her with delight. To be seen but not to be. and maybe not yet to see.



### **Echoes**

The position of the other participant- the patient- in the health-care encounter was of limited ethical interest in that she was characterised as a passive receiver of benefits rather than as an independent agent. The dichotomy between the two positions, that of morally active professional and of the inactive patient, was most clearly evidenced in the traditional medical model of health care in which the two roles were clearly delineated on an institutional level. (Shildrick 1997:8)

### Three Readings

Margaret (Somerville 1999:183) too asked what was needed.

Echoes. In the corridor, in another cottage, Phoenix says of the PhD process, “it’s in my body, swirling around” (pers com. 2004).

And again I ask what do I need to bring? Just me. I am the thesis. My body my self. Diabetes, education, constructed body and self and subjectivity. The history of the process taken into this body, this memory. I too hold the history of dealing with the pharmaceutical companies, encrypted in my body, as their drugs, their dealing with me, the short sharp messages of lifestyle and education. I am the thesis. It has worked its way through my body and I write myself on the page.

When we were dealing with Bayer, in search of funding, Le Carré’s book *The Constant Gardener* (2001). was being published. I bought the book but never had the time to read it. I heard an interview with him on radio. Not long after the news broke of the international case against one of the large pharmaceutical companies who were trying to stop the production and distribution of a generic medicine for AIDS being delivered to Africa. Le Carré foreshadows that in his book

*In the corner of the lounge room is a worn warm wooden bookshelf, where I find a copy of the Just So Stories, inscribed Rosalie Hill 1930. Every night here, at the beachhouse, I snuggle down with Viv, deep in doonas and pillows, the thrumming of the surf interspersed with silence, full silence of sea and wind through trees, wildness encasing this island of bodies beds and stories. And I read one story. Each night with great care to the ritual Viv chooses the story for the following night. Afterwards I read myself to sleep. Surprised and pleased that I have found a copy of Le Carré’s The Constant Gardener here.*

I read the book. The only actual pharmaceutical company he names is Bayer (Le Carré 2001:279). I contemplate the junction, in my body between the capitalist and patriarchal systems, the children the tablets, the financial pressures the writing of this thesis. What does a girl need to write a thesis? Just herself. Constructed as she is of all those bits and pieces of life, of readings, of thinkings, of memories and gazes, of

foods and finger touches and boundaries leaking into each other. Of the work she does to keep herself distinct.

Effectively, neither the feminine nor the body itself are valorised as lived presences. In mainstream discourse, the devaluation is even more evident, and the denial more entrenched. Yet, at the same time, as a postmodernist analysis contends, the feminine and the body are each both absent and excessive. In other words, the boundaries of exclusion are never wholly secure against the threat of the absent other to disrupt the unity and definition of the selfsame. Indeed the whole issue of inside/outside is one that this work will problematise, and with it, finally, the very sense that any body can be read as a discrete entity. Where the feminist agenda somewhat shifts the parameters of postmodernist enquiry, however, is in the refusal to read the body only as text. It is both the surface of inscription and the site of material practices, each of which speaks to a sexed specificity. Although intending to deconstruct the essentialism of the highly damaging historical elision between women and their bodies, postmodernist feminists might see, nevertheless, the embodiment of the feminine as precisely the site from which new forms of knowledge could emerge. (Shildrick 1997:10)

Walking with Jill and Fran. Up the hills. Puffing, drawing in breath ragged and catching, muscles tight around my ribs, words jagged. I discuss the seminar format. Fran says “Make three points. There is a completion in three, the trinity, and all that”.

I want to stop at three readings, but there is a fourth, a fifth, multiple readings through time and space.



In this chapter the body is reconfigured as a site of contested global and patriarchal power. As a starting point I set up as the privileged text the contextualised knowledge of two women living with and researching diabetes. The first reading was a cohesive story of two women sharing their learning about diabetes. I contrasted this to the representation of fixed knowledge about diabetes in the form of print-based diabetes educational material. In the second reading I brought to the surface the complex intersection between sexed bodies and gender construction. This analysis made visible the working of power structures through colonising discourses. The third reading disturbed the binary through the inclusion of the body in the text. It was at this point

## Three Readings

that I established that my body is the thesis. The essentialist self was interrupted by multiple and constructed subjectivities and readings.