

January 1995

## Dementia, discourse, difference and denial : "who did I become?"

J. Stirling

*University of Wollongong*, [jstirl@uow.edu.au](mailto:jstirl@uow.edu.au)

Follow this and additional works at: <https://ro.uow.edu.au/ltc>

---

### Recommended Citation

Stirling, J., Dementia, discourse, difference and denial : "who did I become?", *Law Text Culture*, 2, 1995, 147-159.

Available at: <https://ro.uow.edu.au/ltc/vol2/iss1/7>

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: [research-pubs@uow.edu.au](mailto:research-pubs@uow.edu.au)

---

## Dementia, discourse, difference and denial : "who did I become?"

### Abstract

If I am no longer a woman, why do I still feel I'm one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk against my skin? If no longer sensitive, why do moving song lyrics strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone!

Western medicine's fascination with the human brain and its workings is still marked by blurred boundaries between the mappings of neuro-anatomy and culturally inflected interpretations of neuro-psychology. This essay attempts to trace some of the intersections and overlaps between biomedical discourse and cultural politics as they come together in constructing the figure of the dementia body.

# DEMENTIA, DISCOURSE, DIFFERENCE AND DENIAL: 'WHO DID I BECOME?'

Jeannette Stirling

If I am no longer a woman, why do I still feel I'm one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk against my skin? If no longer sensitive, why do moving song lyrics strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone! <sup>1</sup>

Western medicine's fascination with the human brain and its workings is still marked by blurred boundaries between the mappings of neuro-anatomy and culturally inflected interpretations of neuro-psychology. This essay attempts to trace some of the intersections and overlaps between biomedical discourse and cultural politics as they come together in constructing the figure of the dementia body. —

Not all nuances of meaning, either biomedical or cultural, sited with the dementia body will be addressed here. Nor will this essay refute the current biomedical model of Alzheimer's Disease. Rather, it is a meditation on the social, medical and legal vicissitudes faced by the dementia sufferer and their immediate social network. It will also raise questions about the psycho-social limits inscribed on the body of the dementia patient by the institution. I want to explore extended ways of thinking about the dementia body; to consider some of the processes by which this failing body is supplemented and subjectivity displaced as the social subject becomes medical patient. Throughout this paper I will be using the term 'dementia' to refer to senile dementia of the Alzheimer's type and multi-infarct dementia.

In relation to theories of the body articulated by Julia Kristeva, Elizabeth Grosz, Linda Butler and Alphonso Lingis, I will discuss the dementia body as an 'improper body'; a body of both excess and decomposition. The aged, disenfranchised body is traceable throughout these theoretical models as a shadowy presence. I will also speculate on the ways that the disruptive body of dementia is refigured and contained through the discourses of biomedicine and medical law. Is it possible to maintain or re-articulate

---

cultural and social heterogeneity once the subject has become the object of the clinical gaze? Is it possible to deflect the denial of difference that accretes within the standardising practices of biomedicine? Clues to these questions might be found in an examination not only of the divisions between dementia and so-called normality, but also of the connections. The processes that produce the normalised and medicalised body as they come into conjunction will also be discussed. To this end, I will take into account the various ways that the dementia subject is indoctrinated into the specialised communities of Dementia Specific Hostels.

Expressions such as 'that person is not in their right mind' or 'this person has lost/is losing their mind' are part of our everyday language. They signify social perceptions of a shift between so-called normal and abnormal behaviour in an individual. The term 'dementia' carries similar connotations. *Blakiston's Medical Dictionary* defines dementia through its etymology in the Latin word *demens*: 'out of one's mind'. If being in one's right mind is both a cultural and a medical norm, how do these interwoven systems of signification register the person who is in the process of losing their mind? If, because of brain injury or disease, the one we know 'is no longer her or himself', then whom do they become?

In the topology of the healthy body the brain occupies a privileged position. It is the primary symbol of humanity, associated with intellect, reason and creativity. The brain is also considered the locus of subjectivity. The spectre of dementia is distressing precisely because it attacks these higher faculties and disrupts our cultural myths about a wise and dignified old age. It destabilises the hope that the legacy of an advancing maturity will include respect and social status, as well as providing a serene space beyond the passions that drive youth and middle age. The figure of the dementia body signifies the demands of a socially unmediated materiality. It functions as the re/presentation of the body on the brink of the 'abyss' in the symbolic order (Kristeva 1982, Gross 1990).<sup>2</sup> In the rhetoric of narratives about the brain, not being 'right minded' in old age becomes a trope connoting the irrational, the wilful, the intractable, in culture as well as medicine.

In 1990 the World Health Organisation described dementia as:

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation (Jorm et al 1993: 1).<sup>3</sup>

An unclouded consciousness, concomitant with a slow and insidious onset, is crucial to a diagnosis of dementia rather than some other form of neuro-psychological dysfunction. Whilst the patient is alive the disorder is typically described by its observable symptoms; clinical assessment is reliant on the medical gaze and the presupposition of a norm. Histological diagnosis can only be confirmed after death.

Michel Foucault claims that:

In order to know the truth of the pathological fact, the doctor must abstract the patient: He[sic] who describes a disease [or syndrome] must take care to distinguish the symptoms that necessarily accompany it, and which are proper to it, from those that are only accidental and fortuitous, such as those that depend on the temperament and age of the patient (1973: 8).<sup>4</sup>

In other words, the diagnostician must avoid conflating signs of difference with signs of disease. This is the problem faced by the medical professional when using current diagnostic tools to identify and map dementia in the living body. How are the boundaries between pathology and socialisation located and identified when it is the subject's intellect and cognitive function that are the focus of the diagnostician's gaze?

Although the Mini-Mental State Examination (MMSE) is deemed a 'useful screening test' (Jorm et al 1993: 24), and is widely used in this country to aid diagnosis of dementia, it can give false positive results. This occurs primarily because the test is predicated on specific assumptions about the subject's knowledge of and relationship to the world beyond corporeal boundaries. Consequently, those who have a cultural view substantially at odds with the criteria laid down by the examination will register as embodying signs of dementia. The MMSE will also register dementia symptomatology for those subjects with a limited intelligence unrelated to dementia, and those from a social environment significantly different to the one assumed by the test. Ascription of meaning in this dialogue between patient and diagnostician is fraught with potential for misinterpretation, and the test's useful application seems contingent on a cultural and social proximity between the participants. The MMSE's reliability in establishing correlatives between cognition and competence to make decisions is also questionable.

The changes wrought on the body by dementia have been likened to the plight experienced by Gregor Samsa in Franz Kafka's short story, *Metamorphosis* (Moody 1992: 87).<sup>5</sup> Kafka's narrative explores the way that Gregor's family react to the event of his change. At first they are horrified, and deny his presence in the alien persona that has become part of their lives. Gradually, there is adaptation which entails a forgetting of the person who

---

existed pre-metamorphosis. Gregor has become the other: he is expunged from the core realities of Samsa family life.

As dementia progressively marks the body, various social processes begin to fragment; long established standards of personal hygiene break down, and the sufferer may experience difficulties with eating. The ability to recognise the faces of family and close friends eventually fails as the syndrome continues to redefine the body. In advanced stages of the disorder the sufferer becomes incontinent of urine and/or faeces and may lapse into a vegetative state: 'mute, [totally] withdrawn from the world ... confined to bed, with limbs in a characteristic position of flexion'.<sup>6</sup>

Within the prevailing symbolic systems of culture and biomedicine, the morphology of corporeality in the late phases of dementia comes to signify the abject or the grotesque.<sup>7</sup> The dementia process reasserts the improper body as the symbolically sanctioned body falls into a state of increasing decomposition. The subject is returned to a pre-symbolic state, to a space that Gross calls 'the underside of the symbolic' (1990: 89). Ethnicity, gender, class and education are no protection against dementia and the salient feature here, from a cultural standpoint, is the implicit yet vigorous urge to deny the possibility of this particular dysfunction for ourselves. This denial is accomplished through the marginalisation or containment of the disruptive body within the regimes of biomedicine as the dementia body eventually becomes relegated to the status of *infrahuman*.

The dementia figure occupies the subject position of other in relationship to dominant realities, and Evelyn Fox Keller's observations about the significance of language in establishing meaningful relationships between variant realities capture the plight of the sufferer very well:

Sharing a language means sharing a conceptual universe. It means more than knowing the 'right' names by which to call things; it means knowing the 'right' syntax in which to pose claims and questions, and even more critically it means sharing a more or less agreed-upon understanding of what questions are legitimate to ask, and what can be accepted as meaningful answers (1992: 27-28).<sup>8</sup>

Disruptions in language use are a part of the dementia process; there are hesitations and gaps in the subject's abilities to use language effectively. Circumlocution and confabulation become the compensatory means by which the dementia patient seeks to maintain verbal communication and connection with the 'right minded'. As speech patterns regress they become simplified and circumspect; long, rambling phrases replace specific words. Eventually these phrases become reduced to short, sometimes garbled, responses or *non sequiturs*.

So when do the 'right minded' stop listening in any meaningful way to the dementia speaker? When do we start to disassociate the dementia subject from the person who shared our life before the metamorphosis began? When does the notion of a shared language, and therefore a shared conceptual universe or 'reality', become so fractured and dissipated by the sufferer's pathology that we begin to discount statements made and questions asked by them simply because it is easier not to listen? These questions have a critical part to play in the ethical dilemmas currently facing our society and the medico-legal system; not the least when it comes to issues of consent.

To give 'consent' as defined by *The Oxford Dictionary* is to 'Voluntarily accede to or acquiesce in what another proposes or desires; to agree, comply, yield'. Further, it is 'concurrence [or] permission' in an event. It is these definitions of 'consent' that are closest to the meanings adhered to in British and Australian law (Young 1986: 12-26).<sup>9</sup> Giving and, by inference, withholding consent within the context of medical practice remains somewhat of a minefield. Unless faced with a medical event as specified in Part 5, Division 2 of the *Guardianship Act (GA)*, a doctor must obtain consent before medical treatment can be implemented. This is crucial in safeguarding the medical practitioner against future accusations of medical assault or malpractice. In the past, when the patient was unable to give consent on their own behalf, consent was accepted from the next of kin. This process was not legally valid, and the medical practitioner remained at legal risk. Recent changes to the *Guardianship Act* now specify who can legally act as decision-maker on behalf of one who cannot give consent for her or himself.<sup>10</sup>

The debate about what constitutes consent, or even more contentiously, what constitutes 'informed consent', has been a feature of the terrain in that juncture between medicine and the law for some time (Herz et al 1992, Finucane et al 1993, Hancock 1993).<sup>11</sup> The spirit of the concept is about autonomy; the right of the social subject to exercise agency over what happens medically to their body. Increasingly, this ideal has been backgrounded by the litigious exigencies of medical practice and current application has the concept of consent prescribed by a series of medico-legal criteria that position the patient as agent in their own medical treatment only insofar as this agency is legally expedient for the medical practitioner.

In a paper exploring the concerns attached to current arguments about consent, and competency to give or with hold it, Paul Finucane et al point out that questions of competence often arise from conflict between the health care provider and the patient. Although the paper calls for self-analysis on behalf of the medical practitioner in these instances, it also acknowledges that 'If the benefits are great and the violation of autonomy is minimal, paternalism may be justifiable, and the wishes of the patient may in some

---

cases be overridden' (1993: 401).

Consent within a medical environment has become (generally) less concerned with the exchange of information about treatment options and necessarily more concerned with the legal requirements of medical practice. Less about the proliferation of communication between the medical and non-medical and increasingly a dialogue between the two variant but contiguous discursive systems of medical practice and medical law. The reasons for this shift are far too complex to explore within the parameters of this essay. However, given the intricacies of the debate and the ramifications of medical consent, it is not difficult to gain a sense of the difficulties faced by the subject with cognitive and/or language difficulties in trying to negotiate this system.

Diana Friel McGowin provides a rare and telling insight into some of the problems faced by the dementia subject/patient in her autobiographical text, *Living in the Labyrinth*. The observations she brings to bear on her own plight are even more compelling given the medical view that dementia patients often have little or no ongoing awareness of the significance of their symptomatology. McGowin recounts the devastating effect that an impatient husband's 'wrap it up hand signal' has on her speech patterns: 'At the sight of that wretched hand sign, my speech would immediately falter and I would begin stammering, losing my train of thought altogether' (1994: 99). With equally devastating effect, she would be urged by other family members to slow her speech to facilitate an understanding between her and listener(s).

Transpose this type of verbal interaction into the formalised settings of the institution, with its attendant unfamiliarity which challenges even the most articulate to be confidently coherent, and some of the difficulties faced by the dementia sufferer in trying to maintain a voice that will register beyond their symptomatology become patently obvious. McGowin also writes evocatively of her frustrations in the early days of the disorder. When trying to get the neurologist to listen to *her* accounts or narratives about her bodily experiences, she continually came up against a moment in those exchanges when these empirical observations were deemed irrelevant or even counter-productive to the process of diagnosis. The privileged position that biomedical discourse assumes over the body facilitates a displacement of subjectivity as the body is repositioned in terms of pathology. How is it then possible to negotiate a speaking position from within that dominant regime?

Most of the literature on dementia has a section on the 'aggression' sometimes manifested by the dementia patient. However, much of the textual information available on aggression is marked by uncertainty as to the pathological significance of this 'phenomenon'. Writing for the Australian Alzheimer's Association, Zsoka Prochazka et al claim that:

Some people with dementia can become very aggressive and completely unreasonable. It is often exaggerated, uncalled for, and possibly not even directed to the person who bears the brunt of the outburst (1990: 31-32).<sup>12</sup>

Marshal F Folstein and Frederick W Bylsma cite research suggesting that 'aggressive patients were more likely to have a premorbid history of aggression ...' (1994: 33).<sup>13</sup> That is, this behaviour was part of the subject's pre-medicalised social behaviour and not necessarily a pathological signifier of dementia. Despite ambiguities about the significance of aggression, it is placed unproblematically within the parameters of dementia symptomatology. Yet there is very little theorising about why it occurs. Underscoring both of these texts is a failure to make explicit connections between the normal and the pathologised body.

Medical concern has been primarily directed towards coping strategies for carers. It is significant that many of the current therapies used in dementia care — therapies such as psychosocial management, validation therapy, diversionary and normalisation therapy, music therapy — whilst *thought* to positively enhance the quality of life for the dementia patient, are *definitely* seen to 'promote higher standards of nursing care' (Jorm et al 1993: 32) by improving the attitude and behaviour of carers and hostel staff. Fluctuations in the behaviour of the one afflicted are deemed to be merely part of their pathology rather than a response to the particularities of their situation.

The medical gaze assumes a great deal about dementia; for instance, it also assumes that a flattened affect — an absence of emotional display — signifies a lack of emotional experience. McGowin's account flies in the face of that assumption, at least as a generality. It may well be that irritation and anger, those acts that are currently refigured as 'aggression', are signifiers of the extreme frustration and despair experienced by the dementia sufferer trying to maintain a 'voice', or even a space from which to speak, against devastating physical and institutional odds.

The prospect of being subjected to imposed realities for 5-10 years when one's own is already being fragmented by failing health is daunting. Even without the added distress of dementia, these other-imposed limitations would be difficult to tolerate over time. It seems logical and proper to express concern, or even dissatisfaction, if environmental circumstances are counter-productive to personal needs. However, those afflicted with dementia are constrained in the ways that they can express dissatisfaction and distress, becoming enmired in a co-operative/disruptive patient dichotomy.

In mapping the dementia body, biomedical discourse is bound either to pathologise the social behaviour of the subject, or dismiss it as irrelevant to the project of diagnosis. This constitution of the body has far-reaching

---

effects for the life of the subject beyond diagnosis, and the marks of this discursive induction are readily observable in Dementia Specific Hostels.

Members of a Dementia Hostel community are typically mobile and socially interactive in that they enjoy and are able to engage in relationships of love, hate, rivalry, competition and alliance with other community members, albeit sometimes at a micro-level. Dementia is the mark of their communality, but beyond that they are as diverse and marked by social difference as those in wider communities. Because dementia communities are founded on the premise of a shared cognitive disorder, they are structured primarily as medical sites. The more innovative are self-consciously homelike and some effort is made to background their utilitarian function. Nevertheless, the discursive system informing their hierarchical structure precludes even these residences from functioning as anything other than institutional extensions.

Contextualisation of the body into the discursive regimes of a medico-legal system necessarily incurs a loss of freedoms and rights for the dementia subject. Concepts of personal autonomy are constructed and controlled by designated carers. Hostel community residents are, at the very least, deemed to be in 2nd stage or moderate dementia. This usually means that they will have appointed a representative who has their Enduring Power of Attorney<sup>14</sup> or will have been made charges of the Governmentally administered Guardianship Committee. However, this legal aspect of the disorder varies widely, and the availability of information to concerned parties prior to the need for an increase in care requirements seems to depend very much on the social status or class of the subject(s).

Organising an Enduring Power of Attorney after dementia has started to run its course is problematic; the legal system requires that the subject (principal or donor) be cognisant of the legal and social implications of designating an appointee (attorney) to act on their behalf. Given the language difficulties experienced by dementia sufferers and the problems associated with trying to maintain focus, establishing whether or not a subject has cognition of the consequences of her/his actions in this matter is fraught with pitfalls.

An alternative to instantiating an Enduring Power of Attorney is to have the Guardianship Committee either appoint a guardian or assume that responsibility in the absence of an appropriate individual appointee. The legal criteria of the medical system require that someone (as specified Part 5, Divisions 2, 3, 4, 5, GA) give consent on behalf of intellectually impaired people before non-urgent treatments take place. Ideally this is someone who has knowledge of and respect for that individual's overall wishes about their body in relationship to biomedical technology; someone who is familiar with the subject/patient's own bodily narratives. However, the ideal rarely comes

into play here, and although the Guardianship Committee may act with best intentions to safeguard the rights of the intellectually impaired person, it is difficult to see how the dialogue between this institution and the medical practitioner avoids becoming a dialogue between two discursive systems over the pathologised body.

Necessarily erased from this dialogue are the value-systems and desires of the pre-medicalised subject. The body of the patient is reinscribed through the biomedical writing of its disease. This body, as it has been produced through the language of biology and symptomatology, is then understood and interpreted within specific frames of reference that exclude dimensions of meaning relevant to subjectivity.<sup>15</sup> In other words, the rights safeguarded by this system are the rights of the discursively generated 'patient' and not necessarily the rights or desires of the unified subject. There is a split between the ailing, silenced body as it is constituted by the institution, and the socially sanctioned, articulate body.

Personal autonomy decreases exponentially as care requirements increase and the subject becomes progressively inscribed by the medico-legal system. That which does not register within these systems is denied or erased; issues of sexuality, cultural history and class become the intangible detritus expunged from the official narratives (case histories, juridical texts) mapping the dementia body. In a sense, the subject afflicted with dementia is under siege not only from the neurological degeneration robbing them of intellectual life and autonomy but also from a discursive system fundamentally geared to register difference as a signifier of pathology.

The homogenising processes of the dominant regime function to determine and police what is normal (appropriate) and abnormal (inappropriate) behaviour, what is natural and what is unnatural. So, with apologies to Jack Nicholson, one who has enjoyed a life-long cultural practice of 'dancing naked with the devil in the pale moonlight',<sup>16</sup> once intextuated into the medical-legal system determining the parameters of dementia, may have signs of difference and dissidence, of unscripted pleasure and *jouissance* redefined as further evidence of symptomatology. The unorthodox becomes part of the diagnostic field.

Processes constructed to contain the transgressive body are observable within hostel environments, and those residents who partake of mutually consenting sexual alliances, or indeed any activity founded on mutual or private pleasure disapproved of by the hierarchy governing their lives, will suffer the intervention of carers. The resident/patient will be subject to prevailing institutional value systems regardless of any pre-medical difference from those systems. It is futile to assert agency when this intervention occurs; dissension and/or so-called disruptive behaviour are registered as signifiers of dementia.

---

Society is not adept at accommodating notions of sexuality when it comes to the aged. In his keynote address at a recent conference on sexuality and medicine, Alphonso Lingis referred to graffiti popular on Paris walls during the sixties: 'The young make love, the old make obscene gestures'.<sup>17</sup> This slogan poignantly encapsulates the prevailing belief in Western culture that 'sexual pleasure' and 'geriatric' are somehow mutually exclusive concepts. Resistance to the notion of aged sexuality is further exacerbated when the aged body is subject to cerebral dysfunction. If the aged body is denied erotic potential within our culture, the aged, dysfunctional body is anathema to eroticism. Yet again, McGowin's narrative seeks to destabilise this reading of the body and reclaim her right to eroticised pleasures: 'I desired, and physically and emotionally needed warm, passionate touch; to feel my body acquiesce and spasmodically explode in return' (McGowin 1993: 85).

There is very little written about sex and dementia. What has been written is inflected through a heterosexual imperative and seems to reconstitute in narrative economies age-old concerns about female and male sexuality. Folstein and Bylsma's research into the noncognitive symptoms of Alzheimer's disease worries that some male patients seem to develop a 'sexual apraxia' (1994: 33) that leaves them 'clumsy and uncoordinated'. The use of gendered pronominals to construct the following textual excerpt on sexuality problematises female sexuality as being potentially disruptive to decorum as 'she' becomes 'sexually demanding':

Sometimes the sexual behaviour of a person with a brain disorder may change in ways that are hard for (her) partner to accept or manage. When the impaired person cannot remember things for more than a few minutes (she) may still be able to make love, and want to make love, but will almost immediately forget when it is over, leaving her spouse or partner heartbroken and alone (emphasis added. Mace et al 1991: 216).<sup>18</sup>

Unfortunately this textual practice also lends the advice to the beleaguered partner a sense of the parodic as it goes on to reassure: 'It can be devastating to a spouse when a person who needs so much care in other ways makes frequent demands for sex' (Mace et al 1991: 216). When reading this no doubt well-meaning reassurance, it is difficult not to imagine a significant proportion of heterosexual women snorting derisively.

These texts reflect and reproduce wider cultural concerns about female and male sexuality, and whilst I have no wish to minimise the impact of socially disinhibited behaviour within an enclosed community,<sup>19</sup> I think we need to begin to reassess the ideologies and assumptions encoded in the terms 'appropriate' and 'inappropriate' as they pertain to the sexually active

dementia subject. There is also a need to theorise particularities of what constitutes disinhibited or hyper sexuality and analyse the ways that these 'symptoms' are inscribed onto the female and male body respectively.

McGowin writes with some humour of being 'equipped with a sex drive accelerating at the speed of a rocket but with nowhere to drive' (1994: 84). Her account further highlights the lack of readily available information on dementia and sexuality. She is at loss on how to cope with her libidinous urges until a much trusted female friend suggests she try using a vibrator to avoid 'inflicting' her needs on a reluctant husband. The solutions available to McGowin would be inaccessible to the Dementia Specific Hostel resident; they would be deemed 'inappropriate'. Currently, concepts of what constitutes 'appropriate' or 'inappropriate' expressions of sexuality are open to interpretation and cover a range of sexual behaviour from masturbating publicly to privately caressing a non-spousal partner or object. Not surprisingly, given the orthodoxy of the medical discursive system, homosexual or lesbian sexual activity is gestured toward in the most cursory way as a 'symptom' of disinhibition. In these contexts of sexual conservatism, the question 'Who did I become?' connotes the dislocation experienced by the dissident as s/he is processed by the system.

As we move towards the end of the millennia, debates on the ethics and practicalities of self-authored future directives about our relationships to medical technology are being voiced. The laws proscribing assisted suicide and euthanasia are being re-evaluated and, in the Northern Territory, rewritten. People with profound dementia can no longer speak for themselves on these issues. And as the system currently stands, those still near the beginning of that continuum are silenced as they become the product of a regime that 'thrusts into oblivion all those stammered, imperfect words without fixed syntax in which the exchange between [dementia] and reason [is] made' (Foucault 1971: xii).<sup>20</sup>

Within the symbolic order that shapes the way that both cultural and medical signifying systems register those who have lost/are losing their mind, the abject body has no position from which to speak. To continue to authorise the relationship between the dementia and non-dementia communities solely through the abstracted discursive systems of medicine and law is to continue to deny differences inscribed on the pre-medicalised body; to continue to deny the value systems that have preceded the subject's assimilation into the medico-legal system.

McGowin claims the right to speak from within the labyrinth, to deflect the objectification generated by her role as dementia patient. John Wiltshire suggests the crucial lessons to be learned from patient narratives. He argues that biomedical progress has been 'attained at the price of the suppression of the narratives of its subjects' (1995: 40).<sup>21</sup> Within dominant medical

---

narratives, difference is erased and the speaking subject silenced. We need to construct analytical models and ways of talking about the dementia subject that will address the elisions and silences that presently mark the narratives producing her/his body. This re-articulation of social difference and heterogeneity must come from beyond the parameters of a medical discursive system – if for no other reason than to avoid finding ourselves asking in future times ‘Who did *I* become?’.

## NOTES

<sup>1</sup> McGowin Diana Friel 1994 *Living in the Labyrinth* Dell Publishing New York 114

<sup>2</sup> Kristeva Julia 1982 *Powers of Horror: An Essay on Abjection* Trans Leon S Roudiez Columbia University Press New York

Gross Elizabeth 1990 ‘The Body of Signification’ in *Abjection, Melancholia and Love* John Fletcher et al eds Routledge London 80-103

<sup>3</sup> Jorm A F and Henderson A S 1993 *The Problem of Dementia in Australia* Australian Government Publishing Service Canberra

<sup>4</sup> Foucault Michel 1973 *The Birth of the Clinic* Trans A M Sheridan Routledge London

<sup>5</sup> Moody Harry R 1992 ‘A Critical View of Ethical Dilemmas in Dementia’ in *Dementia and Aging: Ethics, Values, and Policy Choices* Binstock Robert H et al eds The John Hopkins University Press Baltimore and London 86-100

Kafka Franz 1992 *Metamorphosis and Other Stories* Trans Willa and Edwin Muir Minerva London (first published 1933) 7-63

<sup>6</sup> Nicholi Armand M M.D. ed 1988 *The New Harvard Guide to Psychiatry* The Belknap Press of Harvard University Press Cambridge, Massachusetts, and London 367

<sup>7</sup> This association between the body beset by dementia and the figure of the grotesque in Western literature was suggested to me by the work of Greg Ratcliffe, Wollongong University, April 1995. In a paper tracing the construction of the grotesque body in art and literature, he argues that this ‘improper’ body is repressed as the proper body becomes subject to the rules of society. However, the two bodies are inextricably related: the normative body and the grotesque body contest the same space.

For further discussion of the concept of abjection and its usefulness in thinking about the body of excess or transgression see Butler Judith 1990 *Gender Trouble: Feminism and the Subversion of Identity* Routledge London 132-134

<sup>8</sup> Keller Evelyn Fox 1992 *Secrets of Life, Secrets of Death: Essays on Language, Gender and Science* Routledge New York and London

<sup>9</sup> Young Peter W 1986 *The Law of Consent* The Law Book Company Limited Sydney

<sup>10</sup> N.S.W. Statutes Reprinted Acts, ‘Guardianship Act 1987 No. 257’, 1-57. Reprinted as in force at 23 January, 1995 to include all amendments to Act 1994.

No. 39

- <sup>11</sup> For example see, Herz David A Looman Janice and Lewis Shirley Kane 1992 'Informed Consent: Is It a Myth?' *Neurosurgery* 30/3: 453-458  
Finucane Paul Myser Catherine and Ticehurst Stephen September 1993 'Is She Fit to Sign Doctor? - Practical Ethical Issues in Assessing the Competence of Elderly Patients' *The Medical Journal of Australia* 159/20: 400-403  
Hancock Linda 1993 *Defensive Medicine and Informed Consent* Australian Government Publishing Service Canberra
- <sup>12</sup> Prochazka Zsoka et al 1990 *Dementia: Memory Loss and Confusion* Alzheimer's Disease and Related Disorders Society (SA) Inc Eastwood SA
- <sup>13</sup> Folstein Marshal F and Bylsma Frederick W 1994 'Noncognitive Symptoms of Alzheimer Disease' in *Alzheimer Disease* Terry Robert et al eds Raven New York 27-40
- <sup>14</sup> Section 163B and Section 163F of the Conveyancing Act 1919. Comments are specific to the Act as it stands in N.S.W. July 1995
- <sup>15</sup> For discussion of how the body is transcribed and interpreted through cultural and institutional narratives see Grosz Elizabeth 1994 *Volatile Bodies: Toward a Corporeal Feminism* Allen and Unwin St Leonards 117-119
- <sup>16</sup> Reference to Jack Nicholson as 'The Joker' in the film *Batman*.
- <sup>17</sup> Alphonso Lingis University of Melbourne July 1995  
See also, Lingis Alphonso 1984 *Excesses: Eros and Culture* State University of New York New York  
1989 *Deathbound Subjectivity* State University of New York Press Albany
- <sup>18</sup> Mace Nancy L and Rabins Peter 1991 *The Thirty-Six Hour Day* The Johns Hopkins University Press Baltimore and London
- <sup>19</sup> For example, see Alexopoulos P August 1994 'Management of Sexually Disinhibited Behaviour by a Dementia Patient' *Australian Journal on Ageing* 13/3: 119
- <sup>20</sup> Foucault Michel 1971 *Madness and Civilization: A History of Insanity in the Age of Reason* Trans Richard Howard Routledge London (first published 1971)
- <sup>21</sup> Wiltshire John 1995 'The Patient Writes Back' *Hysteric* Issue 1 40-57