

ALZHEIMER'S DISEASE NARRATIVES
AND THE MYTH OF HUMAN BEING

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I put off writing this section for the longest time, squeamish at the thought of it for some unnameable reason. And then it occurred to me: I have no desire to yoke anyone's name to this text. I wouldn't want to imply adjunct responsibility for its many flaws.

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Table of Contents

Alzheimer's disease as loss of self.	1
Looking at Alzheimer's disease.	4
The construction of Alzheimer's disease	7
Narrative knowledge	15
Illness narratives	17
Medicine's hero myth.	19
Dementia as disaster.	22
Genres of experience.	26
Self and story.	31
The metaphysics of dementia	37
The subject of the binary order.	39
Human mind, primate body.	43
The narrative self.	47
Individual identity and the fate of mankind.	51
Conclusion.	56
References.	58
Curriculum Vitae	

Alzheimer's disease as loss of self

The 'loss of self' trope is a pervasive shorthand for the prototypical process of Alzheimer's disease (AD) in the popular imagination. Turned into an effect of disease, the disappearance of the self accommodates a biomedical story of progressive deterioration and the further medicalization of AD, a process which has been storied as an organic pathology affecting the brain or, more recently, a matter of genetic calamity. This biomedical discourse of AD provides a generic framework for the disease and is reproduced in its illness narratives. The disappearance of self is a mythic element in AD narratives; it necessarily assumes the existence of a singular and coherent entity which, from the outside, can be counted as both belonging to and representing an individual person. This Western self is both object-like and hidden, kept within the bone house of the body.

AD narratives are recursively produced through the circulation of generic narrative structures. The loss of self, as the rhetorical locus of AD narrative, limits the privatization of the experience and reinscribes cultural storylines—storylines about what it means to be a human person. The loss of self as it occurs in AD narratives functions most effectively in reasserting the presence of the human self, in contrast to an anonymous, inhuman nonself; as AD discourse details a loss of self, it necessarily follows that the thing which is lost (the self) always already existed. The private, narrative self of individual experience thus functions as proxy to a collective human identity predicated upon exceptionalism: an escape from nature and the conditions of the corporeal environment. The narrative self is merely the newest incarnation of the mind which, at the time of its invention as an insubstantial substance via Descartes, was simply the newest incarnation of the soul:

I knew that I was a substance the whole essence or nature of which is simply to think, and which, in order to exist, has no need of any place nor depends upon any material thing. Thus this 'I,' that is to say, the soul through which I am what I am, is entirely distinct from the body and is even easier to know than the body, and even if there were no body at all, it would not cease to be all that it is. (Descartes 19)

Descartes utilizes the concept of a Christian soul, eternal and immaterial, but reimagines the content of that soul: thought becomes paramount in this revision of human essence. Thought becomes spirit. The manner in which AD discourse allows for a loss of human existence independent of physical death reinforces ancient conceptions of human identity as a master species, an extra-species kind. As John Gray states, “Most people today think they belong to a species that can be master of its destiny” (3). This means not being a species in the usual sense of the term, not being subject to the body, to instinct, to forces outside one’s understanding or control.

AD discourse flows with this conception of human difference, of human progress; biomedicine guarantees an eventual cure, and thus an eventual permanence of self. Elizabeth Herskovits defines AD discourse as “the public consciousness of Alzheimer’s, a consciousness that is produced by the totality of discourse—that is, all that is said, written, and known—about Alzheimer’s” (147). This totality is made up of fragments, with biomedical assertions a part of the whole; the discourse of AD cannot be lifted out of the cultural milieu which informs its composition. Even as biomedical assertions about AD appear to dominate the rhetorical construction of dementia (a generic and not necessarily pathological term for cognitive decline), a Western metaphysics is foundational to its configuration. Investigating the narrative construction of AD thus necessitates an investigation into the metaphysical fragments which are implicated in its making. Initially, this involves interrogating the construction and function of narrative itself, especially illness narrative, as a method of knowledge and a genre of social practice—and the twin imperatives of narrative identity and coherency which the genre demands.

Illness narratives, as a generic form, maintain a metaphysical order. AD narratives, especially when utilizing the loss of self trope, express a particular fragment of this metaphysical order: the dislocation of human being from nature and the resulting tension between human consciousness (as self-consciousness) and a nature which is anonymous, without authorship, and without awareness of itself as existing in time.

Rob Dillman proposes that “a metaphysical element is present in most scientific conjectures, and it is no different in AD research” (130). Following Dillman, it is important to recognize how personal and biomedical narratives of disease are created in the presence of already circulating metaphysical structures. Dillman begins by examining the very notion of disease:

Although the common everyday use of the term *disease* suggests that we can speak about it and manipulate it as if it were a natural entity (such as the everyday use of concepts such as ‘time’ or ‘gravitational force’), in effect, what we are doing is taking an idea or Kantian categorization into reality. (131)

Using the conventional AD vocabulary of plaques and tangles, those entities which mark the destruction of the brain/mind/self, it becomes increasingly difficult to speak of AD as anything other than an eventually and inevitably locatable process, an abnormality which much be fixed. The figurative elements of AD discourse, the center of which is the loss of self trope, allow for an investigation of the rhetorical construction of the disease and point toward a metaphysical foundation. Revealing how conversations about AD tend to hinge upon Western conceptions of the human self—its disposition, its significance, its duty, its thusness—allows for a change in perspective, or a way of enlarging the conversation, not only about AD but also about our place in the world and what it means to be human.

The argument made here is that the loss of self documented through illness narrative reasserts an ancient order of the self-as-essence or thought-as-spirit. As a point of difference, AD narratives which narrate the presence of a newly opened and increasing void of self perpetuate an original existence of the self. The individual self, as potentially lost, further functions as proxy for a collective human identity, an identity defined by autonomy and productivity. This human identity is exceptional in comparison to others of every kind, especially beings (bodies) associated with nature and death and disruption. All of these aspects are metonymically associated with each other through group categorization with the nonhuman. By contrast, the self as a distinctly human possession or essence is

associated with immortality and destiny, an always available future. Human identity as expressed at the individual level, as self, functions to maintain the narrative of human becoming/being as autonomous and productive, inevitably completing the project of human liberation from nature, or death, or ignorance (all may be said to represent the same thing).

Human liberation, in this sense, doesn't require a specific objective; it merely requires the idea of a human *telos* coterminous with a universal *telos*—a human-centered universe. The self functions to support the narrative of a teleological human identity. Such narratives reaffirm, through their constant recirculation, a metaphysical supposition about humanity's identity and position in the world.

Looking at Alzheimer's disease

"In this book we glimpse at the varied faces of Alzheimer's Disease" (Henn): So announces the introduction to *Alzheimer*, Peter Granser's photography collection which captures the demented residents of a German care facility. Given that Granser displays a penchant for portraits, one may be invited to assume that the faces of AD are human faces, one and the same. In an accompanying essay to the book, American studies scholar Christoph Ribbat explains that Granser's perspective on AD has to do with identity, with "assault on the identity, the creeping, inexorable loss of self." Granser's repeated use of portraits thus cedes to the conventional AD narrative: the person has been overtaken by the disease, dislocated by disease; the face of the person is the face of the disease. From this perspective, AD is a private condition, an individual disease. Because we cannot really see AD, we must look for the signs of its presence, its consequences. We must look for what it leaves behind after subtraction, and for what it alters by its occupation.

Mostly, we hunt for and find absence, loss. And this loss is not the same type of loss provoked by a disease such as AIDS, which Ribbat utilizes as a character foil—

reminding the reader that the tragedy of AD is of a different magnitude. AD is not, after all, a direct threat to the survival of the human species as an organism on earth. What is elemental to AD is that intangible loss of self, a loss measured through impairment—through measurements of decline in cognitive functions such as language and memory.

In the rhetoric of Granser's book, AD is understood as something which can be seen or captured on film; its trace can be perceived through the portraiture of persons diagnosed with the disease (notwithstanding, for the moment, how uncertain the diagnostic process really is). The viewer can only come to the book in order to glimpse something categorical about the disease, perhaps to detect its essence, and must read each photograph with suspicion, as a detective, looking for the visual evidence of pathology. As Susan Sontag notes, "Most subjects photographed are, just by virtue of being photographed, touched with pathos" (*On Photography* 15). In this vein, the photograph marks difference, announces a revelation of something and announces the boundaries of what is normal (healthy) and what is abnormal (diseased).

The text which frames Granser's collection is a necessary supplement, lest the detective misinterpret the photographs, or worse, not know *how* to read them. The title, introduction, and closing essay to the collection all work to contextualize what is glimpsed; the text provides the code for viewing, the code for shaping meaning. What is it that is captured in Granser's photographs? According to Ribbat, we can see dementia, or at least a version of it. Further, Ribbat says, what Granser has captured is authentic because "those portrayed are clueless" and "don't present themselves to the camera." The implication is that Granser has photographed people who no longer know what it means to pose, who are (no longer) self-conscious when in front of a camera. Granser's portraits thus resemble scenes of nature, quiescent landscapes. The reader can be assured that the demented are not performing for the camera, not making subjects of themselves. Simultaneously, Granser occupies the role of wildlife photographer, hidden from sight, a receptive and innocent eye.

According to Ribbat, Granser's photographs don't invoke the same power as an author who writes, and thus actively frames, a story about AD—an author who names the victim and describes the elements of victimization, because here “the photographer remains invisible, the protagonists anonymous” (Ribbat). The photograph doesn't require the overt presence of the photographer, because the photograph itself functions as its own evidence, as a mirror of reality. Sontag warns that “despite the illusion of giving understanding, what seeing through photographs really invites is an acquisitive relation to the world that nourishes aesthetic awareness and promotes emotional detachment” (*On Photography* 111). The loss of identity, of subjectivity, which Granser's project professes to *document*, as if the subjects were merely caught in natural acts, is actually constructed; the portraits act as representations of a kind. The (anonymous) subjects thus exist as objects to be gazed at, objects which stand for something other than their individual selves, pathology incarnate. And to borrow again from Ribbat, their ‘cluelessness’ is meant to offer further proof of their lack of agency. Each portrait could be replaced by another dozen of its type because the project is a record of pathology. In this way, the photographs achieve the same sort of interchangeability and representative power as a clinical case narrative.

Granser's images can be classified as a kind of pornography. Although what is usually taken to matter in discussions of pornography is the content, such as sexual explicitness, Susanne Kappeler challenges the content criteria for defining pornography and asserts that what matters about pornography is the way it functions as “a form of representation” (2). And what matters about forms of representation is who maintains the speaking position, who has the power to craft the image, and who has the power to accept or affirm the image. Such an approach has also laid the groundwork for discussions of ecopornography, a way of investigating how representations of scenes and objects of nonhuman nature are similar to sexual pornography (Welling 55). Representation, according to Kappeler, creates a triangular relationship of exchange, a relationship between the viewer/consumer,

the viewed object, and the author/distributor. The distributor is hidden and produces apparently natural images. His invisibility obscures the power which the author wields over the image or narrative. As Kappeler explains, the distributor mediates the relationship between viewer and viewed, and what is exchanged between image maker and viewer is the code of viewership, the way to gaze.

Irrespective of content, pornography, according to Bart Welling, works to “code the viewer’s eye” in ways that construct “an all-seeing but simultaneously invisible consuming male *subject* to its marginalized, decontextualized, powerless, speechless, unknowing, endangered, pleasure-giving, commodified, consumable female *object*” (53). As Kappeler notes, between image maker and image consumer there exists a shared method of viewing, in that the viewer takes on the same subject position as the image maker. We assume that a photograph meant for public distribution (rather than an image made for private record) will show us something of interest, will *reveal* a reality, something which already exists and has simply been captured, frozen. The photographed object may appear unaware, but the viewer is apt to understand the message, especially when the meaning is further shaped, as in Granser’s work, by the work of the title, the introduction, a closing essay, all of which echo a cultural discourse that acknowledges and supports the supposition that dementia is a process of personal disintegration. Granser’s images are not records of natural scenes, but just another typical production in the discourse of AD. They cannot show us anything we don’t already know. And what we know of AD is anonymity, the loss of the self.

The construction of Alzheimer’s disease

By definition, all narratives of AD are medicalized narratives, in that AD narratives utilize the concept of pathology as their natural or inherent foundation and continue to rely upon a biomedical idiom in the development of the narrative plot and characters. Such

plot developments emphasize deterioration and tell stories of what's been lost, or more precisely, in the rhetoric of the disease, what's been taken away. Whether these narratives take the form of memoirs, journalistic accounts from caretakers, or fictionalized stories, the emphasis is on the strangeness of the condition, a strangeness geometrically produced in relation to the progression of disease, which is always a progression of abnormality. For Diana McGowin, living with AD is akin to living in a labyrinth: because she "looks okay" to others, her disabilities upset status quo social expectations (115). In fact, the apparent (physical) normalcy of the afflicted is one of the elements that adds to the mystery of AD, how it can lurk in plain sight. The progression of the disease, plotted in narrative, emerges through a cataloguing of emerging deficits, disappearing abilities, shifting character traits and noticing (or else being quite unaware, depending upon the perspective) a widening gulf between a past self, a whole self, and an increasing void of self.

Within the AD construct, health, as a standard of normality, is contingent upon a particular kind of wholeness: that of a singular and continuous self demonstrated via an individual's personality and a standard life history. The loss of self trope found in AD discourse makes plain that the self is figured "as extrinsic to the body" (Shildrick 17). Because AD is also simultaneously figured as a process of "losing one's mind," we can see an associative link between the mind and the self. In AD narratives, the self exists prior to the symptomatic expression of the disease. The more symptomatic one is, the more one becomes representative of the disease, a transformation continuous with the voiding of the past self.

The diagnostic process only complicates the construction of the disease as a natural kind. AD cannot normally be diagnosed before death, unless some special circumstance allows for an incidental brain biopsy, such as in the case of Cary Smith Henderson who received a diagnosis of early-onset AD after a biopsy revealed the proof of the disease: the presence of plaques and tangles, those conventional markers of the disease. Henderson writes in his illness memoir, "As one of the very few absolutely verified Alzheimer's

people. . . that's the best thing you can find in purity, so with the biopsy you can be absolutely sure I am pure, no strings attached" (63). Anything other than the proof of plaques and tangles is delayed as a probable diagnosis, confirmation upon death. The signs of the disease are thus looked for through the behavior and interaction of the person being examined. In a biomedical setting, an interview with the patient coupled with the narrative evidence from additional, intimate informants provides interpretive evidence of the disease. The case file of Frau D., the first diagnosed case of AD compiled by Alois Alzheimer, contains pages of interview transcripts with the patient and noted observations about her disordered behavior: the licking of a hairbrush, uncooperative behavior following removal from an isolation unit, inability (refusal?) to produce a written phrase when asked (Maurer, Volk, Gerbaldo 13-18).

In his illness memoir, Thomas DeBaggio reproduces a section of his neuropsych exam—an interview intended to ferret out cognitive decline or disorder—a reportedly six-hour affair. DeBaggio includes details from a report on “a sub test of social judgment and practical knowledge” which poses questions such as, *What would you do if you saw a movie theater on fire?* DeBaggio, who scores mild to moderate impairment in this section, answers that he'd “yell fire” (16). The report also notes that DeBaggio does not “know why it is better to borrow money from a bank than a friend and why a marriage license is required” (16). Of course, what is being investigated here is a type of knowledge which has no application outside of very particular cultural contexts. There is no indication in DeBaggio's text or others like it whether AD diagnostic interviews accommodate other cultural backgrounds or even the personal background (that is, the private tastes or values) of the person interviewed. The evaluation of such a test—wherein “not quite right” answers exist—suggests an imperative toward a particular cultural awareness and adherence, a particular set of social values.

It must be asked: What function does this screening serve in such cases, especially when there is no cure and little in the form of treatment for the disease? Ursula Naue and

Thilo Kroll posit that these diagnostic interviews “can be seen in the context of societal dynamics that aim to identify mechanisms for early identification of productivity loss” (29). Thus, the person who has tested positive for impairment belongs, instantly, to a pathological category, the criteria defined through the concept of impairment, of abnormality. The positive screen signals the emergence of AD and thus a developing void of self.

This void of self is known and defined by loss of autonomy and productivity. Cary Smith Henderson states in his memoir, “Sometimes I feel very uneasy about the whole thing, that I should be out making money or I should help people more. I just feel so darn useless at times. I just feel a sense of shame, in a way, for being so unable to do things” (18). The shame of idleness is created in the cultural valorization of progress, a progress which is the natural birthright of humans and which is evidenced in our cultural artifacts, our money system, our marriage rites. In being unable to interact with cultural evaluations of marriage or money borrowing, the demented announce an unwillingness (through the loss of a will itself) to reinscribe cultural values and thus an unwillingness to contribute to the human project “toward the elimination of evils and the final emancipation of human beings” (Shildrick 3). It is this loss of human will that defines the disease and must ultimately be reversed.

The creation of AD as a diagnostic category coincided with a wider trend in psychiatric research at the time, a belief that organic pathologies caused the symptoms of mental disturbance or impairment, a belief pursued in opposition to Freudian assertions regarding psychological disturbance as the source of mental disorder (see Dillman; Shenk; Whitehouse, Maurer, Ballenger). Dillman explains that Kraepelin—the director of the clinic where Alzheimer conducted his clinical work and research, and the person responsible for first publicly naming and classifying the disease—conceptualized the mind and brain as parallel entities, such that changes in the brain would be mirrored through the expressive potentials of the mind. As novelist Jonathan Franzen writes in his retelling of the

discovery of the disease, “Alzheimer’s plaques and tangles provided welcome clinical support for. . . [the] contention that mental illness was fundamentally organic” (Franzen). Kraeplin’s identification of AD also modified the conventional understanding of senility as a consequence of aging, effectively setting apart the two processes.

Plaques and tangles were no doubt key to this distinction, as organic markers considered *additional to* (abnormal to) the aging process. For Alzheimer, however, in contrast to Kraeplin’s conception of the disease, the presence of plaques and tangles were *not* the marks of a unique disease event. A year after Kraeplin announced the disease, Alzheimer concluded that the cases so described were not “caused by a specific disease process,” but were “atypical forms of senile dementia” (qtd. in Dillman 136). Apparently, Alzheimer was unwilling to refigure the conventional conception of senile dementia as a normal manifestation of aging. For Alzheimer, what made the condition Kraeplin called AD unique was where it occurred in one’s timeline; AD could only be considered pathological when it happened to someone too young to be experiencing typical senility.

Age continues to be a stumbling block in the conceptualization of dementia. The irony is well expressed in the following statement: “As life expectancy increases, the number of AD patients increases to the extent that it has been called a ‘major killer’” (Dillman 139). McGowin disagrees that AD is a terminal illness, stating that in conjunction with having a “chronic” and “progressive” condition, “we eventually, being mere mortals, expire” (115). Indeed, to construct AD as a cause of death in every instance of its presentation obscures the rising correlation of the disease with age. Our problem in discussing age comes with distinguishing between a measurement of human development (and possibly, deterioration) and a measurement of time. In any case, there appears to be, in AD, some overlap in the two measurements, such that one could predict with some accuracy general biological changes related to age. Menopause, for instance, is typically considered an age-associated event (though it doesn’t have to be). Although menopause has been medicalized and stigmatized, leading to medical intervention for some, the process itself

remains categorically exempt from disease status. Menopause thus functions primarily as a conceptual device, a way of discussing a variable biological process.

This seems to be the position Alzheimer took: senility was a not-inappropriate (i.e., natural) outcome of aging that might biologically present in anyone given *enough* aging, while its *premature* expression was deemed abnormal. This debate continues to circulate. Hughes, Louw, and Sabat, for instance, agree that dementia is an age-related process in the vast majority of cases, but they also identify AD as a disease, even as they acknowledge that “at the most objective end of ‘mental’ illness (that is, in the field of ‘organic’ dementias), it turns out there is no hard scientific boundary between disease and normality” (2). Have we tumbled into a rabbit hole? Indeed, the behavioral and perceptual outcomes which signal pathology in the earlier stages of AD are likely to be found in an aging population in general. As such, the reclassification of senility into a disease needs to be properly contextualized and thoroughly problematized. To wit, Elizabeth Herskovits explains that plaques and tangles “are not specific to the disease and, in fact, can be seen in healthy elderly brains and often are not present in the brains of individuals clinically diagnosed with Alzheimer’s” (149). This certainly complicates not only the diagnostic process, but also the conceptualization of AD as predicated upon the presence of plaques and tangles—or visible medical symptoms.

Dillman reminds us not to be confused by disease categorization, to keep in mind that the category has a function, but that the description and function are not always congruent with reality (131). According to Dillman, the concept of disease, when it comes to AD discourse, is constructive, in that the claim—that plaques and tangles are markers of an organic pathology leading to the disease—asserts its own method for research and investigation of therapeutic possibilities (148). The problem for Dillman is that disease “is accepted as a ‘given’ in order to investigate changes as if they expressed ‘disease.’ Yet it is not a given, because no one is sure whether AD is two or even more diseases—or even

no disease at all” (148). The concept of AD thus functions as a scheme for interpretation and classification, a method of organizing a set of observations and evaluations.

The potential negative effects of belonging to this classificatory scheme, of being screened into the category of the demented, is borne primarily by the patient. Herskovits explains that “diagnostic labeling facilitates social and medical control of the individual and contributes to the erasure of the individual’s subjectivity and agency” (152). Naue and Kroll concur, stating that a presumption of “loss” implies a necessary devolution of one’s individual identity (29). Naue further explains that the construction of dementia as a disease, as something distinct from species senescence, reinscribes the category of demented others who, although *wrongly* afflicted, nevertheless suffer social criticism (“Self-care” 321). McGowin voices this sense of stigmatization: “I feel my lack of worth acutely when I am in large groups of people. Being in a crowd or even in a busy thoroughfare overwhelms me. All those people ‘of worth,’ with places to go—who know where they are going” (112). AD is different from other diseases, DeBaggio states, because it “destroys the mind, without which you lose your sense of being human” (142). What counts as human is a socially constructed category, a matter of personhood; and what counts as personhood is certainly not continuous with human animality: there is a difference, in this construction, between the bone house and the spirit living within. We come back to Descartes: the corporeal substance of the human is separable from what really matters to *being* human—the thinking, immaterial substance of personhood.

The individually felt alienation conveyed by DeBaggio is an expression of the social position of the demented: as suspect beings, existing somewhere between life and death, between self and no-self. Naming a disease provides it with a thing-like stature in the world, a thing that can be looked at. Yet, AD is not a fact, but a “reality *claim*,” in that “it is impossible to tell what AD really *is*” (Dillman 150). Even as the disease concept effectively performs certain economic and political functions in the organization of research funding, pharmaceutical ventures, social programs, and disease associations, the most

important function of the disease concept, especially in narrative form, is as a method of organizing human experience into metaphysical compartments. The disease concept and accompanying narrative of AD work to preserve a collective human identity and a tandem narrative of continual human progress.

Narrative Knowledge

In its association with biomedical practice, narrative has largely been cast as a way of asserting the validity of individual illness experience, making it parcel to ethical practice. Attending to stories potentially repositions the patient within the medical encounter; that is, insofar as the patient's voice is given space, the potentially dehumanizing proclivities of medical discourse and practice are disrupted. Howard Brody, for instance, advocates the use of narrative in the space of the patient-physician interaction as an "ethical safeguard" (79). Narrative as a facet of biomedical practice would thus seem to be contingent upon recognizing personal narrative as a legitimate form of knowledge, *in conversation with* a biomedical discourse about categories of health and disease or disability—a discourse which asserts that there is a truth to such categories, truths which can be revealed via technological discovery.

Narrative, from this perspective, looks like something which can be added to biomedical practice, and thus subtracted from or left out of it. That narrative is still considered separable from medical practice appears to mark the limits of its knowledge-producing capacities: contemporary thought distinguishes between individual perception (the stuff of personal narrative) and an objective truth independent of any subjective perception (the stuff of science). However, rendering narrative a communicative container for private experience limits a thorough problematizing of narrative as rhetorical device, and therefore as knowledge-constructing. Likewise, asserting that a biomedical perspective on AD is the only true or legitimate perspective obscures the rhetorical function of that perspective, and certainly obscures the inherently narrative nature of biomedical discourse itself, the way biomedical discourse is composed of metaphysical fragments. While narrative knowledge appears to be defined against scientific knowledge, something confined to the realm of the individual, the distinction is false. The distinction has more to do with representation, with who has the power to speak. Narrative is made to be the human edge of knowledge, as if knowledge (in its objectively real form) were something other than

human. But human knowledge is never anything other than human knowledge, whether it belongs to the category of the scientific or not.

Lyotard identifies narration as “the quintessential form of customary knowledge,” or knowledge regarding what constitutes the ‘good’ of a culture or social group (19). Knowledge, for Lyotard, is not reducible to what is true or false, but rather what is inside or outside—what is socially accepted versus what is taboo. According to Lyotard, narrative knowledge circulates on its own authority—the teller and the receiver of such narratives play distinct roles, but it is in the act of relaying narrative knowledge that the legitimation of knowledge occurs (23). Cultural knowledge is always narrative knowledge, always placed inside of a set. Here we would do well to reiterate Dillman’s assertion that disease “is accepted as a ‘given’ in order to investigate changes as if they expressed ‘disease’” (148). Narrative knowledge poses as truth, as something other than subjective, when it poses as testimony, as a reproduction of reality. As Derrick Jensen explains, cultural practices (which would include the naming and categorization of disease) are rhetorically constructed from narrative knowledge, from a collection of stories that would “teach us how to live” (37).

Narrative may be the only way to give meaning to personal experience, especially given our current notions of individuality—a metaphysical construct which positions social actors as atomistic beings, each person a protagonist in their own life narrative. And yet, life narrative is bounded to the narrative of Human Being, and a narrative history both linear and ‘progressive.’ Jensen points out that the historical imagination itself is a form of narrative knowledge, in that the notion of human history as endlessly progressive and cosmically liberated “holds us captive” to “notions of forward and backward” (41). Personal narratives tend to take form within this historical imagination, rendering life neither cyclical nor embroiled in an always contextual and changing present, but rather as something which unfurls—a sequential process, something which will happen once, uniquely, and never again.

Illness narratives

Illness narratives belong to a different genre of life story. For Jerome Bruner, all narrative is narrative of disruption, arising “only when constituent beliefs in folk psychology are violated” (*Acts* 39). Folk psychology here refers to locally circulating beliefs which are entirely foundational to cultural practices, similar to Lyotard’s narrative knowledge—the metaphysics of a society, the narrative knowledge which structures lives. Illness narratives, thus understood, are only nominally forms of life writing, a performance of life writing, and their most important function is to maintain notions of what elements should compose the prototypical human life. Because illness narratives are separable from the standard biographical treatment, as stories of disruption detailing experiences ending in recovery (either literally, in the biomedical sense of recovery, or figuratively, through a discovery of meaning), disease or disability continually occupies a position of aberration. Illness is always the obverse of health, which is given as a normal standard of human life (Shildrick 17).

Illness narrative is distinguished from life writing as a meditation on the pathological, a story wherein normalcy breaks and must be fixed (broadly construed). In illness narratives, generally, the expression of truth, of the legitimate narrative knowledge which counts as truth, is a truth of the self: the continuance of a healthy/normal self which is always located at some point prior (backward) or some point further (forward) in relation to the narratively present abnormality. That which cannot be fixed nevertheless remains *fixable*, the means of which only need to be discovered. Illness narratives thus also function as foreshadowings for technological histories yet to be written, the prodromic movements toward a cure.

AD narratives tend to relate a story of senseless deterioration, a story not just of loss, but of pathological loss. Without the generic conventions of the illness narrative genre, the shape of an AD narrative might resemble that of a life narrative: the usual beginning, middle, and end. Indeed, before the construction of AD as disease, an aged person ex-

hibiting dementia was acknowledged to be experiencing a qualitatively normal event of human life, the standard senility of old age. The AD narrative, in contrast, is a story with an abruptly bent middle, a shortened life-story of a person intruded upon by a malevolent force. DeBaggio, for instance, compares AD to a “deadly, rampaging weed” that begins to “sprout” in his body (44), while the narrator of Genova’s novel *Still Alice* figures it as a “blazing fire” that leaves no survivors (117).

AD narratives function as cultural memories of the normal self, how a person should have—but didn’t—reach the natural end of their life story. Health, in this perspective, is natural to human society, at least as far as health is figured as a technological, historical destination. As a disease, separable from aging, dementia announces a transgression where one should not naturally exist, a disruption of the prototypical order of things. The narrative of health, by contrast, is orderly, productive, and performed by an autonomous and moral agent. In the same manner, a good narrative, according to Garro and Mattingly, is also orderly and productive:

A failed story is one that leaves the audience wondering why anyone bothered to tell it. A story may be well formed from a purely structural perspective, and it may have a clear ‘point,’ but if the audience doesn’t know why the point matters to them, if the events in the story never touch them, then the story doesn’t work. (3)

A good narrative is thus never disruptive in and of itself, but rather functions to reassert an order, to reassert the dominant strands of cultural knowledge. Anne Hunsaker Hawkins posits that the proliferation of illness narrative, or what she calls pathography, “may reflect some pervasive and current cultural myth—one that privileges narrative and that validates the authority of personal experience” (186). Hawkins explains that the events of a story need not be factual so much as *meaningful*. This indicates that what is valued in ‘new’ narrative knowledge—that is, personal narrative—is the relaying of an already circulating metaphysical reality. The authenticity of a story is a manifestation of its adherence to the cultural order.

The interactions of self and story in the creation of personal meaning is contingent upon those folk psychologies or metaphysical constructs which order cultural meaning. Bruner, for example, asserts that “trouble is a narrative idea,” and wonders how humans “get knowledge” of what counts as a situation of suffering, what Bruner calls “plight” (“Human Plight” 8). Bruner’s inquiry implies that ‘plight’ is a natural kind, in that knowledge of suffering is a matter of empirical measurement and interpretation, a matter of discovering the relevant characteristics of it. However, ‘plight’ is not produced in the void of a natural “notion of normality,” as Bruner implies (“Human Plight” 8), as if ‘normality’ existed as a solid state in the world in organic opposition to suffering, arranged, for instance, like the sun and moon. Suffering, rather, is produced in the circulation of cultural knowledge about what should count as suffering; normality thus merely poses as *a priori*, as a natural kind, with suffering as its pathological counterpoint.

That narrative so often takes up the subject of ‘trouble’ shouldn’t distract from the ultimate purpose of such narratives: to reassert the natural, normal order of things by alerting us to normality’s absence. Suffering thus never achieves ‘normal’ status and instead becomes normality’s obverse object. Although attending to personal narratives may be one way to resist an impersonal biomedical method of practice, personal narratives of illness nonetheless reinscribe prototypical structures set forth by a biomedical discourse of health and illness, a biomedical discourse which also propogates a rhetorically constituted metaphysical/cultural order.

Medicine’s hero myth

Western medicine’s stature and identity are discursively continuous with a Hippocratic tradition that effectively modernized the states of disease and healing, transforming physical malady into a natural (as opposed to supernatural) and logical event. Given the limited understanding of human anatomy/physiology or microbiology, the primary duties

of the Hippocratic physician were to collect observable data, offer counsel, and not add suffering—hence the iconic Hippocratic oath to do no harm. The contemporary notion of the physician-patient relationship descends from this tradition; what is implied is a relationship of communication and tactile care.

The myth of Western medicine as a scientific turning away from ritual belief in the supernatural has developed into an imperative for natural truth, truths which are not just discovered but accessed and manipulated. This makes medicine a protagonist in the story of human knowledge, that drama of Man liberating Man from the trenches of nature. In this story, humanity evolves, escaping the circumstances of creaturely powerlessness under nature's thumb to a technological mastery over nature. As John Gray says, "Science promises that the most ancient human fantasies will at last be realised" (123). Modern biomedicine has taken up the identity and therefore the cause of science. Medical practitioners are the technicians of the natural and therefore naturally pathological human body, a machine-like assemblage of archaic parts which fail, decay, and die. Science, in this story, is the fix, the means by which we will free ourselves from our unfortunate, merely incidental, mortality.

When Roy Porter constructs "a short history of medicine," the narrative begins with the discovery of human disease as a physical manifestation, rather than a metaphysical condition. Porter tells a story of human invention and ingenuity waging a battle against bacteria and viruses, a story about the extension of human senses through technology, and a story about the making of a contemporary medical practice that commits its own chemical and surgical violence upon the body. In these stories, the progress of medicine is defined by an increasing use of technology through increasing interventions. Medicine is one more instance of the triumph of technology via human insight.

Porter's history is not a history of patienthood, although the spectacle of the medical subject lurks, implicitly, as a site for digging, the place of discovery and invention. Medical practice requires the consent of the patient who, in the medical encounter, lacks the

agency of the physician to interpret and act upon the body. In the narrative of medicine, patients are a population of parts, entirely exchangeable in the economy of biomedical practice; they are of a type, of a genre of pathology. Physicians no longer solely depend upon a patient's narrative of illness, not when the body can be mined for clues, not when a regimented interview process can yield all the information sufficient for further investigation or, as in the case of dementia, expert interpretation. Hawkins reports that the subject of a medical narrative is, fundamentally, a body *reduced* to an array of biological cause and effect, whereas the subject of an illness narrative is a person in the esteemed sense of the word (12). Through illness narrative, the patient becomes author of their own story: a protagonist within a personal and cultural narrative. Illness narrative expresses an 'unverifiable' reality, whereas the typical medical case study is alert to the medical 'facts' of the case.

And yet, despite our apparent preference for the character of rational man, it is not technology alone that allows medicine to effect its cures. The mind, that thing which strikes us as separate from the body, will promote its own cures, as the placebo effect reveals. Howard Brody explains the power of symbolic healing (or suffering), as that witnessed in the placebo response:

As a general rule, patients will be more inclined to get better when they are provided with satisfactory explanations for what bothers them, sense care and concern among those around them, are helped to achieve a sense of mastery or control over their illness and its symptoms. Patients will become worse when the illness remains mysterious and frightening, when they sense social isolation and lack of support, and when the illness is accompanied by a feeling of helplessness. (80)

The positive effects of care, Brody explains, are best achieved by listening to the patient's story, lest the physician's explanation and course of treatment appear formulaic and not uniquely targeted toward the individual's situation. Attending to illness narratives thus appears to produce more positive outcomes. Further, contrary to the common assumption that objective, scientific knowledge is fundamental for medically effective outcomes,

Arko Oderwald claims that “the idea of an objective reality may be counter-productive in medical practice” (83). Oderwald contends that biomedical practice is, essentially, a necessarily narrative practice; medical practices are formed in adherence to reigning narrative knowledge about what seems logical, practical, and decent.

The role of the physician, Oderwald points out, is strictly limited, in that “they have to obey certain rules that are bound to society” (85). The entire physician-patient encounter is bound to such rules, all formed in relation to cultural knowledge about what constitutes the social boundaries of the encounter. Patient and physician thus defer to a readymade order, the rituals of the medical encounter, in order to arrive at some explanation of the individual’s perceived problem. “As narrative,” Oderwald explains, “biomedicine is kept at a distance from the life of the patient, is different than the life of the patient. As reality, biomedicine appropriates the life of the patient and is declared to be identical with the patient’s feelings” (86). Pathology is mapped onto the body of the patient, as the body becomes all surface, without interior. The identity of the patient is constructed in response to narrative knowledge of illness. Mapping disease entities, making disorder/disease something which is embodied, reveals the disruption as a function of some other, dominant discourse—a metaphysical category which marks the center and margin of what is acceptable and what is taboo.

Dementia as disaster

Susan Sontag writes, “Science fiction may also be described as a popular mythology for the contemporary negative imagination about the impersonal” (“Imagination” 220-21). Sontag’s analysis of the generic elements of science fiction films provides a useful parallel to scientific narratives of disease. As Sontag explains, the alien invaders or otherwise malignant forces at the center of the science fiction monster/disaster story are always depicted as other than human, in the sense that they are without individual wills. They

are biological automatons or participants of the hive mind, essentially mindless at the individual level (“Imagination” 221). By extension, Harry Moody explains that what matters in AD narratives is a loss of dignity predicated upon a loss of group identity subsequent to a loss of personal identity. Using Kafka’s “The Metamorphosis” as a point of comparison, Moody writes that just as Gregor Samsa’s sudden transformation into an insect upsets his position in the family, “so too, the dementia victim takes on the feature of an infrahuman animal, a pet, who lives among human beings but no longer shares their world” (87). Monsters, whether in the science fiction narrative or a disease/disability narrative, represent a dumb and wanton nature, a nature of either excess or deficit, of infection or contamination.

Like “The Metamorphosis,” AD narratives usually begin in a private sphere, with what bizarre or out-of-self behavior the family notices or denies. Denial is a prevalent feature among caregivers of those with AD, according to Anne Hendershott, even when denial precedes diagnosis (2). What Hendershott implies is that change should always be immediately suspect, that change should be *symptomatic*. For Hendershott, denial is never about confusion, about the ineffable, about not knowing how to interpret a new terrain of experience, but is a refusal to recognize what is already, and immediately, available for interpretation. There are only normal and abnormal, and the boundaries between these two states are clear and either acknowledged or ignored.

Moody, on the other hand, allows that AD is “an illness of a peculiar kind,” wherein “the situation resembles the film *The Invasion of the Body Snatchers*, where alien invaders take over the bodies of ordinary people who continue to resemble their previous selves” (87). This follows the commonplace Alzheimer’s trope of the loss of self, and imparts a sense of the legendary slow creep of the disease. The word *insidious* is often associated with AD. Writing of his own process of denial in interpreting symptoms of dementia in the behavior of his father, Jonathan Franzen writes, “I can see my reluctance to apply the term Alzheimer’s to my father as a way of protecting the specificity of Earl Franzen from

the generality of a nameable condition” (Franzen). As Franzen explains, turning behavior into a catalogue of possible symptoms turns the person into an alterable compendium of parts, a series of effects. And this is in contrast to a much older story, that of the ensouled body—the person who conducts his or her self. For Franzen, recognizing AD doesn’t just change the story of his father, it changes the concept of personhood, threatening to render “our beloved personalities to finite sets of neurochemical coordinates” (Franzen). Exchanging the story of the ensouled body with the story of the machine maintains a conception of the material world as basically meaningless and without soul. Once reduced to a sequence of chemical effects, personalities can no longer be loved, but only looked at.

In an age of medicalization, the soul hardly seems to exist, and the apparent wholeness of the body no longer certifies individual life. As Shildrick explains, “Technological and clinical advances. . . [have] figured the self not only as extrinsic to the body, but the body as an essentially socially isolated, self-contained mechanism” (17). No social responsibility toward the body exists, only toward the individual. Interpreting the symptoms of AD involves hunting for the individual, grasping after the interior of the body, looking for the soul—and to measure those moments against the dumb motions of a fizzling brain. The mind is the new soul. The body remains the body: a surface, a reflective surface. AD memoirist McGowin, gazing at her reflection in the mirror after receiving a diagnosis of early-onset dementia, announces, “I looked perfect. I looked untouched. No one could tell just by looking at me that I wasn’t perfect any more” (74). Just as in *The Invasion of the Body Snatchers*, the likeness of the person no longer guarantees their existence or an authentic self-expression.

Even at later stages of the disease, Franzen continues to see evidence of his father’s will, or ego—what he calls the “soul-like aspects of the self” (Franzen). This will, says Franzen, is an expression of some original and interior self, something which existed prior to AD and continues a subterranean existence. Thus, Franzen’s father and the symp-

omatic effects of the disease are separable at specific points, usually at moments of vocalized self-reflection which Franzen seems to find insightful or touching. That is, in certain recognizably emotional moments with his father, Franzen rediscovers him, sees him gasping for air beneath the surface of the disease.

In this story, the conventional, dualistic ideologies of human nature remain. The self is a (mindful) passenger who loses control of his corporeal vehicle, and verbal self-reflection is not a brain process but a metaphysical power, a power to make one's self present. The mind is disarticulated from the brain just as the soul is disarticulated from the body. The monster or invader of the science fiction film precisely lacks this element of self-reflection, having no authentic mind nor soul. According to Sontag, "The dark secret behind human nature used to be the upsurge of the animal—as in *King Kong*. The threat to man, his availability to dehumanization, lay in his own animality. Now the danger is understood as residing in man's ability to be turned into a machine" ("Imagination" 222). And yet, the machine and the animal are not a binary pair, and no imperative exists to distinguish between the two. Often they are one and the same. Descartes, for instance, collapsed meaningful distinction between animals and machines, announcing that a well-ordered machine "having the organs and the shape of a monkey or of some other animal that lacked reason" could effectively pass as an animal (31). All material bodies are machine-like, says Descartes, but what marks the boundary between beast and man is man's ability to reason and to communicate his reason. Humans evidence their exalted species position, unlike merely vocal animals, by *reflecting on* what they are saying (32). This evidence of reflection is finally what preserves Franzen's recognition of his father's continued individuality, even if it's found within the exoskeleton of Alzheimer's.

Not every AD narrator is as charitable as Franzen. While Moody invokes Kafka's "The Metamorphosis" as one parallel to the conventional AD narrative, he certainly prefers *The Invasion of the Body Snatchers*. The transformation in "The Metamorphosis" is too abrupt, Moody says, to truly coordinate with the process of AD (87). And yet,

this is not the most significant contrast between the two stories: Kafka's story provides an in-the-know protagonist, someone with self-awareness. Samsa's transformation is not entirely incomprehensible to himself. While his family is convinced of an abrupt, new non-existence, Gregor Samsa knows he has not disappeared, but rather changed form. Yet, even as his body is transformed, the new form remains a site of human meaning through continued occupation within the family home, capturing the traces of a former identity. The victim of a body snatcher, in contrast, is entirely absent, entirely insensible to one's former identity; the body snatcher who passes for real suggests a more terrifying prospect involving not denial but deceit. But between these two monster stories, we find the basic permutations of metaphysical conjectures with regard to AD: questions of what constitutes human being (self) and what constitutes death (no self).

Genres of experience

The 'point' of a narrative never arises from the narrative itself, but from the narrative's interaction with other narratives. For Garro and Mattingly, narrative functions, fundamentally, as a means of "decoding and reframing the past to make sense of the present and provide an orientation for the future" (7). However, 'decoding' cannot be a matter of seeing what was always already there, but rather a method of invention and interpretation. Narrativized experience is produced in the interaction of what is sensed, what is remembered, and what is scripted. Contradictions tend to be obscured or pushed aside in favor of causally linear explanations.

As David Shenk points out, when it comes to memory, "recall is never replay" (56). Memory does not function like a recording device, capturing whole or undiluted observations and sensations (as if such a thing existed in the first place). Although many theories of memory have come and gone since Plato, Shenk explains that the current understanding of memory casts it "not as a substance, but as a system" (51). Memory is

a coordinated happening, and the more a memory is remembered (that is, the more often the happening is coordinated in approximately similar ways), the more entrenched the happening becomes. At the same time, memory is always new, never an object which can be retrieved and examined. Thus, remembering is always an act of invention, so to speak. Mary Douglas further complicates this act of framing experience:

Perceiving is not a matter of passively allowing an organ—say of sight or hearing—to receive a ready made impression from without. . . . Recognising and remembering are not matters of stirring up old images of past impressions. It is generally agreed that all our impressions are schematically determined from the start. As perceivers, we select from all the stimuli falling on our senses only those which interest us, and our interests are governed by a pattern-making tendency, sometimes called schema. (45)

Or, as John Gray more simply states: “Our perceptions are fragments, picked out from an unfathomable richness—but there is no one doing the selecting” (71). Pattern-making is implicated in the formation of known experience, memory, and narrative perception, but it is not a willed activity. Pattern-making is also a feature in genre theory, in that genres are created out of the boundaries and scripts of social performance, and social behavior tends to be stereotyped enactments and responses. Carolyn Miller explains that genre is “based in rhetorical practice, in the conventions of discourse that a society establishes as ways of ‘acting together’” (163). Genres, as social behavior, are produced in the wake of cultural narratives about how to live; like memory, they are recalled in the moment of their happening.

A fundamental, generic aspect of narrative is sequencing, with the concomitant notion of cause and effect, of linear unfurling, such that past is always behind or backward to the present, the future ahead or forward from the present. One event must follow another while being simultaneously present in that other, either as memory or destiny. According to Kai Mikkonen, narrative is typically associated with spatial metaphors of travel. In the trope of “the journey,” with its events of leaving and arriving and its encounters along the way, “we have come to understand personal life and mental development as a voyage”

(286). Mikkonen approaches these spatial/travel tropes as cognitive metaphors which forcefully shape narrative possibilities, such as the narrative expectation of linear or causal sequencing, while preexisting narratives produce competing “maps and itineraries” of experience (294). Such mapping is an unavoidable generic aspect of narrative.

Mapping experience, locating the self within a sequence, involves communicating a situational geography with generic landmarks of experience which are nevertheless uniquely experienced and expressed. In the case of illness narrative, such landmarks might include symptom arrival, medical encounters, diagnosis, and so on. Lisa Snyder’s *Speaking Our Minds*—a collection of individual stories constructed from interviews with people diagnosed with AD interspersed with Snyder’s analysis—makes use of such landmarks as an organizing structure for every narrative, although Snyder’s vocabulary for the landmarks reflects variety. For instance, every interview/interpretation begins with *first signs* or the *onset* of diagnosis and ends with a revelation of personal meaning or prospect about the future. In articulating one’s story—locating one’s experience—in a geography that is already well mapped, genre announces the possibilities and limits of expressing individual experience within an omnipresent group identity.

‘Decoding’ and ‘reframing’ is thus a matter of realizing a particular shema, of ordering memory and experience into the current generic geography; such action also presents a method of revising one’s narrative identity, an identity constructed in relation to circulating cultural criteria of the protagonist/author position. Derrida and Ronell link genre to a process of normalization: “As soon as genre announces itself, one must respect a norm, one must not cross a line of demarcation, must not risk impurity, anomaly, or monstrosity” (57). Applying to genre this notion of discursive power, one can apprehend the function of illness narrative as a genre: to preserve already circulating structures of health and disease or disability. Bruner states, “just as our experience of the natural world tends to imitate the categories of familiar science, so our experience of human affairs comes to take the form of the narratives we use in telling about them” (“Narrative Construc-

tion” 5). But he has perhaps missed an important point in raising a distinction between a scientific experience of reality and the artful experience of human psychology: the possibility that experience of the natural world is itself predicated upon narratives of human experience. This implies an endlessly recursive process of interpretation, as the invention of categories delimits the traits of membership and membership reasserts the category. As such, the categories of science may be in *imitation* of our experience of the natural, which is itself constructed. Indeed, metaphysical constructs, to invoke Dillman again, are normally found represented in biomedical discourse. One such construct is found in the distinction between the body and the person in health care.

The distinction between the subjective and the objective is commonly preserved (and the limits of human knowledge obscured), as the relationship between illness narrative as an authentic telling of the illness experience and the categorization of disease as described by biomedical discourse is one of mutual legitimation. That is, the announcement of the disease also announces the generic boundaries of the illness experience which will necessarily follow, and this experience, in narrative form, will reassert the fact of the disease. Memoirs of Alzheimer disease continually recount the education process which follows diagnosis, a process of learning what will come. What follows, however, is that every struggle becomes a struggle stemming from disease: every fight with a spouse, every moment of anxiety, every task done poorly or not at all is an effect of Alzheimer’s—the thing that is always there, exerting its influence.

This circularity is further witnessed in the distinctions made between disease as an objective, biological reality, a natural kind properly found in the world, and illness experience as subjective. One might be willing to concede, then, as Conrad and Barker do, that the experience of illness is socially constructed while denying the social construction of disease—indeed, any rhetorical construction of the biological—such that illness narrative, to use a spatial metaphor, is a personally produced topographical map, while disease is the ground of reality upon which the map is based. Conrad and Barker grant a “widely

recognized conceptual distinction between disease (the biological condition) and illness (the social meaning of the condition)” (67). Such a distinction is tenuous, nothing more than a move to preserve the discursive boundaries of biomedical discourse as a route to objective reality versus artful or impressionistic experiences of the human subject. In fact, this pose of reality is necessary for maintaining cultural (collective and individual) faith in the myth of the exalted Human Being, as well as the primacy of scientific discourse over alternative discourses.

The distinction between disease as a natural kind and illness experience as individual story is found again in narrative medicine, a discourse which asserts that illness narrative in a sense *heals* medicine, as it “returns the voice of the patient to the world of medicine” and “does so in such a way as to assert the phenomenological, the subjective, and the experiential side of illness” (Hawkins 12). ‘Return,’ of course, implies that this missing voice was not always missing. The narrative of splitting and recoupling follows the generic boundaries of a healing narrative, the split figured as an instance of suffering: “At the heart of suffering,” Howard Brody suggests, “is the feeling that what ought to be whole is being split apart” (84). According to Brody, reattachment, or healing, occurs at the intersection of telling and listening, the same intersection at which Lyotard’s process of legitimation takes place. Hawkins explains that pathographies tend to stick to conventional narrative structures, an attempt to make illness coherent and orderly (160). Illness must be made to fit a certain schema, a certain genre. And illness narrative as a genre tends to take its cues from biomedical discourse.

Illness, in fact, is not validated as illness until it has been granted a geography of disease for personal experience/expression; anything else is malingering, or psychological torment. For example, Michelle Murphy details how so-called environmental illness, or Multiple Chemical Sensitivity, has been discussed in “conventional” biomedical discourse as an “illegitimate diagnosis,” making it “a postmodern version of women’s age-old ability to psychosomaticize their distress” (88). Illness narratives thus occupy a liminal zone,

locating, on one hand, a universal and medicalized body, while also announcing the singular illness experience, the unique (because individual) story. The geography/sequence of events presents as reality, while the interpretation remains singular and subjective. The geography consists of the facts of the body and disease, while it is the self which travels the narrative structure.

Self and story

The link between story and self is not insignificant in the production of illness narrative. According to Hawkins, in personal narrative, “self and story validate each other” (188). For Hawkins, this validation is a matter of esteeming individual perspective and also a way of locating a sequence of events: the self asserts the authenticity of the story, while the narrative form confirms the very existence of personal experience, and thus of the self. The reality of self and story exist in equilibrium. We can perceive, then, the implications of this link between self and story for the person in a state of advanced dementia, who is incapable of producing the sort of coherent and good story dictated by conventional narrative structures. Reflecting on his father’s AD, Jonathan Franzen writes, “This was his disease. It was also, you could argue, his story. But you have to let me tell it.” And yet, we don’t get his father’s story. His perspective is entirely absent and the resulting narrative is a conglomeration of medical discourse on AD coupled with Franzen’s (admittedly weak) memories and reflections on the events leading to his father’s diagnosis, institutionalization, and death.

Here, disease and story correspond to one another, validate the other. Franzen’s father, his supposed self, is not a necessary element of the narrative. This is a recognizable feature of AD narratives: the supplanting of the person who becomes spectacle to the disease. Unlike other illness narratives wherein the illness experience must be accorded a certain position within a life narrative, even if as a moment of interruption, AD limits the

possibility of a prototypical life narrative; the disease, in a sense, overtakes the self and renders the self meaningless. The disease takes over not just what is told, but who does the telling.

Wendy Roy links the inability to narrate the sequence of one's life to the vitality of the "loss of self" trope, as the continuity of a self through time/space is evidenced through life narration. A sequence in Hamilton's *Glimmers* illustrates the point well. According to the book's back copy, *Glimmers* is "a deeply moving account of one's woman's journey into Alzheimer's disease." The narrative is told from the perspective of Hamilton, a nursing home volunteer who befriends Elsie, a woman exhibiting signs of dementia. In one sequence, Hamilton questions Elsie about her relationship to persons in a collection of photos found on her dresser. According to Hamilton, Elsie not only cannot recognize her husband and daughter in these photos, which are apparently two decades old, but she cannot even recognize herself (95-7). Hamilton writes, "The despair of not being able to recognize oneself is one of the darkest images of Alzheimer's disease. It cuts to the core of our identity" (104). What is meant by this act of recognition, of course, is recognizing one's self backward and forward in time/space, acts of location and projection.

This sort of mental activity also rests upon notions of psychological cause and effect, which entails a certain amount of self-reflection. Activities of the current self must be related to activities of a past self, which are always one and the same, and only different in the sense of separated by metaphysically irrelevant distances of space and time.

Except, in the case of AD narratives, coherency and continuation of past, present, and future forms of self are threatened by AD. For instance, in his memoir *Losing My Mind*, DeBaggio weaves together three distinct narratives: the medical narrative of AD (as an object of historical and medical inquiry), an autobiographical thread which accounts for the time prior to the disease, and a pathographical thread which relates DeBaggio's own illness experience of AD, which is structurally distinct from the autobiographical thread. The narrative effect is division: DeBaggio's past contains elements of his real/whole self

which is disrupted with the arrival of the disease, while AD poses as an evil and shadowy marauder, an actively destructive *thing* working upon DeBaggio's mind, an object which effects a split in identity from pre-disease to post-disease. Post-disease, DeBaggio is a contaminated and disintegrating self/mind/person. The structure of the memoir, with its three, distinct narrative threads, provides for the split of the self from the story of the disease. That is, DeBaggio's self is not commensurate with the disease event, but an aspect which *lives* prior to and is intruded upon, eventually to be destroyed, as the projected future self is a nonself, an entirely diseased self, a non-narrativized being. What is ultimately being validated, in narratives of this type, is the conventional narrative of AD which asserts a loss of self.

Self and story continue to validate one another, but through the negation of both, as the disease destroys narrative ability and thus self. Following diagnosis, the only story left to narrate is one of disintegration, and it must borrow its major and generic plot points and modes of character development from the medical narrative of the disease.

Yet, an alternative narrative of AD exists, and with it arises an alternative conception of what constitutes the self. J. Bernlef's fictional rendering of dementia in *Out of Mind*, for instance, never explicitly references the disease model of dementia. *Out of Mind* does invoke conventional elements of a disease narrative, but also resists the genre, particularly in the way the novel problematizes the issue of who gets to speak, or what counts as an articulable subjectivity. In narrating the progress of dementia through his protagonist Maarten, Bernlef utilizes the usual landmarks of a disease narrative: the first sign of symptoms, the growing distinction between a then and now self, and the struggle experienced by family members and a medical establishment to resolve that distinction. However, Bernlef doesn't approach the process of dementia as a disintegration of the self, a disappearance of subjectivity, but rather as a process of emergence—a newly emerging subjectivity wherein the boundaries between self and other transform, and in some sense collapse. Disintegration is thus repositioned as a process not just of the individual,

but of the spaces between individuals; disintegration is a by-product made from resisting the demented's transformation, from holding on to the past, rather than flowing with the present.

This resistance happens from both inside and outside the process. Just as Maarten's wife Vera struggles to make sense of Maarten's new self (and ultimately is unable to do so) so too does Maarten. As Vera says to Maarten's doctor, "Sometimes he's like a stranger to me. I can't reach him" (63). Similarly, Maarten struggles, at moments, to reach the self he once took as his: "Under this life stirs another life in which all time, names and places whirl about topsy-turvy and in which I no longer exist as a person" (63). Their individual struggles, however, remain individual, and in fact a space of understanding is never created. Vera continues to resist Maarten's transformation, even though she is the one capable of bridging the distance now opening between their former selves. The reader is never sure how much control Maarten has over his experience, as he vacillates between ecstasy and terror (and indeed, his terror often takes on an ecstatic tone).

What is clear is that Maarten is aware of becoming someone, or something, else. "I am being split open from inside," he announces. "It is a process I cannot stop because I myself am that process" (94). Indeed, in Bernlef's narrative, the moment of initial symptom expression is a moment of permeability, a moment when Maarten's sense of self merges with the environment as he blames his poor memory on the surrounding snow (7). This permeability with the surrounding environment—or to phrase it a different way, the environment that his self is in process with—remains the major element of his dementia experience throughout the novel. His collapse into (or merging with) winter, water, light, and surrounding objects comes in tandem with his failing use of language:

Words, that's what provides energy, they are themselves energy. A human being should be made of words. Totally. It's so obvious. (At last something of worth again, supply of words there must be, that's what can save the situation, stories, supply, import of stories.) (135)

In coming back to story, Maarten can retain his unique self, the human self distinct from his surroundings. Yet Bernlef resists positioning this human self, the languaged self, as anything other than merely status quo, and violently so. By the end of the novel, Maarten's inability to maintain his own (separate) narrative leads to his nightmarish institutionalization.

Self, within conventional narrative structures, is that entity which can be lifted out of history, lifted out of context, lifted out of environment—a memory which can always be resurrected into the present by apparent recall and correspondence to the flesh of the recaller. The despair which comes in no longer being able to conjure this self is an effect; the mistake in this is to privilege the self of story, to the exclusion of other conceptions of self. Adherence to this dominant conception of self as continuous through time and space, as evidenced in narrative form, comes from privileging story itself. Indeed, Jerome Bruner considers narrative as entirely necessarily for the functioning of human society (“Human Plight” 3-4). However, Michelle Ballif argues that conventional narrative structures construct “legitimate subjects,” subjects which move narratives toward generic teleological ends (92). The two prototypical narrative structures Ballif identifies as most influential are the “Aristotelian Linear Narrative” and the “Freudian Triangular Narrative”:

These narrative conditions prescribed by Aristotle and implied by Freudian psychoanalytic theory have been embraced and re-prescribed over and over again with few amendments. A ‘good’ and ‘satisfying’ story is the story that cures the subject by making him/her whole, and thus legitimate. The cure is the history, is the ordered, linear story, the ordered, triangular story. It is a story with a beginning, a middle, and an end. (94)

Ballif adds that this story is one of general progress and “of the progression of a hero toward the final goal which, more often than not, is the state of Manhood—of autonomy, courage, maturation, selfhood” (94). The hero of the AD narrative, however, is not the disappearing self which instigates the production of the illness narrative; nor is it the disease. The hero is medicine itself. The progress of biomedical science in effecting a cure for the disease is the projected future end, the cure which will return the disappearing self

to wholeness. Yet, this story is one more generic expression of a larger narrative: that of the (techno)logical liberation of Man from base existence, the supremacy of culture over nature. According to Margrit Shildrick, a major strand of Western thought since the Enlightenment “holds that in the exercise of reason we are guaranteed progress toward the elimination of evils and the final emancipation of human beings” (3). The hero of the biomedical illness narrative is Man; the villain is disease; the disaster is illness. “Autonomy, courage, maturation, selfhood” are projected aspects of a self-motivated (or willed) human evolution toward the teleological end of human immortality through biological control and stasis, a final liberation of the self/mind from the fatal contingencies of the material body.

The metaphysics of dementia

“The body. . . is the enemy of survival,” Arthur Frank writes (33). What Frank’s statement implies is that survival, as an objective, can be had independent of the body; ‘survival’ thus implies something other than corporeal survival. The AD trope of loss of self picks up this disjuncture. Cohen and Eisdorfer make a metonymic construction in comparing the loss of self to a loss of sensory perception (deafness, blindness) or a loss of limb—except rather more profoundly disabling and “frightening” (22). The authors quote the daughter of a woman diagnosed with dementia as saying that “the death of the mind is the worst death imaginable” (22). And yet it is the body which is ‘snatched’ by the disease; it is the body that fails to protect the mind.

The self is an amorphous given, an insubstantial substance, a veritable thing roosting in the cage of the body. The death of one is not commensurate to the death of the other, and thus the self can go missing from the body. The death of the mind expresses the end of the self (just as the death of the body would) while the body-as-organism requires no self for survival. The self is thus a detachable center of narrative experience.

The metaphysical structures that shape the existence of the separable self also shape our discourse of the body in health, disability, and disease. Biomedical discourse itself, ostensibly subject to a rhetoric of technological reason, is subject still to the metaphysical configurations which position health as “some kind of given; a normative state which can be restored by defeating the abnormality of disease” (Shildrick 17). When Joan Kleinman and Arthur Kleinman advocate for a medical anthropology which would “examine how culture infolds into the body (and reciprocally, how bodily processes unfold into space)” (711), they are taking up the the same theme, the way in which cultural practices shape individual experience, how individual experience contributes to cultural knowledge.

The body, like a landscape, exists as the public space or ground of experience for the mapping of cultural narratives. Bodies are thus “animated” into cultural existence, into history, via the vibrant “inner space” of individual experience which is nevertheless parcel

to a collective, cultural experience (Kleinman and Kleinman 710-11). The construction of the universal, medicalized body, however, problematizes individual experience. Franzen conveys the effect in his response to his father's diagnosis of AD:

Conditions have symptoms; symptoms point to the organic basis of everything we are. They point to the brain as meat. And, where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self. Seeing my afflicted father as a set of organic symptoms would invite me to understand the healthy Earl Franzen (and the healthy me) in symptomatic terms as well to reduce our beloved personalities to finite sets of neurochemical coordinates. Who wants a story of life like that? (Franzen)

Diagnosis makes a person overtly subject to a generic discourse. More precisely, the person diagnosed functions as an object in that discourse, a site marked by the signs of disaster. In that transformation, the person's individuality is essentially reduced as the individual represents a type and group identity dominates. Often, in later stages of dementia, the person's entire behavioral catalogue is interpreted as an effect of the disease process (Dillman 147). The person thus becomes a 'case' of AD, a void of individuality: a mere biological human organism distinguished by a lack of decent-mindedness.

Disease, in its manifest generality, always threatens to usurp personhood or individuality, but the pervasive rhetoric of AD as a process of self-disintegration has created something monstrous from dementia, and perhaps, by association, from aging itself (Herskovits 148). In the documentary film *Quick Brown Fox*, for example, the narrator's mother, diagnosed with AD (the disease being the true subject of the documentary), is introduced to the audience in cinema effect: the only sound is an insistent tick-tock of a clock, the camera obviously handheld, shaky, the camera lens slightly fish-eyed and distorting the edges of the image as the demented woman appears, alone in the space of the camera, shuffling or stumbling in slow motion. The entire scene seems designed to communicate something warped. Similar tactics are used in *Partial View*, a photojournalistic work that combines transcribed text from sound recordings made by Cary Smith Henderson, a self-described "pure," or verified, case of AD, and Nancy Andrews, who contributes black-and-white

photographs of Henderson and his family. A few of Andrews' photographs are developed in such a way as to convey chaos or confusion, using effects such as blurring or layered negatives. In these works, the image of AD is conveyed through visual disorientation, in a manner that is simply not available for exploitation in verbal or written narratives of the disease. There is no pose of naturalism in such photographs; the display of unreality manifests the evaluation of the distributor, overtly coding the material for the viewer's consumption. The individual body, the snatched body, captured in these images is incidental to communicating the major trope of the disease, which must be authored into view.

Figures of the demented as an emptying or snatched body rely upon a discourse independent from biomedical discourse. In Western thought, the body is normally a generic container for the self, an avatar or vehicle for the performance and expression of the interior and private self. This figure of the self replicates the figure of the soul, as temporary passenger of the body and therefore temporary visitor to Earth. As such, we cannot investigate this dualistic perspective, wherein subject and object co-exist in a moment of self-awareness, and which is metonymically represented and valorized (via mourning its lack) in AD narratives, without noticing the relationship such a construction ultimately displays: a relationship of human alienation from Earth, an alienation, even, from the figure of the human organism.

The subject of the binary order

A major presupposition in the development of this topic is that language is largely figurative, rather than primarily literal. Alex Carson explains what is entailed within this "linguistic turn":

To all who have taken the linguistic turn. . . reality is always something we reflexively construct from within language. This is a critique of the idea that the truthfulness or accuracy of language could be measured against an external,

objective world or reality. Language, via the linguistic turn, is seen as having a reflexive or constitutive function which rather than revealing knowledge or reality, produces or constructs that reality. (198)

This approach removes the notion that language is built upon a “ground” of reality and is useful in undressing the evaluative functions of language, revealing language as a complex perceptual and social act. Descartes may have faulted “animals” for not speaking the language of humans (57), but the only animal that requires any type of human language, and the only animal that can exercise all the potentials of human language—which appears as little more than a device for social function—is a human. Approaching language as primarily metaphoric with literal elements also allows for a different perspective on binary thought, which is fundamental to Western suppositions about reality and what ontological categories exist in the world.

The following binaries are familiar: mind/ body; male/ female; good/evil; life/death; human/nature; reason/emotion; health/disease; active/passive; subject/object. As Susan Léger says, the “hierarchical arrangement of these terms” has been profusely illuminated (332). To wit, Shildrick explains that the primary term of these binaries, the left/ side term, always functions as the standard, while the /right side term is different from that standard, “and what is expressed as different is a counter-identity, rather than a radically alternative identity” (110). Thus, the terms do not express opposites as such, or the boundaries of a continuum, but rather express an evaluation of what is central and what is marginal, what is inside and what is outside. The categorical difference between the two terms, Léger explains, is created from the asymmetry of the construction, the evaluation. The counter-identity of the nonprimary term is an identity of void, of lack. But because the categories are not natural kinds, are indeed figurative, the overall categorization of what is primary and what is counter educe metonymic relationships. For instance, just as “man is the true form of humanity” within the philosophical canon (Tuana 8), so too, by association, does “mind” appear within the “true form of humanity.” And just as man (in true form) is

rational, active, good, and healthy, so too is mind (in true form) rational, active, good, and healthy.

Counter-identities also exist in metonymic association with one another, and are associated with the void of ‘true form’ (what counts in constructions of human identity). If woman is the pathological void of man, she is so because her body is too much, and her mind not enough. In binary construction, left-side and right-side terms tend to congregate as representatives of a categorical kind: the true form, and its counter—its lack. Self, as a the true form of humanity, must necessarily be healthy, autonomous, rational. Anything other or less is associated with the void of self. We can see through this the social function of binary thought in constructing identities or ways of being, as the individual self is constructed in reference to an already circulating narrative of collective human identity and destiny.

Shildrick offers an example of the associative logic at work in binary constructions:

The universalised, and more or less quiescent, body of phenomenology is essentially male and healthy, and the subjectivity that is defined over and against that body is a highly normative construct. In consequence, the inescapable and distinctive embodiment of those persons deemed to be in less than normative health becomes a determinant of their being treated as less than full subjects, as less than capable of independent moral agency. (169)

Approaching binary constructions as metonymic functions allows us to understand the process of dehumanization which Shildrick is describing. The healthy body is not detected; it does not make itself known; it cannot be guilty of committing the crime of illness: “Sometimes there is a feeling of guilt for having Alzheimer’s. I should have known better. Something should have been different. Maybe I’m no damn good. You’re worthless, you can’t hack it” (Henderson 59). The healthy body, the natural kind, is distinct from the unhealthy body, which is a body of “corporeal engulfment” (Shildrick 16)—the body which will fail the self, the body which will not defend the self. When the self is present, the body disappears; but the unhealthy body is subject to disease or disability,

not subject to the self. This is the method of narrative usurpation wherein the individual self is replaced by disease or disability.

We can look anew at the function of the illness narrative genre: to draw the distinction between the proper human identity—whole, autonomous, productive, independent of the body—and the counter-identity, the lack, which is left once the human identity is “broken.” Shildrick draws a connection between the sick body and the feminine, and here we witness again the associative logic of the counter-identity:

The relationship between the (broken) body as other and the feminine as other, both in relation to the masculine subject, is a highly complex one, and suggests again that those defined as sick are engendered as female. What both seem to encompass is the paradox that what is devalued is also the most threatening. (170)

Understood as the reassertion of a natural ordering, the presence of the “devalued” represents the threat of disruption, the presence of an ‘other’ discovered in the void of what *should* exist. In their proper place (figurally and literally), however, these disruptions serve to legitimate the natural order: just as the trope of loss of self affirms the existence of the individual self, the individual self serves as proxy for a collective human identity understood as entirely primary in appearance: a subject unto himself, good and reasoned, healthy and active of mind.

Sherry Ortner calls “the secondary status of woman in society. . . one of the true universals, a pan-cultural fact” (67). Ortner theorizes that this universal evaluation has to do with the identity of woman as being continuous with something “of a lower order of existence” and identifies this lower order as nature—specifically, nature as the void of culture, which is the effect of human consciousness (72). Ortner imagines something like a zone of proximity, with women at the margins of the cultural enterprise, the human identity, and thus closer to nature and less than fully human; further, woman is essentially incapable of “transcending” nature in the same way man is (73). A woman’s body, to return to Shildrick, is always already a pathological body, always closer, in the associa-

tive, metonymic logic of the metaphoric binary, to an anonymous nature, to death. When Genova's protagonist performs a self-diagnosis in an effort to explain why she feels as though she is losing her mind—a process later revealed as the symptoms of dementia—menopause is her first presumption, identified by an “appalling list” of symptoms delivered via a Google search: “This was just the natural, next phase in her life as a woman” (25). Where “woman” is found in discourse, she signifies a type, a generic; likewise, the demented is always subject to the generalities of the condition, an erasure of specificity. The feminine shares space with the ill, with the disabled, with the nonwhite, with death: as bodies of nature. Indeed, all these kinds are expressions of the perception of nature as the void of human culture—the void of a proper human consciousness. And in consequence of a biomedical imperative toward heroism, toward deliverance—the human project of liberation—those *kinds* which have been medicalized are subject to control, to a fix, to a cure.

Human mind, primate body

As an effect of binary ordering, the category of the self is granted a normalized status—it is the thing which can be lost. The nonself, like the anonymous animal, is discovered as an absence. Moody announces a “danger” in “thinking about the ethics of dementia in terms of the analogy of animal rights or any view that makes dementia patients into something less than human” (90). Even as the first project of animal rights is to undo an entrenched ethical distinction between the nonhuman and the human, Moody recognizes how the loss of self trope replicates the anonymity of the animal.

Strachan Donnelley finds in contemporary thought that the fundamental defining trait of humanity is the perception of and esteem for individuality in the form of selfhood or personhood. Donnelley asserts that what prevents us from “fixing our ethical obligations to animals and wider animate nature” is a lack of an “adequate understanding of animals

as individuals and humans as organisms” (21). Indeed, this would seem to fix the problem, to reveal the problem as a matter of perception. However, a metonymic association exists between individuality and autonomy, because individuality is figured as an aspect of the private, interior being which *inhabits* the body.

Donnelley points out that our conceptions of selfhood are discontinuous with the physical body, such that there is an evidenced split between the apparently psychological self (private, interior) and the apparently material body. Donnelley traces this development, what he calls the “bifurcation of nature,” to the scientific paradigm shift of the sixteenth and seventeenth centuries, “which has dominantly influenced our Western, technological, and political culture ever since” (22). Donnelley positions Descartes as lead architect of this cultural shift, as others have, pointing especially to his construction of a *res cogitans* and *res extensa*, distinct substances of mind and body:

In this division of reality Descartes stripped nature of all agency, subjectivity, and purposiveness, which he lodged (only) in the minds of human beings. Nature was rendered a mere dynamic, causal, mechanistic, and material affair, ‘mere matter in motion,’ precisely as the new mathematical science required.
(22)

From this perspective, modern scientific thought *effects* a splitting of substances. Anna Peterson, however, connects Cartesian thought to an evolved Christian metaphysics based upon notions of human exceptionalism, represented, for instance, in the Genesis account, wherein a monotheistic God creates man and woman in his own image and grants Man dominion over the Earth and the remainder of its lower creatures (28-41). According to Peterson, “Modern Western philosophy fused the Christian concept of an eternal soul (the image of God in humanity) with the more secular concept of the rational mind” (38). Strictly speaking, Donnelley is thus correct in asserting that science demanded a new configuration of reality, but such reconfiguration was necessary in order to accommodate an already circulating order, an order which had to be reformed for an emerging idiom. Descartes’ thought simply relegitimated preexisting narratives of human identity, trans-

forming the story of human exceptionalism from an overtly religious fable into a modern one. The inner and immaterial soul is thus exchanged for a psychosocial interior; both remain insubstantial substances whose presence is known through realization alone. That humans can logocentrically conceive of things which do not exist—as Meinong says, “there are objects of which it is true there are no such objects” (83)—presents a problem.

Human exceptionalism is not logical within the modern mindset. There is no reason, as such—within a mathematical idiom—to evaluate the thing called the human mind, or the catalogued traits of that mind, as inherently more valuable than the material form which is said to house it, to cart it about. There is no reason, as such, to judge humans as more progressive—or, in a yet newer idiom, as more evolved—than other animals. There is no reason to judge evolution itself in evaluative terms, or to construct a telos of evolution. What accounts for such perceptions, however, is the presumption of human exceptionalism, the yet circulating concept of a divinity, a divinity located in the interior, called the mind or soul, the essential proof of self.

Humans have certainly struggled to corral traits of the human mind, positing ‘us alone’ behaviors such as language use, tool use, self-consciousness, deceit, empathy, so-called cultural (human-consciousness) developments such as gardening or domestication of other creatures (see Midgley). Enough ethographic observation has been collected to negate such distinctions, even though a popular strand of public discourse on evolutionary theory accommodates a vision of human destiny based on exceptionalism: the evolutionary ladder. In the trope of the evolutionary ladder humans occupy a high position over the ‘lower’ life forms. Humans alone have been sifted out and destined for liberation from the heap of nature, selected and destined for the same greatness as usual: to be liberated from nature, liberated by our own, evolved will.

Donnelley points out that as humans we are uncomfortable identifying ourselves as organisms of the Earth. Just as Descartes adjusted the concept of human exceptionalism for the emerging vocabulary of his time, so have we adapted the Darwinian revelation of

kinship by supposing a purpose to evolution: us. This view of human identity, according to Christopher Manes, replicates the *scala natura* of Christian thought, described by Manes as “a depiction of the world as a vast filigree of lower and higher forms. . .with humankind’s place higher than beasts and a little less than angels” (20).

We find these same relationships replicated in stories of dementia. Charles Pierce, for instance, imagines humanity as an advanced stage and dementia as a backward movement into animality, nonspecificity and anonymity:

I may move through the stages myself—a specimen until I am a lower primate, until I am a brain down the hall. My father was a specimen. Then he was a lower primate. Then he was a brain down the hall. . . .It’s possible that we are moving into a time in which we will be a society of specimens—not all of us doomed to be lower primates, but. . .we will, all of us, look for causes deep within what we are, a querulous culture of potential disease. (98)

Pierce refers here, by “causes deep within,” to the genetic factors implicated, according to recent research, in the expression of Alzheimer’ disease: “You get it from bad genes” (Pierce 48). Genova’s protagonist also blames her genetics for her AD, blames her father’s “lousy” and murderous DNA.

Human DNA, in such accounts, is destined for an evolving perfection; bad DNA is a plague for humanity—a potential disrupter of the human project—but constructed as entirely separable from the human “species,” in that one day all those monstrous, murderous mutations will be effectively weeded out. The logic of this depends upon the narrative of human exceptionalism, because in reality there is no evaluating DNA as good or bad. Such evaluation comes in presupposing a standard of the normal, of the good. According to Gray, “Darwinism is now the central prop of the humanist faith that we can transcend our animal natures and rule the Earth” (31). In judging that we can control our DNA at some future point, we are locating human identity not in the materials of the human body and its environment, but in a narrative identity replicated in our cultural artifacts and institutions.

The cultural importance of personal identity is highly visible within the discourse of AD, especially in the idea that dementia effects an “erosion of a person’s core personality and selfhood” (Hinton and Levkoff 459). Identity disruption is a prevalent way of ‘making sense’ of AD. As Hinton and Levkoff state, “Though the person is there physically, a discontinuity exists between his identity before and after the onset of the illness” (461). The discontinuity is not perceived as a physical discontinuity (the way, for instance, a profound physical change such as paralysis or limb amputation may be perceived as changing one’s social identity), nor even a social discontinuity, in that the social stigma of AD is often cast as a natural reaction to the monstrous loss of identity. The loss of identity is a *private* loss, a loss of self and autonomy which *then* disrupts the social.

The narrative self

In contemporary bioethics, selfhood is commonly discussed as a narrative identity, although the vocabulary of narrative identity as a fiction is not often employed. Rather, personhood is made real through narrative capacity, which depends upon a particular state of human consciousness. In this construction of personhood, Marya Schechtman utilizes John Locke’s theory on the persistence of personal identity with some amendment. Schechtman explains that Locke disregarded the survival of any substance (mind or body) as a condition for personhood, and instead emphasized consciousness in the maintenance of identity. Schechtman explains that this has primarily been interpreted as an emphasis on personal memory, in that one has access, through memory, to a personal past which could be linked to the ongoing present.

Schechtman finds this reliance upon memory as a condition of personal identity to be problematic and messy in practice because memory is neither robust nor accurate. Schechtman prefers connecting consciousness and personal identity to the private apperception of the self: the perception of self-consciousness. Schechtman offers Locke’s def-

inition of person in support: a “thinking, intelligent Being, that has reason and reflection, and can consider it self as it self, the same thinking thing in different times and different places” (qtd. in Schechtman 11). Likewise, “the failure of such self-consciousness. . . signals the end of the person” (11). This way of connecting consciousness to personal identity is similar to Descartes’ conception of self as the insubstantial substance revealed in the presence of thought: how the very act of ‘seeing’ one’s self, through thought, furnishes the proof that one is a thinking substance.

Schechtman’s construction, however, relies more heavily upon a narrative constitution of the self—of apprehending one’s self as a Being in time and able to deploy interpretive techniques for knowing that self:

To have the kind of self-conception that constitutes personal identity on the view I am urging (call it the “self-understanding view”), one must not just know about some collection of past experiences and think of them as hers, she must see her life as unfolding according to an intelligible trajectory, where present states follow meaningfully from past ones, and the future is anticipated to bear certain predictable relations to the present. This does not mean that a person’s life course is entirely under her control, only that she can see connections between how things were, how they are, and how they are likely to be. Having a self-conception does not just amount to knowing that one has a past and will have a future, but also involves seeing these as inherently interconnected and rich with implications for one another. (18)

The self is not just temporally located, then, but also makes interpretative sense of one’s experiences. We can perceive in this configuration of self that the demented may still be refused the category of personhood. And yet, an adherence to narrative identity is explored as a dignity-preserving practice within the discourse of Alzheimer’s care, via bioethical assertions about the place of advance directives in the preservation of autonomy. Blustein, for instance, relies upon a narrative theory of self to argue “that proxy decision-makers are to act as continuers of the life stories of those who have lost narrative capacity” (20). In this way, Blustein’s argument is essentially similar to Ronald Dworkin’s on the role of advance directives in Alzheimer’s care.

In connection with a loss of autonomy, Ronald Dworkin presents an argument for limiting the real time autonomy of those with dementia in favor of what he terms precedent autonomy, such that any decisions a person makes before *becoming* demented are held to during their ‘absence.’ Decisions made in the past, then, such as refusing medical care in the event of a life-threatening illness, would take precedence over the best interests of the ‘now demented’ person. What needs to be explained first is that Dworkin believes “that personal identity does survive even the most serious dementia” (“Autonomy” 6). This is a facet of a larger discussion in bioethics concerning the nature of the self through time. The question that has been posed and debated is whether or not the same self persists through time, or whether a self can be fragmented into a pre-disease self that would be thought of as distinct from the disease self.

In *Life’s Dominion*, Dworkin proposes that cases of dementia are similar to cases of prolonged unconsciousness, such as vegetative states. Dworkin discusses at length a medical student’s account of a demented woman, Margo, who, by the student’s account, is one of the happiest persons he has ever known (see *Life’s Dominion* 229-233). Dworkin then imagines that a competent Margo, years before, signed a document authorizing the withholding of treatment in the event of a life-threatening illness. Dworkin holds the position that Margo’s previous decision takes precedence, irrespective of her current quality of life. This conclusion comes from Dworkin’s assertion that there is a recognized difference between a person’s experiential interests and critical interests. Dworkin explains that experiential interests are matters of sensual taste in daily activities, while critical interests are rather more ideological, having to do with the manner in which one approaches one’s life (201-202).

Critical interests thus appear to be continuous with narrative identity, given Schechtman’s criteria. Dworkin holds that Margo’s original, critical interests continue to exist despite her own inability to apprehend them. They persist, in fact, because humans, according to Dworkin, have an interest in ‘whole’ and dignified lives:

The suggestion that a period of unconsciousness or dementia before death might make that life worse as a whole than if death had come sooner introduces a very different kind of standard for judging lives; it judges lives not just by reckoning overall sums of pleasure or enjoyment or achievement, but more structurally, as we judge a literary work, for example, whose bad ending mars what went before. (*Life's Dominion* 27)

The narrative must go on, must arrive at teleological closure.

Evaluating critical interests as qualitatively more important than experiential interests, as Dworkin does, displays a certain bias for a generic performance of selfhood, a narrative selfhood. In asserting that others, not the demented, should 'continue' a life story, one is merely conserving a generic element, that of being "responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest" ("Autonomy" 8), wherein these traits are nonetheless culturally constructed. Ballif would no doubt remind us that Dworkin is invoking prototypical story-shapes of linearity or triangularity in such a bid for narrative coherency.

Following Dworkin's construction, the self should continue its inevitable journey as an expression of manhood/humanity. The private self, thus envisioned, is indeed a cultural artifact, a construction that does not necessarily require the complicity of the supposedly private individual. In evaluating one's life as an unfolding script, one is appropriating circulating narratives and making one's self subject to them, proxy to a human identity. The continuance of a life story in effective absence of the narrative self of that story is simply the same: the maintenance of a human identity which includes a notion of autonomy: autonomy not just of the private self, but of humanity as a whole. The demented is thus made to represent the sanctity, the dignity, of human life in the abstract.

Selfhood, occupying an ancient position once occupied by the soul and mind, perched in the body but not of the body, continues to be conceived as a detachable type; as such, one can lose one's selfhood and become in the social process of dehumanization something less than or other than fully human—analogue to an animal or vegetable, no longer 'higher than' nature but closer to it. Fromm explains that the valorization of thought is

created in the realization of physical frailty, as a way for humans to seemingly transcend nature, the creation of a substance, a being that “Nature could not naysay” (30). When all other human traits are revealed as unexceptional, part of a family of animal behavior, the individual self remains as the only evidence necessary for exceptionalism.

The nonself which appears in AD discourse (as AD itself, a usurpation of the person) performs the generic role of nature incarnate, a nature which is out-of-place, out of order: AD is the contaminant which creates the void of personhood. There is no way to reliably define nature, except as that which lacks the qualities of human identity, replicated in the vocabulary of personhood as self-consciousness, rationality, a sense of responsibility (Smith 47). But we can also identify a second sense of ‘natural’: as that which is orderly, or metaphysically placed. The natural place for nature, including bad genes, is *out there*, away from humans. From this we can perceive that ‘nature’ itself is constructed, ordered, and subject to a particular function: nature is an other-than-human presence; it serves as the landscape, the background, of the human narrative; as a character, nature functions as a foil for human identity, as an agent of disaster.

Individual identity and the fate of mankind

Tom Kitwood has been instrumental in refiguring the standard medicalized approach to dementia, both in the rhetorical framing of the disease and care of those diagnosed. Kitwood introduced, for instance, the concept of malignant social psychology, asserting that the totality of behavioral features expressed by a demented person could not be ascribed to a disease process because the social milieu in which the demented person is immersed will necessarily impact functioning. According to Kitwood, “If the cause of the whole downward process of dementia is attributed to disease processes in the brain, we are no longer in the realm of science, but of neuropathic ideology” (67). That is, ignoring the impact of social relationships on the behavior and functioning of the demented in favor

of rigidly constructed medical explanations, wherein the disease process alone is made to account for every aspect of a person's functioning, is in fact less than scientific. Kitwood is careful to explain that his understanding of malignant social psychology, including neuropathic ideology, does not presuppose a maliciousness on the part of caretakers, but is rather "part of our cultural inheritance" (46). Kitwood shows that many of the apparently aberrant behaviors labeled as effects of the disease are actually results of depersonalization.

Following Kitwood's thesis, Steven Sabat has recorded the presence of "excess disability" in cases of AD; the concept of excess disability proposes that a disjuncture may exist between a person's functioning versus their actual potential for functioning. According to Sabat, excess disability in cases of AD occurs when the person labeled with dementia is treated in such a way as to diminish or ignore functional abilities. As such, caretaker treatment tends to reproduce congruent behaviors in response. This work demonstrates, ultimately, that AD is not a private disease, and not a disease which merely affects families. It is a disease expressed socially, and expressed in such a way as to validate its social construction.

Kitwood states that our care of the demented "contains the residues of at least four depersonalizing traditions: bestialization, the attribution of moral deficit, warehousing, and the unnecessary use of a medical model" (45). What Kitwood does not do, unlike, for instance, Post or Herskovits, is attempt to account for *why* such depersonalizing practices occur, or why dementia has become a contemporary motif of disaster. Looking at Kitwood's catalogue of depersonalizing practices, however, it is remarkable to notice what similarities can be drawn between the treatment of those with dementia and the treatment of animals. Bestialization alone would seem to guarantee two following modes of depersonalization Kitwood identifies, in that 'beasts' tend to have little or no moral standing in Western culture, and warehousing of animals (in farming, entertainment, and as research objects) is traditional.

In fact, Kitwood's construction depends upon casting persons and animals as opposing figures, exactly the rift between 'individual' and 'organism' Donnelley identifies. As such, depersonalization involves being treated like an animal, which is precisely why Moody announces that an ethical approach to dementia which takes cues from an animal rights model is inherently dangerous, threatening to analogize the demented "into something less than human" (90). Of course, this only reveals the current weakness of an animal ethic to recognize personhood status in anything other than what is already supposed to constitute personhood. Thus we are drawn back into an already circulating knowledge built upon human exceptionalism, a human exceptionalism which depends upon demarcations of beast and Man.

Bestialization is a process, then, that affects not just humans who can no longer exhibit and circulate the traits of human exceptionalism, but everything else which fails to perform as human. Other animals are distinguished in this way by what they lack: most significantly, an inability to express a narrative identity that is both mythic and unique, historical and progressive. The individual as potentially heroic asserts the always inherent potential of the individual self in service of the collective, as representative of the power of mankind. Those deemed human, therefore, must necessarily represent the capacity or potential for human heroics: that which will contribute to the project of humanity, a project of progress toward eternal liberation.

"Animals present a challenge to humans," says Erica Fudge (7):

Alongside and sometimes working against the desire for communication persists. . . a fear, and this fear manifests itself as disgust. The disgust is directed towards animals, but it might be fair to see the disgust as being *about* humans, about ourselves. We are horrified that there is a kinship between us and them. . . and we wish to wipe it out; annihilate it. (8)

Likewise, the terror of AD is a terror about what it really means to be human. Gray states, "Our image of ourselves is formed from our ingrained belief that consciousness, selfhood, and free will are what define us as human beings, and raise us above all

other creatures” (38). AD threatens these traits of human exceptionalism, exposes them as rhetorical constructions which depend upon an impermanent ability to believe in them.

What is so bothersome about the demented is their inability, at a certain point, to be bothered by their own condition (see Dworkin, *Life's Dominion* 230). Man, properly understood, must apprehend himself as different, as separate, as exceptional. Ernest Becker summarizes this vision:

His body is a material fleshy casing that is alien to him in many ways—the strangest and most repugnant way being that it aches and bleeds and will decay and die. Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever. It is a terrifying dilemma to be in and to have to live with. The lower animals are, of course, spared this painful contradiction, as they lack a symbolic identity and the self-consciousness that goes with it. They merely act and move reflexively as they are driven by their instincts. If they pause at all, it is only a physical pause; inside they are anonymous, and even their faces have no name. (26)

The split Becker identifies is only the condition of being able to apprehend one's self as both subject and object. The trap is in believing in the dualistic conception of reality such thinking may engender, as dualism is a way of seeing reality that replicates the perceptual split effected by this mode of self-awareness. The 'towering majesty' of man is not a fact of nature; it is a metaphysical construction, a human order. When Becker announces that animals “live in a world without time, pulsating, as it were, in a state of dumb being” (26-7), he can only mean that animals live without a sense of stored time, a sense of time as an object which can be accrued or lost: time as an investment. But in fact, time in this way does not exist, and that humans have created such a thing is not a mark of exceptionalism so much as delusion.

The progress of humanity, the fate of mankind, as it were, depends upon such a notion of time, which is why the imperative for productivity exists; 'dumb being' is non-progressive, and therefore non-liberatory. Animals, as such, have no hope of investing themselves in their own liberation *from* being *into* time as history. The demented, like-

wise, display their uselessness by no longer contributing to the cultural project of humanity. Watching his demented father, Pierce glimpses “the ruined city as if from above, its history all burned away and gone” (xxxii). Dementia, for Pierce, is a slide back into animality, and the burning fire of AD is figured as a disaster for civilization. If illness is so often figured as a separate space, it is because the human project has no room for rotting. History is not made out of base existence, but out of a grasping and striving. Turning dementia into a technological project reinforces human potential, and contributes to the liberation narrative, the *telos* of mankind.

Conclusion

Robert Pogue Harrison states that “in its personification of loss” the human corpse is “the site of something that has disappeared, that has forsaken the sphere of presence” (92). As Pierce says of AD, “This disease killed the person long before the person actually died” (54). But the human corpse is not the only site of disappearance. The demented, those who have lost the self, are also sites of disappearance, for it is the disappearance of the animate personality of the dead that signals loss; it is not enough for a human body to be animate, to be living—the body must contain a productive human self, or else be a mere organism. According to Becker, “the idea of death, the fear of it. . . is a mainspring of human activity—activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man” (xvii). Becker explains that whereas the body is always bounded by death, the individual self is capable of a lasting heroism, freedom and immortality. Existential psychologists such as Becker reformulated Freud’s theory of repression rejecting the notion that sex was the primary repression motivating human behavior, and highlighting instead a fear of death as the motivator of human culture (see Becker). However, we must now recognize, given the figure of the demented as selves lost, that it is not physical death, as such, that provokes fear and repression. According to David Loy, who finds the psychoanalytic theory of repression convincing as a concept, the primary repression is not sex, not death, but the lack of *self*—knowledge that the individual self, conceived as that which is singular, interior, and separable, does not exist (15-23).

The notion of the individual self, in possession of a single body, as a locus of experience and expression, is intertwined with the notion of a human exceptionalism, which is predicated upon a human identity constructed as singular and unique among those creatures which have being. Of course, an exceptional human kind depends upon exceptional, individual members, just as exceptional individual members must necessarily locate their individual identities within an inherited human identity. As such, the individual is always

bound to the collective identity, always limited in expression to that which preserves a unique human dignity. Cultural narratives are not ‘adapted’ to personal narratives so much as personal narrative is subject to the cultural narrative; it does not, in fact, exist separable from the cultural narrative. These narratives provide limited possibilities for ‘making sense’ of experience. Narrative selves are thus locatable within proper human narratives, as beings that exist *in* time, not *as* time. When time is incidental in this manner, change becomes malignant, becomes something in need of fixing. The ‘end’ must always be consistent with its beginning. As Dworkin says, “Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying—the emphasis we put on dying with ‘dignity’—shows how important it is that life ends *appropriately*, that death keeps faith with the way we want to have lived” (*Life’s Dominion* 199). Of course, a way of life is a cultural construct, not a given. Death, then, is the final investment in human dignity, in human identity. The human corpse does not pose a threat to that identity, given the notion of the insubstantial substance destined for eternity: soul, mind, self. Dementia might complicate the construction of human identity, but the rhetorical construction of a ‘loss of self’ reasserts the presence of a self, and transforms AD, as discursive construct, into another landmark of the human project, a project marked by exceptionalism and eternal liberation.

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