

WRITING THE “SELF-DETERMINED” LIFE:
REPRESENTING THE SELF IN DISABILITY NARRATIVES
BY LEONARD KRIEGEL AND NANCY MAIRS

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Abstract

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Leonard Kriegel and Nancy Mairs’ autobiographical works can be read as counternarratives to American literature’s and American society’s dominant discourse on disability. Chapters in this study examine Kriegel’s use of the quest narrative as a means for creating a heroic autobiographical self; his use of masculine imagery to counter stereotypes of disability and emasculation; the family’s role as a microcosm of society, working to construct – for better or worse – both Kriegel and Mairs’ sense of themselves as ill and disabled; Mairs’ relationship between her body and her identity, and how her essays work to counter the American cultural assumption that ill and disabled women are asexual or otherwise less than functional human beings; and, finally, the ways in which Mairs’ essays have served as her vehicle for political engagement with American culture. Ultimately, through insisting that their work maintain a focus on their singular, very individual identities, Kriegel and Mairs achieve visibility within American culture and eventually come to enlightened understandings of themselves as they *are* and not how American society has traditionally viewed the disabled.

Approved:

Robert J. DeMott

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For my family.

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Introduction

Disability, Invisibility, and American Autobiography

The path to the authentic self winds through the acceptance of the risks of disease, the legacy of accident. –Leonard Kriegel

By scrutinizing my life I could see how it had been made and could also, if I wished (and oh, I wished!), change it. –Nancy Mairs

Stories are antibodies against illness and pain. –Anatole Broyard

I.

“Literature does its best to maintain that its concern is with the mind; that the body is a sheet of plain glass through which the soul looks straight and clear, and, save for one or two passions such as desire and greed, is null, and negligible and non-existent,” writes Virginia Woolf in “On Being Ill” (Woolf 4). First published by T. S. Eliot in the *New Criterion* in 1926, Woolf’s essay laments that illness has not taken its place among love and battle and jealousy, the “prime themes of literature” (4). She calls for a new language in literature to help express illness, a language “more primitive, more sensual, more obscene” (7), which captures the confessional, often rash truths of illness which “the cautious respectability of health conceals” (11). More than fifty years after the publication of Woolf’s essay, American author Reynolds Price laments the paucity of autobiographical works treating the reality of illness and disability in American culture. After undergoing major surgery and radiation treatment for spinal cord cancer which leaves him paraplegic, Price yearns for “companions” in books by authors whose voices come “from the far side of catastrophe, the dim other side of that high wall that effectively shuts disaster off from the unfazed world” (Price 180). Finding only a “slim

row of printed matter” along these liens, Price writes his own book on his experience with cancer, *A Whole New Life*, in an effort to fill some of the void.

A Whole New Life was, in fact, just one of a number of autobiographical illness narratives to emerge from American writers in the 1980s, and the trend not only continued, but has flourished since the 1990s, coinciding with increased activities of the disability rights movement and the passage of the Americans with Disabilities Act in 1990. Leonard Kriegel, Nancy Mairs, Kenny Fries, William Styron, Lauren Slater, Andre Dubus . . . the list of American writers publishing critically acclaimed memoirs of illness and disability since the 1980s goes on and on. We have, it seems, discovered the language for illness that Virginia Woolf was searching for.

Despite the emergence of this new body of American literature, this new literature of the body, and the ill and disabled body in particular, disability studies scholars David Mitchell and Sharon Snyder are wary that the discourse of disability that has emerged in the past twenty-five years has been largely shaped by the autobiography genre. The positive benefit of this discourse is that the autobiographical narrator provides a “unique subjectivity that evolves out of the experience of disability as a physical, cognitive, and social phenomenon,” they write (Mitchell *Body* 9). Additionally, by representing disability as a private and minority concern, autobiographical narratives of disability seek the “attention of the culture because the social arena has proven inadequate to the tasks of responding – both legislatively and morally – to a population located on the fringes on institutional access” (10). Despite these benefits, Mitchell and Snyder warn against what they see as an inherent flaw of disability narratives: their penchant to feed the public’s

appetite for confessional writing, which serves to overshadow these narratives’ “attendant social and political contexts” with “emotions of pity and/or sympathy evoked by the reader’s identification with the narrator’s personal plight” (11). As such, they argue, disability life-writing “cannot *singularly* provide the interpretive paradigms needed to revise cultural understandings of disability” (11 emphasis mine).

It is true that autobiography *alone* cannot change cultural understandings of disability experience, but I argue that first-person narratives of illness and disability do play an important role in making the ill and disabled more visible in a society that has traditionally marginalized their existence. G. Thomas Couser in “Conflicting Paradigms: The Rhetorics of Disability Memoir,” notes that autobiography has historically served marginalized groups in American society as a sort of “threshold genre” (79). It has played an important role in helping to expand the American literary tradition to include African American, Native American, and women writers, for example. Couser argues, and I agree, that autobiography can serve people with disabilities in much the same way: “If marginalization is in part a function of discourse that excludes and/or objectifies, autobiography has considerable potential to counter stigmatizing or patronizing portrayals of disability because it is a medium in which disabled people may have a high degree of control over their own images” (78). This kind of self-representation is a source of liberation, Couser explains in “Disability and Autobiography: Enabling Discourse:”

Insofar as autobiography is the literary expression of the self-determined life, the genre that may be said to embody personal autonomy, it seems an ideal medium for contesting the association of disability with dependence

and invalidity. Writing autobiography . . . may enable individuals with disabilities to cross back over the border into the mainstream, or better yet, to cross out that border. (292)

While people with disabilities may eagerly be writing autobiographical disability narratives as an effort to enter mainstream American culture, Couser warns that disabled writers should be aware that the literary marketplace has traditionally required various kinds of distinction from writers of autobiography – they must have had a life that is worth writing about. For the disabled writer, however, her distinction, her disability, may work to “disqualify” her as an autobiographer, “unless it can somehow be made the focus of the book, the hook for the reader” (293). The danger here, Couser notes, is in running the risk of reducing one’s life to a case study, “reifying disability and thus reinforcing marginalization. In addition, the cultural values of autonomy and independence that autobiography celebrates are not entirely sympathetic to people with disabilities; to some, they are unattainable, hence inappropriate ideals” (293).

As a consequence of these cultural values, Couser explains that the American literary marketplace has traditionally sought illness and disability narratives that “conform to preferred plots and rhetorical schemes,” and what “characterizes these preferred rhetorics,” Couser writes, “is that they rarely challenge stigma and marginalization directly or indirectly” (“Conflicting” 79). The traditional rhetorics Couser defines include “triumph over adversity stories,” which tend to create “Supercrips” of their authors, removing stigma from the work’s narrator but reifying it for others with similar disabilities (80). Gothic rhetorics, or the “rhetorics of horror,” on

the other hand, portray illness and disability as dreadful conditions to be avoided at all costs and tend to confirm negative stereotypes of the disabled (81). Other traditional disability narratives Couser identifies include stories of religious conversion, whereby authors gain religious insight as a result of illness or disability, and nostalgia narratives, through which authors mourn the loss of their previous, able-bodied lives (83-5).

Cultural expectations about the lives of disabled people, then, often shape the rhetoric of narratives about disability and minimize the potential of autobiography to liberate its authors. The resulting paradox, Couser confirms, is that those disabled writers who *do* represent themselves through autobiography are not always representative of others with disabilities (“Disability” 293). It is this paradox that disability scholars and activists such as Mitchell and Snyder speak to in their criticism that autobiography fails to address the concerns of the American disability *community*. However, as Couser notes, some autobiographies by the ill and disabled *do* address these concerns. While traditional narratives frequently fall into the rhetorics Couser identifies above, he also notes the “counter-hegemonic potential” of illness narratives which write against the American grain of these rhetorics.

Such counternarratives challenge and undermine the limited medical paradigm of disability. . . . In their consciousness of their own condition as culturally constructed and as shared by others their authors may move beyond the familiar formulas of disability memoir and point the way to broader critiques of the construction of disability in America today.

(“Conflicting” 89)

In “Empire of the Normal,” Couser especially notes the counter-hegemonic potential of narratives “whose authors address their membership in a larger community or culture of disability, texts that function as first-person *plural* accounts of disability, in part because they reflect the growth of disability consciousness” (309)¹.

Vying for more discourse that speaks to the disability community, Mitchell and Snyder embrace the types of autobiographical projects Couser describes here. While I, too, value the counter-hegemonic nature of these texts, I argue that first-person *singular* narratives are capable of reflecting the same sense of a growing disability consciousness, even if their authors do not always define themselves in light of the larger disability community. In particular, I examine autobiographical works by American authors Leonard Kriegel and Nancy Mairs to draw attention to the ways they control the representation of themselves in their work. As disabled writers, they not only counter cultural representations that have previously occurred at the expense of the ill and disabled, but they also refuse to remain invisible within American culture.

While both Kriegel and Mairs write as first-person singular narrators, and by this I mean that their work focuses on their own, very individual experiences and not the experiences of disabled people as a group (first-person plural), they are both fully aware of the social consequences of the social construction of their conditions. As such, both write against what scholars in disability studies describe as the medical model of disability, a model through which the ill and disabled are viewed only in terms of their impairments. As social construction and medical versus social models of medicine are important to my dissertation project, I will take a moment to define these concepts here.

The medical model of disability emphasizes finding cures for what ails us, and it places the responsibility of working toward these cures on the ill and disabled themselves, compounding the social message that they are damaged and in need of being fixed. Under this model the ill and disabled are represented as deviant or abnormal, perpetually seen as patients. This “medicalization” of disability has far-reaching negative consequences, Simi Linton explains in *Claiming Disability*. It

casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to *disability*, colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and “treat” the condition and the person with the condition rather than “treating” the social processes and policies that constrict disabled people’s lives. (11)

Rejecting the medical model of disability and viewing it through a social model lens, however, disability is seen as a social construct. Leonard Davis and Simi Linton explain that this new approach to studying disability culminated with the passage of the Americans with Disabilities Act (ADA) in 1990. The definition of *disability* under the ADA, they say, is consistent with the socio-political model embraced by the disability studies field. Under the act, a person is considered disabled if he or she

- has a physical or mental impairment that substantially limits one or more of his/her major life activities;
- has a record of such an impairment;

- or is regarded as having such an impairment. (Davis 3)

The language of the ADA is evidence that American society – at least at the legislative level – is beginning to accept this constructivist approach to disability, for it “recognizes that social forces, such as myths and fears regarding disability function to limit opportunity,” Davis and Linton write. It acknowledges that “even in the absence of an impairment, people can be discriminated against,” such as in the case of people with facial disfigurements, or people expected of having AIDS or mental illnesses (3). In *The Rejected Body*, Susan Wendell further illuminates the social construction of disability in American culture. Much of this construction, she says, grows out of the physical structure and organization of society itself through its

failure or unwillingness to create ability among people who do not fit the physical and mental profile of “paradigm” citizens. Failures of social support for people with disabilities result in inadequate medical care, poor communication services, inadequate training and education, poor protection from physical, sexual, and emotional abuse, minimal opportunities for social learning and interaction, and many other disabling situations that hurt people with disabilities and exclude them from participating in major aspects of life in their societies. (41)

II.

Excluded from participating in society, people with disabilities often report feeling invisible in American culture. In focusing on Leonard Kriegel and Nancy Mairs for my dissertation, I have chosen authors who not only both write against the medical

model of disability, but who have both expressed feeling invisible within a culture which marginalizes disability. Kriegel argues that the cripple² does not “even possess the sense of being actively hated or feared by society, for society is merely made somewhat uncomfortable by his presence” (Kriegel “Uncle” 413). American society treats the cripple “as if he were an errant, rather little schoolboy. The homosexual on public display titillates, the gangster fascinates, the addict touches – all play up on a nation’s voyeuristic instincts. But the cripple simply embarrasses. Society can see little reason for recognizing his existence at all” (414). Kriegel clearly expresses his understanding of the social construction of the disabled when he writes:

while [the disabled man’s] physical condition is not imposed from outside, the way in which he exists in the world is. His relationship to the community is, by and large dependent upon the special sufferance the community accords him. And whether he wishes to or not, the cripple must view himself as part of an undefined community within the larger community And regardless of how much he may desire to participate in the larger community, the cripple discovers that he has been offered a particular role that society expects him to play. (421)

Kriegel learns about this role first-hand upon returning home from a two-year stay at a rehabilitation home after he contracts polio as a child. He recalls, “almost everyone *did* things for me – except, of course, to see me. For to have seen me would have entailed recognizing my existence as an individual *me*, that kind of personal encounter that results

in a stripping away of stereotype and symbol and a willingness to accept the humanity of the other, at whatever personal cost” (422).

Kriegel contends that society has continued to refuse to see him as an individual:

There is no way, of course, to define degrees of alienation and invisibility with any sense of accuracy but one can suggest that if most persons are only half-visible, then the cripple . . . is wholly invisible . . . for the world itself has perfected the ability to see what it wishes to see and only what it wishes to see. . . . The cripple’s “condition” is an abstraction; he himself is not quite real. Who is going to recognize *me*? asks the cripple. But society has already called into question the very existence of that *me* for it refuses to look at that which makes it uncomfortable” (423).

An important distinction to note in Kriegel’s argument here is his call that the *individual* disabled American be noticed in American culture. He is not expressing a need for recognition of the disability *community*. Indeed, he finds that America has already shown that it has “time for cripples” in the plural, Kriegel argues, “to be held up for compassion, to be infantilized on telethons;” it has “a great deal of room for us in a heart open to praise for its own generosity” (Kriegel *Falling* 64). But American culture only sees what it wants to see, Kriegel contends, so that what cripples

invariably discover is that our true selves, our own inner lives, have been auctioned off so that we can be palatable rather than real. We can serve the world as victim or demon, the object of its charity or its terror. But the only thing we can be certain of is that the world would prefer to turn a

blind eyes and a deaf ear to our real selves – and that it will do precisely that until we impose those selves on the world. (65)

Of course, the most immediate vehicle Kriegel has for imposing himself on the world is his own writing. He acknowledges this in his noting that the “guiding reality” behind writing his first autobiographical book, *The Long Walk Home* was “that *I*, my first-person singular, had lost part of its substance” (42). “Still,” through writing, he adds, “one can address one’s own accidents with empathy, with the recognition that to put the life of a cripple down on paper is to challenge accident, perhaps even to sustain a temporary triumph over it” (43).

In seeking this triumph over his life, however, Kriegel does not view himself as outside of the American tradition of autobiography, and he does not view his works as belonging to a separate canon of disability literature. “Like Franklin, I want my life to serve as exemplum,” he writes. “Like Adams I want writing about that life to be an act of vengeance upon a universe unaware of that life’s very existence An autobiographical voice in a writer constitutes no more, and no less than an attempt to thrust the self against the times” (Kriegel *Falling* 218). Indeed, Kriegel’s work is grounded in the masculine autobiographical tradition he emulates. His work, *The Long Walk Home*, in particular, is an autobiography in the very traditional sense of the word – a story of a life, or part of life, told as a continuous narrative. In her essay, “Women’s Autobiography and the Male Tradition,” Estelle Jelinek notes that “chronological, linear narrative” through which writers “unify their work by concentrating on one period of their life, one theme, or one characteristic of their personality,” is one commonly

accepted feature of autobiography, but male writers are more apt to write in this vein than women (*Women's* 17). Another feature of male autobiographies that Jelinek describes is men's tendency to

idealize their lives or to cast them into heroic molds to project their universal import. They may exaggerate, mythologize, or monumentalize their boyhood and their entire lives. . . . This view of their childhoods as idylls of innocence and redemption and of their lives as heroic seems to be a male literary tradition. The proclivity of men toward embellishing their autobiographies results in the projection of a self-image of confidence, no matter what difficulties they may have encountered.

Although Kriegel's work recounts moments of shame over his illness and doubts about his masculinity, he also writes himself into the hero role of the masculine tradition by writing his childhood journey as a hero's adventure. Many other autobiographical essays by Kriegel also revolve around the traditionally masculine themes of success, progress, and his relationship to the times, all themes that Jelinek recognizes in her essay as indicative of American autobiographies by men. Contemporary critics have both embraced and criticized Kriegel for this very masculine nature of his work. He is praised for his portrayal of the "vital, courageous characters" that people his essays (Nash 796), but he is often taken to task for hyper-masculinity. Male and female reviewers alike have faulted him for his portrayal (or lack thereof) of women in his writing, or, as Susan Nash describes in her review of *Falling Into Life*, for writing in such "highly gender-inflected language" that he "represents male and female as separate, mutually exclusive

categories,” to the extent that he gives “the impression that it is somehow more tragic for a man than for a woman to lose the use of the legs” (795). Reading Kriegel’s occasional essays in *The New York Times*, in 1985, Polio survivor David Cole likewise questions Kriegel’s view of women “enduring” polio, while the men and boys in his work are portrayed as “fighting back” (Cole 70). Cole’s review also laments that Kriegel’s personal heroes are male ones, and Elizabeth Hanson echoes this lament in 1998 in her review of *Flying Solo*. In particular, Hanson wonders why Kriegel does not consider the pain his polio must have caused his mother (Hanson 387). While these criticisms of Kriegel’s individual essays or single collections are valid, they do lose their potency when considering the canon of his work. Kriegel does address the guilt he feels over his mother’s pain, for instance, in his first book, *The Long Walk Home*. And he even extols the virtues of Wonder Woman, a female role model, in work written after Cole’s review. As he ages, Kriegel’s overall understanding of women and their approach to illness changes as well. Rather than viewing them as simply enduring, a term which implies passivity on their part, he comes to understand in his latest book, *Flying Solo* in 1998, that “women are better able to accept physical disability as part of who a person is. . . . For women, the body is rarely the essential person, the center of being” (144). My chapters on Nancy Mairs certainly prove otherwise, as Mairs views illness and disability, and her disabled body in particular, as her core self. Even though Kriegel still seems to reject the idea that disability experience can be the same for women and for men, his views of women with disabilities have at least evolved somewhat over time.

Kriegel is the author of six books and a recipient of both Guggenheim and Rockefeller fellowships, and reviews of *Flying Solo* reflect an appreciation for his contribution to American letters. One critic praises Kriegel's "lyrical" style and the "powers of [his] reflective language" that remains "smart, flinty, and unfailingly interesting" (Pinsker 58). Another reviewer appreciates Kriegel's "lively and relevant literary references" which contain no "trace of academic stodginess" (*Publishers* 64), and yet another finds his "spirited essays" to be both "serious but incisive" (Taylor 670). Also notable in reviews of Kriegel's work today is a positive reception of his very singular voice. Ed Peaco praises Kriegel's ability to remain "true to his own experiences," for example (Peaco 106). And Sanford Pinsker admires the ways Kriegel has "transmogrified" the "ravages of the body" into a "voice utterly his own – and into an art that speaks for the vulnerable humanness we all share" (Pinsker 58). These positive reviews and his frequent, ongoing publication in both popular national venues such as the *Nation*, *New York Times Magazine* and *Best American Essays* attest to Kriegel's continuing appeal to American readers, one of whom is American poet and essayist Nancy Mairs.³

Although she came to use a wheelchair much later in life than Kriegel, Mairs has also known not only the stigmatizing effects of this very visible symbol of her disability, but also its ironic power to render her *invisible*. In her chair, Mairs claims to literally inhabit the margins she otherwise inhabits metaphorically. Physically situated beneath the notice of others, wheelchair users, she notes, occupy a space "literally outside the field of vision of those in the center, so that the latter trip unawares and fall into the laps of those

they have banished from consciousness unless these scoot safely out of the way” (Mairs *Waist-High* 59). Even when using her Amigo, a three-wheeled electric scooter which decreases her level of fatigue and offers her a greater range of mobility within her community, Mairs still feels invisible in society. Riding her scooter, Mairs says she is reduced “to the height of a seven-year-old, with a child’s attendant low status” (Mairs *Carnal Acts* 89). In crowds, she says, she sees nothing but buttocks; when accompanied by a friend, service people, like a gate agent at an airport, ask her friend what her seating preference is, without addressing her directly. The effect, Mairs says, is that she often wants to “shout to the lofty world, ‘Down here! There’s a person down here!’ But I’m not by their standards, quite a person anymore” (89).

In addition to considering her invisibility as a disabled American woman, Mairs has also seriously considered her position as a disabled American autobiographer, and the role of the growing canon of disability literature in general. Mairs worries about the increased production/publication of memoirs by the ill and disabled, questioning publishers’ eagerness to snatch up anything remotely similar to other works that have achieved both critical and commercial success (she names Sytron’s *Darkness Visible* and Kaysen’s *Girl, Interrupted* as examples), in hope of discovering more diamonds in the rough. She wonders, “besides me, does anyone read it as literature? Can one? Should one? How? And do I want to risk the possibility that, in the process of being studied generically, varied and distinctive literary projects (my own among them) may become ghettoized as ‘crip lit’?” (Mairs “Victim” 20).

Clearly, Mairs' concerns point to her desire, like Kriegel, to be read as an *individual*, not as a member of a victimized community, creating what others have pejoratively referred to as "victim art."⁴ For this, she says, "I have a clear reason for redeeming victim art by holding the literature of personal disaster to the standards I value in other literature: nobility of purpose, intellectual stringency, linguistic precision and grace, freshness of insight, moral significance. Works that wholly miss the mark aren't victim art but victim dreck" (20). Mairs expands on her ideas in her essay "The Literature of Personal Disaster" published in *Voice Lessons: On Becoming a (Woman) Writer*. Here, Mairs considers what is at stake for the writer of personal disaster:

Choosing to speak publicly about affliction is risky for both men and women but for different reasons: for the woman, because the behavior (public utterance) is culturally impermissible; for the men, because the condition (physical or mental weakness) is proscribed. . . . Clearly the woman who undertakes to publish a book about her miseries, or about anything else, has already decided to transgress, at whatever cost, the taboo on female speech; thus she has resolved the crucial issue before beginning her project. But the man, who is expected to speak publicly but not to expose his infirmities, may have to struggle with this conflict of (self)interest in the writing itself (128).

The self-interest Mairs speaks of is as key to her own autobiographical projects as it is to Kriegel's, for it is through exposing herself that she becomes visible within American culture. She understands this not only as a goal, but as a responsibility of her work:

“Those writers who seek to console and hearten must make themselves and their anguish wholly transparent, revealing not illness as metaphor but illness as illness, in order to persuade the skeptical reader, through the very writing, that survival (at least till the last page) is possible” (129).

For Mairs, the stakes of writing about illness and disability are not just personal, but literary, and she strives in her own work to meet the same standards of literary merit that she judges other disability narratives by. As literature, she says, these texts should hold up to the same standards we use in our literary analysis of fiction or poetry. In particular, she explains that the best narratives of personal disaster are not whiny, or written out of self-pity. They also have aesthetic value that texts of more purely documentary nature do not have (such as a human interest story followed in a newspaper, for example). I concur with Mairs’ notion that “the writing about personal disaster which functions as literature tends not to be “about” disaster at all;” these writers “transcend their separate ordeals to speak generally, and generously of the human condition” (133). I argue, however, that they can achieve this effect in their work without losing sense of their authentic selves. With Mairs, I also agree that as critics, we should not lower the standards by which we critique such works. Indeed, my impulse to examine Mairs and Kriegel for this project stemmed, in part, from the fact that they both hold advanced degrees in literature. They are both fully aware of the American tradition of letters within which they write, and their work stands the test of literary critique.⁵

If Mairs’ work transcends her disability, it also transcends the confines of traditional American autobiography. While Kriegel strives to write from within the male

American tradition, Mairs strives to write against it. What has emerged within the feminine tradition of American autobiography are works that are episodic and anecdotal, discontinuous and disruptive (Jelinek *Women's* 18-19). Although Mairs' *Remembering the Bone House* is an autobiography, unlike Kriegel's autobiographical quest narrative, hers does not unfold chronologically, but spatially, organized around her memories of the houses she's lived in. Mairs' other book publications, like Kriegel's are collections of essays. Even in these works, however, one can trace the very linear, logical unfolding of Kriegel's essays, whereas Mairs embraces the essay as Montaigne does, for its "contemplative, exploratory, even equivocal, not definitive" form (Mairs *Waist-High* 17).

In her essay, "Transforming the Tale: The Auto/body/ographies of Nancy Mairs," Susannah B. Mintz describes the subversive nature of Mairs' work as an essayist. "Mairs writes against two traditions: the 'masculine' model of conventional autobiography, with its underlying ideology of stable, unified, and disembodied selfhood, and [as Mairs describes in *Carnal Acts*] 'the rules of polite discourse' that inhabit both women's speech and the articulation of disabled experience" (254). Mintz's summary of Mairs' style is useful in forming our understanding of certain parameters of both the male and female tradition of autobiography. Mairs

eschews the 'certitudes,' as Sidonie Smith describes them, that organize men's life-writing: 'chronological time, individuality, developmental selfhood, myths of origins, the fixedness of identity, bodily wholeness, the transparencies of referentiality, the will to knowledge, the unified

self.’ She disturbs the ideals of literary and cultural patriarchy, literalizing the fact of her own disrupted and disruptive body. (255)

And just as Kriegel has been both criticized and praised by contemporary reviewers for staking a claim to the male literary tradition, Mairs has been both criticized and praised for her disruption of it. Reviewer Laurie Graham sees *Carnal Acts* as a “bit of a hodgepodge” (Graham BR7), and Nicholas Christopher thinks the fragmented style of *Remembering the Bone House* leads Mairs into pretension and narcissism (Christopher BR 23). However, when Alane Salierno writes of *Ordinary Time* that Mairs’ “approach might be too ‘nontraditional’ for some whom it might otherwise have reached,” she also applauds Mairs’ writing voice, “which is lean, agile, surprising, both graceful and disarmingly direct – a voice both conversational and literary” (Salierno 24). Others describe Mairs’ style as “original, colorful, first-rate,” her humor as “earthy,” her persona as “vibrant” (*Publishers Waist-High* 56). And, finally, whereas one reviewer finds Mairs’ intimate details about her life “more exploitive than revelatory” (*Publishers Remembering* 63), another applauds her “insistence on living and writing her life, choosing ‘exploration and its attendant risks,’” and revealing her experience to the reader “without apology or apologetics” (Norris 270). Although she has received mixed (though mostly positive) reviews for her later collections, Mairs’ first essay collection, *Plaintext* received widespread critical acclaim. She also won a 1984 Book Award for Poetry from the Western States Art Foundation for her collection, *All the Rooms in the Yellow House*, and she received a National Endowment of the Arts fellowship in 1991.

III.

Writing respectively within the tradition of American autobiography and against it, Leonard Kriegel and Nancy Mairs' autobiographical works can also be read as counternarratives to American literature's and American society's dominant discourse on disability, a discourse that represents the ill and disabled as plot devices, as metaphoric tropes, or as freakish or damaged individuals in need of cures for their ailments. Such negative representation of the ill and disabled in fiction, film, and American culture has been widely documented by literature and disability studies scholars. Some of the most influential, full-length studies include *Extraordinary Bodies* by Rosemarie Garland Thomson. This often cited text is a seminal book of value for both disability and literary studies. It analyzes the ways disabled people and disabilities are portrayed in American culture, and especially American literature. Thomson's introductory chapters offer discourse in disability and identity and representation, in addition to disability theory. With this framework in place, Thomson examines the cultural work of American freak shows. The last two sections of her book analyze specific literary texts under the umbrella of two disparate themes: "Benevolent Maternalism and the Disabled Women in Stowe, Davis, and Phelps," and "Disabled Women as Powerful Women in Petry, Morrison, and Lorde."

Another valuable text is *Narrative Prosthesis: Disability and the Dependencies of Discourse* by David Mitchell and Sharon Snyder. In this text, the authors "address the meanings assigned to disability as a representation of identity in narrative art" (Mitchell 1). First, Mitchell and Snyder analyze narrative conventions that utilize disability for

literary characterizations – what they call a “metaphorization of disability” – while abandoning any contemplation of “the difference that disability makes as a socially negotiated identity” (10). They examine literary tropes of disability through the opposing lenses of Montaigne and Nietzsche, moving on to analyses of the figure of Richard III as a “confounding prototype” of deformity, and a study of *Moby-Dick* and the “language of prosthesis” (12). Mitchell and Snyder’s concluding chapters include a study of “Modernist Freaks and Postmodern Geeks,” comparing Anderson’s *Winesburg, Ohio* and Dunn’s *Geek Love*, and a chapter focusing on a number of key authors who are frequently taught in American high schools and colleges: Faulkner, Salinger, Harper Lee, and Ken Kesey. They argue that disability studies methodology can enhance our understanding of these texts but has been ignored in past criticism and pedagogy (13). For example, *The Sound and the Fury*, they write, “parallels the violence enacted upon the body of a person with Down’s syndrome with the South’s corruption at the hands of the North;” *Catcher in the Rye* “critiques entertainment mediums for perpetuating a pervasive logic of eugenics toward people with disabilities;” *To Kill a Mockingbird* critiques the segregation of disabled people and the attendant mythmaking that results;” and *One Flew Over the Cuckoo’s Nest* “interrogates the damaging ethos of charity as well as the institutional incarceration that reduces disabled people’s lives” (167). In addition to examining the above texts, Mitchell and Snyder briefly recognize Hemmingway’s *The Sun Also Rises*, Steinbeck’s *Of Mice and Men*, and Keyes, *Flowers for Algernon* as other literary American works through which we “sense the disability ‘lessons’ that infuse U.S. educational curricula, the contemporary literary canon, and film history” (167). It is

through this media, they says that we “encounter disability most often and most viscerally,” and they call for scholars in disability studies to recognize this fact (167).

Finally, *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840-1940* by Diane Price Herndl is grounded in her belief that women’s illnesses are not taken seriously by American culture. Her study strives to uncover the reasons for Americans’ attitudes toward and interpretations of ill women. She examines discourse of illness as it appears in literary texts, focusing specifically on the image of the invalid woman – an image she claims has a 150 year-old history in American culture. Her work, she writes, “analyzes the history of that literary figure and the responses to it, which are materially connected to how women’s illnesses are interpreted through legitimating, or de-legitimizing, reactions to those illnesses” (Herndl xiv).

While the collections above are notable as full-length studies of disability and literature, Kriegel can also be noted for his evaluation of literature and disability in his essays. Kriegel frequently makes references to cripples in American literature in his work, and he treats the topic fully in his essay “The Wolf in the Pit in the Zoo,” an earlier work (“The Cripple in Literature”) revised for his 1991 collection, *Falling Into Life*. In this essay, Kriegel delineates what he sees as a variety of common cripple-types in all of literature. He begins with a discussion of Richard III, in whom he says Shakespeare “provides us with the two fundamental images that cripples are accorded in Western Literature:” fear and pity (Kriegel “Cripple” 32). These images have not changed much since Shakespeare’s time, although, Kriegel argues, there have been a number of variations upon the theme. Despite these variations, literature’s message has been the

same: “The cripple is threat and recipient of compassion, both to be damned and to be pitied – and frequently to be damned as he is pitied” (32). In particular, Kriegel views Richard III as a “Demonic Cripple,” because he inspires fear in others. As a demonic cripple, he is “consumed by an isolation that goes beyond accident to harden into the very center of his existence” (Kriegel *Falling* 132). Ahab, of course, is America’s demonic cripple, an “essential cripple,” Kriegel writes, who “remains the most powerful portrait of a cripple in all of American writing” (131). Like Richard III, Ahab’s “sense of himself is dominated by physical insufficiency” (130); a “pervasive sense of absence forces each of them to plot and scheme and burn with the need for revenge” (“Cripple” 35).

Differing from the demonic cripple burning with vengeance, is the “Charity Cripple,” a character who “soothes and entertains;” instead of inspiring fear in others, he plays upon charitable impulses and “perpetuate[s] in his audience the illusion of its own goodness” (*Falling* 132). The quintessential charity cripple that Kriegel has written about elsewhere in his work is Tiny Tim, who as both poor and crippled pulls at the heart strings of Christian sentimentality that Kriegel says Dickens shared with his audience (133). In America, Melville’s charity cripple, the Black Guineau in *The Confidence Man* of course “parodies the idea of the cripple as the recipient of other men’s giving” (133).

Kriegel writes that both the demonic and charity cripple types are “defined from outside their existence. The one image reflect[s] the culture’s fears and taboos, the other its sentimentality and aspirations, but neither reflected the life of the cripple as it was lived in America” (135). The “Realistic Cripple,” and the “Survivor Cripple,” however, do. For the realistic cripple, like Tennessee William’s, Laura, Kriegel contends, “the

cripple's problems were neither singular nor symbolic. Rather they were viewed as human problems. . . . The realist cannot really believe that a part can stand for the whole, that a wound can claim a character's essence" (37). And finally, the survivor cripple – Saul Bellow's William Einhorn – is the cripple who endures. And "his endurance is attractive, both to himself and to the audience," Kriegel says, "for it is constructed around his understanding of the limitations it has imposed on him" (38). Kriegel says Bellow's crippled pool hall owner from *The Adventures of Augie March* contains the kind of human depth that he seeks from disabled literary characters yet rarely finds.

In *Narrative Prosthesis*, Mitchell and Snyder describe Kriegel's discontent over the lack of realistic portrayals of the disabled in literature as a common theme of the "negative image school of criticism," which finds "literary depictions to be, at best, wanting, and, at worst, humiliating" (18). There is a "direct correlation" these scholars argue, "between debasing character portraits and demeaning cultural attitudes toward people with disabilities" (18). From this view, a call for a "new social realism" – which argues for more realistic (though not necessarily positive) representations of the disabled – has emerged from the study of disability in literature, a perspective that Mitchell and Snyder attest has increased critical interest in autobiography (18). In addition to the social realist model of analysis, Mitchell and Snyder summarize other critical modes that engage disability in the humanities. New Historicism has sought to "perform an anthropological unearthing" of images of disability to reconstruct people's views of the disabled and "human variation" through the ages (25); biographical criticism has tended to perform analyses of critical readings of disability by both disabled and able bodied

scholars, examine the relationship between literature and medicine, or include disabled writers' interpretations of the characterization of disability through history (30). Finally, Mitchell and Snyder note a growing trend in the humanities of examining "transgressive reappropriation," the "subversive and hyperbolic meanings invested in disabled figures" (35). As an example, they point to the culturally subversive act of disabled writers' reappropriation of terms like *cripple* and *gimp* (35), an act, I will add, that resonates, as I will later show in my individual chapters, within the work of Kriegel and Mairs, who both describe themselves as cripples. This "ironic embrace of derogatory terminology has provided the leverage that belongs to openly transgressive displays," Mitchell and Snyder write:

The power of transgression always originates at the moment when the derided object embraces its deviance as value. Perversely championing the terms of their own stigmatization, marginal peoples alarm the dominant culture with a canniness about their own subjugation. The embrace of denigrating terminology forces the dominant culture to face its own violence head-on because the authority of devaluation has been claimed openly and ironically. (35)

I am sure that Mitchell and Snyder do not mean to suggest that critical discourse on disability and literature occurs only within the sampling of critical approaches that they have provided, or that it consistently applies only one angle of critical interest at a time. To be sure, my own project's engagement with the critical fields above is varied. I certainly highlight the subversive – what I call the counternarrative – aspects of Kriegel

and Mairs' works throughout my chapters, and in studying autobiography, my project naturally takes on aspects of bibliographic study as well. As a New Historicist, I examine my authors' responses to the social construction of their disabilities, and as a Social Realist, I argue that their autobiographical works are important, as they provide intimate, realistic portrayals of people with disabilities. Through writing their disabled lives both Kriegel and Mairs control their own images and counter cultural representations of the disabled that have traditionally been at their expense. Ultimately, through insisting that their work maintain a focus on their singular, very individual identities, they achieve a kind of visibility in American culture that their marginalized status as disabled people otherwise would not afford them. Essay after essay, Kriegel and Mairs not only maintain this visibility, but eventually come to enlightened understandings of their authentic selves – themselves as they *are* and not how American society has traditionally viewed them.

In addition to engaging with current critical discourse on disability in literature, my project also expands upon the tradition of autobiography studies in American literature. Estelle Jelinek explains that autobiography criticism began with Georg Misch's 1907 *History of Autobiography in Antiquity*, but it did not gain momentum until after World War II (Jelinek *Tradition* 1). James Olney argues that the first important critical text in autobiography studies is Georges Gusdorf's essay, "*Conditions et limites de l'autobiographie*," in which Olney says, "all questions and concerns – philosophical, psychological, literary, and more generally humanistic – that have preoccupied students of autobiography from 1956 to 1978 were first fully and clearly laid out and given

comprehensive and brilliant, if necessarily brief, consideration” (Olney 9). In their bibliographic essays, both Jelinek and Olney enumerate the wide range of critical studies in autobiography since the publication of Gusdorf’s seminal essay. For instance, Olney notes twelve articles and four full-length studies on American (male) autobiography from 1964-1977 (14). Some interest in women’s autobiographies emerged in 1973 with the publication of Sidonie Smith’s essay, “The Song of the Caged Bird: Maya Angelou’s Quest after Self-Acceptance,” and in African American autobiographies more generally with her publication of *Where I’m Bound: Patterns of Slavery and Freedom in Black American Autobiography* in 1974 (16). At this time interest in women’s studies sparked additional curiosity in women’s autobiographies, which had traditionally been ignored by critics. Olney sites Patricia Spacks’ critical contribution in 1975 with *The Female Imagination* (16), and we can now add the subsequent publication of Jelinek’s *The Tradition of Women’s Autobiography: From Antiquity to the Present* in 1986, *Autobiographics: A Feminist Theory of Women’s Self-Representation* by Leigh Gilmore in 1994, and *Women, Autobiography, Theory: A Reader*, edited by Sidonie Smith and Julia Watson in 1998, as examples of just a handful of late twentieth century contributions to the field.

To their bibliographies Olney and Jelinek can also now include critical studies of autobiographies by the ill and disabled. Published in 1993, Anne Hunsaker Hawkins’ book, *Reconstructing Illness: Studies in Pathography*, is frequently noted in disability studies as the first critical study of this kind. Hawkins coins the term *pathography* to describe autobiographies and biographies that describe personal experience with illness.

As Hawkins describes, her work studies the “myths, attitudes, and assumptions that inform the way we deal with illness,” and it “evolves into a discussion of issues in contemporary medical practice” (Hawkins ix). Arthur W. Frank likewise studies life stories by the ill in his 1994 book, *The Wounded Storyteller: Body, Illness, and Ethics*. His text considers the *need* of the seriously ill to tell their stories; how these stories are embodied, “told not just about the body, but through it;” the social context which determine which stories get told and how; and the distinction between the experience of illness in modern and postmodern times (Frank 3). While Hawkins and Frank’s texts focus only or primarily on illness experience respectively, G. Thomas Couser’s *Recovering Bodies: Illness Disability and Life Writing*, published in 1997, extends the critical discourse on autobiography to include disability. Couser uses the term, “autopathography” (which I borrow in chapter two to discuss Kriegel’s work) to describe autobiographical narratives of illness or disability, and he distinguishes his work from Hawkins and Frank by noting that he is “more interested in the relation of illness narratives to other forms of life writing and to the discourses of illness and disability. . . . I accent the poetics and politics of illness narrative as both separate and related aspects of the literature” (Couser 13). Each of these important collections identifies numerous autobiographies written by ill and disabled Americans (for the most part), and they illuminate various emergent characteristics of this relatively new sub-genre of American autobiography.

IV.

My own study contributes to this scholarship by moving from the broad-sweeping approach of these critics above to a more focused study of just two authors. From what I have discerned in my reading thus far, mine may be the first full-length work of this kind – a study of the autobiographical literature of two disabled American authors for whom illness and disability are both central and essential to their literary lives. Kriegel and Mairs have both been referenced in works by literary, social, and disability studies theorists, but I am the first scholar to provide an extended study of their work as American literature.

My dissertation consists of five chapters on the work of Leonard Kriegel and Nancy Mairs. I begin, in chapter two, ““I had to make a hero of myself:” Autopathography as Quest Narrative in *The Long Walk Home* and Other Works by Leonard Kriegel,” with the argument that Kriegel’s autobiographical memoir, *The Long Walk Home* and essays in *Falling Into Life* can be read as an autopathographical quest narrative, or hero’s journey. While the quest-like nature of Kriegel’s memoir grounds his work in the masculine tradition of American literature, and masculine autobiography in particular, Kriegel’s work also performs functions indicative of the historical emergence of the contemporary illness narrative, which Frank says, “reclaims the author’s right to tell what is her own experience, it reclaims a voice over and against the medical voice, and it reclaims a life beyond illness, even if illness is the occasion of writing” (Frank *Wounded* 5). As a result of the tensions inherent in “reclaiming” voice, Kriegel’s work functions politically, offering a counter-voice to the dominant discourse of illness and disability in the modern era.

Chapter three, “The ‘Disabled Imagination’ and the Masculine Metaphor in the Works of Leonard Kriegel,” extends my work on Kriegel as I examine his reliance on masculine metaphors, both as an imaginative child retreating into a rich fantasy life, as evidenced in *The Long Walk Home*, and as an adult writer. I argue that these masculine metaphors work to counter dominate images of emasculated disabled men in American culture, and I examine these metaphors in detail as I explore Kriegel’s changing relationship to and definitions of imagination in this chapter. I argue that these changes ultimately help him discover his authentic voice as an American writer, and that this voice helps him maintain visibility within American culture.

In my next chapter, “Leonard Kriegel, Nancy Mairs, Family, and Disability: Writing Beyond the Familial Self,” I look at autobiographical work by both Kriegel and Mairs. I argue that in their work the family functions as a microcosm of society, working to construct – for better or worse – their sense of themselves as ill and disabled. In acknowledging their respective family’s influence on their disabled identities, both Kriegel and Mairs illustrate that as disabled persons they have had to acknowledge the extent to which their identities have been constructed by both familial and social forces. Part of their acknowledgement takes place, necessarily, through an experience of self-erasure, but eventually, they are able to regain the power of self-construction and move toward claiming – and writing – their authentic selves.

Next, I focus on Mairs individually in chapter five, “Ain’t I *Still* A Woman?: Feminism, Sexuality, and the Disabled Woman in the Works of Nancy Mairs.” My examination of Mairs’ essays for this chapter shows how she works to counter the

American cultural assumption that ill and disabled women are asexual or otherwise less than functional human beings. I examine Mairs' representation of herself through her writing, the relationship between her body and her identity and how she negotiates this relationship in light of the shifting balance of power within her marriage, and, finally, the activist implications of Mairs' work when facilitated by others in an academic setting.

Finally, in chapter six, "Nancy Mairs: Essayist and Activist, Writing Through the 'Gift of a Difficult Life,'" I argue that for Mairs, the essay has been her vehicle for political engagement with American culture, and the means through which she insists on visibility and representation for all disabled women and men within our society. While a good many of her essays – especially those in more recent collections – may seemingly speak more broadly for those within the disabled community, her work remains grounded in the personal. Though socially conscious in their scope, even Mairs' more activist-minded essays remain autobiographical; they continue to insist on the value of her singular experience, her life as an *individual*. Ultimately, I argue that these memoirs, and others like them, are essential for forwarding the goals of the disability rights movement. Offering unabashed, politicized portrayals of disabled life, Mairs' work moves beyond what Davis and Linton call the "human interest stories and tales of courage and fortitude, described in the disability community as tales of 'overcoming'" (3), and offers, instead, an "alternative framework," focusing on the "political and social variables" that shape the lives of the disabled (3). Essentially, Mairs' essays not only serve as a voice for the disability rights movement, they also represent a personal identity behind an emerging

canon of American literature currently beginning to receive serious attention within the academy.

Enamored by Kriegel and Mairs for their contributions to American autobiography, and intrigued by the political nature of their writing, it is my pleasure to discuss their work for my combined audience of literary scholars and disability theorists. It is my hope that my efforts can help elevate the status of illness and disability narratives, and autobiography in particular, this “literature of personal disaster,” as Mairs terms it, within the humanities. I am bolstered by recent evidence in our field – the inclusion of the *Conference on Disability and the University* papers featured in the March 2005 issue of *PMLA*, for instance – that the academy is well on its way to agreeing that our discussions of illness and disability in literature (in all genres) are just as important as our discussions of race, class, and gender, just as vital to our understanding of the human condition.

Notes:

¹ Some of the texts Couser notes include: *The Body Silent* by Robert Murphy, *Missing Pieces* by Irving Zola, and Anne Finger’s *Past Due*.

² While considered derogative by many people with disabilities, I often adopt the term “cripple” throughout my dissertation when referring to Kriegel and Mairs because it is the term that they have both chosen to describe themselves and use regularly. When referring to the disabled community in generally, I use “people with disabilities.”

³ In a March 2006 personal email from Nancy Mairs, she informed me that she is a “great admirer” of Kriegel’s work.

⁴ The most public use of this term was by dance critic Arlene Croce in *The New Yorker*, when she refused to review Bill T. Jones’ 1994 performance, *Still/Here*, which features video of people talking about their terminal illnesses in the act. Instead of viewing the performance and offering a review, Croce wrote her now infamous response, “Discussing the Undiscussable,” which details at length her reasons for not attending the show: “By working dying people into his act, Jones is putting himself beyond reach of criticism,” Croce wrote. “I think of him as literally undiscussable – the most extreme case among the distressingly many now representing themselves to the public not as artism but as victims and martyrs. . . . I cannot review anyone I feel sorry for or hopeless about” (quoted in Mairs “Victim” 20). In “Victim Art and

Victim Dreck,” Mairs notes that she never realized that some critics might find critical evaluation of art “distasteful, if not downright impossible,” but as she discovers, a camp of critics disdainful over what they have come to term “victim art” has emerged. Mairs feels certain that Croce’s response to Jones’ work is motivated by her desire to “discredit an entire category of creative endeavor which she labels – in a phrase she plainly considers oxymoronic – ‘victim art’” (20), and she views Croce as “slavering beast, thwarted because her prey, to use Croce’s terms, ‘has taken sanctuary among the unwell’” (20). Mairs reminds Croce, however, that there is no sanctuary among the unwell – nor should there be in terms of judging the art that the ill and disabled produce. “Artistic works must not be excluded from critical consideration simply because of their maker’s afflictions,” she writes, but it is “not enough from a literary point of view,” she adds, “to have had A Very Bad Experience . . . and lived to tell the tale. Nor is it even enough that the tale thus told merely instruct, inspire, and/or console. Illness, disability, and death can, and must, provide no proof against rigorous aesthetic judgment” (20).

⁵ There are certainly numerous works of “personal disaster,” to use Mairs’ term, that I do not read in the same “literary” vein, works, that are perfectly readable and interesting, but may, like Mairs says, be more documentary in nature. I have in mind, for example, Gilda Radner’s *It’s Always Something*, about her struggle with ovarian cancer, and Pulitzer Prize winning journalist Tom Halliman’s *Sam*, a chronicle about a boy with an extreme congenital facial deformity. Both works are engaging and were both best sellers, but they do not have the same literary quality of much of Mairs and Kriegel’s work, which display adept use of literary techniques: metaphor, symbol, allusion, ironic points of view, etc.

Chapter One

“I had to make a hero of myself:” Leonard Kriegel’s *The Long Walk Home* as Autopathographical Quest Narrative

*Ill people need to be regarded by themselves, by their caretakers,
and by our culture as heroes of their own stories. –Arthur W. Frank*

*. . . it was as if I had to encompass the myths of my own experience,
to accept as meaningful in myself the peculiar pleasures of combat
that mark the life of the cripple. –Leonard Kriegel*

Whether its source is disease or accident, disability is personal. –Leonard Kriegel

In the summer of 1944 an eleven-year-old boy set off for a two-week summer camp and did not return home for two years. He was an active boy, a boy whose thoughts of summer turned to playing stickball in the streets of the lower middle class, Bronx neighborhood he grew up in, and he looked forward to his first sojourn from home alone (Kriegel *Long* 4). From the start, because his father needed much convincing before he was allowed to go, the boy “looked upon this journey as a skirmish with [his] fate” (4), unaware that fate would turn out to be a formidable contender, a “knife of virus [that would] sever legs from will” (4), cutting his childhood short with illness and disability.

The boy was Leonard Kriegel, and his story, his autobiographical memoir, is *The Long Walk Home*, a work in which Kriegel says he “tried to re-create with neither sentimentality nor false piety the experience of having polio” (Kriegel “Manhood” 120). Here, Kriegel recounts his summer camp experience and the following two years of his childhood spent at the New York State Reconstruction Home in West Haverstraw, receiving painful treatments and grueling rehabilitative instruction for his disease. The narrative also covers his return home and briefly summarizes his college years.

Throughout the various chapters of the narrative, Kriegel writes of ultimately losing the use of his legs and his progressive use of a wheelchair and crutches and leg braces for mobility.

As its title suggests, *The Long Walk Home* can and should be read as a journey, a quest narrative. On one level, the memoir details the literal journey of Kriegel's long awaited return to his family home after his polio rehabilitation. On a metaphorical level, however, Kriegel's journey is one of self-discovery, his quest as an adolescent to find an authentic self in his newly crippled body. In taking this journey Kriegel not only discovers this authentic self, he writes a compelling quest narrative worthy of admiration as part of our American literary tradition. *The Long Walk Home* is additionally significant, however, for being one of 20th century American literature's first illness narratives to challenge the dominant literary discourse on illness and disability in our culture, performing some important functions of illness narratives that Arthur W. Frank has identified as indicative of the historical emergence of the contemporary illness narrative.

Like other illness narratives Frank describes, (though Frank does not mention Kriegel's work in particular) Kriegel's autobiography struggles "to gain a public voice to tell a private experience," and sustains the "primacy of one's own voice vis-à-vis the medical voice" (Frank "Reclaiming" 4)⁶. Frank explains that these overlapping tensions reflect the ways in which contemporary illness narratives are "distinct in the work of *reclaiming*" they must do. "The narrative," he says, "reclaims the author's right to tell what is her own experience, it reclaims a voice over and against the medical voice, and it

reclaims a life beyond illness, even if illness is the occasion of writing” (5). As a result of these tensions inherent in “reclaiming” voice, Kriegel’s work functions not only as autobiography, but as autopathography, as G. Thomas Couser defines the term, with political importance. In his essay, “Autopathography: Women, Illness, and Lifewriting,” Couser defines *autopathography* as autobiographical works in which illness and disability are “squarely in the foreground of the narrative” (65). More specifically, when using the term *autopathography*, Couser has in mind illness narratives that are political in nature, those that “contest cultural discourses stigmatizing the writer as abnormal, aberrant, or in some way pathological” (Smith 187).⁷ Lifewriting of this nature “critiques social constructions of the disabled body and incorporates a counternarrative of survival and empowerment that reclaims the individual’s or loved one’s body from social stigmatization and the impersonalization of medical discourse” (188). As autopathography, aspects of Kriegel’s illness narrative, *The Long Walk Home*, in addition to individual essays published elsewhere, work in this same way, acting as counterdiscourse to the dominant discourse of illness and disability in the modern era. In Kriegel’s work, this counterdiscourse emerges, in part, through the ways he manipulates the well-known narrative convention of the quest narrative, a traditional form not only of myths and canonical literature, but of illness narratives as well.

I. On Reading The Wounded Storyteller

In *The Wounded Storyteller: Body, Illness, and Ethics* Arthur W. Frank examines published illness stories to identify three narrative voices common to illness narratives: the restitution narrative, the chaos narrative, and the quest narrative. The restitution story,

Frank explains, is a story in which a patient seeks a diagnosis and cure for his ailments. It is the dominant story told by the recently ill and it is a narrative that “reflects a ‘natural’ desire to get well and stay well” (78). Frank notes the ways in which American culture has internalized the restitution story, learning this narrative from our medical institutions which “model how illness is to be told” (78), and from the “most pervasive...the most insidious model of the restitution story. . . the television commercial for non-prescription drugs” (79). These models represent a culturally preferred master narrative of illness, Frank claims, a narrative that belies the “modernist expectation that for every suffering there is a remedy” (80). As story, the purpose of the restitution narrative is to illustrate how the ill person is made well and returned to the status quo (90). The sickness itself is not memorable to the teller of the restitution tale, but the restitution may be. As Frank notes, “restitution makes a good story after the fact only if it was unexpected,” and the teller of the restitution story has limited responsibilities beyond “taking one’s medicine and getting well, wellness being defined in contrast to illness” (91). Ultimately, restitution stories “bear witness not to the struggles of the self but to the expertise of others: their competence and their caring that effect the cure. In this witness restitution stories reveal themselves to be told *by* a self but not *about* that self” (92).

Differing from the restitution narrative, the chaotic narrative presents a view of illness in which there is no recovery. Whereas the restitution narrative is preferred because it melds with the master narrative of American medicine, the chaos narrative is discouraged and rejected as anxiety-producing. In the chaos narrative, “the losses, the pain, the incoherence of suffering become so overpowering that language cannot

resocialize what has happened” (Frank “Reclaiming” 7). Indeed, as Frank claims, chaos stories are “anti-narratives” in that they cannot “literally be told but can only be lived” (*Wounded* 98). The “person living the chaos story has no distance from her life and no reflective grasp on it. Lived chaos makes reflection, and consequently storytelling, impossible” (98). The chaos story, then, is “what can never be told; it is the hole in the telling” (101).

Finally, Frank defines what he concludes is the most dominant illness narrative – the quest narrative. These narratives “meet suffering head on; they accept illness and seek to *use* it,” Frank writes. “What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience” (115). Frank suggests that unlike restitution narratives, in which the ill surrender their voice to medical professionals, and chaos narratives, in which the ill have no voice at all, it is only through the quest narrative that the *teller*, the ill person himself, is afforded the opportunity to tell his own story (115). And in telling his story as a quest narrative, the ill man can tell of his “searching for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges” (117).

Frank identifies three facets of quest narratives that help describe these narrative journeys more specifically and may overlap in any story: memoir, manifesto, and automythology. In the illness narrative that is memoir, Frank notes that writers merge the telling of their illness story with other memorable events of their life. Celebrities and other public figures are most likely to write this type of memoir, where “the illness constantly interrupts the telling of the past life, although alternatively, memories of the

past life interrupt the present illness” (120). As is the case with Gilda Radner’s cancer memoir, Frank notes that “the public person’s split between media image and experienced reality is always a subtext of these stories and sometimes an explicit topic” (120). Despite this split, the writer of memoir does not usually come to any special insight at the end of their journey, rather than learning to incorporate their illness into their life (120).

Frank describes the memoir as the most “gentle” facet of quest narratives, and his second facet, the manifesto, as the least gentle (120). In the quest narrative that is manifesto, writers contend a certain responsibility to others upon their return from illness. Their truths become prophetic, Frank claims, and often carry demands for social action, as illustrated by such works as Audre Lorde’s *Cancer Journals*, where Lorde strives to use her “suffering to move others forward” with her in her fight for social reform (121).

Finally, Frank calls the last facet of quest narrative the automythology⁸. Often embracing the metaphor of the Phoenix that arises anew from ashes and flames, Frank explains that automythological quest narratives fashion “the author as one who not only has survived but has been reborn. Like the manifesto, the automythology reaches out, but its language is more personal than political. Individual change, not social reform, is emphasized, with the author as an exemplar of this change. The authomythologist may be an unwilling hero, but he is never an unwitting one” (123).

As I will show in my discussion of *The Long Walk Home*, it is clear that Leonard Kriegel is enacting the role of automythologist. While his work here has political ramifications as autopathography, which I will highlight, he does not write as a political

activist for the disabled community. Instead, Kriegel's story remains largely a personal one, the story of a boy, who "like any 11-year-old boy, wanted to place [himself] within the American spectrum. And in order to do that, Kriegel writes, "I had to individualize illness" (Kriegel "Body" 25), and "I had to learn to be my own hero, my own role model" (*Flying* 41).

Readers encounter Kriegel's hero self in the form of Lennie in the *Long Walk Home*. Representing the boy, Lennie, as he recounts his journey to selfhood, Kriegel seemingly becomes a character in his own life story, the literary survivor-hero he can relate to. Kriegel has noted that some early reviewers of the book thought it was a novel; and certainly this is not surprising when considering the extent to which Lennie's adventure in the *Long Walk Home* resembles the traditional hero's adventure of mythology, as thoroughly documented in Joseph Campbell's highly regarded work, *The Hero With a Thousand Faces*. As noted previously, the title of Kriegel's autobiography, *The Long Walk Home*, suggests this traditional platform for reading and interpretation of the mythic and symbolic elements in the work. Like traditional quest narratives, *The Long Walk Home* traverses many of the stages of the hero's journey previously identified by Campbell. Throughout the journey, however, Kriegel reminds us that his is not simply a quest narrative, but an *illness* narrative. As such, both his illness and his disability are central and essential to the narrative, a surprising turn for readers more used to the able-bodied hero's tale.

Frank reminds us that the quest narrative – or, to use Campbell's well-known term, the *hero's journey* – consists of three stages: the "call, the road of trials, and the

return” (Frank “Reclaiming” 7). Frank aptly applies these stages of the hero’s journey to illness narratives when he describes the “call” as

recognizing a symptom not just as the sign of a disease but as the beginning of a journey. Accepting the call means accepting the illness as affecting one’s life. The issue is not restitution but working out the changes illness brings. These changes occur in the course of trials, including sufferings of surgery and stigma. The trials are not minimized, but they are progressively understood as teaching something and thus gaining meaning. (8)

Kriegel complicates the traditional quest narrative by infusing it with the concerns of illness and disability, but he also complicates the traditional illness narrative, and the traditional polio narrative in particular. He eschews themes of restitution and conversions – which by their very nature recall a certain reliance on others – and maintains the very singular voice of the rugged individual, the male American autobiographer.

This singular voice is essential to Kriegel’s view of himself. In his writing and in his life, Kriegel has rejected categorization, being seen as just part of a larger group of cripples. He insists on his individuality, a singularity that some disability activists, ironically, criticize him for. Kriegel adopts distinguished social psychologist Erving Goffman’s term *normals* to describe the able-bodied and to explain his stance: “For the normals, we [cripples] possess a collective presence. For if cripples prove themselves capable of defining their own lives, then what excuse can normals offer for their failure? If cripples break with the restrictions placed upon their existence and insist that they will

be what they have earned the right to be, then where does that leave the normals?” (Kriegel *Falling* 68). Kriegel adds, “only by turning stigma into strength can cripples avoid the categorization the normal world insists on thrusting upon them” (68). For Kriegel, this strength is in his writing, in seeking and defining his own, authentic self. He understands that the “task of the cripple is to re-create a self, or rather to create a true self, one dependent upon neither fantasy nor false objectivity. To define one’s own limitations is as close as one can come to meaningful independence” (“Uncle” 430).

II. Lennie Kriegel’s Journey Home

The first stage of the hero’s journey, we remember, is the departure, that moment when the hero accepts the call to action that sets his adventure in motion. In *The Long Walk Home*, readers familiar with quest narratives might falsely identify Lennie Kriegel’s moment of departure as the moment he leaves the safety of his Bronx home and boards the bus for summer camp. He has, after all, never been away from home before and great adventures must surely await him. Kriegel quickly informs us that the journey he has embarked on is much larger than his camp experience, as camp-life itself teaches him little that he had not known before (5).

It is not camp, then, that calls the hero Lennie into adventure. His departure, instead, is aligned with Frank’s findings about other illness stories in which the call for departure “is the symptom: the lump, dizziness, cough, or other sign that the body is not as it should be” (Frank *Wounded* 117). For Lennie the sign that all is not well first comes when his friend, Jerry, takes ill at camp and goes to the camp infirmary. Later that day, Lennie, too, feels the first symptoms of the invisible virus beginning to damage his young

body. In an ominous moment that foreshadows his future, Lennie's legs buckle under him when he rises from his bunk to use the bathroom (Kriegel *Long* 6). Kriegel recounts the moment as a "weird initiation" as the "floor began to whirl and the wire-mesh shadows exploded as my body crashed dumbly into darkness" (7).

As in the traditional quest narratives that Campbell describes, in illness narratives the call to adventure may initially be refused by the hero-to-be. This refusal, Frank notes, may present itself as an ill person's denial of symptoms. However, once symptoms become unavoidable and diagnoses are made, the call must be answered. It is at this point that the ill person crosses what Campbell describes as the first threshold of the journey, and what Frank notes may be represented as the hospitalization or surgery that determines the extent of an illness (Frank *Wounded* 117-18).

Lennie Kriegel has little opportunity to refuse the adventure he has been called to take, but he does attempt, at first, to refuse it. As he falls to the floor several times that first night in the infirmary, he very briefly shifts "the blame from my legs to the floor, which was in fact rotten and warped" (Kriegel *Long* 7). Later that night he questions whether his "loss of balance and the sullen terror that fed on itself with each passing moment, was simply a temporary nightmare from which I would awaken in the morning or whether I was, indeed to die" (8). As Lennie wrestles with these thoughts throughout the night, he feels a "thick somnolent deadness that was creeping up from my ankles" (8). In his terror and pain, he tries to shut out the agonized screams of his friend Jerry, waging his own battle with the polio virus in the next room. Lennie prays to God for relief from the noise, for anything to quiet the boy. Waking in the morning with a guilty concern for

Jerry's well-being and his own realization that he could not move, Lennie is swept across the first threshold of his journey when he leaves camp by ambulance.

Frank notes that after the hero accepts the call and crosses the first threshold of his journey, the second stage of initiation begins (*Wounded* 118). Here, the mythic hero embarks down the path of trials, "easily identified in any illness story as the various sufferings that illness involves, not only physical but also emotional and social," Frank writes (118). In recalling writing *The Long Walk Home* in his essay, "On Manhood, Disease, and the Authentic Self," Kriegel admits that reliving the particular trials of his journey through illness was a trial in itself. He writes:

I assumed that what would prove to be difficult would be those scenes in which I relived the pain, the sense of helplessness, the loss of dignity that the onset of disease inevitably produces. . . . What was actually difficult to write about truthfully were all those minor wars which ended in not-so-minor defeats – falling at a subway exit and waiting for someone to pick me up; daydreaming about the strength and power I knew were rightfully mine, only to look in the mirror and find reality mocking my very presence. (120)

In *The Long Walk Home*, Kriegel describes the first of these minor wars as a bridge that had to be crossed (13). When Jerry dies that first night in the hospital, new feelings of hatred and rage awaken in Lennie for what he calls the "blind and uncaring universe that had no use for the child I was" (12). His trial, however, comes in being forced to acknowledge feelings of guilt when his terrified mother visits him in his

hospital room on the second day of his stay. It was in that room that Kriegel writes he “first counted my owings to the world and balanced them against my owings to myself” (13). Watching the frightened figure of his mother, Lennie sees in her face the “appeal of self-pity and the harshness of accusation” (13), and he realizes in that moment that “disease, too is a sharing” (13), that his illness will have social implications. He thinks about his family and the guilt he feels in this moment builds to the point that his “budding concept of the child as solitary victim died. I had done this, I saw, to them, too” (13). And in admitting this guilt, Lennie senses that his will not be a solitary journey. Like it or not, he says, “I could never make it entirely alone, for the self would not admit so heavy a burden” (13). Here, Lennie is learning about the reciprocity of disease, the social impact his illness will have on his network of relationships.⁹

While Lennie’s first trial is an emotional hurdle, the next challenges he faces after being transferred to a second hospital are purely physical. He recalls the institution as a “dream of agony” (19), and the week he spent there as “the week that was the dead center of my pain, the real birth of my hate and my fear, my love and my pity, my new man” (20). At Willard Parker Hospital Lennie views himself at war with his surroundings. From the “beady-eyed Macbethed witch” nurse who fingered his rectum to move his bowels each morning, to the bugs in his oatmeal and the indignity of having to be fed by that same nurse he hated so, to his first painful spinal tap and catheterization, Lennie comes to view the hospital as enemy territory (21). The doctors and nurses are people to escape from, his experience something to be survived. That Lennie does survive his week of trials at Willard Parker becomes a testament to his physical strength and inner

fortitude. He emerges from his ordeal with a sense that he has won a round in the battle with the virus. “I lived,” Kriegel writes, and this fact all but obliterates the week of pain and humiliation he has endured. Whatever else had happened, Kriegel notes, “I knew by then, without anyone having told me, that I would be alive in the future, next day, next week, next year, forever maybe, because the polio had already done its worst” (24).

Having survived the critical early stages of the virus, Lennie is transferred to the New York State Reconstruction Home in West Haverstraw, a place he comes to view as “my sanctuary and my prison,” a “metaphor for dead legs” (25). Although he has already proven himself both mentally and physically before arriving at this new facility, it is here, in West Haverstraw, that Kriegel feels he “matched myself with my fate and met the time of my trial” (25). Not all of the trials he faces during this period are physically painful, but they all have a lasting impact on Lennie as he negotiates the new self emerging from what illness has left behind.

Kriegel notes that it was not the pain of those early weeks at West Haverstraw that is the most memorable – enduring hot pack treatments and stretching exercises – but the “unalleviated boredom” (35), a lethargy so great that “even the anguish of recognizing my body as an object for others soon passed” (35). Ultimately, Kriegel writes, embracing the language of the quest, it was a time of tests:

It was very much like school. I was being tested. The pain was a test, and waiting for sleep at night when I remembered too much was a test, and the hot packs, and the stretching, and the sweat, and the just lying there, and the smell of that mattress – it was all just a way for them to learn whether I

was good enough. I wasn't quite sure of what I had to be good enough for. Maybe to show that I could suffer in silence as well as any of the others. Hot packs. Sweat. Lying on the mattress. Tests. All tests. (35-6)

Just as he makes it through his earlier physical and emotional trials, Lennie passes the tests of his first few months in rehabilitation. Though he battles with the home's imposing itself on his life, he admits that by the end of his first year he comes to need its comfort (39). When one of Lennie's first friends in West Haverstraw is discharged home, he is forced to consider the eventuality of his own return to normal society. By this point, he is aware that

the experience of the disease had changed me, changed me far more drastically than I could ever hope to understand. It was not, as I say, the expectation of remaining a cripple. . . but something far more meaningful, a sense of immutable destiny that was neither noble nor tragic but that still separated me from that world I came more and more to think of as "the outside." (47-8)

In thinking about "the outside," Lennie recognizes that new trials lie ahead of him. His sense of comfort at the Home is shattered by the "new threat" that, like his friend Jojo, he will one day be forced to leave (48).

This threat of having to eventually rejoin society outside the home is heightened by a trial of his own making when he sneaks out of the home with his friends and ventures into the nearby town. To fully appreciate this adventure, however, one must understand Lennie's new reliance on his first wheelchair. When Lennie makes enough

physical progress in his initial rehabilitation, his legs are put in casts and he is allowed the use of a wheelchair. He views his move up to the chair as a “triumph.” No longer confined to the hospital ward, he is now able to explore the Home in detail and venture outside to the grounds as well. In the wheelchair, young Lennie feels both free and powerful for the first time since contracting the polio virus.

Lennie makes use of this new freedom, cavorting with the other wheelchair users in the ward. He quickly learns, however, that despite this new freedom his disability holds him at the mercy of others. When his friend Willie is rude to the Governor when the man visits the hospital, Willie’s nurse punishes the boy by restraining him in his bed for the rest of the day and revoking his wheelchair “privileges” for three days (60). Kriegel makes it clear that the word *privileges* is the nurse’s word and not the boys,’ that it was a “rotten thing to do” (60). In this moment Lennie gains a frightening understanding of what it means to be crippled and powerless against others wishing to exert their power over him. His power, he learns, cannot reside in the freedom of the wheelchair alone, but will need to be cultivated in aspects of himself that can not be taken away. For the time being, Lennie continues to embrace the power of the wheelchair. Having recently been fitted for leg braces, Lennie knows that his days of unbridled use of the wheelchair are now numbered at the Home. Thus he “looked upon the chair now as if it really were the thread of my survival,” and for weeks he tries to think of some “dramatic way, a moment of truth, in which I could show the world my latest posture” (76).

This opportunity arises when Lennie’s friend Willie comes up with the idea to

stage a “cavalry charge” in their wheelchairs into the nearby town of Garnerville (77). Lennie takes over the leadership of the charge, planning an “invasion” made up of an “alliance of equals” (78). After dinner that night most of the wheelchair users in the ward head out of the hospital in small groups on false pretenses. Lennie then lines the boys up in formation – “two waves of six” – at the top of the hilly road overlooking the town. With no plans for what they will do when they reach the town, the boys race down the hill with great speed and triumphant fun.

As Lennie speeds by the neighborhood houses on his run down the hill, he catches a glimpse of a woman on her porch, “her face vapid with terror and disbelief” (81). When the other boys join him at the bottom of the hill, and they have a better chance to view their surroundings, they, too, take in the reactions of others in the town. A few people gather on porches to stare at the boys. “They’re scared.” Willie says, “They’re scared shitless” (82). While it seems that the boys should feel some pride in the effect their arrival has had on the town – they had staged a cavalry raid, after all – they are, if anything, made uncomfortable by the situation. Lennie quickly suggests they go inside the candy store a few doors down, but when they reach the doorway, the manager blocks their path. In their first brush with discrimination outside the world of the hospital, the candy store owner refuses to let the boys in the store because “they got germs” (83).

Willie becomes angry and indignant, but Lennie and his friend Natey calmly explain to a policeman that they have had polio, that they are no longer contagious, and are simply suffering from the effects of infantile paralysis, a term that is more familiar to everyone. The policeman gestures to the townspeople who have been keeping their

distance from the boys, telling them that they are not contagious, but in their fear and ignorance, the citizens do not venture from the imagined safety of their porches.

Eventually, the policeman convinces the candy store owner to allow the boys inside, and he helps them negotiate the short step up to the store in their wheelchairs. In this moment, “we had won,” Kriegel writes. “And winning was a good feeling, a very good feeling, even though I didn’t want any of his soda or any of his other stuff by now” (84). Returning to the Home in formation once again, Lennie and the boys are not punished for their unsanctioned adventure, their nurse having been informed of the humiliating events by the police officer before their return. And despite his brush with the discriminatory reality that eventually awaits him in the outside world – where he learns that to be crippled is to be treated with pity and fear – Lennie emerges from the experience like a true hero, with a sense of having gained something important.

Lennie’s victory over the shopkeeper is significant, but it is not the last of his trials before being released from the Home. First, he must learn to accept the leg braces he has been fitted for, acquiesce to learning to walk with them, and finally, allow himself to fall (a trial Kriegel details not in *The Long Walk Home*, but in his essay, “Falling into Life,” from the collection of essays by the same name).

Lennie is measured for his leg braces a week before he “celebrate[s] the birthday of [his] polio” (72). While being held in a standing position by the brace-maker and his assistant, Lennie has a flash of panic about his disability. He should have been elated to be standing for the first time in a year, he notes, but what he feels instead is a “new surge of consciousness, frozen, just for a moment in the dark corner of my terror. The legs are

dead, it whimpered, boring into some quiet alley of my twelve-year-old mind” (74). Lennie tries to wipe the thought from his mind and garner, instead, “the courage that was expected of me at that moment” (75). As the hero of his own journey, even at age twelve, Lennie recognizes what should be for him an hour of triumph. He is alive, he realizes, and standing with crutches for the first time since being stricken by illness. Standing with the aid of the crutches, however, he sees himself in a different light than when in his chair. At that moment, Kriegel recalls, “my mind first whispered the word “cripple” to me. I had ignored the word until then, ignored the word and all of its implications” (75). The image is a frightening one, and he fights its grim reality by clinging to the remembered sense of power and freedom afforded him by his wheelchair. “The child in me instinctively rallied,” Kriegel writes. “Not me, I thought. Not me. Cripple, hell. The chair was mine, all mine. And I buried this latest anxiety in the thought that it was waiting for me back at the ward” (75).

In this scene, Lennie comes to view the brace-maker as a threat to his existence (75). As a “smart servant now,” he vows to make an appropriate show of walking with the crutches and braces when they are ready for him, but he refuses to look at his readiness for them as a milestone in his recovery. Rather, the crutches and braces remain, in his eyes, the weapon of the enemy, the means by which American medicine will forever construct him as a cripple. For Lennie, his resistance to using the braces and crutches becomes a “matter of will, a question of assertion” (88). Unlike most of the other boys on his ward, Lennie refuses to surrender himself entirely to medicine. He refuses to give up the notion that at some level it is he, and not the doctors and physical

therapists, who knows what is best for him. Lennie harbors great hatred for the medical practitioners and for “what they were trying to make of me” (88). Kriegel remembers that he was willing to “serve” them up to a point, but that his disease had taught him to “serve only when it was a question of becoming an even better guardian of my soul’s safety” (88).

Kriegel’s portrayal of this struggle between doing what medicine asked of him and doing what he knew was right for his soul challenges the modern medical ideal of restitution at all costs. His narrative in these moments of struggle offers a counterdiscourse to the restitution narrative that privileges the will of medicine over the self-will of the ill. Lennie’s distrust of patriarchal medicine does not change; he continues to view the doctors and nurses as enemies. During his first hospital stay, for example, Kriegel makes it clear that he resents the “foppish doctor who stood at the side of my bed, stroking his chin with his thumb, oblivious to my questions,” and his hateful first nurse, Miss Dunleavy, who, “loyal to the hierarchy of medicine, stood in her matronly modesty awaiting the great man’s wisdom” (23). Lennie takes an equal disliking to his doctor at the rehabilitation home, where he feels like “a body, an object for his probing science” (33). He rejects the modernist view of doctors as all-powerful healers and refuses to emotionally surrender himself to men in whose presence he no longer feels human (33).

In his refusal to surrender himself to modern medicine, Lennie, although he has lost the use of his legs, retains his own voice. And it is the retention of his voice that not only makes it possible for him to tell his story, but makes it a *responsibility* for him to tell it to others. According to Frank, there are three ethics of quest narratives that suggest a

diversity of responsibility in storytelling: an ethic of recollection, an ethic of solidarity and commitment, and an ethic of inspiration (*Wounded* 131-2). An ethic of recollection is practiced when storytellers share memories of past actions. Here, Frank says, there is a moral opportunity for writers to “set right what was done wrong or incompletely” (132), an opportunity to “recollect failure and offer it to others with an indication of what should have been done” (132). Similar to the ethic of recollection through which the communicative voice shares experience with others, practicing an ethic of solidarity and commitment is also other-oriented. However, Frank explains, here, a storyteller “offers his voice to others, not to speak for them, but to speak *with* them as fellow-sufferer who, for whatever reasons of talent or opportunity, has a chance to speak while others do not” (132). Finally, quest narratives practice an ethic of inspiration. This “heroic stance of the automythologist,” Frank notes, “inspires because it is rooted in woundedness; the agony is not concealed,” and the stories show “what is possible in impossible situations” (133).

Despite the concern for others that these three ethical stances suggest, the quest narrative remains a narrative about “voice finding itself,” and this voice is found, Frank contends, “in the recollection of memories. The storyteller’s responsibility is to witness the memory of what happened, and to set this memory right by providing a better example for others to follow” (133).

The three ethics of quest narrative are clearly apparent in Kriegel’s intent for his work. Kriegel often refers to his writing as a way of redressing the events of his life, for example. In his essay, “From the Burning Bush the Autobiographical I,” Kriegel explains:

I have never known a writer – a poet, novelist, or creator of one of those personal myths that go by the name of *autobiography* – who did not desire to redress the facts of his life through the practice of his art. For one of the writer’s secret tasks – secret because it is not the kind of thing writers generally talk about – is to right the wrongs inflicted on him by God or fate or nature or whatever name he chooses for that power which imprisons him within the confines of his own brittle humanity. (202)

That the wrongs Kriegel writes about most frequently stem from his illness and resulting disability is especially significant. Frank claims that “illness is about learning to live with lost control,” and “turning illness into story is a kind of meta-control” (*Wounded* 30). Kriegel has clearly thought about issues of control in relation to his illness. “The control of one’s destiny, even having a voice in one’s destiny is at best problematic for anyone,” he writes; “for the cripple, such control is even more difficult” (Kriegel “Men” 118). In writing about his illness on his own terms, and in explicitly detailing the kinds of scenes above in which he refuses to allow the medical community to construct his image, Kriegel not only redresses the events of his life, but reclaims his voice from this time.

Even as a child, though, Lennie has a politicized sense of himself. As a matter of principle, then, a matter of control, Lennie remains stubborn during his physical therapy. For two months, Kriegel says the physical therapist works on breaking his will over working with the crutches and braces until he eventually gives up on him and puts him in the care of Mr. Benson, the therapist who tends the swimming pool. Unable to swim, Lennie’s resistance to working with the braces is overshadowed by his fear of the water

(*Long* 90). Benson quickly teaches him to swim, however, and Lennie learns to make compromises in his therapy, agreeing to walk on water braces for a half hour each day before being allowed to swim. Soon, he agrees to return to physical therapy, accepting his treatment as a game to be played and swimming afterward as his reward (92). In a short time he is adept enough on the braces and crutches to “fake it like a politician” (92), but he refuses to embrace them as his main means of mobility, for they continue to remind him of his vulnerability, his limitations as a cripple – the fact that in a final test of his abilities, he has had to learn to fall.

Unfortunately, Kriegel does not make note of it in *The Long Walk Home*, but in his essay, “Falling into Life,” he writes about having to learn how to fall with his braces and crutches on as part of his rehabilitation. The act of “falling into life” proves to be one of the most difficult acts of surrender that Lennie would have to perform during his recovery time at the home, and despite describing his illness in this essay as a “strange fall from the childhood grace of the physical” (“Falling” 7), Lennie’s learning to fall is not a metaphor, Kriegel explains; it is real (8). At this point in his therapy, Lennie is less angry at the physicians and more eager to please, which is perhaps one reason Kriegel opts to leave this trial out of the physical therapy scenes of his autobiography, to maintain the angry, willful tone of those sections. The later essay proves that Lennie’s feelings fluctuated during his treatment, but it also proves that Kriegel has made conscious choices about voice and distance in his work all along, working selectively with his memory, and maintaining autonomy over his self-representations.

In the scenes recounted for the piece, Kriegel admits, “the slightest sign of

approval from those in authority was enough to make me puff with pleasure” (10). Despite this eagerness for validation, he is unable to make himself fall to the mat in therapy (10). In a rage over his own cowardice, Lennie feels contempt for himself and plagued by shame, that “older brother to disease” (11), until, finally, one day, without fanfare or epiphany, he is simply worn down enough to let himself go. “Something beyond my control or understanding had decided to let my body’s fall from grace take me down for good,” Kriegel writes, and in finally falling, he finds “I had given myself a new start, a new life” (12-13). It is in falling, Kriegel explains, that his therapist was trying to teach him the “most essential of American lessons: How to turn incapacity into capacity” (14), and it is in falling that Lennie is not only able to embrace the image of himself in braces and crutches that he once resisted so vehemently, but also learn how he might live “*successfully* as a cripple” (15 emphasis mine). Ultimately, Lennie realizes that the “most dangerous threat to the sense of self [he] needed was an inflated belief in [his] own capacity” (15). Kriegel learns that “falling rid a man of excess baggage; it taught him how each of us is dependent on balance” (15). Whether or not the boy, Lennie, had the insight to put it in quite the same terms as Leonard, the adult, Lennie surely understands the necessity of being humbled, for it is upon accepting this humbling, this learning to fall, that his adventure in rehabilitation ends and he is ready to return home.

In addition to being a high point in his quest for selfhood, Lennie’s learning to fall, and Kriegel’s writing about it, has autopathographical significance. Couser treats Kriegel’s essay, “Falling into Life,” briefly in his essay, “Crossing (Out) the Border” in *Recovering Bodies*. Despite Kriegel’s insistence, as noted above, that learning to fall was

literal and not metaphoric, Couser rightfully suggests that Lennie's falling trial can be read as Kriegel's attempt to "revise the trope of disability as a fall from grace" and refuse "allegorical constructions of disability as involving judgment, punishment, or moral failure" (189-91). Lennie's eventual willingness to fall, Couser explains, "paradoxically means resuming some control over his body, his identity, his life script. In a kind of verbal judo Kriegel converts falling from a negative act, linked to damnation, to a positive one, linked to the new life into which it delivers him" (91).

While Kriegel treats falling literally in his essay, his sentiments elsewhere evidence his distaste for literature that supports the view of illness and disability as a fall from grace. In his essay, "The Body of Imagination," Kriegel discusses how the depiction of ill or disabled characters in many 19th century literary works, especially Dickens' portrayal of Tiny Tim, contain a "cloying sentimentality of suffering [which] disguises another belief rooted in religion – that fate is earned. Like many similar beliefs, it reflects a pervasive fear and superstition (26). Kriegel has not only encountered this belief in fiction, but in his own life as well. In *The Long Walk Home*, Kriegel briefly describes his mother as "scouring the dark recesses of her mind to find that moment when she had offended God – for such a child could only be God's punishment on her, or so Goldhammer the butcher's wife had said" (111). He returns to the incident to describe it in more detail in his essay "In Kafka's House" in *Falling into Life*. Here, Kriegel recalls how his mother returned home from errands one day in tears. The butcher's wife – whom the town acknowledged was not "right in the head" – had told her that Lennie's illness was God's judgment upon her.

While he does not believe in God and understands that the woman does not represent the beliefs of his neighborhood, Lennie senses that the butcher's wife "had voiced precisely what my mother herself believed about disease in her own fear-ravaged heart. Illness was judgment. The slings and arrows of fortune might be outrageous; they were never undeserved. Accident, illness, war, famine, disease: punishments visited upon one by the master of the universe" (183). Sleepless and ragged, attending to Lennie at night after his return home, Lennie's mother remains "patient, waiting, thinking that this, too, was her due, that the ledger of her sins was long and endless and that she had no right to expect anything more. Only a miracle" (*Long* 146). She so readily believes her son's illness is God's judgment upon her that she is willing to go to great lengths for a chance to cure him. Kriegel recalls how she seeks out a chiropractor as a last hope of a cure for Lennie:

Nothing else had worked. Maybe he would cure me, would rid our house of the nightly demands, would remove the curse of the malformed, would take the sin into his own all-powerful hands and squeeze it into the hot, crusty air. That was what she live for, to restore to me my legs and to end the torment for herself, to be blessed again in the eyes of her God and of the neighborhood with the knowledge that she was a good mother, as good a mother as hers was. (146)

His mother's journey, however, does not reflect Lennie's own. Upon his return from West Haverstraw, Lennie's crises are not spiritual ones, but physical. Clearly aware

of the structure of the quest narrative in *The Long Walk Home*, Kriegel aptly and simply titles the chapter in which Lennie returns home “The Return.” As we know, the final stage of the hero’s journey is what Campbell likewise calls the *return*. Upon return, the traditional hero, in successfully negotiating his trials and undergoing significant personal transformation, is ready to share the insight he has learned during his ordeal. In the illness narrative, however, Frank says, “the teller returns as one who is no longer ill but remains marked by illness. . . . This marked person lives in a world she has traveled beyond, a status well described by Campbell’s phrase, ‘master of the two worlds’” (Frank *Wounded* 118).¹⁰ As in all quest narratives, the ill hero of a quest narrative derives his moral status from his or her “being initiated through agony to atonement: the realization of oneness of himself with the world, and oneness of the world with its principle of creation,” Frank writes. “Suffering is integral to this principle, and learning the integrity of suffering is central to the boon” the hero receives at the end of his journey” (119).

Having witnessed Lennie’s suffering during his rehabilitation, readers familiar with the quest narrative are eager to see Lennie reach this stage of atonement upon his return home. Kriegel, however, withholds this atonement from readers in the “Return” chapter, disrupting our expectations of the traditional hero’s journey. Kriegel likewise disrupts the expectations of readers of traditional illness narratives which reify the medical model of disability. This medical model, Couser reminds us, presents illness and disability as obstacles that can only be overcome through individual will and determination, and not through social and cultural accommodation (“Conflicting” 80)¹¹. Although much of Kriegel’s narrative does rely heavily on themes of triumph over

adversity, simply put, Lennie's suffering does not end with his "cure," as other triumph narratives and the medical model of illness would have us believe.

Indeed, for Kriegel, who continues to address in his work the trials he faces as a cripple today, the suffering, though lessened in many ways, never ends. In challenging this medical model, as he has elsewhere within his narrative, Kriegel shows how Lennie, just as he feared when he was still in the hospital, must confront the social ramifications of his disability upon his return home. Although he has changed significantly as a result of his rehabilitation experience, it is not until he becomes comfortable with both himself as a cripple in society and society's response to him that he is able to reach the level of atonement Frank speaks of above.

And for Lennie, these negotiations take some time. His literal return home from his journey is marked by public shame. No longer the skinny, active eleven-year-old who had left his house for summer camp two years before, Lennie sees himself now as "hog-fat and baby-soft" (Kriegel *Long* 125). He is self-conscious of this fact as he exits the ambulance that has transported him home with the help of the attendant and his father. A crowd of neighbors has gathered to welcome Lennie home, nodding their encouragement as he steadies himself on his crutches. Rather than gaining strength from this show of support, Lennie is painfully aware of his neighbors' presence, making of him a spectacle. He knows that he will be unable to make it up the stairs to his family's Bronx apartment on his crutches. Kriegel recalls standing in front of the stairs in that moment, "hating them not for having defeated me but for having done it so publicly" (126). His first appearance back in normal society, then, is marked by shame and remorse, his "first

public defeat” and renewed feelings of guilt over his illness.

In returning to his old neighborhood, Lennie has to relearn who he is and what others make of him (129). He is not eager to discover this new self, however, and Kriegel admits to trying to “prevent [his] learning too quickly” by retreating “into the sanctuary of the apartment,” detaching himself from the “crippled adolescent [he] really was” (129). For the next four years he devotes himself to fantasy, a retreat into books and movies. “Fantasy was no more than a long detour,” Kriegel admits, “and while I raced through its fresh wilderness of the mind I knew that such a life could only be temporary, that I would sooner or later, have to ‘face life,’ that horrible cliché of the unaware” (135). Finally, at age seventeen, stuck in bed with a painful case of boils “pitting their own reality against [his] imagination” (150), Lennie suddenly emerges from his fantasy world to embrace the truth – “the kind of truth,” Kriegel writes, “I had never before permitted to invade my consciousness, a total candor that came with all the shock impact of an idea that was to imbed itself permanently within the boundaries of my existence. *I was a cripple*” (150).

Lennie’s self-reflection and new recognition of himself as a cripple, however, does not lead to his reconciliation with that fact, as we might naturally expect for the hero recently returned from his journey. Instead, Lennie’s epiphany causes another moment of narrative tension within the text, serving to push him into an even more traumatic psychic space, as he simply leaves his fantasy life behind him to enter the world of hate. Fueled by his hatred of his own disabled body, Lennie embraces a brutal, manic exercise regimen that proves to be his “first step toward selfhood” (154). He works on reshaping

his body until he believes that “the world now envied my grace and courage, just as I had once believed that the world had fathered my fatness, my helplessness, my terror” (160). After losing thirty pounds by age eight-teen, Lennie slowly re-enters society, seeking “more than acceptance,” Kriegel writes, but “acceptance as the crippled hero” (171). He begins dating and cultivates a new set of male friends the summer before heading off to college. In the activities of that year in which Lennie discovers “a beginning and went off to quarry for my fate” (183), Lennie also begins to discern the self that has been the object of his quest. Upon coming of age, Lennie ultimately learns that “being crippled was something that was distinctively mine, and that through the long years ahead I could lean on the cripple in me as this half-life half-death body of mine leaned on crutches” (183).

In the final chapter of *The Long Walk Home*, titled simply, “Home,” Lennie details his early college years and his relationship with his future wife, Harriet, to whom the book is dedicated, Kriegel writes, for “crippling my myth of the cripple,” in part because she insists that he does not have to play the role of tough-guy cripple. By the end of the book readers realize that although Kriegel takes some liberties with the quest narrative form in an effort to challenge readers’ expectations of his work, his autobiography ultimately fulfills all the steps of the hero’s journey, and like most quest narratives, ends in “some expression of how the self has been changed by the experience of suffering” (Frank “Reclaiming” 8). While Kriegel’s entire autobiography is a testament to this change, the work closes with an incident which allows him one final expression of his new sense of self.

Before taking Harriet back home one evening before they are married, Lennie receives a drunken, nervous call from a woman he does not know. She claims to have spent time at the home in West Haverstraw after Lennie's release, but that they have friends in common. She wants to bring the friends by the same evening. The encounter serves as another small trial for Lennie who is nervous about seeing the children, now adults, he has purposefully lost contact with since leaving the home as a teenager. "I knew my sense of my own singularity had kept me from meeting other cripples," Kriegel admits. "Such a meeting, I believed, would be far too draining, would pull the stopper on my own strength" (Kriegel *Long* 204). Despite his discomfort about the potential meeting, Lennie agrees to allow the group to pick him up for an outing that evening. He remains tense, however, before their arrival. "I did not want to measure my achievement realistically," Kriegel writes, "to see how far I had come in my departure from the world of the crippled, as if that achievement could do no more for me in the long run than heighten my sense of guilt" (205).

When Lennie's old friend Kenny arrives to pick him up, he has with him Marilyn, the woman who initiated the phone call to Lennie earlier in the evening, and a woman in the front seat of the car who is unable to turn around to look at him. Kenny holds a mirror in front of her face so Lennie can see her from the back seat. It is Andrea Catten, a girl from his time in West Haverstraw who had once, Kriegel remembers, been "designated 'Lennie's girl'" (209). Lennie is uncomfortable in her presence, in the fact that she can not turn to face him and that she remains, for the most part, silent. Made self-conscious suddenly by his circumstances, Lennie suggests that the group eat in the car. Admitting to

dreading “the sight of four cripples on crutches offending the Saturday-night splendor that was the world,” Kriegel recalls never having felt more alien than in that moment (209). “I was neither ‘normal’ like Iggie or Harriet or ‘the boys,’” he explains, “nor was I glued to the sticky closeness of the wounded, like Kenny and Marilyn and the beautiful face I wanted to scream my guilt to even while I wanted nothing so much as to flee it. I was . . . But what?” (210).

Not surprisingly, the few hours Lennie spends with the group are a strain for everyone as they soon realize they have little in common to talk about. Watching the group, Lennie despairs over their very “settled lives” that seem “incredibly ugly and yet terribly noble, anchored to a defiance of convention – their joining forces – that went beyond where I could go” (211). He pities them for their seeming lack of ambition, an absence of the striving he feels constantly in his own life, but then he wonders if what he is feeling is actually pity for himself. He thinks, even, they should all be dead, but he does not elaborate on these feelings (211).

We might read Lennie’s feelings of alienation as a countercultural move on his part to judge his fellow cripples as though he is not crippled himself. This stance, however, does not mesh with the strides Lennie has made by this point in the narrative in accepting his condition. On the other hand, Lennie’s revulsion inspired by meeting his fellow cripples reiterates the powerful urge in American society to not identify with disease. Here, we see Lennie once again rejecting the cripple model he struggled against years before, when being fitted for his leg braces back in the Home. Certainly there is narrative tension between who Lennie is (a cripple, like his old friends) and who he

perceives himself to be (the cripple-hero, who, through his trials, has become stronger, more self-actuated than his peers). However one might read the scene, Kriegel's willingness to recognize his ambivalence towards his peers, in itself, works as a counter-moment within the text, as few traditional illness narratives, and polio narratives in particular, exhibit this kind of willingness to explore these kinds of negative or paradoxical feelings.

Daniel J. Wilson has found that almost all of more than fifty polio narratives he has studied are "structured as accounts of triumph over adversity" (Wilson "Covenants" 25). In Kriegel, however, Wilson admits that he finds an anomaly. "Only Kriegel, in his narrative and his numerous essays on this experience, emphasized the rage, anger, and hatred, that must have been more widely felt" (25), Wilson explains. Kriegel allows his anger and rage to surface, whereas other polio narratives commonly serve as profiles of "good handicapped people" who happily accept a "covenant of work" required for their recovery, thereby also accepting the "'social taboo' against bitterness"(27). This stance is explained in a publication published by the Association for the Aid of Crippled Children which Wilson discovers during his research. Here, the editor explains that this social taboo against bitterness requires

that the handicapped person "express his pain, his desires, his hopes, and his anguish only in the most superficial manner; if he expresses his bitterness deeply or with any sense of personal tragedy, he risks alienating the nonhandicapped. . . As long as the handicapped individual is cheerful and lighthearted, he is, like the jolly fat boy, usually accepted by his

peers.” (quoted in Wilson 26)

This kind of thinking reflects what Frank describes as most North Americans’ “cultural reluctance to say that their lives have gone badly in some significant respect and to mourn the loss of what was desired but will never happen. Our contemporary version of stoicism borders on denial. The good [illness] story refuses denial, and thus stands against social pressures” (Frank *Wounded* 63). As Wilson finds, however, the bulk of the polio narratives he studies accentuate the positive, and do not, as Kriegel is willing to do, narrate “disappointment or failure” (Wilson “Covenants” 26).

Unique from other polio narratives in both tone and purpose, Kriegel’s autobiography and essays resist categorization in much the same way that Kriegel himself rejects being labeled by society. “Recent attempts to politicize disability reflect an equal unwillingness to treat it realistically,” Kriegel maintains. “Instead, we have developed a language of prosthetic inkblots to measure illness by. Disabled, handicapped, physically challenged, differently abled – like Adam naming the animals, we label our afflictions” (Kriegel “Body” 26). To be labeled “‘disabled’ or ‘handicapped’ is to deny oneself the rage, anger and pride of having managed to survive as a cripple in America” (*Falling* 61). Despite social taboo, both in his work and in his life, Kriegel claims the full range of emotions that are rightfully his to claim, not as a disabled man, but as an American man.

What makes the exploration of taboo emotions ironic in Kriegel’s work is that they are *normal*. According to Erving Goffman in his well-known study *Stigma: Notes on the Management of Spoiled Identity*, it is “in his affiliation with, or separation from, his more evidently stigmatized fellows, that an individual’s oscillation of identification is

most sharply marked” (107). It is not surprising, then, that Lennie’s unexpected encounter with the crippled friends from his past brings his feelings of ambivalence into focus. As Goffman notes,

the stigmatized individual may exhibit identity ambivalence when he obtains a close sight of his own kind behaving in a stereotypical way, flamboyantly or pitifully acting out the negative attributes imputed to them. The sight may repel him, since after all he supports the norms of the wider society, but his social and psychological identification with these offenders holds him to what repels him, transforming revulsion into shame, and then transforming ashamedness itself into something of which he is ashamed (108).

These feelings of shame are essential for Lennie as his journey to self-hood comes to a close. After the failed outing with his peers, he returns alone to his parent’s house and quietly cries in his room, cursing himself, Kriegel writes, “for what I had won. And even more, what I had lost” (Kriegel, *Long* 212). It is a brief but cleansing moment in which Lennie is able to account for who he has become and relieve himself, momentarily anyway, of the obsession to remake himself that has driven him since his seventeenth year:

I would do no more than mark time until I could move out to capture myself at some later junction in my life. For the war with the virus was over. Dead. Finished. Ended. Cripple I was and cripple I had earned. The style my own, the debt paid – to myself and to the polio. And by me. I was

especially proud that I had done the paying. (212)

Indeed, Lennie begins to relax into a self he can live with, one that feels less alienated in the world around him. “I no longer had to prime myself to face a world that did not threaten to kill me or swallow me up, except insofar as it killed or swallowed up anybody,” Kriegel writes in his autobiography’s final note of hope. “And I knew then that if I wanted to I could walk forever. At the cost of legs, I had won a self. How much cheaper a price could I have expected to pay?” (213)

III. Disability Politics and the Singular Self

Kriegel’s first readers in 1964 applauded his conclusion to *The Long Walk Home*, for it champions the masculine self-sufficiency of the Cold War era. Reviewing the novel for *The New York Times*, Richard Shepard, for one, praises Kriegel for his “superb craft and keen insight,” noting in particular, that *The Long Walk Home* is “not the usual ‘How I licked...’ sort of autobiography.” He credits Kriegel’s lack of sentimentality and appreciates the absence of “phony revelation” one might find in restitution or conversion narratives of the day (Shepard 35). Kriegel’s strength, Shepard concludes, is in his “ability to see himself and his world so clearly” (35). While at least one reviewer despised the work, arguing that it “depresses and embarrasses with its long angry passages,” and parades “borderline –blasphemous opinions” (Gabriel 682), others agreed with Shepard’s assessment. Writing for *The Nation*, a publication which continues to support Kriegel’s work today, Mel Rosenthal praised Kriegel’s style and quality of introspection that “make this book a literary experience, one that transcends the usual reminiscences of sickness and survival” (Rosenthal 144). Thus, Lennie’s journey

becomes a singular, memorable experience, one that breaks with an established tradition of illness narratives, yet remains, artistically, “in the center of an American artistic tradition” (144). Many of today’s readers, however, especially those readers who are disabled themselves and may also be disability rights activists, are not seeking stories of singularity, but of community.

Disability rights activist, David Mitchell, for one, questions the ability of autobiography to act as counternarrative to representations of the disabled in other literary forms. Furthermore, he questions the ability of the very singular autobiographer to effectively speak for the community of the ill and disabled. He elaborates on these views in his essay, “Body Solitaire: The Singular Subject of Disability Autobiography.” Here, Mitchell argues that in fiction disability “functions largely as a metaphor of social collapse, while in autobiography disability represents the coordinates of singular subjectivity. The distinction is important because most literary critics in disability studies have argued that autobiography offers up a necessary antidote to the objectifying symbolism of artistic representation” (311). Unlike other disability scholars, Mitchell explains that he does not “champion life writing as a corrective to the insubstantiality of literary portraits” (312). He argues, instead, that disability life writing “tends toward the gratification of a personal story bereft of community with other disabled people. Even the most renowned disability autobiographers often fall prey to an ethos of rugged individualism that can further reify the longstanding [negative] association of disability with social isolation” (312).

That Kriegel’s work champions values of rugged individualism and masculinity is

not surprising when considering that at age seventeen, upon reading Hemingway for the first time, Lennie found himself seeking a surrogate father, a “father-by-adoption” after whom he could pattern his own existence. In “Hemingway’s Pain” in *On Men and Manhood*, Kriegel explains that from Hemingway he sought “an approach to manhood in which those attitudes he had made so meaningful in his fiction might prove to be a basis on which I could build my own ability to endure adversity” (93). To read Hemingway at age seventeen was to learn, Kriegel says, how to be an American man (94). Most importantly for Lennie, in Hemingway he discovers the “relationship between endurance and manhood” (93), and he was urged on through Hemingway’s “insisting that even if the tragedy of life was inevitable, the styles with which one approached that tragedy were the very stuff of meaning” (95). This quality, Kriegel notes, this endurance of pain, is the quality Lennie senses he needs in his own physical struggle against the polio virus. And through Hemingway’s call for endurance, Lennie hears the call to “make myself over, to repair my body so that I could reach into manhood” (103). And through endurance, Lennie find his self:

It was Hemingway who helped make me aware – that pain spoke of *my* ability, *my* endurance, and finally *my* sense of manhood that I was advancing against the world. . . . Hemingway made it possible to understand that pain was a test and that it promised a singular presence, a self that, whatever its limitations, was identifiably *yours*. (105)

Lennie eventually views Hemingway as a dangerous man for a cripple to read at age seventeen – he learns that “Jake [Barnes’] way was too easy” – but for a time he takes

comfort in Hemingway's call to "maintain loyalty to an unchanging myth of the self" (191). Lennie's love of Hemingway and his trust in the author's hyper-masculine code of behavior belies his acceptance of Cold War masculinities – the rugged individualism and strenuous living espoused by Teddy Roosevelt. Author Suzanne Clark argues that after World War II Hemingway emerged as "the very model of a certain tragic masculinity" (Clark 83)¹². In this light, it is not surprising that through reading Hemingway, Lennie "learned to live and to see whether, having been broken in body by disease, I might still be as good a man as I thought I had a chance to be" (Kriegel, *On Men* 108).

The Long Walk Home, of course, is Kriegel's tribute to the journey of becoming this man, and his later collections continue, in part, to highlight the ways he has continued to seek that man throughout his life. For some readers, however, maintaining the myth of the self is too singular a process. In particular, Mitchell faults Kriegel's most recent collection of autobiographical essays, *Flying Solo*, for its failure to document disability as a communal identity. Instead, he argues, Kriegel's essays appeal only to the "singularity of experience that appeases a reader's desire for the intimacy of confession and the narrative demand for individual exclusivity" (Mitchell 312).

Although Mitchell does not mention Kriegel's earlier work, as Kriegel's current themes, and many of the incidents he recalls are similar to those that appear in *The Long Walk Home*, it is safe to assume that Mitchell would feel the same about Kriegel's full-length autobiography as he does about his more current essays. It is true, in fact, that Kriegel's concerns in his work have not changed much in the intervening forty years: he continues to search for and champion the singular, authentic self. Mitchell claims,

however, that “disability does not rob one of singularity so much as it banishes the disabled subject to a life of oppressive idiosyncrasy and distasteful exclusivity. In this sense, the quest for singularity in Kriegel’s book [*Flying Solo*] proves misguided” (313); it presents yet another example of the disabled living “their representational lives largely outside the circuit of human community” (313).

Kriegel’s work may lack a sense of community with the disabled, but Mitchell does concede that *Flying Solo* succeeds in presenting its thesis – in part, a “defense of mid-century masculinity” (313). And “one idea of import that does come out of this resuscitation of 1940’s masculinity,” Mitchell writes, is that the “Victorian notion of muscular male ‘self-reliance’ proves to be very much at home with the singularity bequeathed to individuals with disabilities. Each strives to discover the self as an island amidst experiences that prove profoundly interdependent” (314). As Kriegel’s work strives towards this same self-discovery, Mitchell concedes that he does so by “eschew[ing] euphemistic language and political trends in order to offer readers an unflinching glimpse at a disabled life” (314). Despite these concessions, Mitchell’s concluding account of Kriegel’s work remains negative. He writes:

Yet even his embrace of the self-objectifying label of “cripple” comes off as a stubborn affectation for the politically objectionable. There is a rhetorical stoicism that *Flying Solo* attempts to pass off as unsentimental intimacy with the experience of disability. In the end, this refusal on Kriegel’s part to adopt more updated terminology comes across as little more than insensitivity to twenty-five years of disability activism. (314)

While Kriegel might, in effect, be alienating some of his potential readership through his failure to adopt the terminology of the disability rights movement, what Mitchell fails to acknowledge is that Kriegel's intent in writing is not bent towards disability activism. If he does not embrace the language of the disability rights community, it is because he has no pretensions of speaking for it. In fact, Kriegel finds that the whole topic of illness was "simpler before it was turned into a political cause and a literary category" (Kriegel "Body" 25). He is skeptical of the emerging factions within disability politics and maintains his view that

a cripple has no choice but to go it alone. Yet like women, blacks and gays, we are told that our problems are more psychological than physical. The therapeutic left tells us to struggle not for jobs and independence but for images as it urges us to embrace disability. Christopher Reeve endures quadriplegia with dignity and grace, only to find himself criticized by "disability advocates" for hoping to cure his paralysis rather than looking at his body's helplessness as "beautiful." The right offers us the one message it offers for all problems: Be humble, trust in God and be grateful for the charity of your fellow man. (25)

Kriegel rejects the politics of both the right and left in his work and in his life, just as fervently as he rejects the idea that there is a literature of disability. He writes neither for cause nor canon. For Kriegel, "writing is an act of vengeance, not an act of persuasion," he reminds us. "The fact is that I write out of a selfish desire to alter the truth of my life, a truth I still find unbearable. I write so that I can look at what happened in my life and

measure it against what I believe – somewhere so deep inside me that it has burrowed into the hidden corners and uncharted depths of my entire existence – should have happened (*Falling* 85).

Despite his rejection of contemporary disability politics, *The Long Walk Home* contains a number of poignant autopathographical moments of political importance that warrant its reconsideration by today's readers. As shown, the narrative acts, in many ways, as counterdiscourse to the dominant discourse of illness and disability in the modern era. Lennie's insistence on being viewed as an individual and not just a part of a group, is likewise a political act, an act through which he learns one of the most valuable lessons of his quest: before he can become a hero to any community, he must first become a hero to himself. And in the final analysis, it is Kriegel's individuality, his singular, authentic voice that enabled him to write *The Long Walk Home* and continues to enable his writing today, writing, that he says, without apology, "was, is, and I suspect, shall remain strictly personal" (86).

Notes:

⁶ Frank nominates Stewart Alsop's *Stay of Execution*, published in 1973 as the first book to illustrate these narrative tensions he describes, but I offer up Kriegel's work of 1964 as an even earlier example.

⁷ Some authors reject the terms "pathography" or "autopathography" to describe their autobiographical work. Nancy Mairs, for instance, contends that the terminology suggests that her work itself is sick, and she prefers the phrase, "literature of personal disaster" to describe her work and other disability narratives. Couser, however, suggests that autopathography "is a sign of cultural health – an acknowledgement and an exploration of our condition as *embodied selves*" ("Autopathography" 65).

⁸ Frank points to Oliver Sacks' *A Leg to Stand On* and Norman Cousins' *Anatomy of an Illness* as two automythologies of illness that closely resemble other traditional quest narratives in literature. Both of these authors and texts are frequently referenced in disability studies.

⁹ I examine his relationship with his family in particular in more detail in chapter four of this dissertation.

¹⁰ For the ill, Campbell's "master of two world's" concept might bring to mind Susan Sontag's metaphor of the ill as travelers. Although Frank does not refer to Sontag in *The Wounded Storyteller* in his chapter on quest narratives, where it seems to me a likely place to make a comparison between her theories and Campbell's, he does note her travel metaphor in his first chapter, "When Bodies Need Voices," when he discusses remission societies – groups of people who are "effectively well but could never be considered cured" (8). Sontag's travel metaphor, he reminds us, describes people as citizens of two kingdoms – the kingdom of the well, and the kingdom of the sick. She writes: "Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (quoted in Frank 9). This notion of dual citizenship, Frank notes, "suggests a separation of these two kingdoms. The remission society is left to be either a demilitarized zone in between them or else it is a secret society within the realm of the healthy" (9). In terms of quest narrative, Frank might note that the sojourner's return from the kingdom of illness to the kingdom of remission is a hero's return in which the ill not only become masters of two worlds, as Campbell suggests, but masters of three: the ill, the healthy, and that world of remission in between.

¹¹ For more on the medical model of disability, see my introduction.

¹² In her book, *Cold Warriors*, Clark compares Hemingway's post-war code of masculinity with the Rooseveltian ideal. Hemingway resists Roosevelt's ideals of "national manliness" (69) in favor of individual masculinity, she writes, yet he "took the Roosevelt hero as his theme" (68). He "debunked the glory of war" (68) theme advocated by Roosevelt, yet he embraced and continued Roosevelt's pursuit of "accurate description that would record an act of discover" (69).

Chapter Two

The “Disabled Imagination” and the Masculine Metaphor in the Works of Leonard Kriegel

To experience we have to imagine; imagination is consciousness struggling to gain sovereignty over its experience. –Arthur W. Frank

How odd that we are at once tethered to the truth of our bodies and yet, at the same time, utterly free to sculpt ourselves. –Lauren Slater

We see the writer in the metaphors he creates for his existence, just as we hear the writer’s voice in the myths that nurture him. –Leonard Kriegel

Writing *Intoxicated By My Illness* during the last fourteen months of his life while dying from metastatic prostate cancer, Anatole Broyard laments the fact that most narratives about illness disability focus only on the waking life of the patient and have “little to offer about the imaginative life of the sick” (16); they do not tell much “about [the patient’s] daydreams or fantasies, about how illness transfigures you” (14). Privileging the imagination, Broyard takes issue with Susan Sontag’s popular and influential work, *Illness as Metaphor*. Focusing, he says, more on the “conceptualization of illness than [on] the daily experience of it,” Sontag is “too hard on metaphors” in her push for a truthfulness regarding illness (18). “While she is concerned only with negative metaphors,” Broyard writes, “there are positive metaphors of illness, too, a kind of literary aspirin. In fact, metaphors may be as necessary to illness as they are to literature, as comforting to the patient as his own bathrobe and slippers” (18):

Just as a novelist turns his anxiety into a story in order to be able to control it to a degree, so a sick person can make a story, a narrative, out of his illness as a way of trying to detoxify it. In the beginning I invented

mini-narratives. Metaphor was one of my symptoms.

In thinking and writing about his illness this way, Broyard says writing became a counterpoint to his illness. “It forces the cancer to go through my character before it can get to me” (24). And an inherent part of Broyard’s character, his metaphoric imagination, is his style. Broyard believes in what he calls “the therapeutic value of style,” and that “every seriously ill person needs to develop a style of his illness. . . . I think that only by insisting on your style can you keep from falling out of love with yourself as your illness attempts to diminish or disfigure you” (25). “Adopting a style for your illness,” Broyard writes, “is another way of meeting it on your own grounds, of making it a mere character in your narrative” (62).

It is not surprising that a writer such as Leonard Kriegel would find Broyard’s work appealing. In fact, Kriegel recommended Broyard’s work to me personally in conversation at Ohio University’s 2005 Spring Literary Festival, and he frequently recalls Broyard in his literary essays. Like Broyard, Kriegel has had a profound relationship with his imagination since his polio-related paralysis at age eleven. His autobiographical work not only reflects heavily on the various imaginative views of himself during childhood, but also relies, as Broyard’s does, on metaphor as a key component of its style. Just as Kriegel has a style for his work, he also maintains a style for his illness.

In *The Long Walk Home*, the boy, Lennie Kriegel, relies heavily on his own imagination as well as escapist, fantasy-inducing pursuits such as reading and going to movies to get himself through harrowing medical treatments or humiliating public experiences during his treatment and recovery from polio as a boy. Privately yearning for

opportunities to be heroic and beloved by all, or simply retreating out of hatred of himself and others, Lennie imagines himself as a pitcher, a boxer, a lover, and more, as he struggles through late childhood and adolescence in search of a new, authentic self. This retreat into the imagination is a common theme have noticed in other narratives by adult writers recalling childhoods affected by illness, deformity, or disability.¹³ Of these writers, Leonard Kriegel's work is especially interesting from a literary perspective for the way he stylizes this theme through his use of masculine images and metaphors. These masculine images and metaphors have a twofold effect on the narrative which contributes to the socio-political nature of Kriegel's work. As the hero of his own quest, the boy, Lennie, embraces the masculine imagery of his vivid imagination to gain an immediate sense of power over his debilitating surroundings. Kriegel, the adult author, however, emphasizes masculine imagery throughout in an effort to set his work firmly within a tradition of masculine American autobiography, a move which helps to counteract the dominant American view of the disabled man – and by extension, the disabled male author – as emasculated.

As Kriegel depicts in *The Long Walk Home*, Lennie first relies heavily on his vivid, masculine imagination during his first hospital stay to alleviate his feelings of guilt, fight physical pain, to relieve boredom, and to wield as a weapon against enemy doctors and nurses. Upon Lennie's waking in the hospital, the doctor, in the true patriarchal spirit of medicine at the time, informs Lennie and his mother that the virus had, Kriegel writes, "ended its frontal attack upon my body. . . . It had stopped its march before it reached the upper part of the stomach" (14-15). From the start, then, Lennie is encouraged to view the

polio virus as an enemy of war, something capable of attacking and marching, and, in his case, retreating before it could do more harm.¹⁴ In his essay, “The Body of Imagination,” Kriegel says, “the image I chose [for the virus] was taken from the wartime propaganda of comic books and my virus looked like a sinister “Jap,” America’s yellow, bucktoothed, eyeglasses-wearing enemy” (25). Embracing the war imagery his doctor has suggested to him, and influenced by talk and the media images of World War II (he enters the hospital one month after the Normandy invasion, when the hospital is experiencing a stretcher shortage [19]), Lennie hears his doctor’s orders as barked to others “like an army sergeant” (19). And he prepares himself mentally for the painful transfer from the stretcher back into his bed after treatment by imagining himself at war. Remembering his father’s encouragement to ““be brave. If it should hurt you terrible even, still, you be brave”” (17), Kriegel recalls,

I thought of what I had read about war and suffering and closed my eyes to smell the rain-freshened earth of Normandy, my mind repeating that sound, *Normandy, Normandy, Normandy, Normandy*. . . . It was an intriguing toy, this courage was . . . until I felt the hot stone slab of pain that was the doctor’s hands in the small of my back and I felt my body rising, like yeast-filled dough, in the still-cool morning summer air. This was what my father had really meant, I thought, bitter with a sharp sense of betrayal. But this was not what I had meant, or what *Normandy* had meant either. And yet, I tried. I drove tooth into tooth with that cheap Hollywood consciousness of the victim, a prisoner of the Nazi Gestapo.

Then the pain laced from the small of my back to my legs, ankles, feet,
toes, to my shoulders, chest, neck, head, until my teeth-grinding courage
was shattered by the howl of the shorn Samson in my bones. (19)

In this scene, Lennie attempts bravery by calling up the masculine imagery of war. Though he senses that some of these images stem from Hollywood's cheap fabrication of the courageous hero-victim, he has faith that embracing this kind of masculinity will get him through his ordeal. In this instance, however, Lennie senses an important American belief about disability: his illness is his Delilah, it has the power to emasculate.

The emasculating potential of illness is an important lesson for Lennie to learn early on, as American culture enforces the idea of the disabled as powerless. In his essay, "Fighting Polio Like a Man," Daniel J. Wilson explores male polio survivors' response to mid-twentieth century masculinity. Wilson explains that the polio epidemics of the 40's and 50's occurred at a time when many believed that American manhood was in crisis (120). "Cold war-era cultural critics worried that American men had lost their strength, vitality, and autonomy in becoming victims of a smothering, overpowering, suspiciously collectivist mass society," Wilson writes (120)¹⁵. With their masculinity already being questioned by American society, disabled men and boys at the time were at greater risk for stigmatization. Quoting Robert Murphy's study of the effects of paralytic illness, Wilson explains, "'paralytic disability constitutes emasculation of a more direct and total nature. For the male, weakening and atrophy of the body threaten all the cultural values of masculinity: strength, activeness, speed, virility, stamina, and fortitude'" (121).

In an effort to fight the emasculating potential of his illness, Lennie continues to

retreat into the masculine scenarios played out by his imagination after he is transferred to the Reconstruction Home in West Haverstraw. At first, he continues to view his hospital confinement as something he needs to escape. Again embracing the Hollywood ideal, he pictures the home as the “Alcatraz of my exile” (Kriegel *Long* 25). He sees himself as “Humphrey Bogart then,” Kriegel writes, “the Rock looming above me as big as a childhood dream of cruelty on the passive white screen of my soul. The Rock! I came to it in fear and I left in love, and I look back at it now with all the old, unfinished wars still raging within me” (25).¹⁶ Like his masculine hero, Lennie must escape from an institution in which he feels unjustly imprisoned. While he cannot literally escape before the conclusion of his treatment and rehabilitation, Lennie continues to find brief moments of respite in imagination and memory.

During the long days on the ward, he conjures up baseball players smashing homers at Ebbets Field, and he recalls himself performing physically active pursuits. He remembers his first two-wheel bicycle, for example, and the man who used to chase him through the gardens near his home. He recalls a boy in tears whose nose he bloodied after being called “Christ killer” (36). In each of these images, Lennie recalls himself or others excelling in tasks requiring physical strength. He is unwilling to let go of his image of himself as the strong, physically active boy he once was before his fight with polio.

That Lennie clings to images of his pre-polio self makes sense, for in the hospital he has few male role models upon which to create a new image of himself. And in the American society he lives in, he has only one role model who is both male and disabled: F.D.R.¹⁷ In President Roosevelt, Lennie finds an “easy god to worship” (56). Admitting

to being “no longer sure about God,” Lennie is “sure about the President,” Kriegel recalls. “Sometimes as I wheeled through the corridors, I pronounced his initials, ‘F.D.R., F.D.R.,’ over and over again, finding the cheap reassurance of worship in the sounds” (56). While his other mates in the ward worshipped Hollywood starlets, Lennie keeps a scrapbook of Roosevelt. That the confident and charismatic man meets with powerful world leaders such as Churchill and Stalin is proof to Lennie that the President had “won. And the promise of his victory was that I would win, too” (57). In his mind, Lennie builds F.D.R. up as the ultimate masculine hero. The voice he hears on the radio is “grand and austere, yet filled with as soft personal warmth” (57), and as Lennie reads all the biographical information he can find on the man, and all the “words of his enemies” (57), he is filled with the certain knowledge that F.D.R. is an invincible ally. Kriegel writes:

He fought my virus with me. And the war itself I began to think of as a war to end all virus. I would sometimes pull his face – *my President*, my personal savior – from out of my nightly darkness, reciting to him my growing doubts or my unspectacular yet necessary achievements. And he would smile down at me, like a god should, and tell me whether I had done right or wrong. I was one of his chosen and I had elected myself.

(57)

Lennie believes F.D.R. has the power to save the world from virus, and he also believes that “with one mighty roar” the man can strike all enemies down, “for my god,” he writes, “was a great and mighty god. There was nothing he couldn’t do” (58). Of course, Lennie learns that however strong his metaphorical thinking of the president, the one

thing Roosevelt cannot do is live forever. When he dies, Lennie feels, simply, that “God had died” (58). He feels utterly alone. “And how terrible a threat his death was,” Kriegel recalls. “The world rushing into darkness, the hoarse pleas of unknown, muffled voices begging for forgiveness, faces and hands streaming with blood, my own legs withered and atrophied. For the moment, the virus had won” (59).

Roosevelt’s death causes Lennie to think about his own mortality, an issue that is further complicated by his conflicting feelings about his approaching manhood. In the spring when he is bar mitzvahed, he is troubled both by his “growing dislike of God’s tyranny” and of leaving the hospital for the day and “facing the world [he] had known before the virus” (110). He does not rejoice in this important celebration of his manhood and looks forward to the event with dread for the pity others will feel for him. As if to confirm his fears of the event, when Lennie arrives at the synagogue in West Haverstraw for his bar mitzvah there is no wheelchair access available and the stone steps leading up the portal have no banister for him to be able to climb them on his own. Rather than entering through the front door, he must use a side entrance where his father and a taxi driver have to lift him over a couple of short steps to a landing (113). When Lennie enters the building it takes him some time to adjust to the darkness. The first person he recognizes is his mother, “her face contorted in a savage smile” (113). From the door he must walk twenty feet to the podium set up for him in front of the rows of seats. He is unable to walk the distance without stopping to rest, and when he reaches the front, Kriegel recounts, “my father and a member of the congregation picked me up and carried me up the four marble steps onto the podium” (114). Lennie is literally carried into

manhood.

Lennie clearly recognizes the irony of the situation and he resents being on display, the congregation waiting for him to perform: “*So, we’re waiting,*” he imagines his family and the strangers in the synagogue thinking. “*So go to it, child-turned-man. Legs you don’t have. But a mouthpiece, that you have*” (114). In that moment Lennie is “terrorized because I was now a man, guilty with the curse of the malformed, and I was to pledge my honor, my faith, my gratitude, to my parents and relatives and, above all, to that God whom I hated at that moment with the pure hate of the victim but who had seen me, according to Rabbi Been, through the difficult years to manhood” (114). Lennie recites his speech, accepts his family’s gifts and their congratulations, but he remains conflicted on the meaning of the day, wondering if he can separate the man from the disability: “A boy, a man; a crutch, a brace. Words knotted at the place of meaning – a boy, man; a crutch, a brace; a birth, a life” (115).

I. From Fantasy to Realism

Lennie’s new manhood is soon marked by another beginning, his being discharged from the hospital and returning home as effectively “cured.” Whereas a traditional restitution narrative would describe this as a time of triumph, Kriegel marks this period in his life as another one of adversity. His recovery and rehabilitation prepare him to move around in the world successfully, for the most part, but they do not prepare him to *live* in it. They do not make him a man. Sensing this fact, Lennie does not look forward to leaving the comfort and safety of the hospital and returning to his old Bronx neighborhood where he is especially concerned about falling in public. In rehab, he tells

his friend, “‘We all fall. It’s like we all eat and sleep and go to physio. Here, it’s natural. But that’s not what I’m scared of. . . . what about when you’re lying on the ground [outside the Home and in society] and you look up and there’s some bastard shaking his head. It’s pity. That’s what it is for him. And then you have to ask him to help you. What about that?’” (50).

For four years after returning home, Lennie avoids this possible scenario by spending most of his time indoors, retreating again into fantasy: “Reality shredded into a million scattered pieces as my mind performed its ritual dances,” Kriegel writes, “—ball player, union leader, soldier, lover, fighter, killer, politician, doctor, lawyer, Indian chief. Nothing could interfere. Nothing” (148). Uncertain about his own manhood, he continues to embrace the masculine heroes of sports or famous men, such as Clarence Darrow, making the evening newspapers, in an effort to move “away from the reality the mirror told me was mine,” Kriegel confirms. “Reading, listening to the radio, anything that allowed me to detach myself from the crippled adolescent I really was. I became an even more avid baseball fan, for now that I couldn’t play I needed even more the stimulus of evaporating into myth. I was Pete Reiser or Pee Wee Reese, rarely Lennie Kriegel” (129).

When Lennie finds himself becoming fearful of his future, his fantasy world is a comfort to him. Like his favorite Hollywood actors, he can slip easily into any role he wishes to play. When he wonders, “how do you become a man without legs? Can you touch a woman without legs?” (130), he reminds himself of this easy availability of fantasy: “Importance, dignity, these belong to you too,” Lennie tells himself. “Keep them. But never forget, when it becomes too tough, you can be Pete Reiser or Eugene

Debs. Never forget that” (130). In his essay, “Homage to Barney Ross” in *Falling into Life*, Kriegel reiterates the importance of fantasy in his life. “Fantasy proved a gift both of and for the disease-ridden imagination,” he writes. “I owe my virus that much. For it was the disease-ridden imagination that recognized that before the day came that I could claim myself, I would have to claim all my imaginary selves” (54). That Lennie finds these imaginary selves through the masculine role models of baseball players and other sports figures is significant for Kriegel’s narrative. First, Lennie is trying to recapture a sense of the boy he was before his illness. Before he is stricken by polio, it is clear in the narrative that Lennie takes pride in his strong body and that sports are important to him. Kriegel recalls, “I was big for my age, strong, a rather good athlete, which is always the holed ace in a young boy’s quest for leadership” (*Long* 6).

Lennie, to be sure, will always be interested in sports; athletics are ingrained in his psyche. It is also interesting to note, however, that sports metaphors are commonly found in polio narratives. In his essay, “Covenants of Work and Grace: Themes of Recovery and Redemption in Polio Narratives,” Daniel J. Wilson studies the narratives of about fifty people with polio, represented in twenty-five book-length autobiographies and biographies published between 1947 and 1989, and twenty-eight shorter pieces published between 1936 and 1991 (25). In part, Wilson finds that therapists, doctors, and nurses all “responded to the disease and to the rigors of rehabilitation by relying on familiar images and metaphors. The medical professionals sought to inspire their patients by appealing to the widespread notion that hard work inevitably brought rewards. For others imbued with competitive instincts, a sporting challenge served to motivate” (31). This covenant of

hard work, Wilson contends, “enabled patient, therapist, and doctor to discover what nerves and muscle function remained, to build toward maximum physical recovery, and to regain some sense of power, some sense of self, in a life shattered by disease” (31).

Kriegel taps into the images inherent in the covenant of hard work, as Wilson describes it, especially, as we have seen, in his viewing the virus, at times, as a sporting challenge. It is possible that these images may be ingrained in him through his experience at the hands of the patriarchal practitioners that made use of these same images for motivational purposes. America’s expectations for men and boys during the 1940’s fueled these images in an era when, as Kriegel writes in his essay, “Taking It,” a man was “expected to face adversity with courage, endurance, determination, and stoicism” (*Falling* 55). Polio, especially, he feels, “was a disease battled by being tough, aggressive, and decisive. And by assuming that all limitation could be overcome, beaten, conquered. In short, triumph over polio’s effects lay in ‘being a man.’ One was expected to ‘beat’ polio by outmuscling the disease” (56). In his research Wilson discovers that Kriegel is not the only male writer to present polio as a disease meant to be tackled like a man, “rejecting dependence and passivity in favor of actively resisting the limitations imposed both by a crippled body and by an unaccommodating society” (Wilson “Fighting” 119). Although he does not specifically discuss these images at length in the works by the authors he studies, Wilson finds, in fact, that similar myths of the warrior and the athlete helped numerous youths through their recovery. Rather than succumb to the emasculating effects of their illness, the men in Wilson’s study embraced “the cultural values of masculinity – strength, aggressiveness, toughness, activity, stamina,

and fortitude – [that] were allies in the struggle to recover muscle function and to achieve something approaching a normal life” (121).

While this tough, resilient thinking is a part of the lexicon of American medicine at the time, Wilson fails to note that Lennie’s reading about ball players or fantasizing about being a sports hero is also, clearly, very much his own way of expressing his masculinity and the kind of manhood he desires. In addition, Kriegel’s work is essentially different than the other polio narratives Wilson describes because the majority of Lennie’s masculine triumphs occur only in his imagination. In admitting this, Kriegel complicates the usual “triumph over adversity” story, offering a counternarrative not only to American culture’s view of the ill and disabled, but to polio victims’ view of themselves.

Lennie’s fantasies, then are only triumphant in that they offer him a means of escape. As the “‘real world’ grew more difficult and less appealing,” Kriegel writes elsewhere, “I bombarded myself with images of muscular prowess” (Kriegel *Falling* 43). In one such fantasy, Lennie imagines himself as a boxer while getting his legs massaged:

The massages permitted me to fantasize about being a prize fighter who had just won the heavyweight championship of the world and who was being rubbed down on the dressing table. It became one of my most enjoyable fantasies. As Mr. Courant massaged my dead knees and calves, I would rehearse the fight, slowly coming out of my corner, hands knotted into two huge fists, protecting my face, stalking my opponent. The thrill of the warrior’s approach with the knowledge that I was already the

victor, cleansed and purified by the effort of my dream, my opponent's face a penitential mask for all those who had ever hurt me (*Long* 145)

In fantasies such as this one, Lennie privileges the violence and physicality of masculine brute force. Kriegel explains that boxing fantasies were some of his most common during childhood. He fantasized about fighting, he says, because he worshipped power (*Falling* 44). And in his fighting fantasies, he sought something different than in his fantasies of other sports:

It wasn't the resurrection of movement I craved, nor was it the almost unbearably sweet memory of the tingling sensation in my wrists as bat connected with ball. I depended upon my fantasies about fighting for something deeper, as sense of myself as still possessing the very power whose absence threatened to destroy me even as I dreamed, spurred on by my weakness. Pretending I was a fighter promised to freeze the drift into helplessness, to give me back a voice in my fate. What other fantasy would allow me to see myself once again imposing my presence on my world? (47)

Whether dreaming about the athletic prowess of baseball players or the masculine power of boxers, for four years Lennie avoids life outside his Bronx apartment in favor of the life he lives within his vivid imagination. Kriegel admits, "if life was frequently no more than a fantasy, it was, at times at least, a rich one" (*Long* 147). And, if only temporarily, Lennie's rich fantasy life fuels his image of himself as a man. At the movies, especially,

he can retreat into an “afternoon dream of manhood,” where nothing can hurt him (142). In watching Gunga Din, Jesse James, or a charge at Iwo Jima, all of Lennie’s feelings of “impotence, confusion, withdrawal, terror, and shame died during those rich hours in the dark, [his] body straight and strong and sure now, [his] mind the king of its own custom” (142). In fantasy, Lennie triumphs, but he is acutely aware that his imaginative victories are fleeting, as when he leaves the movie theatre to find the light “exposing the reality that was I as I walked back up Bainbridge Avenue, my head still full of dreams, but the alley of salvation closing around me as the eyes that belonged to others pierced time to tell me that I had to wait for the next week to live” (142). When Lennie approaches his seventeenth birthday, he abruptly discovers that an internal life of fantasy can only serve him so far, that despite his masculine fantasies, he eventually always has to return to the real world where he feels inevitably, that he is less a man. He still has to face society, and society sees him as a cripple. And in growing older, Lennie feels forced “simply by the power of a greater mobility I would not admit to myself I didn’t want, to get around more and more in that world below my window, I found it more and more difficult to maintain the myth” (149).

The myths of his childhood are, in fact, shattered when Lennie succumbs to a case of boils: “And that was where my new man was conceived,” Kriegel quips, “—in bed with boils” (149). Lennie had experienced boils as a regular nuisance as a result of walking with his leg braces and crutches, and in the past he had looked upon them as an opportunity to stay indoors and daydream, escaping the “eyes that burned through me in the streets” (149). On this occasion, however, his boils are especially painful. As he looks

upon the stickball game his brother and his friends are playing down in the street below his window, he attempts to slip into the “familiar, comfortable, reassuring” daydream of becoming whichever one of them he wanted to be (149). But as he watches, the boils ache, “contracting with meticulous regularity” (150). Lennie tries to ignore the boils as he has done in the past, watching the ballgame and becoming, in his mind, any of the players, “just as I always became whoever it was necessary for me to become,” Kriegel recalls. But unlike in the past, Lennie cannot ignore the pain of the boils, a pain so insistent they interfere with the masculine myths he has embraced so dearly for the past four years:

. . . the boils just throbbed, like a neon sign flashing on and off, on and off, on and off. And then the myths dropped away forever, to die permanently in a sudden burst of anguish and despair. Because *I was a cripple*. Not a ball player, not a hero, not a lover, not even an adolescent, but a cripple. Nothing but a cripple. And now each contraction of pain said to me, “You are a cripple, a cripple, a cripple.” That was all – so simple, so brutal, a truth, the kind of truth I had never before permitted to invade my consciousness, a total candor that came with all the shock impact of an idea that was to embed itself permanently within the boundaries of my existence. *I was a cripple*. (150)

With this realization, Lennie’s masculine fantasies fall away; crying, he turns from the window to mourn them.

That Lennie is watching a stickball game from his window during this epiphany is

especially poignant, for it is not only the physicality of the game that he mourns in this scene, but also the imagistic language of sports – stickball, perhaps, and baseball in particular – that has helped fuel his childhood fantasies. In his essay, “From the Catbird Seat: Football, Baseball, and Language,” Kriegel shares his belief that “baseball remains intimately tied to language” (217). It is descriptive and imagistic, he says, and “it is tempting to think of baseball as the writer’s game” (217). Even as a child, Kriegel realizes that the game of baseball is “anchored in words” (218). He notes that as a seven-year-old listening to Red Barber’s radio broadcasts of the Brooklyn Dodger games he suddenly became aware of the power of language. “Barber gave depth to reality and intensity to emotion,” Kriegel writes; his broadcasts made his “audience aware that words, too, were part of baseball’s magic. My love of baseball and my sense of how language could command attention arrived simultaneously” (219). It is not surprising to learn that the imaginative Lennie enjoyed the games which were relayed back to New York by tickertape even more than the live broadcasts. He excites in the “re-creation” of the game. “That made it an even more intense experience,” Kriegel recalls. “It demanded language that could enforce the claims of the invisible world and make what was not seen more vivid, more real than what was seen. As Red Barber re-created not only the action on the field but the heat and humidity of the dog days of August, he would make my soul sweat” (224). Kriegel, the adult writer, comes to feel that the language of “baseball feeds literature” (218); for Lennie, the boy, the language of baseball feeds his personal mythology, the fantasies of himself as Yogi Berra or Dizzy Dean, whom he admires as much for their playing ability as their witty banter that delights him through childhood

(218). As Lennie turns from the window in tears to attend to his boils, aware that the fantasies of his childhood are slipping away, he must also be aware that the beloved language of those fantasies is also lost to him.

Suddenly, the language of fantasy is replaced by the language of grim reality. Although Kriegel does not mention it in *The Long Walk Home*, his epiphany during his ordeal with the boils – which seems unusually sudden in the narrative – is also influenced, in part, by Lennie’s change in reading habits at the time. In his essay, “In Bed with Boils: Literary Realism as Salvation’s Mentor,” Kriegel describes how during his two-year hospital stay, and for nearly four years upon his return home, reading sheltered him “from the mundane threats posed by the normal world” (62). Reading, he writes, “allowed me to merge my own need for a heroic healthy self with the full-blown fantasies depicted in pulp magazines with names like *Amazing Stories* and *Action Adventures*,” where he reveled in “trashy two-dimensional stories” filled with “action and movement” (62-3). Once afflicted with boils and forced to stay in bed on this occasion, however, Lennie’s reading habits – and his view of the world – abruptly change when his father brings home three books given to him at work quite unexpectedly by the very literate wife of a dentist. The books – James T. Farrell’s *Judgment Day*, Richard Wright’s *Black Boy*, and Norman Mailer’s *The Naked and The Dead* – change Lennie’s view of himself forever. Used to the language of baseball and pulp fiction novels that have fueled his own fantasies, now, suddenly, Lennie finds himself reading “words demanding that I look at the world as it was, the world I was living in. For the first time in my life,” Kriegel admits, “language gestured not toward fantasy but toward the here and now. And for the

first time in my life, I was asked to acknowledge the difference between words which framed fantasy and words which insisted that I confront all the skeletons in all the closets – my own and everybody else’s” (63). In reading these works of literary realism, Lennie finds himself “forced out of fantasy into the world” (64). They introduce him to a world of literature he had not connected to previously, and they inform his own beginnings as a writer as he comes to view writing in a new light:

Reading those books made me aware that writing did not have to feed fantasies. Writing had only to recreate the world – a world which, I was to learn, was both more oppressive and more thrilling than fantasies constructed so that I might live with what the virus had done to me. Until then, reading had buffered me against a physical life that seemed to point in the direction of a distinctly unpleasant future. Recognizing the pain as well as the possibilities of my situation was precisely what I had hoped the printed word would enable me to avoid. (65)

But “these three writers were telling me that the world as it was remained the only world I could *choose* to live in” (67).

And yet, despite their influence Kriegel does not mention these writers in *The Long Walk Home*, no doubt because their influence does not support the kind of hero he is intent on making of himself in his memoir. His project is not to represent himself as a “Realistic Cripple,” a term he describes in his essay, “The Cripple in Literature.” “Literary realism,” he explains, “sees all men as potential victims and sees their victimization as more or less equally interesting. The Realistic Cripple can make little of

his wound, because his wound is neither his essence nor the reflection of his glory” (37). Lennie, on the other hand is a “Survivor Cripple,” another cripple-type Kriegel identifies from American literature and describes as a “man who endures and in his endurance discovers survival as a cause in itself” (38). The survivor cripple is not demonic, as Kriegel defines Ahab, and he is not the object of charity, as he describes Tiny Tim, but at the same time, “he assumes that his wound has given him certain prerogatives, has set him apart, has denied his ‘ordinariness.’” (38). William Einhorn from Bellow’s *Augie March* is Kriegel’s example of a survivor cripple: “His physical helplessness neither ennoble nor damns him,” Kriegel writes, “and he remains an example of what other writers can do with the figure of the cripple” (*Falling* 145). Although he is only a secondary character in Bellow’s novel, and he is a character of ill repute, the crippled poolroom owner attracts Kriegel’s admiration because “the only model available to him is what he finds in his own life” (146). And it is this understanding that Kriegel brings to his own work, and indeed, his creation of himself as a hero, a Survivor Cripple, in *The Long Walk Home*.

Whether inspired from boils or from books, whatever tears Lennie sheds over the loss of his childhood myths are quickly replaced by anger, as he comes to embrace the reality of his own life. As he begins to think about what others have made of him, he curses the *theys* of the “horrible, real, outside world,” the “*they* of a God” he no longer believes in, the *they* of his mother and father, and brother, and friends, and the *they* of the doctors and nurses at the Home, all those “people who came like mendicant saviors to lay their sloganized comfort at my feet” (*Long* 151). Lennie vows to get even with all who

have stolen his myths and his imagination. He promises to take control over his own body and “show them all,” by molding the “fat of my body into muscle, until my body could do whatever my mind ordered it to do” (152). In this brief but life-altering moment, the hate boils up in Lennie; it “knotted in [his] stomach and gave way to a dry, hard rage” (152). This anger, however, is cathartic. In recounting his boils experience yet again in his essay, “A Few Kind Words For Anger,” Kriegel explains, “anger taught me that I could still make demands upon mind and body, that to be a cripple did not mean that one was relieved of the obligation to be a man. If anything, to be a cripple meant that the need to be a man was stronger and even more decisive” (*Flying* 54).

Now feeling a need to assert some control over society’s construction of him as a cripple, Lennie bids farewell to the imaginative realms of childhood and channels his anger into a new obsession with exercise – an effort to strengthen his arms and shape his body into a literal masculine form. Wilson argues that Kriegel’s mission to change himself through physical therapy and exercise suggests that he “accepted the covenant that hard work promised victory over the virus” (Wilson “Covenants” 28). In Wilson’s study, however, hard work and receiving God’s grace are closely aligned in ways we do not see in Kriegel’s narrative. Wilson contends that a covenant of grace represents the efforts of nearly all the polio survivors’ narratives he studies. They strive to “achieve some level of understanding, some sense of acceptance and resignation, or some faith in God’s ultimate purpose as a means of coming to terms with their remaining disability” (24); they had to “find grace, acceptance, and redemption with what the virus had left them” (25). This sense of grace, of accepting God’s wishes, Wilson adds, often coincides

with newly found or newly strengthened religious faith, so that “the experience of polio only confirmed [patients’] belief in God” (33). Without this experience of grace, Wilson writes, without this redemption, “these healing stories could not have ended in their characteristic triumph over polio” (24). Kriegel, however, as noted previously, provides a counternarrative to these other polio narratives, with their decidedly conversion-like undertones. When recalling his purpose for writing his illness narrative, Kriegel admits that he wanted to “write a book free of the sentimentality and cant and papier-mâché religiosity usually found in such books” (Kriegel *Falling* 87). Illness narratives or fictional works overflowing with religious sentimentality, he writes, “work to disguise disease and disability and encourage the ill and disabled to simply “trust in God’s goodness and man’s charity” rather than their own goodness, or their own abilities (“Body” 26).

As a non-believer, Kriegel writes elsewhere, he feels “the cripple’s presence merely testified to a calculus of accident. One could accept the implication of such mathematics, since one’s acceptance was beside the point. Both believers and nonbelievers were powerless to change the way things were” (*Falling* 177). Lennie has clearly rejected God by this point in the narrative and is not open to receiving His grace. Kriegel concedes, however, that “something in me was desperately looking for salvation when I was sixteen and lay in bed with boils” (“In Bed” 67). He finds this salvation, in part, by reading Farrell, Wright, and Mailer. Once he is able, with the help of these texts, to look at his life from a more realistic perspective, however, Lennie finds he can also find redemption through the power he wields over his own body. Exercise, Kriegel

recalls, “was the first step toward selfhood” (*Long* 154), and “in the arms was my salvation” (154). Wilson concedes that “grace might also come in more secular guises” (Wilson “Covenants” 34) and that Kriegel’s obsession with exercise serves as a “*kind* of redemption” for him (emphasis mine 35). Later, however, Wilson maintains that “grace and redemption have proven elusive for Kriegel” (37), a statement which I feel belittles Kriegel’s feelings about the importance of exercise during this time in his life.

Kriegel also admits in the narrative, however, that he realistically understands that his obsession with exercise is perhaps another form of fantasy:

But it was fantasy that had nothing to do with an imaginative life. I had to protect the growing self within me, to nurture the awakening power of my body, to break through all the old possibilities my imagination had offered into the promise of real selfhood. To be! That was it. I had to be. (Kriegel *Long* 154)

In this mindset, Lennie retreats from the world around him and into an “embryo of selfhood” nurtured through exercise. He does push-ups in his room until he collapses in pools of sweat, considering each painful lifting of his body as a “victory” over everything he hates (155). And this hate carries, him, Kriegel recalls. It carries him through an hour’s workout before breakfast, two hours of “brutal exercise” after his hour of home-schooling, and, later in the day, twenty-block walks through the neighborhood, wearing his braces and crutches, “the muscles in [his] shoulders so swollen with fatigue and pain that each step was a burning screw twisted deeper into [his] flesh” (155). After dinner, Lennie’s grueling routine continues, as he walks to the city park for an additional two to

three hour workout on the monkey bars (156).

Lennie's desire to better his body is productive in the sense that the strength he gains from his efforts offers him both greater mobility and a healthier psyche in the end. On the other hand, Lennie's family expresses concern over his manic exercise, he refuses to listen to their pleas that he take things more slowly. In fact, he turns away from his family and friends altogether in favor of his pursuit of bodily strength. And as he grows stronger and proud of the weight he is losing, he becomes even more self-confident and more self-reliant. For instance, he loses his old fear of doctors and nurses. Once the enemy, they now seem "ridiculous" to him as he works gracefully with the weights and parallel bars during his weekly rehabilitation. He sees them "plodding through tasks that were as unreasonable as they were silly" (158). Most importantly, he proves, in their presence, that he no longer needs their – or anybody's – assistance, for "by this time," Kriegel writes, "I had learned how to balance all my weight on one arm while doubled over and boost myself with the other arm on a single crutch – an important victory, for it freed me of asking for help when I fell" (158).

After losing thirty pounds and gaining immense strength in his upper body during his summer of exercise, Lennie believes "that the world now envied my grace and courage, just as I had once believed that the world had fathered my fatness, my helplessness, my terror" (160). For the first time, Lennie feels like a "man among men, notwithstanding knees that were strapped to steel" (160). Kriegel, however, notes his own naivety in this passage, hinting to readers that Lennie's victory is not complete, despite his new feelings of masculinity: "It didn't occur to me then, that the world did not care,

that it was as indifferent to me and to my triumph as it was to everyone else” (160).

In a significant scene in this chapter it is clear that Lennie’s temporary manic existence has not alleviated his concern over how others view him. More specifically, despite his perfecting his upper body, he still feels the stigma and shame of his disability. Mid-summer, Lennie is puffed with pride over his bodily transformation, a change he sees as a “healthy, childish, brutal game called ‘getting even’” (161), and he looks forward to a trip to a mountain lake retreat with his family. Feeling his newfound manhood is “invincible” (162), Lennie plans a water ritual through which he can cleanse away the last remnants of adolescence and emerge a man. Recalling looking out over the water of the lake, Kriegel writes, “It was here that I would do it. My sex, my manhood, my power, my destiny, the end of the adolescence I had never had – it lay on the surface of the lake, as cold and green and wet and waiting as the water itself” (162). The next day, Lennie rows out to the middle of the lake with his brother. He takes off his pants, unstraps his leg braces, informs his brother to row twenty feet ahead of him, and slips cautiously into the water (162).

As Lennie swims he feels that “neither time nor memory” can hurt him (163). Relaxing, he floats on his back a few moments before he swims “savagely,” triumphantly to the other shore (163). Kriegel describes his feelings of invincibility in the water:

The water, the sun, the dock at the other end of the lake, the obliteration of time, the manhood I was reaching for – these were all waiting for me. And I was never going to die. I knew that as I cut through that water, because I was somehow bigger and better and taller and smarter and higher and

lower than anything or anyone that had come before me. Like God, I was. I felt as if my body were being thrown swiftly through the air, higher and higher, and the world was a clear, undisturbed vision beneath me, small and distant and beneath me. (164)

Lennie's great swim is a powerful and moving scene in the narrative. Readers rejoice in his physical triumph and believe, as he does, that he will be reborn out of water into the manhood he has been seeking. The scene is made more poignant, however, by the fact that Lennie's victory is short-lived. His arms, made strong enough through exercise to propel him across the lake, have not, in the end, propelled him toward redemption. He is not the god, after all, that he imagined himself to be. As Lennie pulls himself up on the dock, he rejoices in his victory while putting his shoes and braces back on. Suddenly, however, he feels self-conscious, worrying someone may see his braces, his atrophied legs, from shore. In this brief moment of self-consciousness, Lennie makes an important discovery: "I had won over the lake," Kriegel writes, "but I had lost the real victory in my fear of being seen. My body remained an anachronism, a cripple's body. And no matter how many pushups I had done, no matter how many lakes I would swim, I remained ashamed of revealing that body to others" (164).

In acknowledging the shame he feels in what otherwise would be a moment of triumph, Kriegel also acknowledges that for him, rehabilitation of the body does not lead to triumph over his disability. Even at age seventeen, Lennie is acutely aware of the degree to which his disability and his sense of self are socially constructed. Not until he comes to terms with the social stigma of his disorder will he find the authentic self he has

been seeking. His efforts are hindered, however, because despite all he has learned about the pitfalls of embracing a masculine fantasy of himself, masculine posturing has been ingrained in him through American society. Lennie feels the negative effects of this societal influence on his first date. The event begins well, and Lennie even feels the victory of a Hollywood lover when he “cops a feel” in the darkened movie theatre. As he walks his date home, however, he falls in front of her, and, feeling emasculated in her presence, he views her as an enemy:

Barbara picked up the crutches. She had a certain sure dignity of touch that gagged me for the moment, holding the crutches as if they were not wooden crutches but rather spears, clean and agile and shafted in their ability to pierce flesh. I knew little enough about the terror of the phallus then but it was with me for sure. This was my potency, my strength; like Samson’s hair, this was the feeder of my manhood. I pushed up straight, using one crutch hand to boost myself, then grabbing the other crutch from Barbara’s hand. (168)

As Barbara enters her hotel, Lennie hates her for having tried to soothe him, for trying to make him feel less embarrassed, and for brandishing the tools through which he displays his masculine physical strength as weapons against him. Given the 1940s script of masculinity that Lennie is following, it is not surprising that he feels threatened in this scene. He is not yet emotionally capable of accepting Barbara’s gesture of comfort.

Exhausted from the long walk and feeling “weak and flabby,” Lennie turns to head back to his own hotel, determined to not accept rides from passing cars. The length

of his journey is, of course, suggestive, as Lennie finds himself on yet another long walk home. In a rage of humiliation, he cries as he walks into the night, feeling he has lost an important battle. Kriegel recalls he was crying because

Barbara's softness had turned to stone in my hands, crying because the fever in the blood was now no more than the desire not to be humiliated any further, crying because I had come so close to the greatest and most necessary of all the incestuous loves, the love of the self, only to have it wrenched from my grasp. (169)

By the time he returns to his hotel, Lennie is at the peak of his rage, vowing revenge on everything. He spends the next day in a whirl of self-pity, feeling the "world was rancid with the smell of my disease" (170). Ultimately, though, Lennie finds that his defeat with Barbara is a minor one. In time, his emotional wounds heal and Lennie ultimately reaches a point in his life where falling in front of a woman has a much less dramatic outcome. In college, for instance, when he falls in front of his future wife, Harriet, she makes him feel more "normal" than ever. Harriet simply says, "You fell," and her response, Kriegel writes, was the "kind of response which took the wind from my sails, the rage from my soul, and left me feeling helpless in that physical being I had worked so long and hard to create – just another man who fell" (*Flying* 145).

Although *The Long Walk Home* does not recount this experience and Lennie's new level of maturity, the quick summary of years at the end of the narrative suggests Lennie's moving toward it. The book ends, as noted in my previous chapter, on a positive note, with Lennie feeling he has paid his debt to polio and has discovered his authentic

self. There is a sense that his physical, emotional, and social battle with the virus is over.

As Wilson correctly notes, however, Kriegel's

subsequent essays over a quarter of a century recount his continuing struggle to make sense of his crippling, to reshape a usable past out of the chaos of pain and limitation. . . . [He gives readers] some insight into the continuing struggle that is the lasting legacy of polio. Kriegel's accounts of this forty-year struggle to create a self starkly reveal the difficulty of sustaining affirmation or triumph over a lifetime marked by pain, disability, and limitation. (Wilson "Covenant" 38)

Kriegel first learns that the effects of polio will be lasting a year and a half after the publication of *The Long Walk Home*, when he breaks his wrist in a fall. The incident makes him realize that the virus would not only "stimulate and irritate" him for the rest of his life, but also become the obsession of his future writing. "The virus had created me," he writes. "The virus had been transformed into the mote in the writer's eye. In taking my legs it had given me a way of looking at the world and at myself. Nothing I would ever write would be free of its legacy" (Kriegel *Falling* 87).

Kriegel understands, then, that his illness and disability pervade his whole life. As Wilson confirms, Kriegel returns to the topic of polio throughout his writing career. In fact, Wilson views Kriegel's writing and his earlier manic exercise as playing similar roles in Kriegel's life. "Shaping and reshaping the past through writing gave free reign to fantasy and permitted Kriegel to recapture his unfettered life before polio and to attempt to come to terms with the rupture and limitations brought by the disease and its physical

and spiritual cost,” Wilson writes. “The exercise and the writing were linked by the common hunger to create a self in opposition to the virus. If anywhere, it was in validating his ‘life by creating a sense of his selfhood out of physical pain and chaos’ that Kriegel has found a kind of grace, redemption, and peace, however temporary” (Wilson 36). While this secular *kind* of grace may be different to what Wilson finds in most polio narratives, for Kriegel it has made all the difference. That his redemption comes through anger and an unabashed desire to reap revenge upon his illness is no less cathartic for him than redemption through faith is to other polio survivors. It is through embracing illness and disability that he finds – and writes – his authentic self. Primarily an autobiographical writer, he has not avoided that his illness, his disability, *are* his life, and while he does write on other topics besides being a cripple, his illness story does inform, if not dictate, the bulk of his lifewriting.

Indeed, Kriegel’s collective lifewriting is significant in that it gives us the unique perspective of his illness through the decades, when, as Wilson notes, only two other writers in his study write more than one account of their polio experience. In continuing to write about disability as a lifetime challenge, Kriegel offers a more realistic model of disability which contends that living with chronic illness and disability is a constant battle. With this contention, he provides a counternarrative to the medical model of illness and disability that considers the struggles of the ill and disabled as effectively over once their bodies are rehabilitated and they no longer need immediate medical care. What is especially interesting about Kriegel’s body of work from a literary perspective, though, is the fact that Kriegel not only provides counternarrative to society’s dominate discourse

on disability, he provides counternarrative to his own work. He is not afraid to reevaluate the ideas in his own writing in his continuing search for authenticity. In his essay, “On Manhood, Disease, and the Authentic Self,” written fifteen years after the publication of *The Long Walk Home*, for instance, Kriegel feels much differently about the ending of the narrative, which reads: “At the cost of legs, I had won a self. How much cheaper a price could I have expected to pay?” (*Long* 213). In reflecting on various of his works for his essay, Kriegel admits:

I can think of no sentence as singularly untruthful as that last. I would give a great deal to be able to take it back today. For I know now how truly expensive such victories are, how fragmentary, how terribly short-lived, how ludicrous to call the price ‘cheap’ and how essentially demeaning to the legitimate and painful demands I had made upon myself. . . . The price is never cheap. And that authentic self is never quite won (“Manhood” 120-21).

The lesson that living with chronic illness or permanent disability is a lifelong battle is a valuable lesson for the ill and disabled who have sought solace in illness narratives that tell them to surrender themselves to American medicine, or to God, or to simply grin and bear it, while their physical and social trials continue. Kriegel’s narratives, then, may come closer to representing a broader range of experiences and emotions than traditional restitution and conversion narratives that a larger population of both disabled and able-bodied persons can relate to.

II. From Illness, the Writer's Voice

As an adult writer, Kriegel's life comes full circle, as he once again embraces the vivid imagination he rejected as a teen in favor of sculpting his body. Now, however, he recognizes that it is his body, and the polio virus in particular, that has given him a writer's voice. "For it was that virus," Kriegel writes, "which taught me how to see and what to look for. And it was that virus which forced me to recognize that in writing about who I was and how I lived, I was still speaking for that eleven-year-old boy, the *who* I should have been and the *how* I might have lived" (*Falling* 85). Indeed, for over forty years Kriegel has made his reputation as a writer by mining what he calls the "imagination housed in the damaged body" ("Body" 29). He knows that "as a writer [he has had] to conceive of the life not lived [a life without polio] in order to understand the life lived" (*Falling* 86).

Kriegel explains that cripples living consciously as cripples are constantly obsessed with their bodies, an obsession that affects their imaginations as well as their use of language. "The body lurks like some giant termite gnawing at the imaginative life we knew before illness had control not only of our physical existence, but also of our sentences," Kriegel writes ("Body" 25),¹⁸ but he also discovers that "to enter what Susan Sontag called the 'more onerous citizenship' of illness is to discover that language can defend the broken body" (29). Kriegel not only feels this way about his own work; he recognizes a similar role in the imaginations of other contemporary disabled writers:

The multiple sclerosis that forces [Nancy Mairs] into a wheelchair also gives her strategies for survival and strategies for imagination. Writing

about the life that illness makes her live, she must speak of the life she has been prevented from living. This is the price the crippled writer pays. One is always imagining what might have been if . . . Bodily loss is the source of the strength of this writing – as true of Andre Dubus as it is of Mairs – as well as its weakness. To be obsessed by the body is a common denominator for writers forced to accept that more onerous citizenship. Yet the acceptance imposes its narrowness on us, cripples our focus even as it emerges from the crippled body. We are different from normal writers because for us the imagination is housed in the damaged body.

(29)

Arthur W. Frank likewise contends that tellers of illness stories are different from other writers in the way that their illnesses not only interrupt their lives but also disrupt their memories (Frank 60). “The memory that is disrupted is a coherent sense of life’s sequences,” Frank writes: “the present is not what the past was supposed to lead to and whatever future will follow this present is contingent” (60). Furthermore, “the past is being remembered with such lucidity because it is not being experienced as past; the illness experiences that are being told are unassimilated fragments that refuse to become past, haunting the present” (60). Frank’s ideas here can pertain to Kriegel in the sense that he views his writing as a way to seek revenge on the past that interrupted his present. Always haunted by what might have been, Kriegel has continued to examine the life unlived in his work:

A 60- year-old man in a wheelchair still dreams of hitting a baseball as he

did when he was 11. He cannot help it; that the dream is ludicrous is beside the point. . . . Ordinary dreams are often puerile, but they have the great advantage of also being specific as they measure the sick body against that time before it seized control of imagination. Desire is always linked to memory, and the literature of bodily affliction turns on the moment before illness imprisoned the writer in her dead limbs or cancerous growths or the exhaustion of the effort he must make to get into a car. It is not much in the way of compensation to note that only words can resurrect the time before one had to combat the anguish of the broken body. The reader may find inspiration in those words. But all that the writer finds is loss revisited and the sound of imagination—screaming.

(Kriegel “Body” 30)

Today, as Kriegel examines the life lived against the unlived life, his imagination not only continues to scream, it continues to embrace the masculine imagery and metaphors that served him so well as a child recovering from the effects of polio, and as an adult writing about those effects in *The Long Walk Home*.

As Wilson notes in “Fighting Like a Man,” Kriegel, like many polio survivors, has experienced post-polio syndrome, decades, now, after his initial rehabilitation. The symptoms of post-polio syndrome include “new muscle weakness, increased fatigue, increased muscle pain, decreased endurance, and the loss of hard won function” (128). For men, Wilson adds, post polio syndrome “poses new challenges to their masculinity. The hard won victories of rehabilitation are slipping away, and the metaphors of battle

and competition that sustained their youthful struggles against the disease have lost their power to inspire and motivate” (128). Ultimately, Wilson finds that the “masculine ethos that had spurred [the men and boys’] recovery could not always be sustained over a lifetime of living with a disability” (126); rather, these men have “had to alter their relationship with their disability and their sense of manhood as they aged” (127).

Kriegel has written about his own struggle with post-polio syndrome in his essay collection, *Falling into Life*. Wilson recounts Kriegel’s struggle briefly in his own essay, focusing on Kriegel’s return to using a wheelchair fulltime for mobility. Kriegel’s return to the wheelchair is symbolic of letting go of the masculine defiance that fueled his insistence on walking with braces and crutches through most of his adult years. As evidence that his definition of masculinity has changed as he has aged, Wilson notes Kriegel’s surprising finding that returning to the wheelchair was not the “‘spiritual death’ he had feared” (129). Wilson adds, “after forty years of crutchwalking, forty years of struggle, defiance, and resistance, it was time to say ‘no more,’ and to recognize that he had put up a good fight but that the time for that particular fight had passed” (129). What Wilson fails to notice in Kriegel’s case, however, is that although his views on masculinity may have changed in regards to his wheelchair use, he still embraces mid-twentieth century ideas and images of masculinity in his current work. As the title of his most recent collection of essays, *Flying Solo: Reimagining Manhood, Courage, and Loss*, suggests, Kriegel has continued to grapple with the meaning of these images – the meaning of manhood – throughout his life. And just as masculine themes have remained prevalent in his work, masculine metaphors have not lost their power to inspire and

motivate him – only where they once inspired a will over the body, they now inspire his writing.

In the introductory essay of *Flying Solo*, Kriegel explains the purpose of his project. This book, Kriegel writes, “speaks of how one can endure the rage of loss, how memory creates debts out of loss, and how illness haunts memory forever. From the pain and humiliation illness insisted upon, I would define the man I was to be” (7). One stand-out essay in the collection, “Hitting the Clock,” focuses, Kriegel writes, on the “single moment that somehow measures my life” (104). Being drawn, as he is, to the masculine imagery of sports prowess, it is not surprising that this moment in Kriegel’s life revolves around baseball. The essay recounts a day in 1943, when Lennie, pre-polio and about to turn ten, is playing baseball in the street with his friends. Kriegel recalls feeling an “intense pleasure, the renewed sense of expectation” over his own body as he “crouch[s] above an oblong piece of cardboard taken from somebody’s father’s laundered shirt and held to the ground by a large gray stone” (104). He is about to “hit a baseball over the ditch of the empty lot behind the block-long apartment house” (104). Though he is unaware of what his future, in just over a year, has in store for him, the images of the pebble-strewn lot “have already chosen me,” Kriegel writes. “In memory, each pebble tells me that I cannot choose the images that forever will lie in wait to ambush my ambition” (105), for it is from that lot that Lennie hits his greatest homer:

As if in slow-motion newsreel, I watch my follow-through twist me into
the child-muscled grace of a still-unmarked not yet ten-year-old body.

Once again, I feel the rush of pleasure that tells me that my bat has met the

ball. I have hit it well. My left knee kisses the ground in exaggerated triumph as the ball sails out of the lot and high over the rooftops linking one store to another on Bainbridge Avenue in a black sweep of tarpaper. As if it had been caught by God's invisible hand, the ball suddenly seems to halt in midair, like a gull floating on the wind. And then the ball drops like a buzz-bomb onto the large black clock hanging above the liquor store. (106)

Lennie hits the clock – and time stops. In memory, Kriegel finds his pre-polio self frozen in this moment of physical prowess. For Lennie, “hitting the clock on the fly is like hitting the sign at Ebbets Field advertising a men's haberdashery store” (107), and after hitting it, he finds himself wanting “the unending promise of this moment, the feel of my body, coiled like a taut spring, about to leap into a future as intimate as it is to be perfect,” and today, Kriegel admits he still wants it (108).

For Lennie, of course, the promise of the moment goes unfulfilled, when fourteen months later he contracts the polio virus. But the memory alone is enough to fuel Kriegel's imagination, fueling his desire – and, in turn, his writing – for the unlived life. Kriegel writes:

To this day, I still tell myself that if polio hadn't struck me down I would have been the best ballplayer who ever emerged from the Bronx. . . . I never really believed the loose stuff of such fantasies. But I have always believed that memory is the true mother of justice. That being the case, what choice do I have but to hunger

after my own unlived future? Never mind that the pride I take in my prowess masks the complexity of what disease has done to me. I know that the measure of a man's prowess remains in the eye of the beholder. So why expect me to settle for some drab realty when I can still hear the echo of that liquor store owner's, "Another Babe!". . . It's the promise of his words that I choose to believe. And that promise is testimony enough.

(110)

While Kriegel admits that in his late twenties his memory of hitting the clock "embodied a nostalgia so perverse that it threatened to wreck havoc on any chance I had to live a normal life," and later as, "a man of sixty, even baseball begins to grow boring," he questions why men of sixty in America are expected to give up their "remnants of desire" (111). For it is "not vanity but that moment of fulfillment that feeds a man the sense of self he cannot do without," Kriegel explains (113). And though he claims not to seek his pre-crippled self in his recurring memory of hitting the clock, he is still "subject to the pull of [his] unfulfilled ambitions" (113). In hitting the clock, that single moment that stopped time for Lennie, Kriegel seeks the possibilities of a future that was not to be – his unlived life. In his final paragraph of the essay, he describes this relationship between memory and the imagination, an evocative description that captures the essence and purpose of much of his lifewriting:

Yet even if death itself is lurking around the corner, it is memory and imagination, those two tempestuous lovers, who continue to speak to the moment in our lives before we were forced into the actual future. That is

why, over and over again, that image of a boy crouching above a piece of cardboard pressed to earth by a stone returns to memory. It's not his lost prowess that boy is searching for, nor is it for legs still able to do what legs are supposed to do. It's for that single moment that may still be persuaded to carry him into his other past, to bring him home to a life he never lived and let him rest, if only for a brief interlude, in that alternative reality he still hungers for, where the real future waits to be claimed and where all a boy needs to make it his own is the courage to swing and to follow through. (114)

As suggested by this single example from *Flying Solo*, the masculine metaphor, the topic of manhood, shaped Kriegel's work as much when writing this book in his mid-sixties, as it shaped his work in his late twenties, while writing *The Long Walk Home*. Still writing and presenting and publishing his work today in his early seventies, Kriegel maintains these obsessions. In his essay "Superman's Shoulders: On The Healing Power of Illusion,"¹⁹ for instance, Kriegel is inspired by the death of actor Christopher Reeve to reflect on Reeve's quintessential role as the man of steel in Hollywood's series of *Superman* films. Kriegel admits to delighting in Reeve's portrayal of the comic book superhero who once tantalized his imagination as a boy. Kriegel is drawn to Superman as a boy of seven, but after he contracts the polio virus, the superhero comes to mean even more to him as he develops an "unabashed passion" for Superman's shoulders, in much the same way that he comes to love his own strong shoulders that he relied upon to carry him on his crutches: "In the secret alleys of imagination, their strength was as mythic as

Superman's. A cripple learns to love what he needs – a boy with dead legs needs nothing more than strong shoulders" (3).

With aging, however, Kriegel's strong shoulders begin to rebel against him with the pains of arthritis and bursitis, and the death of Christopher Reeve reminds him of his own mortality. But Superman, Kriegel argues, essentially died eight years earlier, when Reeve's spinal cord was crushed in a horse-riding accident: "The fall that made him a cripple made the world's most powerful body an object of pity, transforming the Man of Steel into a creature so frail that it was dependent on machines to breathe and electric chairs to move" (5). When Reeve dies, however, Kriegel writes that his death affected him as no other had in recent memory, not because his beloved Superman was lost forever, but because of what Reeve inspired in him for not accepting his fate, for believing in "the illusion of invincibility:"

. . . he lived his final years trying to come to terms with what every cripple must sooner or later come to terms with – to recognize that determination, courage, and will are simply not enough, that no matter how tough one may be one must still confront the rage of all the humiliations fate imposes on the body, and that even a body of steel can be forced to acknowledge the passive daring that every cripple must claim if he wishes to be independent. (7)

Reeve's "passive daring" was in his belief and public insistence that he would walk again. Kriegel admires Reeve's "insistence that bodily resurrection was a real possibility," and even though Kriegel himself has been crippled since age eleven, he says

he believed Reeve's claim that he would walk again (8). He solutes Reeve's rejection of those in the medical community who encouraged him to give up the illusion of recovery and to embrace rehabilitation efforts instead (8), and he came to view Reeve as a new kind of Superman, one who "assumes defiance for everyone forced to live with a broken body" (10). Part of Reeve's defiance that Kriegel honors is in his refusal to "glory in being crippled for the sake of what is now called 'the handicapped community'" (10). He would not become a spokesperson for this community, and Kriegel explains that "his insistence that he would walk again was mocked [by disability rights activists] which viewed such desires as treason" (13). The handicapped community hoped Superman could help "make being crippled acceptable," but it was not acceptable to Reeve, Kriegel writes: "That he refused to surrender his dream of triumphing over what broke him was his heroism" (13).

In honoring Reeve, Kriegel honors his being "brave enough to resist the world's demand that he behave realistically" (14), and that he held tight to the "healing power of illusion" that Kriegel himself responded to as a crippled boy, fantasizing about running, and that he still responds to now, "still dreaming of hitting a baseball and running through grass and what sand feels like between the toes," understanding, what Reeve did, that it is "more courageous to live with illusion than without it" (14-15). Holding onto his 1940's childhood illusions of masculinity may date Kriegel too much for some of today's readers. His obsession with manhood and masculine imagery remains fascinating nonetheless, especially in light of the different ways that Kriegel returns to these obsessions over and over as he ages and gains new insights into the events of his past and

the cultural moment of post-war masculinity, now long gone. The enduring quality of Kriegel's work lies not in the endurance of these topics and images, however, but how, in Kriegel's hands, these very specific, personal events of his life remind all readers what it is to be human, what it is to suffer human pain. Through Kriegel, we learn, as he does, "how to organize pain into memory, how to give memory voice, and how to speak truthfully of all those losses the heart would carry within itself because of what happened to the body" (*Flying* 7). Reading Kriegel, the disabled and able-bodied, men and women alike find a place in the imagination to deal with pain.

Notes:

¹³ See Lucy Grealy's *Autobiography of a Face*; Natalie Kusz's essay, "Vital Signs;" and David Shields' autobiographically influenced novel, *Dead Languages*, for example.

¹⁴ In her seminal work, *Illness as Metaphor*, Susan Sontag rejects commonly used war metaphors for illness. Sontag's work changed many writers' thinking and writing on illness. Kriegel's memoir, written in 1964, before Sontag's work was published, captures a cultural moment in American medicine – the "be tough, fight for a cure" mentality – that many disability rights activists criticize today as the medical model of disability. Although today's reader may argue that Kriegel's work perpetuates our thinking of illness in ways Sontag thinks is unproductive, we have to remember Kriegel's use of many different masculine metaphors throughout his narrative: the war metaphor is just one of many of his other masculine images.

¹⁵ Prior to World War II, Teddy Roosevelt served as the American ideal of masculinity. In *Cold Warriors*, Suzanne Clarke explains that this ideal was propagated through Roosevelt's own writing which "asserted the value of manliness, nationalism, conservation, and the western experience of strenuous activity in the out of doors together with the more global, imperialist, and capitalist aims made spectacular by the filmed charge up San Juan Hill and inscribed by the construction of the Panama Canal" (67).

¹⁶ Kriegel relies on readers to remember Bogart's 1947 film, *Dark Passage*, which he alludes to here, a film in which Bogart escapes from Alcatraz after being framed for his wife's murder.

¹⁷ Interestingly, some contemporary disability rights activists condemn the Roosevelt administration for the deception they played on the American public by making FDR seem more mobile than he really was. Lennie is clearly not aware of any of this social posturing. He needs the disabled, male role model and is comforted by the fact that the man holds the most powerful position in the nation.

¹⁸ In his essay, "The Body of Imagination," Kriegel also notes other ill and disabled authors for whom he feels the body has become imagination's focus. Illness and/or disability has made or "remade" them as writers (26). He notes and/or briefly discusses, in order, Nancy Mairs, Andre Dubus, Stanley Elkin, Anatole Broyard, Paul Monette, and Harold Brodkey. Kriegel provides a helpful list of suggested readings of these and other authors at the end of his essay, from which I began much of my own study of illness narratives.

¹⁹ This essay is forthcoming in the *Southwest Review* 91:2 (2006). I am using it in advance of publication with permission of the author. The page numbers I refer to are from Kriegel's manuscript draft.

Chapter Three

Leonard Kriegel, Nancy Mairs, Family, and Disability: Writing Beyond the Familial Self

The family, the microcosm into which we're born, inevitably serves as the model for our wider systems of relationships. . . . Those of us who want a genuinely new world order – equitable, inclusive, tolerant, pacific, filled with jokes and festivals – must develop our ideas about family, and our families themselves, in the light of that correlation.

– Nancy Mairs

In *Autobiography of a Face*, Lucy Grealy explains that at age fourteen, having survived cancer in her jaw after a grueling two years of surgeries, radiation, and chemotherapy treatment, she eagerly scans the yellow pages for a horse stable she might work at during the summer. Finding a stable in need of hands, she announces her success to her mother who responds, “Did you tell them about yourself?” (Grealy 6). Grealy admits that it “never occurred to [her] to mention cancer, or [her disfigured] face” to the woman who ran the stable (6). Until that point, she says, “I was “still blissfully unaware, somehow believing that the only reason people stared at me was because my hair was still growing in” (6). Before Grealy has a chance to truly enter society at large, then, her mother suggests that she should be concerned about how others will react to her disfigured face – that she should be ashamed of her disfigurement. Grealy’s mother, in effect, embodies society, voicing the societal message that Grealy herself soon comes to embrace: “I *was* my face. I *was* ugliness” (7). Grealy’s view of herself is constructed, in part, by the American society she lives in. What is especially interesting in her case, however, is that her shame begins at home.

Disability studies theorists make much (and rightly so, I believe) of the concept of

illness and disability being a social construction and argue against the traditional medical or “deficit model” of illness and disability. The medical model, psychology professor Simi Linton and her colleagues explain, has traditionally been accepted by most academic curricula; it conceptualizes illness and disability as problems that “reside in the individual, requiring remediation, treatment, or intervention to amend or compensate for what is perceived as wrong, missing, or dysfunctional” (Linton 5). Under this model, the “meaning accorded to disability is that it is a personal medical condition, rather than a social issue; an individual plight, rather than a political one” (5). In an effort to make the social model of illness and disability the new dominant model, disability studies theorists such as Linton examine the social construction of illness and disability to illuminate the ways in which people with disabilities are “disabled” as much by their culture as by their impairments alone. Linton, for example, examines disability in the academy, offering suggestions for the sciences, arts, and humanities to start reconsidering and reconstructing our ideas about illness and disability in the classroom. Susan Lonsdale, Adrienne Asche, and Michelle Fine, to name just a few, are known for their theoretical work on the social construction of disabled women, and Paul Longmore and Lauri Umansky have written *The New Disability History*, which captures the “experiences of cultural devaluation and socially imposed restrictions” on the disabled throughout American history (Longmore 4).

As evidenced above, much has already been done in the field of disability studies to study the social constructs of the disabled. None of the disability studies theorists I have encountered in my reading, however, have specifically considered literary

depictions of the family's role in the construction of the ill and disabled. As acknowledged above in Lucy Grealy's work, and, as I will discuss in this chapter, in the autobiographical works of Leonard Kriegel and Nancy Mairs, family clearly functions as a microcosm of society, working to build – for better and often worse – ill and disabled family members' sense of self²⁰. Through their work, Kriegel and Mairs illustrate that as disabled persons they have had to acknowledge the extent to which their identities have been constructed by both familial and societal forces. Before this acknowledgment takes place, however, they experience of kind of self-erasure, an incident or series of incidents, through which they submit themselves to the identity-shaping control of others at the expense of expressing their true selves. It is not until both authors recognize the extent to which they have participated in the suppression of their true identities that they are eventually able to regain the power of self-construction and move toward claiming – and writing – their authentic selves.

For Kriegel, the influence of the family first shapes his feelings of guilt over contracting the polio virus and his subsequent paralysis. From his mother and father, he discerns that illness is something to be feared and pitied, and that he is expected to face his ordeal with bravery. While he finds comfort among the temporary family of boys in his rehabilitation hospital, Lennie learns that the bonds of friendship among the disabled are likewise temporary. Back in his family home, Lennie's newly developing sense of self is confused by his family's need to cure him, a confusion that leads to an erasure of his old self and his increased dependency on the family while he accepts their views that he has been chosen to suffer. It is not until Lennie recognizes the negative effects of his

family's influence that he is able to work at reclaiming his body on his own terms through exercise, and later through writing his life.

For Mairs, whom I focus on in more detail in this chapter, as my previous chapters cover Kriegel's work in depth, the process of self-erasure occurs more slowly. While the onset of Kriegel's illness and paralysis is sudden, Mairs is ill with various ailments throughout her childhood and young-adulthood before she develops the symptoms of multiple sclerosis which eventually cripple her. As a child, Mairs is considered difficult and hypersensitive by her family. She becomes self-conscious by her mother's dismissal of her depressive episodes and made to feel that she must suffer alone in her illness. Additionally, Mairs family members seek to repress all difficult emotions within the family, and consider illness as one of the many family secrets to be kept from outsiders. Mairs explains how this repression of feelings within the family leads to her lack of mental and physical well-being, and how the secretive nature of illness in her family causes feelings of shame over her own conditions, which ultimately leads to a dangerous denial of her physical symptoms. Mairs loses her sense of self when she gives up control over her own body and life, first in a mental institution, and later trying to play the traditional role of the good wife and mother that her family and culture expect of her. Like Kriegel, however, she eventually recognizes the ways in which the dynamics of her family have shaped her negative views of herself. Ultimately, she is able to peel away the layers of this familial construction and rebuild herself – and her self-esteem – through her writing.

I. The Familial Gaze and the Erasure of the Self

In much of his autobiographical work, Leonard Kriegel describes in great detail his finally coming to accept his life as a “cripple.” As a boy, however, Kriegel suffers from feelings of guilt over his condition, and he views his battle with polio and his subsequent paralysis as something he has “done” to his family (Kriegel *Long* 13). In *The Long Walk Home*, one of the first trials that Lennie has to face shortly after contracting the polio virus is facing his mother for the first time. He learns, as he watches her frightened figure across the room, that “disease is not a selfish thing,” that, inevitably, his family and friends will feel the effects of his illness (13). Kriegel recalls: “I first read it on my mother’s face, on a day that she entered a child’s room to slice his selfhood in half. I could not fight it, and as she bent over me, her eyes brimming with tears, I yelled, ‘Mamma, I’m sorry.’ She had the unconscious grace to cry. And I cried with her, relieved that I had won forgiveness” (14). In the first hours of his illness, then, Lennie feels from his mother’s initial reaction that in his illness he has become less of a self, in fact half of a self, in her eyes. Next, whether in denial herself, or in an effort to protect Lennie from reality, Sylvia Kriegel informs him that he has contracted polio, but that it was “nothing to worry about,” that he would soon be “fine” (14). It is not until two weeks later, when Lennie is sent on to the rehabilitation home that he learns the connection between polio and infantile paralysis and better discerns the truth about his situation. These early pages of *The Long Walk Home* offer a quick glimpse into the power of the family to influence the identity of the ill and disabled. From his mother’s emotional reaction, Lennie learns that his illness has harmed his mother, and he feels guilty for it. From her verbal response, her eagerness to shield him from the truth of his condition, he learns that his

illness is something to be feared. While Lennie's mother's fears are warranted, they have a negative effect on Lennie's sense of self.

Lennie's mother is not the only one in his family to affect his burgeoning sense of his disabled self, for Lennie feels similarly in his father's presence. In one of the most important moments of the narrative in terms of influencing Lennie's early construction of himself as a patient, his father says, "Be brave. If it should hurt you terrible even, still, you be brave. I don't want that it should, Sonny. Believe me, I don't want it should hurt you. Better it should hurt me, But even if it should, you be brave. That's the way you get better" (17). From this very brief but emotional speech from his father, Lennie fashions a personal response to his illness, that, for better and worse, affects his rehabilitation and recovery, and indeed, the way he views his illness and disability for the rest of his life. At age eleven, he commits to facing his trial "like a man."

Although Lennie bravely faces his paralysis and subsequent rehabilitation in the hospital, he is much less sure of himself when it comes time to face both his family and society outside of the hospital. As the day for Lennie's bar mitzvah approaches, for example, he dreads having to see his friends and family. "I would have to stand before them," Kriegel writes, "before all of them, acknowledging my crime, my guilt, offering a sad imitation of manhood in exchange for the absolution of pity" (111). He imagines his mother, who feels Lennie's illness is a curse against *her*:

sick, bewildered, torn with terror, believing that this polio-shaped child of her time and impatience was God's curse upon her, [and his father] a hard-working, perpetual victim, who had expected something different from me

– a savior for himself, for all the Jews even. And my brother Abe, whose childhood I had cut off when my mother had a series of what the family embarrassingly referred to as “breakdowns” during the first six months of my sickness. Abe would be there, too, and in his eyes I would read the terrible burden of guilt. I was afraid to face the family. . . for the family, like God, was a judge, and it could be just as vindictive, just as enraged, as He was (111).

In the rehabilitation home Lennie had enjoyed the comfort of what sociologist Erving Goffman describes in his groundbreaking work on stigma as “sympathetic others” (Goffman 20). The first set of sympathetic others a stigmatized person can turn to are other individuals who share his stigma (20), Goffman says. Lennie finds sympathetic friends in the home, boys like himself, who fulfill the role Goffman describes by providing Lennie with instruction, moral support, and comfort, and who accept him as a person who really is “like any other normal person” (20). When Lennie first arrives at the rehabilitation home he is pushed through the ward of boys on a stretcher en route to the isolation room. What could have played out as a scene of increased anxiety on top of the already frightening experience he was undergoing, turns out to be an easy initiation to ward life, as he realizes that he is among his own kind. Rather than making a spectacle of Lennie, the boys merely glance up at him “uninterestingly,” Kriegel writes, or silently watch him pass by with “uncurious, staring faces” as he rolls toward the isolation area (Kriegel *Long* 29). After his initial isolation, Lennie makes friends easily with the boys on the ward, comparing symptoms, and learning from them the future course he can

expect his treatment to take while at the home. He is comforted by them and quickly gains a sense of trust in this new, extended family.

Like a well-functioning family, the ward nourishes Lennie. “I fed on its spirit,” Kriegel recalls, and he literally feeds on a full range of “plentiful” foods that are “different from the daily run of juice, cereal, and milk that had been my allotment at home” (39). In fact, Lennie adapts so easily into his new environment that he offers little evidence in the text of his being homesick. Kriegel recalls that after the first four months in the home, he thinks less and less about returning home, aware, he says,

that the experience of the disease had changed me, changed me far more drastically than I could ever hope to understand. It was not, as I say, the expectations of remaining a cripple . . . but something far more meaningful, a sense of immutable destiny that was neither noble nor tragic but that still separated me from that world I came more and more to think of as “the outside” (48).

Already, Lennie senses that he has become “other,” in spite of the fact that his parents visit him often in the home and are supportive of him during his stay there. Indeed, they act as a second set of sympathetic others, even buying Lennie his own wheelchair to help him gain mobility and adapt more quickly to his surroundings.

Lennie’s adaptability to the ward is a sure benefit to him, but it is not without its price, as we can note in the way his experience further coincides with Goffman’s theory of stigmatization. Goffman notes that living

among his own, the stigmatized individual can use his disadvantage as a

basis for organizing life, but he must resign himself to a half-world to do so. Here, he may develop to its fullest his sad talk accounting for his possession of the stigma. . . . On the other hand, he may find that the tales of his fellow sufferers bore him, and that the whole matter of focusing on atrocity tales, on group superiority, on trickster stories, in short, on “the problem,” is one of the large penalties for having one. (Goffman 21)

As Kriegel expresses, for example, he had an innate sense that “hospital friendships are simply the accident of environment, even more than other childhood friendships are” (Kriegel *Long* 46):

For us, friendship was simply the sticky closeness of disease, an alliance born of doubt that spread like a cancer, feeding on the same pressures, the same dreams, envious of whatever existed outside of the ward with the same kind of envy, a sullen vicious alliance that bound us together even while it left each of us to brood on his minor destiny. (46)

Lennie senses that once he leaves the home, his old friendships there will die; he knows his friends will become strangers: “How could the wounded seek out the wounded?” he writes. “Here, we were like the others; there, in the city, we would dread the sight of each other, evading the moment of recognition. For how could we pity each other – we who demand pity from the world?” (119) Thus, Lennie dreads his final release from the hospital on two levels. Not only will he be forced to re-enter the world of judgment and pity, he will lose both the comfort of the hospital and the companionship of the people who understand him best.

Lennie's sense of this change is symbolized when he does return to his family home to discover the freedom he once felt in his wheelchair at the hospital does not extend to life in the Bronx. Away from his crippled friends in rehab, his chair suddenly becomes nothing more than a symbol of disability: "If anything," Kriegel confirms elsewhere, "removed from a world in which everyone had been crippled, I felt the stigma of my situation even more" (*Flying* 95). Lennie yearns to fit back into his role in the Bronx neighborhood as the athletic boy who left it two years before. He is eager "to prove myself worthy of admiration of the 'normal' men and women I saw in my neighborhood," but he soon learns to "despise such conventional desires. But if you hunger after what others assume as a right, you make yourself over in the image of those others – no matter how poorly the suit fits or how twisted the tie's knots" (40).

While Lennie seeks to make himself over in the image of the "normal" people in his neighborhood, it is clear by the response of many of the people in Lennie's life upon his return that they do not understand the kind of progress he had made in terms of managing his disability while in the hospital. Although Lennie is still a few years away from discovering what he'll later describe as his authentic, crippled self, before coming home he had at least accepted that medicine had done all that was possible for him. When he returns home, he finds that his family remains bent on curing him. The first words he hears are his grandmother's. Embracing him, she intones, "You should only be well. . . . Now that you're home you should only be well" (*Long* 127). She trusts that God will help, that "we [not only Lennie, significantly, but the *family*] will rejoice yet" (127). When his brother arrives in the doorway with Lennie's wheelchair, Lennie is suddenly

filled with anger over the device. He swears that he'll never use it again. "If I can't walk, then I'll. . ." he breaks off (127), but his cousin, Leo, fills Lennie's silence, and, like his grandmother, focuses on the future. "You'll walk," he says. "Don't worry, you'll walk" (127). Rather than legitimize Lennie's anger here by embracing it, Leo pushes Lennie to accept his family's belief that somehow he will be cured. Accepting this belief has negative ramifications for Lennie, for as medical sociologist Arthur Frank warns in *At the Will of the Body*, when an ill person is told that all he has to do is focus on getting well, "he is also being told that all he *can* do is be ill," and in American culture especially, Frank remind us, "just being ill has no value" (123).

Undoubtedly, his family's talk of cure confuses Lennie's sense of self. Having once been proud of the progress he had made in rehab, it now, perhaps, seems for naught. While Lennie struggles with this new conflicting sense of himself, he also begins to live under the assumption, along with his family and, indeed, his entire neighborhood, that he has somehow been chosen to suffer. This socially constructed meaning for his disease encourages Lennie to feel that "there was something gallant about suffering, some powder charge of divinity that set me apart from all others. Suffering was the universal leveler, and I had been leveled for the benefit of all" (128). And of all of his family, his mother, throughout his "suffering," maintains the hope that it will lead to a cure – that after Lennie suffers enough, judgment will be lifted from his shoulders and he will walk again. Although Lennie knows that beyond his two years of initial treatment, physical therapy is unable to reach his long-dead nerves, he allows his mother to remain hopeful for a cure. With her constant yearning for a cure, however, she is unable to move beyond

thinking of him as ill, when in fact he has recovered fully to the extent that his body will enable him. And with his mother's emotional impasse on this issue, Lennie, on some level, is also unable to move beyond his illness. Thus, he attends the various additional physical therapy sessions and doctors' appointments his mother sets up for him, where he continues to view himself as a patient (139).

In maintaining this unnecessary role of the patient, Lennie represses the much more self-confident, active, and physically rehabilitated boy who left the hospital, a boy we sensed would soon learn to be independent outside of rehab, as soon as he learned to negotiate the social constructs of his disability. This negotiation is delayed, however, when Lennie allows himself to become more dependent on his mother than he had ever been on the doctors and nurses in the hospital. He senses that his first two years at home cause his mother to suffer even more than his two years of rehabilitation away from home, and as an effect of this perceived suffering, he is willing to capitulate to her needs at the expense of his own sense of self (145). While he was in the hospital, he explains, she never saw him living amongst the able-bodied, but rather against the backdrop of other disabled boys who all maneuvered through their world in their own manner with ease. Once home, however, Kriegel recalls that his mother became "both servant and victim. It was hard, exasperating, tiresome, and although she didn't complain, my guilt fed on each passing day. And yet the only way I could justify myself, the only way I could rid myself of the guilt, was to call on her yet more" (145). In finding additional reasons for needing her, Lennie justifies his needing her at all, but in the process, he loses touch with the independent and capable boy he had become during rehab.

“UNLESS YOU’RE AWFULLY CAREFUL, BODIES GET YOU IN TROUBLE”

Like Leonard Kriegel, Nancy Mairs’ autobiographical works frequently show her family’s changing influence in the construction of her identity. Mairs has been writing for over twenty years about her experiences with depression, agoraphobia, and multiple sclerosis. Although her work shows that her family – first her mother, most specifically, and later her husband and her children – often serves to construct her identity, especially at the onset of her various illnesses, after twenty years of living with MS and her other disorders, and after becoming, through her writing, a voice for the disabled, she is in a better position to not only resist these constructions, but to advocate for more positive, more authentic views of herself.

In her second collection of essays, *Remembering the Bone House*, Mairs returns to the houses of her youth to help her remember the ways in which her childhood and teen years, in addition to her years as a young wife and mother, helped inform the woman she has become. The essays in this collection clearly demark the family’s role in the development of its members, and in Mairs’ case, the construction of herself as a future patient.

In the opening pages of *Remembering the Bone House*, Mairs explains the importance of the family in the creation of the self. How, through the repetition of family stories, our memories begin before we have the capacity for remembering them on our own. “Adults,” she explains, “provide the texts for their pre-reminiscent children. But the children must tease out the subtexts for themselves, without being told, as a rule, even that this task exists, let alone how to go about it” (17). Part of the subtext that Mairs

teases out is that in addition to not being the boy her parents yearned for, she is considered the difficult, hypersensitive child of the family. She is, she explains, the “one who deviates from the family’s most cherished values, which in my case tend toward the Yankee conventions of thrift, diligence, restraint, discretion, modesty, a cheerful though undemonstrative disposition, and, as soon as we’re old enough, a vote for the Republican ticket” (17).

Mairs reflects that much of the difficulty she causes within the family springs from her depressive nature, which she believes is caused, in part, by the early death of her father in a traffic accident when she was age four (Mairs *Ordinary* 51). This death, as expected, has a devastating affect on the family. Mairs’ mother, while grieving, is forced by practical matters to move on quickly, relocating herself and the children from the army base they are living on at the time, back to her Massachusetts home, and going back to work to take care of them. Though her mother is forced to move forward, Mairs’ own development within the family is hindered, crippled, even, by the loss of her father.

Not only does her father’s death cause her grief, it also contributes to her perfectionist tendencies, which, in turn lead to bouts of depression. Being more like her father in appearance than other children in her family, Mairs constantly finds herself compared to him at family gatherings, where the conversation ultimately turns time and again to memories of the happy-go-lucky man they once knew. “If families tend to designate difficult children, they also have golden ones,” she explains. “My daughter will be one of these. My father was another. Beloved throughout his life, he is burnished to perfection in death” (*Remembering* 24). That Mairs resembles her father in looks only

makes life all the more difficult for Mairs:

I am thrilled by this identification, of course, wanting nothing more than to be my father's daughter. But as time goes on, I sense it as a burden, too. My task is to embody all Daddy's excellent qualities so that they won't be lost, with him, from the world. I'm not at all certain I'm equal to this task. But if I'm sulky, or clumsy, or lazy, I'll prove myself an unworthy vessel, and everyone will mourn. At The Port, then [her father's family home in Kennebunkport, Maine], I have to bear myself very, very carefully, as though I were spun from glass. (24)

To complicate matters, Mairs also begins, at an early age, to equate her father with God – they were both in Heaven, after all, and she suspects they both have the same high expectations of her. “Falling short became my greatest dread,” she writes in her collection *Ordinary Lives*, “and, not surprisingly, my most frequent fault” (53).

Mairs places herself under undue strain as a child, trying to live up to her father's image and to perhaps escape the role that has been assigned to her as the “difficult” child. But it is not only the memory of her father that makes her young life difficult for her. She is also more self-conscious, more uneasy about her physical body than the other children around her – a fact that her mother – the next most important influence in her life – dismisses. Mairs recounts one incident in which her younger sister's head struck her hard under her chin while they were bouncing on their bed. “I run howling into Mother's room, certain that the ruin of my body is upon me,” Mairs writes:

She laughs – perhaps the first but certainly not the last time she'll laugh at

what she calls my “dramatics” – and assures me that teeth always fall out of five-year-old children. I stop crying, but a certain uneasiness about my body is never allayed. Later, in the front bedroom overlooking the river, having come down with some sort of aching and queasiness, I lie in the big double bed and memorize the exotic birds on the wallpaper while the others leave on a jaunt, the first of the hundreds, probably thousands, of hours I spend alone, ailing mildly, while the rest of the world goes off for some fun (25).

As suggested above, Mairs learns to suffer in silence – and that her suffering does not register, necessarily, despite her mother’s offering of small comforts, with the rest of the family. Although she is too young to recognize it at the time, in their response to her various ailments, her family is functioning as a microcosm of a society embracing the medical model of illness. They consider Mairs’ complaints her *individual* problem that she is responsible for fixing, rather than focus on issues within the social environment of the family which may be contributing to her lack of well-being.

FAMILY SECRETS: AN ABSCESS GROWS IN SILENCE

In her collection of essays, *Ordinary Time*, Mairs reiterates her mother’s casual response to her emotional outbursts and periods of depression. Since she has always felt close to her mother, Mairs says, “to have her shrug off as ridiculous my declarations of a pain that I came to fear was driving me mad stung me bitterly” (52). By her fifteenth birthday, Mairs’ loneliness is so great, her search for love so desperate, that she notes in her diary that she has asked God to take her life, and for the first time, she says, she

means it. “The rest of my life,” Mairs writes, “would be shaped by these themes: depression, detachment from both human sympathy and life’s meaning; an ecstatic, erotically charged desire for death” (59). Her mother’s refusal to acknowledge her burgeoning depression as a child and young adult certainly confounds her feelings, but Mairs says her mother continues follow a policy of “no emotional rescue” (94), which highlights the family’s refusal to tackle its own dysfunction:

No one comes out and forbids us to talk about our anger or explains what might happen if we did speak, but I have a clear premonition of disaster though no idea what form it might take: desertion? divorce? death? I can’t even get as far as naming it. I just feel in my bones that it lurks behind our submerged furies. In order to ward it off, we have our several outbursts, got over them as best we can, and resume our routines as though nothing had happened. On the whole, this process works and we all remain functional, I suppose because we persist in loving one another despite our differences. But the wounds fester. At least mine do. I can’t speak for anyone else because they’ve never told me. I wind up with emotional absences sealed away under scar tissue which will one day poison the lives of those in the new household I establish: the consequence of refusing permission to speak. (94)

These silences, these repressed feelings and shameful family secrets are a controlling theme in much of Mairs’ autobiographical work. Time and again she provides examples of not being allowed to express her emotions within her family and her belief that the

effect of this repression is crippling: it contributes to her lack of mental and physical well-being. Nonetheless, through her family conditioning, she knows she must not express her feelings. “This is the relation to speech adopted by my family,” she explains:

You may prattle (indeed, should prattle in order to fill silences that might otherwise turn awkward or productive) all you like, but you must not express emotionally troublesome thoughts: fear of losing your mother’s full affection, say, or uneasiness at being forced to live with a stranger, especially a man, even a nice man. By the time of Mother’s marriage, I know well which utterances are permissible and which are not. I have no trouble with the joy I feel at seeing Mother happy in a way new to me, or with my excitement at having a normal family like my friends. I swallow the impermissible bravely, like milk of magnesia, before they quite erupt into my mind. What spews forth is vomit, not forbidden words. (90)

Silence of the family, repressed feelings, she shows, literally make her sick. “The price of this restraint,” she writes, “however, is an emotional absence as a result of which I’ll have trouble recognizing that my words and actions have genuine power to wound” (93). As a child, though, she is unable to make this discovery because she is never allowed to express her natural, hostile thoughts about her loved ones.

Mairs not only learns to absorb her hostile feelings as a child; she also learns that in her family there lies a strict demarcation between what may be aired in public and what must be kept private. One of Mairs’ family’s repressed secrets is the suicide of her maternal grandfather. The event is not talked about at all in the family, his death only

referred to as his having come “to a bad end” (60). Mairs writes that her mother “will finally allow [that he shot] himself to death in the throes of passion for a woman who jilted him and ran off to California. I, too, will turn out to be a suicide,” she says, “Except for this taint, unrecognized until much later in my life, I’ll never feel connected to him at all” (*Remembering* 60). What is significant in Mairs’ brief discussion of her grandfather is her feeling that she has received the “taint” of his suicide in her own suicidal tendencies. Had her family talked openly about his death, she would be less likely to refer to it – and by extension her own suicide attempts – as shameful. What’s more, if her family had not cloaked her grandfather’s death in secrecy, Mairs’ doctors may have been able to diagnose and treat her own depression more accurately and at an earlier age.

Like her grandfather’s suicide, illness and disability in general in Mairs’ family is treated much as it is in society at large: with fear, silence, shame, and misunderstanding. Mairs’ sense of these emotions as a child helps construct her response to her own illnesses and how she expects others to respond to her. Mairs’ paternal grandmother, who she refers to as Garm, has diabetes, for example, and she remembers as a child watching her prepare her insulin each morning, boiling the glass syringe and needle and sucking the insulin into the syringe from the little bottles stored in the refrigerator. Although these preparations were commonplace in their home, Garm, she writes, never allowed anyone to watch her give herself the injection (73). Here, illness again takes on a mysterious, perhaps, shameful aura for Mairs at an early age, which has a direct result of her own handling – her avoidance, actually – of her own depression.

At summer camp when she is nine, for example, while the other children are

enjoying themselves, she writes that she is “so unhappy that, for the first time in my life . . . I think I am going to die” (53). Rather than discuss her homesickness with the camp counselors, however, Mairs keeps her sadness to herself, crying in the latrines and in her cot at night. “How could [the counselors] guess to comfort a child who denies her own sadness?” she writes (54). And Mairs, as much of her writing attests, continues to deny her own sadness for years to come:

I discover that the feelings other people might find unacceptable can be hidden in the same place from which I watch myself and others acting out socially acceptable stories, a kind of cache hollowed out behind my surface self: the Virgin Mary, the Tin Woodman, Nancy. From now on I will bury my inner life deeper and deeper beneath the best imitation of a lively and cooperative child I know how to inscribe. It musn’t be a very good likeness, since people seem increasingly to label me moody, hypersensitive, perfectionist: in a word, difficult. But the semblance strikes me as infinitely preferable to the wretched being secluded within. The dissonance between the person I feel myself and the person I think others perceive me to be grows so sharp that, before many more years, I’ll think myself crazy. (54)

In 1950s, affluent, small town Massachusetts, after all, she writes, “a child here is supposed to be cheerful, robust, sociable, polite, and obedient to elders. She should always look as though she’s having a terrific time. She should always *be* having a terrific time. No long faces here” (111). She cannot tell her mother that she feels like she is going

mad, for in Massachusetts, she says simply, “We do not crack up” (112), and psychopharmacology not being as advanced then as it will later become, Mairs writes that nobody in Enon would have likely been knowledgeable enough to treat her depression as the biochemical imbalance it turns out to be; therefore, the cause of her depression she says “goes unattended for years” (112).

Mairs’ mental state as a child is confounded by feeling betrayed by her body at age thirteen. Her periods become debilitating, inducing “nausea, diarrhea, hemorrhaging, and the kind of pain that sucks the whole world down into itself and sets itself up in the world’s place” (113). The current theory about menstruation at the time, she writes,

holds that menstruation being a natural process, dysmenorrhea is caused not by physiological problems but by a woman’s refusal to accept her own femininity, I’m also stuck with the guilt. If I were a true woman, none of this would be happening to me. The doctor defers my guilt into adulthood when, without doing a pelvic examination, he diagnoses a tipped uterus and says that my cramps will diminish after I have a baby. (115)

Her mother, on the other hand, refers to the whole process, simply as ‘the Curse,’ encouraging Mairs to think of it in the same light (113). But thinking of her difficult periods as a curse encourages Mairs to feel both blame – she must have done something to deserve this – or victimhood – curses, after all, are cast upon one by malevolent outside forces. Eventually, she writes, she stops calling her period “the curse,” unwilling, finally, to “confer power through a name on something already strong enough to throw [her] around like a ragdoll” (115). It is not until she is in her thirties, that she finds a

female gynecologist who concludes, simply, “‘You just have cruddy periods,’ and after that,” she says she is able to see herself as a “victim suddenly redeemed from blame,” and is able to “settle down with my cruddy periods to wait for menopause” (115).

Menopause is a long way off when she is a young adult, however, and what is especially important to note about these years is that before Mairs graduates from high school she already identifies illness as an essential aspect of herself. At this point, she does not have a diagnosis for her various, intermittent symptoms: queasiness, sore throats, trembling hands, abdominal pain, and chronic fatigue that affect her daily life, so these symptoms are not validated as being real, as Mairs notes in her journal at the time:

I drag myself along day after day as though my bones were condensing and transforming, through some improbable alchemy, from porous calcium to solid granite. These I regard as “unreal” symptoms, impermissible to bother others about, just another wearisome outbreak of Nancy’s “dramatics”; and so they are complicated by a sense of alienation, both from others and from my own body, which serves as in instrument not of pleasure but of torture (116).

If she had not been silenced previously by her family, made to feel shame for her complaints, she could have been treated sooner for these ailments, made to feel less alone in her symptoms and not that illness is something that belongs to her alone. Without this support she notes that “by the time I’m feeling continually ill, I’m old enough to believe that illness belongs to my body, as though ‘I’ were somehow separate from that entity and could even, with the correct attitude and discipline, transcend it, by which I mean

ignore it and leave it behind, the way you give the ugly sweater your great-aunt bought you for Christmas to the Salvation Army as soon as you've appeared in it a few times" (117).

Ignoring her body, Mairs denies her symptoms the necessary care that, in hindsight, they obviously warranted. Rather than adjusting her hectic school, church, and social schedule to accommodate her fatigue, for example, she keeps up her hectic pace, until, "fatigue, plainly rooted in this frenzied pace," she writes, "becomes the constant gray undertone of my days but I never accept its authenticity":

I berate myself for it as my shortcoming, my personal failure, a physical frailty setting me apart from others. Neither do I recognize my reclusive nature, which renders the relentless social interaction I have to sustain excruciating, and if I did recognize it, my shame would only flare higher. Mother's tacit disapproval of my wandering off alone hunts me, but precisely because it *is* tacit, I lack words for thinking about the problem" (118).

By this time, she yearns to be alone to read, daydream, and watch television, but these solitary activities are suspect in her family, so that when she does do things alone for and by herself, she feels guilty for these simple pleasures that could have actually given her body the relief it needed.

Mairs' family and society, of course, do not change to allow Mairs the psychological care she obviously needed as a young adult. Ultimately, later as a young wife and mother, she ends up signing herself into the Metropolitan State Hospital in

Waltham, Massachusetts for a standard ten day medical evaluation and stays there for over six months (206). While there, Mairs begins to feel stigmatized because of her depression, especially by her family. Her in laws, for example, do not come and visit her while she is hospitalized, despite the fact that they live close by. “Their shame at my condition intensifies my fear that I have now forfeited my place among the ordinary human lives I fitfully long to rejoin on ‘on the outside’” (206), she notes. Although Mairs knows she needs treatment, she does not see herself as bad off as some of the other patients around her. As a result, she initially resists the medical care she now finds herself under. “I am a mental patient. I do not act; I endure. I receive, but do not participate in, my treatment. When I resist, I am accused of not wanting to get well. No one interprets my resistance as a sign of health” (208). Here, we see the beginning of Mairs’ understanding that she will need to become an advocate for herself, that she will need to fight to reconstruct the socially accepted view of her identity. Part of what Mairs reacts against is the fact that her female psychiatrist never sits her down to discuss her treatment “woman to woman” (209). The chemical imbalance in her brain is never explained to her, nor the fact that this imbalance can be treated, but that her depression will likely recur in the future. Significantly, Mairs adds in *Ordinary Time*, “I was certainly never told that the world held others like me – young intense women terrified of flaw or failure – and because my background set me apart from most of the people confined with me, I didn’t figure it out for myself. . . . And my treatment at Met State aimed at returning me, not so much transformed as resigned, to precisely the context in which I’d cracked up in the first place” (109).

Under this traditional, patriarchal medical model of treatment, then, Mairs endures an erasure of her self: she is expected to allow the physicians to speak for her, to surrender herself fully to their care. While she begins to resist this model, she finds that she prefers not to resist it when she is ultimately sent to a chronic ward for treatment. Like Leonard Kriegel who gives in to his therapists and eventually learns to fall while wearing his leg braces, Mairs is willing to become the “good girl” on the chronic ward, sensing that to act otherwise would not be to her benefit. She takes her medication, attends group and individual therapy sessions, and undergoes twenty-one shock treatments (*Remembering* 210). When her depression eventually begins to abate, she finds she is bored with the drab surroundings of the hospital and ready to return home. She does not leave more knowledgeable about her condition, however; she does not even have a name for it or realize that she will suffer its symptoms for the rest of her life. It is not until she *is* able to find a term through which she is able to construct this aspect of herself that she is able to gain some semblance of control over her attacks. “I am an agoraphobe, I will discover for myself long after Dr. Julian has released me from her healing clutch, and these [symptoms] are called panic attacks,” she explains. “Once I figure that out, I learn to survive them, though I hate them just as much as when I thought they meant I was crazy” (210).

After Mairs leaves the hospital, she gets on with her life, part of which includes having her second child. Having Matthew, however, turns out to be an even more traumatic experience than having her daughter, Anne. Because the infant is jaundiced at birth, Mairs’ physician erroneously informs her that she will not be able to breastfeed him

because he will be allergic to her milk. She is given a shot to dry up her milk without her consent and ends up feeling cheated of the opportunity to bond with the new baby in that way. The experience, indeed, has the most profound effect on her:

Nothing else that happens to me – not my father’s early death, not the nervous breakdown I’ve recently survived or the one that still lies ahead, not the multiple sclerosis that will soon begin crippling my body, not even the melanomas George will develop, giving us the real tank of our mortality – nothing wounds me like this botched pregnancy and childbirth. It acts like the bite of the brown recluse spider, which inflames and necrotizes the flesh until it sloughs away, refusing to heal. It arouses an impermissible grief, one that has – unlike madness illness, death – no social form to contain it. I have never heard another woman utter it. In this sense, I spend the rest of my life in the dark and alone. Matthew’s birth is the only episode in this book that makes me howl as I write it (216).

On top of the violence that she feels has been committed against her by her doctors, Matthew turns out to be a miserable baby who cries inconsolably. She is certain that something is wrong with him, but his pediatricians assure her that since he is gaining weight and thriving, he is fine. When George does not share her concerns she feels the stigma of her time in the mental hospital coming back to haunt her:

“Don’t worry so much,” George replies, in what I’m coming to recognize as his Nancy-spent-six-months-at-Met-State-and-we’ve-got-to-take-that-into-account tone. “Matthew’s just fine.” He’s going to give me the same

line, with the same degree of condescension, in all the years to come. What he means by it is, *I do not (or do not choose to, I'm not sure which) perceive a problem here, and therefore no problem exists. If Nancy perceives a problem where no problem exists, then she's screwed up and may be safely ignored.* He sees in the situation not a conflict to be resolved but evidence of a defect in my maternal character (218).

When the baby gets a little older, Mairs considers going back to work – in part to give herself a break from this child who cries up to eight hours a day. Rather than support Mairs in her choice to pursue work outside the home, her family supports the socially prescribed life-script that, ironically, she once so ardently wished to live by. Her place, she is reminded, by her mother in particular, is in the home. In fact, her mother accuses her of abandoning her children when she expresses her emotional need for more than her family life can provide (*Ordinary* 146). As a result, Mairs writes, “I was haunted throughout their childhood by the conviction that my professional life, which I believed I needed not just for the money but for my sanity, rendered me neglectful and selfish” (147). To assuage this guilt, Mairs remains at home with her children and takes on freelance editorial work. She falls steadily into a depression without realizing the symptoms sneaking up on her. Again, she explains her experience of knowledge being withheld from her in the past that could have helped her here: “No one ever taught me what signs to look for so that I could care for myself responsibly. They probably didn't think I *could* care for myself. They thought only doctors could do it” (*Remembering* 219). Clearly what Mairs recognizes now is that the medical model of care she was once under

may have cured her temporarily, but it did not give her the skills to care for herself. This approach encourages a revolving door system of treatment as necessary, rather than the self sufficiency and self agency Mairs slowly becomes aware that she needs.

II. From Self-erasure to Self-construction

When Lennie Kriegel begins to surmise an air of acceptance at home in regards to his disability, some four years after his return home, he is finally able to let other's hopes for a cure slip away and regain control again over his own body. It is at this time that he partakes in a manic exercise campaign to gain strength in and sculpt his upper body. For the first time he understands that he has been clinging to his mother's belief in the medical model of illness and disability that continually feeds her hopes for a cure. She is, in fact, frightened by Lennie's excessive exercising and the anger driving Lennie during his exercise routines, and she pleads with him to eat more and exercise less (Kriegel *Long* 156). "This," Kriegel says, "was not her idea of getting better. You got better by listening to doctors. You got better with God's help" (156). She sees Lennie's exercise as yet another plot against her, another curse that she is meant to suffer (156). This time, Lennie is unwilling to put his search for an authentic self on hold for her sake. He is through with being a patient, and he angrily orders her from room when she interrupts him. "'Get out of this room!'" he commands her, "'You hear me! Get the hell out of this room!'" (156) for he "had enough hatred in [him] to withstand her and [his] father and anyone or anything else that tried to stand in [his] way" (157). In ordering his mother from his room, Lennie takes an important step toward taking control over the construction of his identity as a cripple. While he is hurtful toward his mother in these

scenes, they mark a necessary moment in his maturation. I have fully examined Lennie's personal development from this point on in his life in my previous two chapters, describing Kriegel's own acceptance of his disability and his struggle for authenticity in both his life and writing. In this chapter focusing on the family, however, it is relevant to note that while Kriegel has successfully negotiated the reconstruction of his crippled-self on his own terms, he has never stopped considering the role of family in his life and how it continues to shape his understanding of his life.

In his latest collection, *Flying Solo*, for example, Kriegel acknowledges that not only has his family played a role in the construction of his disabled self, his disability has played an essential role in constructing *them*, and in particular, his brother, Abe. Although Kriegel notes briefly how Lennie feels guilty for the ways in which his illness causes his brother Abe's childhood to be cut short as much as it has his own, Abe is mentioned infrequently in *The Long Walk Home*. The boys are shown only once in conversation, and the only time we recall Abe's presence is when Lennie is watching him play stickball down in the street outside his bedroom window. The one scene in which the boys are shown alone together is when Lennie enlists Abe's help in his plans to swim across a lake. As noted in my previous chapter, the scene represents Lennie's end of adolescence as he dives into the water to be reborn into his new sense of himself as a man. As he slips in to the water, Lennie feels his brother's apprehension and happiness for him, and he feels closer to him in this moment than he has in all the years since his return home. Kriegel recalls, "I thought of the last time when I had been this close to him in doing something, when the stick met the ball and his wrists and mine fused in a wish

that was like death to me now,” but his thoughts do not linger on Abe as he turns his focus back to his body and swimming to the shore (163).

Although his brother Abe does not play any other significant roles in Lennie’s adventure in *The Long Walk Home*, Kriegel does return to the topic of his brother in his essay, “Fathers, Sons, Brothers, Strangers: A Meditation on Courage, Memory, and Belonging.” Here, Kriegel writes that it is in contemplating his brother’s life that his truest self is revealed, for “to see one’s brother is to see oneself anew, alone in the nerve-jangling funhouse of imagination’s eye” (*Flying* 174). Kriegel writes that he feels his brother’s sense of injustice over the polio that crippled him but also cut his own childhood short (175). Just as Lennie was constructed by his family’s response to his illness and disability, so, too, does Lennie’s illness and disability construct his brother’s. While much of his essay describes what Kriegel *imagines* his brother feels about him, it is suggested at the start of the essay that the two men have discussed the ways in which Lennie’s illness interrupted their respective childhoods. “Through the telephone wires,” Kriegel writes, “the sullen imperatives of Abe’s accusations demand recognition. He wants an older brother ready to acknowledge that *his* life was forced to accommodate itself to *my* illness” (175). Giving Abe the acknowledgement he needs proves difficult for Kriegel, despite the fact that he feels his brother’s rage “hammer down” on him, even if only in his imagination (175). As Abe talks about his own lost childhood and adolescence, Kriegel admits that he retreats further in to feelings of resentment over his own losses. Even in his “imaginary confrontations” with him, all he can do is listen in silence, “proof enough that deep down,” he says, “I believe he is right” (176). And to

“acknowledge a blood brother’s rage is to acknowledge the most powerful of links. Disease *is* a sharing” (176). In accepting this unbreakable bond, Kriegel opens his mind and heart to new ways of looking at himself. “I listen to my brother unfold his version of my life,” Kriegel writes, and in doing so, Kriegel’s insular self becomes less singular, his cripple-hero less heroic, as he imagines himself reconstructed in his brother’s eyes:

In imagination, I am condemned to listen to his words as they sting my flesh like pellets from a BB gun. I must look at the self my brother sees, in that landscape which, even as it grows distant, defines the man each of us has become. Only this time my search is not for what of myself I see back there. It is for what of my brother was left back there with me. (177)

On this journey into the past, Kriegel recognizes that both he and Abe are not only brothers, but men trying to understand the forces that have shaped them (177). Both men understand that the past is their own to interpret, but Kriegel senses that his illness still affects his brother’s feelings. Recognizing these feelings, whether real or imagined, informs Kriegel’s writing, where he reflects on his life and strives to “balance it out” in his effort to “stand as a man” (191).

Like Kriegel, Mairs, in recognizing both familial and social construction of her disability, is ultimately able to sift through the layers of this formation to discover a more authentic sense of self. One way, of course, that Mairs has discovered this more authentic self is by breaking the silence of the body, and the disabled body in particular, in her writing. Despite her family’s need for privacy, she tells the story of her body and of how her family helped – for better or for worse – to shape it. As illustrated above, her family’s

repressed emotions certainly exacerbated her inner turmoil. In addition to these emotionally driven silences, her family also suppressed talk about the body – especially bodies in trouble. The effect of this additional suppressed layer of talk within the family is to increase Mairs’ feelings of shame about her own ailing body, both while still living with her family as a young adult, and also later in her life when she is diagnosed with multiple sclerosis.

At age twenty-nine, Mairs moves to Tucson, Arizona, to begin graduate school. Soon after, she begins to experience the first symptoms (dropping things, stumbling over things, suddenly developing a limp) of what – after being incorrectly diagnosed as a brain tumor – is later diagnosed as multiple sclerosis. Told she may have a brain tumor, Mairs approaches her new illness differently than she has dealt with her depression in the past. Grown suspicious of the medical model of care that has encouraged blissful ignorance about her body’s ailments, she is finally determined to arm herself with information before handing herself over to the care of others (233): “I once trusted an obstetrician and a pediatrician too much and the damage to my soul has never healed,” she says, recalling the trauma she suffered after the birth of her son. “This time, I want to participate, and if necessary to balk, every step of the way” (233).

Once Mairs has her diagnosis – chronic and progressive, degenerative multiple sclerosis – she is relieved to “have *something*, something real, not a nameless mystery” (234). Later, when she takes on the role of teaching medical students how to give neurological exams to MS patients, she will stress that they not try to protect their patients from the knowledge of their disease (as her own doctor at first tries to protect

her), but to tell them their diagnosis and prognosis (234). With the knowledge of her disorder, Mairs begins to approach her body differently:

Now I am who I will be. A body in trouble. I've spent all these years trying alternately to repudiate and to control my wayward body, to transcend it one way or another, but MS rammed me right back down into it. "The body," I've gotten into the habit of calling it. "The left eye is weak," I say. "There's a blurred spot in the right eye." As though it were some other entity, remote and traitorous. Or worse, as though it were inanimate, a prison of bone, the dark tower around which Childe Roland rode, withershins left, withershins right, seeking to free the fair kidnapped princess: me. My favorite fairy tale as a child turns out to have nothing to offer my adulthood. Rescue from the body is merely another word for death. Slowly, slowly, MS will teach me to live on as a body (235).

When Leonard Kriegel throws himself into his manic exercise routine to sculpt his upper body and make himself a man among men, he ultimately discovers, that despite his greatly increased strength, a cripple among men he remains. Nonetheless, while his family pushes for a cure, he is ready to live, as a body, in the body he has. Mairs' similar epiphany has the same emotionally freeing effect on her as Kriegel's has for him, but similar to Kriegel, she must learn that despite her newly defined sense of self, others will continue to construct her – and affect her new view of herself – as they will. Consider, for example, her children's role in affecting Mairs' feelings about herself. Living in a house that becomes too difficult for her to manage as her MS symptoms increase, Mairs finds

that her children, older now, come to see her as “the Big Meanie,” the one who sets their curfews and makes them do dishes – the “parent who has to be wrong, no matter what I do. . . . In the process, they’re creating me, and I hate who they need me to be” (250), she writes. As if being the Big Meanie is not troublesome enough, Mairs also feels as guilty about being home with her children as she once was made to feel guilty for considering working outside the home and away from them. After her MS became disabling, she says that she often felt guilty about her role in her children’s lives,

as though my condition automatically transformed me into a bad wife and mother, as though my presence among them could bring them only deprivation and misery. And, to be honest with you, I think I really have made them feel deprived and miserable at times, more times than I would wish. But I might have done so even without MS. People who live for a long time together bound closely by love, inevitably disappoint and hurt, as well as gratify and please one another (*Carnal* 126).

Mairs recalls one incident in which the family went to a scheduled family counseling session without her one day because she was ill. At the session, they spent the time complaining about the problems her MS caused (126). When she heard about the session, she of course feels like a scapegoat, that her “MS may have simply served, more often than not, as a handy hook to hang our disappointments on,” (126), but even this she has come to understand: “When my family projected their bad feelings, and the helplessness they felt to understand or stop those feelings, onto my MS, they were providing themselves some much-needed focus. Here was something real, clear, definite, something

they hated, something they could struggle with and defy and perhaps even come to terms with one day” (126).

Eventually, lest her own new sense of self as *a body* be completely subsumed by her family’s antagonistic views of her, Mairs resists further erasure of her self by finding a place to escape to. She rents a studio apartment, to gain some independence from her family during the day and to have a place to write (*Remembering* 250). Around this time, a tumultuous extramarital affair she is having comes to an abrupt end and she finds herself slipping into another depression. “The fact that I’m having a breakdown strikes me abruptly and with perfect clarity. I go on having the breakdown anyway. Knowledge is no proof against certain kinds of disaster. Maybe most kinds. Part of me knows I am ill; another part sneers incredulously, accusing me, (in Mother’s long familiar words) of dramatics” (252). Despite the strides she has made in taking responsibility for her MS, her acceptance of herself as a “body in trouble” does not seem to extend to her mental health. She can not get past the damaging familial construction of herself as oversensitive. While one part of herself knows she is ill and propels her to seek medical attention from her neurologist and psychotherapist, another part remains wary of such help, wary of being pulled out from the urge of wanting to kill herself (252). After meeting with her lover, who assures her that their relationship is over, Mairs takes an overdose of Elavil. When George calls her at the apartment later that night, she is still lucid enough to tell him that she has taken the pills, but she barely has the energy to unlock the door for him to come over and save her. It seems, after all, that her favorite fairy tale does have something to offer her adult life. Despite her arguments to the

contrary, she has slipped into the role of the damsel in distress, the body in need of saving. MS, then, having perhaps taught her to learn *how* to live as a body, as she says, has not likewise taught her to *want* to live. And when George, her own Childe Roland, does arrive to save her, he does not swoon with relief that he has reached her in time. Rather, he is openly furious with her for not telling him she was again in the grips of a depression (253). The fair maiden, it seems, despite her upbringing in an environment of denied emotions, is still expected to know better.

At the hospital she receives a massive dose of antidepressants that “blasted me out of my depression in a kind of shortcut to normalcy” (254). When she returns to her normal routine, she is able to put her failed love affair behind her, and she begins to write stories, poems, and essays at an increased pace. Ultimately, she writes her way toward healing. Her writings, she says, “are carnal acts, enabling me to inscribe the earthly life I’ve tried to flee: its tricks, its sweet poisons. They dis-enchant me. I’m awake. And I will write my self into well-being” (245). Mairs’ discovery of a new passion for language gives her confidence to exert herself at home. When she gives up her apartment and returns home after her suicide attempt, she demands to have a space of her own where she can continue to write and find peace within the busy household. The household complies, but just over a year later, George announces that he wants to leave her. George is leaving, in part, because he finds her difficult, a label, she at one time accepts, but now questions, unwilling now to play the “Big Meanie” role that the family has constructed for her, in part, because of her illness (258). Her unwillingness to play the role, however, does not deflate her family’s need to continue to cast her in it. For the first time, though,

Mairs seems to have the strength of mind to question it. She confesses:

When I mention to Anne that her father finds me difficult, she sighs explosively: “Don’t we all!” They do, they do, and the family counselor we’ve started to consult falls right in with them. Of course I take their word for it. What else can I do? A woman with a crippling disease who runs away from home and tries to kill herself is unquestionably hard to deal with. But maybe, it occurs to me in a rush, I don’t have to be all that difficult. Maybe their treatment of me, and Mother’s before them, has thrown me in to that architectural position, and I’ve been fool enough to occupy it all these years because it’s what everybody, including me, expected (259).

Despite this pivotal moment in her understanding of the ways that others have sought to construct her over the years, and her own compliance in becoming the person they have anticipated, Mairs concedes that if she really is so difficult to live with, no one should be forced to live with her. Likewise, however, she argues that she should not “have to live with people who assume that I’m a madwoman, a bitch, a problem – the lexicon varies depending on the speaker but the message remains the same. People who demand that I play those roles. Who treat me as though I’m playing them both when I am and when I’m not” (260).

When George actually decides not to leave the family, Mairs says it is perhaps because he really is the saint a reviewer noted him to be.²¹ She has after all, she says, worked to construct that image as much as he has worked to construct her own. “I have

consistently presented him as a saint, sharing the construction of this fiction with him, his parents, my parents, my siblings, our children, our friends, and eventually my readers” (260). While on the one hand she suspects that George stays because he sees himself as the only one capable of holding things together, on the other, despising herself, she says, “I’ve grown convinced along with everyone else that only a saint could bear life with me” (260). Though she has grown stronger in her sense of self, these sentiments clearly suggest that the strides she has made at this point are tentative. Somewhere inside the woman who feels tainted, shamed by her grandfather’s suicide, still remains.

When Mairs turns forty her first book of poems, *All the Rooms of the Yellow House* wins the Western States Book Award and is published, and her essays collected in her University of Arizona doctoral dissertation, *Plaintext* are published two years later. That she has finally succeeded as a writer lightens her heart and mood, but it can not contend with the problems within the family. As her daughter leaves for college around this time, Mairs is left to deal with her emotionally distant, punk rock son, who she says steals, lies, and despises her and George. George, however, sides with the boy, calling Mairs bitchy for getting angry with the teenager. Mairs is eager to run away from the situation. “If I stay,” she writes, “I have to continue to operate, as the family always has, in the teeth of the premise that I’m a crazy bitch whose unreasonable demands and desires must be gotten around as best as anyone can, because George’s reality depends on this premise” (264). Her psychotherapist encourages her to not allow the others to drive her from her home, and she stays until, two years later, she has the opportunity to accept a renewable lectureship at University of California, Los Angeles. She arranges with

George that if the position works out for her he will follow later (265). The day after arriving in Los Angeles, Mairs trips in the parking garage elevator at her apartment building and breaks an artery above her left eye. Thus battered and bruised, she begins her teaching position at UCLA, relying on an electric wheelchair, which she has begun to use more frequently, to zip around in her surroundings. For the first time in a long time, she starts to feel better about herself. After six months in LA she begins to regard herself not as a crazy woman, but simply a woman alone (267). And she has time to reflect on her family life in Tucson. “Then,” she writes, “I was scrambling as fast as I could away from the stifle of domestic life: the way it seemed to cramp my creativity and deaden my sexuality. I thought I would die of suffocation. Now I sense that I was really scrambling out from under the projections of others” (267); finally, she begins to sense that no matter what, “all that happens can be accepted, incorporated, celebrated” in her life (267). In LA she proves that she is capable of taking care of herself, despite her failing body, but she also finds that she misses the support and company of home. After coming into enough money to live on while she writes her next book, she decides to return home to George and become a full time writer. Her writing continues to get published and she is asked to speak at the National Multiple Sclerosis Society in Seattle, an experience which encourages her to feel “like somebody” (270)²².

In gaining this sense of becoming *somebody*, Mairs becomes more adept at understanding and critiquing how this *body* has been socially constructed. As I have shown above, she is acutely aware of the ways her family informs her identity from inside the microcosm; she also recognizes how people outside of her family make

assumptions not only about her own, but also about her family's identity as a result of her MS. More specifically, she reflects on the views of those in the "helping" professions: doctors, nurses, physical therapists, psychiatrists, etc. "These people," she notes, "are generally physically fit themselves, and they seldom live with people who are chronically ill. Moreover, they have been trained to search out, diagnose, *and then relieve or cure* problems. Thus when they encounter a person with MS, and often that person's family, they immediately assume that this cluster of people is in trouble and that "being in trouble" is always a bad way to be" (*Carnal* 121). After living with MS for seventeen years at the time of writing her essay, "Good Enough Gifts," Mairs concludes that "the assumption that MS is bad for the family ignores the possibility that MS may also be, in a variety of ways, good for the family; and the helper who tries to intervene in the family's dynamics, assuming they must be 'sick' in some way, risks damaging whatever wholesome processes may be going on" (121).

This more positive view of her illnesses and disability is indicative of the tone of her essays collected in *Carnal Acts*. In this work she works to reconstruct the negative view of her disability and decides to stop focusing on the difficulties of living with MS in her work. "There's nothing anyone can do to make it go away," she says, so "I'm going to stop talking about how bad it is" (121). At the same time, she says she is going to strive to reject the conventional family narratives that we in American society accept as the norm, the narrative we see in movies and television (*Leave it to Beaver*, *Family Ties*, and *The Cosby Show* are her examples) which, week after week, present a new problem that "in no more than half an hour's time, with the affectionate and good-humored

support of the other family members, resolves to problem to everyone's satisfaction" (122). None of these shows "depict the same problem week after week after week after week," she writes, none of them depict the difficulties of living with MS, where "the problem doesn't change week to week, it never gets resolved, and you can't even switch the channel when you're bored" (123). And because of this, Mairs thinks it all the more important to eschew the messages of these shows. "It is difficult, I think, to reject these conventional narratives, which we have learned by hear, which comfort us with their predictability. But if we want to lead authentically healthy lives, we have to let them go" (123). Mairs urges others with chronic illness to reject the narrative norm and accept that "the important point about the stories we tell ourselves about our lives: We make them up as we go along You may choose to view your life as the saddest story ever told and yourself – whether you have MS or love someone who has MS – as a tragic figure in its center," but "most people who live with MS are looking for ways to spin out tales about love and strength and accomplishment" (125). Many of these tales, Mairs shows, emerge out of the family, a family not in entirely as much trouble because of her MS as others would assume. While her family experiences pain, Mairs notes that in her work and in her life she tries to "*normalize* that pain, making it seem not rare and tragic but natural and manageable" (125). After all, she says, "the presence of pain in a family doesn't have to mean that the family's in trouble, disintegrating under the pressures of living with chronic illness, ready to fall apart at any moment. That's one possible story. But there are plenty of others" (125).

The story Mairs commits to telling is the one about the advantages living with

chronic illness has afforded her family: first, she says, is coherence. In a culture where many family members are living their very separate lives, split between work and school and extracurricular activities, the MS family has at least one concern in common: illness, and this concern helps the family cohere in a kind of “sharing of affliction,” she argues (130). This sharing, Mairs believes, does not have to have the effect of crippling the family; it often can create bonds that make the family stronger (131). Her MS has also created tolerance within her family, she says. Unlike her experiences as a child, in part, this tolerance has allowed her own family to “accept the presence of troublesome feelings as normal to our human being. Even more important, however, we can learn to tolerate the presence of adversity in our lives,” and “together with coherence and tolerance, the family with MS can learn responsibility for their own well-being” (132). And it is with these lessons in hand that Mairs encourages us to take a different view of the calamities that befall our lives. “Since we get to choose how to interpret the events that befall us,” she writes, “why not look on them as gifts?” (133).

Of course, Mairs has come a long way from accepting the familial construction of herself as a difficult, hypersensitive child, to being able to *interpret* her own life and look at her illness as a gift. Indeed, we might suspect this stance of smacking for New Age hocus pocus, if Mairs had not done the work of proving her ability to interpret her life through her writing. And *this*, her writing, is the gift she both gives and receives. In finally having the opportunity to express herself freely to others, she comes to recognize her self: “I am *somebody*,” she writes. “A body. A difficult body, to be sure, almost too weak now to stand, increasingly deformed, wracked still by gut spasms and headaches

and menstrual miseries. But some *body*. Mine. Me. In establishing myself as a writer, however modest my success, I have ceased to be *nobody*. I have written my way into my embodied self, and here I am at home” (*Remembering* 271).

Reading their bodies as inscribed by the family, both Leonard Kriegel and Nancy Mairs provide a microcosmic view of the social construction of illness and disability. Their insistence on examining their own development constructed, in part, by others, serves as a counternarrative to the medical model of illness and disability that seeks to isolate their development within their impairments alone. “Disability,” Tobin Siebers writes, can be viewed as “the effect of an environment, hostile to some bodies but not to others, requiring advances in social justice rather than medicine” (Siebers 738). In the works of Kriegel and Mairs, the environment which frequently affects them is a familial one, and the justice sought is the power to uncover the familial scripts and rewrite their authentic embodied selves.

Notes:

²⁰ While I will be pointing out a number of negative influences of Kriegel and Mairs’ families (as Kriegel and Mairs represent them, of course), I in no way mean to suggest that their families’ influences are entirely negative, nor that all families of other ill or disabled people are portrayed similarly in literature. Indeed, a number of illness/disability narratives have emerged that depict the family in the role of social advocate for the ill and disabled, especially narratives in which the parent/author is representing an ill or disabled child in his or her work. The most notable of these is literary critic Michael Bérubé’s *Life as We Know It: A Father, A Family, and an Exceptional Child*.

²¹ She does not name him here, but it is Nicholas Christopher, whom I cite in my introduction.

²² I emailed Mairs in March 2006 to inquire about what work she presented at this gathering. She replied that she could not recall what she read specifically, but that it was probably something from *Carnal Acts*, which she was working on at the time.

Chapter Four

Ain't I *Still* a Woman?: Feminism, Sexuality, and the Disabled Woman in the Works of Nancy Mairs

*One simply cannot **be** without being a body.* –Nancy Mairs

The status of untouchable is a very unreal and lonely one, although it does keep everyone at arm's length and protects as it insulates. But you can die of that specialness, of the cold, the isolation. It does not serve living. –Audre Lorde

In *Ain't I a Woman: Black Women and Feminism*, bell hooks explains that African American women “were disappointed and disillusioned when [they] discovered that white women in the [feminist] movement had little knowledge of or concern for the problems of lower class and poor women or the particular problems of non-white women from all classes” (188). In much the same way that black feminists felt ignored by white feminists in the 1960's, disabled women have frequently reported feeling invisible within the feminist movement, in part, because they are often considered asexual.

Sociologist Rannveig Traustadóttir at the University of Iceland has conducted extensive research in disability and its affects on women's lives in particular. In the online source *Women with Disabilities: Issues, Resources, Connections Revised*, she summarizes disabled feminists' grievances with the feminist movement at large. First, disabled feminists find that their experiences have been excluded from feminist scholarship. While feminist analysis has sought to be inclusive in terms of race, class, and sexual orientation, women with disabilities remained overlooked, as late as the mid 1980's, despite calls for more scholarship in this area.²³

In addition to feeling as though their physical presence has been overlooked,

disabled women feel that their own writing or other published writings about them have also received scant attention from feminist scholars; “...instead [feminist scholars] have joined men in relegating women with disabilities to a realm beneath their intellectual and political ken” (Asch and Fine quoted in Traustadóttir). Evidence of this stance is suggested by the simple lack of accessibility disabled women encounter in their efforts to participate in feminist meetings and conferences, typically held, P. Israel has reported, in inaccessible places (cited in Traustadóttir)²⁴. Not only are these meetings inaccessible to women with mobility impairments, blind and deaf women also feel shut out from their proceedings as conference materials are usually only offered in print, and sign language interpretation is usually not available.

Ignoring the physical needs of disabled women at their conferences is indicative of many feminist groups’ lack of interest in other general issues specifically faced by women with disabilities.²⁵ Women with disabilities might be viewed as in special need of support from the women’s movement, as they are often seen, as Traustadóttir notes, as reinforcing traditional stereotypes that depict women as “helpless, childlike, dependent, needy, victimized, and passive.” Ironically, however, it is this widely accepted view of women with disabilities which discourages the feminist movement from embracing them. As Asch and Fine suggest, “...non-disabled feminists have severed [disabled women] from the sisterhood in an effort to advance more powerful, competent, and appealing female icons” (quoted in Traustadóttir). Viewed as weak and incompetent – both physically and intellectually by American society – disabled women do not depict the images of strength the feminist movement seeks to portray. This view is unfortunate, for

as scholar Kristin Lindgren argues, “a focus on the body in trouble can contribute to the feminist project of revaluing bodily experience and to the development of more nuanced and inclusive theories of the body” (Lindgren 147).

Until more inclusive theories of the body *are* commonly accepted, the notion that the disabled are weak and childlike will continue to encourage the American public’s widely documented belief that women (and men) with disabilities are asexual.²⁶ In fact, Nancy Mairs writes, “the sexuality of the disabled so repulses most people that you can hardly get a doctor, let alone a member of the general population, to consider the issues it raises. Cripples simply aren’t supposed to Want It, much less Do It” (Mairs *Carnal* 90). This stance has severe social ramifications. As Traustadóttir explains, information about birth control, sexual relations, and childbearing is often not passed along to women with disabilities because they are not viewed as sexually active. The fact is, however, that many women with disabilities have criticized not only the feminist movement but also the disability rights movement for not “addressing sexuality as a political issue similar to housing and transportation. For example, Waxman claims that many people with disabilities consider sexuality to be the area of greatest oppression: ‘We are more concerned with being loved and finding sexual fulfillment than getting on a bus’”(quoted in Traustadóttir).

In her essay, “Integrating Disability, Transforming Feminist Theory,” Rosemarie Garland Thomson laments this fact that many disability scholars are unaware of feminist theory, and many feminist theorists are not familiar with disability studies (Thomson 74). Thomson argues that integrating disability as a category of analysis in feminist studies

can deepen, expand, and challenge feminist theory (75), and she defines the ways in which feminist disability theory “engages several of the fundamental premises of critical theory,” namely, the ideas

(a) that representation structures reality, (b) that the margins define the center, (c) that gender (or disability) is a way of signifying relationships of power, (d) that human identity is multiple and unstable, (e) that all analysis and evaluation have political implications. (77)

To elaborate on these basic premises, Thomson structures her essay around four “fundamental and interpenetrating domains of feminist theory and suggests some of the kinds of critical inquiries that considering disability can generate within these theoretical arenas. These domains are: (a) representation, (b) the body, (c) identity, and (d) activism” (77). I borrow loosely from Thomson’s structure for this chapter and refer to her ideas to show how the study of disabled women’s autobiographical works, and the study of the work of Nancy Mairs in particular, can answer Thomson’s call to deepen, expand, and challenge feminist theory and in turn help make disabled women more visible within the feminist movement.²⁷

Disabled women’s autobiographies, their memoirs, their personal essays, all written from the point of view of singular (though not singularly constructed) selves, powerfully provide the intimate and immediate details of their lives in ways that the findings of researchers, presented as scholarly articles within their fields, traditionally do not. Additionally, while sociological research most often speaks of and for the community, the disabled woman’s autobiographical essays speak of and for the various

aspects of her dynamic self. And it is this rendering of her very specific, individual experiences that prove that her philosophies are shaped by more than her disabilities, and by more than her acceptance or rejection of feminism, a message that both women's and disability rights movements might make better use of. Finally, it is this message, this self-representation of the individual, singular self that helps make the disabled woman writer not only visible within feminist movements, but in the eyes of the American public.

Nancy Mairs, as I have shown in the previous chapter, focuses on the intimate, daily pulse of living her life with agoraphobia, depression, and multiple sclerosis. In addition to unearthing the varied ways she has been constructed by others in her role as a disabled American woman, much of Mairs' work pushes readers to accept what sociologists already know – that ill and disabled women, despite their illnesses and disabilities, are *still* sexual beings. My examination of Mairs' work for this chapter shows how Mairs works to counter the American cultural assumption that ill and disabled women are asexual, one-dimensional, or otherwise less than functional human beings. In particular, I examine Mairs' representation of herself through her writing, the relationship between her body and her identity and how she negotiates this relationship in light of the shifting balance of power within her marriage, and, finally, the activist implications of Mairs' work when facilitated by others in an academic setting.

I. Breaking the Silence, Representing the Self

In discussing the ways in which disability functions concurrently with other systems of representation, Thomson convincingly argues that since Aristotle – who, she reminds us, considered women “mutilated males” – Western thought has “long conflated

femaleness and disability, understanding both as defective departures from a valued standard” – able-bodied maleness (78). Indeed, Thomson reiterates, Western culture has made a habit of adopting the “language of deficiency and abnormality” to devalue women in particular, and to represent women, the disabled, and people of color as “dependent, incomplete, vulnerable, and incompetent” (79). Nancy Mairs, however, refuses to allow this kind of cultural representation to structure the reality of her life. She fights against the devaluation of women in her work by first exposing the discrimination she has encountered in her own life. She refuses the efforts of others to devalue her by writing about herself, by making her life experiences visible in a culture that assumes her life is without meaning, and in turn, she contributes to the growing American discourse on disability and the body.

In 1987 Mairs had an opportunity to express her concerns over the representation of disabled women to a broad American audience when she was invited by the *New York Times* to write a short series of “Hers' Columns.” It was at this time in her life that Mairs made the shift from writing fiction to writing essays full time.²⁸ Collected in *Carnal Acts*, the first of Mairs’ “Hers’ Columns” describes her search for representations of herself – a forty-three-year-old, crippled woman – in the American media, especially film, television, and advertising (31). After this particular column originally ran in the *Times* in 1987, one reader wrote to the paper to praise Mairs’ handling of the topic, agreeing with her assessment that depicting the handicapped in television commercials would “go a long way toward validating the very existence of the disabled” (Mayer C9). Not surprisingly, Mairs did not discover the validation she was searching for. During her

research, what she finds is one television movie in which the heroine, diagnosed with MS, falls in love with her handsome doctor who discourages her from taking the trip of a lifetime to Kenya. “Capitulation into the arms of a man who uses his medical powers to strip one of even the urge toward independence is hardly the sort of representation I had in mind” (Mairs *Carnal* 32), she laments. Likewise, she explains, in the popular film version of the play, *Children of A Lesser God*, Mairs finds that disability is taken as the major premise of the work, but the film excludes the “complexities that round out a character and make her whole. It’s not about a woman who happens to be physically disabled; it’s about physical disability as the determining factor of a woman’s existence” (32). Also considering the lack of representation of the disabled in commercials, Mairs concludes that advertisers have chosen to “deny the existence of me and my kind absolutely,” despite the fact that she views herself as a Great American Consumer (33). In a later essay published in the *Nation*, Mairs concludes:

the mediated picture of disabled life is so untrue to life’s realities as to encourage the view that people with disabilities constitute sores on the social body to be eradicated rather than the wens and freckles to which any flesh is heir. To counteract such a view requires voices – linguistically sophisticated, intellectually nuanced and politically astute – capable of articulating the issues raised by the full inclusion of people with disabilities in society. (“On Being Fair” 30)

Mairs’ essays offer American culture one of these voices. But Mairs’ efforts to represent disabled experience more truthfully than the media do not proceed unhindered. Before –

or at least while in the midst of – giving us the intimate details of her life as an ill and disabled woman, Mairs must eschew the familial and societal taboos which forbid or devalue her autobiographical project. As I have previously noted in chapters three and four, Mairs’ own family remained guarded against public exhibition of their private lives during Mairs’ childhood. In addition, Mairs’ mother discouraged the expression of emotions that were anything but joyous. Even – or especially – after Mairs had established herself as a poet and essayist, her family’s imposed silences managed to spill into her writing life, attempting to discourage her from being a writer at all. In *Carnal Acts*, for example, Mairs reminds readers that in her family she “gradually learned, one never utters anything even faintly disagreeable, and huge chunks of human experience are at least faintly disagreeable” (57). Even benign acts within the family, the little things the family cherish are to be kept secret, Mairs discovers. When a cleaning woman finds a copper pillbox belonging to her mother that was a souvenir from a trip with her now deceased father, Mairs recounts the story to one of her aunts. “Mum was wonderfully happy,” she tells her aunt. “I think it acted as a symbol of their life together, and getting it back made Dad seem a little less dead to her” (58). “Oh,” her aunt exclaims, “don’t write that. Please don’t ever write that!” (58). Mairs examines the situation as indicative of the silences she has grown up under: “I suspect that what I might have written would violate no discursive rule. I think she was grasping the occasion to insinuate a larger message: not ‘don’t write *that*, but ‘don’t write *at all*.’ A tongue like mine, given to revealing the small, intimate details of family life, ought to be silenced utterly” (58).

While Mairs experiences this kind of silencing first within her family, for women

this is a cultural condition, the kind of “discursive constraints [that] function most stringently to repress the feminine in human experience” (58). Mairs experiences this kind of cultural repression targeted at her own writing when she is the only female MFA graduate student in a poetry writing workshop at the University of Arizona. She recalls that the male members of the group assured her that her work was not only technically sound, but “brilliant,” but that it also was not very “interesting” (59). “The same group had gone wild, a couple of meetings before, over another member’s poem about his first visit to a whorehouse,” she explains. “I got the message: whorehouses are interesting; wifehood, motherhood, even mistresshood are not” (59). The experience, she recalls, almost convinced her to stop writing, and even though she decided not to stop, in writing *Carnal Acts* in the mid 1990’s she still senses a pervasive lack of interest in women’s writing: “In college workshops and editorial offices, at writer’s conferences and reviewer’s desks, women’s words continue to be devalued” (60). Even her own mentors and editors have wondered aloud when she’ll “get around to some ‘real work,’” she says, “by which they seem to mean something perhaps less personal and certainly less ‘limited’ by feminist perspective” (62).²⁹ This kind of devaluation leads to the misrepresentation of women, Mairs writes, or it leads to women writers “depicting not their own experiences but male pornographic fantasies of feminine experience” (60). Instead of pandering to this limited view of women, Mairs encourages women writers to write truthfully about their bodies – whether they be disabled or not – as she does in the essays of her début work, *Plaintext*.

For Mairs, to write truthfully about her body is to write, in part, of its failings, to

represent her disabled body as it *is*, not how American culture fantasizes it should be. The essays in *Plaintext* raise topics that Mairs returns to time and again in her later collections: depression, suicide attempts, electric shock treatments. Clearly, hers' is a "body in trouble," as she later describes it, a body that because of increasing debilitation from MS tends to trip and to drop things. She describes herself as a woman who "lurches around the house and crashes to the floor in front of [her children's friends], who gets attacks of anxiety in the middle of stores and has to be cajoled into finishing simple errands" (*Plaintext* 66), to the extent that her life often seems to her a "series of small failures to do as [she] ought" (12). Mairs is as truthful in the description of her body's difference from accepted norms, as she is about the feelings of shame she owns over her body's failures. Mairs assures us in her essay, "On Having Adventures," the opening chapter of *Plaintext*, that while her body refuses to move gracefully through the world, she has come to a graceful acceptance of its truths. In this short essay Mairs describes how she has learned to redefine her take on the world around her with the onset of illness. Specifically, and as a writer in particular, she has learned to reconstruct and refine her definition of adventures – the things that happen in her life that she ultimately finds interesting enough to write about: her houseful of cats, and fish, and snakes; lunch with friends; her body. Because of MS, Mairs explains:

each morning that I wake up, that I get out of bed, is a fresh event,
something that I might not have had. Each gesture that I make carries a
weight of uncertainty, demands significant attention: buttoning my shirt,
changing a light bulb, walking down stairs. I might not be able to do it this

time. Inevitably the minutiae of my life have had to assume dramatic proportions. If I could not love them, delight in them, they would likely drown me in rage and in self-pity, that tempting, obliterating sea. (6)

Thus, while Mairs has had to refine her definition of adventure – making it “smaller and smaller” – as her illness has progressed, she remains “unwilling to forgo the adventurous life: the difficulty of it, even the pain, the suspense and fear, and the sudden brief lift of spirit that graces – unexpectedly, inexplicably – the pilgrimage” (7). However small her adventures, Mairs’ essays offer American culture a truthful, unmediated depiction of disabled life. And while she may not have been aware of it while writing her first essay collection, Mairs’ devotion to the minutiae of her life in her writing has contributed to her creation of a body of work that in many ways meets the goals of today’s feminist disability studies, a discipline which Thomson describes as confronting the “limits of the ways we understand human diversity, the materiality of the body, multiculturalism, and the social formations that interpret bodily differences” (Thomson 75).

In reconsidering *Plaintext*, however, Mairs admits that she did not realize that in writing truthfully about her body she was breaking new ground for women writers. “If I had known it,” she writes later in *Carnal Acts*, “I suspect I’d have been too intimidated to make a peep. At that point I knew only that I’d spent most of my life baffled and in pain over events and feelings that, I was just beginning to sense, weren’t peculiar to me. But because they existed in the realm of the linguistically impermissible, I hadn’t been able to speak of them aloud and, in sharing them with others, ease their weight” (60).

By writing her life, Mairs trespasses into this realm of the linguistically

impermissible, not only in terms of her topic, but also in terms of style, thereby further testing and expanding the boundaries of the American memoir. At least one reviewer of *Plaintext* praised Mairs for her refreshing authorial voice, a “clear and distinctively personal voice of a very specific woman” (Klass 21). This very personal voice is important to Mairs and she strives to make it a woman’s voice, though she admits she does not have a clear sense of what “women’s writing” might be (Mairs *Voice* 86). Introducing her choice of writing in fragmented, spatially organized essays in *Remembering the Bone House*, though, Mairs explains her attempt to consciously avoid logical coherence and rationalization, which she defines as “the outstanding feature of phallogocentric discourse in general” (9). Her goals, she writes, are

to avoid these qualities, their reassuring rigidity and muscularity beloved by all of us who are products of the ivory phallus. To abandon the phallic narrative structure inculcated there: exposition, complication, climax, denouement.³⁰ To refuse its critical questions: What does this mean? Why does it matter? To embrace the past as “meaningless,” as “matterless,” without “worth” in an economy based on the scarcity of resources, on the fear of running out: of reasons, or memories, of precious time. To seduce the impatient reader boldly: *Here, let’s take our time. We’ve got plenty more where it came from.* To dare to dally. These are the risks for a woman who experiences her past – the past in which she lived as a body, which dwells in her body still – as a bower (9).

Influenced by the thinking of French feminist Hélène Cixous, Mairs believes women

have been “constrained by a [masculine] discourse that proscribes the feminine erotic plot” (*Voice* 112). Thus, a “woman’s only recourse is the ‘theft’ of language with which to ‘write her body’ – ‘the act that will realize the un-censored relationship of woman to her sexuality,’” Mairs writes, citing Cixous (112). It is “through writing her body,” Mairs adds, that a woman “may reclaim the deed to her dwelling” – her bone house (112). In one of the very few scathing reviews I have read of her work, Nicholas Christopher contends that Mairs’ attempts to experiment with form and feminist theory in *Remembering the Bone House* result in little more than a tired “ranting” and essays “burdened” by “tedious descriptions, vapid asides and interminable interior monologues laden with first names that seldom seem to develop into rounded characters, incidents, or themes” (Christopher 23). The fragmented nature of her work, he says, leads to pretension and narcissism (23). Other readers of the work, however, defend Mairs’ project. Responding to Christopher’s review in the *Times*, Brenda Webster argues that Mairs “gives us all, male and female, the permission to deal openly with material that is essential if we want to understand how our identities were constructed and how they can be transformed” (Webster 43).

Susannah B. Mintz concurs with Mairs’ assessment of her work, further explaining that Mairs writes against two traditions: “the ‘masculine’ model of conventional autobiography, with its underlying ideology of stable, unified, and disembodied selfhood, and [what Mairs calls in *Carnal Acts*] ‘the rules of polite discourse’ that inhabit both women’s speech and the articulation of the disabled experience” (Mintz 254). When read collectively, Mairs’ essays work to further expand

the boundaries of traditional autobiography. Her collections, Mintz argues, “create heterogeneous ‘bodies’ of writing that range through memory, experience, and location in a way that simultaneously suspends the progress-narrative of classic autobiographical prose and evokes the open-ended corporeal reality of living with multiple sclerosis” (254). And is it this aspect of corporeal reality of her work, her insistence on representing her body, that helps Mairs gain visibility within American culture.

II. Affairs of the Body, Affairs of the Heart

One text in which Mairs continues to evoke this open-ended corporeal reality while making the linguistically impermissible suddenly not only permissible, but ordinary, is her memorable and compelling essay collection *Ordinary Time: Cycles in Marriage, Faith, and Renewal*. Here, Mairs writes candidly about her marriage and her conversion to Catholicism, capturing the often difficult realities of her married life, which of course are complicated by illness and disability. With unflinching directness, the personal details and revelations of these essays work to shatter the conception that women’s writing – their lives – are uninteresting. At the same time, they also work against the accepted myth that disabled women’s lives are, by nature, weak, passive, and asexual. Indeed, by welcoming readers into her daily life through her essays, Mairs shows how rich, how complex, how full of sexual tension her life as a disabled woman – and by extension, the lives of all disabled women, the lives of all women – can be.

One of the issues that offers both complexity and tension in *Ordinary Time* is infidelity. Not only are disabled women capable of being married, the collection reminds us, like other married woman in America, they have husbands who are capable of

cheating on them, and with whom they are likewise capable of being unfaithful. And as in any household, these events lead to strained relations and complicated emotional responses. For example, Mairs opens the book with her recollection of hearing about her husband's two-year affair with another woman for the first time. Although she admits to numerous affairs of her own throughout all of her essay collections, it becomes clear in this collection that she does not equate her own transgressions with her husband George's. For George's affair, he admits, was a "kind of marriage" and it is this emotional transgression which sends Mairs reeling into a tailspin of grief (Mairs 17). It is not his physical infidelity that slights Mairs, but his emotional one. Though she admits that "in brief passionate bursts [she has] transgressed the sexual taboos that give definition to the Christian marriage," she feels she has remained faithful to her marriage vow in viewing marriage as "something one did once and forever" (20). George, of course, transgresses this vow by *feeling* married to the other woman.

Although Mairs does not know it at the time, in hindsight she realizes that George's two-year affair and his emotional distance toward her at this time is instrumental in the construction of her self-image. She describes these years as some of her most wretched emotionally, even though she was not clinically depressed at the time. And she comes to view George's lies (working late and doing charity work as a cover to go meet the other woman) as harmful to her psyche: "by lying to me, he permitted – no, really encouraged – me to believe that my unhappiness was, as always, my fault," she writes. "When I expressed concern and sadness, he blamed our chilling relationship on me: I was distracted, too bitchy, not affectionate enough... . Ah, he knew my self-doubts

thoroughly” (21).

Through her analysis of her husband’s structuring of her as the one to blame for his infidelity, Mairs offers a counternarrative to cultural stereotypes that attempt to blame women for their husband’s transgressions. It is not always that women are too bitchy or not affectionate enough, it is that their husbands have often constructed them to feel so. What becomes troublesome about Mairs’ discussion of both her own and George’s affairs, however, is the way in which she ultimately rejects her own counternarrative by blaming her disability for both George’s and her own transgressions. Ironically, as a feminist thinker, she sometimes makes the feminist mistake of not considering her disabled body worthy of equitable treatment. While Mairs may be breaking boundaries in speaking of sex – and of a disabled woman’s sexual relationships in particular – unlike Anne Finger³¹ and others who challenge feminists who seem to have left disabled women behind, Mairs sometimes does not get beyond viewing herself as damaged goods. In this light, she occasionally buys in to the cultural intolerance for “human variation and vulnerability,” to borrow Thomson’s phrase, blaming her disability for the problems in her marriage and not the inherent flaws in the relationship itself.

In recalling her portrayal of George in her essays, for example, Mairs admits she has “publicly canonized him” through her essays: “Any man who could stay with a crazy, crippled, unfaithful bitch like me had to be more than humanly patient and loving and long-suffering and self-abnegating and . . . oh, just more than human” (26). Additionally, before she learns of George’s affair, Mairs notes that when asked by others if George has been unfaithful, she always replied that she believes him when he tells her he has been

true. She tells herself, however, that he “ought to go, get out now, while he’s still fairly young, find a healthy woman free from black spells, have some fun. No one could blame him” (26). While she believes he has been faithful, then, she also sees herself – because of her disability and illness – as being unworthy of his fidelity. It is not until she learns of his infidelity that she understands her own role in George’s slow ascendance to sainthood, and it is in coming to *this* understanding that Mairs’ meditations push her – and her readers – beyond unquestioningly accepting the social stereotype of disabled women being sexually unappealing. “The veneration of others must be seductive,” Mairs writes, as she comes to see that George has benefited from her portrayal of him as a saint, and that she has contributed to his remaining silent about his affair and has spent additional emotional energy – unbeknownst to her at the time – because of it. “A saint’s wife readily falls prey to self-loathing,” she explains, “since comparisons are both common and invidious, and recuperation, if it occurs at all, is a protracted and lonely process” (26).

As she suggests here, Mairs’ marriage and her own self esteem suffer a severe blow before she can begin the process of uncovering the damaging ways that she and George have constructed themselves and each other in their marriage: “I knew from the start (how? how?) that any failings in our relationship rested with me; I could not believe him capable of working us any harm; and so whenever our marriage sputtered and stalled like my old Volvo when the timing went off, I never scrutinized his behavior, only my own” (117). For years, then, Mairs remains unhappy in her marriage: “I was unhappy in it, stricken with grief and guilt for my unhappiness, and unspeakably lonely” (120). In

delving deeper into her life and continuing to tell the story of her complex relationship with George, however, Mairs succeeds in coming to her own feminist understanding of the unequal balance of power within her marriage, an imbalance which both she and George have created. Mairs also shows, however, that it is possible for the couple to reconstruct their lives and views of each other afresh. For instance, when George is diagnosed with malignant melanoma – the incident which precipitates his confessing his affair in the first place – Mairs realizes that he is ready to shake off the saint label she has constructed for him through her writing and look at himself clearly. He wants neither the benefits nor pitfalls of living under others' false views of him: "He wants to be loved as he is," Mairs writes, "not as we – his mother, my mother, my sisters, our daughter, his students, our friends, maybe even Sandra herself [George's mistress] – have dreamed him" (28). Although we do not get to hear George's side of the story, unmediated through Mairs, one senses that his willingness to forego the role of the saint in their marriage is one of the first steps the couple takes toward renewing their commitment to each other.

Detailing her turbulent relationship with George, Mairs proves that disabled women have real problems and concerns in their lives that reach beyond the realm of their disabilities. Of course, many of Mairs' marital problems stem from her depression and multiple sclerosis, but at the end of the day, she insists, she is *still* a woman, like any other, concerned with the trials and triumphs of her life. And what's more, she is still a woman with the same sexual needs and frustrations as her able-bodied counterparts, a fact that, once recognized by American culture, can work to move disabled women from

the margins of society in the eyes of the able-bodied at the center. In her essay, “Transforming the Tale: The Auto/body/ographies of Nancy Mairs,” Susannah B. Mintz reiterates the idea that Mairs’ willingness to portray the disabled body “engaging in and enjoying sex” is:

in obvious opposition to the dominant cultural assumptions about the disabled and women alike. . . . Mairs protests the mind-bending contradiction of inhabiting two mutually exclusive, and multiply oppressive, constructions: the asexualized abnormal, sterile body of the disabled, and the inescapably sexualized, shameful body of Western culture. She represents herself as mature and psychologically astute, as a woman of considerable patience and experience, . . . as a woman no longer persuaded by culture’s tale of her own objectification and thus at ease with the fact of her body, eager for its pleasures – is, in short, more self-actualized than many “normals” (266).

We can see this self-actualization in Mairs’ ability to recognize and share the difficult emotions she feels concerning George. For example, the chemotherapy treatments George receives for his melanoma eventually leave him impotent. Mairs is bitter at this time, thinking that George’s mistress, Sandra, got the best of George physically, the sex, while, although she is the one who gets to keep George in the end, she will be the one – in an unhappy tradeoff – who will have to deal with his eventual death (Mairs *Ordinary* 30).

Mairs takes risks – as she often does in her work – in writing about her feelings

here, especially in light of the fact that readers can point to some obvious flaws in her reasoning. For instance, she despises Sandra, she says, for “her willingness to risk [her] marriage without a thought” (30). It seems Mairs has not fully considered her own sentiment here. Not only does she not know *what* Sandra was thinking during the affair, Mairs, too, as evidenced by her other works, if not this essay in particular, has admitted to having affairs with married men. Was *she* willing to risk those marriages without a thought? How might she react if others attempted to define her intentions as such? Trudy Bush, writing for *Christian Century*, likewise feels some “unease” over Mairs’ handling of her extramarital affairs in her work. She regrets that Mairs “seldom considers the effects her infidelities had on her husband and children,” and she does not consider the additional pain she may cause them by revealing such intimate details in her work (314). Although at the close of her first chapter in *Ordinary Time* Mairs admits that both she and George have “unquestionably wounded each other horribly and each bear full moral responsibility for the other’s pain,” she remains unconvincing that she considers herself as morally culpable as George. She acquiesces that her own affairs may have encouraged George in his, but that “morally they stand separate” (Mairs 30). She does not explain her meaning here, but readers recall her stance at the beginning of the piece: she remained emotionally married to George during her trysts, while George committed emotional polygamy – claims which may not ring convincing enough for many readers.

Mairs’ feelings about her own affairs are also complicated by her disability, for no matter how hard her collection of essays strives to depict her as an ordinary woman, with ordinary sexual appetites, her extraordinary body remains an essential element to each

piece. Mairs proves that her body is quite capable of the same desires as others,' but what some readers may find troublesome is Mairs' reluctance to take full responsibility for these desires. Instead, she sometimes blames her illness and disability for her own indiscretions. Mairs views her own affairs as "personal growth," for example. They are "infrequent, short-lived, noncommittal, generally discreet and passionate" affairs that awaken her, she says, from the depths of torpor that only much later would she learn was clinical depression (123). She even wonders if "biochemistry [can] legitimately be held responsible for sin" (123), and she confesses that she considers herself, because of her illnesses, to be powerless to resist these affairs (123).

Mairs notes that she loses interest in having affairs. Due less to her conversion to Catholicism, than to the simple fact that the "highs and lows" of the affairs wear her out (125), it is clear that she views her deteriorating body as a source for her lack of interest in affairs. She reaches a point in which she does not consider herself attractive enough to lure a man: "within a few years I'd grown too old and crippled to interest men in that way," she writes, and she also credits her newly balanced biochemistry: "certainly it's more than coincidence that my depression was brought under medical control at about the same time" (125). Finally, however, she is able to look beyond the effects of her illness and disability to claim that her true lack of interest in having additional affairs stems from a change in her moral attitude, a decision to "assume responsibility for rousing myself," she writes, "to attend to what I was doing" (125).

At this time in her life, Mairs attends to life choices, her writing, and her marriage. Although their sex life is changed by George's impotence, Mairs' depiction of

their continuing physicality with each other furthers the argument that the ill and disabled can retain their sexual impulses. It also argues, as Mairs herself notes in *Waist-High in the World*, against the notion that a sexual relationship cannot be maintained when one partner is responsible for the daily care of the other – a role that both Nancy and George have played for each other during their marriage. Despite the fact that their various illnesses have caused all the “veils” to drop before them (he’s had to change her wet pants, she says, and she has gazed upon his E. coli infested wound), they not only remain attracted to each other, but “have grown so familiar with each other’s physical realities,” she writes, that they “love each other more unabashedly and inventively as time goes on” (53). Mairs explains:

Whether for making love or not, our bodies – one twisted and nearly inert, the other scarified, both softening now with age and indulgence – instinctively seek each other out. Even our most mundane interactions bear an erotic charge. . . . he may stroke my neck when he brings me a cup of coffee. And since my wheelchair places me just at the height of his penis . . . I may nuzzle it in return. We carry on a constant, often hardly conscious, corporeal conversation regardless of our other pursuits and preoccupations. Without my disability to throw us together thus habitually, our bodies might spend their days racing separately from one activity to another, coming across each other only in time to tumble into sleep (54).

Citing this same eloquent passage in her essay, Mintz rightly concludes that its power is

not just in its rendering of the disabled as *sexual*, but that it renders them *normal*. And “it is *disability*, Mairs provocatively claims, that renders her ‘normally’ sexual, disability that enlarges the experiential field to enable her to locate the extraordinary in the ordinary,” Mintz writes:

What seems most stunning about this manifesto for the eroticism of quotidian chore is that Mairs is not so much describing *actions* that are radically different from what the non disabled world routinely perform, but rather a mode of *perception* that allows her to view those activities differently, investing them with meaning according to a different conceptual frame. In this way the passage stands as a dazzling exposure of the limitations of the world view of ‘able-bodiedness,’ with its monological definition of the sexual, the erotic, the tender (Mintz 267).

Mairs’ passage above and Mintz’s ensuing discussion of it are important in light of my own argument that Mairs’ work is capable of expanding and challenging, not only feminist theory, but American culture’s concept of disabled women. Mairs not only renders herself capable of very ordinary sexual impulses, she proves that she is capable of redefining eroticism, challenging, as Mintz notes above, limited cultural views of physical pleasure. In writing of her simple, erotic pleasures Mairs forces our culture to imagine what it previously thought unimaginable, to visualize what it previously has refused to see: a disabled woman who repudiates the stereotype of asexuality ascribed to her by not only embracing her sexuality, but celebrating it publicly.³²

III. On Being Catholic, Feminist, and Disabled

Mairs' self-described change in moral attitude begins to affect all aspects of her life. As she begins to take personal responsibility for her actions, she likewise becomes more spiritually, politically, and socially aware. It is not surprising, then, that her writing not only reflects these concerns, but also begins to take on more meaning for her. And as she inscribes her life, readers see that, indeed, her life, despite her disability, is productive and fulfilling to her and can be meaningful to others as well.

Part of Mairs' meaningful contribution to American culture through her essays, for example, comes through her unique stance as both a Roman Catholic (which she became at age thirty-four) and a feminist (which she says she became a couple of years later) and how she reconciles these seemingly contradictory aspects of herself. Mairs' disability also informs and complicates her reflections on her experiences as both a Catholic and a feminist, but it is clear through some of her thinking that her disability does not always take precedence in forming her views. For instance, although Mairs converted to Catholicism at age thirty-six (about the same time she discovered feminism – a decade later than everyone else, she quips), she does not accept all the tenets of the church, especially its views on women's bodies and on birth control in particular.

The Catholic church encourages women to feel ashamed of their bodies, Mairs argues. In her essay "Whose Body?" she describes how, when her marriage was in trouble, she once sought the counsel of a minister who often counseled students at the University of Arizona. After briefly questioning her about her sex life with George, Brother Tim asks if she and George participate in oral sex. She confirms their practice,

and he condemns her, assuring her that she and George have willingly allowed the devil into their lives through the practice of sodomy. Mairs leaves Brother Tim's counsel in disgust and fear for the mental health of other students who have been encouraged toward self-blame for the world's problems because of their sexual practices (*Ordinary* 203). While Mairs assures readers that in her experience Brother Tim is an anomaly among the other Catholic clergy she has come in contact with, she finds that his ultimate message is not uncommon in the Church: "The disgust for the body, particularly the sexualized female body, which makes such ministry conceivable suffuses Church attitudes and practices so thoroughly as to seem inherent in, rather than imposed upon, human consciousness," she writes (203).

Mairs' criticism of the church is clearly marked by feminist philosophy, but her own moral compass is guided by a blend of both Catholicism and feminism. As a Catholic feminist, for instance, Mairs claims she is both pro-choice and anti-abortion. She believes that "reproductive questions lie so radically in the realm of private conscience that they ought to remain outside the legal arena altogether," but she notes that in general if a woman were to ask her counsel in the matter of abortion, she would counsel against the procedure (206). While in tune with both feminist thinking (being pro choice) and church counsel (rejecting abortion), Mairs' experience as a disabled woman also complicates her stance on abortion. While she rejects abortion *in general*, her early work argues that abortion is acceptable as a means to protect the health of a disabled woman or to prevent the birth of a disabled child. "Why would anyone want us to produce a damaged child or a child whose mother was too ill to care properly for her?" Mairs asks

in *Ordinary Time* (150). Mairs offers an example of a disabled woman she has in fact counseled to seek an abortion. When her friend Bonnie who has cerebral palsy finds herself unexpectedly pregnant by her fiancée who has lost both his legs in a motorcycle accident, Mairs counsels her to follow her doctors' advice and abort the child because the medication she is on will likely cause severe genetic damage to the child. She encourages Bonnie to abort her baby, go off the medication she is currently on, and then try for another child once the medication is out of her system (207). Although Mairs does not question the couple's ability to serve as good parents despite their separate disabilities, here, she clearly sides with cultural arguments that support the abortion of disabled fetuses based on quality-of-life (the belief that a disabled child will lead a less fulfilling life than one who begins his or her life as able-bodied) and anti-suffering (the belief that a disabled child will suffer) tenets. Mairs' stance is ironic in light of the many disability rights activists who argue against selective abortion, countering the idea that disabled lives are not worth living. Anne Finger, noted previously, for instance, meets this cultural stance head-on when she is invited to speak as a disability rights activist to a feminist group discussing the "Baby Doe" issue in the early 1990's. This issue received much attention in the press when an unnamed couple decided (with their doctors' support) to withhold lifesaving medical care from their disabled newborn, and the child starved to death in the hospital. At the meeting Finger is told by another woman in attendance that if Finger had been *her* daughter, and if she had known that she would contract polio, she would have aborted her and killed herself as well.

Three years after the publication of *Ordinary Time*, by which time Mairs has

become more of a disability rights activist herself, Mairs revisits the issue of abortion in her essay, “Freeing Choices” in her collection *Waist-High in the World*. Although she confesses here that she does not have an “unambiguous” answer to the abortion debate, she complicates her earlier stance – and feminist theories that argue for reproductive freedom at all costs – by more fully considering the social implications of aborting defective fetuses. Specifically, Mairs reflects on what has now become a common practice in American society, the use of amniocentesis to detect birth defects (and the sex of a fetus) in utero. She questions our society which implicitly agrees that aborting a child because of its sex is impermissible, but aborting “an imperfect one is not merely legitimate but, many would argue, socially responsible” (108). Soon, she posits, American medicine may have the technological capabilities to detect genetic predisposition toward MS, and “what then?” she asks (108). Mairs notes that in a society where medical care and quality educational programs are not equally accessible to all, and parents of disabled children often find themselves “pretty much on their own,” she is glad that her own mother “never faced the option to ‘spare’ me my fate, as she might have felt obliged to do” (109-10). And even though she admits that she could not blame a woman for choosing “not to test her mettle in this way” by giving birth to a disabled child, the problem, she notes, “is that if you eliminate one flaw, you throw out the whole complicated creature” (110-11). Mairs reminds us that aborting fetuses will not rid American culture of disabilities (as anyone can become disabled at any age due to a whole variety of life mishaps), but she worries that advances in medical technology that permit the discovery of more and more genetic defects prior to birth will, in turn, result in

more prospective parents deciding to terminate pregnancies in an effort to avoid these defects (112). What this development will do, she argues, is make the social position of the disabled

even more marginal by emphasizing that no one with the power to choose would ever have permitted them to exist. Their own choice to survive will seem suspect. *We're doing everything we can to exterminate your kind,* the social message will read, *and we'd get rid of you too if only we knew how.* No one will ever say this. No one will have to. (112)

Mairs' changing and increasingly complicated stance on abortion reminds readers that her philosophies cannot be predicted by her religion, her disability status, or her alliance with feminist causes. Again, this is a message of which both women's and disability rights movements might make better use. Thomson reminds us that "feminism increasingly recognizes that no woman is ever *only* a woman, that she occupies multiple subject positions and is claimed by several cultural identity categories" (*Gendering* 88). Mairs expands on this recognition by proving in her work that no *disabled* woman is ever *only* a disabled woman.

And, as Susannah Mintz points out, Mairs' essays are likewise not constructed by a singular "speaking self," but rather informed by past, present, and future "Nancys," to the extent that "a unified 'Nancy Mairs' disappears in Mairs's refusal of the norm that would marginalize her, and in this multiplicity of selves, between whom likeness can be no more fully guaranteed by bodily continuity (since her physical state is ever-changing) than by consciousness, desire, or memory" (Mintz 259). Ultimately, the expression of

Mairs' multiple selves – the self multiply constructed – works to remind readers of just how “ordinary” she is. While Mairs sometimes presents her body as a “freakish cultural other,” Mintz argues that such description “underlines the cultural code that defines beauty and success by a single set of near-impossible criteria” (260). When Mairs expresses her own uneasiness with this criteria in relationship to her own body, Mintz rightly suggests that she “invites a new sort of powerful identification [with other American women who have felt the same societal pressures to live up to impossible standards of beauty] that brings her body back from the margins” (260). Through this identification with the very ordinary societal pressures felt by able-bodied women, Mairs increases her own visibility in American culture and reiterates her stance that although she is disabled, her preoccupations do not vary much from the American public's. But as the narrative voice of her essays attests, her way of expressing these preoccupations does.

Certainly Mairs' analysis of her own life along these lines has political and social ramifications of which she is aware. For “to depict disabled people in the ordinary activities of daily life is to admit that there is something ordinary about disability itself, that it may enter anybody's life,” she writes in *Carnal Acts*. “If [disability] is effaced completely, or at least isolated as a separate ‘problem,’ so that it remains at a safe distance from other human issues, then the [reader] won't feel threatened by her or his own physical vulnerability” (33). The effects of this kind of effacement for the disabled, Mairs explains, are self-degradation and self-alienation, and the denial of disability in our culture can also have serious ramifications for TAPs (Temporarily Abled Persons):

Ours' is the only minority you can join involuntarily, without warning, at

any time. And if you live long enough, as you're increasingly likely to do, you may well join it. . . . But it will be a good bit easier psychologically if you are accustomed to seeing disability as a normal characteristic, one that complicates but does not ruin human existence. Achieving this integration, for disabled and able-bodied people alike, requires that we insert disability daily into our field of vision: quite, naturally, in the small and common scenes of our ordinary lives (34).

IV. The Disabled Woman Writer in the Classroom

In writing her disabled body, Mairs shows that "it is simply one more form of human corporeality," Mintz writes, "but at the same time it might also serve as a liberating metaphor – for multiple perspectives, for resistance to oppression, for a way of making difference radically visible, not merely to reinscribe the 'normal' body, but as and in itself" (265). When educators showcase this kind of radical difference in the classroom, they have the potential to participate in what Thomson describes as "academic activism," a "methodology of intellectual tolerance" (Thomson 99). By deepening feminist thought through the complication of disability analysis in the classroom, Thomson explains, one learns to develop a methodology which tolerates internal conflict and contradiction:

This method asks difficult questions, but accepts provisional answers. This method recognizes the power of identity, at the same time that it reveals identity as a fiction. This method both seeks equality and it claims difference. This method allows us to teach with authority at the same time

that we reject notions of pedagogical mastery. This method establishes institutional presences even while it acknowledges the limitations of institutions. This method validates the personal but implements disinterested inquiry. This method both writes new stories and recovers traditional ones (99).

Mairs' essays, by their very nature, require the type of methodological analysis Thomson describes above. And successful analysis of disability along these lines has the power to more fully integrate the sociopolitical world, Thomson adds, for "as with gender, race, sexuality, and class: to understand how disability operates is to understand what it is to be fully human" (100).

In her contribution to the co-written essay, "Becoming Visible: Lessons in Disability," Barbara A. Heifferon argues the benefits of using disability-focused texts such as Mairs' essay, "Carnal Acts," in the composition classroom. Mairs' work, Heifferon says, has the power to "disrupt societal taboos about what is or is not acceptable coping strategy and can also resist conventional binaries regarding perfect/imperfect bodies" (Brueggemann 372). In an attempt to "debunk concepts of 'normalcy' and 'ideal bodies,'" Heifferon adopted Mairs' text for her composition course. Her students' reactions are worth mentioning here, to illustrate the gendered response to Mairs' writing.

In "Carnal Acts," as Heifferon reminds us, Mairs notes that she is unable to speak politely about the body as a woman who has experienced childbirth, physical love, and disease and disability. Indeed, she has come to view her own writing about these intimate

experiences as carnal acts, each of which, Heifferon says, “confronts issues such as disability labels, stereotyping, and cultural biases toward the differently abled body” (383). In particular, “Carnal Acts,” is Mairs’ response to a group of women at a small liberal arts college who have invited her to speak on how she “copes” with her disability and how she found her “voice as a writer.” Mairs admits in the essay that the most difficult aspect of adjusting to her disease is that it “rammed my ‘self’ straight back into the body I had been trained to believe it could, through high-minded acts and aspirations, rise above” (Mairs *Carnal* 84). Unable to “rise above” her body in the “Western tradition of distinguishing the body from the mind” (85), Mairs feels the shame of her body all the more. “A woman’s body,” she writes, “is particularly suspect, since so much of it is in fact hidden, dark, secret, carried about on the inside, where, even with the aid of a speculum, one can never perceive all of it in the plain light of day, a graspable whole” (86). Mairs notes that as a “cultural woman” she cannot escape these feelings of shame: “I bear just as much shame as any woman for my dark, enfolded secrets. Let the word for my external genitals tell the tale: my pudendum, from the Latin infinitive meaning ‘to be ashamed’” (86). In speaking of the shame she feels for her body, Mairs proves that her disability does not make her immune to the gaze of an American culture that views women with suspicion. Indeed, she notes that because of her disability she is rendered “doubly other, not merely by the homo-sexual standards of patriarchal culture but by the standards of physical desirability erected for every body in our world” (86). Although she must contend with feeling doubly other, Mairs argues she does cope with her disability most of the time through speaking about it. She has found her “antidote to shame” (91)

by speaking about it, and about the whole experience of being a body, specifically a female body, out loud, in a clear, level tone that drowns out the frantic whispers of my mother, my grandmothers, all the other trainers of wayward childish tongues: “Sssh! Sssh! Nice girls don’t talk like that. Don’t mention sweat. Don’t mention menstrual blood. Don’t ask what your grandfather does on his business trips. Don’t laugh so loud. You sound like a loon. Keep your voice down. Don’t tell. Don’t tell. Don’t tell.” (91)

Mairs, of course, does tell, and Heifferon describes her students’ differing reactions to this intimate rendering of her body and her experience. “The young women in the class were clearly moved by Mairs’ words and were sympathetic and emphatic,” Heifferon writes, but the “young male students were outraged, not just ‘grossed out’ by descriptions of body functions and other things that go awry in MS, but angry, furious, livid in the classroom” (Heifferon 383).

As Heifferon’s university’s composition program calls for a “hands off” approach to presenting the reading material for the program-wide final, she was unable to *teach* Mairs’ essay to her students. She reports that she did find it necessary, however, to encourage her students to rhetorically analyze their own in-class reactions to the piece. What was it about the topic of disability, she asked them, that caused the women in the class to respond with sympathy and the men with anger? (384). Later, when reading her students’ written responses on the final, she surmised that her male students had been “outraged at the schism between the idealized body image of women they see projected

in the culture and the body image Mairs wrote about,” and they were “equally outraged by her admission of self-doubt, weakness, and disability” (384).

Mairs’ essay certainly shatters the male fantasy image of women perpetuated by the media which “offers no alternatives to the Barbie doll ideal, a totalizing gesture that wipes difference from our cultural map,” Heifferon writes (385). Indeed, Mairs’ response to our culture’s construction of the ideal woman informs much of her work. In her critically acclaimed essay, “On Being a Cripple,” in her first collection, *Plaintext*, for example, Mairs explains that she sometimes suffers bouts of self-loathing for being a cripple. It is not the physical limitations that her disability creates that cause this self-hate, however; it is, she says, for not being able to live up to ideal standards of beauty. “Physical imperfection, even freed of moral disapprobation [society used to equate deformity and disease with evil, Mairs reminds us], still defies and violates the ideal, especially for women, whose confinement in their bodies as objects of desire is far from over” (16). Though the ideal has changed through the ages, Mairs notes, the ideal woman “is never a cripple” (16). Mairs admits, “when I think about how my body must look to others, especially to men, to whom I have been trained to display myself, I feel ludicrous, even loathsome” (17), but despite these feelings, she knows that at the center of these feelings is her hate not for herself, but for her disease, and “I am not a disease,” she stresses. “And a disease is not – at least not single-handedly – going to determine who I am, though at first it seems to be going to” (17).

While Mairs does not allow her disease to define her, she does admit to being forced by her disability to embrace herself in the flesh (*Carnal* 96). The result of this,

she says, is that she is unable to write “bodiless prose.” Her voice, she says, “is the creature of the body that produces it:”

I speak as a crippled woman. At the same time, in the utterance I redeem both “cripple” and “woman” from the shameful silences by which I have often felt surrounded, contained, set apart; I give myself permission to live openly among others, to reach out for them, stroke them with fingers and sighs. No body, no voice; no voice, no body. That’s what I know in my bones. (96)

In refusing to be defined solely by her disease, and by refusing to write bodiless prose, Mairs strives to ‘normalize’ the disabled body in collections such as *Plaintext* and *Carnal Acts*, and it is perhaps this act of normalizing, this refusal to remain invisible, that makes Heifferon’s male students initially uncomfortable. As Mintz notes, Mairs’ rendering of the body not only makes it recognizable by the dominant culture, it also provides a model for other people living with illness or disability. “Mairs’s essays thus proceed as a series of dislocations, which invite but also refuse identification, which insist on the ordinariness of her daily life but never neglect to attend to its constructedness as ‘other’ (Mintz 256). Heifferon’s students clearly react to these dislocations along gender lines, the women feeling invited into her work, while the men refuse identification with it. Heifferon suggests that in addition to buying into images of women perpetuated by the American media, many of her young male students react to Mairs negatively because they have formed their own “identities based on their own strong, healthy bodies, and because they are young and abled, their initial response to a disabled woman’s body is an

angry one” (Brueggemann 385). As Mintz aptly describes, however, to read Mairs is to ultimately “witness the extraordinary ordinariness of the body – all bodies, any body” (Mintz 269), and once Heifferon’s male students recognize this fact, they are able to move beyond their initial angry response to Mairs’ work in their reflections on her essay for their final paper.

One student whom Heifferon offers up as an example realizes that the initial anger he feels over Mairs’ admitting the trouble she sometimes has with coping with her disorder stems more from his own submerged feelings about his father’s death than feelings about Mairs herself. In the essay, Mairs claims, as noted above, that through speaking and writing about her disability she has finally been able to cope with it. And this admission, Heifferon says, helps her own student cope with his father’s death through writing. He writes:

For me speaking about my father’s passing would be too traumatic right now. Until this semester I’d never even written about it, but now I’m glad that I finally did. I found solace in writing about my dad, and when I was through writing about his death, I felt as though a weight had been lifted off of my shoulders. (Heifferon 386)

Like Mairs, Heifferon says, this student finds that “bringing the unspeakable to the foreground helped him to understand that he did not need to embrace the idealized model of masculinity (strong, silent type) along with the idealized model of femininity. Instead, the disability text opened up an opportunity for him to express his own grief and loss” (368). Here, a single essay by Mairs has the power to open up one boy’s expression of

grief. And *this* is the power of autobiography, a power magnified by Mairs' essay collections, where time and again we meet her singular, though multiply constructed, self. Speaking specifically and individually of and for herself, Mairs insists on the value of her life and thereby gains visibility within American culture, connecting with her readers – whether they be young men in college assigned her work for a composition final, or disabled women who have sought out her collections purposely – essay by essay, one reader at a time.

Notes:

²³ The contention between disabled women and the feminist movement has been widely documented by disability scholars since the 1980's. For further research, Traustadóttir cites the influential anthology, Fine, M., & Asch, A. (Eds.) *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Philadelphia, PA: Temple University Press, 1988; Hannaford, S. *Living Outside Inside: A Disabled Woman's Experience: Towards a Social and Political Perspective*. Berkeley, CA: Canterbury Press, 1985; Eisenstein, H., & Jardine, A. (Eds.) *The Future of Difference*. New Brunswick, NJ: Transaction Books, 1985; and Spelman, E. *Inessential Woman: Problems of Exclusion in Feminist Thought*. Boston, MA: Beacon Press, 1988.

²⁴ Traustadóttir cites: Israel, P. "Editorial." *Resources for Feminist Research*, 14 (1), 1-3, 1985.

²⁵ Traustadóttir cites a number of sources who argue this point and whose work strives to bring these issues to the forefront of public debate. See Blackwell-Stratton, M., Breslin, M. L., Mayerson, B. A., & Bailey, S. "Smashing Icons: Disabled Women and the Disability and Women's Movements." in Fine & Asch, noted above. Davis, A. "Women with Disabilities: Abortion and Liberation." *Disability, Handicap & Society*, 2(3), 276-284, 1987; Finger, A. "Claiming All of Our Bodies: Reproductive Rights and Disability." In S. E. Brown, D. Connors, & N. Stern (Eds.), *With the Power of Each Breath: A Disabled Women's Anthology*. Pittsburgh, PA: Cleis Press, 1985.

²⁶ For further scholarship on this documentation, Traustadóttir directs us to Matthews G. F. *Voices from the Shadow: Women with Disabilities Speak Out*. Toronto, Ontario: The Women's Educational Press, 1983.; Shaul, Dowling, & Laden, "Like Other Women: Perspectives of Mothers with Physical Disabilities." In M. J. Deegan & N. A. Brooks (Eds.), *Women and Disability: The Double Handicap*. New Brunswick, NJ: Transaction Books, 1985; and Waxman, B. F. "The Politics of Sex and Disability." *Disability Studies Quarterly*, 9(3), 1-5, 1989.

²⁷ Of course others are also doing this work of expanding feminist thought today. Feminist psychologists I have already referenced such as Asch and Fine and sociologists such as Traustadóttir, whose work expresses an interest in both feminism and disability, for example, continue in their work to document and argue against the myth of disabled women as weak and ineffectual, childlike and asexual. These scholars, and others like them, have made strides since the 1980s to make the disabled – and especially disabled women – more visible in American culture.

²⁸ The only sample of Mairs' fiction that I have come across appears as the opening piece of her essay collection, *Carnal Acts*. Mairs notes that the story, "Shape," which was written ten years earlier and revolves around the tensions between a disabled mother and her teenage daughter, represents her first public attempt to "address the issues of embodiment forced on me, as both a practicing mother and a practicing artist, by multiple sclerosis" (*Carnal* 7). Mairs notes that in writing the story, she felt too much distance between herself and her disabled narrator, and felt, instinctively, that fiction would not be the right form for her. Later, in choosing to write autobiography, she says, "Rather than remove myself from my life, as I felt I was using fiction to do, I've tried to scribble myself deeper and deeper into it" (8).

²⁹ Mairs does not mention these less-than-enthusiastic mentors and editors by name. She also does not mention here (as it would invalidate her point) that she has had the good fortune to work under some other very forward thinking mentors. Her PhD dissertation committee at the University of Arizona, for instance, allows her to write an "original literary dissertation" – her collection of essays in *Plaintext* – rather than a more traditional study of someone else's work, which she expresses was the norm for students receiving PhDs in literature at that time. (Mairs *Voice* 35). These committee members, whom she acknowledges in the introduction to that work are: Susan Hardy, her director; Barbara Babcock, Jerrold Hogle, and Patrick O'Donnell. In the preface to *Remembering the Bone House*, Mairs also credits Sidonie Smith for her supportive tutelage in the autobiographical essay in particular. So, while Mairs points to discrimination within the field, her own experience has not been one *entirely* based on discrimination.

³⁰ Certainly Leonard Kriegel's quest narrative, *The Long Walk Home*, fits into this pattern of paternalistic, phallogentric autobiography which Mairs strives to avoid. But as suggested by my chapters on Kriegel, his work is provocative not for breaking with American tradition – in terms of form – but for providing a counternarrative to the American view of disability while remaining steadfast within the literary tradition.

³¹ Finger's autobiographical work, *Past Due* tells the story of her difficult pregnancy and childbirth, post-polio. She challenges the cultural stance that the physically disabled cannot or should not have children or be allowed to make their own choices regarding childbirth and childcare.

³² For other autobiographical works of this nature by disabled Americans, see Connie Panzarino's *The Me in the Mirror*, a memoir which discusses the author's experience with the congenital, crippling disease, Spinal Muscular Atrophy; her long time love affair with Vietnam Veteran and author Ron Kovic; her eventual turn to lesbianism; and her work as a disability rights activist. Kenny Fries offers a male perspective in *Body Remember*, a memoir, which, in part, represents his efforts to counter the stereotype of the disabled as asexual (Fries has congenital deformations of his legs, but says there is no scientific name for his particular "birth defect"). His memoir illuminates his gradual understanding of the various social constructions of himself as Jewish, homosexual, and disabled.

Chapter Five

Nancy Mairs: Essayist & Activist, Writing Through the “Gift of a Difficult Life”

Wholehearted commitment to people who are poor, afflicted, or oppressed, although it inevitably necessitates political choices and leads to shared political action, must first be rooted in personal conversion. – Nancy Mairs

Imagine a woman. A writer. A woman writer with multiple sclerosis, who, after being arrested for protesting nuclear bomb testing, returns to her home in Tucson, Arizona, rolls up to her writing desk in her wheelchair, and begins to write an essay about her day. What does she title her work? “Disability and Political Activism”? “Disability, A Personal Experience”? If the woman is American essayist Nancy Mairs, neither title will do, for as her work about her experience as a disabled woman attests, Mairs resists a split between the personal and the political. It is a stance that has historical ties to much of the feminist thinking she has embraced in her life.

In “Disability and Feminist Perspectives: the Personal and the Political,” Carol Thomas compares women’s personal narratives that emerged out of the women’s movement and became especially popular in the 1970s and 1980s to the personal narratives that have emerged out of the disability rights movement and have been popular since the 1990s. In particular, personal narratives by disabled women “‘give voice’” to their authors, “something,” Thomas writes, “that feminists identify as a key political act: making the personal political” (68). “This ‘bringing in of the personal,’ or ‘writing the self,’ is a hallmark of feminist approaches more generally,” Thomas adds. “The point to emphasize here is that the significance of this is not just that women’s voices are heard

for the first time – crucial though this is – but that it gives rise to new ways of understanding what knowledge is and how it is produced” (68). As I note in my introduction to this project, when it comes to autobiographies by people with disabilities, not all scholars and activists within the disability community are in agreement regarding the ability of personal narratives to affect political change. Also aware of this contention within the field, Thomas explains that this disagreement echoes the “place of the personal” during the women’s movement:

It was this kind of public/private split which enabled some male-dominated left-wing political organizations in the 1970s to argue that issues such as domestic violence, sexual relationships and women’s roles as housewives and mothers were not ‘real’ political issues because they were about ‘private’ life and belonged to the domestic domain. In Disability Studies, such a distinction sustains the view that some ‘personal’ issues to do with living with either disability or impairment effects are ‘private’ matters which should not be foregrounded by the disability movement. . . . This anti-experiential position ignores the tremendous social and political gains made by a movement – the women’s movement – which placed ‘personal experience’ at the very heart of its theoretical concerns and political actions. (74-5)

Like the American feminist essayists who came before her, Mairs centers her personal experiences within her theoretical concerns and political actions. Whether focused on bomb testing in the desert, the representation of people with disabilities in the

media, access to public buildings, or euthanasia, Mairs' essays have become her vehicle for political engagement with American culture, and the means through which she insists on visibility and representation for herself and for all disabled women and men. Although many of her essays – especially those in more recent collections like *Waist-High in the World* – do speak broadly for those within the disability community, her work remains grounded in the personal. Though socially conscious in their scope, even Mairs' more activist-minded essays remain autobiographical; they continue to insist on the value of her singular experience, her life as an *individual*. From a literary perspective, this feature of Mairs' work continues the bloodline of the American tradition of autobiography – a tradition which celebrates individual experience. On the other hand, the singular voice of her work has interesting social implications for those disability scholars who remain unconvinced of the political power of the disabled autobiographer. Mairs does not eschew the power of community action, but her work reminds us that communities are made up of *individuals* with unique needs and experiences. Begin to see the individual, her work suggests, and we will begin to embrace the whole.

I. The Activist at Work

Mairs' inclination for involvement in social issues is documented by her local Tucson newspaper, the *Arizona Daily Star*. An online search of the paper's archives reveals that she organized one of 160 national "Poets Against the War" readings to protest America's impending war with Iraq in 2003; moderated panels on anti-censorship at the Tucson Poetry Festival in 2000; was a guest speaker for the National Organization for Women conference in Tucson in 1997; and even participated in a 48-hour reading

marathon to benefit the Tucson Area Literacy Coalition in 1994. Mairs' social activism is also documented in much of her writing. In *Ordinary Time*, for example, she notes that after college she eventually became aware of her own "erratically increasing awareness of and commitment to social justice" (72). Her social activism began with opposition to the Vietnam War.... a "path that would one day lead beyond simple opposition to radical pacifism," she explains (76). Later, she joined Citizens for Participation Politics, a group of politically-minded Catholics she met while at the University of Arizona. Eventually, Mairs admits that she was drawn to reject her Congregationalist upbringing and to convert to Catholicism at age thirty-four in part because of this particular Catholic community's commitment to community action (80). In Tucson, anyway, she found that the nuns and parishioners alike volunteered on farms and in jails, and they ran for state legislature (86). By the time she is in her forties, Mairs is immersed in social activism in her life, and her essays, likewise, strive to instruct readers of the ways in which the disabled body can be used as a political body.

In her essay "Faith and Loving in Las Vegas" in *Carnal Acts*, for example, Mairs writes of marching for the first time in protest against nuclear testing in the Nevada desert. In her wheelchair, she crosses the line into the private property of the Nevada Nuclear Test Site with a small group of other able-bodied protesters, including her husband, George. It is the first time in over twenty years of social activism that she and George have ever "committed civil disobedience" and they are "glad to be surrounded by loving and oft-arrested friends," for they, too, expect to be arrested for their actions (67). When the Nevada deputies begin to handcuff the protesters, however, they skip over

Mairs. She politely says that she would like to be handcuffed along with the others, but the deputy tells her that the sheriff has told him not to take her along on the bus to jail with the other detainees: “We can’t take you in there,” she recalls him saying, “We can’t handle the wheelchair on the bus” (68). She informs the deputy that she can walk the short distance to the bus, and he reluctantly agrees to cuff her. She is pleased with her actions, but has a brief moment of fear when she worries that the deputies left behind with her wheelchair will “punish” her by vandalizing it. She asks them to take good care of it, and they kindly promise her they will (68).

Mairs notes that there is another protester on the bus who is also disabled, a man post-polio, who walks with a crutch. The deputies do not hesitate to cuff him, however, and once on the bus, he is not singled out, as she feels she is, by a deputy who attempts to use the fact of her disability as an argument against her protest. He informs her that eighty percent of the testing done at the nuclear plant does not involve weapons testing. ““They test drugs to help people like you,”” he says. ““It’s the twenty percent I’m here about,”” Mairs responds, noting that others on the bus “express anger at his laying such a ‘trip’ on me, but though I’m shocked, I don’t feel angry. I feel touched. He’s tried to reach out for me as best he can” (72).

Just as the deputy reaches out to her, other protesters also take a special interest in Mairs as she is led past the holding pen area. They cheer her on, and while she at first feels “inwardly embarrassed” for what she interprets as the able-bodied mistaking her as a hero because of her disability, she later feels that she has at least put her crippled self to good use: “People with able bodies sometimes mistake cripples for heroes,” she explains.

“They forget that I’m doing just what they’re doing, only more clumsily. Such self-deprecation denies, however, my real use to them as an emblem of the value of this action. What they are doing is hard. My presence assures them that it is not too hard, that all of us can do whatever we must, here, now, and wherever else we are called” (72).

Mairs not only sees herself as an emblem of strength for the able-bodied during the protest, she also views herself as a representative of the disabled. She can’t, she says, divorce herself from her ailing body, and because of this, her trespassing means something different to her than to the others. “My crossing the line bears another kind of weight from theirs,” she writes. “It is not a straightforward individual act of civil disobedience. Like it or not, I cross not foremost as a private citizen, but as a representative of those people who, despite their disparities, get lumped as the result of their physical disabilities into a single class” (73). Whether or not other disabled people would want to be associated with Mairs in her act of civil disobedience, she says, nonetheless, that whatever she does reflects on them (73). This knowledge creates a moral conflict within her. Although, on the one hand, she is at the test site with the express purpose to break the law, on the other hand, as a representative of the disabled, she feels “constrained to be a ‘good cripple,’ cheerful and patient, so that whoever might roll along in my wake someday will find the way eased: a stance wholly at odds with the disobedience I am here to practice” (73).

Mairs’ decision to protest the nuclear testing is an individual one, but as she notes above, she realizes that her actions may have reverberations within the disability community, a realization which proves her increasing personal connection with that

community and her continuing concerns over the representation of the disabled in American culture. By the time Mairs writes *Carnal Acts* in 1996 she is a well established poet and essayist, and she has started to become a voice for the disabled community – being asked to speak at MS conventions and publishing her essays in journals marketed to people with disabilities. Two years after the publication of *Carnal Acts*, Mairs also played a political role for the disabled at the national level as one of seven plaintiffs to bring suit against the Greyhound bus company for non-compliance with the 1990 American's with Disabilities Act's statutes on accessibility of public transportation. As a result of the suit, the federal court ruled that Greyhound and all bus carriers must make their fleets handicapped accessible (with the installation of wheelchair lifts) by 2012 (Associated Press 1998). As suggested here, Mairs' public persona has become, in part, one of a disability rights activist. In the introduction to *Carnal Acts* she explains that the final six essays of the work were written with the disabled audience in mind, suggesting that her activism had already extended to her literary persona as well.

Mairs recognizes that through her writing she has become a voice for other people with disabilities in American culture, but she does not, herself, always embrace the community-based language and thinking of some other disabled Americans. For instance, she clearly rejects the group-speak that sometimes emerges from within the disabled community, as she explains in her collection *Waist High in the World*. In her essay, "Challenge: An Exploration," Mairs informs readers that she does not approve of Americans' penchant for using broad-sweeping euphemisms to describe disability experience, descriptions that prove that our society does not want to "confront the radical

transformations of our bodies” (101). For this reason, Mairs writes, “I call myself a cripple. I do so because the word is the most accurate and precise I’ve found, meaning that I no longer have full use of my limbs” (101). Mairs addresses this issue of naming earlier in her standout, oft quoted and anthologized essay, “On Being A Cripple,” in *Plaintext*. Here, Mairs notes that she is aware that “people – crippled or not – wince at the word ‘cripple,’ as they do not at ‘handicapped’ or ‘disabled. Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger” (9). Despite how her family, or society, with its politically correct labels for groups of people choose to construct her, Mairs’ calling herself a cripple helps her gain control over her self-representation, and it likewise politicizes this construction of herself. Simi Linton agrees that words like *cripple*, *gimp*, and *freak*, when used by people with disabilities, have a “transgressive potential. They are personally and politically useful as a means to comment on oppression because they assert our right to name experience” (Linton 16). Like Leonard Kriegel who also adopts the term, Mairs says she uses the word only to describe herself, for “society is no readier to accept crippledness than to accept death, war, sex, sweat, or wrinkles” (Mairs “On Being Fair” 10). And by “society,” here, Mairs does not refer only to able-bodied Americans’, but to many people with disabilities as well. This point plays out interestingly enough when another woman with MS reads an excerpt from “On Being a Cripple” and takes issue with Mairs’ appropriation of the term. Calling Mairs at home, the woman encourages her to embrace a euphemism for her disabled status instead. “In our group,” the woman

explains, “we refer to ourselves as the physically challenged. It suggests a much healthier attitude” (*Carnal* 101). Mairs believes that everyone has the right to describe themselves as they see fit, but she admits that even though her own attitude is often in need of a cure, she does not think that a “dose of language like ‘physically challenged’” can do the trick, “for the simple reason,” she writes, “that I have no idea what that phrase means” (101):

The purpose of a word is to identify a phenomenon precisely and distinguish it from all other phenomenon. And though, when I’m faced with one of the pigeon-toed shopping carts at the Safeway which, with all my strength I can barely wrestle up one aisle and down the next, I *know* that I’m physically challenged, I don’t see how that phrase distinguishes me from anyone else who works hard or plays hard – from, say, the latest climber struggling up the face of Mount Everest. And, lurching along from ice cream to paper towels, I *am different* from that woman in her parka and goggles, face cracked and blackened, setting out on the last day’s exhausted plod to the summit. Not better, or worse, but different. And I have to recognize that difference, not disguise it, in order to live authentically, that is, according to my true self. (102)

For Mairs, then, her sense of difference is pivotal to her coming to a true understanding of herself, especially as she considers her position in all of American culture, not only the disability community. Therefore, while her essays can certainly speak to the concerns of people with disabilities, readers never venture far from the understanding that her work first speaks her *own* emotional and physical concerns. Though undiluted and political, her

essays remain personal, though communal, they do not always embrace the language of her marginalized community; instead, they maintain that essential connection to the individual, singular self.

II. Nobody's Disabled Heroine

Through maintaining this connection to her individual experiences and values in her work, Mairs not only gains visibility as a disabled woman in American culture, she also increases her cachet as an authoritative speaker on disability issues for varied audiences. She makes use of this authoritative stance in the last six essays of *Carnal Acts* which she devotes specifically to the theme of “how to live deliberately and responsibly in the face of a chronic incurable degenerative disease that limits physical freedom and satisfaction without turning either to jelly or to stone” (14). These essays, she says, “provide a rough but accurate sketch of what can go on in an MS family,” but she adds that this experience is “universal enough, in style if not in detail, to be recognized by people unaffected by MS” (15). Here, then, Mairs is not only addressing the disabled and people with MS in particular, but all readers. In particular, she also wants readers to understand that MS is not a death sentence, that she can and has had a life full of rewarding experiences – breaking the cultural stereotypes of what others expect she is capable of. “You may feel surprised, even skeptical, at my tendency to concentrate on the positive contributions MS has made to [my family’s] way of living in the world and relating to it and one another,” she explains. “To the outside world people like us seldom get the chance to name our blessings, since outsiders assume that chronic illness must offer unmitigated misery and that celebrating as well as bemoaning our lot makes us

either Pollyannas or perverts” (15).

That American citizens have a difficult time imagining that people with disabilities can have rewarding lives is frequently documented by sociological research. In their influential book, *Women With Disabilities*, Adrienne Asche and Michelle Fine cite one study in which researchers asked college students to describe their associations for the term “disabled woman.” In the responses of over 100 students, Ashe and Fine note that the disabled woman was “virtually never depicted as wife, mother, or worker” (15). Clearly, the disabled woman is not expected to play the same life roles as other women in American culture. She is expected to live her life unmarried and without children, an expectation which, as Asche and Fine document, “anecdote, interview, and autobiography corroborates [with] the census data and the stereotype of the disabled woman as alone” (14). As Mairs reminds us, however, “even a woman too crippled to tie her own boots or drive a car can, at least if she has a partner who shares her sense of plenty, find a place in the vast web of transactions that binds and sustains the human family” (*Ordinary* 167). And Mairs’ autobiographical essays support this stance, offering a counternarrative to cultural expectations that her life should be otherwise. Through the depiction of the life roles she *does*, indeed, play, Mairs argues that disabled women can and do function as wives, mothers, and workers in American society. This is the picture of disability that Mairs clearly encourages her readers to associate with, despite the accepted norm.

While Mairs’ experiences break with societal expectations and the realities of most other disabled women’s lives, she insists that she does not want to be read as a

heroic survivor in the battle over illness. Lamenting reviewer Nicholas Christopher's description of her work as a "valiant battle against multiple sclerosis," she explains how she "hated the way he reduced the existence I have painstakingly constructed to the corpses and smoldering rubble of a battlefield and set me, a heroic figure, wounded but still defiant in the middle of the waste: another silly story of the sort little boys make up for their Transformers and GI Joes. . . . I am only doing what I have to do. It's enough" (*Carnal Acts* 18)³³. Unlike Leonard Kriegel, whose autobiographical persona actively embarks upon a hero's journey in an effort to discover his authentic self, Mairs does not aspire to represent herself as the heroine of her life. She does not read or write her life as a quest narrative – as the patriarchal model encourages – with its crises, climax, and resolution. And yet her work, despite her best efforts to encourage readers to view her otherwise, does provide a heroine figure for other disabled women looking for disabled role models.

As I noted in chapter five, Mairs has found scant representation of disabled women like herself in the media, and there likewise remains a lack of realistic representation of disabled women in literature. In her essay, "In Search of a Heroine: Images of Women with Disabilities in Fiction and Drama," for example, author Deborah Kent, who is blind, recalls her search as a teenager for authentic disabled heroines in literature to whom she could relate, heroines for whom happy endings did not rely on being cured of their disabilities or illnesses, or for whom "true validation" was not a "gift that could be bestowed only by a man" (92). Even as a teenager, Kent says she sensed the importance of the marriage theme in literature. Today, with a more mature understanding

of the cultural assumption that “disabled women are disqualified from this supreme feminine fulfillment,” she notes that it is not surprising that more authors have not chosen to realistically depict disabled women in literature. Kent writes, however, that as a young reader the heroine she searched for did not even have to fulfill all her romantic dreams: “the heroine I sought needed only to feel good about herself, to express this positive feeling in the way she lived her life” (93). What Kent finds as an adult surveying over thirty novels and plays for her essay is that this heroine rarely exists:

Whether she is blind or deaf, facially disfigured or paraplegic, the disabled woman is typically shown to be incomplete not only in body, but in the basic expression of her womanhood. Frequently she is a victim – her disability the lingering reminder of some hideous accident or vicious act of violence. Generally she is both physically and economically dependent upon others, constantly draining their resources and giving little in return. Where men are concerned, she is nearly always “someone of no account.” Most of these characters, at one point or another in their histories, express bitterness, despair, and self-loathing. Their anguish is generally seen as the inevitable outgrowth of the disability itself. Social stigma, which is in fact responsible for so much of the pain endured by disabled women in real life, is seldom explored or even acknowledged. The girl with a clubfoot is miserable because she cannot dance; the blind girl longs for the sunsets she will never see. They do not rebel against the world’s view that they are helpless, useless, pitiable, and undesirable. (93)³⁴

Kent acknowledges in her essay that “a number of disabled women have written autobiographies” about their disability experience, but she concludes her essay with the hope that more disabled women writers will begin to feel more free to translate their life experiences into fiction and drama. “It is my hope,” she says, “that in the decades ahead we will create our own heroines: women whose lives hold meaning not merely for those of us who are disabled, but strike a universal chord with the joys and heartbreaks of women everywhere” (110).

Kent’s call for more representation of disabled women in fiction and drama written by disabled women is worthy, but Kent too easily dismisses the cultural value of disabled women’s autobiographies. In Nancy Mairs’ work, for instance, we find the heroine Kent has been seeking since her youth. Mairs refuses to look upon her lot with pity, and she maintains a positive outlook about her life. Furthermore, she disproves the cultural narrative that insists there are no traditional happy endings for disabled women: she marries; she has two children of her own and adopts another; she works and is actively involved in her church and community; and she becomes a loving, albeit often frustrated and weary, caretaker to numerous others (both human and animal) who drift into and out of her household throughout her adult life. While fraught with the difficulties she encounters while performing these roles as a disabled woman, Mairs’ essays advocate for the unquestioned acceptance of disabled women in these roles. In this sense, she is an activist for her own way of life. She discourages our thinking of her as heroic because part of her activist stance is to prove that the actions she performs daily are as ordinary for her as they are for millions of other disabled and able-bodied Americans alike. She is

heroic, then, only in light of the fact that this representation has *not* been accepted by American culture. Through continuing to write about her daily life in her essays though, Mairs continues her campaign for the kind of visibility within American culture which will ultimately change Americans' views about the disabled. And *this* is Mairs' "valiant battle."

III. How to Change the World

Deteriorating physically each year from the effects of her MS, there are few topics Mairs currently addresses in her writing that are not situated within the theoretical framework of her stance as a disabled woman. Not surprisingly, one of the activist causes she has embraced is equal access to public spaces for people with disabilities. She writes about this issue in "Opening Doors, Unlocking Hearts," in *Waist-High in the World*. Here, she begins her argument for equal access with her acknowledgement that because of the degenerative nature of her disease, for her, "no accommodation is ever final" (88), and she wants American society to acknowledge that: "As a disabled woman, I find that my physical and social environments send the message that my presence is not unequivocally welcome or vital," Mairs writes. "I am not looking for reassurances just now. I want to change the world" (88).

Mairs' crusade to change the world begins at the construction phase. Addressing readers in second person, Mairs hypothetically invites herself into their homes to test their ability to accommodate her disability. Of course she finds many barriers to her movement and argues that while she certainly does not expect her readers to rearrange their homes to contain her, many of the problems of public access she encounters can

easily be solved during the design stages of our homes and public buildings. Construction industry fears about the costs of access-minded building, however, prevent the installation of grab bars in every bathroom, for instance, even though, as Mairs argues, if they were manufactured in mass, difference in costs would be negligible (89). Ultimately, what really prohibits accessible construction, Mairs argues, is Americans' widespread denial that they will ever *need* such amenities: ramped building entrances and extra-wide doorways to accommodate wheelchairs, public transportation that includes wheelchair lifts and hand controls, elevator panels in brail, and emergency services equipped for the hearing and speech impaired. In requesting these accommodations, Mairs comments that "no one expects all impediments to be miraculously whisked away. In insisting that others view our lives as ample and precious, we are not demanding they be made perfect" (106).

In the meantime, Mairs is willing to continue to make the lives of people with disabilities more visible in American culture by writing about *her* life and *her* needs. And she is willing to talk about things that others are ashamed to discuss. Like toilets: "Someone has got to talk about toilets, even though Mother said not to, or the nondisabled will go on rushing into and out of public rest rooms without even seeing the barriers. And what ever goes unseen goes unchanged" (96). Mairs is just as passionate about changing America's public toilets as she is about changing American's attitudes toward the disabled. She is not ashamed to relate the experiences she has had with nondisabled people who have treated her as though she is simply depressing, a blight on their American landscape. One cab driver, she writes, actually shouts at her, saying that

people like her (people who need assistance with a wheelchair) should not be out riding around in his cab, but back in her home where she belongs. In sharing her experiences, however painful, Mairs exposes American sentiments about the disabled, “aversions,” she writes, “that in subtler forms, poison the atmosphere like a fine gray mist, indiscernible but for the headache and lassitude it induces” (101). These sentiments make Mairs all the more determined to “roll out among” the nondisabled more frequently – both literally, I suspect, and, more broadly, covering a greater distance, in her writing. “I want people to grow accustomed to my presence,” she adds, “and to view mine as an ordinary life, less agreeable in some of its particulars than theirs but satisfying over all” (104):

The more perspectives that can be brought to bear on human experience, even from the slant of a wheelchair or a hospital bed, or through the ears of a blind person or the fingers of someone who is deaf, the richer that experience becomes. If it is possible and pleasant for me and my kind to enter, the world will become a livelier place. You’ll see. (106)

Mairs certainly makes the world a more lively place by offering her own perspectives not only on topics regarding public access, but also in her work which considers more volatile and publicly debated issues such as abortion and assisted suicide. In these, as in her other essays, Mairs’ experience as a disabled woman remains steadfastly visible at the forefront of her debates. In her essay, “Learning from Suffering,” in *Christian Century*, for example, Mairs evaluates the practice of assisted suicide in America and its proponents, such as Dr. Jack Kevorkian, commonly referred to

in the press as Dr. Death. In light of Kevorkian's crusade of mercy, she cautions readers to not accept the widely held view that the chronically, even terminally ill and disabled consider their lives unnecessary (a social view perpetuated, I will add, by the 2004 "best picture" award winner *Million Dollar Baby*, in which the female prize-fighter convinces her boxing coach to kill her after she becomes paraplegic). "As a person with a disability," Mairs writes, "I am assumed by many to lead a life without worth, and plenty of them would be glad to help me end my misery" (448). Mairs explains that medical personnel, professionals trained only to cure the body, often look upon incurable disabilities such as her degenerative multiple sclerosis as "hopeless," and that even some neurologists express a "distaste" for her neurological disorder in their refusal to treat MS patients (481). Doctors do not, it seems, want to take on patients they will be unable to cure. Mairs suggests that this stance is supported in our American culture that "commonly confounds social value with economic productivity" (481). Unable to hold or acquire jobs, many disabled Americans, she argues, find that their lives are rendered "fruitless" by a society that considers its disabled citizens to be a drain upon its resources. In an extreme example of this stance in action, Mairs notes that Americans with disabilities have even reported being required to sign do-not-resuscitate orders before receiving hospital care (481). The offending institutions in these cases are willing to offer a standard level of care for the disabled, but looking at them as hopeless cases, and thus less valuable as human beings, they are not willing to expend their own resources for the heroic life-saving measures they deem unnecessary.

Elsewhere, Mairs notes that this attitude is encouraged when public figures such

as Christopher Reeve, “on prime-time television, with all the money in the world to pay for round-the-clock personal care, [suggest] that public resources were being wasted on maintenance for disabled people, specifically those with spinal-cord injuries, that would be better spent finding a cure” (“On Being Fair” 30)³⁵. Mairs argues that the attention Reeve received in the press because of his celebrity may have had negative ramifications for other disabled Americans seeking equality within American society over the race for a cure. She explains:

A great many people with disabilities are considerably less eager to be cured in some hypothetical future than to find, right now, a reliable and affordable aide to help them perform a bowel evacuation every other day. Indeed, some resent society’s relentless drive to fix them, implying as it does that they are defective and thus undesirable as they are. . . . Calamity, even terminal illness, does not necessarily engender a desire for death, as many hospice workers can attest, although accompanying poverty, helplessness, intractable pain, rejection and abandonment may. Something is fishy when a society accepts that a particular segment of its members naturally prefer to be dead. (30)

This cultural assumption that the disabled are defective, undesirable, and would prefer to be dead ties back into Mairs’ feelings about assisted suicide, which she considers in much the same light that she considers abortion, for in both practices, she argues in her essay “Freeing Choices,” the “mute message – that one is an accident that ought not to have happened – is communicated . . .” (*Waist High* 112). And in concurrence with her stance

on abortion, Mairs says she remains adamantly pro choice on the matter of assisted suicide, though the question of “choice,” she reminds readers, “is vastly more complex than politicians, legislators, and religious fundamentalists make it” (113). And for Mairs, part of that complexity stems from that fact that she looks at this political issue from within the folds of personal experience. As a depressive who has attempted suicide on more than one occasion, Mairs reminds readers that she now must monitor herself carefully for symptoms suggestive of a “downward spiral” back into the depths of depression. Learning to acknowledge these symptoms and curtail their attendant suicidal tendencies, Mairs says she has “spent a good deal of my life struggling to deny myself the death to which [assisted suicide] activists would like to guarantee me the right” (114). In particular, Mairs questions suicide rights activists’ use of the term “rational suicide” to distinguish between the kinds of people the right-to-die movement proposes to advocate for. Supposedly, by proposing to only help facilitate “rational suicides,” irrational suicide attempts like the ones Mairs herself experienced would be prevented. Mairs argues, however, that through her own “intimacy with self-destructive urges,” she has come to understand that “suicide becomes imperative only when one loses sight of all other alternatives. . . . Since hopelessness is a distinctive symptom of depression, which is an emotional disorder, actions carried out in a despairing state seem to me intrinsically irrational” (116).

The social construction of disability in American culture is another concern for Mairs when considering such volatile issues as assisted suicide:

I think it is very, very important to distinguish ‘disability,’ which is a

social construct rather than a medical diagnosis, from some of the circumstances associated with it, often by people who have little direct knowledge of physical and mental limitations and their consequences. Like all negative terms, “disability” is part of a binary, existing in relation to a privileged opposite: that is, one is “disabled” only from the point of view of another defined by common social values as “able”(13). . . . “I” am disabled, then, only from “your” point of view (and “you” from “mine”). Whoever gets to define ability puts everyone else in place, which (human nature tending to define one’s own as the proper place) then becomes other, outside: a cheerless and chilly spot (14).

Considering these values working behind the social construction of the disabled and the issue of assisted suicide, Mairs argues that “behind the view of death as a ‘right’ to be seized and defended lurks the hidden assumption that some lives are not worth living and that damaged creatures may be put out of their misery” (120). And while Mairs admits to wanting to be in charge of her life – and her death – her experience as a disabled woman in a society that does not accept disability encourages her belief that no amount of state or federal regulation of assisted suicide “can eliminate the subtle pressure to end a life perceived by others to be insufferable” (121). “If ideally, I ought never to have [been] born,” Mairs explains, “and if my dependent existence creates a burden on those who must care for me, then don’t I have not merely the right but the obligation to die? How can I honorably choose otherwise?” (121).

While she is aware that some terminally ill and disabled people clearly do want to

die, Mairs encourages readers to more readily embrace the fact that many more actually enjoy their lives quite a lot. They do not view themselves as hopeless cases, and they reject those who can not imagine their worthy lives beyond their disability. In describing those who subscribe to this view – including herself – Mairs explains:

We tend to repudiate the medical model of disability, which views us as sick and in need of a cure, and the mechanical model, in which we are broken and require repair. We see disability as a social construction. It's the assumptions and insensitivities of the majority that assign limits to bodies and minds that work in "deviant" ways. Some would go so far as to say that society et' large is responsible for dis-abling us, and that with more ramps, texts in Braille, interpreters and other such modifications we would live just as easily in the world as anyone else. ("Learning" 481)

In refusing to view herself as in need of repair, Mairs, through her canon of writing thus far, proves that despite her disability she is fully present in her life. And although her disability may cause both emotional and physical suffering, this suffering, in and of itself, is not, she argues, "an aberration or an outrage to be eliminated at any cost," as the medical model of disability implies. Suffering, she says, "strikes me as intrinsic to the human condition. I do not like it. I'm not asked to like it. I must simply endure in order to learn from it. Those who leap forward to offer me aid in ending it, though they may do so out of the greatest compassion, seek to deny me the fullness of experience I believe I am meant to have" (481).

Indeed, much of the strength of Mairs' activist essays resides in the proof of this

fact – that she is capable of enjoying the fullness of experience – by detailing the varied life experiences she does have, convincing us that her fighting against her suicidal tendencies and choosing to live her disabled life is an “honorable choice” despite her fears, her physical pain, embarrassment, and personal difficulties. In her essay, “Doing it the Hard Way” in *Carnal Acts*, Mairs reflects on her daughter’s choice to join the Peace Corps after her college graduation rather than looking for the high-paying job her education could surely secure her. Instead, she travels to Zaïre to help rural farmers build and stock their own fish ponds to increase their levels of self-sustainability. Mairs notes that numerous friends and family questioned Anne’s decision, but Mairs respects her daughter’s quest for adventure and personal growth, her willingness to face potential difficulties. Typical of Mairs’ activist-themed essays, “Doing it the Hard Way” moves from Mairs’ musing on a topic – in this case her daughter’s decision to join the Peace Corps, despite the difficulties she is sure to encounter there – to personal example from her own life, to exploring the larger, social ramifications of the topic at hand.

Should the prospect of picking up and moving to rural Zaïre seem too remote for her readers, Mairs reminds us of the difficulties people face in their daily lives. For Mairs, of course, that difficulty is living with MS, but the “lost job, the child gone wrong, the parent with Alzheimer’s, the marriage truncated by death or divorce” can all infuse our lives with difficulty, Mairs writes, and it is “then we have to choose how we respond to the ‘gift’ of a difficult life” (110). Aware that most readers will not consider the prospect of difficulty a “gift,” Mairs’ activist goal for this short essay is to encourage her readers to view difficulty in a new light. Mairs argues that American culture has

encouraged us to “Take it easy,” and to “Kick back and relax” to the extent that *difficulty* has become “something of a dirty word in our society” (111). We are shamed by difficulty, she says; we buy into cultural assumptions that “to experience difficulty suggests some sort of weakness,” that in discussing our difficulties we run the risk of being accused of whining and self-pity (110). We want, after all, Mairs writes, “to appear independent and capable, those most valued traits of the American psyche, or at least, failing that, to be considered a trooper, a good sport” (111). But, Mairs asks,

What’s wrong with “difficulty”? I want to know. I want to know. I want to redeem it, as both a word and a concept. I want to speak it out loud, without apology, in the same matter-of-fact tone I’d use to say, “I prefer black cats to spotted ones,” or “My daughter has been known to eat grasshoppers.” And then I want to figure out how I can not merely admit to having a difficult life but also use the difficulties I’ve acknowledged to enrich that life. (111)

It is in full knowledge of these difficulties, then, that Mairs agrees to travel with George to spend Christmas with Anne in Africa, an experience she describes in her essay, “Where I Never Dreamed I’d Go and What I Did There,” in *Carnal Acts*. Getting to Africa is an adventure in itself, confounded by Mairs’ anxiety over airports – places she says have the ability to send her “over the emotional top” (*Waist-High* 190). This anxiety is “specific and acute,” she says, relating “almost solely to my physical helplessness” once being cut off from her wheelchair (191). Mairs notes that when she travels (to Africa in 1988 or anytime) there are no uniform policies among US airlines for handling

disabled passengers. How she is treated, she says, “depends not upon regulations but upon the whim of the individual [airline] agent” (192).³⁶ Therefore, Mairs is understandably distressed when she hears before her Africa trip begins that a Lufthansa Airlines agent has summoned Anne to the airport for a meeting about Mairs’ impending flight. He tells Anne that the airport can not “risk the liability of providing any assistance” to her mother. He warns her that there are no jetways connecting the planes to the terminals in Africa and that he could not guarantee that the airport’s single wheelchair would be available for her when she arrives. Mairs would have to walk down the stairs from the plane and traverse the tarmac to the terminal without the help of airport personnel (*Carnal* 148). Considering these difficulties, the agent asks Anne, “Do your parents know what they’re doing? Are they sure they really want to come here?” Anne says *yes*, and George agrees – they will manage (148).

When Mairs does arrive in Africa, she and George do manage just fine on their own. He helps her down the steep stairs to the tarmac to find her own wheelchair waiting for them. Mairs says she believes she could not have made the trip to the terminal on foot, but quips, “You never know what you can do until you have to do it,” an adage that serves as a refrain for this piece. And this adage is put to the test when Mairs arrives at Anne’s village in the Kinshasa bush, where there is no electricity, no running water, and the special, accessible latrine Anne has commissioned a local carpenter to build for her visit is fully open to the surrounding jungle on one side. Still, she manages these difficulties and enjoys the unique life experience she is having (154).

Because she can not roll her wheelchair through the jungle, Mairs remains behind

in the village as Anne, George, and the local farmers hike to the fish ponds Anne has helped them build and stock. Mairs has heard much of these ponds through Anne's letters, and when it is time to harvest the ponds, in a rare moment of grief over the freedom her MS has cost her, she is saddened that she will not be able to join in the celebration. Although he cannot communicate with her in English, one of the fish farmers senses Mairs' grief and offers to carry her to the harvest. The scene is both comic and touching, a testament to the human spirit in the face of difficulty: The man carries her

at breakneck speed, down half a mile of steep, slippery hillside. By grasping my left wrist in my right hand, I can keep my arms around his neck. The rest of me is too weak to cling on, and so I bounce against his back, as limp as a Matadi flour sack. When he feels me slipping, he stops and bends sharply forward, hitching me higher. The ground lurches up toward my face abruptly, then recedes as he resumes his course, his rubber boots slapping the muddy path. I can't believe what I'm doing. I can't believe I am plummeting through the jungle on the back of a man to whom I can say nothing but "mbote": literally, "good." I couldn't ask him stop if my life depended on it. (156)

Later, after the harvest, and after two men have shared the trickier task of carrying her back up to the village, Mairs reflects on the farmers' assistance. Without modern conveniences, she realizes, their lives necessitate physical labor (158). It is not uncommon in the village, for example, for family members to walk forty kilometers to the hospital to check on the condition of a loved. "In this context," she says, the men's

actions are not so “mysterious: If you come upon a woman whose legs don’t work, you carry her” (158). Whatever the men’s motivation, Mairs appreciates their care. Because of them, she is “enabled to witness the process that shapes the contours of Anne’s new life” (156). At the end of the trip, Mairs asks herself, “What if I’d never come. . . How could I bear never to have seen this?” (160). But the question, Mairs knows, is rhetorical for a woman who is willing to accept both the gifts and the challenges of living a difficult life. “This is the only way I know to live as a woman with multiple sclerosis,” Mairs writes:

not to listen to the ominous questions of Lufthansa agents but to hear instead the confidence (even if you think it’s misplaced) of the daughter who believes that you’re sure what you want to do, of the husband who says you can manage together, of yourself in whose pronouncement that “You never know what you can do until you have to do it” hides the stronger, even more enabling message, “If you decide you *have* to do something, you’ll do it.” (161)

Whether she is writing about the personal difficulties she has faced as a disabled woman or the personal joys she has experienced in the same body, Nancy Mairs’ motivation for writing is the same as any American writer’s: to connect. Her desire, she says is to “contact others, to share my experiences with them, to stir them to recognition of the similarities that underlie their experiences and mine, to illuminate and delight in and laugh over the commonplaces of human life” (*Remembering* 6). Mairs is aware of the inherent dangers of focusing too much on her disability in her writing, though, and she

consistently strives to connect the lessons she has learned as a disabled person to the American world that exists beyond the wheelchair ramp to her home. Always concerned about the cultural messages embedded in her work and the work of other disabled writers, Mairs laments that many autobiographical accounts of illness and disability “concentrate so fully, almost claustrophobically, on the singularities of disabled life that they fail to reflect the ways in which such life is indistinguishable from any other sort: fueled by the same appetites, fraught with the same anxieties, replete with the same delights,” Mairs writes in *Waist-High in the World* (12):

My hope is that, in scrutinizing some of these elements common to the human condition – among them adjustment to change, body image and sexuality, the need for both independence, and nurturance, the ceaseless search for equality and justice and pure pleasure – through the lens of my own experiences and those of people I know well, I can bring to life their particular significance in terms of disability. (12)

And in speaking of disability in terms of something that is common to the human condition, Mairs often reminds us that disability – in one form or another – is something that most Americans will likely contend with at some point in their lives. With today’s sophisticated medical technology and a life expectancy that has increased more than 30 years since the early 1900’s, more Americans who are born with or develop illnesses and disabilities will survive, Mairs says, “living longer and more publicly than ever before” (17). Thus, she writes, “my interest in this subject, though intensely personal, is by no means private. Something without precedent is taking place, and we need a theoretical

and imaginative framework for evaluating and managing the repercussions” (17).

Mairs is correct. Something without precedent *is* taking place – for not only is the theoretical framework she calls for emerging through the field of disability studies, disabled Americans are emerging from the margins of our culture, made visible, in part, because of a relatively new and growing genre of American autobiography. Whether we call works in this genre “pathographies,” “autopathographies,” “auto/body/ographies,” or just “life writing,” first-person singular works by Nancy Mairs, Leonard Kriegel, and others for whom illness and disability are as central and essential to their writing as they are to their daily routines, are changing the way we view the ill and disabled – both in literature and in our lives.

Notes:

³³ Mairs does not actually name Christopher in her book, but I discovered the quote during my research on Mairs. I refer to Christopher’s negative review of *Remembering the Bone House* in the *New York Times* in chapter one.

³⁴ For full-length scholarship on representation of the ill and disabled in literature, see Diane Price Herndl’s *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840-1940*; David T. Mitchell and Sharon L. Snyder’s *Narrative Prosthesis: Disability and the Dependencies of Discourse*; and Rosemarie Garland Thomson’s *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, as referenced in my introduction.

³⁵ Notice the difference here between Mairs’ views and Kriegel’s response to Christopher Reeve, which I noted in chapter three. As a disability rights activist, Mairs would rather Reeve not speak at all than to speak ideas that do not mesh with the goals of the disabled community as a whole. Kriegel, who does not view himself as an activist, on the other hand, supports Reeve’s decision to not become a spokesperson for disability rights groups by holding on to the hope – or the illusion, as Kriegel says – for a cure.

³⁶ Mairs notes that unlike busses and trains, airlines are exempt from complying with the Americans with Disabilities Act passed in 1990. Instead, airlines come under the jurisdiction of the earlier Air Carriers Access Act, which she says is less stringent than the ADA (*Waist-High* 192).

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