

Writing from "Waist-High":  
Nancy Mairs's Autobiographical Essays and the Subject of Disability

by  
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## Abstract

Nancy Mairs is a feminist writer with multiple sclerosis who has written several autobiographical texts about her life with an illness. She is an exemplary figure of the possibilities of autobiography. As a writer of autobiographical essays, the narrating subject positions herself in interweaving, multiple subject positions. This thesis explores three subject positions within Mairs's work: the diagnostic subject, the anecdotal subject, and the subject of others.

As a diagnostic subject, Mairs counters medical discourse and diagnoses herself with multiple sclerosis. By recounting her interactions with the medical establishment, she reveals flaws and recommendations for change within the system. Her precise use of terminology carries over into other areas of her life, and she is successful in making the reader aware of the influences of language on thought processes in everyday life.

As an anecdotal subject, Mairs inverts the dominant Western European cultural narratives of invalidism in America. Through anecdotes of her personal experiences, which are carefully constructed, the readers' emotions are turned away from pity and shame regarding the disabled and towards hope in understanding a richer and more complex world. She displays fragmented and often ambivalent experiences of her life in a wheelchair.

As a subject of others, Mairs includes the works of others into her own writing. The writings of family members, general members of the public, and scholars find their way into her writing. These heterogeneous voices serve various functions within her project, and as a collective they serve as ways in which she knows and routes her construction of herself.

As a writer of autobiographical essays, Mairs aims to write about her life with an illness in such a way as to "heal" herself (deal with her disease mentally and emotionally) and to aid others in identifying with her experiences. She also aims to expose what it means to be invisible precisely because of an obvious physical (ironically visible) disfigurement in modern American society. Mairs achieves these narrative goals by exploring multiple subject positions as the diagnostic subject, the anecdotal subject, and the subject of others.

For all those who exist "waist-high" in the world we inhabit together

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Short Titles

CA: Mairs, Nancy. Carnal Acts. Boston: Beacon Press, 1996.

EB: Thomson, Rosemarie Garland. Extraordinary Bodies: Figuring Physical Disability in America Culture and Literature. New York: Columbia University Press, 1997.

PT: Mairs, Nancy. Plaintext. Tucson: University of Arizona Press, 1996.

RB: Couser, Thomas. Recovering Bodies: Illness, Disability, and Life Writing.  
Madison: University of Wisconsin Press, 1997.

RBH: Mairs, Nancy. Remembering the Bone House: An Erotics of Place and Space. New  
York: Harper & Row, Publishers, 1989.

WH: Mairs, Nancy. Waist-High In the World: A Life Among the Nondisabled. Boston:  
Beacon Press, 1996.

VL: Mairs, Nancy. Voice Lessons: On Becoming a (Woman) Writer. Boston: Beacon  
Press, 1994.

## Preface

While reading various articles on the study of autobiographical practices, I came across the notion of a peculiar phenomenon; those who write autobiography tend to be the ones reading it (Egan 1).<sup>1</sup> As a second-generation American of South Asian descent, I have kept journals about my experience as an ethnic and racial minority since I was eight years old. During my sophomore year of college, I realized that those who are marginalized have a unique perspective on mainstream American culture. In particular, Gary Okihiro's Margins and Mainstreams was my first introduction to this concept (175).<sup>2</sup> In his discussion about Asian Pacific Americans and the legal challenges they have faced in the courtroom throughout American history, Okihiro explains that their struggles have highlighted the finer points of justice in mainstream American culture. The concept that the perspectives of minorities—whether they be racial, ethnic, gender, class, or disabled—have real and tangible consequences has stayed with me throughout my undergraduate education. I have also constantly questioned the motivations behind my own writings about being a minority in America.<sup>3</sup>

In writing this thesis, my mission is two-fold. I hope to understand my own motivations for writing autobiographical narratives, as well as to understand and to educate others as to what agendas are created in the autobiographical mode of writing carried out by writers like Nancy Mairs. Just as nondisabled minorities have done and continue to do, the voices of those with disabilities can educate us about the mainstream ableist American culture that we live in. It is important for all of us, especially my future physician colleagues, to be able to read these narratives and take with us a sense that we



have entered another dimension of our world that could one day, at any moment, by virtue of an accident or a diagnosis of a chronic disease such as multiple sclerosis to either ourselves or those for whom we care dearly, become our daily reality.

Part of daily life for those with disabilities is facing the dominant cultural narratives that mainstream American society assumes as "normal." One claim that I make in my thesis is that through life-writing, Mairs inverts the dominant cultural narrative that demands "normal" people feel pity for those who are disabled.<sup>4</sup> She shifts attention away from pity and towards understanding a world rich in complexities that can seem incomprehensible to those not directly experiencing it. I thought about this claim one snowy night in early January, as I was walking home from the Central Campus Recreational Building, a place where there is no readily visible entrance for people who use wheelchairs.

I saw a young woman, probably a college student, wheeling her way in the direction I was headed. As I was walking behind and to the side of her, I could see her strong arms pushing the wheels of her wheelchair. I wanted to ask her if she needed any help; there was ice on the ground and it was freezing outside. But I wasn't sure how my offer of help would be interpreted. I didn't mean to offer her what might be construed as pity, but rather a helping hand. Before I got the courage to ask, we approached the top of a hill and she slid down it without using her arms to push her wheels, racing ahead of me. Not realizing that she would slide down so quickly, I almost ran to catch her. But I saw her hair fly up and her head turn—and a slight, enigmatic smile cross her face that I would like to think was directed my way. It was a smile that I will never be able to interpret.

### Introduction: Nancy Mairs as a Writer of Autobiographical Essays

While in her late twenties, Nancy Mairs learned that she had multiple sclerosis. As a disease, multiple sclerosis is particularly marked by its degenerative nature. It is a disease of the central nervous system that can affect all motor and sensory functions in the body. Since then, she has lived thirty years of what she would call a new life (WH 29). After losing her ability to walk, and part of her vision, she is now in a stage of the disease where she can only use her right hand. She must also use an electric wheelchair called a "Quickie P100" (WH 45-6). As she has lost various faculties, Mairs has been forced to deal with different stages of her disease. This has not been easy; among other things, she struggles with agoraphobia and suicidal bouts of depression (PT 13, 21). She maintains that she has dealt with her situation because she has been forced to—and that the reader would have to manage as well should he suddenly find himself in a wheelchair (CA 18).

Nancy Mairs has been writing since her youth, and that writing has provided her with a means to make sense of her life with a disability (PT 98-99).<sup>5</sup> As a self-identified feminist writer, she has embraced her illness and her experience in dealing with it (PT xi). In the past eleven years, Mairs has produced six collections of personal essays. In order of publication, these are Plaintext, Remembering the Bone House: An Erotics of Place and Space, Ordinary Time: Cycles in Marriage, Faith, and Renewal, Voice Lessons: On Becoming a (Woman) Writer, Carnal Acts, and Waist-High in the World: A Life Among the Nondisabled. Mairs testifies throughout her narratives to the importance of writing itself in the process of coming to terms with her disability. She admits that writing is not

an easy way to forget about herself, but on the contrary, it “absorbs my attention utterly” (WH 4). Her narratives, while intertwined with many other aspects of her life, convey her obsession with sharing her experiences as a “cripple” and are inclusive of the events that have led up to her existence “among the waists of the world” (8). In Waist High in the World, she states:

I use inscription to insert my embodied self into a world with which, over time, I have less and less in common. Part of my effort entails reshaping both that self and that world in order to reconcile the two...I can't become a 'hopeless cripple' without risking moral paralysis; nor can the world, except to its own diminishment, refuse my moral participation. (60)

Herein lies the main reason behind why Mairs writes about her life with a disability—it is a calling to reconcile the differences between a nondisabled world and a self that is marked by her disability. Writing is a means to exercise her “moral participation” in society as she writes candidly about her life with a disability. Not using her voice she would risk “moral paralysis”—or a condition she identifies with the “hopeless cripple” who makes no contribution to the world.<sup>6</sup> The modifier used in both “moral participation” and “moral paralysis,” signifies her sense of responsibility toward herself and society (WH 60).

Society, especially mainstream society, has much to gain from Nancy Mairs's life-writing/narratives. In the midst of a divisive society in which disabled people are positioned against “normal” people, she attempts to understand and to transcend the binary opposition between the “normal” and the disabled. This thesis will primarily examine three collections of personal essays— Plaintext, Carnal Acts, and Waist-High in

the World—because they are related collections primarily focusing on her life with a disability.<sup>7</sup>

Plaintext, derived from Mairs's doctoral dissertation, encompasses many aspects of her life besides dealing with a chronic degenerative illness; she also writes about being a mother, a foster parent, a wife, a graduate student, a teacher, and “an inmate in a state mental hospital,” among other roles (RBH 262, VL 2). It was the first anthology of prose she published, and was received with much controversy as she resisted strong cultural narratives of traditional motherhood. Instead, she portrayed the roles of motherhood and disability as difficult and richly conflicted (CA 122-123).

Mairs wrote Carnal Acts in response to a question posed by a student about how she copes with multiple sclerosis and how she found her voice as a writer (81). In this text, Mairs explains her refusal to be ashamed because of her disability and because of her “carnal acts” (CA 91-92).<sup>8</sup> Discussing the ways in which she discovered her voice, she abandons the “‘nice girl’ routine” (Miner 291). She writes that Carnal Acts enabled her “to inscribe the earthly life I’ve tried to flee: its tricks, its sweet poisons” and that “I want...to grub around for the roots connecting experience with belief and action” (RBH 254, CA 11) This is a text about having the courage to utter her experiences—even if they are considered “unspeakable” (CA 63).

Waist-High in the World is about the private and personal aspects of Mairs's life in a wheelchair. In this book, she offers a more broad-based and systematic look at the life of a person in a wheelchair than two of her previously published books (Plaintext and Carnal Acts). From the perspective of being “waist-high,” Mairs has written a series of essays in which she describes “a life among the non-disabled.” She takes up both

personal and public issues of being a representative of the disabled community, of her declining health, and of her family members' experiences in dealing with her illness.

Through Plaintext, Carnal Acts, and Waist-High in the World, Mairs insists that her voice be heard. The metaphor of writing as an expression of voice is literal for Mairs because now she can no longer write by hand or type for extended periods of time. She literally uses voice-activated equipment to continue her work (VL 149). Voicing her story, literally and figuratively, Mairs self-reflexively engages with life-writing as self-construction. An autobiographical text, argues Sidonie Smith in A Poetics of Women's Autobiography, "becomes a narrative artifice" (5) and therefore it is not possible to read Mairs' autobiographical narratives as if one is reading her life. Recognizing the concept of autobiographical narrative as "narrative artifice," Mairs writes:

The important point about the stories we tell ourselves about our lives:  
We make them up as we go along. Instead of accepting someone else's tales about princes and monsters and omniscient daddies, we come up with fresh material. We get to choose how the story goes. We can't select every event and detail, of course. We can't decide, for instance, whether or not someone gets MS. MS just *happens*. But—and this is the exciting part—we can choose how we will respond to that happening, what kind of role we will give it in the story we're making up as we go along. (CA 124)

She is especially aware of how people make meaning and know themselves through their experiential histories—by selectively telling their stories. Her authority to selectively tell her story arises from the fact that it is her life she is writing about. Mairs assigns roles to

parts of her story, using her personal experiences to make larger commentaries on society and the people who inhabit it.

Memory, the past, and identity are all constructed through the process of writing—they are re-membered, or literally put back together after being separated within the individual. Mairs explains, “the past, that ramshackle structure, is a fabrication. I make it up as I go along. The only promise I can state about its ‘reality’ is that I ‘really’ remember (reembody? flesh out anew?) the details I record; that is, I don’t deliberately invent any of them” (VL 118-119). In writing out the literal configuration of the word “remember,” Mairs communicates that all memory is selective and created—just as something reembodied is fleshed out anew. The agency in autobiographical writing, therefore, lies in making meaning and specifically in making the meaning of the past. She does not portray herself as a victim, but rather as a self-empowered survivor.

Thomas Couser, a pioneer in examining disability and life-writing as a genre in literature, states that autobiography is a promising medium through which to gain self-empowerment. Exploring the differences in the effects of photography and life-writing, Couser argues:

As a verbal rather than visual form, writing may offer a kind of neutral space for self-presentation and the renegotiating of status. Moreover, insofar as autobiography is the literary expression of the self-determined life, the genre may be said to embody personal autonomy, it seems the ideal mode for contesting the association of disability with dependence.

(RB 182)

The “neutral space” that allows “self-presentation” of a “self-determined life” is an accessible medium for minorities—who are usually denied such spaces in which to express themselves. Autobiography, unlike photography, allows the telling of a story without the assumptions or stereotypes that characteristically arise from visual media which presume that the gaze of an onlooker is unaided, real, and able to see the “truth” about a story (Eakin 3).<sup>9</sup> Autobiography, then, contests “the association of disability with dependence” by demonstrating that the disabled have voices that are capable of being heard by themselves—through written narrative.

Thomas Couser terms the writings of disabled people autopathography.

Autopathography is a category which includes “autobiographical narratives of illness or disability.” These illnesses or disabilities heighten “one’s awareness of one’s mortality,” threaten “one’s sense of identity,” and disrupt “the apparent plot of one’s life” (5).

Autopathography allows people to confront and to write through these effects. Mairs’s autobiographical narratives can be classified as autopathography because they re-present illness and its disabling effects on her body. In the process of writing about her life, she writes about her heightened sense of mortality, her sense of identity, and the ways in which multiple sclerosis has changed the plot of her life. The concept of autopathography will prove useful as a lens through which to frame and to examine her autobiographical narratives.

In her autopathography, Mairs negotiates multiple subject positions. In order to understand herself as an ongoing subject of disability, always in process and not as a fixed and coherent Nancy Mairs, she routes her construction of herself through these subject positions. Autopathography, a genre of life-writing about the disabled body,

could take various forms—including memoirs, journals, testimonies, or more traditional forms of autobiography. In Mairs's case, autopathography takes the form of collections of essays.

During a telephone interview, Mairs stated that she didn't necessarily choose the essay form. She claims, "I kind of fell into it" and continues:

I discovered as a graduate student while I was teaching undergraduates that I liked reading essays. They are self-contained, and take a reasonable amount of time to get through. At the time I had a very busy and fragmented life, with many hats. I think a lot of young women do. The essay seemed to fit the shape and nature of a woman's life—a fragmented life. I would write and it just happened that I would write about twenty typewritten pages each time. It seemed reasonable that I had accomplished something in those twenty pages. They can be considered complete when they are part of a whole.

The essay, conducive to a woman's busy and often fragmented lifestyle, is an ideal forum for Mairs to explore multiple subject positions arising from her experiences as a disabled woman writer. The essay form also resists positing the subject as fixed and coherent.<sup>10</sup> Rather, when placed in a collection of related essays, the essay allows the subject to develop and to tell more than one narrative.

Mairs's use of the essay form, therefore, is provocative. Couser has described the essay form as "a tentative form that approaches its subject obliquely" (191). Mairs herself states that she prefers the essay because "it's contemplative, exploratory, even equivocal, not definitive. If there are absolute answers to the kinds of questions I ask, I



don't know them' (WH 17). In addition, she suggests her predilection for the essay form arises out of liking its "power to both focus and disrupt" (VL 4). She uses the essay form rather than a more retrospective mode, like memoir (a traditional autobiographical form), because it allows her to examine issues in a "neutral space" (RB 182) without necessarily forming conclusions or teleological destinations for the reader.<sup>11</sup> In fact, the essays written by Mairs resist a neat and tidy progression towards an end; her essays "doubleback" on each other and explore issues non-linearly.

Given the fragmented nature of essays that narrate her story non-linearly while simultaneously having the power to "focus and explode," they allow Mairs to explore multiple subject positions (VL 4). This thesis explores at least three of her multiple subject positions: the diagnostic subject, the anecdotal subject, and the subject of others.<sup>12</sup>

As a diagnostic subject, Mairs counters medical discourse and diagnoses herself with multiple sclerosis. She recognizes how medical discourse constitutes "doctors" and "patients" and how it objectifies and fragments patients in the process. By recounting her interactions with the medical establishment, she reveals flaws and makes recommendations for change within the system. Exposure of the way medical jargon acts simultaneously to remove agency from the patient and to empower the physician also carries over into her examination of everyday language and its metaphors. Her precise use of terminology makes the figures of everyday speech transparent and unabashedly available for the reader to scrutinize in turn.

As an anecdotal subject, Mairs uses experiences from her everyday life in order to invert the dominant Western European cultural narratives of invalidism in America.<sup>13</sup>

Through carefully constructed anecdotes of her personal experiences, the readers' emotions are turned away from pity and shame regarding disabled people and towards hope in understanding a richer and more complex world. In the process, she displays fragmented and often ambivalent experiences of her life in a wheelchair. As she makes meaning of the past in the present (through the creation of anecdotes), memory plays a key role in determining what is at stake for Mairs in life-writing.

As a subject of others, Mairs' incorporates the works of others into her own writing. The writings of family members, general members of the public, her past self and scholars find their way into her writing. These heterogeneous voices serve various functions within her project, including sustaining ongoing dialogues about disability and writing. As a collective the voices of others serve as ways in which she knows and routes her construction of herself.

As a writer of autobiographical essays, Mairs's purposes are multiple. She aims to write about her life with an illness in such a way as to "heal" herself (deal with her disease mentally and emotionally) and aid others in identifying with her experiences. In this way, Mairs asks her readers to cross the borders between ability and disability—to breach the binary opposition between the "normal" and the "abnormal." She also aims to explore what it means to be invisible precisely because of an obvious physical (ironically visible) disfigurement in modern American society. By interweaving positions of the diagnostic subject, the anecdotal subject, and the subject of others, Mairs achieves the multiple purposes that she has set out to fulfill as the composite narrative/autobiographical subject. Her writing, considered more broadly, places the "problem" of disability within society, not the individual.<sup>14</sup>

### Countering Medical Discourse: The Diagnostic Subject

*Patients make good doctors because it is the responsibility of patients to take an active role in the relationship between a doctor and a patient. A lot of people take a passive attitude [as patients], and a lot of doctors take an authoritative one. The reciprocity within the relationship gets lost. The best medicine takes both into account.*—Nancy Mairs,

Telephone Interview

As a person diagnosed with multiple sclerosis, Nancy Mairs enters the medical establishment. In her interactions with the medical establishment, Mairs has experienced what happens when there is no cure for the correct diagnosis of an illness such as multiple sclerosis—a hesitancy on the part of medical doctors to state that a person has it. She has also experienced several misdiagnoses—including an initial diagnosis of a brain tumor.<sup>15</sup> Mairs's interactions with the medical establishment go beyond having multiple sclerosis; she has also had to deal with her own agoraphobia, suicidal depression, and her husband's metastatic melanoma. Memories of these interactions are contained within her autobiographical narratives.

Negotiating the medical system, Nancy Mairs is subject to one diagnosis after another. In the process of exploring what it means to be the subject of diagnosis, she reconfigures what it means to be a doctor and a patient. She also examines the effects of diagnosis upon individuals subject to it. Recognizing that the patient is often rendered passive by the act of a doctor's diagnosis, Mairs is interested in re-inscribing agency with

the patient. She exposes the effects of medical jargon, and similarly unveils hidden assumptions behind figures of speech in everyday language.

The social construction of doctor and patient roles unfortunately has traditionally placed doctors in an overly authoritative position to know what is “best” for the passive patient. According to Irving Zola:

The doctor’s power over the medical establishment remains virtually absolute. They have enormous administrative power within the institutional settings in which they practice. More important...they remain the chief technical functionaries in the actual practice and public representations of medicine. It is still the medical profession which defines and identifies new diseases, diagnoses illness in individuals, and presides over the medical management of patients. (55)

Zola identifies the site of medical practice—the hospital—as playing an integral part in the creation of a doctor’s agency. The doctor, while the patient is in the hospital (or “institutional setting”), is to preside “over the medical management of patients” (55). The application of business terms such as “management” is not a new phenomenon, but its use in reference to “patients” is still dehumanizing and objectifying. Patients are people, and people are not a business. Part of Talcott Parson’s description for the sick role of the patient is to “not [be] held responsible for his/her condition” (Ehrenreich 43).<sup>16</sup> Doctors are the ones who “identify illness in practice...and undertake to supervise those identified as “ ‘sick’ “ (45). Doctors, therefore, are frequently described as controlling agents within the medical system.

A large part of a doctor's control stems from the use of medical language, also known as medical jargon. Perri Klass explains that one function of medical jargon is "to help doctors maintain some distance from their patients. By reformulating a patient's pain and problems into a language that the patient doesn't even speak, I suppose we are in some sense taking those pains and problems under jurisdiction and also reducing their emotional impact" (76). Medical jargon can have the effect of objectifying patients' experiences and creating distance between the physician and the patient so that the physician doesn't become too personally invested in the patient.

The effect of medical jargon is to reduce the "emotional impact" of a patient's problems for the sake of the physician. Patients, by having their real problems and suffering disguised or reduced by jargon, experience a trivialization clouded by confusion. Jargon is often used in the diagnosis of illness. According to Susan Sherwin, "[medical] explanation ... is particularly significant in the medical structuring of experience. Medicine is a purposeful activity that is directed at manipulating reality through making predictions (diagnosis) and offering treatment (providing preventative strategies and cures)" (192).<sup>17</sup> Here "explanation" has the same meaning as medical jargon—because it is used in order to explain a patient's condition. Because the doctor is the one who knows the jargon's translation, and the patient doesn't, the doctor can be seen as "manipulating reality through making predictions." The doctor's diagnosis is a way of manipulating reality—or naming a set of symptoms as an illness. Diagnosis, according to Sherwin, is a " 'complex means of social labeling' " (192). Through her

narratives, Mairs counters medical jargon (an aspect of medical discourse) and self-diagnoses her illness.

Thomas Couser discusses medical diagnosis without the patient's presence: "Since the birth of the clinic, diagnosis has depended less and less on face-to-face dialogue between patient and physician; physicians can and do make their diagnoses in consultation with specialists on the basis of evidence supplied by their patients' bodies—in the absence of patients themselves" (RB 22). In other words, a medical diagnosis is often made independent of the patient's presence, and then is presented to the patient as jargon. Mairs inverts this process. She diagnoses herself without the doctor's presence, and presents it to the doctor in the form of a question without using medical jargon.<sup>18</sup>

Initially, Mairs was diagnosed with a brain tumor. She thought she would die from it—she even called it the "kiss of death" (WH 26). She says she's never been sorry about the initial misdiagnosis because everyday after learning that she did not have a brain tumor "has been kind of a gift" (PT 11). Mairs recalls hearing that she has a "demyelinating syndrome of unknown etiology" (WH 26) from a neurologist and reflects: "If I'd been more medically sophisticated, I'd have recognized this as a code phrase for multiple sclerosis, the most common condition caused by loss of myelin. As it was, several months passed before, having recognized my symptoms in an article in Parade magazine, of all places, I asked him, "Do I have multiple sclerosis?" (WH 26-7). The fact that she had to wait "several months" to have a hint of what her disease was called, and then "of all places" recognized her own symptoms in a common magazine unveils shock laced with tones of anger and confusion toward her doctor, someone who

was “more medically sophisticated,” and supposedly able to understand the consequences of such a diagnosis. While Mairs self-diagnoses her multiple sclerosis, the doctor still has to confirm the diagnosis. She describes how she has to wait another eighteen months before she has “discernible damage in more than one place” of her nervous system (WH 27) that signals the onset of multiple sclerosis.<sup>19</sup>

In addition to her positioning herself as in control of her diagnosis, Mairs critiques the medical establishment by challenging the position of physicians, the construction of the disabled as having no sexual drive, and the abortion of possibly disabled fetuses.<sup>20</sup> For instance, in Waist-High in the World, she says of doctors that “a few are capable of forthrightness about this disease” (5).<sup>21</sup> This is the tone of a woman who has been through much with the medical establishment, a woman aware that her physical presence reminds doctors of their limitations:

I have always tried to be gentle with my doctors, who often have more at stake in terms of ego than I do. I may be frustrated, maddened, depressed by the incurability of my disease, but I am not diminished by it, and they are. When I push myself up from my seat in the waiting room and stumble toward them, I incarnate the limitation of their powers. The least I can do is refuse to press on their tenderest spots. (PT 20)

Because she incarnates the “limitation of their powers” and refuses “to press on their tenderest spots,” Mairs portrays herself as forgiving and tactful with her doctors—when it would ideal if it were vice versa and the doctors were tactful.

Mairs also comments on the belief that many, including the medical establishment, have about sex for the disabled. In a chapter entitled "Home Truths,"

Mairs states:

The general assumption, even among those who might be expected to know better, is that people with disabilities are out of the sexual running. Not one of my doctors, for example, has ever asked me about my sex life...People with disabilities can grow so used to unstated messages of consent and prohibition that they no longer "hear" them as coming from the outside, any more than the messengers know they are "speaking" them.

This vast conspiracy of silence surrounding the sexuality of the disabled consigns countless numbers to sexual uncertainty and disappointment.

(WH 51-2)

In a move to resist consigning the disabled to asexuality, Mairs describes (in detail) her own sexual experiences (WH 53-54). Other writers, including John Hockenberry, have also been noted for their candor and frankness in discussing their sexuality (RB 203). Like other disabled writers, she asks the reader to accept the possibilities of sex for the disabled, a concept many "normals" are unwilling to think about because they have been taught by mainstream society that sexuality doesn't exist for the disabled. As Couser elaborates, "the need to use a wheelchair literally lowers a person's stature (and implicitly, status), and the apparent uselessness of the lower body implies a lack of potency, sexual and otherwise" (RB 184). Medical discourse is representative of society's erasure of the idea of sexuality for the disabled, rarely discussing it, if at all.



In countering medical discourse with her narratives, Mairs does not decry the use of scientific language to describe her condition in more detail. In fact, she actually turns to this language in order to describe it in Plaintext:

Multiple sclerosis is a chronic degenerative disease of the central nervous system, in which the myelin that sheathes the nerves is somehow eaten away and scar tissue forms in its place, interrupting the nerves' signals.

During its course, which is unpredictable and uncontrollable, one may lose vision, hearing, speech, the ability to walk, control of bladder...the list of possibilities is lengthy, and yes, horrifying. (11)

In this description, she mixes lay terminology with scientific terminology—but the reader has to know what “myelin” and “degenerative” mean in order to understand this passage.<sup>22</sup> Her counter to medical discourse, then, is not one-sided or fanatic. It is grounded in the reality that some terms cannot be replaced and still retain their meaning. Multiple sclerosis is a disease that is characterized by serious interruption of nerve signals—which can cause the effects she listed. Her description, or use of medical terms, is perhaps meant for a broad audience. The audience, which undoubtedly includes medical professionals and people who will be future patients of the medical establishment (and sometimes medical professionals who are also patients), is given the opportunity to see medical discourse used as everyday language.<sup>23</sup> Perhaps others, like a young nineteen-year-old woman named Jennifer, who reads Mairs's work, will recognize symptoms and in turn be able to diagnose themselves (WH 4). Although Mairs has not explicitly stated this as a purpose for her writing, when Jennifer calls her after reading an essay in which Mairs had

elaborated symptoms of multiple sclerosis, she writes, “what I’m supposed to do about Jennifer, of course, is to write a book: one in which she can recognize and accept and even celebrate her circumstances, but also one that reveals to those who care about her what needs and feelings those circumstances may engender in her”

(6). Mairs writes Waist-High in the World for other people—including people who have multiple sclerosis. It serves, in a way, as an introduction to one person’s experiences that go against the notion that “chronic illness must offer unmitigated misery and that celebrating, as well as bemoaning our lot marks us as either Pollyannas or perverts” (CA 15).

Her examination of medical discourse and its effects on people carry over into her examination of hidden meanings behind figures of speech used in everyday language. Nancy Mairs is brilliant with words, and in using them precisely, she is able to construct her narrative such that readers are forced to admit to themselves that “ ‘slovenliness of our language makes it easier for us to have foolish thoughts’ ” (PT 10). Or if not foolish, then an improper usage of language that reflects contemporary cultural assumptions. In Mairs’ case, she resists contemporary cultural assumptions by terming herself a cripple and by exploiting the weaknesses in using language loosely in order to highlight its effect on herself and people like her.

Plaintext and Waist High In the World are both texts that include Mairs’ defense of using the term “cripple” to define herself. Along with a few other disabled writers who oppose the use of euphemisms that disguise their conditions (Couser 217), she claims her authority to use language by naming herself. Mairs writes:

As a cripple, I swagger... As a lover of words, I like the accuracy with which it describes my condition: I have lost the full use of my limbs. I refuse to participate in the degeneration of the language to the extent that I deny that I have lost anything in the course of this calamitous disease; I refuse to pretend that the only differences between you and me are the various ordinary ones that distinguish any one person from another. (PT 9-10)

Mairs' move to claim the term "cripple" for herself has been praised as well as criticized by many people because of the derogatory connotations attached to it. But Mairs states her refusal "to participate in the degeneration of the language to the extent that I deny that I have lost anything in the course of this calamitous disease" (PT 10). In this way, Mairs subscribes to George Orwell's thesis that " 'the slovenliness of our language makes it easier for us to have foolish thoughts' " (PT 10).

Commenting on Mairs' choice of the word "cripple," Rosemarie Garland Thomson states, "Mairs is not simply celebrating the term of otherness or attempting to reverse its negative connotation; rather, she wants to call attention to the material reality of her crippledness, to her bodily difference and her experience of it" (25).<sup>24</sup> Thomson points out Mairs's desire to communicate that a "disabled person" doesn't mean "cripple," because the latter focuses on the loss of limbs and the physical reality that she can no longer walk.<sup>25</sup> Furthermore Thomson argues that the act of labeling is a gendered one in Mairs's case (EB 25).

Even though she claims the term “cripple” to label herself, Mairs subscribes to the social model of disability because she locates the “problem” of disability not in herself but rather in a society that lacks adequate facilities for the disabled (Couser 180).<sup>26</sup> She states it is a major problem for being able to work as well, let alone live in a society that ignores the disabled (WH 92-93). She also takes the reader through a potential visit—her coming to call at the reader’s house. She explains, in detail, what obstacles she would face—from the bathrooms and doorways to bookcases. She believes the lack of change in construction of a house or building is not cost, but rather “obliviousness fed, without doubt, by denial” (WH 89). She ends her discussion by outlining the possibility for a richer human experience:

There are rewards for making the world physically and emotionally accessible to all people, including benefits that accrue to society as a whole. 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 both possible and pleasant for me and my kind to enter, the world will become a livelier place. You’ll see. (WH 106)

These last words, a direct address to the reader, are meant to remind the reader that Mairs advocates a certain cultural visibility for the disabled, as well as literal architectural changes that need to be made to public and personal spaces because “whatever goes unseen goes unchanged” (96).

Other choices of language point to Mairs's precise use of words in order to convey her thoughts. In all three texts, she uses figurative language in order to convey literal meanings. For instance, in Carnal Acts, she describes having to tackle an intellectual problem as necessitating "fancy footwork" (81). This is followed immediately with "and my feet scarcely carry out the basic steps, let alone anything elaborate" (81). She seems to enjoy pointing out to the reader the ways in which everyday language is loaded with conceptions of ability, especially ability related to motility. In yet another narrative, she writes, "[Anne] is tolerant when I stamp my feet (figuratively speaking—if I really stamped my feet I'd fall in a heap and then we'd both get the giggles) and refuse to take my peach-colored shirt to [the] Honduras" (76, Plaintext). The image of stamping her feet is one that she uses to make the reader aware of figurative language, because in her case it would have physical consequences if the words were interpreted literally. She even notes parenthetically what the effect would be in interpretation if one read the statement literally. In Waist High In the World, Mairs uses the verb "roll" instead of "moved," or "walked" because she actually rolled to the side of a hallway and hugged a wall (59).

In a crowd of "normal" people, Mairs states, "my only recourse was to roll to one side and hug a wall" to avoid being virtually molested by "hips and buttocks and bellies pressing my wheelchair on all sides" (WH 59). The effect of using the infinitive "to roll" (one that people normally don't associate with wheelchairs) is to make the reader aware of the fact that she writes from a wheelchair. In order to understand or try to picture the scene, the reader must imagine her rolling along in a wheelchair. So even if readers can

avert their gaze from the wheelchair and the person in it in real life, they cannot do so in reading the text!

As a diagnostic subject, Mairs inverts the idea Couser presents about medical diagnosis. She counters medical discourse by diagnosing herself, and reconfiguring what it means to be a “doctor” and “patient” in the process. Mairs’s belief that medicine is a collaborative effort comes through in her essays, especially by the time she starts to teach medical students how to give neurological examinations. By recounting her interactions with the medical establishment, she reveals flaws and makes recommendations for change within the system. Exposures of medical jargon and the hidden messages behind everyday language are interwoven throughout her essays. Working together, Mairs’s analyses reveal parallel ways in which mainstream society constructs illness and disability in the minds of its members. Medical discourse attempts to neutralize the language of disease and to protect the physician from becoming too close to the patient, while mainstream society’s sloppy usage of coded language reveals a set of hidden assumptions regarding people with disabilities.

## Inverting the Dominant Cultural Narrative: The Anecdotal Subject

*Beware that it's an angled vision of the world.*—Nancy Mairs, Telephone Interview

*Narratives of somatic dysfunctions explore the ways in which culture constructs illness and disability...one common purpose [of these narratives] is to invalidate dominant cultural narratives of invalidism.*—

Thomas Couser, Recovering Bodies: Illness, Disability, and Life Writing  
(12)

Just as Nancy Mairs's precise use of language invalidates dominant cultural assumptions behind common figures of language, her use of the anecdote serves to invert the dominant cultural narratives about the disabled. The anecdotes chosen come from essays that draw upon Mairs's everyday life experiences, which are grounded in her "angled vision of the world" as a disabled writer.<sup>27</sup> Representative of what is at stake for Mairs in constructing these anecdotes, they are constructed carefully. They allow her and her readers to look at the past as if it were the present, and to look into the future when conditions may be different for the disabled—when perhaps there will be no need to invert the "dominant cultural narratives of invalidism" (Couser 12).

As Mairs writes through her experiences as a disabled person, she determines the positives of her situation and tries to live a life as fully as she possibly can. The world of the disabled that Mairs' portrays is a more positive one than the dominant cultural

narrative of disability that invokes pity and sorrow upon viewing a disabled person. She explains:

You may feel surprised, even skeptical, at my tendency to concentrate on the positive contributions MS has made to our ways of living in the world and relating to it and one another. 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 marks us as either Pollyannas or perverts. (CA 15)

The idea that all disabled people are considered either “Pollyannas or perverts” speaks volumes about cultural assumptions that pervade society about those with chronic illnesses and physical disabilities. Mairs is quick to point out that having MS is not a good “thing,” but she does resist cultural narratives that state how she and others should presumably feel about her condition. Later she goes on to explain how multiple sclerosis can even be good for a family, and her insight comes directly from a person speaking from her everyday experiences (121).

In fact, Mairs openly states in the beginning of Waist High In the World that one of her reasons for writing it is to provide a guide of sorts, a “Baedeker for a country to which no one travels willingly” (6). She asks people to read her book “not to be uplifted, but to be lowered and steadied into what may be unfamiliar, but is not inhospitable space” (18). She clearly uses the conventional notions of height and weight to express her desire for the reader to see her life (literally) from her perspective—one made rich and complex but not necessarily as devastatingly shattering as common public perception imagines it. Later on, she states:



I don't think it's the normals' own fault that they lack disabilities to deepen and complicate their understanding of the world. Mine is alien terrain, and strangers are bound to make gaffes in it...I think of myself as a cultural intermediary. Some of the tourists in my country can be gauche, but if I instruct them patiently, maybe they'll absorb some of the mores and feel at ease. (WH 72-73)

This is the world Mairs wants her "normal" readers to see, to visit, perhaps even to integrate, into their own. She wants to map it for them. The subtitle of this book, in fact, reveals how she views her place in this world—as a "Life Among the Nondisabled." The cover of the book reinforces the perspective of being "waist-high" by prominently portraying a white woman's waist and belly-button.<sup>29</sup> The strong implication of seeing the world from the height of a wheelchair as eye-level with the waist is referred to often in her text.

One reviewer, Donna Seaman, writes that Waist High in the World is an "upbeat account of life in a wheelchair," which is shaped by Mairs' "lucidity, humor, literary finesse, and freedom from sentimentality" (93, Booklist). This humor, which is something she says she didn't have before her life with multiple sclerosis, is embedded in anecdotes in all three of her texts.<sup>30</sup> The anecdotes included in this chapter demonstrate her humor, wit, and craft. Each is carefully written and tells a story, but also contains a message or an agenda to make the reader view Mairs's experience (and the experiences of people like her) in a particular way. The first relates her own foray into understanding another person's culture, one that is marginalized in relation to mainstream American

culture. This anecdote foreshadows the ones she will write later on about her understanding of the world from the position of a disabled person.

In Mairs's first work of published prose, Plaintext, she devotes an entire chapter to her interactions with a student—an Arabic woman named Lamia. The chapter is named after the translation of Lamia's name, which means "Woman With Full Red Lips" (33) in Arabic. The inclusion of this story is significant because it traces the way in which Mairs becomes aware that those who are minorities (ethnic minorities and by extension, the disabled) understand far more about those who exist in the mainstream (non-ethnic minorities and by extension, the non-disabled) than vice versa. She describes a conversation with Lamia:

I am at a disadvantage, and there seems to be nothing I can do about it. We are speaking in my language, which Lamia has studied for ten years and in which she converses fluently, even idiomatically. I don't know her language at all—I don't think I'd recognize it as Arabic if I overheard it... We are... surrounded by emblems of my culture: Outside my office students are lounging on the mall, men and women together, in almost equal states of undress... playing Frisbee, eating popcorn and Fritos and ice cream cones, calling out plans for Friday-night beer blasts... I have never left this country, this culture, much less gone so far as the Middle East. She understands far more about me than I can hope to understand about her, and I keep feeling that I am asking the wrong questions. I don't know what to do with her answers. I jot them down... knowing I can't make an

accurate representation but hoping I will see eventually not merely face and form but something of what animates the face and form. (33-34)

This excerpt speaks to Mairs' attempt to portray this woman's life. She admits that she may be misrepresenting her, but she tries to capture their mutual feelings as best she can. It is significant that Mairs is able to admit that Lamia knows much more about her and her lifestyle as an American than she can know about Lamia's background. The power in Mairs' language exists in the juxtaposition of clear and concise statements (such as her being at a disadvantage) with elaborate details signifying emblems of American culture that place her at that disadvantage in understanding Lamia. It is also significant that even though they are conversing in her native tongue, English, Mairs still thinks that she is at a disadvantage in understanding Lamia.

Her insight into how an outsider can understand mainstream American culture far more than she can comprehend the outsider's culture is significant because she will later write about her world as a disabled writer as one that the mainstream barely understands. Telling the story of Lamia and her coming to understand the differences between their backgrounds foreshadows how she will come to write about living with a disability in the future.

The story about Lamia is found in Mairs's earliest published prose, Plaintext. Significantly, this was before multiple sclerosis had fully manifested itself by physically disabling her. Of the three texts primarily examined in this thesis, it is the one with the least attention given to her struggle with multiple sclerosis. The anecdote about Lamia foreshadows how Mairs's writing will serve partly as a guide for those without exposure to the disabled. Mairs wants the reader to take the position she had to take when hearing

Lamia's story. She wants the reader to position herself as a stranger trying to understand a "waist-high" worldview, as much as Mairs understands the world of the "normal" reader. Mairs virtually becomes the subject of her anecdote (Lamia)—a minority who must attempt to make the mainstream see her perspective of the world as much as she understands the workings of the mainstream. One anecdote that captures a representation of Mairs's worldview as a disabled person is in Carnal Acts. She relates the experience of falling flat on her back while her dog greets her with kisses:

Imagine me, for instance, coming home from a shopping trip one winter evening. As I enter the screened porch, Pinto, my little terrier puppy, bounces forward to greet me, throwing my precarious balance off. I spin around and fall over backward, whacking my head on the sliding glass door to the house, but a quick check (I'm getting good at those) suggests no serious damage at this time. This is called a pratfall, a burlesque device used in plays and films for a surefire laugh. In keeping with this spirit, I start to giggle at the image of this woman sprawled flat on her back, helpless under the ecstatic kisses of a spotted mongrel with a comic grin who is thrilled to have someone at last get right down to his level (114).

It is doubtful that Mairs laughs every time she falls, but her construction of this episode serves the function of allowing the reader to see a different perspective. In asking the reader to draw a parallel in imagining her slip as a pratfall used specifically to evoke laughter in a play, as well as a dog happy to be joined by her in his world, she deflects emotion away from pity and toward the understanding of a different world rich in complexities. Regarding pity, Mairs bluntly states, "Because nondisabled people pity us,

they presume that we must also pity ourselves. This supposition may actually function as a powerful antidote, inasmuch as almost every cripple I know, sensing it ever day, resents and actively repudiates it" (WH 32). When the onus is on the disabled person to deflect others' unsolicited pity, life becomes complex as the disabled person must come to terms with her own feelings as well.

Rosemarie Garland Thomson, in writing about complexity in the life of a disabled person, states: "Disability...can be painful, comfortable, familiar, alienating, bonding, isolating, disturbing, endearing, challenging, infuriating, or ordinary. Embedded in the complexity of actual human relationships, it is always more than the disabled figure can signify" (14).<sup>31</sup> Mairs is extremely adept at communicating the complexity in her life that has arisen from having multiple sclerosis. As she writes, it becomes clear that she would prefer to judge of the quality of her life, rather than to have others do it. In relating her experiences with "normal," nondisabled people in a public space, a wry humor leaps from the page as she describes episodes of being ignored or shoved to the sides of a room.

In Waist-High in the World, she recalls a luncheon honoring the Dalai Lama. She was in a small hallway when fourteen hundred participants suddenly came out of a room. Not seen by anyone, she was forced, literally, to move to the edge of the hallway and "hug a wall" (59). One part of the anecdote made the story very funny, in an ironic way. When she writes directly to the reader, "Let me tell you, no matter how persuaded they were of the beauty and sacredness of all life, not one of them seemed to think that any life was going on below the level of her or his own gaze" (59). By pointing out that the crowd who made her feel unwelcome and unseen was one that believed strongly in the beauty of human life, she conveys a subtle but strong message: those in wheelchairs

are marginalized, literally and figuratively, by even the most caring of mainstream society. Not only does she want "normal" readers to realize that they are part of mainstream society, whose members have the privilege of choosing whether to see people like her, but also that "disability is at once a metaphorical and a material state" (58).

The anecdote about the Dalai Lama convention involves Mairs's interaction with the nondisabled. As such, it portrays the vast differences between her own limited physical abilities and the nondisabled unlimited ones. She states:

I remain aware during every waking moment, and also in many of my dreams, that my legs don't work, that only one of my arms works...that my neck strains to hold up my heavy head, that my world is hemmed by walls to be banged, that the "them" from whom I'm now divorced are the nondisabled, bounding around heedlessly and hailing one another through the empty air above my head. (WH 15)

Mairs's poignant immersion in the reality of how she doesn't fit in among the nondisabled is evident as she describes her physical limitations. Her relationship to the nondisabled world centers on her body relates to the public, which includes many of her readers. In response, her readers might ask, "How does she relate to other people with multiple sclerosis?" The move from the "nondisabled" world to the world of the disabled is perhaps best depicted by another anecdote in which Mairs describes her involvement in a community of people with multiple sclerosis.

Mairs describes a day when a television crew visits her water-exercise class:

"Oh, the poor things!" I laughed. "They have no idea we're capable of having fun." I looked around the pool. There was handsome Fritz, whose

MS hardly shows except in his slightly halting gait. Joe was propped in the corner, head bobbing, wasted arms and legs churning the water. With the leg bag into which her catheter empties taped neatly in place, June, still pretty and stylish at sixty-eight, trailed a scent of expensive perfume above the stink of chlorine. Karen didn't have a leg bag, and her urine floated in its sealed pouch on the blue surface. Chip, though shy, joined in our laughter as we tried to stay upright while our feet traced a grapevine from one wall to the other...Our spirits were simply high. A stranger might see us as grotesque, I suppose. Once I probably would have done so myself. Now, each week I see a group of friends lucky enough to be free at 11:00 on a Thursday morning for an hour of exercise. (WH 15-16)

This anecdote illustrates not only that Mairs interacts with others like herself, but also that her perspective has changed significantly from when she was first diagnosed with multiple sclerosis. She invalidates the notion that the disabled are "grotesque" by portraying her friends in such a positive and humane light. Each person is more than just a person with multiple sclerosis—Fritz is "handsome," June is "pretty and stylish at sixty-eight," and their spirits high without any particular reason (WH 16). The beauty of the scene lies in comparisons also—the scent of perfume versus the chlorine "stink" and even Karen's translucent yellow urine pouch floating over clear blue water! In her portrayal of a community spending time together, Mairs inverts the notion of a grumpy disabled person, completely shut off from society.

In writing these anecdotes, Mairs relies extensively on her memory. Given the nature of autobiography, this is not unusual. What does stand out, however, is that these

constructions of memory contain a risk on the part of their author. James Goodwin, in his discussion of the role of memory in autobiography, states that "memory reconstructs and recreates, often more with an eye toward the present moment of remembering than toward the past experience remembered" (12). Mairs acknowledges this and is self-reflexive about the act of constructing the past out of memory for the present. She states:

We can impose a grid of time onto our memories, much as we sketch lines of a latitude and longitude on a globe, a useful device for knowing when or where we are in relation to some event or spot used as a reference point. But the memories won't yield up their freight in response. For that we have to let go of lifelines and plunge into the multiple modalities—sensory, emotional, cognitive—which have encoded the past and will release it, transformed, into the present. (RBH 9)

Mairs wishes to convey the "freight," or cargo, located within episodes of memory. By unloading the "sensory, emotional, cognitive," she is able to make sense of her memory, and of her past as it relates to her life in the present.

To be able to tell her story so as to make meaning of the past in the present is extremely important to Mairs. The risks taken in her work to construct and to represent (literally re-present) the past in the present is evident in her use of the anecdote. From trying to understand the parallel universe of an Arab woman's experience as an ethnic minority in America to writing about her own experiences as a disabled person among the nondisabled, Mairs demonstrates the importance of telling (and reading) the stories of those who are marginalized. Through these anecdotes, she not only shares stories but also renders important observations about mainstream American society.



Cultural narratives that render the experiences of the disabled as unimaginable and even inhumane hurt the disabled in ways most people cannot imagine. Mairs is a representative of the people most affected by dominant cultural narratives of invalidism—the disabled. Her use of the anecdote serves to counter and to invalidate the dominant cultural narratives about the disabled not only for herself and other disabled people, but also for all members of society.

### Including Multiple Voices: The Subject of Others

*A person doesn't have MS alone.*—Nancy Mairs, Telephone Interview

Pausing and lowering her voice, Nancy Mairs simply stated a fact of her life—and a fact of the lives of millions of people. “A person doesn’t have MS alone,” nor does a person write only through her own voice. Having multiple sclerosis has affected those closest to her as well as members of the general public who read her work. Other people who share her experience of having multiple sclerosis have voices that need to be heard—and Mairs embraces their voices in her texts. She makes meaning through subsequent autobiographical essays and positions herself as the subject of others in the process. As a subject of others, she includes the writings of family members, general members of the public, scholars, and her past self. She does so in order to sustain an ongoing dialogue with multiple readerships through which she relates to both the private and public aspects of the world. By constructing her arguments around, against, and next to the texts of others, Mairs braids their writings into her own. Excerpts from the writings of others serve as focal points through which she knows and routes her construction of herself. She addresses and engages these multiple readerships uniquely, and also validates her own agendas in writing personal life-narratives.

Mairs creates an ongoing dialogue with multiple readerships by creating a specific kind of reader. Conscious of her creation of an ideal reader, she states, “I cannot write myself without writing you, my other” (VL 118). In a New York Times Book Review

article, she also reflects, “I know as a writer that the ‘you’ required by such an ‘I’ must be unusually vivid and available. That is, in writing I construct an ideal reader possessing these characteristics” (26). The ideal reader, according to Mairs, is one who is able to think openly with an active imagination in order to view a different, non-ableist culture. Effects of creating specific readers include forcing them to think about mainstream society and its views of the disabled, sustaining a dialogue with her readers and those whose work she has read, and the exploitation of language in order to subvert the dominant cultural narratives about the disabled.<sup>32</sup>

One of the most prominent ways that Mairs’s addresses her readers is by sustaining a dialogue (through her writing) with them—especially the ones who write to her or about her in response to her writings. Groups of readers’ responses she addresses include the reviewers of her books and general members of the public who read the essays in her books as well as in the New York Times.

After one reviewer of Voice Lessons writes, “It is obvious...she wasn’t meant to be an academic...she wasn’t cut out for a career as a critic. What is obvious is that she is a real writer” (3). In response, Mairs poignantly states:

I could have wept, if frustration any longer had the power to elicit the tears reserved now for anguish unspeakably deeper. In a single sentence she reimposed the very dichotomies I had constructed the book in order to call into question, putting electrified fences around the categories “academy,” “criticism,” and “writing” to keep the various critters from intermingling, maybe interbreeding to create some nameless monster very like the one I

aspire to be...I am not a “real writer.” I am a writer. Without  
modification. (3-4 VL)

In this response, Mairs effectively doubles her critical edge. She refutes the critic’s categorization of her writing as “real” and “unacademic.” She also posits the reviewer as creating her as a “monster” not only because her writing embodies interdisciplinary study but also because she is a disabled person. Mairs places herself in multiple subject positions, and often these positions counter popular cultural narratives. For example, the beliefs that a disabled woman can’t have a sex life or be a mother are two popular misconceptions.<sup>33</sup> When Mairs uses the word “monster,” the double meaning it takes on is apparent to those who understand the historical significance of the word.

In an analysis of the construction of disabled figures and the concept of the “monster,” Rosemarie Garland Thomson states:

Scrupulously described, interpreted, and displayed, the bodies of the severely congenitally disabled have always functioned as icons upon which people discharge their anxieties, convictions, and fantasies. Indeed, the Latin word *monstra*, “monster,” also means “sign” and forms the root of our word *demonstrate*, meaning “to show.” (56)

Although Mairs is not “congenitally disabled,” she is physically disabled. The reviewer’s positioning of Mairs, in her words, as a “monster” is to put her on display as an embodied form of the reviewer’s “anxieties, convictions, and fantasies.” She embodies the anxieties aroused by mixing categories the critic doesn’t wish to see combined (academy, criticism, and writing). Mairs chooses to respond to the critique of her book in her book—a significant way of publicly defending herself. In doing so, she explores

exactly what has interested her—"the crucial role that learning to decipher texts—both my own experience and the works of other writers—has played in my writerly evolution"

(4). Mairs dissects the reviewer's criticism in order to make sense of exactly what offends her—the fact that the critic missed the entire point of her book. She knows that the questions arising out of the peer's criticism are not just private ones—and so she writes about them in the preface to make perfectly clear what her intentions are in Voice Lessons.

Another example of Mairs' ongoing public dialogue with her readers occurs when she includes responses to her New York Times "Hers' Column."<sup>34</sup> She states that the letters arrived so quickly after publication that she "felt almost engaged in dialogue" (CA 8). She juxtaposes reader responses—including one that called her a "female chauvinist sow" and another that said "If you are being given a chance to write the 'Hers' Column, try to write something worth reading" (CA 8) with a statement about how the letters from an Adult Basic Education Class (whose members "were laboriously making the transition, attested by the letters themselves, from illiteracy to literacy") are some of her most treasured. Doing this puts her participation in journalism in perspective—there are people who critique harshly because of their expectations and backgrounds and others who will cherish the writing because they don't necessarily approach it with preconceived notions of what constitutes acceptable material for the New York Times "Hers' Column."

Mairs also uses other people's testimonies not just to dialogue or to offer running social commentary but also to frame and to route the construction of her own narratives.

She includes writings by family members, young disabled women, and published authors of other autopathographies/illness narratives, her past self, and scholars in order to construct her own narratives.<sup>35</sup>

The inclusion of pieces written by family members serve to highlight that Mairs' life with a disability affects those closest to her—that the life of a disabled person is not just his or her life, but it is intertwined with the lives of his or her family members. The most intimate people in her life are each given a space in her narrative. Her husband, George, and her biological children, Anne and Mathew, have written about having a disabled person as a wife and mother, respectively. George writes about achieving the “impossible” with Nancy by visiting Virginia Woolf’s garden and house in England, and Anne writes about her mother’s inability over time to participate in family camping trips (WH 34-35). His writing evokes the power of a sustained relationship of love. Her children’s narratives focus on anger and frustration but also on the fact that their mother is as “normal” as any other mother (WH 43) from their perspectives. The effect of including family members’ voices is to demonstrate the very tangible ways that multiple sclerosis affects entire families and not just the person diagnosed with it.<sup>35</sup> In addition, Mairs gives tribute to how her family has helped her cope with her disease by including their voices in her texts. Perhaps the most poignant of the three is Mathew’s piece, entitled “The Day I Knocked Mom Down” (WH 55).

Matthew’s narrative contains a memory in which, as a sixteen-year-old, he was arguing with his parents at the dinner table. Because his mother tried to get up before he was finished talking, he physically tried to “shove her back into her chair” (55). He

writes with a pain that conveys severe regret for making his mother feel inferior to him because he had the physical power to push her. He writes:

Those next few seconds will certainly follow me forever The look of shock on her face as she collapsed, missing the chair entirely, the pure anger emanating from my dad...the knowledge that I really had to go now and that something had changed forever and that there would be no returning from this event, these are the impressions of that moment. (55)

In response, Mairs publicly states in her text that she would do anything to erase this memory from his mind, because it was the action of a clumsy and angry teenager who wasn't thinking. It was also the action of a male who had the power to physically dominate/stop a woman from doing what she wanted. Perhaps this story also says something about the complexity of relationships, especially upon a son differentiating from his mother. The fact that this memory still has affected her son years after the fact bothers her simply because "too much time has passed for it to serve us" (55). Her son's story is one that conveys that the life of a disabled person is not just singular; it is intimately intertwined with the lives of those around that person. It also demonstrates Mairs's determination to structure her narrative around that of others; she could have told this story in her own words. Her son's writing is important as it functions as a voice that clearly expresses the pain of the past. Exemplifying the way writing makes memory immediately available and documented, "The Day I Knocked Mom Down" also shows how such an incident is hard to forget.

Another way Mairs aids others in identifying with her experiences is to include the voices of other disabled writers. As an editor of young disabled women's entries for a

Glamour magazine article, she includes their voices as well as how she came to compile the article to best represent them. Mairs writes about these young women as a community of writers who display “frankness, grit, and good humor” (WH 127). Common themes in their works include revisions of identity caused by their disabilities when acquired later in life (as opposed to congenitally) and the desire to represent themselves as capable of meaningful work and sustained relationships. Mairs’s discussion of the differences and similarities within such a variety of writers is fascinating. Most prominent, perhaps, is a discussion about craving social contact:

Many recognized that what seems to be rudeness on the part of nondisabled people often arises from ignorance and fear, which can be more crippling in their own way than a physical disability, and that the best way to relieve these is through education. Their advice was pragmatic: Treat a disabled person as an intelligent and responsible adult...Remember that not all disabilities are apparent...If she does have a disability, ask “How may I help?” and then follow her instructions carefully...If she’s in a wheelchair, sit down whenever possible so that you can converse eye-to-eye...Above all, don’t offer her pity. (138)

This advice about how to interact with a disabled person is important. Mairs demystifies the questions readers may have about the disabled and how they want to be treated.

Mairs summarizes the voices of these women in a coherent way. In the process of doing so, she gives her own voice the credibility of collective authentication.

The inclusion of scholars in her work may also serve to give credibility to Mairs’s voice. More importantly, she is able to include them as focal points from which she



writes her own ideas. In a telephone interview, Mairs stated that she used French feminist theory (including that of Julia Kristeva and Hélène Cixous) and the theory of other writers because she found them fascinating. She said the nature of French feminist prose is much different from theoretical prose styles in the United States in that it is not tidy and is very fragmented. She related to that sense of fragmentation as a graduate student because she had so many varying roles drawing her attention in multiple directions at once. As the excerpts are representative of the fragmented nature of Mairs's writing, the reader is allowed to see how they ignited a response from Mairs, offered her feminist modes of gender analysis, and kept her obsessed with writing itself.

In one of the most revealing essays of Carnal Acts, Mairs includes an excerpt from Cixous: " 'Every woman has known the torture of beginning to speak aloud...heart beating as if to break, occasionally falling into loss of language, ground and language slipping out from under her, because for woman speaking—even just opening her mouth—in public is something rash, a transgression'" (95). Cixous strings a series of thoughts together, which mirrors Mairs's response in both content and form. Mairs writes:

The voice I summon up wants to crack, to whisper, to trail back into silence. "I'm sorry to have nothing more than this to say," it wants to apologize. "I shouldn't be taking up your time. I've never fought in a war, or even in a schoolyard free-for-all. I've never tired to see who could piss farthest up the barn wall. I've never even been to a whorehouse. All the important formative experiences have passed me by. I was raped once. I've borne two children. Milk trickling out of my breasts, blood trickling

from between my legs. You don't want to hear about it...Forgive me. I didn't mean to start crying. I'm sorry...sorry...sorry...." (CA 95)

Cixous's writing enabled Mairs to use her voice—to express it in all of its uncertainty, anger, sorrow, and bodily experience. In her response, Mairs never lets the reader forget that she is a *woman* with multiple sclerosis. She expresses why her voice as a woman is important by expressing how it is not the story of a man's experiences. Cixous's quote demonstrates how Mairs is able to generate responses that express the uneasy and the unspeakable. Emerging through the voice of another woman writer, she voices her experiences as a woman. When she repeats her apology "I'm sorry," she writes in fragmented prose similar to Cixous's—the writing that helped her generate a response in the first place.

In addition to including the voices of feminist scholars in her work, Mairs inserts her past journal entries and writes about them. She makes herself the subject of her past self. She includes her past journal entries in order to engage with a "past Nancy," a past that constructed a "future Nancy" who now exists (PT 18). She demonstrates how she has dealt with multiple sclerosis over time, and how she changed in the process. The intertextual dialogue between an essay in Plaintext ("On Not Liking Sex") and in a later text, Waist-High in the World, ("Body in Trouble") shows how Mairs engages with her writing of the past.

The first essay, "On Not Liking Sex" (PT 79-92), is based off an earlier essay. Mairs calls this original essay a "brittle, glittery piece," and continues, it is "a kind of spun confection of the verbal play I'd like to engage in at cocktail parties but can muster only at a solitary desk with a legal-size yellow pad in front of me" (PT 79). The voice

here is obviously the voice of an earlier Mairs, for now she uses voice-activated equipment to write (VL 149). The eight paragraphs of the earlier essay are included within “On Not Liking Sex,” and each paragraph serves as a focal point for discussion in the larger essay. She dissects her past writing, particularly noting how “sex” has become shorthand for “sexual activity, particularly sexual intercourse” (PT 80). Examining one paragraph in which she discusses the phrase “the personal is political,” she writes, “Here’s the heart of the matter—politics—and I’ve dashed it off and done it up with ribbons of lesbianism and feminism so that the plain package hardly shows” (PT 82). In a humorous analysis of her previous explanations of “not liking sex,” Mairs more thoroughly explores the heart of her original argument in simpler language:

Politics. Power. Submission. Force. Violation. Possession. Sex is not merely a political act; it is an act of war. And no act is ever “purely personal.” It is a nexus that accretes out of earlier and other acts older than memory, older than dreams: The exchange of women, along with goods, gestures, and words, in the creation of allies; the ascription to and penetration of the maidenhead in rituals for ensuring paternity and perpetuating lineage; the conscription of women’s sons for the destruction of human beings, of women’s daughters for their reproduction; enforcement of silence...I am no original but simply a locus of language in a space and time that permits one—in politics as in sex—to fuck or get fucked. Aggression is the germ in all the words (PT 83-84).

Mairs’s powerful statement regarding the act of sexual intercourse and its connections to aggression and the treatment of women demonstrate her feminist stance much more

clearly than her previous writing. Persuasively, she engages the reader in a tour de force of ideas that seem to pour furiously out of her. This excerpt shows the influence of French scholars' fragmented prose on her work as well. In Waist-High in the World, Mairs offers a counter essay that dialogues with "On Not Liking Sex" using a very different format.

"Body in Trouble," Mairs's essay "on liking sex," describes her current view on sex. She writes: "I really do like sex. A lot. Especially now that issues of power and privacy that vexed me then have resolved themselves with time" (WH 52). She also frankly discusses her husband's impotence and that "in precluding intercourse it has forced us to discover alternative means to intimacy" (WH 52-53). She explains:

Even our most mundane interactions bear an erotic charge. I don't mean that we pant and grope every time he tugs my sweater over my head or adjusts my bedclothes. Rutting adolescence lies many years in our wake. But 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 (though Cock-High in the World struck me as just too indecorous a book title), I may nuzzle it in return. We carry on a constant, often hardly conscious, corporeal conversation regardless of other pursuits and preoccupations. (WH 54)

Mairs addresses, humorously and bluntly, how she has come to adjust her sex life. The style and mood of this excerpt is very different from that of the excerpt from "On Not Liking Sex." Not only are the sentences complete, the tone is much calmer. The reader is allowed to see a very different Mairs—one whose perceptions have changed over time.

Readers may be able to identify with her dialogues that engage her past self, especially if they also write their own autobiographical texts.

By constructing her arguments around, against, and next to the texts of others, Mairs carries out an ongoing dialogue with her readers and positions herself as the subject of others. The excerpts allow her readers to ponder texts that have shaped Mairs's understanding of herself as conveyed through her writings. She makes meaning through these texts, authenticating her voice and demonstrating how it changes over time. She exhibits intersubjectivity in process—an ongoing dialogue between multiple understandings of herself.

### Conclusion: Disability and the Cultural Politics of Invisibility

*I think visual representation is very important. I can describe myself, but I don't always do a good job. It's different when people see me...The cover of Carnal Acts is quite ironic. She's doing something with her legs that I haven't been able to do in years!*—Nancy Mairs, Telephone Interview

*Disabled people, like black people/people of colour, women, and so on, are aware that their bodies are constructed as the site of oppression...In my experience of being a disability photographer, disabled people need space to tell the story, the journey, of their body and in doing so, reclaim and be proud of themselves.*—British Photographer David Hevey, 117-118.

*Ungrotesque, routine pictures of disabled people in advertising, "art" photography, films, and so on, are hard to find. With the same regularity that bodies of color were kept out of the mainstream, and even the avant-garde, media in the pre-civil rights years, so too are disabled bodies disqualified from representing universality.*—Lennard Davis, 64.

What does it mean to be visible in a society precisely because of an obvious, physical disfigurement? Why is it important to aid others in identification with Mairs's writing?

An overarching concept governing Nancy Mairs's multiple subject positions as the diagnostic subject, the anecdotal subject, and the subject of others is her visibility as a writer. Mairs states the need for a human community that understands her experiences (and by extension, the experiences of others like her) in "When Bad Things Happen to Good Writers" :

Your presence is especially vital if I am seeking not to disclose the economic benefits of fish-farming in Zaire, or to recount the imaginary tribulations of an adulterous doctor's wife in 19<sup>th</sup> century France, but to reconnect my self, now so utterly transformed by events unlike any I've experienced before as to seem a stranger even to myself, to the human community. (The New York Times Book Review 26)

In this poignant statement about her readers and the role her writing plays in connecting her with other human beings, Mairs makes clear that the events which she has gone through put her in a particular position to need this tie. She achieves the creation of ties with her readers through her writing. She realizes that she is able to communicate with people through her writing in ways that she might not be able to in person. Part of this has to do with the paradoxical situation of being a disabled person in America—someone whom most people choose not to "see," or to acknowledge as fully human, because of obvious physical disfigurement. The choice not to acknowledge a disabled woman is rooted in the fact that she is not the "ideal woman." According to Mairs, the "ideal woman" of today's American society:

Lives on the glossy pages of dozens of magazines, seems to be between the ages of eighteen and twenty-five; her hair has body, her teeth flash

white, her breath smells minty, her underarms are dry...she is trim and deeply tanned; she jogs, swims, plays tennis, rides a bicycle, sails...she travels widely...always in the company of the ideal man, who possesses a nearly identical set of characteristics...*She is never a cripple.* [my emphasis] (PT 16)

Mairs offers a gendered analysis of the “ideal woman,” who has all the characteristics of the popular, sexually desirable female in American society. The “ideal woman” is in direct opposition to society’s construction of the asexual “cripple.” Robert Murphy’s description of the physically disabled parallels Mairs’s—except that he doesn’t address gender. He adds the element of fear instead. In The Body Silent, he states:

The disabled...contravene all the values of youth, virility, activity, and physical beauty that Americans cherish...Most handicapped people, myself included, sense that others resent them for this reason: We are subverters of an American Ideal...And to the extent that we depart from the ideal, we become ugly and repulsive to the able-bodied. People recoil from us, especially when there is facial damage or bodily distortion. The disabled serve as constant, visible reminders to the able-bodied that the society they live in is shot through with inequity and suffering, that they live in a counterfeit paradise, that they too are vulnerable. We represent a fearsome possibility. (116-117).

The descriptors in this excerpt reveal of the extent to which “normal” perceptions of the disabled have permeated the cultural construction of disability. The “subverters” seems to be subverting by choice, and the “inequity and suffering” that exist in “counterfeit



paradise" is something that cannot be avoided but can be easily overlooked or avoided. For something about the world of the disabled makes "normal" Americans feel as though they live in a world that is not real, but rather fake. The "fearsome possibility" may stem from the fact that anyone, by virtue of an accident, an illness, or old age can join what is rapidly becoming the largest minority group in America. Some estimates place the number of disabled at 40 million (Couser 217). Although not all disabled have visible disfigurements, it is striking to note that such a big minority population can be treated the way it has been treated for so many years.

Another possible reason for the fear described by Murphy could stem from a subconscious awareness of a paradox that exists within modern American notions of beauty and its Western Greco-Roman European tradition. Lennard Davis, in his discussion of disability and visibility, points out that modern American society is fixated on bodily perfection even though it is paradoxically rooted in a Western Greco-Roman tradition that venerates the broken and imperfect body of the Venus de Milo as the ultimate standard of beauty and wholeness. He states:

In the Venus tradition, Medusa is a poignant double. She is the necessary counter in the dialectic of beauty and ugliness, desire and repulsion, wholeness and fragmentation. Medusa is the disabled woman to Venus's perfect body. The story is a kind of allegory of a "normal" person's intersection with the disabled body. This intersection is marked by the power of the visual. The "normal" person sees the disabled person and is turned to stone, in some sense, by the visual interaction. In this moment, the normal person suddenly feels self-conscious, rigid, unable to look but

equally drawn to look. The visual field becomes problematic, dangerous, treacherous. The disability becomes a power derived from its otherness, its monstrosity, in the eyes of the “normal” person. (55)

Davis captures the essence of the paradoxical situation many disabled people face—interactions with “normal” able-bodied people who are “unable to look but equally drawn to look.” By using a Greek myth almost everyone is familiar with, Davis is able to show a parallel situation in a founding myth of Western culture. As Medusa has the power to turn people into stone, so does the disabled figure. In having the power to freeze people and stop them from further interacting with the disabled person, the disabled person is positioned as the culprit by which interaction is frozen. Such a positioning furthers the negative cultural narratives of the disabled.

Rosemarie Garland Thomson explains the effects of a “normal” person’s gaze: “the stare is the gesture that creates disability as an oppressive social relationship. And as every person with a visible disability knows intimately, managing, deflecting, resisting, or renouncing that stare is part of the daily business of life” (EB 26). Thus, what is defined as “normal” and “disabled” depends not just on representations of disability but on the responses generated upon sight of the disabled body by a non-disabled one. Mairs comments on the “stare” in an interesting way, adding a twist to Thomson’s argument. Mairs states a realization she has upon going to Africa to visit her daughter in the Peace Corps:

In Africa, people stare at oddities. I like that, I find. In the States, people are always averting their eyes...the consequences of this custom is that I feel invisibilized, if there were such a word; negated; disappeared, to use

the term Latin America has given us. "If I can't see you," the eyes sliding uneasily away from my body tell me, "you can't be you." Not *you*, that is, *the way you really are*: lurching along on a cane or hunched in a wheelchair, with curled-up hands and skinny stick legs. I feel, when someone looks away, too awful to contemplate. Myself, I'd rather feel like an event. (153 CA)

In drawing on a term that is not even a word in the English language ("invisibilized"), she redefines what it means to be a disabled person in American society. Making an analogy with Latin American "disappearances" in which thousands of people were killed in political and civil wars, she puts a twist on the way the reader perceives the idea of being invisible. Raw emotion and feeling are evident in the last line of this quote—the way people act around her affects her more deeply than people might think.<sup>36</sup> Although she doesn't address what it means to draw on a metaphor from another cultural context, it is significant that she felt differently in Africa, where people stared at and talked to her—where she felt like an "event" (153). Instead of deflecting a stare, Mairs claims that she would rather manage a stare from a "normal" person. In her analysis of visibility, she wants readers to picture her for what she really looks like—a human being who has lost the use of her legs and other parts of her body. She wants to be recognized as a human, not as a Medusa. In that way, Thomson is correct in stating that negotiating the looks of others upon the disabled body is an everyday occurrence for the disabled, but incorrect in saying that the looks of others are not wanted at all. Mairs, in experiencing the openness of a culture in which "poverty and disease are elements of daily life for all but the most privileged (and most corrupt) citizens" (152), is able to come to terms with the ambiguity

arising from feeling invisible in America precisely because of her obvious physical disfigurement.

The effect of exploring issues of invisibility and its binary opposite, visibility, is not only to inform her readers, but also to help create a sense of community for those with disabilities—to aid others in identifying with her experiences. Although she claims to speak for herself and that she is not a representative (WH 12), she is well aware that her story is one that is shared. She writes, “I hope that I speak truthfully about all our lives. Because I think that my ‘story,’ though intensely personal, is not at all singular. Beneath its idiosyncrasies lie vast strata of commonality, communality” (VL 119). One of the commonalties for those with physical disabilities is the way that they are seen by the American public, but virtually ignored and treated as though they are invisible. In writing about this phenomenon, she makes the “normal” reader aware of this particular problem that people with disabilities face. Sharing her fears and ordeals reveal the extent to which American perceptions about bodily imperfections have permeated the culture.

Another way of creating a community is to speak on behalf of that community in order to influence the reader to think a particular way. One strategy Mairs uses is to cite a list of suggestions of things that “normal” people should do when they are around people who are disabled. These suggestions always assume that the disabled person is a woman by using the pronouns “she” and “her” (WH 138). Another strategy is to take stances on political and ethical issues. She takes strong stances on the enforcement of the American with Disabilities Act, as well as on issues of abortion and euthanasia. The former discussion is made by comparing treatment of the disabled in Africa, America, and England. The latter discussion is perhaps the most poignant, as she describes her life and

the judgments on human life people will have to face in the future when genetic testing becomes more common.

Writing against abortion practices in which fetuses are predetermined to be physically disabled or genetically predisposed to diseases is a move to create a community by ensuring that they will be around in the future. She writes:

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...no amount of regulation can eliminate the subtle pressure to end a life perceived by others to be insufferable. If ideally, I ought never to have [been] born, 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? (WH 121)

The two rhetorical questions at the end of this statement have the effect of going beyond Murphy’s construction of the disabled as a “fearsome possibility.” These questions show the hidden logic behind the assertions that some human life is not worth living, and that decisions about terminating a life can be strongly affected by the dominant cultural narrative because one may believe the stereotypes and the beliefs if surrounded with them. Mairs argues for a social climate in which members of mainstream society recognize that disabled people can have lives worth living. In the process, she visibly (through writing) speaks for the “invisible,” disabled community.<sup>37</sup>

As a writer of autobiographical essays, Mairs's purposes are multiple. She aims to write about her life with an illness in such a way as to "heal" herself (deal with her disease mentally and emotionally) and aid others in identifying with her experiences. In this way, Mairs asks her readers to cross the borders between ability and disability—to breach the binary opposition between the "normal" and the disabled. She also aims to explore what it means to be invisible precisely because of an obvious physical (ironically visible) disfigurement in modern American society. Through multiple subject positions as the diagnostic subject, the anecdotal subject, and the subject of others, Mairs achieves the numerous purposes that she has set out to fulfill as the composite narrative/autobiographical subject.

These three subjects, however, are not as clear-cut and discrete as they may seem. In fact, their fluidity can be seen upon further examination of how they relate to Mairs's aims in writing about her life. In that she aims to heal herself (deal with her disease mentally and emotionally), she writes through her illness and performs a self-diagnosis. She also tells anecdotes in order to show the world as more rich and complex. In a way, she tries to heal the pain caused by the domination of strong cultural narratives that demand pity for the disabled. She also uses other people's writings in order to give her own writing a set of ideas through which to "explode and focus" (VL 4). Family members, members of the general public, scholars, and reviewers all influence how Mairs views her work as a means of healing herself.

Aiding others in identification with her relies on using everyday experiences filled with concrete detail. It also requires approaching and taking stances on issues such as abortion, sexuality, and the labeling of people. Dealing with issues of visibility and

invisibility undoubtedly aids others in knowing that they are not alone in their experiences. It also helps “normal” readers to question their reactions to those who are obviously disabled. By exploring her interactions with the institution of medicine, she allows others to identify with her experiences. In looking at issues of visibility and invisibility, Mairs’s discussion of a patient-physician relationship and the way in which anecdotes uncover serious flaws within mainstream culture apply.

Mairs’s autobiographical writing does more than “heal” herself (deal with her disease mentally and emotionally) and aid others in identifying with her experiences, and explore issues of visibility and invisibility.<sup>38</sup> Her writing also challenges readers to enter into a dialogue with her and to see the disabled for who they are—people with complex lives like all other humans. As David T. Mitchell and Sharon L. Snyder state:

Mairs describes the private coordinates of bodily experience as a sporadic and unpredictable biological march into future deterioration. The value and appeal of her work hinge upon its no-nonsense approach to the traumas and ironies of a life that remains ambiguously tethered to the daily experience of pain and bodily breakdown. Her narrative style offers a shockingly intimate portrait of a disabled woman who unveils her most private thoughts and scathing self-critiques as a way of using disability to burrow down into the psychic and physical depths of human affairs. (10)

Even though she claims that she is not a member of the “inspirational class” of writers (WH 18), her writing challenges and inspires readers to change the dominant cultural narratives that stifle those with disabilities and confine them not *to* their wheelchairs, but rather *by* them in an ableist society and culture (RB 180). She refuses to position the

“problem” of disability within the individual. Nancy Mairs asks mainstream society to stop averting itseyes and to stop staring. Instead she asks the mainstream to start seeing, to realize that “patients make good doctors,” that “a person doesn’t have MS alone,” that every person’s “vision of the world” is angled. Paradoxically, Mairs uses extremely candid and personal narratives of her life with a disability to deflect attention away from the disabled individual and toward mainstream society.



## Notes

1. See also James Olney's "(Auto)biography."
2. Okihiro's concluding remarks on examining the margins of historical consciousness—race, gender, class, and culture—explains that "the view from those sites, those positions, it seems to me, affords a clearer perspective on the mainstream, its location, its ambiguities, and contradictions. Although situating itself at the core, the mainstream is not the center that embraces and draws the diverse nation together. Although attributing to itself a singleness of purpose and resolve, the mainstream is neither uniform nor all-powerful in its imperialism and hegemony. Although casting the periphery beyond the bounds of civility and religion, the mainstream derives its identity, its integrity, from its representation of the Other. And despite its authorship of the central tenets of democracy, the mainstream has been silent on the publication of its creed. In fact, the margin has tested and ensured the guarantees of citizenship; and the margin has been the true defender of American democracy, equality, and liberty. From that vantage, we can see the margin as the mainstream" (175). His last category, "culture," includes those who represent the "perils of the body and mind." I have taken this to include the physically disabled.
3. In Getting a Life: Everyday Uses of Autobiography, Smith and Watson elaborate how autobiographical discourse can be "a palpable means through which Americans know themselves to be American and non-American in all the complexities and contradictions of that identity" (5-6). Much of the writing I did when I was younger concentrated on my identity as an American with a South Asian heritage. For an interesting discussion on immigrant autobiography as it relates to American autobiography, see Sau-ling Cynthia Wong's "Immigrant Autobiography: Some Questions of Definition and Approach."
4. Rosemarie Garland Thomson explains that the prototypical disabled figure in common representation "functions as a lightning rod for the *pity*, fear, discomfort, guilt, or sense of normalcy of the reader or a more significant character [my emphasis]" (EB 15).
5. In Nancy Mairs's "When Bad Things Happen to Good Writers," she shares how she makes sense of her life with a disability through writing. She states: "This process of making sense of a flood of random data also produces the impression—generally quite groundless—of control, which may save one's sanity even though it can't save one's own or anyone else's life...my esthetic drive: to transmute dross—my own hastening physical progress through chemotherapy—into lapidary reality" (25).
6. Although Mairs terms herself a "cripple" in Plaintext, I use the term "disabled" to be consistent throughout the thesis to refer to all people with disabilities. Although the term encompasses those without visible physical deformities, most people interpret "disabled" to mean those with physical deformities in the form of a wheelchair, blindness, and loss of hearing. Thomson states, "The prototypical disabled person posited in cultural representations never leaves a wheelchair, is totally blind, or profoundly deaf..." (EB 13). Mairs also makes clear that although she terms herself a

“cripple,” she does not refer to others like her in the same way. I follow her recommendation because I speak of others in addition to Mairs. I also do not wish to offend anyone unintentionally because the historical practice of using the word “cripple” is rife with negative connotations. Additionally, in a telephone interview with Mairs, she said that the term disabled is one the is highly agreed upon, and that sometimes people make a distinction between “writer with a disability” and “disabled writer.” This is because the emphasis is on writer in the former, and disability is taken to be the modifier rather than the defining characteristic of the writer. She stated her agreement with me in that “disabled writer” more concise when used in prose than “writer with a disability.” She stated that using the other term might just lead into the “slovenliness of language” that tends to happen when people attempt to neutralize language. The word cripple, she said, is “too in your face,” and highly charged to be used at times.

7. Voice Lessons, which is a text about her relationship to writing, will be used to supplement the analysis of the other three texts. Remembering the Bone House and Ordinary Time are memoirs that serve, in her own words, as companions to each other. As memoirs they have specific styles and agendas of their own that set them apart from her other texts, thus I will not be addressing them in this thesis. Mary Jean Corbett defines memoir in “Literary Domesticity and Women Writer’s Subjectivities” as “not an autobiographical text that tells a story about a centered self, but one in which the writing subject recounts stories of others and events or movements in which she and/or other subjects have taken part” (262).
8. Mairs states: “Shame may attach itself to guilt or embarrassment, complicating their resolutions, but it is not the same emotion. I feel guilt or embarrassment for something I’ve done; shame for who I am. I may stop doing bad or stupid things, but I can’t stop being. How can I help but be ashamed? Of the three conditions, this is the one that cracks and stifles my voice...I can subvert its power, I’ve found, by acknowledging who I am, shame and all, and, in doing so, raising what was hidden, dark, secret about my life into the plain light of shared human experience” (CA 91-91). Dealing with shame has been a process, and Carnal Acts is reflective of that process. In this text she writes about “uttering the unspeakable” (53), “doing it the hard way” (107), and “good enough gifts” (117). These chapter titles reflect the foci of her essays and how she has dealt with shame and fear.
9. Eakin states that autobiographical “truth” is not a fixed entity, but rather more of a process (3).
10. In a discussion about the fragmented nature of the essay form, she states, “I prefer to work in the fragmented form of essays, each concentrating on a house or houses important to my growth as a woman. Each house contains its own time, of course. But in emphasizing the spatial rather than the temporal elements in my experience, I attempt to avoid what critic Georges Gusdorf calls, in ‘The Conditions and Limits of Autobiography,’ the ‘original sin of autobiography’ (and, one might add, the outstanding feature of phallogocentric discourse in general)—that is, ‘logical coherence and rationalization’.” (RBH 9) Her use of the essay is also a resistance to traditional autobiography—because her life is not linear, chronological, or necessarily rational.

In fact, her writing is an example of the ways in which autobiographical forms are gendered.

11. I use Couser's descriptive term for autobiography to refer to the essay format because, more than other forms of autobiography, it is the most "neutral," or available for women's autobiographical writing. This is because the essay does not demand chronological storytelling and because more traditional forms of autobiography have historically been dominated by white males. See Elizabeth Winston's "The Autobiographer and Her Readers: From Apology to Affirmation" for a discussion on the changing trend of British and American women writers apologizing for writing autobiography prior to 1920.
12. I recognize that I may be dividing Mairs's multiple subject positions too neatly and that these categories are not discrete, but rather interlocking and interrelated. Even though they are not radically different from each other and no easy differentiation is possible, in the context of this thesis it is useful to differentiate the subjects in order to explore her texts more systematically.
13. In "When Bad Things Happen to Good Writers," Mairs states: "The writing about personal disaster that functions as literature tends not to be 'about' disaster at all. That is, whatever adversity provides the grounds for the project must be embedded in a context both enigmatic and elaborate: the insistent everyday world" (26-27).
14. Although Couser does not talk about external influences on a disabled person's *view of herself*, in talking about the discursive reform surrounding disability, and the differences between individual and social models of disability, he states, "At times, then, the 'cultural construction' of disability can be quite literal—as when the physical environment is built in a way that restricts those who use wheelchairs. (Such individuals are confined *to*, but not *by*, wheelchairs—or rather by the lack of curb cuts, elevators, and ramps available to them. The critical distinction, then, is between the impaired body and its cultural site, for it is the latter that creates *disability*. Individuals with disabilities are still handicapped or disabled by a physical environment that disadvantages them and a culture that excludes or stigmatizes them. (The physical exclusion from public life is consistent with their discursive erasure.) Although these terms seem counterintuitive...their crucial counterdiscursive effect is to displace the 'problem' of disability from impaired bodies to an unresponsive culture" (RB 180). Mairs's subscription to either model of disability (the individual or social), but she does express the latter more than the former. Mairs also uses the term "problem" in describing disability (CA 33).
15. One doctor even told her, when she suffered from depression and suicidal episodes, to get pregnant as a treatment! (PT 132). She was diagnosed as schizophrenic before being diagnosed a depressed woman (136). In addition, before being diagnosed as having a "demyelinating syndrome of unknown etiology" (WH 26), she was told she had a brain tumor.
16. This is not to say that patients are to be blamed for their illnesses!
17. Susan Sherwin takes the term "explanation" as one of four levels of medical terminology reviewed by H. Tristan Englehardt, Jr.
18. Mairs diagnoses herself without the presence of a doctor because she recognized her symptoms as multiple sclerosis while reading an article in Parade magazine. It is

interesting to note that, perhaps as a result, she formally taught medical students how to give neurological examinations (PT 12) and she still does it informally at a local university clinic where medical students are in training (telephone interview).

19. It is significant to note that during the time she was diagnosed, CAT scans, MRIs, and neurological tests specific for multiple sclerosis did not exist. Now, the advances in science and technology have created even larger groups of disabled people as people that would have died previously are being saved (Couser 10). Couser discusses an irony that has arisen from developments in medical science: "As the efficacy of U.S. medicine has increased, public confidence in the medical establishment has decreased" (9-10).
20. This will be discussed in the conclusion.
21. Mairs has had direct experience in teaching medical students to be forthright about a patient's multiple sclerosis. In one striking anecdote, she says: "I recall clearly one young man who had seen a patient with MS that morning. The patient didn't know, and the doctor this medical student was working with didn't want to tell her, because he thought the diagnosis much too horrible to burden anyone...As a general principle, I told the medical student, once you know your patient, you should tell her the truth. Most people I know deal remarkably well with the diagnosis of MS. Most, like me, are relieved to have at least a name for the set of symptoms that may have made them feel lazy or clumsy, if not downright crazy. The person with the problem...was not the patient but the doctor. *He* was the one too horrified by the diagnosis to speak of it. And I don't think it's fair to make patients bear their doctors' problems" (CA 120). Mairs makes clear that the "problem" lies with the doctor in this scenario—his inability to deal with the reality of multiple sclerosis and withholding of a diagnosis for the patient is not a responsible act toward the patient.
22. Myelin is the material around nerves that insulate and ensure the relay of neuronal signals within the nervous system.
23. In regard to future patients of the medical establishment, it is important to note that medical technology is becoming more sophisticated. In the process, it ensures more disabled people will live longer and "more publicly" than ever before (WH 17).
24. I have already discussed why I use the phrase "disabled person" rather than "cripple" in this thesis (see footnote 6)
25. Mairs's choice of the word "cripple" is not without contestation. Susan Wendell, author of The Rejected Body, states that "cripple" is one of "a large number of terms...in English that are used for insulting people with disabilities" (77).
26. Please see footnote 14
27. In the telephone interview with Mairs, her statement "Beware that it's an angled vision" came from a point in the conversation where we were discussing the effects of photography and of writing on the representation of disability. In WH, she states: "My work has always been deliberately and deeply grounded in my own experience because that experience is all I reliably have that no other writer can give" (10). By explaining that her work is unique to her experiences, she is honest and upfront about her particular views as coming from a certain vantage point in society.

28. The idea of creating a "map" for her readers is echoed in the writing of Stephanie McCarty, who is quoted in Waist-High in the World: " 'I feel I have been sent on a journey. I wasn't given a guidebook, so I'll have to draw my own map' " (145).
29. The cover of Waist-High in the World includes as its centerpiece the belly of Sandro Botticelli's The Birth of Venus. Above a section of the belly are white and black "bars" that are countered by the roundness and opposing laterals in the spokes of wheelchair wheels. It is important to note, however, that Mairs stated she had no control over the artwork chosen for the covers of her books. Both the image of the belly of Botticelli's painting and the prison-like image of black and white bars suggests that being "waist-high" is to be limited by the restricted movement of a wheelchair. In the conclusion, I discuss further how Mairs places the "problem" of disability within society rather than the individual, or rather how she is restricted not to her wheelchair, but rather *by* it (Couser 180).
30. In her own words, Mairs states that she is not a disease; it doesn't determine her but rather it has changed her. (PT 17)
31. The complexity of Mairs's life and the difficulty of portraying such a life is perhaps best evidenced in her account of an experience on the "Oprah Winfrey" talkshow. She states, "This was one of the most disagreeable experiences [George and I] have ever shared. The approximately twenty-five minutes left after deleting advertisements...fragmented among at least seven commercial breaks, permitted only the most hasty and shallow remarks. These were dominated by a marriage therapist who had, in the limo on the way from the hotel to the studio, spoken of his ex-wife in the bitterest terms I've ever heard one human being use about another...The communication we'd worked so hard to establish over twenty-five years of marriage was jammed into pure static...it was even worse than it had seemed at the time, a real tour de force of suppressed woman-bashing" (CA 9). In such a forum for telling her story, Mairs's story becomes reduced and simplified, and even worse, misrepresented. For an interesting discussion on the autobiographical structure and content of television talkshows as it relates to therapeutic discourse, see Janice Peck, "The Mediated Talking Cure: Therapeutic Framing of Autobiography in TV Talk Shows," in Getting a Life: Everyday Uses of Autobiography, Ed. Sidonie Smith and Julia Watson (Minneapolis: The University of Minnesota Press, 1996), 134-155.
32. I address Mairs's precise use of language in order to subvert dominant cultural narratives about the disabled at the end of "Inverting Dominant Cultural Narratives of Disability."
33. Mairs documents others' surprise when they learn she is a mother and a writer upon first meeting her. She states, "To some, for reasons outside my control, I will always be a figure of pity, scorn, and despair. 'You're so brave,' they will go on exclaiming, as though only true grit could prod a person through a life as loathsome as mine" (WH 105).
34. Again, Mairs places her analysis of reader-responses in the first chapter of Carnal Acts in order to let the readers know exactly what her aims are in certain essays.
35. Significantly, Mairs states that all of her readers can benefit from relating to an MS family. She states, "I think what goes on in an MS family is universal enough, in style, if not detail, to be recognizable by people unaffected by MS" (CA 14-15). This

point of identification is apparent when during a telephone interview with Mairs, she stated, "A lot of people write to me and say 'you put my feelings into words.' " She continues, "All people have some sort of limitation, and that sense of limitation is what I think draws them toward works like mine, even if the limitation differs from person to person."

36. Mairs supports this statement in the inclusion of others' experiences in Waist-High in the World. Cece Hughley Noel's testimony demonstrates the effects of "normal" people's behavior on the feelings of a young disabled woman with multiple sclerosis. Noel writes: " 'On the days that I need a cane it is very difficult for me emotionally. People who I work with every day fail to recognize me on the street. They tend to avert their eyes from "cripples" and don't meet my eyes or hear my "hello." It can be devastating to win their praise for taking charge of a meeting one day, only to be ignored as a "gimp" on the street, the next' " (136-137).
37. Thomson describes traditional feminist abortion rationale and how it "seldom questions the prejudicial assumption that 'defective' fetuses destined to become disabled people should be eliminated" (EB 26). Mairs is an example of a disabled feminist writer who does question the prejudices behind assuming that a "defective" fetus should be "eliminated."
38. Mairs states, "In writing about my experience, I am, first of all, trying to make sense of it and to make it bearable for myself" (CA 5). In this way, she tries to "heal" herself, or deal with multiple sclerosis mentally and emotionally. She continues in another text, "Writing has always formed the core of my identity, the means by which I have saved and shaped my life" (WH 9). Both statements reflect upon Mairs's awareness of her relationship to writing. She also acknowledges that writing is vital to constructing her identity.

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