

## **First Person: Narratives of Illness, Disability, and Identity**

*Consortium for Culture and Medicine*  
*Fall 2006*

**Tuesdays 4 to 7 p.m.**  
**Room 3109, Weiskotten Hall**

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**Course Description:** In this course we will read first-person narratives of illness and disability to explore the experiences of those who fall outside the boundaries of health and physical ability and what is often perceived as physical and/or mental “normalcy.” We will discuss first-hand accounts of authors whose narratives are becoming increasingly powerful within discourses of medicine, bioethics, and embodiment. We will consider the socio-cultural issues those with serious illness and disability encounter within their families, social groups, and health care settings and examine how these issues mesh or conflict with health care practitioners’ objectives and perspectives. Using the concept of socio-cultural “metanarratives” and also the expectations of plot lines within literary conventions and the book market as a frame, we will consider how narrative influences experiences and understandings of illness and disability, specifically acute versus chronic illness and notions of progress and recovery within disability.

### **Course Topics and Readings**

This course will explore the standard narrative paradigm—the story plot that moves through conflict to a crisis and then resolves—in relation to illness and disability. While acute illness conforms to this paradigm of crisis and resolution (or recovery), chronic illness and disability do not. The course is structured to juxtapose narratives of chronic and acute illness and disability and thus to explore the degree to which the narrative paradigm and conceptions of illness and disability influence (and perhaps even distort) each other. The six book-length narratives listed below will be supplemented by a course packet of shorter narratives; critical readings and relevant medical and health articles will be handed out in class.

Week 1 (8/29): “Okay, So I’m in This Bed”: Introduction to Course  
Introductions  
In-class reading (Grammaglia) and discussion

Week 2 (9/5): Disability and Medicine  
Nancy Mairs, *Waist-High in the World*

Week 3 (9/12): Paralysis and Authority  
Jean-Dominique Bauby, *The Diving-Bell and the Butterfly*

Week 4 (9/19): Appearances and the Self in Print  
Lucy Grealy, *Autobiography of a Face*

Week 5 (9/26): Ethics, the Self, and the Other in the Book Market  
Lucy Grealy, *Autobiography of a Face*

Week 6 (10/3): Resisting the Narrative of Recovery and Norms of Sexuality  
Kenny Fries, *Body, Remember: A Memoir*

10/10: NO CLASS (Fall break for Le Moyne and Upstate)

Week 7 (10/17): Mental Illness and the Narrative of Recovery  
Susanna Kaysen, *Girl, Interrupted*

**Paper Proposals Due**

10/24 Eid Ul-Fitr NO CLASS

Week 8 (10/31): **Midterm Exam**

Week 9 (11/7): Anti-Narrative Narrative  
Donna Williams, *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*

Week 10 (11/14): Illness, Power, and Social Narratives  
Stories from the U.S. AIDS crisis; *From a Burning House: The AIDS Project*  
(coursepack)

Week 11 (11/21): The Other AIDS Crisis: Race, Ethnicity, and Representation  
*Nobody Ever Said AIDS: Poems and Stories from Southern Africa* (coursepack)

Week 12 (11/28): Transplantation and Identification  
Richard McCann, "The Resurrectionist" (coursepack)

Week 13 (12/5):  
**Paper Due**, Wrap-up, and Course Evaluation

### **Course Readings** (available at Upstate Medical Bookstore)

Jean-Dominique Bauby, *The Diving-Bell and the Butterfly* (New York: Vintage, 1994)  
Irene Borger, editor, *From a Burning House: The AIDS Project Los Angeles Writers  
Workshop Collection* (New York: Washington Square, 1996) [COURSEPACK]  
Lucy Grealy, *Autobiography of a Face* (New York: Harper Perennial, 2003)

Kenny Fries, *Body, Remember: A Memoir*, *Living Out: Gay and Lesbian Autobiographies* (Madison: University of Wisconsin Press, 2003)  
Susanna Kaysen, *Girl, Interrupted* (New York: Vintage, 1994)  
Nancy Mairs, *Waist-High in the World: A Life Among the Nondisabled* (Boston: Beacon Press, 1996)  
Nobantu Rasebotsa et al. eds, *Nobody Ever Said AIDS: Poems and Stories from Southern Africa* (Capetown: Kwela Books, 2004) [COURSEPACK]  
Sharon Oard Warner, *The Way We Write Now: Short Stories from the AIDS Crisis* (New York: Citadel, 1995) [COURSEPACK]  
Donna Williams, *Nobody Nowhere: The Extraordinary Autobiography of an Autistic* (New York: Harper, 1994)

### **Course Requirements**

**Attendance:** Every absence after two absences lowers your final grade by a half a point.

#### **Quizzes (15%)**

Short quizzes of multiple-choice, true-false, and short answer questions will be given *most weeks*. Each quiz is worth ten points. The questions will cover the day's readings. The two lowest quiz grades will be dropped and the remaining grades averaged for **the final quiz grade, which is 15% of the final course grade.**

#### **Presentations (15%)**

Each student will give a presentation on the social context and/or biography of one of the authors we are studying. The presentations will be 10 to 15 minutes in length (depending on the size of the class) and will be graded on the selection and organization of information presented, its relevance to the narrative, and, to a lesser extent, the "performance" of the presentation. **The presentation is worth 15% of the final course grade.**

#### **Midterm Exam (30%)**

The midterm exam will be an in-class short essay assignment. You will be expected to discuss the class readings we have covered up to that point in the semester.

#### **Term Paper (40%)**

##### **(8 to 10 pages for undergrads, 10 to 15 for grad students)**

The course paper topic (each student's choice and approved by me) will relate to some aspect of the readings and discussions. Writing the paper will be a large part of the course grade, so students should think carefully about which aspect of the readings they wish to focus on intensively. It might be one element they find in two or more books or short readings, or students may wish to focus on several aspects of a single narrative. During the first several weeks of the course, I will discuss with students how to select a topic for their final papers and how to refine that topic into a question or argument that will lead into a fruitful paper project. **All students** will submit one-paragraph paper proposals (not graded but critical to the success of the final paper), which I will review and comment on. I will provide an overview of and many resources for reviewing essay

form so that students feel clear and confident about writing the paper. I will prepare the students for the paper writing process and leave a portion of each class period open for discussion of papers.

Drafts will be graded on the clarity of writing, the logic of the argument(s), demonstration of comprehension of concepts discussed in class, the coherence, and the persuasiveness of the essay. Form and content are two sides of the same coin; clear, logical, and carefully considered analysis will best reflect comprehension of the ideas set forth in the narratives we read and in our class discussions. All papers will be graded on the clarity of writing, because it is interwoven with clarity of thought. Students will be guided to choose topics that will allow them to focus their energies on clear and straightforward engagements with their topics. Papers must be proofread and edited for grammatical clarity (another component of one's argument). Students will be teamed up to share this tedious but crucial task.

**Undergraduate students** are encouraged to write without resorting to outside perspectives on their topic other than the readings assigned and recommended for the course and to focus carefully on the reading(s) at hand, engaging with their topic by plotting out an outline for the exploration of the question or argument and finding examples from the reading(s) that support or further the question/argument. The paper is a way to think through a specific idea by poring over one or more readings and writing through one's ideas about it/them. Putting your thoughts into writing that can be understood by others and persuades them of your argument demands that you set down and logically organize your ideas and test your hypotheses in a way that oral discussion does not require. Thus students who may not have a background in writing are nonetheless as capable of well-argued writing as students with more experience writing.

**Graduate students** will be expected to read critical, socio-historical, and medical texts relevant to their paper topics and their papers will be graded in part on the aptness of the cited texts and the way that the students integrate them into their line of questioning or argument. The emphasis is on the usefulness of the material cited, rather than on the number of citations. **Grad students are expected to know the rules of proper citation, both ethically and in terms of citation format, and to demonstrate that knowledge in their papers.** I will supply students with resources for reviewing documentation and avoiding ambiguous citation that might appear as plagiarism. Papers must include close readings of the text(s), where either a selected passage or passages are discussed in detail or images, tone, sequence of events, or other details of the structure of the narrative are explored in terms of language and the ideas expressed.

**The Term Paper is 40% of the final course grade.**