

# Illness and Disability Narratives

HADV 7306 R 1

Sarah Lawrence College Masters of Health Advocacy Program

Spring 2016

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Wednesday

12:30 – 2:30 PM

SLC WREX 2

*“The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability.”*

- Arthur Frank, *The Wounded Storyteller*

## Course Description:

The care of the sick unfolds in stories. In recent decades, the literary and social scientific study of illness and disability autobiographies has emerged as a cornerstone of the medical humanities field. Stories of illness and disability possess a special power to engage their readers with the fundamentals of the human condition. While granting us a window into the ill person's experience of their personhood and embodiment, memoirs of illness and disability can also serve to inform us about the larger social, cultural, and political conditions of our time.

In this class, we will tackle questions such as: What does the telling and reading of narratives do for the ill or disabled individual? How can we effectively elicit, interpret, and act upon such narratives? Whose stories are told? Who is allowed to tell their own story? Who owns a story, and what is the role of co-authorship, power, and witnessing in telling and listening? What are the roles of power, hierarchy, prejudice, and oppression in telling and listening? How are individual stories impacted by the familial, cultural, social, institutional, structural, and political contexts in which they are told or heard? And how can personal stories be translated to political advocacy and action?

## Learning Objectives:

At the end of the course, students should be able to discuss how one's identity and position in society can influence the story one tells, whose stories are left out of the modern medical discourse, the different media through which stories can be conveyed, how to navigate intersubjective encounters, and the history of disability activism. The course will meet weekly and run in a seminar style, emphasizing student contributions and insight on the material which will help students gain pedagogical skills and knowledge. We will study texts, which may include works of theory and/or fiction, graphic novels, films, and more, from a variety of fields such as disability theory, narrative theory, anthropology, sociology, philosophy, and political science. Additionally, via completing the final, students will go through the process of constructing an oral history questionnaire, conducting a one hour oral history life-story interview, transcribing the interview transcript, and creating multiple narratives using the interview transcript as a source of information and inspiration.

## **Assessment:**

Grades will be determined by attendance, preparation, and participation (30%), weekly illness narratives (15%), organizing the response questions two times throughout the semester (15%), the midterm (15%), and the final (25%).

- **Attendance, Preparation, and Participation (30%):** This class draws its strength from consistent, enthusiastic participation. Please make every effort to come to class, and contact me as soon as possible if you must miss class. One absence is permitted without penalty; more absences can seriously impact your grade, so please be in communication with me.

Coming to class prepared entails marking up your texts with questions and comments and taking notes while watching movies/other videos. Please be ready to discuss your thoughts by the time you arrive! Our course meetings will revolve around the information you learn and create.

This course is designed to enable you to learn from your fellow students through participating in class discussion. Our experiences in the world are the richest resources we have for contextualizing theory, but they are limited to our own embodied experiences. Listening carefully to others allows us to better understand the variety of social forces at play in the political structures discussed throughout the course. Being in conversation with each other about differences in our experiences allows us to have a more thoughtful, nuanced, and useful discussion, but it requires a great deal of respect as well.

Some of the topics covered in this class may touch on issues that have affected you, your family, or your classmates directly. Constructive class participation includes listening carefully to each other's thoughts and experiences, and thinking thoughtfully about how different experiences are related to each other through social practices.

- **Weekly Illness Narratives (15%):** Every week, students will write a 1 page narrative based on a personal illness/disability/caregiving experience. You will write about the *same* illness/disability/ caregiving experience every week - this way the weekly narratives allow you to go into one experience in depth rather than describing a number of different experiences superficially. You must turn in a hard-copy of the narrative in class. Additionally, each narrative should include a commentary or reflection on how the writing went as well as why you chose to write the way you did.

Although this is an opportunity to explore your own creative writing, as well as to recollect a personal experience of suffering, the goal of this writing is to understand the different way such narratives function. As the course progresses, you will broaden, change, and reinterpret your narratives based on the readings and discussions. You will find in your syllabus suggestions of how to do this – by changing point of view, genre, etc. Each student will be invited to read aloud from at least one of these narratives at some point in the semester.

- **Organizing an Online Discussion Posts (15%):** Each week, one student will be expected to post by Sunday evening midnight a list of 3-5 questions on the webpage that

might guide or lead the class session based on the readings. Each student in the class will have a turn to be an organizer once during the semester. The faculty will organize the webpage for every class session where the organizer will post the questions. Every week, all other students will respond to the organizer's questions and post their responses on the webpage by 7 AM Wednesday morning. Students should feel free to post any additional links, texts, news, etc, that they find relevant to that week's discussion.

- **The Midterm Paper (15%):** This 4-5 page (double spaced) paper is an analysis of a modern Public Service Announcement (PSA). You should pick either a print or television announcement and provide it, along with your paper, for me to view. The idea is to pick a short narrative representation in media and discuss it thoroughly using the perspectives and frameworks from the class – What is the narrative? Whose voice is it? What are the goals of the narrative and does it meet them? What unstated/perhaps unplanned messages does the PSA hold? Since I will have the video or print media in hand, there is no need to describe it point by point – rather, you should assume I am familiar with it and analyze it. Please include any references in either MLA or Chicago Style format.

Each student will give a brief presentation (length TBD) about their midterm paper on the class before spring break.

- **The Final Project (25%):** This is a two-part project. The first part is to interview an individual with a long-term illness/disability/embodied condition. Since this is a lengthy process, you are encouraged to begin thinking about an appropriate interview subject early, and complete your interview by mid-semester. Choose your subject, get their permission and tell the class about who you will be interviewing by week 5. See the end of the syllabus for more specific guidelines on the interviewing process.

The second part of the project is a tripartite paper. The first section should be a 6 – 10 page analytical paper, similar to the midterm, which investigates the interview using theory from the class. The second section should be a recap of the interview similar to what you would present to a healthcare provider – a classic medicalized narrative based only on what “medical knowledge” you gained during the interview. The third section should be a reflection on the difference between these two narratives. What gets left out of the medicalized narrative? What don't healthcare providers get to hear? What are the forces that shape what story is told in any intersubjective encounter? The end result should be about 10 – 15 pages not including your transcript.

Each student will give a 7 – 8 minute presentation about their final paper on the last day of class.

### **Texts We'll Read In Their Entirety:**

Bauby, Jean-Dominique. *The Diving Bell and The Butterfly: A Memoir of Life in Death*. New York: Vintage, 1998.

ISBN-10: 0375701214

ISBN-13: 978-0375701214

Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: U of Chicago, 1997.

ISBN-10: 0226259935

ISBN-13: 978-0226259932  
Lorde, Audre. *The Cancer Journals*. Special ed. San Francisco: Aunt Lute, 1997.  
ISBN-10: 1879960737  
ISBN-13: 978-1879960732  
Porcellino, John. *The Hospital Suite*. Drawn and Quarterly, 2014.  
ISBN-10: 1770461647  
ISBN-13: 978-1770461642  
Small, David. *Stitches: A Memoir*. W. W. Norton & Company; Reprint edition (September 13, 2010)  
ISBN-10: 0393338967  
ISBN-13: 978-0393338966  
Sontag, Susan. *Illness as Metaphor; And, AIDS and Its Metaphors*. New York: Picador USA, 2001.  
ISBN-10: 0312420137  
ISBN-13: 978-0312420130

**Recommended Texts:** Essays from these texts will be provided as PDFs, but you are encouraged to purchase them if you wish and are able.

DasGupta, Sayantani, and Marsha Hurst. *Stories of Illness and Healing: Women Write Their Bodies*. Kent, OH: Kent State UP, 2007.  
ISBN-10: 0873389166  
ISBN-13: 978-0873389167  
Davis, Lennard J., ed. *The Disability Studies Reader*. New York, NY: Routledge, 2013. Print.  
ISBN-10: 0415630517  
ISBN-13: 978-0415630511  
Jones, Therese, Delese Wear, Lester D. Friedman, and Kathleen Pachucki, eds. *Health Humanities Reader*. New Brunswick: Rutgers UP, 2014.  
ISBN-10: 0813562465  
ISBN-13: 978-0813562469

### **Films on Reserve:**

*The Diving Bell and the Butterfly* (also available on Netflix)

*The Miracle Worker*

*Lives Worth Living* (in-class screening)

### **Course Schedule:**

\*denotes reading from a required text

+denotes reading from a recommended text

### **Class 1: January 20, 2016**

*Topic:* Why Do We Tell Stories of Illness?

*In Class:* Lorde, Audre – “Poetry is Not a Luxury” and “The Danger of a Single Story”

TED Talk by Chimamanda Ngozi Adichie

<https://youtu.be/D9Ihs241zeg>

*Due Today:* Nothing

## **Class 2: January 27, 2016**

*Topic:* Telling from the Margins, Telling in Solidarity

*Due Today:*

1. \*Lorde, Audre – *The Cancer Journals* (entire book)
2. Mairs, Nancy – “Carnal Acts” from *Carnal Acts*
3. <sup>+</sup>Hurst & DasGupta – “The History of Women’s Illness Narratives: Private Relationships, Public Voices” from *Stories of Illness and Healing: Women Write Their Bodies*
4. \*Frank, Arthur – “When Bodies Need Voices” from *The Wounded Storyteller: Body, Illness, and Ethics*
5. NARRATIVE ASSIGNMENT: Last class, we talked about why we tell stories and what we can do with stories of illness. Consider writing about the narrative you want or need to tell. Feel free to include the media or discussion from class yesterday in your commentary about your narrative.

## **Class 3: February 3, 2016**

*Topic:* How Do We Tell? Embodied Stories

*Due Today:*

1. \*Bauby, Jean-Dominique – *The Diving Bell and the Butterfly*
2. FILM: *The Diving Bell and the Butterfly*
3. \*Frank, Arthur – “The Body’s Problem with Illness” and “Illness as a Call for Stories” from *The Wounded Storyteller: Body, Illness, and Ethics*
4. NARRATIVE ASSIGNMENT: Consider writing from the point of view of the ill/disabled person’s body.

## **Class 4: February 10, 2016**

*Topic:* How Do We Tell? The Makeup of Stories

*Due Today:*

1. \*Sontag, Susan – *Illness as Metaphor*
2. (One Section Assigned Per Person ) Charon, Rita – “Close Reading” from *Narrative Medicine: Honoring the Stories of Illness*
3. Johnson, Cyree Jarelle – “Disease is Not a Metaphor”  
<http://www.blackgirldangerous.org/2013/07/2013729disease-is-not-a-metaphor/>
4. <sup>+</sup>Schwartz, Lynne Sharon – “So You’re Going to Have a New Body” from *Stories of Illness and Healing: Women Write Their Bodies*
5. \*Frank, Arthur – “The Restitution Narrative” from *The Wounded Storyteller: Body, Illness, and Ethics*
6. NARRATIVE ASSIGNMENT: Consider choosing a metaphor appropriate to your illness/disability story and writing the piece entirely from that perspective.

## **Class 5: February 17, 2016**

*Topic:* How Do We Deal with Ambiguity? Graphic Novels & Medicine

*Due Today:*

1. \*Porcellini, John – *The Hospital Suite*
2. Robot Hugs – “Just Because It Doesn’t Affect You Personally Doesn’t Mean It’s Not Oppressive”

3. Green & Myers – “Graphic Medicine: Use of Comics in Medical Education and Patient Care” from *BMJ: British Medical Journal*
4. <sup>+</sup>(Optional) Keränen, Lisa – “This Weird, Incurable Disease: Competing Diagnoses in the Rhetoric of Morgellons” from *The Health Humanities Reader*
5. \*Frank, Arthur – “The Chaos Narrative” from *The Wounded Storyteller: Body, Illness, and Ethics*
6. NARRATIVE ASSIGNMENT: Consider creating a graphic narrative by folding a sheet of paper into 2, 4, or 6 squares.

### **Class 6: February 24, 2016**

*Topic:* How Do We Hear? How Do We Listen?

*In Class Screening:* Browde & Nossel – “The Power of Two - How Listening Shapes Storytelling” presented at TEDxBrooklyn

<https://youtu.be/JvOriYNJ15E>

*Due Today:*

1. DasGupta, Sayantani – “Narrative Humility” presented at TEDx SLC  
<https://youtu.be/gZ3ucjmcZwY>
2. Anderson & Jack – “Learning to Listen: Interview Techniques and Analyses” from *The Oral History Reader*
3. Jones & Okun – “White Supremacy Culture” from *Dismantling Racism: A Workbook for Social Change Groups*
4. <sup>+</sup>Frank, Arthur – “Being a Good Story: The Humanities as Therapeutic Practice” from *The Health Humanities Reader*
5. \*Frank, Arthur – “The Quest Narrative” from *The Wounded Storyteller: Body, Illness, and Ethics*
6. NARRATIVE ASSIGNMENT: Consider writing about a time a listener shaped the story you told.

### **Class 7: March 2, 2016**

*Topic:* The Role of the Witness

*In Class Screening:* Honoring the stories of illness | Dr. Rita Charon | TEDxAtlanta

<https://youtu.be/24kHX2HtU3o>

*Due Today:*

1. Laub, Dori – “Bearing Witness or the Vicissitudes of Listening” and “An Event Without a Witness: Truth, Testimony and Survival” from *Testimony: Crises of Witnessing in Literature, Psychoanalysis and History*
2. Portelli, Alessandro – “What Makes Oral History Different?” from *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History*.
3. \*Frank, Arthur – “Testimony” and “The Wound as Half Opening” from *The Wounded Storyteller: Body, Illness, and Ethics*
4. NO NARRATIVE ASSIGNMENT THIS WEEK – WORK ON YOUR MIDTERMS

### **Class 8: March 9, 2016 – MIDTERMS DUE**

*Topic:* Midterm Presentations

*Due Today:* Midterm Paper

**March 16, 2016: SPRING BREAK – NO CLASS**

**March 23, 2016: SPRING BREAK – NO CLASS**

**Class 9: March 30, 2016**

*Topic:* Whose Story Is It? Co-Authorship, Dialogic Research, & Narrative Ethics

*Due Today:*

1. Frank, Arthur – “What is Dialogic Research and Why Should We Do It?” from *Qualitative Health Research*
2. Garden, Rebecca – “Telling Stories about Illness and Disability” from *Perspectives in Biology and Medicine*
3. Hardwig, John – “Autobiography, Biography, and Narrative Ethics” from *Stories and Their Limits: Narrative Approaches to Bioethics*
4. NARRATIVE ASSIGNMENT: Consider writing your story from someone else’s perspective

**Class 10: April 6, 2016 – NO CLASS – WORK ON YOUR FINALS**

**Class 11: April 13, 2016**

*Topic:* Whose Story Is It? Co-Authorship & Telling Stories of/for Children

*Due Today:*

1. \*Small, David – *Stiches: A Memoir*
2. Wolfson, Penny – “Moonrise Excerpt” from *The Atlantic*
3. Couser, G. Thomas – “Making, Taking, and Faking Lives: The Ethics of Collaborative Life Writing” from *Style*
4. NARRATIVE ASSIGNMENT: Consider writing about your story using the second person OR consider writing it as if you had a co-writer.

**Class 12: April 20, 2016**

*Topic:* Whose Story Is It? The Caregiver as the (Only?) Hero

*In Class Screening:* Baggs, Mel – “In My Language”

<https://youtu.be/JnylM1hI2jc>

*Due Today:*

[https://youtu.be/SxrS7-I\\_sMQ](https://youtu.be/SxrS7-I_sMQ)

1. FILM: *The Miracle Worker*
2. (One Chapter Assigned Per Student) Keller, Helen – *Out of the Dark*
3. Keller, Helen – Chapters I – VII from *The Story of My Life*
4. (Half the Class) Bascom, Julia – “Dear ‘Autism Parents’”  
<https://juststimming.wordpress.com/2011/08/23/dear-autism-parents/>
5. (Half the Class) Willingham, Emily – “How Not to Write a News Article About Autism: Point-by-Point”  
<http://www.squidalicious.com/2013/10/how-not-to-write-news-article-about.html>
6. Levine, Carol – “Night Shift” from *Stories of Illness and Healing: Women Write Their Bodies*
7. NARRATIVE ASSIGNMENT: Consider writing about what you wish others knew about your story.

**Class 13: April 27, 2016**

*Topic:* How Do We Understand Disability?

*Due Today:*

1. Young, Stella – “Inspiration Porn and the Objectification of Disability” presented at TEDxSydney
2. +Davis, Lennard – “The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century” from *The Disability Studies Reader*
3. Couser, G. Thomas – “Disability & Cultural Representation” from *Signifying Bodies*
4. +Shakespeare, Tom – “The Social Model of Disability” from *The Disability Studies Reader*
5. Dudley, Rachel – “Toward an Understanding of the 'Medical Plantation' as a Cultural Location of Disability” from *Disability Studies Quarterly*
6. NARRATIVE ASSIGNMENT: Consider writing about “the normal” or the consequences of being “abnormal”

**Class 14: May 4, 2016 – DOUBLE CLASS**

*Topic:* Narratives of Disability: Staying Alive Depends On Being Heard and Where Do We Go From Here? Changing Attitudes, Changing Policy

*In Class Screening:* ***Lives Worth Living***

*Due Today:*

1. +Lewis, Bradley – “A Mad Fight: Psychiatry and Disability Activism” from *The Disability Studies Reader*
2. LeBesco, Kathleen – “Quest for a Cause: The Fat Gene, the Gay Gene, and the New Eugenics” from *The Fat Studies Reader*
3. Hedva, Johanna – “Sick Woman Theory” from *Mask Magazine*
4. Chandler & Rice – “Alterity In/Of Happiness: Reflecting on the Radical Possibilities of Unruly Bodies” from *Health, Culture, and Society*
5. (Optional) Lyons, Pat – “Prescription for Harm: Diet Industry Influence, Public Health Policy, and the ‘Obesity Epidemic’” from *The Fat Studies Reader*
6. NARRATIVE ASSIGNMENT: Consider writing about illness or disability as identity.

**Class 15: May 11, 2016 – FINALS DUE**

*Topic:* Final Presentations

*Due Today:* Final Paper

**The Interview Process:**

By mid-semester, you will do a life-story interview of an adult with a long-term illness, disability or other embodied condition. This may be someone you personally know; however, if you are having trouble identifying someone, the faculty can assist with the process of finding an interviewee. The interview process is flexible, and you are expected to develop a series of open-ended questions for your subject that is appropriate to your relationship to them, as well as their life experience and illness. Please look ahead to the reading list for classes 6 and 7 to guide you in your interview process. We will discuss and develop as a class an informed consent form for your subject explaining that this is an educational exercise done as part of a class requirement.



Issues that **may be** addressed during interviews are:

1. The individual's birth, childhood, birth order, family, ethnicity and nationality
2. The individual's education, aspirations, and career/employment
3. The individual's hobbies, likes and talents
4. The individual's accomplishments and challenges (including any substance use/violence history if appropriate to the interview)
5. The individual's partners and children, their sexuality (if appropriate to the interview)
6. The individual's diagnosis including presenting symptoms, diagnostic process
7. The individual's acceptance/lack of acceptance of their illness initially and now
8. If this illness has impacted their family, occupational, romantic, social life and how
9. If this illness has impacted their self-concept, self-confidence, self-esteem and how
10. If this illness has impacted their relationship to the medical community and how
11. If this individual has undertaken/explored any alternative/non-Western modes of healing for this illness
12. If this individual has utilized any support groups around issues of this illness
13. Who this individual's health advocates are and if they are an advocate for others
14. What this individual would like to tell the world about this illness/others with this or any other chronic illness

For more on interview questions, please look at the website for the oral history project Storycorps, [www.storycorps.org](http://www.storycorps.org)

Interviews should be conducted in a mutually convenient place for you and your subject, preferably a quiet environment that is physically comfortable for both. Interviews should be audio taped after obtaining permission from the subject, and subsequently students will transcribe verbatim at least 20 minutes of the interview, including both your comments and your subjects'. Videotape may be utilized if you desire, and segments of either the audio or video of your interview may be shared during your paper presentation the last day of class. (A word of caution – be sure your equipment is functional, pretest it and be comfortable with it. And please, please, bring spare batteries and extra tapes!)