

University of Toronto Scarborough  
Spring 2020  
HLTD53H3 Special Topics in Health Humanities

Tuesdays, 4:10 – 6:00  
Classroom: MW 264

Dr. Cassandra Hartblay  
Office Hours: Tuesday 11:30am-1:00pm; Thursday 11:30am-1:00pm  
UTSC Office: HL222

## **Documentary and Memoir Workshop for Health Humanities**

### *Course Description*

Advanced students of Health Humanities already know that creative work about important contemporary issues in health can help doctors, patients, and the public understand and live through complex experiences. But how, as health humanities practitioners, do we go about making new creative works and putting them out into the world? This upper level seminar will explore Documentary and Memoir as a political practice, including the ethical concerns, methods, and challenge of producing new creative works. Students have an option to write a critical term paper, or to produce their own original documentary or memoir work.

In this course, we explore creative works by physicians and patients, by people living with disability, by those who have had global experiences of disaster, and more. We will look at artistic and compositional practices of documentary writing, film, and theater to draw conclusions about what makes a documentary voice compelling, and what we come to know about human experiences of health, illness, and disability through these mediated expressions. Where is the boundary between fiction and truth? What does it mean to seek to know about another's experience, or to document and share one's own experience? What ethical concerns do documentary and memoir practices raise? What does it mean to cultivate an artistic practice, and what kinds of decisions do documentary and memoir artists make in creating these works?

This year, the course is also supported by an enhancement grant that will allow us to attend a play and have in-person visits from several documentary and memoir creators working on various health advocacy projects.

### *Prerequisites*

To take this course, you must have already completed in good standing at least one course in the Health Humanities minor. It is strongly recommended that students have completed in good standing either HLTB50H3 Introduction to Health Humanities or ANTC61H3

Medical Anthropology: Illness and Healing in Cultural Perspective. The course also pairs well with the new HLTC55 Methods in Arts-Based Health Research course. This will facilitate a shared basis for the topics that we address in this advanced seminar.

### *Course Goals*

Over the course of the term, together we will:

- Encounter, discuss, and analyze new texts and media
- Deepen our understanding of the capacity of narrative to explicate issues of power, authority, and justice in healthcare settings and experiences of health, illness, and disability across the life course
- Describe and recognize the characteristics of memoir and documentary across media genres
- Interrogate divergences between documentary truth, narrative nonfiction, fiction based on fact, and reflexive social science
- Develop methodological techniques and knowledge about memoir and documentary forms in a variety of media including audio storytelling, video storytelling, written formats, and more.
- Analyze how artistic process functions as an arts-based research method
- Review and practice the steps for constructive critique of artistic works, including feedback directly to the artist
- Employ academic writing skills to summarize and analyze
- Term Project Option A: Develop and document a personal creative practice that produces an output designed to make an original statement about issues of power, authority, and justice in healthcare settings and/or experiences of health, illness, and disability across the life course
- Term Project Option B: Write an academic paper that explores (a) documentary and memoir work(s) and presents an original thesis about how documentary and memoir address issues of power, authority, and justice in healthcare settings and/or experiences of health, illness, and disability across the life course

In doing so, we will consider and address the following topics:

- The patient perspective vs the physician perspective
- Dominant culture narratives vs subcultural narratives
- Narrative and empathy
- Truth and fiction
- Representation and Interpretation
- Science and reflexivity
- Technological advancement and bioethics
- The elements of creative practice
- Analysis of creative works
- Justice, power, and authority
- Autism, cancer, HIV/AIDS, chronic pain, blindness, deafness, allergy, mental illness,
- The role of narrative and creative work in training physicians

## **Texts to purchase**

Required:

- Anderson, Patrick. 2017. *Autobiography of a Disease*. Routledge.
- Kron, Lisa. 2005. *Well: A Play*. New York: Theatre Communications Group.
- A blank notebook or journal of your choosing

Suggested:

- Vallejo Peña, Edlyn. 2019. *Leaders Around Me: Autobiographies of Autistics who Type, Point, and Spell to Communicate*.
- Jones, Therese, Delese Wear, and Lester D. Friedman, eds. 2014. *The Health Humanities Reader*. Rutgers University Press.

\*All readings other than required readings will be posted on Quercus as PDFs. Films are DVDs on course reserve in the library.

## ***Assignments***

### **Attendance & Participation**

One missed class (unexcused absence) is allowed. With more than three missed classes, you will start to see a change in your final grade. I am happy to explain details of how I grade attendance for those who are interested or concerned. Attendance means arriving on time, ready to participate, and staying engaged throughout class.

For participation, you should actively contribute to in-class discussions (make at least one comment per class). You can also post comments to the Quercus discussion board before, during, or after class. You are welcome to use technology during class, but please regulate your own use of the myriad available distractions online. If I suspect that you are chatting, shopping, or browsing about something unrelated to class, I will call you. The classroom is a rare social opportunity to engage directly with the people around you, and think with one another; taking yourself out of the conversation is letting yourself and your colleagues down.

### **Discussion Leader Role**

The discussion leader role is an opportunity for all of us to get to know one another's learning style and interests, and for each student to take the initiative on a topic of interest to them. This is not meant to be an onerous assignment, but rather, a manner of distributing some of the labor of doing a close and thoughtful reading between the group members throughout the term. Discussion Leader Role will begin in week three of the term.

Discussion Leaders will be assigned in pairs, and everyone will have at least two turns as discussion leader throughout the term (details will be worked out as the enrollment settles down). We will sign up for weeks in Week Two. Discussion leaders will do the following:

- Post three discussion questions about the reading to Quercus by 6pm the day before class (Monday)
- Share responsibility with co-discussion leaders for facilitating the group's conversation about a given reading. To do this, you may wish to take 5-10 minutes to

share your own thoughts or supplemental materials related to the assigned reading. Then, have several questions and prompts in addition to those on posted on Quercus to put to the group to encourage conversation. What does the reading bring up? How does it relate to the broader themes of the course? What does the author leave out? Discussion Leaders should plan to facilitate for about 20-25 minutes of class (including any materials that you choose to present or share).

- You will receive a discussion leader grade rubric form for each turn as discussion leader. The rubric will be available on Quercus for review in advance.

### **Reading Responses**

Each student must turn in a 2-3 paragraph written response to the assigned readings for FIVE class meetings throughout the term. You may choose any class meeting to turn in your reading response. You do not need to sign up in advance for the reading response. If you would like to write SIX responses and drop your lowest grade, you may do so. Each response will be graded out of 20 possible points, and your final reading response grade will be an average of your scores.

The response is due on the day the reading is due, AT 3PM, or one hour before the start of class. You may turn in one late response in the case of absence, but you will lose 2 points off your total score. Responses should be typed and posted to the discussion board for the week on Quercus.

Spelling and grammar count. You may use the first person to respond directly from your own point of view. Responses need not be overly formal, but you should use clear, standard English. Proofread your response before posting. Give your readers the opportunity to take your point of view seriously.

Responses should review the content of the reading, and answer key questions, including: What is the author's argument or purpose in writing? How does the author define performance? How does the author define culture? What new ideas or themes does the author propose? What are some examples that lead you to agree or disagree with the author's main point? If the example is creative work, how was it made? What process and decisions are behind the work? What might the creator have done differently?

### **Term Project**

Students have the option of developing their own original creative memoir or documentary project related to health, healthcare, or disability, or, of writing a critical academic research paper about a memoir or documentary project related to health, healthcare, or disability. Students will pick which direction they plan to move forward on in week 4 of the term; in week 10, we will hold a peer critique of preliminary project concepts and/or outlines and preliminary bibliographies of written papers; in week 12, we will hold a work day to rehearse performances, view rough cuts for feedback, or work on projects or papers; during the final exam, students will present their final projects to their peers. For those who choose a creative project, the project presentation itself (including the components of an artwork) are weighted more heavily than a short accompanying paper describing the process. For those who choose an academic paper, the research paper itself is weighted more heavily

than a short, informal presentation of your paper findings to your peers. A detailed assignment will be available on Quercus and discussed in class on Week 3 of the term.

A creative work might take the form of a written memoir, graphic novel, documentary play, documentary film, a zine about a specific issue or lived experience, audio documentary (e.g. podcast episode), visual artwork, collection of poetry, performance artwork, etc. Because creative projects require a sustained process of self-reflection and development of ideas, those who choose this option must keep an artist's journal throughout the term, where they record ideas, concepts, thoughts, inspirations, false starts, etc. This is important, because in doing creative work, the process can be as important as the product.

Throughout the term, this upper level seminar will act as a workshop and supportive community for everyone to develop an original term project.

***Grade***

Attendance – 10%

Participation – 10%

Discussion Leader Role – 10%

5 Reading Responses (posted to Quercus) – 20%

Term Project – 50 %

Option A Creative Project breakdown:

Artist's Journal – 10%

Peer Critique:

    Concept Form (Storyboard or Preliminary Concept Statement) – 5%

    Peer Review Feedback – 5%

Written Description of Creative Work – 10%

Final Creative Work

    Written / Visual / Pre-recorded components of the work – 10%

    Presentation of the work and Artist's Statement – 10%

Option B Critical Paper breakdown:

Preliminary Bibliography & Notes – 10%

Peer Critique: Concept Form – 5% + Peer Review Feedback – 5%

Final Presentation – 10%

Final Paper – 20%

**Extra Credit:**

If you attend an approved academic or cultural event relevant to the subject matter of the course and turn in a written description (500-750 words) describing the event content in relation to course material, you may receive 1 point extra credit on your overall grade. To receive full credit, you must critically discuss the course material. Check with the instructor by email or before or after class about possible events.

You may also receive 1 point of extra credit on your overall grade for documented use of the following campus resources:

- [Academic English Check-Up](#)
- [Meeting with a Research Librarian](#) or another faculty with relevant expertise to discuss your term project
- A [one-on-one tutoring session at the Writing Centre](#) to work on some element of your final project (they help when you haven't started writing yet, as well as when you already have a draft)

The maximum extra credit that any one student may accrue for the term is three total points.

### **Late Work and Absences:**

Any planned absences (for family reasons, personal business, health reasons, etc.) should be discussed with the instructor in the first week of class or as soon as possible. It is the responsibility of the student to follow up with an instructor and peers about content missed during an absence from class. In the event of an absence on the day an assignment is due, if the assignment should be turned in electronically.

### **Disability, Accessibility, and Accommodations:**

Please assert requests for accommodations often and early. It is never too late to request accommodations – our bodies and circumstances are continuously changing. You will be asked to make use of formal accessibility services on campus; however, you will not be asked to disclose personal medical information. If there are ways in which the overall structure of the course and general classroom interactions could be adapted to facilitate full participation, please do not hesitate to raise your ideas with the instructor: comments and suggestions about the format of readings, lectures, and class discussions are welcome. Many students benefit from formal accessibility protocols, such as extended time on exams; to make arrangements, please contact the accessibility services office to see if you qualify. You can contact UTSC AccessAbility at [ability@utsc.utoronto.ca](mailto:ability@utsc.utoronto.ca). All students are invited to visit AccessAbility and volunteer as a notetaker.

### **Academic Integrity:**

Academic integrity is essential to the pursuit of learning and scholarship in a university, and to ensuring that a degree from the University of Toronto is a strong signal of each student's academic achievement. UTSC takes cheating and plagiarism very seriously. It is the responsibility of all students to review the rules related to academic integrity, including the [Code of Behaviour on Academic Matters](#). The university also sponsors workshops, trainings, and tutoring for students related to issues such as avoiding plagiarism, proper citation, etc. Visit <https://www.utsc.utoronto.ca/vpdean/academic-integrity> for more information.

In this course, all suspected academic offences will be reported according to the Code of Behavior. Academic offences include:

*In papers:*

- Using someone else's ideas or words without appropriate acknowledgment
- Submitting your own work in more than one course without the permission of the instructor.
- Making up sources or facts.

- Obtaining or providing unauthorized assistance on any assignment

*On tests and quizzes:*

- Using or possessing unauthorized aids
- Looking at someone else's answers during an exam or quiz
- Misrepresenting your identity

*In all academic work:*

- Falsifying institutional documents or grades
- Falsifying or altering any documentation required by the University, including, but not limited to, doctor's notes.

If you have questions or concerns, please ask the instructor or refer your question to the academic integrity office.

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**Schedule**  
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**Tuesday, January 7**

**Week One – No Readings**

In Class:

About this course

Introductions

Participatory exercise: *Modern Love* – by Robert Leleux

Examples of final projects by past students

Syllabus overview – major texts and assignments

**Tuesday, January 14**

**Week Two – Written Memoir: The Personal Essay, Doctors and Patients**

In Class: Observation and Recording Exercise.

Required Reading:

\*Finger, Anne. 1994. "Helen and Freda." *The Kenyon Review*.

\**Excerpt from* Sacks, Oliver. 1992. "A Surgeon's Life" in *The New Yorker*. pp85-92 (of the magazine, or, p. 1-8 of the pdf).

Optional Reading:

DasGupta, Sayantani. "Listening as Freedom: Narrative, Health, and Social Justice." In *The Health Humanities Reader*.

\*Kuusisto, Steve. 2017 ("Selections from *Planet of the Blind: A Memoir*" in *The Disability Studies Reader*. 5<sup>th</sup> Edition. Lennard Davis, editor.

\*Gawande, Atul. 2015. *Oliver Sacks*. In *The New Yorker*.

\*Couser, G. Thomas. "Disability, Life Narrative, and Representation." In *The Disability Studies Reader*. 5<sup>th</sup> Edition. Lennard Davis, editor.

**Tuesday, January 21**

**Week Three – Understanding Documentary & Memoir: Theory and Method**

In Class: Discuss term project assignment. Discuss creative journal.

Exercise: Finding your voice.

Discussion Leaders.

Required:

\*McGillivray, Kelly. 2018. "Living in the midst: Re-imagining Disability through Auto/biography" in *Untold Stories: A Canadian Disability History Reader*. Edited by Nancy Hansen et al

\*DasGupta, Sayantani, and Rita Charon. 2004. "Personal Illness Narratives: Using Reflective Writing to Teach Empathy." *Academic Medicine* 79 (4).

\*Boyce, Carly. 2019. "helping your friends who sometimes wanna die maybe not die." A Tiny Lantern zine.

Optional:

Frank, Arthur. "Being a Good Story: The Humanities as Therapeutic Practice." In *The Health Humanities Reader*. Jones, Wear, and Friedman, eds.

\*Kuusisto, Steve. 2011 "Documentary & Life Writing." *The Journal of Literary and Cultural Disability Studies*. 5.3, 229–242.

\*Chandler, Eliza. 2018. "Disability Art and Re-Worlding Possibilities." *A/b: Auto/Biography Studies* 33 (June): 458–63.

*Selections from* Narayan, Kirin. 2012. *Alive in the Writing: Crafting Ethnography in the Company of Chekov*. Chicago. pp90-91.

hooks, bell. 2014. "'When i Was a Young Soldier for the Revolution': Coming to Voice." In *Talking Back: Thinking Feminist, Thinking Black*, New edition, 10–17. New York: Routledge.

**Tuesday, January 28**

**Week Four – The Critical Essay: Outside Medicine Looking In 1**

In Class: Brainstorm term project topics.

Discussion Leaders

"Open in Emergency" by Mimi Khuc

Required Reading:

\*Jamison, Leslie. 2014. "The Empathy Exams" in *The Empathy Exams: Essays*. Pp1-26.

\*Jain, S. Lochlann. 2013. "Introduction: We Just Don't Know It Yet." In *Malignant: How Cancer Becomes Us*. Pp 1-26.

Optional Reading:

*Contra\** Podcast about "Open in Emergency" with Mimi Khuc

Keranen, Lisa. "This Weird, Incurable Disease": Competing Diagnoses in the Rhetoric of Morgellons. In *The Health Humanities Reader*.

\**Excerpts from:* Lorde, Audre. 1980. *The Cancer Journals*. New York: Argyle.



Martin, Emily. 2007. *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton: Princeton University Press. Library ebook [here](#).

**Tuesday, February 4**

**Week Five – Written Memoir 2: The Book**

In Class:

Reminder to turn in term project concept form next week

Exercise: Creating a Scene

Discussion Leaders

Required Reading:

Anderson, Patrick. *Autobiography of a Disease*. Prelude – Part III.

Optional:

*Selections from* Cameron, Julia. *The Artist's Way*.

*Selections from* Narayan, Kirin. 2012. *Alive in the Writing: Crafting Ethnography in the Company of Chekov*. Chicago. pp9-12.

**Tuesday, February 11**

**Week Six – Written Memoir 3: The Book, continued**

In Class:

Due: Term project concept form due at the start of class

Exercise: Deciding on a Design for a Story

Discussion Leaders

Required reading:

Anderson, Patrick. *Autobiography of a Disease*. Part IV – Coda.

Optional Reading:

*Selections from* Narayan, Kirin. 2012. *Alive in the Writing: Crafting Ethnography in the Company of Chekov*. Chicago. pp12-16.

“Graphic Journalist Victoria Lomasko Sheds Light on ‘Invisible’ Parts of Russian Society.”

2017. *The Ellison Center* (blog). March 14, 2017.

<https://jsis.washington.edu/ellisoncenter/news/graphic-journalist-victoria-lomasko-sheds-light-on-invisible-parts-of-russian-society/>.

\**Selections from*: Lomasko, Victoria, and Thomas Campbell. 2017. *Other Russias*.

**\*\*\*Outside of class: Group field trip to see *Secret Life of a Mother* at Crow’s Theatre**

Tentatively, Tuesday, February 11<sup>th</sup> at 7:30pm (leave together from campus)

Alt dates: Sunday, February 9<sup>th</sup> or Wed Feb 12<sup>th</sup> at 2pm

Details to be confirmed in Week 2 of the term

– UTSC Spring Break –

**Tuesday, February 25**

**Week Seven – Theatre & Performance**

No class meeting. Professor Hartblay away. Post your reading responses as usual. Work on Term Papers / Projects.

Required Reading:

Kron, Lisa. 2005. *Well: A Play*. New York: Theatre Communications Group.

Optional:

\*Pollock, Della. 2005. "Introduction: Remembering." In *Remembering: Oral History Performance*. Edited by Della Pollock. Pp 1-17.

\*Lathem, Laurie. 2005. "Bringing Old and Young Together: An Interview Project." In *Remembering: Oral History Performance*. Edited by Della Pollock. pp. 67-84, especially focus on the section on process, beginning on p72.

*Selections from* Narayan, Kirin. 2012. *Alive in the Writing: Crafting Ethnography in the Company of Chekov*. Chicago. Pp. 75-82

**Tuesday, March 3**

**Week Eight – Beyond Truth & Fiction**

**Fiction & Other Voices**

In Class: Discussion Leaders – *Well* and *Hold Tight, Don't Let Go*

Exercise: Using someone else's writing

Required Reading:

\**Selections from* Wagner, Laura Rose. 2015. *Hold Tight, Don't Let Go: A Novel of Haiti*. New York: Amulet Books. pp1-31.

\*Wagner, Laura Rose. 2010. "Haiti: A Survivor's Story." Salon.Com.  
[https://www.salon.com/2010/02/02/haiti\\_trapped\\_under\\_the\\_rubble/](https://www.salon.com/2010/02/02/haiti_trapped_under_the_rubble/).

Optional Reading:

*A Thrice Told Tale* by Margery Wolf

(*The rest of the book*) Wagner, Laura Rose. 2015. *Hold Tight, Don't Let Go: A Novel of Haiti*. New York: Amulet Books.

**Tuesday, March 10**

**Week Nine – Documentary Film / Autobiography and Autism**

In Class: Preparations for Peer Critique. What is a Critique?

Exercise: Finding the Story by Asking the right Questions

Discussion Leaders (DLs please watch the documentary in advance)

Watch excerpts from the memoir-documentary *Deej*

Required Reading:

\*Chapter 17 in Feldman, *The Critique of Artworks*

\*Excerpts from *Leaders Around Me: Autobiographies of Autistics who Type, Point, and Spell to Communicate*.

Optional:

\*Dumit, Joseph. 2003. "Is It Me or My Brain? Depression and Neuroscientific Facts." *Journal of Medical Humanities* 24 (1): 35–47.

Muzikar, Debra. 2018. "Neurodiversity: A Person, a Perspective, a Movement?" n.d. *The Art of Autism* (blog). Accessed January 9, 2019. <https://the-art-of-autism.com/neurodiverse-a-person-a-perspective-a-movement/>.

\*MacAdam, Rachel. Sept 24 2018. Want razor-sharp focus in your audio stories? This group activity can help. NPR. <https://training.npr.org/audio/focus-audio-stories-exercise-with-your-newsroom/>

**Tuesday, March 17**

**Week Ten – Peer Critique**

Due: Paper Outlines or Draft Artist Statement & Storyboards due

In Class:

Peer Critique

No Required Reading

**Tuesday, March 24**

**Week Eleven – TBA**

In Class:

Sign up for Final Presentation Slots.

Discuss Final Presentation Assignment.

Other details TBA based on class interests

Reading: TBA based on class interests

**Tuesday, April 2**

**Week Twelve – Student Project Workshop**

No Reading

Last week of regular classes

In Class:

Students Workshop and/or work on or research final projects or papers

A formal workshop format will be offered as needed

**-- UTSC Study Break --**

**Date TBA April 8-25**

**Final Exam – Student Project Presentations**

Due: Final Papers (for both Option A and Option B) and Creative Journals and Artist Statements (for Creative Projects) due at the start of Exam Period (counted late if you are late)

**In Class:**

Students present their final projects and papers to the class.

