

LIFE AT THE END OF LIFE

PALLIATIVE CARE AND SERVICE

Spring 2022 - AMST UN 3931 - Section 004 - Th 4:10-6 PM - Hamilton 609



Where Do We Come From? What Are We? Where Are We Going? by Paul Gauguin

CONTACT INFORMATION

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COURSE OVERVIEW

DESCRIPTION

Life at the End of Life (LATEOL) is a seminar designed to provide opportunities for readings and reflections on the experience of volunteer service work. Students will learn how to critically reflect on their experiences working with patients in the context of questions raised in the texts read in the seminar. Students will develop skills necessary to critically reflect on the significance of emotional care as a medical practitioner, as well as form a deeper understanding of the role of palliative care and comfort care in a life cycle of care.

The fieldwork component of the course is met by the student's continued direct service work during the course itself. Students participating in the seminar will volunteer a minimum of 2 hours and up to 4 hours per week communicating remotely with a palliative care patient. Through this, students will provide emotional support and assistance, and serve as a consistent presence for someone experiencing chronic illness, disability, or the end of life. At the core of this framework is the patient; however, it is important to consider the impact this volunteer service will have on the student and Columbia. Therefore, the following specific goals and objectives are outlined to benefit each individual and group involved in this service relationship.

GOALS & OBJECTIVES

Student

- Students will learn how to critically reflect, emotionally and intellectually, on their experiences and that of their long term companions' (LTCs) in the context of seminar readings and discussions.
- Students will explore the emotional, intellectual, moral, and spiritual dimensions of illness, medical practice, and caregiving.
- Students will develop their capacity to share their reflections and experiences communicating remotely with their LTC and consider one another's perspectives.
- Students will gain insight into palliative care as a philosophy of care, and learn about its role in our health care system.

Columbia University

- Students will develop an understanding of their role within their communities, and Columbia University's position in New York City.
- Students will continue to explore values of social justice and social responsibility as they investigate controversial societal, medical, and ethical issues in end of life care.
- Students will use their experiences to better understand the complex interpersonal and societal questions raised in the core curricula of the undergraduate colleges.

Patient

- Students will use their seminar reflections to better inform their volunteer-caregiving experience.
- Students will form attentive, lasting, and consistent relationships with LTCs, serving as an additional advocate within the nursing and health care system.
- Students will develop a sensitivity toward the physical, psychological, and emotional suffering of individuals suffering from chronic illness and disability, and those facing the end of life, and gain insight into practices that aim to comfort and support.

REQUIREMENTS

Attendance & Participation

- Seminar (10% Attendance, 15% Participation)
Students are required to attend all seminar meetings. Seminars will meet weekly for the duration of the semester and students may miss one full class meetings during the entire semester, after which their seminar participation grade will be lowered by 5%. Please inform the instructor if you know that you will miss a session.
- Reflection Sessions (10%)
Students are required to attend the 1 hour/biweekly *At Your Service* reflection sessions. Sessions will be virtual, taking place on Zoom. Attendance will be monitored by the AYS liaison; one absence may be excused.
- Volunteer Participation (25%)
Students are required to volunteer at least 2 hours/week communicating remotely with their assigned LTC. Weekly communication will be checked for completion.

Writing Assignments

- Weekly Reflection (15%)
Students are required to complete brief written reflections on the weekly readings and their experiences communicating with their LTC as they relate to seminar discussions. Reflections should be submitted to Courseworks and are due before each week's class time. Assignments will be graded on completion.
- Final Reflective Paper (25%)
Students are required to complete a final paper (7-10 pages double-spaced) in which they critically reflect on a particular idea or issue they explored in their volunteer service and seminar discussions. While reflective papers will serve as the main evaluation for this course, they are meant to encourage students to develop an understanding of the significance of their volunteer experience and the impact it has had on them as an individual, the resident,

the institution, and the university. Students are encouraged to develop ideas for their reflective papers throughout the semester.

- Call Form
Weekly, students are required to fill a form detailing their calls with their LTC.
- Reflection Project
Students will work in collaboration with the LTC to create a reflection project. The goal of the project is to help LTCs reflect on their life history, and to capture their memories in a tangible way that reflects their unique experiences and interests. All projects should be virtual and will be graded on completion. Further details will be provided in class.
- Class Album
Students should select an artwork, photograph, piece of music, poem or other creative work that they find relates or captures their volunteer experience. Students should submit their selection along with a short description of why they chose it and why it is meaningful to them and their experience with the course. All submissions will be compiled into a class album and distributed to the class.

ADDITIONAL PARTICIPATING FACULTY, INSTRUCTORS, AND COLLABORATORS

- **Chris Adrian**, M.D., Author, Physician, Comfort and Palliative Care, Children's Hospital Los Angeles
- **Janis Freedman-Bellow**, Ph.D., Lecturer, Department of English, Tufts University
- **Rita Charon**, M.D., Ph.D., Chair, Department of Medical Humanities and Ethics, Professor of Medicine at Columbia University Medical Center, Founder and Executive Director of the Program in Narrative Medicine
- **Robert Chodo Campbell**, GC-C, Co-Founder, New York Zen Center for Contemplative Care
- **Michelle Drayton**, Director of Hospice Outreach, VNSNY and program strategist, Project HOPE
- **Eliza Factor**, M.F.A., Author, Founder of Extreme Kids & Crew
- **Linda Golding**, M.A., B.C.C., Staff Chaplain, Coordinator, Pastoral Services Milstein Hospital, NewYork-Presbyterian Hospital
- **Nigel Hatton**, Ph.D., Associate Professor, Literature, University of California, Merced
- **Anthony Lechich**, M.D., Sr. V.P. for Clinical Strategy, ArchCare
- **BJ Miller**, M.D., President and Counselor, Mettle Health

- **Cynthia Peabody**, M.Div., Home Hospice Chaplain
- **Daniel Shalev**, M.D., Physician and Researcher, Division of Geriatrics and Palliative Medicine, Weill Cornell Medicine
- **Maura Spiegel**, Senior Lecturer, English and Comparative Literature, Founder and Co-Director, CUIMC Division of Narrative Medicine, Columbia University
- **Tamara Tweel**, Ph.D., Adjunct, Assistant Professor, Center for American Studies, Columbia University
- **Cristina Ramirez-Urquiola**, M.S.W., Palliative Care Social Worker, CUIMC/NewYork-Presbyterian Hospital
- **Elisha Waldman**, M.D., Division Head, Associate Professor of Pediatrics (Palliative Care), Northwestern University Feinberg School of Medicine

READINGS

Readings to acquire:

- Strange Beauty: A Portrait of My Son by Eliza Factor

All other readings are available on Courseworks.

COURSE SCHEDULE

WEEK 1 (1/20): COURSE INTRODUCTION -*ONLINE*

PROFESSOR ROBERT POLLACK, DR. ANTHONY LECHICH, & DR. CRAIG BLINDERMAN

- “Where in this World is the Human Soul?” by Robert Pollack
- “The Nature of Suffering and the Goals of Medicine” by Eric J. Cassel
- TED Talk (video): “What really matters at the end of life – BJ Miller”

WEEK 2 (1/27): SPIRITUALITY AND RELIGION AT THE END OF LIFE -*ONLINE*

CHAPLAIN CYNTHIA PEABODY & CHAPLAIN LINDA GOLDING

- “Days” by Philip Larkin
- Selections from: *Spiritual Care for Non-Communicative Patients: A Guidebook* edited by Linda Golding
 - TBD

- Selections from: *Awake at the Bedside: Contemplative Teachings on Palliative and End-of-Life Care* edited by Koshin Paley Ellison
 - Chapter 26: “Imagining People Well” by Ira Byock
- “Grief” by Stephen Dobyns

WEEK 3 (2/3): ETHICAL ISSUES AT THE END OF LIFE

DR. CRAIG BLINDERMAN

- “Some Reflections on the Problem of Advance Directives, Personhood, Personal Identity” by Helga Kuhse
- “Beyond Autonomy and Best Interests” by Daniel Brudney
- “Palliative Options of Last Resort” by Timothy Quill
- “A Better Way Out” by Marcia Angell
- “Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper”

WEEK 4 (2/10): CHILDREN AT THE END OF LIFE -ONLINE

DR. ELISHA WALDMAN & DR. CHRIS ADRIAN

- “The Question” by Chris Adrian
- Selections from: *The Private Worlds of Dying Children* by Myra Bluebond-Langner
 - TBD

WEEK 5 (2/17): NON-VERBAL COMMUNICATION AND DISABILITY

ELIZA FACTOR

- *Strange Beauty: A Portrait of My Son* by Eliza Factor

WEEK 6 (2/24): ART, MEANING-MAKING, AND INTERCONNECTEDNESS: RETHINKING CARE -ONLINE

DR. BJ MILLER & DR. CRAIG BLINDERMAN

- *Being Mortal* by Atul Gawande
- “On Being Ill” by Virginia Woolf
- Selections from: *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* by David Rothman:
 - Introduction: Making the Invisible Visible

- Chapter 11: New Rules for the Bedside

WEEK 7 (3/3): WITNESSING THE OTHER *WILL TAKE PLACE DURING REFLECTION TIME

PROFESSOR NIGEL HATTON & PROFESSOR MAURA SPIEGEL

- TBD

WEEK 8 (3/10): NARRATIVE MEDICINE

DR. RITA CHARON

- “What is Narrative Medicine?” by Rita Charon
- “Odour of Chrysanthemums” by D. H. Lawrence

WEEK 9 (3/17): SPRING RECESS - NO CLASS

WEEK 10 (3/24): POWER, GENDER, AND MARGINALIZATION IN HEALTH CARE RELATIONALITY

TBD

- TBD

WEEK 11 (3/31): FRIENDSHIP - ONLINE

PROFESSOR JANIS FREEDMAN-BELLOW

- *Here We Are: My Friendship with Philip Roth* by Benjamin Taylor

WEEK 12 (4/7): CAREGIVING AT THE END OF LIFE

PROFESSOR TAMARA TWEEL

- *Can't We Talk About Something More Pleasant* by Roz Chast
- “The Sense of an Ending” by Rebecca Mead

WEEK 13 (4/14): THE BODY IN PAIN AND ILLNESS - ONLINE

DR. DANIEL SHALEV

- *When Breath Becomes Air* by Paul Kalanithi
- Selections from: *The Body in Pain: The Making and Unmaking of the World* by Elaine Scarry:
 - Introduction

- Selections from: *Illness as Metaphor and AIDS and its Metaphors* by Susan Sontag:
 - Part One: Illness as Metaphor

WEEK 14 (4/21): DISPARITIES IN PALLIATIVE CARE AND HOSPICE -*ONLINE*
MICHELLE DRAYTON & CRISTINA RAMIREZ-URQUIOLA

- TBD

WEEK 15 (4/28): SEMESTER REFLECTION

5/8: FINAL PAPER DUE

Upload to Courseworks by 11:59 pm.

VOLUNTEER INFORMATION

Students will communicate remotely on a weekly basis with their assigned LTC for 2 hours. Students may choose how they wish to split this one hour (i.e., two 1-hour calls, four 30-minute calls, etc). Each week, students must submit a form on Canvas detailing their calls for the week. Students will be provided prompts for their discussions, but are encouraged to also think of their own activities and conversations as part of their relationship-building with the LTC. Communication can include both video calls and phone calls. All students must complete HIPAA training before beginning communication with patients.

Calls should include, but are not limited to:

1. Serving as an advocate for the long-term companion, keeping in mind their individual needs
2. Participating in therapeutic events which can be done virtually, such as reading poetry or playing a game
3. Addressing any requests or concerns of LTCs, or relaying them in the weekly call form
4. Assisting LTC with completing a legacy project

COURSE POLICIES

Class Ethics

- Students are expected to uphold the highest ethical standards in this course. Cheating of any form will only diminish the student's ability to reflect on their experiences. Students are also expected to be truthful and accurate in reporting calls. Columbia University policies on academic conduct will be enforced in all assignments and participation.

Expectations of Students and Instructors

- Students and instructors are expected to engage in continuous academic conversation surrounding subjective experiences and service based learning. Students can expect the instructors to provide academic enrichment to their volunteer experiences. The instructors will be available during office hours or by appointment to discuss any additional ideas or issues that arise.

Disability Accommodations

- Any student requiring disability accommodations must register with the Office of Disability Services (ODS). ODS will determine the student's need for disability services on a case-by-case basis. Any student with concerns and/or registered services should speak to the instructor in office hours or by appointment.