



ST. JEROME'S UNIVERSITY

St. Jerome's University in the University of Waterloo

Department of Philosophy

PHIL 319J section 001 (Fall 2021)

Ethics of End-of-Life Care

(Offered remotely)

Territorial Acknowledgement: *We acknowledge that we are living and working on the traditional territory of the Attawandaron (also known as Neutral), Anishinaabe and Haudenosaunee peoples. St. Jerome's University is situated on the Haldimand Tract, the land promised to the Six Nations that includes ten kilometres on each side of the Grand River.*

Instructor and TA Information

Instructor: Andrew D.H. Stumpf
Office: Sweeney Hall 2109
Office Hours: Wednesdays 2:30-4:00pm (online)
Email: adhstumpf@uwaterloo.ca

TA: Vivian Nguyen (TA for Experiential Learning only)
Email: v54nguye@uwaterloo.ca
Office Hours: By appointment

When sending an email, please include your name, and a reference to this course. If you are unavailable during office hours please email to arrange a meeting at a mutually convenient time.

1. Course Description

What options does a person reaching the end of life have and how can they best be cared for? How can we balance patient autonomy with the expertise of the health-care provider and the demands of the health-care system? This course will help students think philosophically and critically about issues like these in their cultural, historical, and legal context. Specific topics may include consent, human dignity, euthanasia, refusal or withdrawal of treatment, palliative care and holistic patient care, pluralism and diverse understandings of dying, and treatment of the elderly.

To provide the equivalent of a normal in-person course, the remote version of this course will include (a) narrated PowerPoint slides in place of lectures, (b) professor-student and student-student interaction via surveys and discussion forums, (c) weekly announcement videos, (d) online office hours. Students are encouraged to participate by actively raising questions or relevant comments.

2. Course Goals / Learning Outcomes

Upon completion of this course, students should be able to:

- a. Understand the basic concepts of applied ethics in general and bioethics in particular;
- b. Identify the central ethical issues in end of life care;
- c. Appreciate diverse understandings of the significance of dying and death;
- d. Assess the ethical arguments for and against assisted death;
- e. Compare and evaluate assisted living, hospice care, palliative care, and nursing homes;
- f. Form creative and educated strategies for improving the end-of-life experience.

3. Required Texts

Please choose ONE OR THE OTHER of these books. Both available in the UW Bookstore.

- a. Callanan, Maggie. *Final Journeys: A Practical Guide for Bringing Care and Comfort at the End of Life*. New York, NY: Bantam Books, 2008.
- b. Gawande, Atul. *Being Mortal: Medicine and What Matters in the End*. New York, NY: Metropolitan Books, 2014.

4. Required Readings available in Course Reserves (see Course Schedule for dates)

- a. Abel, Julian and Kellehear, Allan. "Palliative Care Reimagined: A Needed Shift," *BMJ Supportive & Palliative Care* 2016:6, pp. 21-26.
- b. Andres, Greg (ed.) "Thinking in Ethical Terms," Ch 2 in *With a Clear Conscience: Business Ethics, Decision-Making and Strategic Thinking*, Oxford University Press, 2021.
- c. Cahill, Lisa Sowle. "Decline and Dying: Cultural and Theological Interpretations," Chapter 3 of *Theological Bioethics: Participation, Justice, Change*. Georgetown University Press, 2005.
- d. Canadian Hospice Palliative Care Association and BC Centre for Palliative Care. "Living Well, Planning Well: An Advance Care Planning Resource for Accessing Your Rights." Print.
- e. "Defining Death," Chapter 10 of *Bioethics in Canada*, Weijer, Brennan and Skelton, eds. Oxford University Press, 2013.
- f. "Death and Decisions Regarding Life-Sustaining Treatment," Chapter 5 of *Biomedical Ethics*, 7th edition, Mappes, DeGrazia and Brand-Ballard, eds. New York, NY: McGraw Hill, 2011.
- g. Dugdale, Lydia. "Finitude," Chapter 2 of *The Lost Art of Dying: Reviving Forgotten Wisdom*. Harper Collins, 2020.
- h. Foley, Kathleen. "Compassionate Care, not Assisted Suicide," Chapter 14 of *The Case Against Assisted Suicide for the Right to End-of-Life Care*," Foley and Hendin, eds. Baltimore: The Johns Hopkins University Press, 2002.
- i. Foley, Kathleen. "The Past and Future of Palliative Care," in *Improving End of Life Care: Why Has it Been So Difficult?* The Hastings Center, Nov-Dec 2005, pp. S42-S46.
- j. Johnson, Sandra H. "Making Room for Dying: End of Life Care in Nursing Homes," in *Improving End of Life Care: Why Has it Been So Difficult?* The Hastings Center, Nov-Dec 2005, pp. S37-S41.
- k. Kitwood, Tom. "Personhood maintained," Ch 4 in *Dementia Reconsidered Revisited: The Person Still Comes First*. New York, NY: Open University Press, McGraw-Hill Education, 2019.
- l. Kluge, Eike-Henner. "Codes of Ethics and the Medical Profession," Chapter 2 in *Ethics and Health Care: A Canadian Focus*. Pearson, 2013.
- m. Murray, Thomas H. and Jennings, Bruce. "Quest to Reform End of Life Care: Rethinking Assumptions and Setting New Directions," in *Improving End of Life Care: Why Has it Been So Difficult?* The Hastings Center, Nov-Dec 2005, pp. S52-S57.
- n. Myers, Jeff; Cosby, Roxanne; Gzik, Danusia. "Provider Tools for Advance Care Planning and Goals of Care Discussion: A Systematic Review," in *American Journal of Hospice and Palliative Medicine* 35(8), 2018, pp. 1123-1132.
- o. Pellegrino, E D. "Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship," *The Journal of Contemporary Health Law and Policy* 10 (1994), pp. 47-68.
- p. Saunders, Cicely. "Hospice Perspective," Chapter 13 of *The Case Against Assisted Suicide for the Right to End-of-Life Care*," Foley and Hendin, eds. Baltimore: The Johns Hopkins University Press, 2002.

- q. Snyder Sulmasy L, Mueller PS, for the Ethics, Professionalism and Human Rights Committee of the American College of Physicians. “Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper.” *Annals of Internal Medicine* 2017; 167:576–578.
- r. Speak Up Ontario, “Advance Care Planning Workbook.” Web Resource: <https://www.speakupontario.ca/resource/acp-workbook-en/>
- s. Stumpf, Andrew and Rogalski, Dominic. “Getting Real About Killing and Allowing to Die,” forthcoming, *Canadian Journal of Bioethics*. Copyright 2021.
- t. “Voluntary Active Euthanasia and Physician-Assisted Suicide,” section 5.3 of *Biomedical Ethics: A Canadian Focus*, 2nd edition. Oxford University Press, 2013.

5. Course Communication & Office Hours

Instructor Communications

For each of the twelve weeks of the course, I will post an announcement video in Learn, including the following components: (a) a heads-up about things you should be paying attention to for that week; (b) a brief summary of that week’s lecture content; (c) responses to any frequently asked questions recently received from the class; (d) brief reflection on / response to the previous week’s participation surveys and discussion forums (where applicable). These videos are important as my way of checking in with you and ensuring we are on the same page. Please be sure to view them.

Live Office Hours

Each week during the twelve weeks of the term, and in the two weeks after classes end, I will make myself available for live interaction every Wednesday 2:30-4:00pm. During those times, I pledge that I will respond right away (as soon as humanly possible) if you:

- send me an email (adhstumpf@uwaterloo.ca);
- message me in Learn live chat;

Outside of my live office hours, I will typically respond to communications from you within 24 hours during regular business days (Monday to Friday, 9am-5pm). I try to take weekends off when possible in an effort to have a bit of a life and spend some time with my family.

I will also reserve time during live office hours for **one-to-one scheduled live video chats**. If you wish to have a video chat with me, please email me in advance (ideally at least 24 hours prior) to set up an appointment. We will use MS Teams. If you need to have a video chat with me but cannot make it during my office hours, I will do my best to work with you to find an alternative time. Again, please email me in advance to arrange this.

6. Course Requirements & Evaluation

	Topic	Due Date	Weight
Participation	Weekly participation surveys	10x during term	10%
	Class Discussion Forum	5x during term	5%
Key Concepts Test	Weeks 1 – 4 Lectures & Readings	Oct 5-6 (Online)	15%
Reflective Assignment	Book Report on Chosen Reading	Oct 25, 11:54pm	15%
Argumentative Paper	Assisted Death Debate	Nov 26, 11:54pm	25%
Final Assignment	Improving End-of-Life Care <ul style="list-style-type: none"> • <u>Option 1</u>: Experiential Learning Activity / Paper • <u>Option 2</u>: Take Home Essay • <u>Option 3</u>: Online Final Exam 	Details TBA, but final due date for all three options is Dec 14, 11:54pm	30%

7. Detailed Breakdown of Course Requirements

1. Participation (15%)

Weekly participation surveys

Each of weeks 2-12 of the course will have an associated participation survey (11 in total), available in Learn only during that week (Mon 9am – Thurs 11:54pm). Each survey completed gives you 1% of your course grade, up to 10% (this means you can afford to miss one of them).

Class Discussion Forum

Five times in the term (weeks 2, 3, 7, 8 and 12) I will create a discussion thread and put up a prompt in the Class Discussion Forum in Learn. Each thread will be available only during the associated week, from Mon 9am to Thurs 11:54pm. Each time you participate in a thread by writing a post of your own and at least two comments on the posts of your peers you will earn 1% toward your course grade. ***Nota bene:*** (a) guidelines for posting and commenting must be followed (see Learn); (b) you can only access the topic/prompt for a given week after you have completed the weekly participation survey for that week; (c) do not confuse this forum with the Open Discussion Forum, which is an ungraded open forum for the course.

2. Key Concepts Test (15%)

This test will be available for you to write in LEARN between 10:00am on October 5 and 11:54pm on October 6. Once you open the test, you will have 1.5 hours (90 minutes) to write it. The test will consist of true / false, multiple choice, and matching questions, and will cover all readings and lecture content up to and including week 4 (ends Oct 1). The goal is to ensure that you've been learning the basic concepts concerning ethics and the nature of death and dying that will frame the discussion of other topics later in the course.

3. Reflective Assignment (15%)

The first assignment will take the form of a maximum 1000-word (4 page) reflective book review of your choice of *Final Journeys* or *Being Mortal* (see the Required Texts section above). I am looking for personal and critical reflection, and engagement with the major themes and topics covered in these books. I am not interested in a mere summary of what the author has said. To be submitted via LEARN dropbox by 11:54pm on Oct 25th.

4. Argumentative Paper (25%)

The 2nd assignment, on the ethics of assisted death, will require you to take and argue for a position in the debate concerning whether or not physician assisted suicide and voluntary euthanasia are morally justifiable. You will be expected to show understanding of different viewpoints within this debate, and to use the ethical and conceptual framework covered in the course to defend your position. Complete bibliographic required for all sources used. Submit a maximum 1500-word (6 page) paper via LEARN dropbox by 11:54pm, Nov 26th.

5. Final Assignment (30%)

You have three options regarding the final exam for this course. **Choose One** of the following:

Option 1: Participate in the course's Experiential Learning (EL) Activity. This will involve attending three to four online tutorial sessions (3/30), writing and revising a proposal with a group (10/30), helping to run an Advance Care Planning session (2/30), and writing a reflective paper (15/30). Submit reflective paper to the relevant Learn dropbox by Dec 14, 11:54pm. Dates and more details for other components of the EL activity will be announced in Learn.

Note: If you wish to participate in the EL activity you must communicate your intention (via the relevant survey in Learn) by 11:54pm on Oct 1.

Option 2: Write a maximum 1500-word (6 page) take-home exam, developing and justifying your own vision for improving end-of-life care in Canada, reflecting selectively on course content (lectures and assigned readings) from the entire course. Submit your paper to the relevant Learn dropbox by Dec 14, 11:54pm.

Option 3: Write a two-hour test in Learn, consisting of true/false, multiple choice, and short answer questions. The test will be open between Dec 13, 10:00am and Dec 14, 11:54pm.

8. Course Schedule (subject to minor changes depending on how the term progresses):

Week	Topic(s)	Readings*
1 (Sept 8-10)	Course Introduction: Ethics and End-of-Life Care	Course Syllabus; Andres, "Thinking in Ethical Terms"
PART ONE: FOUNDATIONAL CONCEPTS		
2 (Sept 13-17)	Health Care Ethics: History, Theory & Practice <i>Discussion forum #1 due by Sept 16, 11:54pm</i>	Kluge, "Codes of Ethics and the Medical Profession" (Chapter 2)
3 (Sept 20-24)	The Health Care Provider – Patient Relationship <i>Discussion forum #2 due by Sept 23, 11:54pm</i>	Pellegrino, "Patient and Physician Autonomy..."
4 (Sept 27-Oct 1)	Advance Care Planning (ACP) & Substitute Decision-Making + MS Teams guest lecture by Sheli O'Connor (Hospice Waterloo) Sept 28, 7-8pm	Myers et al. "Provider Tools..."; Speak Up Ontario, "Advance Care Planning"; Canadian Hospice Palliative Care, "Living Well, Planning Well..."
5 (Oct 4-8)	The Meaning of Dying and Death + Online Advance Care Planning Session (date/time TBA) <i>Key Concepts Test available Oct 5, 10am – Oct 6, 11:54pm</i>	Cahill, "Decline and Dying"; Weijer et al., "Defining Death"; Mappes et al. "Death and Decisions"
<i>Mid-Term Study Break (Oct 9-17)</i>		
PART TWO: PROBLEMS AND SOLUTIONS IN ETHICS OF END OF LIFE CARE		
6 (Oct 18-22)	Assisted Death – Concepts & Context	Stumpf & Rogalski, "Getting Real..."
7 (Oct 25-29)	Assisted Death – The Debate(s) <i>Reflective paper due by 11:54pm on Oct 25</i> <i>Discussion forum #3 due by Oct 28, 11:54pm</i>	<i>Biomedical Ethics</i> , "Voluntary Active..."; Foley, "Compassionate Care..."; ACP Position Paper
8 (Nov 1-5)	Ars Moriendi – The Art of Dying (Well) <i>Discussion forum #4 due by Nov 4, 11:54pm</i>	Dugdale, "Finitude"
9 (Nov 8-12)	Assisted Living & Nursing Homes	Johnson, "Making Room..."; Gawande, <i>Being Mortal</i> (Chs 3-5)
10 (Nov 15-19)	Hospice & Palliative Care	Foley, "The Past and Future..."; Saunders, "Hospice Perspective"
11 (Nov 22-26)	Dementia and Person-Centred Care <i>Argumentative paper due by 11:54pm on Nov 26</i>	Kitwood, "Personhood Maintained"
12 (Nov 29-Dec 3)	Catch Up & Review <i>Discussion Forum #5 due by Dec 2, 11:54pm</i>	None
13 (Dec 6-7)	Farewell! <i>Final Exam (all options) due by 11:54pm on Dec 14</i>	None

- All readings are listed above (sec. 4) and can be accessed electronically via Course Reserves.

- *You are expected to do the relevant readings early each week in order to participate in weekly participation surveys and discussion forum threads in an informed way.*

9. UW POLICY REGARDING ILLNESS AND MISSED TESTS

The University of Waterloo Examination Regulations (www.registrar.uwaterloo.ca/exams/ExamRegs.pdf) state that:

- A medical certificate presented in support of an official petition for relief from normal academic requirements must provide all of the information requested on the “University of Waterloo Verification of Illness” form or it will not be accepted. This form can be obtained from Health Services or at www.healthservices.uwaterloo.ca/Health_Services/verification.html.
- If a student has a test/examination deferred due to acceptable medical evidence, he/she normally will write the test/examination at a mutually convenient time, to be determined by the course instructor.
- *[Note: At St. Jerome’s, make-up midterm exams and quizzes have traditionally been offered on the first Friday following the exam, from 1:00 pm – 4:00 pm, in room STJ 3012. This may not apply for remote learning course offerings.]*
- The University acknowledges that, due to the pluralistic nature of the University community, some students may on religious grounds require alternative times to write tests and examinations.
- Elective arrangements (such as travel plans) are not considered acceptable grounds for granting an alternative examination time.

10. OTHER IMPORTANT INFORMATION

- **Academic Integrity:** In order to maintain a culture of academic integrity, members of the University of Waterloo community are expected to promote honesty, trust, fairness, respect, and responsibility. Check www.uwaterloo.ca/academicintegrity/ for more information.
- **Grievance:** A student who believes that a decision affecting some aspect of their university life has been unfair or unreasonable may have grounds for initiating a grievance. [Read the St. Jerome’s University Policy on Student Petitions and Grievances](#). When in doubt, please be certain to contact the St. Jerome’s Advising Specialist, Student Affairs Office, who will provide further assistance.
- **Discipline:** A student is expected to know what constitutes academic integrity, to avoid committing an academic offence, and to take responsibility for their actions. Check www.uwaterloo.ca/academicintegrity/ for more information. A student who is unsure whether an action constitutes an offence, or who needs help in learning how to avoid offences (e.g., plagiarism, cheating) or about “rules” for group work/collaboration should seek guidance from the course instructor, academic advisor, or the Associate Dean. When misconduct has been found to have occurred, disciplinary penalties will be imposed under the [St. Jerome’s University Policy on Student Discipline](#). For information on categories of offences and types of penalties, students should refer to University of Waterloo [Policy 71, Student Discipline](#). For typical penalties, check the [Guidelines for the Assessment of Penalties](#).
- **Appeals:** A decision made or penalty imposed under the [St. Jerome’s University Policy on Student Petitions and Grievances](#) (other than a petition) or the [St. Jerome’s University Policy on Student Discipline](#) may be appealed if there is a ground. A student who believes they have a ground for an appeal should refer to the St. Jerome’s University policy on [Student Appeals](#).

11. NOTE FOR STUDENTS WITH DISABILITIES

[AccessAbility Services](#), located in Needles Hall (Room 1401) at the University of Waterloo, collaborates with all academic departments to arrange appropriate accommodations for students with disabilities without compromising the academic integrity of the curriculum. If you require academic accommodations to lessen the impact of your disability, please register with AccessAbility Services at the beginning of each academic term, www.uwaterloo.ca/accessability-services/.

12. MENTAL HEALTH SUPPORT

On Campus

- Counselling Services: counselling.services@uwaterloo.ca / 519-888-4567 x32655
- **MATES**: one-to-one peer support program offered by Federation of Students (FEDS) and Counselling Services
- Health Services Emergency service: located across the creek from the Student Life Centre

Off campus, 24/7

- **Good2Talk**: Free confidential help line for post-secondary students. Phone: 1-866-925-5454
- Grand River Hospital: Emergency care for mental health crisis. Extended Assessment Unit
Phone: 519-749-4300 x6880
- **Here 24/7**: Mental Health and Crisis Service Team. Phone: 1-844-437-3247
- **OK2BME**: Support services for lesbian, gay, bisexual, transgender or questioning teens in Waterloo. Phone: 519-884-0000 x222

Full details can be found online at the Faculty of ARTS [website](#)

Download [UWaterloo and regional mental health resources \(PDF\)](#)

Download the [WatSafe app](#) to your phone to quickly access mental health support information

Contact Health Services

[Health Services Building](#)

Call 519-888-4096 to schedule an appointment

Call 1-866-797-0000 for free 24/7 advice from a health professional

Contact Counselling Services

[Needles Hall Addition, NH 2401](#)

Call 519-888-4567 x 32655 to schedule an appointment

counserv@uwaterloo.ca

Note: Due to COVID-19 and campus closures, UWaterloo in-person counselling services are limited, and most support will be provided online or by phone. Students are advised to contact Counselling Services by phone or email.

At SJU, Lindsay Thompson, Wellness Coordinator (lindsay.thompson@uwaterloo.ca), is our student wellness resource and is available by email.

13. WRITING AND COMMUNICATION CENTRE

The Writing and Communication Centre works with students as they develop their ideas, draft, and revise. Writing and Communication Specialists offer one-on-one support in planning assignments, synthesizing and citing research, organizing papers and reports, designing presentations and e-portfolios, and revising for clarity and coherence.

You can make multiple appointments throughout the term, or drop in at the Library for quick questions or feedback. To book a 50-minute appointment and to see drop-in hours, visit www.uwaterloo.ca/writing-and-communication-centre. Group appointments for team-based projects, presentations, and papers are also available. Please see the Writing and Communication Centre website for information on how to proceed in light of current Covid-19 restrictions.

Please note that communication specialists guide you to see your work as readers would. They can teach you revising skills and strategies, but will not change or correct your work for you. Please bring hard copies of your assignment instructions and any notes or drafts to your appointment.