



THE INAUGURAL
Completed Life
Conference

Thursdays
September 3rd through October 8th, 2020
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC

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Conference Schedule of Events

9-11AM PACIFIC | 12-2PM EASTERN | 4-6PM UTC

THURSDAY, SEPTEMBER 3RD

Session One
What is a Completed Life?

THURSDAY, SEPTEMBER 10TH

Session Two
Cases for a Completed Life: Clinical Points of View

THURSDAY, SEPTEMBER 17TH

Session Three
A Case for Objections and Ethical Concerns

THURSDAY, SEPTEMBER 24TH

Session Four
The Completed Life through an International Lens:
Implications of Medical Aid-in-Dying

THURSDAY, OCTOBER 1ST

Session Five
Interdisciplinary Narratives: End-of-Life Challenges that Result in
Organizational Changes

THURSDAY, OCTOBER 8TH

Session Six
Completing Life by Voluntarily Stopping
Eating and Drinking (VSED): A Little Known Yet Readily Available
End-of-Life Option

Conference Virtual Platform

ACCESS INFORMATION: GLOBALMEET

LOGON INFORMATION:

Session One: What is a Completed Life?

[CLICK HERE TO REGISTER](#)
SESSION 1

Session Two: Cases for a Completed Life: Clinical Points of View

[CLICK HERE TO REGISTER](#)
SESSION 2

Session Three: A Case for Objections and Ethical Concerns

[CLICK HERE TO REGISTER](#)
SESSION 3

**Session Four: The Completed Life through an International Lens:
Implications of Medical Aid-in-Dying**

[CLICK HERE TO REGISTER](#)
SESSION 4

Session Five: Interdisciplinary Narratives: End-of-Life Challenges that Result in Organizational Changes

[CLICK HERE TO REGISTER](#)
SESSION 5

**Session Six: Completing Life by Voluntarily Stopping Eating and Drinking: A Little Known Yet
Readily Available End-of-Life Option**

[CLICK HERE TO REGISTER](#)
SESSION 6

TECHNICAL SUPPORT:

If you need technical assistance during the live webcast, access the “help” menu (?) in the top right hand of your screen. You can also send in tech questions using the “Ask a Question” box.

Networking

AT THE CONFERENCE AND BEYOND

SLACK:

<http://bit.ly/completed-life-conference>

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Effective August 31st, 2020

Welcome to the Slack Channel for the Completed Life Conference! We are glad to have you here. In order to keep this virtual space discrimination-free and open to all, your participation will be subject to the following terms:

1. Participants will **not engage in hate speech** or derogatory language based on gender, sex, race, ethnicity, religion, orientation, ability, health status, or class.
2. Information shared by participants within this space will remain confidential unless given express permission by the individual(s) contributing the content in question.
3. “Doxxing,” the practice of locating **personal sensitive information** on participants and sharing with others inside or outside the virtual space, is forbidden and any incident that comes to our attention will result in immediate expulsion from the conference Slack.

By contributing to this Slack channel, you accept the above terms and conditions and agree to engage in kind and compassionate discourse with fellow attendees. Failure to adhere to these rules will result in lost access to the Conference’s Slack Channel.

Participants are welcome to message our Slack Administrator (@Rachel Bloom) if they come across user contributions that violate these rules and these incidents will be reviewed promptly.

We will notify users if and when these terms are updated for any relevant changes.

Best wishes,

Sarah J. Kiskadden-Bechtel
Program Director, The Completed Life Initiative

Welcome

LETTER FROM OUR FOUNDER



FAITH SOMMERFIELD

Dear Friends and Colleagues,

It is a pleasure to welcome you to the inaugural Completed Life Conference. The Completed Life Initiative advocates for self-determination and dignity at the end of life. Our purpose is to promote thoughtful consideration about the meaning of choice for each of us through a forum that encourages open and informed discussions about end-of-life issues.

The point at which any life is complete can be determined only by the individual, based on the values they deem important. A terminal diagnosis might shape the definition of when life is considered “complete.” For example, can I experience joy, see beauty in my surroundings, ambulate safely, engage in meaningful social interaction? Some might want to live until actually overcome by death, while others might wish to die before losing bodily functions essential to their personal dignity. Still others, knowing the likely progression of their disease, might choose to view their life as complete before arriving at the precipice of “existence” where suffering – despite efforts at effective control – does not end.

American culture is generally uncomfortable addressing death. Yet, within this same culture, we embrace the belief that life is a cycle beginning with birth and ending with death. How do we explain this profound cultural paradox? Like many of life’s great unanswered questions, meaning is found through open discussion. My hope in exploring the Completed Life is that we will begin a dialogue that helps us discover new approaches to addressing our mortality.

Other cultures do not share our prevailing “fear of death” mentality. Open discussion of end-of-life choices has been publicly conducted by philosophers, academics and others for centuries. Physician assistance in dying, now often called Medical Aid in Dying (MAID), is legal in The Netherlands, Belgium, Luxemburg, parts of Germany, Victoria Australia, Colombia, all of Canada, and 9 states and the District of Columbia in the U.S. Beginning with Oregon and the Netherlands, there are decades of data available about the absence of abuse in these jurisdictions.

Within the United States, we have seen growing evidence of widespread interest in end-of-life choices. Palliative care is improving in many situations, more treatment options exist for those with terminal diagnoses, and we have begun, slowly, to approve legislation permitting medical aid-in-dying. Voluntary Stopping Eating and

WELCOME: LETTER FROM OUR FOUNDER

Drinking (VSED) is also becoming recognized as an option. Although legal access to medical aid in dying now covers about 22% of residents in the United States, existing legislation remains woefully short of permitting all individuals so desiring to complete their lives with dignity.

Our national respect for freedom should encompass personal choice until the very end of life, and our public policy must come to reflect this freedom. Choice is the vital underpinning of all fundamental human rights, which protect free people from political, legal, social, or medical abuse. Consequently, we must absolutely advocate for the right to self-determination at this time. The Completed Life Initiative therefore seeks to empower every human being to exercise their personal autonomy and ability to self-determine by honoring their judgment of when their life becomes complete.

The Completed Life Conference aims, in a six-week course, to foster open conversation about self-determination. The conference will explore the meaning of a completed life, how individuals can communicate their end-of-life wishes to loved ones, and how their wishes can be honored fully and respectfully even amidst impossibly difficult circumstances.

We hope to engage all people in a continuing conversation on these important issues with the goal of bringing about positive changes in the fields of public policy, education, medical treatment, caregiving and advance medical planning

Sincerely,

Faith Sommerfield
Founder and Director of the Completed Life Initiative

Welcome

LETTER FROM OUR KEYNOTE SPEAKER



TIMOTHY QUILL, MD

Dear Conference Attendees,

As a long-time palliative care physician, I have witnessed first-hand the range of human emotion and decision-making when a patient approaches the end of their life. Most of us hope to live as long and as fully as possible, and then die peacefully. We also hope that our lives will feel “completed” when that happens, and if death comes quickly and easily, we – and those who care about us – will feel lucky we died according to our wishes.

Many will continue to want all available life-prolonging treatments regardless of suffering, especially those who have not had access to medical care and who feel that society has made their lives very incomplete. Fighting disease and trying to live longer are key to living fully for such persons, and this process should be supported fully by the medical system.

Most patients are worried about uncontrolled and unbearable pain and suffering at the end of life; yet, barriers remain regarding lack of patient awareness of the type of medical resources available; what’s involved when individuals pursue these options; and the implications of making these decisions for both the patient and the patient’s family. The first step when a person might be considering options to hasten death is to be sure it is not being motivated by suffering that might be addressed by receiving adequate palliative care.

And yet, those lucky enough to have full access to medical treatments may already feel their lives are “completed,” and might want to skip a period of increasing debility late in life by choosing the time of their own death.

What might be the criteria for making such a choice, and what methods to achieve death might be permissible? Furthermore, what options to end life might be available to those who have lost decision-making capacity? These questions are profound and difficult, but we are all going to have to face them in some form, sooner or later – both for ourselves and those whom we love and care about.

Our medical systems are best designed to help us live as long as possible and fight disease with specialized tools. When disease progression outweighs the benefits of these tools, we have palliative care and hospice systems in place to relieve suffering and help us make timely decisions – specifically, about when to stop fighting and

WELCOME: LETTER FROM OUR KEYNOTE SPEAKER

when to accept that death is imminent. These systems work reasonably well for many of us. Others, however, experience prolonged periods of debility later in life despite receiving skillful medical and palliative treatment, and about half of us lose the ability to make our own medical decisions late in the process.

There is an underlying need for providers to enhance a patient's awareness of their end of life options, which will help the patient make an informed choice most appropriate to them. Heightened competence in how clinicians approach discussions with patients and their families about the patient having the best – or at a minimum the least bad death – possible is therefore integral to what should become the standard of care. A conduit is needed between patients and doctors to help facilitate these difficult conversations.

And yet, barriers persist between providers and patients at the very end of life; indeed, these conversations are often not standard in hospitals or medical facilities across the United States. A major deficiency therefore persists in most patients' lack of awareness of accessible end-of-life treatment options that can support them in their dying experience.

There is great need to standardize conversations between providers and patients – including the goals of care, anticipated outcomes, and side effects – and for the outcome of these conversations to align as closely as possible with an individual's values given their medical circumstances. But standardizing conversations is only the beginning: shifting public policy in the United States is critical to standardizing advance care planning and broadening treatment options toward the end of life.

The Completed Life Conference presents a clinical, ethical, and legal foundation for advance care planning, in addition to real time decision-making with expanded end-of-life options, to become the standard of care for clinicians across the United States, and beyond. I highly recommend this Conference to you and am very glad that you've decided to learn more about this important topic.

Sincerely,

Timothy Quill, MD

Welcome

LETTER FROM OUR PROGRAM DIRECTOR



SARAH J. KISKADDEN-BECHTEL, MS BIOETHICS

Distinguished guests,

I am honored to welcome you to the inaugural Completed Life Conference.

Our Conference comprises a series of six weekly sessions, which aim to address questions that now reverberate so acutely for many of us in light of the COVID-19 pandemic. How do we live as fully as possible, assured that our end-of-life wishes will be respected? How can people be made aware of resources that are typically only made available through palliative and hospice care? And, how do individuals choose to relieve their suffering at the end-of-life while retaining their personal dignity?

This Conference was created to explore the particulars within the spectrum of end-of-life care. The Completed Life Initiative aims to shed the stigma associated with talking about death and seeks to establish a national advocacy and education initiative to promote awareness and access. With the intention of showing people how to advocate for self-determination at the end of life, the Completed Life Conference was therefore created as a forum where you can learn from our world renowned experts about critical details involved in end-of-life treatment, and ways to access the resources and tools to plan your end of life care accordingly.

Affording terminally-ill individuals the opportunity to control their pain and suffering at the very end of life – through expert palliative and hospice care, with the option to access medical aid-in-dying – provides the greatest possible assurance that people can navigate their end-of-life care on their own terms. With the necessary and appropriate safeguards, individuals facing the very end of their life should be assured the dignity of dying on their own terms, as they see fit, in accordance with their own wishes, and with utmost regard to their personal bodily autonomy. This fundamental right of consent is central in medical ethics; it traces back to a court decision from 1914, where Justice Benjamin Cardozo declared that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his [or her] own body...” (Schloendorff v. Society of New York Hospital).

Having access to a variety of end-of-life treatment options enables people to have a conversation with their clinicians and allows them to have the option of—but not a requirement to pursue—seeking palliative, hospice, and aid-in-dying methods. The conversation between patients and their clinicians provides an opportunity to discuss the best medical treatment options available for those specific individuals, who have to

WELCOME: LETTER FROM OUR PROGRAM DIRECTOR

decide for themselves whether they wish to continue for as long as is medically possible or whether the burdens of further treatment are not satisfactory to them as an “additional measure” of their life.

A “completed life” is absolutely unique to each person and cannot be determined externally by others. Mortality deserves reverence, where all human beings are respected for who they are and what they personally believe, regardless of difference of opinion, race, or religion. When individuals approach the end of their lives, their personal choices should occur on their own terms.

The following six weeks comprises presentations from bioethics luminaries across the world. The expertise of our sixteen speakers in the Completed Life Conference is world-renowned, including clinicians, philosophers, and advocates from across the United States, as well as from Australia, Canada and the Netherlands. Throughout this series, you will experience different blueprints of how end-of-life treatment options can be implemented in individual patient care, and the ethical concerns and challenges that arise with different scenarios. Our main priority is to emphasize the importance of having access to end-of-life treatment options, and to help facilitate the ways in which these options can become the standard of care. In order to empower each person to take full ownership of how they tell their end of life story, both the awareness of and the ability to access different end-of-life options is pivotal.

We are delighted that you have decided to join us for our inaugural Conference, and grateful to have you as a member of our burgeoning Completed Life Community. Before we begin, take a moment to read through this brochure to experience a preview of what you will learn in the following six weeks. Please also take a moment to connect with us on social media (@completedlife) and share the word among your friends and professional networks.

And now, without further ado, let us commence with Session One: What is a Completed Life?

Sincerely,

Sarah J. Kiskadden-Bechtel
Program Director of the Completed Life Initiative

Thursday, September 3rd
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC

WHAT IS A COMPLETED LIFE?

KEYNOTE SPEAKER:



Timothy Quill, MD



WITH PRESENTATIONS BY:

Margaret "Peggy" Battin, PhD & Paul Menzel, PhD

Session One explores aspects of how dying can be meaningful even while the acceptance of dying is difficult for many. We hope to see our lives, which hold inherent meaning and value, as "complete" at the time of death – specifically, without suffering and with a sense of peace. However, unbearable suffering or deterioration can badly disrupt such a conclusion of having lived a completed life.

This session will further explore the notion of what it means to live a completed life, with examination of palliative and hospice care considerations, and an overview of how right-to-die laws in present-day jurisdictions generally recognize – in the face of serious medical problems, where patients are in unbearable pain, suffering, and often experiencing a terminal illness – the withholding or withdrawing of treatment, as well as options for patients to control their end of life experience.

CME CREDITS AVAILABLE

THE SPEAKERS: SESSION 1



Timothy Quill, MD

Timothy E. Quill, MD is the Georgia and Thomas Gosnell Distinguished Professor of Palliative Care, and Professor of Medicine, Psychiatry, Medical Humanities and Nursing at the University of Rochester School of Medicine (URMC). He was the Founding Director of the URMC Palliative Care Program and is the Acting Director of the URMC Paul M. Schyve Center for Bioethics. He is also a board certified palliative care consultant in Rochester, New York.

Dr. Quill has published and lectured widely about various aspects of the doctor-patient relationship, with special focus on end-of-life decision making, including delivering bad news, nonabandonment, discussing palliative care earlier, and exploring last-resort options. He is the author of several books on end-of life, including *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (Johns Hopkins University Press, 2004), *Caring for Patients at the End of Life: Facing an Uncertain Future Together* (Oxford University Press, 2001), and *A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life* (Johns Hopkins University Press, 1996), and numerous articles published in major medical journals including “Death and Dignity: A Case of Individualized Decision Making” published in the *New England Journal of Medicine*. Dr. Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the U.S. Supreme Court (Quill v. Vacco).

Dr. Quill is a Fellow in the American College of Physicians and in the American Academy of Hospice and Palliative Medicine, an ABMS certified Palliative Care consultant, a past board member and past president of the American Academy of Hospice and Palliative Medicine, a founding board member of American Academy on Communication in Healthcare. Dr. Quill serves on the Completed Life Initiative’s Advisory Board.



Margaret Pabst Battin, PhD

Margaret Pabst Battin, PhD (nicknamed Peggy) is Distinguished Professor of Philosophy and Adjunct Professor of Internal Medicine, Program in Medical Ethics and Humanities, at the University of Utah. She is a graduate of Bryn Mawr College, and holds an M.F.A. in fiction-writing and a Ph.D. in philosophy from the University of California at Irvine. The author of prize-winning short stories and recipient of the University of Utah’s Distinguished Research Award, she has authored, co-authored, edited, or co-edited some twenty books, among them a study of philosophical issues in suicide; a scholarly edition of John Donne’s *Biathanatos*; a collection on age-rationing in medical care; *Puzzles About Art*, a volume of case-puzzles in aesthetics; a text on professional ethics; *Ethics in the Sanctuary*, a study of ethical issues in organized religion; and a first collection of her essays on end-of-life issues,

THE SPEAKERS: SESSION 1

The Least Worst Death. She has also been engaged in research on active euthanasia and assisted suicide in the Netherlands. She has also published *Ethical Issues in Suicide*, trade-titled *The Death Debate*, as well as several co-edited or co-authored collections, including *Drug Use in Euthanasia and Assisted Suicide*; *Physician-Assisted Suicide: Expanding the Debate*; *Praying for a Cure*, a jointly authored volume on the ethics of religious refusal of medical treatment; and *Medicine and Social Justice*. In 1997 she received the University of Utah's Distinguished Research award, and in 2000, she received the Rosenblatt Prize, the University of Utah's most prestigious award. She was named Distinguished Honors Professor in 2002-03. A second collection of her essays (and fiction) on end-of-life issues, entitled *Ending Life*, was published in spring 2005 by Oxford University Press. She is the lead author of two multi-authored projects, *Drugs and Justice: Seeking a Consistent, Coherent, Comprehensive View* (Oxford, 2008) and *The Patient as Victim and Vector: Ethics and Infectious Disease* (Oxford, 2009). She is the general editor of *The Ethics of Suicide: Historical Sources*, Oxford University Press, September 2015, an extensive sourcebook coupled with an online Digital Archive hosted by the J. Willard Marriott Library at the University of Utah <ethicsofsuicide.lib.utah.edu/>. She is currently completing *Sex & Consequences*, a book on large-scale reproductive issues, including world population growth and reproductive rights; work concerning the difference between "suicide" and "physician aid in dying"; a "personal anthology" of papers on real-world thought experiments with "normative force"; and a set of novel considerations about urban design in the light of ecological, environmental, resource-use, and social issues, called "How to Live in an Italian Hill Town and Still Get to Walmart." She has been named one of the "Mothers of Bioethics." Professor Battin serves on the Completed Life Initiative's Advisory Board.



Paul Menzel, PhD

Paul T. Menzel, PhD is Professor of Philosophy emeritus at Pacific Lutheran University. He has published widely on moral questions in health economics and health policy, including *Strong Medicine: The Ethical Rationing of Health Care and Prevention vs. Treatment: What's the Right Balance?* In recent years, Dr. Menzel has written extensively on end-of-life issues, including physician-assisted death, advance directives for dementia, and voluntarily stopping eating and drinking. With Timothy Quill, Thaddeus Pope, and Judith Schwarz, he is a co-editor of the forthcoming *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death* (Oxford University Press, 2021). Dr. Menzel has been a visiting scholar at the Rockefeller Center-Bellagio, the Brocher Foundation-Geneva, the Chinese University of Hong Kong, and the Monash Bioethics Centre. He is a Work Group member for the Hastings Center's current project on end-of-life choices in dementia and an Advisory Board member for The Completed Life Initiative.

THE CONVERSATIONS: **SESSION 2**

Thursday, September 10th
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC

CASES FOR A COMPLETED LIFE: CLINICAL POINTS OF VIEW



A CONVERSATION BETWEEN CLINICIANS:

Judith Schwarz, PhD, RN

&

Jessica Zitter, MD



MODERATOR:

Hannah Lipman, MD, MS

Session Two will address complicated clinical cases at the end of life and explore care options that can alleviate suffering. This session is designed to help clinicians optimize conversations with their patients at the end of life, exploring how clinicians can broaden patients' awareness of existing resources while they still have decision-making capacity. What remains meaningful to patients at the end of their life in different circumstances varies from person to person, and between families. However, patients and their families often share the goal of managing painful symptoms at the end of life, where the underlying focus of alleviating suffering throughout the dying process is not inherently different. Particular treatment options, such as voluntarily stopping eating and drinking (VSED), will be discussed as an option that may best fit the patient's current diagnosis, prognosis, and personal values.

CME CREDITS AVAILABLE

THE SPEAKERS: SESSION 2



Judith Schwarz, PhD, RN

Judith Schwarz, PhD, RN has been the Clinical Director of End of Life Choices New York and its predecessor organization Compassion & Choices of New York since 2002. She has counseled many hundreds of patients suffering from incurable and progressive or terminal illnesses and their families about end of life options and choices.

She earned a PhD in nursing at New York University where her research explored nurses' experiences when asked by decisionally capable patients for assistance in dying. She completed a MSN at Lehman College, a certification program in bioethics and the medical humanities at Columbia University, and - many years ago, a nursing degree at a hospital program in Denver, Colorado.

Judith has taught ethics and health care law to nursing students, lectures frequently to professional nursing and palliative care audiences as well as to lay groups, and publishes regularly in professional journals. She has recently focused her writing and speaking on the option of voluntarily stopping eating and drinking as a means to achieve a peaceful, patient-controlled death, and has become concerned about the need to complete an advance directives by those newly diagnosed with Alzheimer's disease.



Dr. Jessica Nutik Zitter, MD, MPH

Dr. Jessica Nutik Zitter, MD, MPH is a national advocate for transforming the way people die in America. She is Harvard and UCSF-trained to practice the unusual combination of Critical and Palliative Care medicine. She works as an Attending Physician at a public hospital in Oakland, California.

Dr. Zitter is the author of the newly released *Extreme Measures: Finding a Better Path to the End of Life*. She is a regular contributor to *The New York Times* and her articles have appeared in *The Atlantic*, *Time Magazine*, *Journal of the American Medical Association*, *The Washington Post* and many other publications. Dr. Zitter's work is featured in the Academy and Emmy-nominated short documentary "Extremis," available on Netflix. Her media appearances include CBS Sunday Morning, NPR's Fresh Air with Terry Gross, The Doctors, The Leonard Lopate Show, and a Dr. Oz special, "The Death Show."

A sought-after speaker, Dr. Zitter has presented at numerous venues, including The Commonwealth Club, the American Academy of Hospice and Palliative Medicine, California Coalition for Compassionate Care, University of California at Berkeley's Dean Lecture, and the Caring

THE SPEAKERS: SESSION 2

Coalition Conference. Committed to mainstreaming conversations about death and dying, Dr. Zitter co-created a high school curriculum on Death Education that won top honors in the OpenIDEO End-of-Life Challenge. The idea was piloted at two Bay Area high schools in 2017 and is featured in a forthcoming documentary. In addition, Dr. Zitter co-founded and served as the first medical director of Vital Decisions, a telephone counseling service for patients with life-limiting illness.



Hannah I. Lipman, MD, MS

Hannah I. Lipman, MD, MS is Director of Bioethics at Hackensack University Medical Center and Associate Professor in the Department of Internal Medicine at Hackensack Meridian School of Medicine. Dr. Lipman received her BA in Economics from Northwestern University and her MD from Columbia University. She trained in internal medicine at University of Michigan, cardiology at Tufts New England Medical Center, and geriatrics, palliative medicine and cardiology at Mount Sinai School of Medicine. She earned a Master of Science in Clinical Research at Mount Sinai and completed the Montefiore Einstein Certificate Program in Bioethics. Dr. Lipman has particular expertise in clinical ethics, medical decision making, bioethics education for a variety of learners, and bioethics consultation.

Thursday, September 17th
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC
A CASE FOR OBJECTIONS & ETHICAL CONCERNS



A CONVERSATION BETWEEN:
Gloria Ramsey, JD, RN
&
Daniel Sulmasy, MD, PhD, MACP



MODERATOR:
Samuel Gorovitz, PhD

Session Three will address ethical concerns about hastening death from philosophical and disability rights perspectives, and further examine end-of-life care options from different viewpoints. The discussion will explore philosophical, religious, and diversity perspectives on hastening death, whether a person's serious illness presupposes their dependence on loved ones, and what follows from these considerations. This session will also evaluate the differential significance of serious and terminal illness for disadvantaged communities, underscoring the importance of emphasizing a patient's personal autonomy and values, and how clinicians must evaluate the whole spectrum of a patient's life in their end-of-life planning and care.

CME CREDITS AVAILABLE

THE SPEAKERS: SESSION 3



Gloria Ramsey, JD, RN

Gloria Ramsey, JD, RN promotes and strategically furthers the school's values of diversity and inclusion by bolstering Johns Hopkins School of Nursing's excellence, innovation, and impact within education, practice, and the profession. She has been a nurse and attorney engaged in interdisciplinary research/scholarship related to bioethics, end-of-life care, and advance care planning for more than two decades (Hastings Center, American Nurses Association, American Bar Association). She provides leadership to national projects focusing on end-of-life care and advance care planning for African-American patients/families and persons with disabilities. Ms. Ramsey is an advocate for engaging racially and ethnically diverse populations and faith communities for participation in research and partnering/collaborating on community-based health disparity interventions. She has taught bioethics, research, public health, military ethics, and health policy to DNP and PhD nursing students and interprofessional graduate students. She is a Distinguished Practitioner of the National Academies of Practice, immediate past member of the Diversity Advisory Council of the National Hospice and Palliative Care Organization, and a member of the American Academy of Nursing Cultural Competency and Health Equity and Bioethics expert panels.



Daniel Sulmasy, MD, PhD

Daniel Sulmasy, MD, PhD is Acting Director of the Kennedy Institute of Ethics and a Senior Research Scholar. Dr. Sulmasy holds a joint appointment at the Pellegrino Center for Clinical Bioethics. He is the inaugural Andre Hellegers Professor of Biomedical Ethics, with co-appointments in the Departments of Philosophy and Medicine at Georgetown. His research interests encompass both theoretical and empirical investigations of the ethics of end-of-life decision-making, ethics education, and spirituality in medicine. He has done extensive work on the role of intention in medical action, especially as it relates to the rule of double effect and the distinction between killing and allowing to die. He is also interested in the philosophy of medicine and the logic of diagnostic and therapeutic reasoning. His work in spirituality is focused primarily on the spiritual dimensions of the practice of medicine. His empirical studies have explored topics such as decision-making by surrogates on behalf of patients who are nearing death, and informed consent for biomedical research. He continues to practice medicine part-time as a member of the University faculty practice. He completed his residency, chief residency, and post-doctoral fellowship in General Internal Medicine at the Johns Hopkins Hospital. He has previously held faculty positions at Georgetown University and New York Medical College. He has served on numerous governmental advisory committees, and was appointed to the Presidential Commission for the Study of Bioethical Problems by President Obama in April 2010. He is the author or editor of six books: *The Healer's Calling* (1997), *Methods in Medical*

THE SPEAKERS: SESSION 3

Ethics (2001; 2nd ed. 2010), *The Rebirth of the Clinic* (2006), *A Balm for Gilead* (2006), *Safe Passage: A Global Spiritual Sourcebook for Care at the End of Life* (2013), and *Francis the Leper: Faith, Medicine, Theology, and Science* (2014). He also serves as editor-in-chief of the journal *Theoretical Medicine and Bioethics*. Dr. Sulmasy holds a Ph.D from Georgetown University and an M.D from Cornell University. He joins us from the University of Chicago, where he was Kilbride-Clinton Professor of Medicine and Ethics in the Department of Medicine and Divinity School, Associate Director of the MacLean Center for Clinical Medical Ethics in the Department of Medicine, and Director of the Program on Medicine and Religion.



Samuel Gorovitz, PhD

Samuel Gorovitz, PhD has probed issues of ethics, inclusion, and social justice in medicine and in higher education throughout his career. He first published on moral problems in medicine in the mid-1960s. Then, as a young philosophy professor at Case Western Reserve University, he started a collaboration with Nobel laureate and biomedical researcher Fred Robbins, dean of the medical school.

Born in Boston, Massachusetts, Professor Gorovitz received a B.S. in Humanities and Science from MIT (1960) and a Ph.D. in Philosophy from Stanford (1963). In 2016 he received an honorary Doctor of Science degree from the State University of New York (nominated by Upstate). Professor Gorovitz became dean of the College of Arts and Sciences at Syracuse University in 1986, having taught at Wayne State, Case Western Reserve, and the University of Maryland at College Park. As dean (1986-92), he prompted the college to make key faculty appointments of women in STEM disciplines; commissioned the first Committee on Conditions for Women in the College; and appointed the first woman associate dean in the College's history. He was known for rigor in evaluating slates of candidates, insisting that women candidates be fully recruited and considered before he would approve any faculty offer. After being dean (1986-92), he taught a course in Public Administration for three years. In fall 1996, he was Baker-Hostetler Professor of Law at the Cleveland Marshall College of Law and in fall 1998 was Visiting Scholar in Science and Technology Studies at Cornell. He was Dearing-Daily Professor of Bioethics and Humanities at SUNY Upstate from 2001-04, and for 2004-05 was Visiting Professor of Philosophy and Bioethicist in Residence at Yale. He returned to leadership at Syracuse in 2004 as Founding Director of the Renée Crown University Honors Program, emphasizing the necessity of an increasingly pluralistic and academically diverse program (2004-10). He continues as Professor of Philosophy at Syracuse.

THE SPEAKERS: **SESSION 3**

Professor Gorovitz has published extensively in bioethics and on other topics in philosophy and public policy. His advice on college governance and on health policy has been widely sought. He has given hundreds of invited lectures on five continents, and directed many seminars and institutes for faculty in various disciplines, including an NEH seminar for college teachers and an NIH workshop on research with human subjects. He has been a consultant to PBS, WHO, and many federal agencies. He emphasizes that philosophy is an ideal pursuit for anyone who thrives on minding other people's business.

Thursday, September 24th
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC

**THE COMPLETED LIFE THROUGH AN INTERNATIONAL
LENS: IMPLICATIONS OF MEDICAL AID-IN-DYING**



A CONVERSATION BETWEEN:

Jocelyn Downie, CM, FRSC, FCAHS, SJD,
Ben White, DPhil, LLB

&

Agnes van der Heide, MD, PhD

Session Four will address legislative and policy barriers to patients achieving access to end-of-life resources. This session will focus on how to create policy to mitigate or remove barriers to end-of-life choice, with specific regard to medical aid-in-dying, and how clinicians can better support and implement a defined standard of care across the U.S. for aid in dying. Discussion will further consider a comparative angle from experts in Australia, Canada, and the Netherlands. This comparative lens offers a method of “looking to” other models for how the United States can shape its legislation and policy, which some states have done by modeling their legislation after Oregon’s Death with Dignity Act (1997).

CLE + CME CREDITS AVAILABLE

THE SPEAKERS: SESSION 4



Jocelyn Downie SJD, FRSC, FCAHS

Jocelyn Downie SJD, FRSC, FCAHS is a University Research Professor in the Faculties of Law and Medicine at Dalhousie University. She is also a member of the Dalhousie Health Law Institute. Professor Downie received an honours BA and MA in Philosophy from Queen's University, an MLitt in Philosophy from the University of Cambridge, an LLB from the University of Toronto, and an LLM and doctorate in law from the University of Michigan. After graduation from law school, she clerked for Chief Justice Lamer at the Supreme Court of Canada.

Professor Downie has published numerous books and articles including *Dying Justice*, winner of the 2005 Abbyann Lynch Medal in Bioethics from the Royal Society of Canada. She has spoken at conferences on a variety of health law and policy topics across Canada and around the world. Her most recent writing projects include papers on end of life law and policy in Canada, barriers to access to abortion in Canada, various aspects of the law as it relates to organ and tissue donation and transplantation as well as *Health Law at the Supreme Court of Canada and Canadian Health Law and Policy*. Professor Downie has been the principal investigator on numerous research projects including a \$1.8 million training program in health law and policy funded by CIHR and a \$1.5 million CIHR grant in neuroethics. Professor Downie thoroughly enjoys teaching Health Care Ethics and the Law as well as Legal Ethics and Professional Responsibility in the Faculty of Law and supervising a wonderfully talented group of graduate students and postdoctoral fellows on various aspects of health law and policy.



Ben White, DPhil, LLB

Ben White, DPhil, LLB is a Professor and Director of the Australian Centre for Health Law Research in the Faculty of Law at the Queensland University of Technology (QUT). Professor White graduated with first class Honours and a University Medal in Law from QUT and then completed a DPhil at Oxford University on a Rhodes Scholarship.

Professor White's area of research focus is end-of-life decision-making and his work is interdisciplinary with publications in law, medicine, bioethics and social science journals. He has had funding from four Australian Research Council grants examining law, policy and practice at the end of life. He is also an Associate Investigator in the National Health and Medical Research Council's Centre of Research Excellence in End-of-Life Care. He is currently a committee member of the Australasian Association of Bioethics and Health Law and an editor of 'Health Law in Australia' (3rd ed, 2018, Thomson (forthcoming)).

THE SPEAKERS: SESSION 4



Agnes van der Heide, MD, PhD

Agnes van der Heide, MD, PhD is professor of End-of-Life Care and Decision Making at the Department of Public Health at Erasmus MC, University Medical Center Rotterdam, the Netherlands. She was trained as a physician and epidemiologist and has been working in empirical end-of-life care research since 1995. Her research is focused on epidemiological, clinical, ethical and legal issues in end-of-life care and end-of-life decision making. She has been the principal investigator of many end-of-life care research projects at the local, national and international level. She has co-led the five-yearly nationwide survey studies on developments in end-of-life decision making practices in the Netherlands since 1995 and was one of the main investigators in the studies to evaluate the Dutch Termination of Life on Request and Assisted Suicide (Review Procedure) Act. Currently, she is coordinating an 12-country research project on experiences of dying and preferences in end-of-life care.

THE CONVERSATIONS: **SESSION 5**

Thursday, October 1st
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC

**INTERDISCIPLINARY NARRATIVES:
END-OF-LIFE CHALLENGES THAT RESULT IN
ORGANIZATIONAL CHANGES**



A CONVERSATION BETWEEN:
David N. Hoffman, JD
&
Danielle Spencer, PhD

Academic Director of Columbia University's Narrative Medicine Program

Session Five will explore Narrative as an organizing principle as well as a tool for incorporating the elements of personal narrative that define a completed life. Discussion will begin with how the suppression of personal narrative, through the influences of managed care and the menu-driven electronic medical record, denies patients and clinicians the opportunity to meaningfully discuss and record a plan for implementing patient values and preferences. After examining these unintended consequences of managed care, this session will turn to evaluate the application of narrative medicine, which seeks to establish a value-driven thread connecting the earlier and later phases of patient lives in order to formulate their end-of-life goals and priorities. This session will also assess the legal imperative to respect patients' life choices and the need for clinicians to inquire about, internalize, and memorialize patient choices as a legal obligation and component of the standard of care. Finally, the session will explore remaining opportunities for how clinicians can utilize narrative medicine – alongside other modalities born of the medical humanities – to elevate patients' moral and personal right to describe their own sense of a completed life.

CLE CREDITS AVAILABLE

THE SPEAKERS: SESSION 5



David Hoffman, JD

David Hoffman, JD a health care lawyer and clinical ethicist in New York, where he is a lecturer in Bioethics and full-time core faculty member of the Columbia University Master's Program in Bioethics. He also teaches in the areas of law, medicine and ethics at the Albert Einstein College of Medicine where he holds an appointment as a Clinical Assistant Professor. He also serves as the Chief Compliance Officer for Carthage Area Hospital. Mr. Hoffman is a founding member and current Secretary of the Completed Life Initiative.

Mr. Hoffman has written on a variety of healthcare subjects including use of medical imaging technology in litigation, equal protection rights of physicians, and regulatory responses to the emerging physician shortage, and has served on and advised hospital ethics committees and institutional review boards. He is a volunteer panel Attorney for the Surrogate Decision-making Committee of the New York State Department of Health, Commission on Quality of Care. Mr. Hoffman served as the Chair of the Committee on Bio-ethical Issues of the Association of the Bar of the City of New York (ABCNY), and as a member of the Committee on Professional Ethics of the New York State Bar Association, where he was the principal author of the committee's opinion on internet-based attorney client matching services. Mr. Hoffman serves on the Completed Life Initiative's Advisory Board.



Danielle Spencer, PhD

Danielle Spencer, PhD is the Academic Director of the Columbia University Narrative Medicine Program, and a Senior Lecturer in the Discipline of Narrative Medicine. Dr. Spencer is the author of the forthcoming *Metagnosis: Revelatory Narratives of Health and Identity* (Oxford University Press, 2020) and co-author of Perkins-Prize-winning *The Principles and Practice of Narrative Medicine* (OUP, 2017). Research interests include retrospective diagnosis, contemporary film and bioethics, and healthcare pedagogy; creative and scholarly work appears in diverse outlets, from Ploughshares to The Lancet. Formerly artist/musician David Byrne's Art Director, Spencer holds a B.A. from Yale University, an M.S. in Narrative Medicine from Columbia University, a Ph.D. from Johannes Gutenberg University Mainz. She is a 2019 MacDowell Fellow and a 2020 Yaddo Fellow.

Thursday, October 8th
9-11am Pacific | 12-2pm Eastern | 4-6pm UTC
COMPLETING LIFE BY VOLUNTARILY STOPPING
EATING AND DRINKING (VSED):
A LITTLE KNOWN YET READILY AVAILABLE
END-OF-LIFE OPTION



A CONVERSATION BETWEEN:
Thaddeus M. Pope, JD, PhD
&
David A. Gruenewald, MD, FACP

Session Six will present the evidence that shows stopping eating and drinking (VSED) at the very end of life is an effective method of hastening death. In particular, current tools that are available and legal, like VSED, are not widely known or implemented. Advance directives are important tools to implement VSED. Performing due diligence is important for individuals and families to think about if they consider specifying VSED on their advance directive. This session is designed to illuminate how clinical care teams and long term and acute care facilities can further establish advanced care planning as the standard of care in order for patients to live in a dignified manner until the very end of their life.

The session will conclude with closing remarks from the Completed Life Initiative's President, Jason Smith.

CLE + CME CREDITS AVAILABLE

THE SPEAKERS: SESSION 6



Thaddeus M. Pope, JD, PhD

Thaddeus Mason Pope, JD, PhD is a foremost expert on medical law and clinical ethics. He maintains a special focus on patient rights and healthcare decision-making.

Pope is Director of the Health Law Institute at Mitchell Hamline School of Law in Saint Paul, Minnesota, USA. While he serves in a range of consulting capacities, Pope has been particularly influential through his extensive high-impact scholarship.

Ranked among the Top 20 most cited health law scholars in the United States, Professor Pope has over 200 publications in leading medical journals, bioethics journals, and law reviews. He coauthors the definitive treatise *The Right to Die: The Law of End-of-Life Decisionmaking*, and he runs the *Medical Futility Blog* (with over four million page-views).

Professor Pope works to calibrate the balance between individual liberty and public health in the end-of-life medical treatment context. Specific research topics include: medical futility, unwanted medical treatment, ethics committees, brain death, advance directives, surrogate decision making, unrepresented patients, aid in dying, and VSED.

Prior to joining academia, Professor Pope practiced at Arnold & Porter LLP and clerked on the U.S. Court of Appeals for the Seventh Circuit. Pope earned a JD and PhD (in philosophy and bioethics) from Georgetown University. Mr. Pope serves on the Completed Life Initiative's Advisory Board



David A. Gruenewald, MD, FACP

David Gruenewald, MD, FACP is Medical Director of the Palliative Care and Hospice Service at VA Puget Sound Health Care System. He is Associate Director of the Palliative Medicine Fellowship and Associate Professor of Medicine in the Division of Gerontology and Geriatric Medicine.

His varied clinical interests in patient care near the end of life include the management of symptoms, especially difficult pain management problems; palliative treatments of “last resort” including palliative sedation and voluntarily stopping eating and drinking (VSED); conducting goals of care conversations; and communication skills. His palliative care program development work includes his founding role in building the Palliative Care & Hospice Service at VA Puget Sound HCS in 2004 and the UW Palliative Medicine Fellowship in 2008; and project leadership for a Dept. of Veterans Affairs initiative to improve family meetings in intensive care units.

His published work includes systematic reviews examining the illness

THE SPEAKERS: **SESSION 6**

experience of older adults near the end of life and the evaluation of quality of life in people severely affected by multiple sclerosis; development of a curriculum to improve family meetings in intensive care units; reviews of palliative treatments of last resort including management of requests to stop eating and drinking by residents of long term care facilities; review of barriers and facilitators of end-of-life care for Veterans without secure housing; and assessment of the merits of rationing health care based on age.

Closing Keynote

LETTER FROM OUR PRESIDENT



JASON J. SMITH

Dear Conference Participants,

Thank you for joining us in the midst of a historic moment in time. The COVID-19 pandemic continues to rage, prompting concerns about mortality and, more importantly, the quality of end of life. Throughout these six weeks of the Completed Life Conference, you will be privy to the foremost scholarship and clinical expertise of individuals who go above and beyond in their daily practice as bioethicists and healthcare providers. These are individuals doing their part to change the world. And now, I extend the cordial invitation for you to join us in this important work.

Advocating for the right to self-determination holds personal significance for me. The prospect of someone with a terminal illness suffering beyond measure is deeply harrowing. I have witnessed it firsthand with my dear friend, “Rebecca.” Throughout her later years and especially at the end of her life, Rebecca suffered from multiple sclerosis and significantly deteriorating osteoporosis. Her condition was such that her spine and ribcage collapsed forward, placing tremendous, debilitating pressure on her lungs, other internal organs, and pelvis. Rebecca’s pain was unbearable, its intensity only amplified by her clear and lucid mind. Rebecca would call me every day, agonizing over how the pain management methods available to her were ineffective, and how she dreaded waking up each day in so much pain. She hated being so moribund. Finally, she couldn’t take it anymore, and with no option readily available to ensure that she could die with dignity, she took her own life by suffocating herself with a plastic bag – a most ungracious and undignified death.

If Rebecca had been allowed to die with dignity, she would have been able to conclude her life while she still enjoyed it, when her suffering was much more manageable. Yet, because Rebecca was not classified as a “terminal” patient by her medical care team, she did not qualify for aid in dying and, being forced to endure so much suffering, ultimately took matters into her own hands. In sum, at the end of her life, Rebecca was lucid, and able to make an informed decision regarding her condition as a patient with an irreversible medical condition that would result in her death.

As President of the Completed Life Initiative, I proudly champion legislative and policy efforts to advance medical aid-in-dying across the United States. We are seeking to expand eligibility for medical aid-in-dying beyond current legal restrictions to include those who reasonably deem their lives to be “complete.” We aim to provide not just a legal regime for such freedom, but also the education, networks, resources

CLOSING KEYNOTE: LETTER FROM OUR PRESIDENT

and access to utilize it in any sector of our society.

Now that you have reached the conclusion of the inaugural Completed Life Conference, I invite you to take action. Your continued participation and support for the Completed Life Initiative enables us to continue our grassroots momentum to create an additional national platform for patient rights' advocacy, promoting educational outreach on mortality and personal dignity, and creating positive change within advance care planning nationwide.

I encourage you to join our mailing list and connect with us on social media for news on future opportunities and benefits that you will receive by staying active in the Completed Life Community. Other ways you can become engaged and stay involved include emailing us (info@completedlife.org) and talking to your colleagues and networks about the information that you learned in this Conference. Share what you have learned here and encourage others to get involved.

Thank you again for your presence at this conference. I look forward to seeing you at our next Conference in 2021!

Sincerely,

Jason J. Smith
President of the Completed Life Initiative

Special Thanks

WE ARE GRATEFUL

To our Advisory Board for their enduring devotion and abounding wisdom throughout many months of planning.

Jason J. Smith, President

Delano Copprue, Treasurer

David N. Hoffman, Secretary

Margaret Peggy Battin

Nicole Nuttall

Paul Menzel

Thaddeus M. Pope

Dr. Timothy Quill

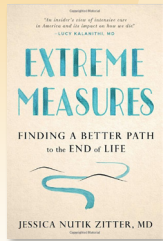
To our Program Director, Sarah Kiskadden-Bechtel, for her tireless efforts in producing the inaugural Completed Life Conference.

To our Speakers, without whom our Conference would be bereft of such luminary insights.

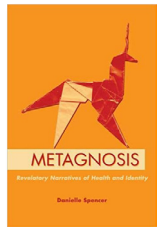
And especially to our Founder, Faith Sommerfield, for daring to ask the question, “what does it mean to live a completed life?”

Recently Authored

RECENT PUBLICATIONS BY OUR SPEAKERS



Extreme Measures
by Jessica Nutik Zitter



Metagnosis by Danielle Spencer



Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death,
edited by Timothy E. Quill, Paul T. Menzel, Thaddeus M. Pope, and Judith K. Schwarz. Oxford University Press, forthcoming in 2021.

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The Completed Life Conference Participants can look forward to being included in our monthly newsletter, and privy to news and updates within the Completed Life Community.

JOIN OUR MAILING LIST TO STAY TUNED FOR DETAILS REGARDING OUR NEXT CONFERENCE IN 2021!

WWW.COMPLETEDLIFE.ORG