

Fall Newsletter

NOVEMBER 2021

VOL. 3



FALL NEWSLETTER 2021

Welcome from Our Program Director

The choice to die on one's own terms is full of complexity. Losing the precious resources that make life worth living - such as the ability to walk and live safely, and enjoy a community of friends and family - are considerations embedded in the fiber of discussion about a completed life. Our Founder Faith Sommerfield's vision to develop an expansive "tent" for the completed life encompasses the many facets of human mortality, inherent to the precept that a completed life will be unique to every person.

It is hard to believe that the *Completed Life Initiative* was founded just two years ago. Within these past two years, and in the midst of the worldwide COVID-19 pandemic, we've accomplished a great deal. We are grateful to have launched our Annual Fall Conference in 2020 and just now concluded our 2nd Annual in 2021; hosted continuing event series, including Lunch Hour sessions, Town Hall meetings, the March Symposium, and Panel Discussions featuring expert insights on the ethical, legal, and medical challenges and components of a completed life; and memorably debuted a Summer Arts Festival that highlighted either a play or a musical about what it means to live well, and die on one's own terms.

As you peruse this Newsletter edition, consider ways in which you can expand the conversation about the Completed Life, and please share your stories with us. We welcome your narrative.

Sincerely,
Sarah Kiskadden-Bechtel
Program Director

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2nd Annual Fall Conference 2021

Our **2nd Annual Fall Conference** concluded after four-session events via Cisco Webex that ran every Tuesday and Thursday between **November 4th-16th, 2021**. The Conference focused on the complications associated with Medical Aid-in-Dying from both a historical and modern perspective. Advocates know the often-insurmountable odds of passing right to die legislation, given that it is still only legal in eleven jurisdictions in the United States. Yet, what happens once the right to die is legal? Does the history of the movement indicate changes in its future landscape? And, what global perspectives on aid-in-dying shed light on the current legal situation in the United States?

Learn more about each conference session below, and remember to spread the word about our Completed Life [events](#) to your networks and colleagues.

Session One – Assisted Dying in the United States: What Happens after Legalization

Presenters: Dr. Frances Norwood, PhD; Dr. Mara Buchbinder, PhD, author of [*Scripting Death: Stories of Assisted Dying in America*](#)

What barriers persist once the right to die is legal? Session One explored the stories of assisted dying in the United States. These stories represent the perspectives of patients, their families, and caretakers, as well as healthcare attorneys and policy makers, who now face what happens after the hard-won battle for legalization. This session explored exactly what challenges remain, as well as seeks insight on how to resolve them.

Fall Conference 2021 (cont.)

Session Two – Narrative Overview of the Right-to-Die Movement in the United States

Presenters: Dr. Timothy E. Quill, MD; Thaddeus M. Pope, JD PhD

Session Two provided a narrative overview of Major Right-to-Die Legal Cases in the United States as a historic and legal roadmap of where we've been as we evaluate the future of the movement. Looking back at major legal decisions, our speakers explored the historic challenges faced by efforts to establish a right to die. Our experts discussed which decisions advocates have had to accept, and which were unsuccessful attempts at passing aid-in-dying; which restrictions were imposed (e.g., framing the discussion in terms of "assisted suicide" compared to "assisted dying"), and how to see these decisions modified; whether and how they are too restrictive; as well as federal attempts to outlaw medical aid in dying.

Session Three – Is the Right to Die being held hostage to a Right to Healthcare?

Presenters: Dr. Lonny Shavelson, MD; Tracey A. Bush, MSW, LCSW

Unwanted care and care that is not well-considered is still the most prevalent assault on people's right to how their lives end. Conversely, those who have a lifetime of experiencing a stark inequity in healthcare coverage may prompt underserved populations to pursue the "do everything" model of end-of-life healthcare. How do we balance the absence of a right to healthcare with avoiding the end-of-life conveyor belt? How would diverse communities wish to be approached and supported regarding their end-of-life experience? Session Three evaluated concerns regarding diverse communities, communities of color, and communities with disabled individuals who may feel targeted or disadvantaged by their lack of access to standard healthcare benefits (e.g. before age of 65 with eligibility for Medicare).

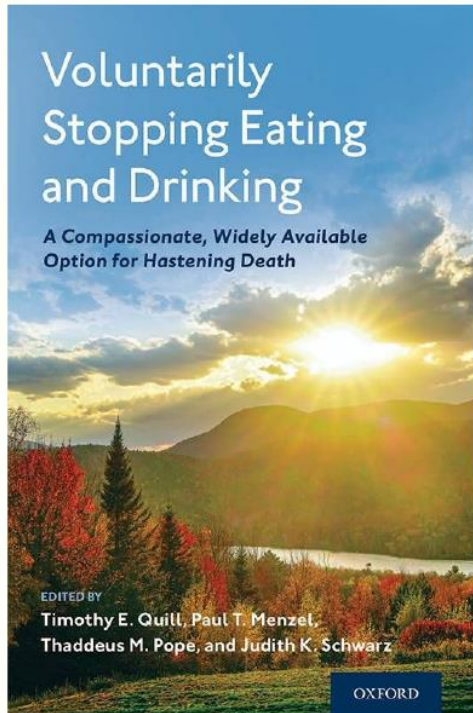
Session Four – Towards a Completed Life: Global Significance of the Right-to-Die movement

Presenters: Asunción Álvarez del Río, PhD (Mexico); Lucas Correa Montoya, JD (Colombia)

What is the global significance of the right-to-die movement, and how does it relate to the big tent concept of a completed life? Session Four explored ways in which countries other than the United States view aid-in-dying, providing information about what is going on in the rest of the world, with specific focus on countries in Latin America. With esteemed end-of-life scholars Asunción Álvarez del Río, Ph.D. and Lucas Correa Montoya, JD, Session Four concluded our conference by highlighting how other cultures are maneuvering end-of-life practices. As we look at existing policies in Mexico and Colombia, we consider how advocates in countries other than the United States navigate end-of-life planning within the global conversation of the right-to-die movement and with specific regard to the implementation of Medical Aid in Dying.



[Watch our 2nd Annual Fall Conference](#)



New VSED book by CLI's Advisory Board!

The *Completed Life Initiative* celebrated the launch of "Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death," published by Oxford University Press, a book that will surely define the clinical ethics standards for a wider range of end of life care options across the United States. Author Dr. Timothy E. Quill is Completed Life's Clinical Advisor; authors Professor Paul T. Menzel and Thaddeus M. Pope are members of our esteemed Advisory Board; Judith K. Schwarz is a similarly esteemed colleague who is Clinical Director at our partner organization, *End of Life Choices New York*.

At the **Book Launch Event on October 21st**, our four authors discussed the process of writing the book, the implications for standard of care and clinical guidelines, and more.

The subsequent event on **Clinical Considerations of VSED on October 28th** took a deeper dive into the clinical challenges that can arise in complex care scenarios, such as advantages, and limitations of Stopping Eating and Drinking by Advance Directive (SED by AD), Comfort Feeding Only (CFO), or Minimum Comfort Feeding Only (MCFO).

Some of the nuances of this book include subchapters on illustrative patient cases - patients who have lost their decision-making capacity and have chosen to stop eating and drinking via advance directive (SED by AD). Additional questions arose from this two-part event series. How do we make VSED more widely known? What are the clinical, legal, ethical, and institutional issues involved with incorporating VSED as part of standard clinical knowledge? And how do we create inclusive dialogue on VSED?

On behalf of everyone at the *Completed Life Initiative*, we extend our wholehearted congratulations to co-authors Quill, Schwarz, Menzel, and Pope for their incredible and ongoing contributions to the field of end-of-life bioethics!

WATCH THE TWO-PART SERIES ON VSED

PAGE 4

CLI Summer Arts Festival Highlights

- **Week One - Till Soon. Anne (musical)**
- **Week Two - Independence Day (play)**
- **Week Three - Life Review: The Hospice Musical (musical)**

The **2021 Summer Arts Festival** brought together gifted storytellers in the performing arts in a three-part event series featuring performances about the Completed Life. This three-part series involved one performance per week in August 2021. Each week's performance featured either a play or a musical about what it means to live well, and die on one's own terms.

In **Week One**, creators of *Till Soon, Anne*, Bobby Cronin and Christine Toy Johnson presented an excerpted rendition of their musical. This musical tells the story of a 34-year old woman in the final stages of brain cancer who invites her closest friends and family to a perfect last weekend, determined to celebrate the life she's been given and embrace the art of letting go. Christine Toy Johnson is an award-winning writer, actor, director, filmmaker, and advocate for inclusion based in New York City. She is the host of the Dramatists Guild's podcast TALKBACK, distributed on the Broadway Podcast Network.

Bobby Cronin is an award-winning composer/writer for theatre, short film, web, dance, and more. He says, "My goal is to work on socially significant art which inspires, challenges, enlightens and elevates. I aim to tell stories of the underdog, the underrepresented, the "weirdo" while shining a light on hypocrisy, judgement, and misrepresentation to ultimately unite us."

In **Week Two**, the creators and actors of *Independence Day* performed an emotionally rich narrative about the completed life. *Independence Day* is a short play that featured two residents in a family care home, along with their healthcare worker. One suffers from Early Onset Alzheimer's and the other from Parkinson's disease. We see the residents as their health deteriorates, and witness the challenges of being ready to die and not having planned for it. This performance was followed by a Q&A with the playwrights and actors, Chuck Jeffries, Mariah Burks, and Gretchen Douma. This session also highlighted the importance of preparing for one's end-of-life wishes long before the end-of-life and the impact on those who care for the not-yet-dying.

Continued on next page...

“*When we have shuffled off this mortal coil,
Must give us pause - there's the respect
That makes calamity of so long life.*”

- *Shakespeare, Hamlet*

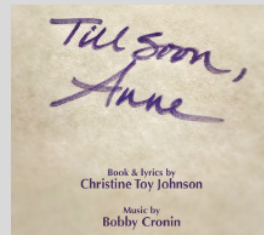
CLI Summer Arts Festival Highlights (cont.)

Week Three featured *Life Review: The Hospice Musical* for the concluding performance of the **Summer Arts Festival**. This event featured a new musical celebrating life, love, and loss at a residential hospice. The story follows our young Rabbi David, the new chaplain at the long-term care facility. He arrives in autumn, eager and naive, caring but lonely. As he ministers to the patients, Rabbi David learns from his patients, even as he cares for them and their loved ones. In *Life Review: The Hospice Musical*, each patient sings their story. We hear from a proud mother remembering snow, a brave but scared young man wondering what's to come, and an older man looking for one last friend. This performance was followed by a Q&A session with the creator of the musical, Cantor Benjamin Kintisch, a cantor, chaplain, and a music teacher. Cantor Kintisch is involved with theater and songwriting as well, resulting in the creation of this truly unique musical. "Life Review" is the first musical he has created. Kintisch recently completed his fourth year of chaplaincy training, having served in both hospice and eldercare facilities.

Music and drama are beautiful methods to express emotionally difficult concepts. Our **2021 Summer Arts Festival** had been a success, thanks to the creativity, passion, dedication, talent, and hard work of all our performers. All three performances powerfully expressed the range of emotions surrounding end-of-life care, dying, and death. We extend our gratitude and appreciation to all Festival performers for their contributions to the arts, for sharing their incredible talents with all of us at the Completed Life Initiative.

Special Thanks to our Performers

Bobby Cronin
Benjamin Kintisch
Christine Toy Johnson
Chuck Jeffries
Elizabeth Coplan
Gretchen Douma
Mariah Burks



Grief Dialogues
HEALTH CARE EDUCATION



Meet the Newest Members of our Team!

We are delighted to introduce to your the newest additions to our Completed Life Team.



Joelle Charles, our new **Program Associate**, earned her Master of Arts Degree from Teachers College studying Anthropology and Education, specifically concentrating on Urban Community. Previously, Joelle has worked as a youth development educator, mentoring, facilitating global awareness workshops, and creating social-emotional and healing-centered content for young people across New York City. In May, Joelle will begin an End-of-Life Doula program at the University of Vermont to continue her education in grief work, caregiving, and wellness. In her spare time, she enjoys outdoor adventures like fishing and hiking, traveling, practicing yoga, and bringing along her dog, Birdie, wherever she goes.

A WORD FROM JOELLE:

“With a warm heart, I begin my role as Program Associate with The Completed Life Initiative. As a student of Anthropology, I care deeply about the stories of others and find joy in sharing narratives that can expand our understanding of the human condition. As a person having experienced loss, I sincerely identify with the ongoing conversation within the CLI community and treasure the moments when individuals are willing to share their personal stories. Looking forward, I am eager to hear from those of you in the CLI community and work alongside you to move forward in compassionate end-of-life care.

With gratitude, Joelle Charles

”



Taj Newman, Intern is a massage therapist and death doula in-training, currently living in Olympia, Washington. Born and Raised in Eugene, Oregon, Taj acquired a Bachelors of Literature from Tel Aviv University in 2014, where she also learned to speak modern Hebrew. She returned to the States after completing her degree, and moved to New Orleans, where she studied massage therapy and was introduced to the life-affirming tradition of second-line funerals. Upon moving back to the Pacific Northwest in 2019, Taj began working as a caregiver, and was introduced to VSED by her client, C., who chose that path. Being a support to C.'s process ignited Taj's passion for expanding the conversation around end-of-life choices. Taj is honored to be a part of the CLI community, and is grateful to carry on C.'s legacy through this work. In her free time, Taj enjoys birdwatching, challah-making, reading and friendship.

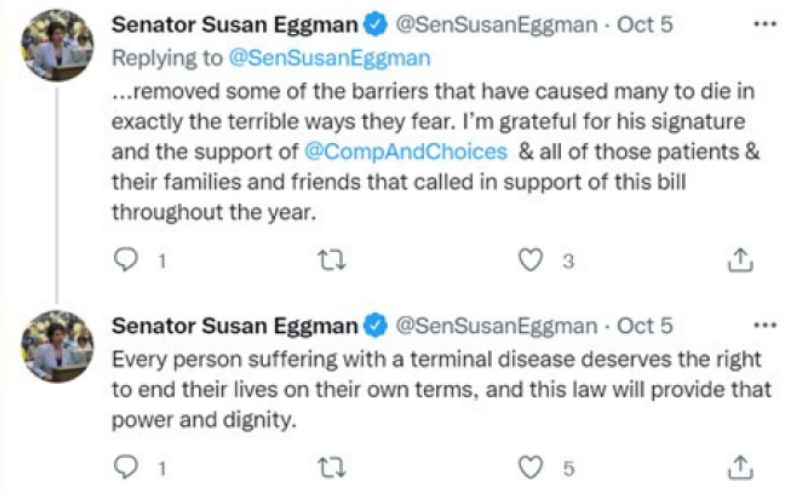


[Learn more about CLI's Leadership](#)

Around the World: Legislative Updates

California

On October 5th, 2021, Governor Gavin Newsom signed into law a six-year extension of California’s End of Life Option Act! Residents of California will have their legal options to medical aid-in-dying for the terminally ill protected until January 1st, 2031. The signing of bill SB380 strengthens California’s end of life option act, by removing unnecessary and redundant barriers that prevent access to aid-in-dying medication, increases provider participation transparency, and extends the Act to 2031. The new bill also shortens the waiting period between two oral requests for the prescription, reducing the waiting time from 15 days to 48 hours, while removing the requirement of having an individual make a final attestation before being prescribed aid-in-dying medication. Senator Susan Eggman, the legislator behind the SB380 bill, tweeted “The End-Of-Life Option Act has provided peace of mind to thousands of dying Californians since 2016” and thanked Governor Newsom for extending this law for an additional five years.



.....➔ [Read more about the update to SB380 here](#)

Around the World: Legislative Updates (cont.)

Massachusetts

Nearly a decade after a narrowly rejected ballot vote, Massachusetts state legislature has reintroduced the bill “An Act Relative to End-of-Life Options,” which would allow patients facing a terminal prognosis of six months or less to obtain life-ending medication. A hearing was held virtually on October 1st, 2021 by the Joint Committee on Public Health. With more than 80 co-sponsors, proponents of the bill including Rep. Jim O’Day are optimistic about its passing, stating “We feel very strongly that this is the year we can finally make it happen.”

[Read more about MA’s proposed bill](#) ←.....

Australia

In Australia, the NSW Voluntary Assisted Dying (VAD) Bill now holds the record for the highest number of co-sponsors to a Bill in the history of any Australian parliament. The bill will give terminally ill people the option to end their lives at the time and place of their choosing, and supporters of this bill look forward to passing this important legislative reform.

.....→ [Read more about Australia’s proposition](#)

Completed Life Initiative - Announcements!



Announcing our new Office Location at 175 Pearl Street in Downtown Brooklyn, New York!

“VOICES OF CLI”
PODCAST



COMING JANUARY 2022

HAPPY
Holidays

Submit Your Story

The *Completed Life Initiative* seeks to connect people with the poignancy of different experiences at the end of life. Telling personal stories and tapping into the power of individual narrative is a compelling way to connect people across state lines and country borders. Jason Smith's testimony about his Aunt Rachel was especially poignant and deeply moving.

We welcome your story about yourself or a loved one. Please contact our **Program Director** via email (s.bechtel@completedlife.org) to learn more about how you can share your story.

Note of Gratitude

The *Completed Life Initiative* is grateful for the continued support and enthusiastic participation in our conferences, panel discussions, lunch hours, and town halls. Your participation at these events has allowed us to continue offering our high-quality programming, in-depth education, and advocating for greater awareness about end-of-life options and the challenges that can arise within the notion of what it means to live a completed life.

We encourage you to continue to access our video archives, additional website resources, and to stay involved in our upcoming programming for 2022. Please spread the word about the **Completed Life** today by sharing with your friends and family, and consider making a donation.

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