

Support for Medical Aid in Dying Increases

By David C. Leven, Emeritus Executive Director and Senior Consultant

There are now close to 60 sponsors of the Medical Aid in Dying Act, A. 2694, S. 3947, in the New York State Legislature, as support continues to grow. The Arc New York supports medical aid in dying, partly due to our efforts. Formerly known as NYSARC, The Arc New York seeks to improve the quality of life for people with developmental and other disabilities. Its endorsement is important, as unfortunately some organizations which work with people with disabilities are opposed to medical aid in dying.

Several years ago, Vince Marrone, lobbyist for EOLCNY, and I met with key leaders of The Arc New York about medical aid in dying. The organization's board of governors then approved a resolution in support of medical aid in dying which has now been publicized and with some media attention. We are very pleased that that The Arc New York has joined other organizations, such as the NYCLU, which also support the rights of people with disabilities, in the effort to legalize medical aid in dying as an option for the terminally ill.

And, LIFE at RCIL – *Living Independently is For Everyone, Resource Center for Independent Living* – broke with the New York State Association on Independent Living, which maintains a position opposed to medical aid in dying, to take a neutral stance. Previously, LIFE at RCIL had been opposed to the legislation. The trend is clear. Organizations and individuals, once opposed or neutral on medical aid in dying, have become supporters or have moved to a neutral position.

The momentum is our side. There is strong support from New York citizens, who support medical aid in dying by a 63% to 29% margin, according to a 2018 poll. Physicians in NY support the Medical Aid in Dying Act by more than a 3 to 1 margin, 67% to 19%, per a 2018 poll.

Legislators and Governor Cuomo, who support

medical aid in dying, should make passage of the Medical Aid in Dying Act a priority. To help make this happen, they must hear from their constituents.

If you have not yet contacted your state legislators urging them to sponsor the Medical Aid in Dying Act, if they are not yet a sponsor, please do so now by sending a letter. Go to our website to see how you can contact them, <https://endoflifechoicesny.org/advocacy/>

Thank you for your support.

In Memoriam: Jane Orans, A Wonderful Person and Supporter of End of Life Choices New York

By David C. Leven, Emeritus Executive Director and Senior Consultant

Jane Orans, a dear friend of End of Life Choices New York, died earlier this year.

I was very fortunate to know Jane for about 15 years. I had lunch with her twice a year at Chat 19, in Larchmont, where she lived, something I always looked forward to, most recently in September. We last spoke in December, two months before she died. I did not know she was ill and was very surprised and incredibly saddened to learn of her death.

Jane was a wonderful, big hearted and feisty woman who always spoke her mind. She was passionate in her beliefs and supported causes in which she believed. She loved her family and kept us informed about endeavors of her grandchildren, whom she cherished.

Jane was extremely generous. She was one of our top donors for many years. She was a vigorously staunch supporter of the right to choose, both at the beginning and at the end of life.

I will always be grateful to have known Jane and for her generosity. I will miss her greatly.

From the Executive Director

By Ayana Woods, MPH



Ayana Woods

I hope you are well and managing these challenging times as best as you can. The past few months have been an extremely difficult time. COVID-19 has put a spotlight on our healthcare system, death and dying, and disparities in care in this country. When

I started as Executive Director in January, I wanted to empower and engage more New Yorkers in both discussions around end of life care and the fight for expanded options. When the pandemic hit, End of Life Choices New York was poised to respond to our state's urgent needs. We used the societal changes as an opportunity to reflect on how we could improve and expand our advocacy, educational efforts, and support programs for caregivers, patients, and providers.

EOLCNY has a long history of providing high-quality presentations and workshops to diverse communities throughout New York. This "new normal" required us to pivot to a digital mode of interaction and become more creative in order to continue our public advocacy efforts, which are more important now than ever. We planned a lot and we made some critical shifts:

- Earlier this year we had scheduled 40 community education programs (20 at New York State libraries) funded by several grants. In the face of cancellations, our staff and interns did a tremendous job incorporating new strategies. We developed an educational video, webinars, and a targeted social media awareness campaign to reach those most impacted by the coronavirus (communities of color and essential workers). I was a featured panelist on NAACP's Crisis Conversations Facebook live show (viewed over 5,000 times) to discuss how COVID-19 impacts decision-making at the end of life for the African American community.
- We planned to participate in an April Advocacy Day in Albany to support Medical Aid in Dying and promote constructive conversations around options for end of life care with the NYS Black, Puerto Rican, and Asian Caucus Women of Color

Subcommittee and other legislators. We continue to advocate for this legislation. We presented a "The Case for Medical Aid in Dying" panel discussion featuring the perspectives of a doctor, lawyer, legislator, person living with cancer and person with disabilities as part of the Reimagine: Loss, Life, and Love global virtual festival.

- We continued to offer our free phone-based counseling service that provides information and support to individuals and families, but realized there were new barriers to completing advance directives. The New York State Proxy Form required a physical signature – which was an impossibility for many due to social distancing. We found a solution to this problem by successfully advocating for an executive order permitting remote witnessing. In collaboration with The Completed Life Initiative, we expanded our work with "The Healthcare Proxy Helpline," providing additional videoconference-based assistance with completing the healthcare proxy form.

We hosted a great "virtual comedy club" fundraiser with a lineup of eight hilarious comedians including Jackie Fabulous (a semifinalist on America's Got Talent), Brian Kiley (the head writer for Conan O'Brien), and Kelli Dunham (a nurse who has been featured in NPR, Time, Showtime, Huffington Post). The goal was to bring some comic relief in these difficult times, raise some funds, and engage a younger and diverse audience that is not always included in the end-of-life movement. We raised \$3,600 that will go toward our educational efforts around advance care planning for underserved communities.

Never has life and death and disparity been more relevant to public and private conversation than this moment in our history.

We would like to build upon this momentum for the rest of the year. We hope to develop additional educational materials, continue to build our online visibility, enhance our website, and collaborate with more community-based partners across the state. We are asking for your support as we continue to expand the reach of our services so all patients in the state can be confident that their end of life treatment wishes are honored and that they can achieve a peaceful death.

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Clinical Director Report

By Judith Schwarz, Clinical Director

WHAT a *challenging* time! These last four months have seen tremendous changes in our health care “delivery” system. There are huge holes in the so-called “safety net.” In addition to suffering so many tragic deaths, we have been isolated and confined within our homes – afraid to go to a hospital to receive interventions even for non-COVID related conditions that should be diagnosed and treated. People continue to avoid hospitals, because they don’t want to be separated from their family members by quarantine rules, if they are admitted. Most doctor’s offices have been closed, although tele-medicine and physician meetings are now becoming widely available for those with an internet connection and ‘zoom’ skills.

As the number of COVID-caused deaths slowly decreases and beds become available in Intensive Care Units, many remain fearful. Even though the rate of new infections is slowing, we really don’t have an accurate understanding about the rate of infection because testing and tracking across the state are not yet adequate to provide that information.

And YET – I do think that things are slowly getting better. We have become quite proficient at frequent hand washing, masking when in public, and practicing social distancing. Doing so definitely slows the spread of this virus. We are beginning to recognize that life in New York as we have known it will require all of us to continue these new behavior patterns for some time to come. I do hope the rules prohibiting a family member from accompanying persons to the hospital will soon be relaxed. Too many people are dying in their homes from conditions that could have been effectively treated if they had only gone to the hospital soon enough.

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Go to <https://endoflifechoicesny.kindful.com> to make a contribution by credit card, or send a check payable to End of Life Choices New York to: 244 5th Avenue, Suite 2010, New York, NY 10001. Gifts of appreciated stock are an easy and beneficial way to make a donation. You can name us in your will or make us the beneficiary of a retirement account or insurance policy. For more information, please call us at 212.726.2010.

In the meantime, I am pleased to announce the completion of several projects with which I have been involved for some months. Along with several co-editors, we have completed and sent to Oxford University Press, our 267 page text entitled, *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death*. In addition to describing the clinical, ethical, and legal aspects of VSED, we also apply those considerations to preparing an advance directive to limit or stop oral feedings in a future pre-specified stage of dementia. We anticipate this book will become available by the beginning of 2021.

I was asked to write a commentary on 12 narratives written by family caregivers for a person with dementia. My commentary is entitled *Caring, When Curing is Not an Option*, and will be published in *Narrative Inquiry in Bioethics*, though I am not sure just when it will come out.

Meanwhile, patients continue to be in touch, wanting to learn about options and choices they can consider, as their particular disease progresses. Recently, a number of folks with ALS [Lou Gehrig’s disease] have contacted me. Interestingly, we have not received calls from persons with COVID-19. I am not sure about the possible reasons or significance of that.

Let us know if there is anything we can do to help you and your family through this difficult time. Our support number is 212-252-2015.

Over the next few months, the best things you can do to help are:

- Follow us on social media and share our posts (Facebook, LinkedIn, Twitter, and Instagram).
- Join our e-newsletter mailing list for biweekly updates (Please sign up on our website).
- Use the letter template on our website to let your local representative know you support medical aid in dying.

EOLCNY board changes

By Terry Perlin, Immediate Past Board President



Terry Perlin

I retired as Board President of EOLCNY very recently, having never banged the gavel, even once. [We don't possess a gavel!] And I am delighted to be succeeded in this post by Christina Coons.

The past decade at EOLCNY has had its ups and downs. A slew of legislative triumphs at the State legislative level has been most welcome. All of us await the legislature's and governor's affirmation of an medical aid in dying law which will guarantee New Yorkers the right to exercise self-determination in choosing to die a peaceful death in lieu of extended suffering in a terminal condition.

Our outreach and education programs have increased enormously among healthcare professionals and the general public. Yet physicians in training and in practice, in this age of electronic medicine and the corporatization of medical practice — even given the growth of hospice as a movement — are still behind in offering their patients the reasoned discussion they deserve about planning for life's completion. There is much more to be done and we at EOLCNY are prepared to do so.



Christina Coons

My fundamental joy in working with this group has been clear from the beginning. The board is a terrific group of smart, upbeat, lively and gifted women and men. Our staff, while small in number, is gifted in moving our efforts — in legislation, education, counseling and in partnering with other like-minded advocacy groups — as never before.

Other U.S. states, near [Vermont, New Jersey] and far [California], among others, have advanced the option of aid-in-dying in this past decade. I shall be particularly proud when New York State joins this list. But it will, as always, take time, labor, and yes, financial support to achieve this noble goal.

Happily, the board and staff remain energized as always. It has been a privilege to serve as board president and I intend to remain a member of the group. I am certain that our new board president, Christina Coons, will advance our causes with her enthusiasm and great organizational and interpersonal skills. Christina is a Hudson Valley bred healthcare leader. She has been part of multiple projects in defining, implementing, and managing care delivery solutions across various patient populations. Christina has strong management and leadership background for the past 10 years with varied post-acute healthcare delivery operation roles, most notably with Visiting Nurse Service of New York, and currently with United HealthCare. She is also the Board Liaison Officer of Westchester chapter for National Association of Hispanic Nurses. We all welcome her to our "family" and pledge to continue to support the work of EOLCNY.



New Internship Program

End of Life Choices New York launched a new internship program in the early spring. We have an amazing group of undergraduate and graduate interns from colleges throughout the country including George Washington University, Smith College, Yale University, Vanderbilt University and Icahn School of Medicine. They were all temporarily displaced from their college campuses due to the pandemic and we created remote opportunities so that EOLCNY could expand its capacity to develop and evaluate programs, create new communication strategies, and strengthen our operations. Here are thoughts from a few of our interns:

As a Masters student in Healthcare Administration, we only touch upon end of life issues. I feel it is exceedingly important to know how we can take care of ourselves, not only at the end of our lives, but in detrimental situations, and what we can do for our betterment. I'm very excited to gain, not only more knowledge on end of life issues but as well as education from executives like Ayana Woods. I believe it is our duty as a younger generation to not only take care of those who have taken care of us but to educate those still learning. These issues need to be more apparent and more publicized and I believe the younger population can tap into social channels seen by all.

[Kirsten Horvath, Masters in Healthcare Administration, Hofstra University– Program Intern](#)

I am interested in helping undocumented and marginalized communities have a better and more fair access to healthcare. Learning about how end of life choices and the prep for such choices does come with privilege and knowing more about this would benefit me and my understanding of how up until end of life choices inequality in healthcare still happens and matters. I hope to learn more about how to spread awareness on such issues and the importance of end of life choices and how that correlates to racism within our healthcare system. I also hope to bring a lot of creative ideas to EOLCNY and help with social media.

[Lola Asnin, Global Health/Spanish major, Allegheny College class of 2021 – Program Intern](#)

As an aspiring consultant in industrial/organizational psychology, I saw this as a fantastic opportunity to help develop HR infrastructure for a small nonprofit dedicated to a noble cause that personally resonates with me. End of life issues are still taboo and I consistently get strange looks from people when I tell them about my organization. But that is how I raise awareness. Society is already starting to move towards accepting medical aid in dying. The conversations need to keep happening and we need to keep shining light on these issues. Most of the looks I get are actually from older folks who may stand face to face with these issues sooner than they

think. Social media is an obvious avenue to spreading awareness, but the biggest impact comes from one-one-one conversations. When people hear someone speak authoritatively about end of life issues and the proposed solutions, they are less likely to want to rebut your statements and more likely to agree, given that we are coming from a place of compassion and our arguments are logically sound.

[Pasquale Tosto, Masters Student in Industrial and Organizational Psychology, Montclair University – Human Resources and Operations Intern](#)

I applied for this internship to learn more about end of life care. It is a very important topic that isn't talked about enough. Especially in a time of a global pandemic, I find this information to be essential. From this experience, I hope to gain an insight into how non-profit works, and how we can spread the word about medical aid and dying. medical aid in dying needs to be brought up more to the younger generation. The only way to raise awareness about these topics is to have that difficult conversation with your loved ones.

[Satrianna Sawasdikosol, Psychology/Public Health Major, Wheton College class of 2021 – Program Intern](#)

I was drawn to healthcare in general because of the opportunity it affords us to make a difference in the individual lives and stories of patients. End of life experiences are often some of the most meaningful, important stories of all—both for patients and their families. So to me, end of life issues represent the epitome of what medicine should do: provide care and ensure the well-being of patients as they live out their stories. Despite this, they are often overlooked in our discussions of medicine and healthcare; this made me want to learn more, and End of Life Choices New York was the perfect organization through which I could do so.

[Isabella Li, History of Science, Medicine, and Public Health/Molecular Biology, Yale University class of 2022 – Public Policy Intern](#)

We have year-round opportunities, please check our website for new opportunities. For more information, you can email info@endoflifechoicesny.org.

EOLCNY Launches Virtual Program

By Lillian Mehran, Director of Outreach and Education

End of Life Choices New York has long had a robust educational program, with presentations and workshops taking place in a wide range of spaces. However, shortly after I began my role as Director of Outreach and Education, we had to cancel all of our in-person events due to COVID-19, just when New Yorkers most needed the information we provide.

Rather than viewing this as a barrier, we recognized it as a challenge that offered an opportunity to innovate and expand our services. By offering both live and pre-recorded online programs, we are able to make our services and information more accessible, and easily connect with New Yorkers across the state.

We launched our virtual program at the end of April in honor of National Healthcare Decisions Day. Some highlights of the program are:

- The release of a video entitled, "Planning for a Better End of Life: A Guide to Navigating Today's Healthcare System." The video provides an overview of advance directives, palliative and hospice care, and available resources. The video is available on our website at endoflifechoicesny.org/education/film-and-video/
- Webinars with libraries on Long Island and in Dutchess County.
- Participation in Reimagine, a worldwide virtual festival on embracing life, facing death, and loving fully in the face of COVID-19.
- Development of a self-study program for social workers (offering continuing education credit) to raise awareness of end of life options and rights for their clients.
- Launch of a pilot Health Care Proxy Helpline, in collaboration with The Completed Life Initiative, to assist New Yorkers in completing the health care proxy form. In this program, individuals virtually met with Advance Directive Advocates to receive support in completing the form, including having the form witnessed, if desired. EOLCNY's successful advocacy was influential in Governor Cuomo's issuing an executive order permitting virtual witnessing for those signing advance directives.
- We increased our social media presence to raise awareness of advance care planning and end of life options and rights. These platforms enable us to spread the word to many, including those in communities we had not previously reached.

We look forward to sharing more about our ever-growing virtual program, and connecting with you again in-person in the future.

If you have an idea for a future event, I encourage you to reach out to me at Lillian@endoflifechoicesny.org.

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