

Medical Aid in Dying Developments

By David Leven, Executive Director Emeritus and Senior Consultant

The Medical Aid in Dying Act has been reintroduced in both houses of the New York State Legislature. The Assembly bill, A. 2694 (Paulin), has some 30 sponsors, including the chair of the Assembly Health Committee. The Senate bill, S. 3947 (Savino), has sponsors from several key committees, including the chair of the Senate Health Committee. The new bill has a number of new provisions which strengthen it in response to recommendations from various organizations.

A poll of citizens across the state shows they support medical aid in dying by a 63% to 29% margin. In every demographic group surveyed, a majority of citizens support medical aid in dying, with just one exception: people who attend church once a week or more.

New York State physicians support the Medical Aid in Dying Act by a 67% to 19% margin, according to another poll. That poll revealed that 63% of the doctors would like to have the option of medical aid in dying for themselves.



Dr. Judith Setla, Medical Director of Hospice of Central New York, Scott Barraco, advocate, and David Leven, EOLCNY ED Emeritus, spoke at our recent Medical Aid in Dying presentation in Syracuse.

In March, New Jersey became the eighth state to authorize medical aid in dying, and the fourth

in five years. Medical aid in dying is also legal in Washington, DC. New Jersey's law goes into effect on August 1. I was proudly involved in early efforts to educate the public in New Jersey about this legislation, having engaged in two debates, one at Rutgers University Law School, and the other on a New Jersey radio show. Both debates went well as the facts, evidence and positive experiences in states which allow medical aid in dying are on our side.

With medical aid in dying now legal in two of our neighboring states, New Jersey and Vermont, it is time for New York to become the next northeastern state to authorize medical aid in dying. Governor Cuomo recently gave his support to medical aid in dying. "I say pass the bill" he said during an April radio interview. "...The older we get and the better medicine gets the more we've seen people suffer for too long." We hope that will serve as a catalyst for the legislature to act on the Medical Aid in Dying Act.

As New York delays, too many dying New Yorkers suffer needlessly. Please take action to help us get the Medical Aid in Dying Act enacted. There are many new legislators in the New York State legislature this year. They, as well as more experienced legislators, need to hear from you, their constituents. To contact them, go to our website at <https://endoflifechoicesny.org/advocacy/contacting-your-legislator/>

To view a new document created by End of Life Choices New York, "Ten Reasons Why Medical Aid in Dying Should be Legal in New York", go to <https://endoflifechoicesny.org/advocacy/why-legalize-dying/>

We will keep you posted on any progress with the Medical Aid in Dying Act. We do this periodically in our email newsletter, so if we do not have your email address, please provide it to us by emailing it to info@endoflifechoicesny.org.

Dementia Directives and VSED

By Judith Schwarz, Clinical Director

It has been about 14 months since we developed and launched the EOLCNY directive that permits individuals with an early stage of dementia (or those who fear developing dementia) to complete a written directive that limits hand feeding when the disease becomes advanced. As you may know, there are two options: one limits all oral intake once capacity is lost and the disease is advanced and the other limits oral intake to comfort focused feeding. Both are accompanied by good symptom management and require a well informed health care agent who acts with the primary care physician to implement and advocate for the patient's choice.

As I reviewed the months since our Fall newsletter, I seem to have spent half my time on issues related to the 'dementia directive': guiding patients and their families through the completion of these documents, answering emails or phone calls about the pros and cons of completing them, and speaking with other health care professionals across the nation about these documents. The remainder of my time is focused on providing patient and family support to those seeking information about end of life options and choices as death nears.

Increasing attention seems to attend the option of voluntarily stopping eating and drinking (VSED) as a means to hasten dying in the face of serious illness and unacceptable suffering and quality of life. We have been contacted by out-of-state hospices who are interested in creating position statements and guidelines for their clinicians regarding patient requests for VSED. I have been pleased to share what we know of the work of NYS hospices who have developed such position statements. And of course, I continue to provide information about VSED to suffering patients in NYS who remain frustrated by the lack of a legal alternative to hasten death in our state. We must continue to fight for legal medical aid in dying in NYS, as our neighbors have successfully done in New Jersey.

I have recently become involved in a new venture related to the topics of a VSED hastened death

by contemporaneous choice or by an advance directive that limits oral intake once capacity is lost. A book proposal that discusses these two topics was recently accepted by Oxford University Press. Written by me and three well regarded experts from different professional backgrounds, the book would be the first of its kind to address the legal, ethical, clinical, institutional, and personal/family issues involved in a VSED choice. Sixty percent of the book will focus on contemporaneous VSED choices made by capacitated patients under a variety of clinical and institutional circumstances. The remaining 40% of the book will be dedicated to VSED by advance directive – a much more clinically contentious and legally uncertain choice. We hope that it will be of interest to clinicians, ethicists, and lawyers, as well as patients and families who seek comprehensive information about these options.

My co-editors include Dr. Timothy Quill, a palliative care physician at the University of Rochester School of Medicine, Paul Menzel, a philosopher and Professor Emeritus of philosophy at Pacific Lutheran University in CA, and Thaddeus Pope, JD, PhD, Director of the Health Law Institute at Mitchell Hamline School of Law in MN. I am honored to be included in such a group of experts; our book is due to be completed by the end of 2019.



EOLCNY board member Peter Strauss, JD, Sarah Egan, MD, and EOLCNY Clinical Director Judith Schwarz, PhD, spoke about advance directives at a meeting of Judges and Lawyers Breast Cancer Alert.

EOLCNY's Leadership Changes

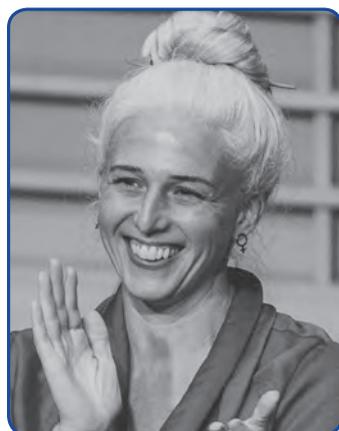
By Laurie Leonard



Laurie Leonard

Serving as the Executive Director of EOLCNY has been wonderful, meaningful work and I am proud of

our accomplishments. However, as I grow older I become more aware that I have a limited amount of time to engage in other projects that I would like to pursue. The only way to create the time for them is to leave this position, so in December I asked our board to begin a search for a new ED. I will continue to do some public speaking for EOLCNY and may assist in other ways, but on June 1 I am leaving the day to day leadership of our organization.



Chelsea Kline

Fortunately, we have found an excellent person to be our new Executive Director: Chelsea Kline, an experienced advocate for social justice. Chelsea graduated from Smith College and Harvard Divinity School. She has worked in higher education, creating and overseeing programs for non-traditional college students. She ran a rigorous campaign in 2018 for Massachusetts State Senate, and won nearly 41% of the

vote. Chelsea serves on the board of directors of the Women's Fund of Western Massachusetts and was appointed by the State of Massachusetts as a Commissioner on the Status of Women and Girls. I am sure you will enjoy meeting her, and that she will prove to be an inspiring and enthusiastic leader.

I am very grateful to all the donors and volunteers who support our work. I have been touched by your generosity and your strong and passionate commitment to improving end of life care.

It has been a pleasure to work for the EOLCNY board of directors, led by Terry Perlin and Peter Rogatz. Our

board members come from a variety of professions but have in common their unwavering support for social justice.

And I would like to thank the highly talented, deeply dedicated staff and consultants to End of Life Choices New York, who work so hard to educate health care professionals and the general public about end of life topics; advocate for laws that will improve end of life care; and counsel those nearing the end of life and their families. They are:

David Leven, who retired as Executive Director in 2016, but who still works tirelessly to expand end of life choices, and has generously shared his extensive knowledge and experience with me;

Judith Schwarz, our Clinical Director, whose inspiring strength and compassion have directly improved the lives (and deaths) of so many people;

Ayana Woods, our Director of Outreach and Education, whose ability to brainstorm new ideas and reliably implement them has brought significant increases in knowledge to all who attend our events or read our materials;

Martha Quiros, our CPA, who has generously donated her time and expertise to ensure we are fulfilling our legal and financial obligations;

Doug Wingo, our Development Consultant, whose wisdom and encouragement have helped us to expand our resources;

Vince Marrone, who has enthusiastically shared his seasoned knowledge of the legislative process so that we can better achieve our goals;

Nick Henderson, our Web Designer, whose creativity and insight have vastly improved our online communications;

And Constanza Prieto Figelist, who we hired this month to be our Latino Outreach Coordinator and is off to a great start.

It has been a pleasure to work with such a talented team, and to have had the opportunity to help to improve end of life care, a cause to which I remain deeply committed.

Latino Outreach Update

By Ayana Woods, Director of Outreach and Education

End of Life Choices New York staff presented a workshop on our Latino Outreach program at the Hospice and Palliative Care Association of New York State 39th Annual Interdisciplinary Seminar and Meeting in Albany in April. New York has a growing aging population and the state-wide problems of poor end of life care may be exacerbated in Latino/Hispanic communities. They are less likely to use hospice, have lower levels of advance care planning, and have poorer access to pain management.



EOLCNY Director of Outreach and Education Ayana Woods and consultant Lillian Mehran present a seminar on our Latino Outreach program at the annual HPCANYS conference.

In 2018, EOLCNY developed and implemented bilingual presentations and materials to educate Latino communities about their rights and options at the end of life. An evaluation of this program found significantly increased awareness of hospice, palliative care, and advance directives. Evaluation Consultant Lillian Mehran and I discussed in our workshop our community needs assessment, program material development, implementation of the program, and the subsequent positive outcomes.

EOLCNY is committed to continuing this important work in 2019. We recently received funding from The Wallerstein Foundation for Geriatric Life Improvement to support additional programs. We will continue to provide free presentations in Spanish on advance care planning, hospice, palliative care, and pain management.

We are also pleased to introduce our new Latino Outreach Coordinator, Constanza Prieto Figelist. Constanza brings a wealth of experience and is excited to apply her legal background to educating and empowering Latino communities about end of life issues. She is a Chilean lawyer from the Pontificia Universidad Católica de Valparaíso, who has studied and worked in Chile, France, and the United States. She currently collaborates as Ocean Rights Lead in the Earth Law Center. Constanza also collaborates with other environmental, feminist and immigrant protection NGO.



Constanza Prieto Figelist

Please contact events@endoflifechoicesny.org if you are interested in hosting a Spanish program for your community.



EOLCNY Executive Director Laurie Leonard presents "What Social Workers Should Know About End of Life Care" to PSS staff.

CEU Workshops for Social Workers

End of Life Choices New York will host a continuing education workshop for social workers on end of life issues on June 12th from 2:00 - 4:30pm at 120 East 23rd Street in Manhattan. Through lecture and discussion, participants will increase their knowledge of end of life treatment options, advance care planning, palliative care and hospice and will be better prepared to help their clients receive more effective end of life care and to have their health care wishes respected. 2.0 live contact hours will be awarded for NYS licensed social workers. The registration fee is \$40.00. For more information please email events@endoflifechoicesny.org.

Donations in 2018

We thank all of our donors for making our work possible. In every spring newsletter we print the names of all donors who gave \$250 or more during the preceding year, unless they requested anonymity.

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If we inadvertently did not include your donation, please let us know so we can put it in our next newsletter! We appreciate donations of all sizes, even though space prevents us from listing everyone.

EOLCNY Board member Peter J. Strauss has been honored by the New York State Bar Association with the prestigious Attorney Professional Award, granted each year to only one lawyer in the state. The award honors attorneys who evidence the highest attributes of professionalism in the practice of law, demonstrating dedication to service to clients and a commitment to promoting respect for the legal system, in pursuit of justice and the public good characterized by exemplary ethical conduct, competence, good judgement, integrity and civility. Peter is a senior partner at Pierro, Connor & Strauss.



New video presentation about end of life options available

We have a new video presentation online for New Yorkers seeking information about legal end of life options that permit a patient to control the circumstances and timing of their death.

Last fall EOLCNY and the Columbia University Master of Science in Bioethics program co-presented "End of Life Choices that Permit a Patient-Hastened Death: Clinical Issues and Concerns in New York State". In this recorded presentation, End of Life Choices New York Clinical Director Judy Schwarz provides a comprehensive overview of Voluntarily Stopping Eating and Drinking (VSED). VSED is increasingly recognized by clinicians as a legally and ethically appropriate end of life option for incurably or terminally ill adults who can make an informed choice to hasten their dying process.

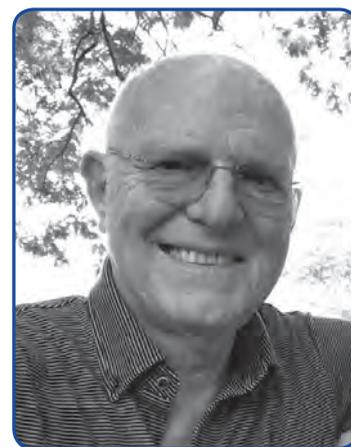
Judy also discusses EOLCNY's new dementia directive which limits the use of hand feeding in the event the patient is in an advanced state of dementia. David Hoffman, Esq., lecturer in Bioethics at Columbia University, also shares his perspective as a healthcare attorney and clinical ethicist. The presenters discuss the clinical issues and the concerns these choices might cause. Go to <https://bit.ly/2UPmBo6> to watch the video.

How to get updates more often

This newsletter only comes out twice a year. If you would like more frequent updates, including announcements of our events, send your email address to info@endoflifechoicesny.org. We send out updates on end of life issues once every week or two. You can unsubscribe instantly and easily, and we will never share your email address with anyone.

Thank you!

We all want a peaceful death for ourselves and our loved ones. End of Life Choices New York provides the education, counseling, and advocacy to help as many people as possible achieve that goal. Your support is needed in order for us to do our work. Please consider making as generous a donation as you can on our website at endoflifechoicesny.org (click on "Donate" at the top of the page), or by using the remittance envelope included with this newsletter. We are a 501(c)(3) nonprofit organization and all donations are fully tax-deductible.



Gary Knisely joined our board of directors in February. He is a retired entrepreneur living in Manhattan who runs a private foundation, produces films, travels and coaches top management of small companies. He is the founder of the GKV Foundation, which supports youth development through the implementation of innovative education initiatives.

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