

A Few Words from Our New Executive Director, Laurie Leonard



On July 1st I became EOLCNY's new Executive Director.

I would like to begin by thanking all our donors and volunteers for their tremendous support. Our educational

programs on end-of-life issues, our legislative and litigational efforts to legalize aid in dying in New York, and the counseling we provide to patients and their families would not be possible without you.

I also would like to express my deep gratitude to David Leven for having so capably guided our organization for fourteen years; I am sure all of you who know David share that sentiment. He has played a key leadership role in having legislation introduced and enacted in New York to improve pain management, palliative care and end-of-life care. He has tirelessly spoken to hundreds of organizations, educating the public, professionals, and graduate students about end-of-life issues. He has written numerous articles and letters to the editor about legislation needed to improve end-of-life care, including the legalization of medical aid in dying. And he obtained funding that enabled EOLCNY to expand its programs and staff, allowing us to take on new projects and reach more people with our services. Fortunately, David will continue to serve EOLCNY as our Executive Director Emeritus and Senior Consultant. He will oversee our legislative efforts to improve end-of-life care, and our lawsuit seeking to

establish medical aid in dying in New York, and he will continue his public speaking and writing about end-of-life issues.

We are nearing the end of the first year of our three-year matching grant from the Open Society Foundations. We have so far received \$270,000 in donations for the first matching period, and therefore need additional donations totaling \$30,000 by October 27th in order to get the full \$300,000 of matching funds this year. Please help us meet this important goal by sending a check made payable to End of Life Choices New York to us at 120 East 23rd Street, 5th floor, New York, NY 10010, or you can pay with a credit card or Paypal by going to our website home page at endoflifechoicesny.org and clicking on "Donate Now" near the top of the page. Whatever amount you give will be doubled by the matching grant!

I am very happy to have been given the opportunity to lead an organization doing such valuable work. I want to do everything I can to improve end-of-life care and increase end-of-life options, so that we all can have a greater chance of having a good quality of life in our final years, and a peaceful death when that time has come.

Please call me at (212) 726-2010 or email me at laurie@endoflifechoicesny.org if you have suggestions or questions about our work.

End of Life Choices New York Leading the Way in Legislative Efforts

By David Leven, JD, Executive Director Emeritus and Senior Consultant

For over a decade we have played a key leadership role in having legislation introduced and enacted in New York. Six of our bills are now law, including the Palliative Care Information Act, the Palliative Care Education and Training Act, a bill requiring mandatory continuing education on pain, palliative care and end-of-life care and several laws designed to increase the number of people who complete health care proxies and have their health care wishes honored.

In our last newsletter we discussed our bill that would legalize aid in dying in New York. That bill was approved by the New York State Assembly Health Committee in May. The next step is for the bill to be reviewed by the Assembly Codes Committee, before it can be considered by the full Assembly and Senate. In addition to the aid in dying bill, we have many other pending bills. Two are described below. When the new legislative session starts in January, these bills, like all others, will have to be reintroduced.

End of Life Choices New York has initiated a bill in the New York State Legislature that would prohibit health care providers from seeking reimbursement for unwanted healthcare treatment. It would also clarify that patients have a right to seek damages if such treatment is provided.

Protection of Patient Care Decisions, A.2140-A (Gottfried)

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David Leven and our lobbyist Vince Marrone in Albany

Just two years ago a poll conducted by Purple Strategies showed that about one in four Americans say that they or a family member experienced excessive or unwanted medical treatment. And, according to the poll, nearly two thirds of those surveyed support withholding payments to health care providers who do not honor their end-of-life wishes.

Currently in New York, if you or a loved one receive clearly expressed unwanted treatment, it is uncertain that damages can be awarded by a court or that healthcare providers will be held accountable.

Please let us know if you or a loved one has received clearly expressed unwanted treatment or care, particularly near the end of life, by emailing me at david@endoflifechoicesny.org. Having specific examples will help us as we continue our efforts to get our bill enacted.

Safe Harbor for Doctors, A.2230 (Gottfried)

This bill will protect health care professionals from criminal liability and professional discipline for prescribing and administering pain medication, when they act within accepted professional standards.

Many patients in New York State suffer needlessly from debilitating pain, caused by inadequate treatment. Many health care professionals are unaware of the

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Our Counseling Services

By Judith Schwarz, PhD, Clinical Director

As the Clinical Director of End of Life Choices NY, it is gratifying to see the increasing number of folks who have 'found' us online and through word of mouth, and contact us seeking information about options and choices as the end of life nears.

As many of you know, I have been providing patient support and advocacy for suffering New Yorkers and their family members for more than a decade. Recently we acquired a new name and website; that has been confusing for many of our loyal supporters, and made it more challenging for those seeking our help to actually find us. However, I am pleased to note that our patient census has been growing each month, and we are now getting calls from New Yorkers in all parts of the state. I suspect that the recent increase in calls and emails may be because we are now the only "Right to Die" organization in NY that continues to provide individualized information and support to those who contact us by calling 212-252-2015 or by emailing me at Judy@endoflifechoicesny.org.

While we have always received calls for help in obtaining and completing advance medical directives, and have advised patients and their families about the relative merits of different documents, we are

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increasingly hearing from two groups of patients. Those in the first group are terminally ill, suffering, and may be close to death. Members of the other group are also suffering; they live with incurable and progressive diseases and are far from the terminal stage of their illness. Members of each of these groups have unique and often distinct problems that require different kinds of advocacy and support.

In coming months I will write more about the needs and concerns of the patients and families in both groups and illustrate how we respond to their needs. My goal in doing so is to better inform you about the patient support that we provide – at no charge- for those who contact us.



Judy Schwarz at EOLCNY Mt. Sinai aid in dying event

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resources available to relieve chronic and acute pain. Some are unwilling to prescribe opioid drugs because they fear that they will be wrongly subjected to prosecution or professional discipline.

A major goal of this bill is to assure health

care practitioners that when they practice pain management in keeping with this and other reasonable standards of care, they will be safe from criminal liability or professional discipline. And that will hopefully result in better pain care for more patients.

EOLCNY Event Explores VSED: Voluntarily Stopping Eating and Drinking

VSED is a way people can legally achieve death on their own terms. It was the topic of June's Barbara Swartz End of Life Choices lecture, "Voluntarily Stopping Eating and Drinking: Exploring an End of Life Option for Suffering Patients", co-sponsored by EOLCNY and the New York Society for Ethical Culture. Two experts on the topic, Drs. Judith Schwarz and Timothy Kirk, discussed the practical and ethical considerations of individuals considering VSED, and the discussion was moderated by EOLCNY Board President Dr. Terry Perlin.



It was a full house for our VSED program. Panel, from left to right: Terry Perlin, PhD, EOLCNY Board President; Tim Kirk, PhD, Ethics Consultant; Judith Schwarz, PhD, RN, EOLCNY Clinical Director. At podium: EOLCNY volunteer Suzanne Hayes.

Schwarz, PhD, RN, and Clinical Director of End of Life Choices New York, spoke in detail about the challenging process of VSED, which typically takes about two weeks from starting the fast until death occurs. She noted the need for support from family and physicians. Schwarz also said that VSED is currently the only legal option in New York State for those seeking to end their lives, other than stopping or never starting life sustaining treatment. Despite the associated challenges, it is often far superior to death in the ICU. *"The whole point,"* she said, *"is comfort...the least bad death that we can manage."*

After Schwarz spoke, Kirk, PhD, Ethics Consultant and Professor of Philosophy, explored five realms in which discussion about VSED touches on issues of ethical significance: the personal, the relational, the clinical, the social/political, and the legal. Kirk noted that in all of these realms the question of whether VSED constitutes suicide arises frequently. However, there are usually significant differences between VSED and the kind of suicidality that warrants psychiatric intervention, especially the lengthy deliberation and collaborative planning a patient must go through before actually undergoing VSED. Kirk stood by the legal validity of VSED as an option for those with decision-making capacity who no longer wish to continue suffering for an unknown amount of time.

The event was filled to capacity, and there was a waiting list of people who wished to attend, so a video recording of the presentation was made. It can be viewed on the internet at [youtu.be—T6JD112yqYo](https://youtu.be/T6JD112yqYo)



On April 12th, EOLCNY sponsored the program **"Aid in Dying: A New Option for a Peaceful Death"**, at the Mount Sinai Medical Center. Pictured from left to right, are panelists Eric Seiff, one of the patient plaintiffs in our lawsuit *Myers v. Schneiderman*; Howard Grossman, MD, Chair of New York Physicians for Compassionate Care; David Leven, Executive Director Emeritus and Senior Consultant of EOLCNY; and R. Sean Morrison, MD, Director of the National Palliative Care Research Center. The event was moderated by David Muller, MD, Dean for Medical Education at Mt. Sinai Hospital.

The Story of Scott and Cathy: Why Medical Aid in Dying Should Be Available in New York

Some of our volunteers are drawn to work with us because they personally experienced a loved one's bad death...a death that could have been made so much easier had medical aid in dying been legal in New York. We asked Rochester, New York EOLCNY volunteer Scott Barraco why he supports aid in dying, and this was his response:

"I am passionate about advocating for aid in dying because I lost my girlfriend to tongue cancer almost two years ago. Cathy Quinn suffered dearly, and it wasn't necessary. Cathy was



Cathy Quinn and Scott Barraco

an extraordinary woman. For two years she battled cancer with a driving determination, relentless stamina, and an incredible wit. She tackled her disease head on. She questioned her doctors, she reviewed her options, and she made critical decisions throughout her treatments. In short, she took charge of her health care, and was determined to beat that evil disease.

The last ten months of her life she took nourishment from a feeding tube. She was unable to eat, drink, taste, smell, or speak. Even under those circumstances she found inspiring ways to enjoy life, and bring joy to

others. She loved her pets, her cute little house, me, and dozens of friends. She spoiled us all.

Cathy was also a realist. After three major surgeries to replace parts of her tongue with other body parts, multiple rounds of radiation, multiple rounds of chemo, a boatload of pharmaceuticals, and countless procedures, the cancer returned for a fourth time. It spread throughout her body. Cathy knew she was going to die. She wanted to go on her own terms. She wanted to have a say in how she died, just as she had a say in every other aspect of her life. She wanted to be able to die in peace, in her own home in familiar surroundings, with those she loved. She earned it, she deserved it - she didn't get it.

Cathy knew she was going to die. She wanted to go on her own terms. She wanted to have a say in how she died, just as she had a say in every other aspect of her life. She wanted to be able to die in peace, in her own home in familiar surroundings, with those she loved. She earned it, she deserved it - she didn't get it.

The option does exist. Aid in dying is available in several states. Oregon has provided this option to its citizens without a hitch for 18 years! We were devastated to learn New York State does not allow it. It made us furious to learn Cathy was helpless.

Cathy's best option to have some control over her death was to choose to stop eating and drinking. This was a far cry from self-administering medicine that would allow her to gently fall asleep, and peacefully pass away at her choosing. How could she be given the choice to hasten her own death, but then denied the most compassionate way of doing it?

Sadly, Cathy never made it to the date she picked to stop eating and drinking. She suffered terrible grand mal seizures the night before. I was unable to take care of her at the home she loved. I want to change the law in New York. I want Cathy's voice to be heard. No one has been able to give me a good reason why Cathy had to suffer the way she did. There isn't one."

Legacy Giving: An Opportunity to Make a Difference

For most of us, the largest and most impactful charitable gift we will ever make is a bequest. We invite you to consider including End of Life Choices in your will or designating us as a beneficiary of your life insurance policy or retirement account. These far-sighted donors help ensure that our unique leadership, advocacy, education and counseling will continue to expand choice at the end of life and improve the quality of care for all New Yorkers, long after we have achieved aid in dying in New York. Please consider joining the Patricia Stryker Joseph Legacy Society, named after one of our most significant supporters, who understands the power of philanthropy in moving our issues forward. Legacy giving is a great way to support End of Life Choices NY, and we hope you will include us in your estate planning. For more information, or to request a planned gift intent form, please contact Laurie Leonard, Executive Director, at laurie@endoflifechoices.org or (212) 726-2010.

Aid in Dying Lawsuit Update

Last year End of Life Choices New York initiated a lawsuit seeking to establish aid in dying in New York. The nine plaintiffs include EOLCNY, three patients, four doctors and Judy Schwarz, EOLCNY Clinical Director. A ruling was sought to permit aid in dying on state constitutional grounds or by finding that the existing law prohibiting assisting a suicide does not apply to medical aid in dying. The lower court, on a motion by the New York State Attorney General, dismissed our complaint. The Appellate Division, First Department, affirmed that decision. Now, we are at New York's highest court, the New York Court of Appeals. The New York Court of Appeals asked our attorneys to submit a letter to the court explaining why our constitutional claims are substantial, which would entitle us to have our appeal to the court taken as of right (instead of having to seek the court's permission to appeal).

Ed Schallert, co-counsel at Debevoise & Plimpton said, *"This appeal raises*

important questions under the New York State Constitution concerning fundamental liberties and equal protection under the law with respect to a dying patient's autonomy, privacy, bodily integrity, and self-determination to control the choice of medical treatment, how much suffering to endure prior to death and how one will cross the threshold to death."

We are hopeful that the court will decide to hear our appeal, and will keep you posted. Please support our efforts to establish aid in dying in New York by making a generous donation today.

Wanda Montalvo Joins EOLCNY Board



Wanda Montalvo

Wanda Montalvo, PhD, RN, was elected to our board of directors at our May board meeting. Wanda is the Associate Director of the Weitzman Institute, a division of Community Health Center Inc. She is a nationally recognized leader with over 25 years of experience

in leading national initiatives, quality improvement in primary care and research. Her previous leadership roles include: Northeast Director for HRSA/BPHC National Health Disparities Collaborative (HDC), Chief Clinical Officer of the Community Health Care Association of New York, and Director of the NYS Health Foundation Diabetes Campaign. Wanda has served on several national committees: Partners Investing in Nursing's Future, the CDC/NIH National Diabetes Education Program Operations Committee (co-chair), and most currently the RWJF Future Nurse Scholars Initiative. She is a RWJF Executive Nurse Fellow and Jonas Nurse Leader Scholar. Her Doctor of Philosophy is from Columbia University School of Nursing. Wanda has several peer-reviewed publications focused on leadership, political skill and the mentoring of nurse leaders. Her extensive knowledge and experience will be of great value to End of Life Choices New York.

Sara Myers dies

Sara Myers was the lead plaintiff in *Myers v. Schneiderman*, our case seeking to establish aid in dying as a right in New York. She died on August 16, at the age of 61.



Sara Myers

Our Clinical Director Judith Schwarz says, "Sara was determined to stay alive to see the end of this important legal case that, if won, would have afforded her the option of medical support in controlling the timing of her death. For years, she had managed the symptoms of her ALS disease with that goal in mind, but also wanted to retain independence and dignity in her final months. Her body gave out, but not her will and determination. She was surrounded by wonderful friends and family who she had known since her college days, and she was helped by several amazing

aides. While she did end up requiring institutional hospice care for the final days of her life, her friends went with her, and will remember always her indomitable spirit and eloquence. It was my privilege to know her, and to help a bit, in keeping her comfortable in those final months."

Ed Schallert, a partner at Debevoise & Plimpton and co-counsel in *Myers* said: "I was so sorry to hear that Sara had died. I was so impressed with Sara's determination and grace in dealing with this litigation. My only hope is that a case with her name can lead to change."

Kathryn Tucker, Executive Director of the Disability Rights Legal Center and co-counsel in *Myers* commented: "The most we can do for Sara now is to see her name on the case that establishes the right of terminally ill New Yorkers to be empowered with the autonomy to choose a more peaceful death when confronted by suffering they find unbearable. It would be a great legacy for her. We will redouble our efforts to see this happen."

Please support Sara's goal to have medical aid in dying available in New York, which we will continue to fight for on her behalf, by making a generous contribution in memory of Sara. Your contributions will also support our free-of-charge counseling service directed by Judy Schwarz, who was very helpful to Sara during the past two years.

In closing, here are Sara's own words, from a statement she made a year and a half ago:

"Four years ago I was diagnosed with ALS, a terminal disease which is paralyzing my entire body, piece by piece, while my emotional and intellectual capacities remain intact. It's unclear how much time I have left before I'm unable to breathe anymore. If I choose, I can be kept alive artificially, completely reliant on a mechanical device for breathing, and a feeding tube for nutrition. But, more important than the choices to prolong my life with this horrible disease, is the right to choose how to die with it."

"When the time comes, I want to be able to gather my loved ones around me and bid them good-bye while I am of clear mind and able to share those final moments. When the pain and suffering of the disease strips away the good parts of my life that I can still enjoy, and my life becomes intolerable, I want the choice to ask my doctor to aid me in my dying. I am suing the State of New York to remove the legal barrier between my doctor and myself to help me achieve a peaceful and dignified death, at the time and place of my choosing."

Five ways you can help

By Ayana Woods, MPH, Director of Outreach and Education

“Never believe that a few caring people can’t change the world. For, indeed, that’s all who ever have.” – Margaret Mead



End of Life Choices New York seeks a world in which all of us have a death consistent with our own wishes and values. There are several ways you can support us in our mission to raise awareness and advocate for improved care at the end of life in New York.

Host a presentation

Knowledge is power. To advocate for our own end-of-life care, we need to know our rights and make plans. Host a presentation for your company, school, or community organization to educate staff, students, caregivers, or members about end-of-life options in New York. Our staff can provide free presentations tailored to meet the needs of your audience on end-of-life topics such as hospice, palliative care, advance directives, and aid in dying. To request a presentation, please email ayana@endoflifechoicesny.org or call 914-410-0528.

Make us a resource

Add EOLCNY to your list of resources on your website and share our educational materials at your programs. We can answer questions about end-of-life planning and provide guidance in completing advance directives. We provide free individual counseling to patients and their families about end-of-life issues. Call 212-726-2010 or email info@endoflifechoicesny.org

Spread the message

Please like our page and share our posts on Facebook and follow and retweet us on Twitter (@EOLCNY). Encourage others in your network to sign up for our email newsletter. Talk about the movement to improve care and expand choices at life’s end with your community and tell people about End of Life Choices New York specifically. Tell them how important it is to have a health care proxy. Let them know about proposed legislation and litigation in New York to establish aid in dying here, just as it is legal now in five other states.

Support the legislation for aid in dying

Your voice is crucial. Let your New York State legislators know that you support aid in dying. Go to our website at www.endoflifechoicesny.org to look up your representative’s contact information or call us at 212-726-2010 for assistance. Write a letter to the editor of your paper about why aid in dying should be legal in New York. Let us know if you are interested in participating in a lobby day in Albany. In-person lobbying from constituents is still the most effective method for reaching elected officials. Your personal stories can have a huge impact on legislators and provide the education necessary to dispel some of the current myths.

Volunteer

We are a nonprofit organization and sometimes need the support of volunteers. Our volunteers assist with event management, tabling, writing/editing and administrative work. Email ayana@endoflifechoicesny.org or call 914-410-0528 to request a volunteer application.