

Medical Aid in Dying Report

By David C. Leven, JD

Disappointing ruling in aid in dying lawsuit

The right of terminally ill, mentally competent adults to choose a more peaceful death was dealt a significant blow in September by New York's highest court. The New York Court of Appeals upheld the dismissal of the case at an early stage, before we had the opportunity to go to trial.



Attorney Ed Schallert of Debevoise & Plimpton argues our case in the Court of Appeals. Also pictured: Co-counsel Kathryn Tucker.

Our lawsuit, *Myers v. Schneiderman*, sought to establish the right of competent terminally ill patients to receive a prescription for medication that they could ingest to achieve a peaceful death if confronted by suffering they find unbearable.

The court's opinion did not, in our view, sufficiently address our argument that medical aid in dying is fundamentally different than assisted suicide and that the statute which bans assisting a suicide should not apply to the conduct of a doctor who prescribes life ending medications for a dying patient. It gave short shrift to our state constitution equal protection and due process claims.

Our attorneys have made a motion for reargument based on what we assert were legal and factual errors in the decision. It argues that the case should not have been dismissed before trial, saying *"This case implicates one of the most deeply and profoundly personal decisions New Yorkers will*

make in their lifetime: how much suffering to endure before crossing the threshold to death when brought inexorably to that threshold by terminal illness. The answer to that question turns on the individual's most deeply held preferences, values and beliefs, which deserve careful consideration by a fact-finder".

Although motions for reargument are rarely granted, we are hopeful that this one will be, as we believe we have very strong and sound arguments. We will continue to do everything possible to achieve the legalization of medical aid in dying in New York.

Legislation Gaining Support

Although the Medical Aid in Dying Act, A.2383 (Paulin)/S.3151 (Savino), did not reach the Assembly or Senate floor for a vote this legislative session, new organizations are joining to support the bills and momentum is gaining.

Just in the past year numerous organizations have come out in support of the Medical Aid in Dying Act. These include the New York State Senior Action Council, the New York State Public Health Association, the New York Civil Liberties Union, the New York State Academy of Family Physicians, Housing Works, MPAC (Mobilizing Preachers and Communities) and the New York Society for Ethical Culture. If you are affiliated with or know of any organization which you think might be supportive, please contact me, davidcleven@aol.com, 914 907-6156.

Additionally, the Medical Society of the State of New York (MSSNY) will soon be surveying its members on the issue of medical aid in dying. We are hopeful that MSSNY will reconsider its current opposition to medical aid in dying as have other state medical societies, several of which have taken neutral positions in recent years.

If you have not yet contacted your legislators urging them to support the Medical Aid in Dying Act, please do so today. Information on how to do so is on the EOLCNY website, at <http://endoflifechoicesny.org/advocacy/contacting-your-legislator/>

EOLCNY Palliative Art Conference Receives Praise

By Ayana Woods, MPH

On June 7th End of Life Choices New York held an all-day palliative art conference in collaboration with Fordham University's Graduate School of Social Service, focused on using the arts to improve care at the end of life. Over 100 people attended and their feedback about the day was overwhelmingly positive. Here are a few of their comments:

"The conference was a joy to be at, I learned more than I shared, and I think the best part of what happened was the renewal and creation of community and commitment around making death better. I know I certainly am renewed in that work."

"Really touching, uplifting, illuminating, humanistic and fabulous. I am so happy I attended, and that all these wonderful, talented people work in healthcare."

"I like how different disciplines presented their perspectives in an interactive way. I was engaged the whole time. Inspiring, refreshing and invigorating."

"Music, comics and film programs were terrific-- touching and encouraging in the ways they show how to enhance the lives of EOL patients and ease the hurdles of caregivers."

"It was ALL useful, complementary, and fascinating"



Audience at our Palliative Art Conference.

Barbara Sarah, founder of the Oncology Support Program at HealthAlliance Hospital in Kingston, started the day by explaining how that program uses arts-based palliative care activities (music performance, memoir groups, improvisational theater, poetry, music therapy) from day one of a patient's diagnosis through the progression of the illness.

Then Joanne Loewy, Founding Director of the Louis Armstrong Center for Music and Medicine at Beth Israel Medical Center, discussed the ways music therapy helps patients face the end of life and eases

the acceptance of death with dignity, comfort, and a sense of lasting legacy.



Left to right: MK Czerwiec, Jack Coulehan, Carolyn Jones, Barbara Sarah, Susan Orkand, Joanne Loewy

Jack Coulehan, a physician and medical educator whose poetry has been nominated for a Pulitzer Prize, demonstrated how reading and writing poetry helps heal the wounds of caregivers, as well as relieving the suffering of their patients.

Susan Orkand, a professor and the education clinical coordinator in the graduate dance/movement therapy department at Sarah Lawrence College, led the audience through interactive movement experiences and explained how attention to breath, gesture, and movement can open doors to further explore meaningful thoughts and feelings.

In the afternoon, MK Czerwiec, Artist-in-Residence at Northwestern Feinberg Medical School, demonstrated how writing, drawing, and reading comic books can facilitate difficult discussions around advanced care planning and end of life care. She showed the audience examples of graphic novels and memoirs that portray end of life care, including her own work "Taking Turns: Stories from HIV/AIDS Care Unit 371"

The final speaker of the day was Carolyn Jones, an award-winning filmmaker. She showed a preview of her newest project, the documentary *Defining Hope*, that tells the story of patients dealing with life-threatening illness as they move between ICUs, operating rooms, hospice care, and home. This film follows these patients, others, and the nurses that guide them along the way as they face death, embrace hope, and ultimately redefine what makes life worth living. End of Life Choices New York will partner with Carolyn to host screenings of *Defining Hope* across New York State in November.

VSED and Dementia

By Judith Schwarz, PhD

About a year ago, I participated in the first conference dedicated to the topic of voluntarily stopping eating and drinking (VSED) at Seattle University School of Law. I told the audience that it took more than fifteen years to pass the Family Health Care Decisions Act (FHCDA) in New York, the law that finally authorized a family member or close friend to be a surrogate decision maker for a person who had not completed an advance directive before losing decision making capacity.

Many of the Upstate legislators who drafted the FHCDA are advised and counseled by Catholic bishops and conservative rabbis. Under the FHCDA, surrogate decision makers are not allowed to decide about forgoing oral feedings for an incapacitated loved one because oral feeding is not considered 'health care'.

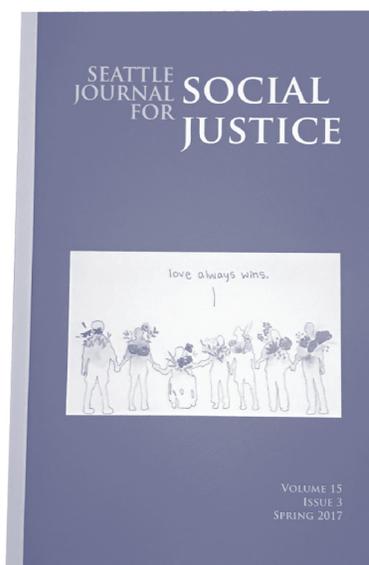
In my subsequent remarks, I mentioned that VSED is the only legal means for patient-controlled dying in New York. Although there are other options to hasten death, they require actions and support by a medical team and occur in an institutional setting. VSED usually occurs in the patient's home with family or friends in assistance along with hospice support for those who are terminally ill. Under such circumstances, VSED is generally a peaceful kind of "slipping away" death that occurs within a few days to two weeks after the start of the fast.

discuss their end of life concerns, fears and wishes. Some callers want to know how to get copies of the various NYS medical advance directive forms and what to include in them. We strongly encourage all New Yorkers to complete a health care proxy form so they have an appointed agent who knows their values and wishes with regard to end of life conditions they would not want to endure. A well informed and zealous advocate is the best defense against unwanted or inappropriate medical interventions.

The health care proxy law is silent on the issue of oral or assisted feedings, thus there is no current prohibition regarding an agent's right to decide about forgoing assisted/hand feedings. This has become increasingly relevant to my work, as growing numbers of callers with a recent diagnosis of Alzheimer's disease are desperate to learn how they can avoid the final stages of this incurable and progressive disease. In my article I describe the comprehensive written directive (Living Will) that I and a physician colleague, Peter Rogatz, developed for use by those with terminal or incurable and progressive diseases. This document specifically states that once a certain stage of dementia occurs, along with the loss of mental capacity and ability to self-feed, the appointed health care agent will direct caregivers to provide effective palliative/comfort care while withholding oral/assisted feedings. The written document can be produced as written corroboration of the now incompetent patient's previous thoughtfully made decisions about assisted feeding.

There are potential challenges to having such documents and directions honored by caregivers, particularly if the patient is in an institutional setting. And no court has yet considered the validity of documents that direct the withholding of oral feedings under the clinical circumstances of advanced dementia. Nonetheless, we think these documents are an important addition to the usual instructions appointed health care agents bring to the medical team when considering end of life care for an incompetent patient. Appointing a health care agent is an effective way to avoid the limits on a surrogate's choices about assisted feedings that exist under the FHCDA.

Those of us who spoke at the conference were asked to write a VSED-related article for one of the law school's journals – the Seattle Journal of Social Justice. Those articles were published recently; mine is entitled "Alzheimer's Disease and Written Directives to Withhold Oral Feedings: Clinical Challenges in New York State." I started out by describing the calls we get here at EOLCNY from New Yorkers who want to





On October 3rd Dr. Timothy Quill presented "Palliative Options of Last Resort: What is possible in New York now and in the future?" at Hofstra University. The event was sponsored by End of Life Choices New York, the Hofstra Northwell School of Medicine, and Northwell Health.



NBC News Left Field has produced a powerful six-minute video about the need for medical aid in dying. It features End of Life Choices New York; two of our advocates for aid in dying, Scott Barraco and Barbara Backer; and attorney Edwin Schallert.

The video was produced by Carlos P. Beltran and can be seen on the home page of our website, www.endoflifechoicesny.org.



A special performance of "My Own Tongue" was done for EOLCNY major donors on October 5th. The play demonstrates the need for the legalization of aid in dying by using the true story of cancer patient Cathy Quinn. Pictured here are actors Rik Walter, Suzanne Hayes-Kelly and Cheryl Royce. Suzanne developed the play based on Cathy Quinn's blog.

Barbara Swartz Lecture

By Deborah Grayson, MPH

In September 140 people attended EOLCNY's Third Annual Barbara Swartz Lecture, co-sponsored by the New York Society for Ethical Culture. Dr. Haider Warraich, a highly regarded physician and author, spoke persuasively and compassionately about his book *Modern Death*, and why he wrote it.

Dr. Warraich, a cardiovascular fellow at Duke University and past instructor at Harvard University, is a much-published writer. He's from Pakistan where the process of dying is usually brief. When he began to practice medicine in America, he was struck by the ability of Western technology to delay death, which in turn has caused us to lose touch with the role mortality plays in the life cycle. "Death is intrinsically tied to life, yet it is something most of us have trouble understanding. We spend our time running away from it," he said, and added, "People have always feared death, now they fear dying."

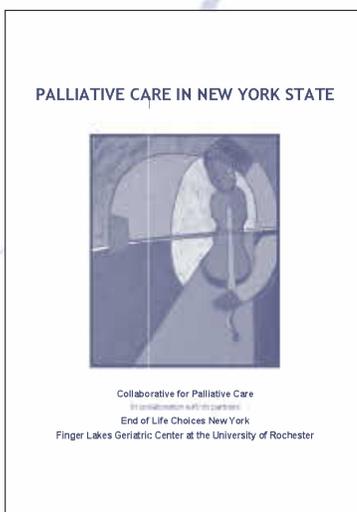
While working in Massachusetts, a Physician Aid in Dying bill went before their legislature. Dr. Warraich was surprised to learn that most of his colleagues, particularly the older ones, were against something he saw as a logical and benevolent alternative to prolonged dying. During his presentation he discussed the arguments he developed to rebut naysayers.



Dr. Haider Warraich

The lecture was videotaped and is available on the EOLCNY website at endoflifechoicesny.org.

Palliative Care Booklet Available



A useful booklet on palliative care and advance care planning, "Palliative Care in New York State" is now available. It was produced by End of Life Choices New York, in collaboration with our partners, the Collaborative for Palliative Care and the Finger Lakes Geriatric Education Center at the University of Rochester. The booklet was funded by a grant from The New

York Community Trust. It contains over 50 answers to common questions. Copies can be downloaded from the EOLCNY website at endoflifechoicesny.org/education/resources

Support our year-end campaign

Donate at
www.endoflifechoicesny.org

We are a 501(c)(3) nonprofit organization. All donations are tax-deductible.

End of Life Choices New York, through leadership, advocacy, education and counseling, seeks to expand choice at the end of life and improve the quality of care for New Yorkers, ensuring that their values and wishes are respected.

From Our Executive Director

By Laurie Leonard



Matching grant

Thanks to the generosity of our donors, we met our match! The exact total was not available as we went to press, but we did meet and in fact slightly exceed our goal of fully matching our \$300,000 grant from the Open Society Foundations. In mid-September we were \$50,000 short of the goal; during the next four weeks 125 donors chipped in to close that gap. We are very grateful!

Donor names

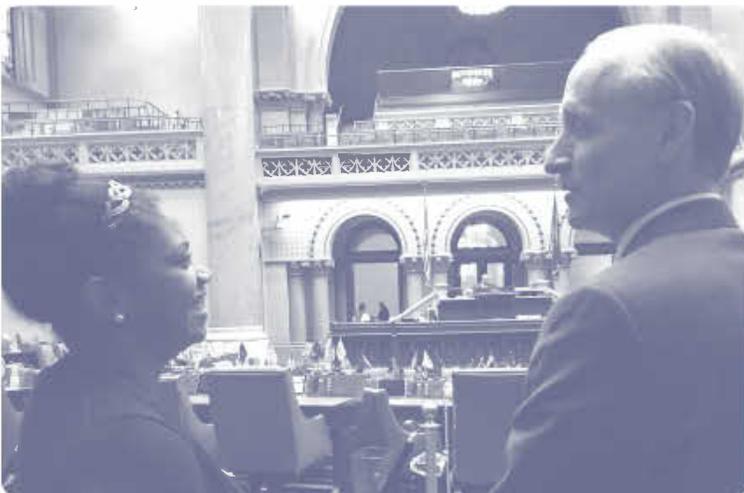
A list of all donors who have contributed at least \$250 during 2017 will be published in our Spring 2018 newsletter.

Speaker's bureau

This year EOLCNY spoke to more than fifty organizations, educating the public, students and medical professionals about advance directives, hospice and palliative care, pain management, end of life treatment options, and medical aid in dying. Our programs are presented free of charge; their content and length can be adjusted to meet a group's specific needs. If you would like to find out more about our programs, or know a group that might be interested in booking one, please contact our Director of Outreach and Education, Ayana Woods, at ayana@endoflifechoicesny.org or call us at 212.726.2010.

Newsletters

Our print newsletter only comes out twice a year. If you would like more frequent updates about end of life issues (once every week or two), please send your email address to us at info@endoflifechoicesny.org. You can easily unsubscribe if you change your mind.



Director of Outreach and Education Ayana Woods and lobbyist Vince Marrone at the state capitol in Albany, working for the passage of the Medical Aid in Dying Act.

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