

## Update On New York Aid in Dying Legislation and Litigation

By David C. Leven, JD

We are continuing our many efforts to have legislation enacted in New York to legalize aid in dying. We have been working very closely with the sponsors of the Medical Aid in Dying Act A. 2383, S. 3151. Just recently we conferred with Assembly Members Amy Paulin, a lead sponsor of the bill, and Richard Gottfried, chair of the Assembly Health Committee, as they seek support from their colleagues on the Health and Codes Committees, the two committees that will first consider the bill.

In March, Ayana Woods, Director of Outreach and Education, Dr. Bruce White, volunteer Scott Barraco, our lobbyist Vince Marrone, and I met with legislators and staff of those committees. Our meetings went very well and we are hopeful that each of the assembly members will vote to approve the Medical Aid in Dying Act. Some did convey their support.

In our meetings, in response to the claim by opponents that the many safeguards in the bill are still not adequate, we pointed out that there are no statutory safeguards for other options which hasten death such as a patient who decides to have a ventilator withdrawn or a patient who voluntarily stops eating and drinking or one who is suffering from intractable pain and dies after palliative sedation. And, in response to the concern raised by some in the disability rights community about the potential for abuse, we pointed out that Disability Rights Oregon has not received any complaints of exploitation or coercion since passage of the aid in dying law in that state in 1997 nor is there is any other evidence of abuses.

Please support the Medical Aid in Dying Act by writing to your legislators. Go to our website [endoflifechoicesny.org](http://endoflifechoicesny.org) for instructions.

Regarding litigation, our case to establish aid in dying in New York is moving forward. We

are asking the court to rule that the laws that ban assisting a suicide do not extend to aid in dying. When those laws were enacted they were intended to prevent private citizens from assisting others to commit suicide, but they were not intended to apply to the conduct of a physician who prescribes medicines for a dying patient who may take them to achieve a peaceful death. We also contend that patients have the right to aid in dying under the due process and/or equal protection clauses of the New York State Constitution.



*David Leven speaking with Dr. Timothy Quill at our booth at the Hospice and Palliative Care Association of New York State conference.*

The New York Court of Appeals has informed us that the date of the oral argument in Albany by the attorneys in the case will be on May 30th. We are particularly pleased that there will be numerous amicus (friend of the court) briefs filed in support of our position. We have worked very hard to secure this support as well as counsel to represent the various groups. Briefs will be or already have been filed on behalf of medical and religious organizations, criminal defense and elder law attorneys, the New York Civil Liberties Union, survivors, law school professors, and legislators, among others. We are hopeful that the court will issue a favorable ruling and send the case back to the trial court for further factual development and a trial.

## From Our Executive Director

By Laurie Leonard

This issue of our newsletter highlights the many exciting projects we have been engaged in recently: our efforts to legalize medical aid in dying with legislation or by litigation; the advocacy event we held to teach citizens what they can do to help create change; our upcoming palliative care conference that will focus on how the arts can educate and empower both providers and patients; and our highly praised counseling services.

All this work to improve end of life care of course requires financial support, especially since almost all our services are provided free of charge. We encourage you to help us continue our work by making as generous a donation as you can. We have a \$300,000 matching grant from the Open Society Foundations, but we will only receive that amount if we can match it with other donations. A donation can be sent to us in the



*Executive Director Laurie Leonard teaches social workers about advance directives at the Brookdale Center for Healthy Aging.*

envelope included in this newsletter, or made on our website at [endoflifechoicesny.org](http://endoflifechoicesny.org). We are a 501(c)3 nonprofit organization and all donations are fully tax-deductible. You will be helping to improve end of life care for all New Yorkers.

## Our Aid in Dying Advocacy Training



Almost 100 people attended our April event in which we suggested ways people can advocate for the legalization of aid in dying. Actors Rik Walter, Suzanne Hayes Kelly and Cheryl Royce performed a reading of an original play based on the true story of cancer patient Cathy Quinn and her boyfriend Scott Barraco. After Cathy's death, Scott became an advocate for aid in dying, and after the play the real Scott Barraco talked about his experiences.



If you would like to participate in the movement to legalize aid in dying, you should write to your legislator, urging them to support the Paulin/Savino Medical Aid in Dying bill. We have a sample letter on our website that you can use or modify. Letters are most effective if they go to the legislators for your own district, so there are also links on our website to pages that will allow you to easily look up their names and addresses. To access the instructions and the sample letter, go to the home page of our website at [endoflifechoicesny.org](http://endoflifechoicesny.org).

# Alzheimer's Disease and Advance Directives

By Judith Schwarz, PhD



A number of New Yorkers with a newly diagnosed and early stage Alzheimer's have contacted our consultation service. They express great anxiety about what lies ahead for themselves and their families. They want to know whether we can help them avoid the final stages of this incurable and progressive disease. One of the options we discuss is whether they would want to be 'hand fed' when they lose both decision making capacity and the ability to feed themselves in the advanced stages of this disease.

One of the realities of the final stages of Alzheimer's and other dementing diseases is that a reflexive opening of the mouth often occurs, when a spoon touches the side of the mouth of very cognitively impaired patients. This reflex persists long after the patient has lost the ability to make informed choices about continuing or forgoing treatment. If a patient appears to 'cooperate' in hand feeding, in the absence of a previously completed advance directive to the contrary, they will be fed until they completely lose the ability to swallow safely.

While most New Yorkers who appoint a health care proxy instruct their health care agent to refuse artificially provided nutrition and hydration via medical devices, they probably

have not thought about the pros and cons of being spoon fed by hand during the final stages of dementia. This is an important consideration that requires careful discussion about the benefits and burdens of this option.

Unless a person with decision making capacity stipulates in writing the circumstances under which they want to forgo hand feeding, they will be spoon fed, possibly for years, during the final stages of this disease. Continuing hand feeding may be an appropriate intervention for some, but it ought to be an informed choice. Others may seek to avoid prolonging the final stages of this disease by leaving clear written instructions about strongly held values to guide treatment decisions by future care-givers.

It should be noted that such written directions have not yet received judicial review or legislative recognition. Including instructions about forgoing hand feeding is a fairly new addition to advance medical directives. We hope such a review will occur in the near future.

These are serious and important conversations we are increasingly having with members of our community. We welcome your inquiries.

## How Judy Can Help You

End of Life Choices New York is very fortunate to have Judith Schwarz on our staff. She is a PhD prepared nurse who is one of the most experienced and highly respected end of life counselors in the country. As part of our mission to improve end of life care, we offer Judith's counseling services to patients and their families.

Here are a few of the many comments we have received about Judith from those who have used her services:

*"My friend passed Sunday morning. Her passing was pain-free, very gentle and*

## Our Newest Board Member

*peaceful thanks in large measure to your expert medical and emotional support. Your help has been immeasurable. You are a treasured gift, Ms Schwarz...your coaching was equally stabilizing in getting me, her family, and most importantly, my friend, through this. I cannot imagine navigating this without you. Lucky, indeed, are those who have received and will receive your loving care. I join countless others who have benefitted directly and indirectly from you."*

*"Judy was so helpful to me, my mother and my family relative to my Mom's terminal illness and end of life issues. She provided invaluable advice and afforded us tremendous guidance, compassion and at the end of the day...she became a very caring friend. I am personally so grateful to Judy and your organization for the support and services you gave our family through Judy."*

*"Thank you very much for your help in a time of great crisis...We'd especially like to thank Judith Schwarz for her exceptionally poised and perceptive interventions; she was of great comfort to us in a time of need."*

Judith helps clients talk openly and honestly with family members, friends, and health care providers about health care wishes, and she advocates for patients whose end of life wishes aren't being honored. She also advocates for patients who many not be getting optimum pain or other symptom management. She can explain the pros and cons of various options so that the client can make an informed decision about them.

A generous grant we received from the Open Society Foundations allows us to offer Judith's services at no charge to clients. We encourage you to call her at 212-252-2015 or email her at [judy@endoflifechoicesny.org](mailto:judy@endoflifechoicesny.org) if you are in need of counseling or have questions about such topics as advance directives, palliative care, and hospice.

In January the EOLCNY board of directors was delighted to elect Fred Schwartz, MD, to the board. Fred has been the Medical Director of Hospice of New York for 14



years. He is also an Adjunct Assistant Professor of Medicine at Cornell University Medical College and a Founding Member of the American Academy of Hospice and Palliative Medicine.

Fred has previously served as the Medical Director of Visiting Nurse Service of NY Hospice Care, the Emergency Department at Mt. Sinai/Beth Israel Hospital, the Emergency Department at Beekman Downtown Hospital, Beekman Hospital's Emergency Care Institute, and Telemetry Control of Emergency Medical Services of NY. His volunteer work has included being a physician on a kibbutz in Israel, being a Buddy for people with AIDS at GMHC, and serving as a Quaker volunteer in a maximum security prison. He is a graduate of Albany Medical College.

## Palliative Art: Our First Full-Day Event!

By Ayana Woods, MPH

End of Life Choices New York will be hosting our first full day conference, in collaboration with Fordham University Graduate School of Social Service, on June 7th. "Palliative Art: Using the Arts to Improve Care at the End of Life" will focus on how the arts can educate and empower both providers and patients. End of Life Choices New York is honored to have an amazing array of speakers for this event. The agenda is below, along with expanded information on two of our speakers.

### Keynote: **"Living Fully with Illness": A Model Community Program for Palliative Care**

Barbara Sarah, LCSW-R

### **Using Music as A Transient Element of Passage in End of Life Care**

Joanne Loewy, DA, LCAT, MT-BC

### **Words that Heal: Poetry in Palliative Care**

Jack Coulehan, MD, MPH

### **Breath, Gesture, and Movement: Dance/Movement Therapy in Palliative Medicine**

Susan Orkand, MA, BC-DMT, CMA, ERYT

### **Comics and Care: Turning the Pages from Life to Death, Graphically Speaking**

MK Czerwiec, RN, MA

### **Documentary Storytelling: Experiencing the End of Life Through the Lens of Patient Care**

Carolyn Jones, Filmmaker

Workshops:

#### **Living Fully with Illness Workshop**

Barbara Sarah, LCSW-R

#### **Reflective Drawing and Comic-Making Workshop**

MK Czerwiec, RN, MA

MK Czerwiec is a nurse who uses comics to contemplate the complexities of illness and caregiving. She is the Artist-in-Residence at Northwestern Feinberg School of Medicine and a Senior Fellow of the George Washington School of Nursing Center.

MK says that *"the arts have an important role to play in end of life care, for patients, families, and caregivers, because they help us make meaning of what we are experiencing. The arts help us assemble and share our stories"*. MK thinks many people will be surprised to see how relevant making and reading comics can be in end of life care. She believes that comics are a safety zone, even for difficult topics, that can help us navigate the worlds we face, process the stories of death, and communicate our own care preferences, values, and priorities.

Susan Orkand is a professor in the graduate dance/movement therapy department at Sarah Lawrence College. Her session *"Breath, Gesture, and Movement: Dance/Movement Therapy in Palliative Medicine"* will help attendees to understand the importance of nonverbal elements in palliative care. These elements include observing the subtleties and rhythms of the breath, small every day gestures, and larger expressive movements in the whole body.



*Ayana Woods leading a group exercise*

According to Susan, *"Oftentimes during the end of life phase, when the body is failing and emotional intensity is heightened, utilizing the arts enhances expression, interpersonal communication, and memory making."* Susan hopes to show the audience that when the physical body is fragile, and end of life may be near, bearing witness and emphasizing can be a very powerful way to work in palliative medicine.

## Donor Makes Generous Bequest

EOLCNY was deeply grateful to receive in March a bequest form from Jill Byatt, notifying us that she has included a generous bequest to End of Life Choices New York in her will. Jill's late husband Elliot Epstein was counseled by our Clinical Director Judith Schwarz. The gift was made in Elliot's memory and to salute his courage. Jill shared with us these touching details about Elliot's final months:

*"This gift is made in my beloved Elliot's memory and to salute his courage. Before we learned about EOLCNY, read its materials and consulted with Judy, Elliot was in despair. His brain was sharp but his body had let him down. He could not stand, walk, cook a meal, paint a painting, or hold a pen and feeding himself was becoming more difficult. To move from bed to wheelchair was impossible without excruciating pain. He could not take care of his bodily needs. Even swiping a page on his Kindle was fraught with difficulty. He could*

*do nothing that made life worthwhile from his point of view. While he kept up a good front with his quirky sense of humor, going along with the doctors, nurses, aides and social workers, he made it very clear that he wanted out. And when everything was in place and he was ready, he took charge of his own destiny. That is bravery! I shall be forever grateful to Judy and your organization for the priceless guidance and loving support."*

If you would like to make a bequest to EOLCNY, you can obtain a bequest donation form by contacting Executive Director Laurie Leonard at [laurie@endoflifechoicesny.org](mailto:laurie@endoflifechoicesny.org), or by downloading it at <http://bit.ly/2nSK51R>. If you have any questions please call 212-726-2010. A legacy gift will help to ensure that our leadership, advocacy, education and counseling can continue to expand choice at the end of life and improve the quality of care for all New Yorkers. And if you are in need of end of life counseling yourself, please do not hesitate to call Judy Schwarz at 212-252-2015.



Elliot Epstein in 2011

## Donations Since Winter Newsletter

We thank all of our donors for making our work possible. The following donations were made between 10/21/16 and 4/19/17. We will print the names of all of this year's donors in our Winter newsletter.

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Correction of donor name in last newsletter: Raymond Lightstone (\$1,000-\$2,499)

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.

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