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After Brittany Maynard: Next Steps for Aid in Dying

Lawsuit Seeks to Expand Civil Rights of Dying: Dying NY Patients, Doctors, Disability Rights Center Seek Aid in Dying for Mentally Competent, Terminally Ill Patients

New York, NY - A New York woman dying of ALS, a New York man dying of AIDS, a New York lawyer with cancer, prominent New York physicians, the national nonprofit disability rights advocacy group, Disability Rights Legal Center (DRLC), and End of Life Choices New York (EOLCNY) today filed a lawsuit in the State Supreme Court to clarify the ability of mentally competent, terminally ill New York patients to obtain aid in dying from their physician if they find their dying process unbearable.

The patients and doctors are asking the court to declare that physicians who provide a prescription for medication to a mentally competent terminally ill patient - which the patient could consume to bring about a peaceful death - should not be subject to criminal prosecution under existing New York law, which makes a crime of assisting another to “commit suicide.” The lawsuit argues that the choice of such a dying patient for a peaceful death is not “suicide,” and the physician is not assisting such a patient in “committing suicide.”

Further, the lawsuit argues that patients facing the end of their lives have a right under the New York State Constitution to make autonomous decisions about their bodies and how they will die. The lawsuit is filed in the wake of the death of terminally ill patient Brittany Maynard, who had to move to Oregon since the law of her home state, California, like New York, is unclear about the legality of aid in dying.

“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. Eventually, this disease will rob me of my ability to breathe,” said patient plaintiff Sara Myers, who has amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease. “There is no medicine to stop or even slow the progression of this disease. 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.”

“I am determined to take what steps I can to die with dignity, and to have some choice and control over my final weeks, days and hours. I want every day to matter. I want to live my life being aware, able to love, and to be loved consciously,” Myers said.

“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,” Myers said. “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.”

Steve Goldenberg, 55, of New York City, dying of AIDS, told the news conference that, “I have many life-threatening diseases that result from AIDS. I’ve lived with the AIDS infection since 1989. It has caused an endless series of medical crises that have brought me to today, where I face the end of my life. I’ve had to have toes amputated, am unable to swallow solid food, many episodes of pneumonia, wasting syndrome, cancer of the larynx, obstruction of my throat, and chronic severe pain, just to name a few. I have fought the debilitating disease with all my strength. I’ve undergone difficult and disfiguring surgeries, radiation and a cornucopia of pain and other medications.”

“Each day my strength wanes, and I sleep most of the day. I can’t go out or socialize with friends, and I see the end coming. I want my doctor to care for me as I die as he has so incredibly during my life with AIDS. I want to have some control, choice and dignity as I conclude this life and fight against AIDS. In New York today, my doctor fears even discussing aid in dying with me. I am asking the court to clarify that my doctor can provide medication I could ingest to achieve a peaceful death,” Goldenberg said.

Patient plaintiff Eric A. Seiff, an attorney and former Assistant District Attorney, said, “I’ve had bladder cancer for over a year and have been fighting it, submitting to surgery, chemo and now a clinical trial. I continue to run and work and do all I can to maintain my health. Last week I learned the cancer has spread to my lungs. I must be realistic that a spreading cancer promises a declining health and the ultimate destruction of my physical health. When I was in college, I watched my mother die an excruciatingly slow death from terminal illness, and I vowed that I would not submit to the same. I have lived a full and rewarding life, with a great deal of autonomy and control over my own affairs and person. Should I decide my dying becomes unbearable, I want my physician to be able to prescribe medication I can take to achieve a peaceful death. This will enable me to maintain autonomy and control, which is important to me.”

Physician plaintiff Dr. Timothy Quill, Professor of Medicine, Psychiatry and Medical Humanities; Director, Center for Palliative Care and Clinical Ethics, University of Rochester School of Medicine, said he joined the lawsuit because “relief of suffering – and with it the possibility to face dying in a manner consistent with one’s values and medical circumstances - must be available to suffering patients now.”

Dr. Quill was the lead plaintiff in *Vacco v. Quill*, a lawsuit that reached the U.S. Supreme Court in 1997. The Court there refrained from finding a federal constitutionally protected right for dying patients to obtain prescribed life-ending medicines, at that point in time. But the court invited states to grapple with the issue.

“In the 18 years aid in dying has been available in Oregon, and more recently in other states, it has become clear that aid in dying provides many patients with peace of mind, and it empowers a small number of dying patients to achieve a dignified and peaceful death at a time of their own choosing. As a physician, I want to be able to respect my patients’ wishes to achieve a peaceful death should they want that option,” Dr. Quill said.

“It is time for New York to clarify that suffering, dying patients have the right to choose a peaceful death through aid in dying,” said DRLC Executive Director Kathryn Tucker, co-counsel to the

plaintiffs. “Patients trapped in a dying process they find unbearable should be able to turn to their physicians and ask for medication they could consume to bring about a peaceful death. Physicians should not fear prosecution for providing such patients aid in dying.”

Tucker has been counsel in similar cases that established access to aid in dying in Montana and New Mexico, and was lead counsel in the federal constitutional cases, *Quill v. New York* and *Glucksberg v. Washington*.

“This lawsuit represents a vitally important step to ensure that a patient can direct his or her care,” said Edwin Schallert, of the law firm Debevoise & Plimpton LLP, co-counsel to the plaintiffs. “Patients already have the right to make certain decisions in New York that can control the timing and manner of their deaths, either by choosing certain treatment or by having it withheld or withdrawn. The lawsuit seeks to make it clear that New Yorkers who are terminally ill and mentally competent have another option that gives them control, avoids a perceived loss of dignity and reduces suffering they find unbearable.”

Physician plaintiff Dr. Howard Grossman, an internist specializing in primary care, lesbian, gay, bisexual and transgender medicine and HIV care, said, “Our medical system already allows physicians to make decisions to manage a terminal patient’s death. What we seek to do is enhance the patient’s ability to control it themselves, with the help of their family and their physician.”

“I have been involved as an advocate for patient access to end of life choices for many years. I have patients who are terminally ill. Under current laws and practice, I can speak to them about all kinds of medical interventions, more surgeries and more medications. I can offer more pain medications, but with the large amount they are almost always already on, this would probably render them even less functional,” Dr. Grossman said.

“I have patients who, on several occasions, have asked me if there is any way that they could end their own lives as things continue to worsen,” Dr. Grossman said. “I am forbidden from discussing this subject in any way that would help the patient to make better decisions. I cannot provide my patients with medications that they could use to end their lives, and I cannot even advise how to do it if they got medications on their own. These heroic and suffering patients are left to make these decisions themselves without my medical guidance, on which they have depended for many years.”

Dr. Samuel C. Klagsbrun, MD Executive Medical Director and Owner of Four Winds Hospital in Katonah, NY as well as Four Winds Saratoga Hospital, said he became a plaintiff in the lawsuit because, “I have spent many years caring for patients with cancer, helping them and their families deal with their suffering. It’s time to help these patients facing the end of life to have a choice in ending their needless suffering.”

Dr. Charles Thornton, a neurologist and professor at the University of Rochester Medical School, and another physician plaintiff, said, “Patients dying of ALS often have an extraordinary burden of suffering as the disease progresses. Many of these patients would be comforted to know that a peaceful choice of aid in dying is available.”

The lawsuit seeks to empower dying, mentally competent New York patients with the same choice patients have in Oregon, Washington, and Vermont where statutes permit the practice, and in Montana and New Mexico, where supreme courts have protected the practice.

End of Life Choices New York Executive Director David Leven said, “We see New York patients and

families suffer needlessly, and physicians feeling that they are prohibited from providing medications that their patients want, and which they wish to prescribe. No dying patient should be forced to endure suffering they find unbearable.

“It is time for New York to catch up with other states and respect the rights and decisions of patients. No dying New York patient should have to move to another state to have his or her end of life decisions respected,” Leven said.

Nurse and end-of-life counselor, and plaintiff, Judy Schwarz said, “As a clinical coordinator working with dying patients for over a decade, I have been privileged to provide counsel and support to decisionally capable, terminally ill New Yorkers and their families. Many of my patients wanted to know whether there was a physician who would help them to die. Patients often said they just wanted to be able to take a pill and go to sleep. They were often bitterly disappointed when I had to tell them about the laws in our state. I firmly believe, based on my experience as a nurse and as a counselor for the terminally ill, that those who are near death should have the right to aid in dying.”

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The lawsuit Complaint is posted on the websites of the two organizations sponsoring the effort: Disability Rights Legal Center (DRLC) is a national organization whose mission is to champion the rights of people with disabilities through education, advocacy, and litigation. Advocacy to empower a dying patient to choose a peaceful death is consistent with DRLC’s overarching mission of empower individuals with information and autonomy over their own bodies, lives and medical decision-making. Abundant data from Oregon, Washington and elsewhere shows that aid in dying presents no risk to people with disabilities. DRLC is proud to participate in advocacy efforts to expand end of life choice. DRLC includes programs focused on the needs of patients with cancer and HIV/AIDS, www.disabilityrightslegalcenter.org

End of Life Choices New York (formerly Compassion & Choices of New York) is the leading organization in New York working to improve care and expand choice at the end of life. As a patient and family centered organization, it has been advocating for, and counseling, patients and families for 15 years, educating the public and health care professionals, and it has initiated and secured passage of key legislation, including New York’s Palliative Care Information Act and Palliative Care Education and Training Act, www.endoflifechoicesny.org.

Editor’s note: Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed. From www.als.org