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Carol Sieger

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ADDRESSING AND DISPELLING MISCONCEPTIONS SURROUNDING THE PHYSICIAN-ASSISTED SUICIDE CONTROVERSY

CAROL SIEGER*

Thank you for the opportunity to include myself, as well as Choice in Dying, in part of what I hope will be an ongoing, continuing discussion regarding the issue of physician-assisted suicide.

Choice in Dying is a national, not-for-profit organization.1 We are in a unique position in that it is our mission, as the oldest and only national organization devoted solely to a broad range of end of life issues, to secure the right of patients to make decisions about their end of life medical care and to promote quality care for dying patients.2

Now, the organization’s work includes a professionally staffed national hotline where we respond to approximately three to five thousand individuals each month, requesting facts and counsel-

* B.A. (Psychology) State University of New York at Albany; J.D., Hofstra University School of Law. Ms. Sieger is the Staff Attorney at Choice in Dying and has professional training and experience in elder law and healthcare. Prior to her appointment at Choice in Dying, Ms. Sieger was an associate at Russo & Atlas, an elder care law firm, where she consulted clients regarding estate planning and advance directives, resolved nursing home placement issues, appeared before administrative law judges in connection with the denial of Medicaid benefits and handled Family Court support matters.

1 See Amicus Curiae Brief of Choice in Dying in Support of Neither the Petitioners or the Respondents at *1, Washington v. Glucksberg, 117 S. Ct. 2258 (1997) (No. 96-110) and Vacco v. Quill, 117 S. Ct. 2293 (1997) (No. 95-1858), available in 1996 WL 656277. In 1976, the Euthanasia Society of America was renamed the Society for the Right to Die, and in 1991 again renamed Choice in Dying. Id. Choice in Dying is an organization that is well recognized for pioneering living wills. Id. They operate a national hotline for patients and their families. Id.

2 See id. at *1 (explaining Choice in Dying's mission which is to secure right of patients to make decisions concerning effecting their end of life medical care and to promote improving quality of care dying patients receive); see also Ann Fade, Right to Die: New Law and Policy Issues Appear While Old Ones Remain Unresolved, 11 No. 2 HEALTHSPAN 3, 5 (1994) (discussing broad range of services Choice in Dying provides including counseling and free legal information for families and healthcare providers concerning end of life decision making).
ing. In addition, Choice in Dying also provides public, professional and physician education and we also monitor the changes in state and federal law with regard to end of life issues.3 One of my principal roles is crisis resolution.

Choice in Dying takes no position as far as the legality or the constitutionality of physician-assisted suicide.4 However, the position that we do take is that this issue needs ongoing, complete debate. As part of the continuing debate, Choice in Dying did deem it crucial that the United States Supreme Court be fully informed about a number of issues. Consequently, we provided the Court with an amicus brief,5 although we consider the brief to be more informational in nature.

So, you might say we are presently taking a neutral stand as public debate continues. Although we remain neutral in this debate, Choice in Dying is still able to discuss the present controversy. Presently, many factors contribute to the current controversy about medical care at the end of life.6 Current medical technology can prevent or cure many diseases7 and significantly improve the quality of life for those suffering from chronic disabilities.8 That same technology, however, is being used to dis-

3 See Amicus Curiae Brief of Choice in Dying, supra note 1, at *1 (noting that in addition to patient counseling services Choice in Dying provides educational services to physicians and monitors changes in both federal and state legislation relating to end of life decision making).

4 See Richard E. Coleson, The Glucksberg and Quill Amicus Briefs: Verbatim Arguments Opposing Assisted Suicide, 13 ISSUES L. & MED. 3, 102 n.4 (1997) (noting Choice in Dying's amicus brief did not take positions on physician-assisted suicide, however, organization's long standing involvement provided guidance to Court in deciding issue).

5 See Amicus Curiae Brief of Choice in Dying, supra note 1, at *1.

6 See Lakshmipathi Cherulli et al., Intensive Care for Critically Ill Elderly: Mortality, Costs and Quality of Life, 155 ARCHIVES INTERNAL MED. 1013, 1013 (1995) (noting that factors such as reforms in organization and delivery of healthcare, changes in nation's demographics contributed to controversy surrounding physician-assisted suicide); see also John D. Lentos et al., The Illusion of Futility in Clinical Practice, AM. J. MED., July 1989 at 81, 82-83 (contending that disagreements among physicians concerning point at which medical treatment becomes futile has contributed to physician-assisted suicide controversy).

7 See Michael J. Malinowski, Capitation, Advances in Medical Technology, and the Advent of a New Era in Medical Ethics, 22 AM. J.L. & MED. 331, 341 (1996) (noting that improvements in medical technology have decreased death rate from diseases and raised life expectancy); see also Lois Shepherd, Sophie's Choice: Medical and Legal, 72 NOTRE DAME L. REV. 103, 128 (1996) (contending that modern medicine has created expectation of healthier lives).

8 See Terry Fielder, The Relief Business: Treatment Efforts Targeting Previously Unmet Medical Needs, CHI. STAR TRIB., May 4, 1997, at 1D (discussing Medicare's new emphasis on improving quality of life for those with chronic medical conditions); John Morrisey, Outcomes, Chronic-Care Consortium Develops Living Tool to Help Integrate Services, MODERN HEALTHCARE, Feb. 19, 1996, at 33 (stating that healthcare is shifting
tort and prolong the dying process.  

The problems raised by the misapplication of technology and the lack of accessibility to good palliative care are compounded by widespread public and professional confusion or ignorance. Significant gaps still exist in the available empirical evidence concerning physician-assisted suicide. As a result, public debate is still at a comparatively formative stage. This is evident by the fact that five years ago we might not have had this symposium.

As with any emerging body of thought and practice, there is inherent instability which augurs both progress and risk. In order to minimize the risk, Choice in Dying has felt compelled to address and resolve several areas of confusion in our amicus brief. Some of these issues have already been discussed and I will point them out again so you understand our position.

The major point of concern is that there seems to be misinformation and misunderstanding about life sustaining treatments, including artificial nutrition and hydration. Life sustaining
treatments include not only artificial nutrition and hydration, but also treatment such as cardiopulmonary resuscitation (CPR), mechanical ventilation, and kidney dialysis.\[^16\]

However, the Ninth\[^17\] and Second\[^18\] Circuit Courts seem to imply, in both their opinions, that artificial nutrition and hydration were somehow qualitatively different from the other forms of life sustaining treatment.\[^19\] For example, both courts used language, such as starvation, to refer to and describe artificial nutrition and hydration.\[^20\] In fact, there was a wonderful article out called *The Sloganism of Starvation.*\[^21\] The problem with using the term "starvation" is it is emotion laden and it raises frightening images of hungry, otherwise healthy people who are prevented from obtaining desired food.\[^22\]

It is important to any discussion of this issue to remember that artificial nutrition and hydration are medical treatments.\[^23\] Consequently, artificial nutrition and hydration should not be distinguished from other forms of life sustaining treatment. In

\[^16\] *See* THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND CARE OF THE DYING 4 (1987) (defining life-sustaining treatment as "any medical intervention that is administered to a patient in order to forestall moment of death); *see also* Council on Ethical and Judicial Affairs, *Decisions Near the End of Life*, 267 JAMA 2229, 2229 (1992) (explaining that life sustaining treatment includes "mechanical ventilation, renal dialysis, chemotherapy, antibiotics and artificial nutrition and hydration").


\[^18\] *See* Compassion, 79 F.3d at 829 (categorizing artificial nutrition and hydration as different from other life sustaining treatments); *Quill*, 80 F.3d at 729 (discussing artificial nutrition and hydration in context of starvation).

\[^19\] *See* Compassion, 79 F.3d at 829 (using term starvation to refer to artificial nutrition); *Quill*, 80 F.3d at 729 (referring to artificial nutrition as starvation).

\[^20\] *See* Compassion, 79 F.3d at 823 (scrutinizing *Cruzan* argument that once artificial means of nutrition and hydration ended, Nancy Cruzan died from deliberate self starvation, not underlying illness); *Quill*, 82 F.3d at 729 (stating "the withdrawal of nutrition brings on death by starvation, the withdrawal of hydration brings on death by dehydration").

\[^21\] See *Stephen P. Von Derhoef*, *In re Grant: Where Does Washington Stand on Artificial Nutrition and Hydration*, 13 U. PUGET SOUND L. REV. 197, 233 (1989) (stating that use of word "starvation" to refer to withholding of artificial nutrition conjures up emotional images of people being starved).

\[^22\] *See* *Cruzan v. Harmon*, 760 S.W.2d 408, 412 (Mo. 1988) (stating that artificial nutrition, as well as hydration, are medical life sustaining treatments); *see also* Edward R. Grant & Cathleen A. Cleaver, *A Line Less Reasonable: Cruzan and the Looming Debate Over Active Euthanasia*, 2 MD. J. CONTEMP. LEGAL ISSUES 99, 1182 (1991) (reiterating that according to American Medical Association, artificial nutrition and hydration are medical treatments).
addition, there is no evidence that individuals who are depend-
ent upon artificial nutrition and hydration, whether alert and
aware, or partially or severely neurological impaired, would ex-
perience discomfort if these treatments were foregone.\textsuperscript{24} In fact, 
extensive, indirect evidence indicates that foregoing artificial nu-
trition and hydration could actually facilitate a natural death 
without discomfort.\textsuperscript{25}

Another source of concern for Choice in Dying is the blurring of 
the distinction between the withholding or withdrawing of life 
sustaining treatment and physician-assisted suicide.\textsuperscript{26} There 
are important distinctions between the two\textsuperscript{27} and it is critical, 
from a healthcare perspective and as far as our organization is 
concerned, that these distinctions be maintained. I do not want 
to go through another analysis regarding informed consent, bat-

\textsuperscript{24} See In re Estate of Longeway, 549 N.E.2d 292, 295 (Ill. 1989) (declaring that it is 
doubtful that patients in persistent vegetative state could experience pain and discomfort 
from withholding artificial nutrition and hydration); Mark Strasser, \textit{Assisted Suicide and 
the Competent Terminally Ill: On Aiding Treatments and Extraordinary Policies}, 74 OR. 
L. REV. 539, 589 (1995) (stating that some believe that death by starvation, as well as by 
dehydration, may be painful but if patient is insensate, he may not feel anything). \textit{But 
dissenting) (contending that pain and suffering as result of starvation or dehydration 
could be prolonged because death may take time); Robert L. Lapointe, \textit{The Removal of 
Feeding Tubes: Has the Right to Die Reached Its Limits}, 24 NEW ENG. L. REV. 185, 209 
(1989) (stating that death by starvation and dehydration is slow, as well as uncomfortable).

\textsuperscript{25} See In re Conroy, 486 A.2d 1209, 1236 (N.J. 1985) (recognizing that artificial nu-
trition and hydration to prolong life may be more painful or stressful than dehydration or 
starvation); \textit{In re Grant}, 747 P.2d 445, 453 (Wash. 1987) (contending that it is no longer 
clear that dehydration and malnourishment will always be painful to terminally ill pa-
tients); \textit{see also} Nancy Dies, \textit{Outlined By Debate Over Right to Die}, N.Y. TIMES, Dec. 27, 
1990, at 1 (stating that Nancy Cruzan's parents claimed she was peaceful throughout 
removal of feeding tubes, showing no sign of discomfort).

\textsuperscript{26} See Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 296-297 (1990) (Scalia, J., 
concurring) (stating action-inaction distinction is irrelevant because cause of death in 
both cases is patient's conscious decision to put end to own life); \textit{In re Gardner}, 534 A.2d 
947, 955 (Me. 1987) (stating that decision to refuse artificial life-sustaining treatment 
does not constitute suicide); McKay v. Bergstedt, 801 P.2d 617, 627 (Nev. 1990) 
declaring "substantial difference" between person desiring to terminate their life and 
person deciding not to interfere with natural consequences of their condition); \textit{In re 
Coyler}, 660 P.2d 738, 743 (Wash. 1983) (stating that death results from natural causes 
when life sustaining equipment is removed).

\textsuperscript{27} See Cruzan, 497 U. S. at 280 (stating "the majority of states in this country have 
laws imposing criminal penalties on one who assists another to commit suicide. We do 
not think a state is required to remain neutral in the face of an informed and voluntary 
decision by a physically able adult to starve to death."); \textit{see also} Yale Kamisar, \textit{The "Right 
[hereinafter \textit{Right To Die}] (questioning how rationale of Quill and Compassion in Dying to 
limit physician-assisted suicide to terminally ill patients will be upheld in Supreme 
Court); David Orenttiener, \textit{The Legalization of Physician-Assisted Suicide: A Very Modest 
Revolution}, 38 B.C. L. REV. 443, 444 (1997) (distinguishing suicide assistance and treat-
ment withdrawal by arguing that only latter is morally acceptable).
terry and the common law, however, I will just briefly discuss the distinctions.

The foregoing of life sustaining treatment refers to the avoidance of medical treatment that is necessary to sustain life. Since these life sustaining treatments artificially postpone natural death, the withholding or withdrawing of these treatments remove that obstacle to death. In addition, the right to withhold or withdraw life sustaining treatment is not limited to the terminally-ill, nor to competent adults because limiting such a right to terminally-ill competent patients, may be constitutionally impermissible.

Finally, as a way of contrasting analogy, another way to look at this topic is to examine the result of a failure to comply with an individual’s wishes. If a failure to comply with the request for withholding or withdrawing life sustaining treatment would subject an individual to unwanted treatment, then such failure would make him or her basically a virtual prisoner of medical technology. The imposition of life support often involves highly invasive equipment and procedures, and that is a more serious interference with personal liberty.

28 See Amy Haddad, Ethics in Action (Ethical Questions Regarding Assisted Suicide), RN, Mar. 1, 1997, at 17 (stating that forgoing life sustaining treatments simply means declining intervention).

29 See Washington’s Natural Death Act, WASH. REV. CODE. § 70.122.020(4) (1985) (defining life sustaining treatment as any procedure or intervention which utilizes mechanical or artificial means to sustain, restore or supplant vital functions; however, nutrition and hydration is only defined as life sustaining treatment if it serves to postpone death); see also Elizabeth Helene Adamson, The Right to Refuse Life Sustaining Medical Treatment and the Noncompetent Nonterminally Ill Patient: An Analysis of Abridgment and Anarchy, 17 PEPP. L. REV. 461, 470 (1990) (stating that most life sustaining procedures serve to delay moment of death by excluding medication or procedure to alleviate pain).

30 See The Right to Die, supra note 27, at 511 (contending that because of Equal Protection Clause there is no reason why non-terminally ill person who made voluntary, informed decision to die, should be denied right to have assistance to achieve death).

31 See Cruzan, 497 U.S. at 287 (O'Connor, J. concurring) (stating “[a] seriously ill or dying patient whose wishes are not honored may feel captive of the machinery required for life sustaining measures or other medical interventions. Such forced treatment may burden that individual’s liberty interests as much as any state concern...”); see also Nancy Watkins Anderson, Life and Death in Washington State After Cruzan v. Director, Missouri Department of Health, 16 U. PUGET SOUND L. REV. 249, 317 n.264 (1992) (arguing that allowing physicians to refuse to take patient off life sustaining treatment makes patient prisoner to technological advances).

32 See Cruzan, 497 U.S. at 281 (describing decision to withdraw life support is “deeply personal” decision which is protected by Due Process Clause); see also Alan Meisel, The Debate Is Not Over, Supreme Court’s Ruling Just Puts Question Back to Court of Public Opinion, PORT. OREGONIAN, June 27, 1997, at B09 (asserting that decision of terminally ill patients to forgo life sustaining treatments is private, intimate de-
A failure to comply with the request for physician-assisted suicide, on the other hand, would restrict patient autonomy, but would not amount to a bodily invasion. The cases of Compassion in Dying and Quill once again call upon the United States Supreme Court to address the limits of governmental power and the scope of individual autonomy.

There is another blurring of the distinction between physician-assisted suicide and the potential double effect of pain medication in certain circumstances. The term “double effect” refers to the administration of pain medication with the intention of providing relief from suffering, with the possible secondary effect of hastening death.

It is important to understand that hastening of death is theoretical. Therefore, it is impossible to determine whether the disease or the medication is responsible for the precise moment of death. There is widespread consensus, among ethicists and
within the law, that the double effect is a morally acceptable risk in the context of the great suffering of the terminally-ill. In addition, we do have technology available for managing pain and other symptoms associated with terminal illness.

One of the big concerns is that such technology is not routinely provided. For example, even though we have a wonderful hospice program, only about 15% of the terminally ill are actually made part of the hospice program. That phenomenon is due to a number of different factors.

It is important to note, in light of similar language in the Ninth Circuit, that it is a misconception that severe discomfort is invariably associated with the final stages of a terminal illness. Pain and other physical symptoms, in most circum-

39 See Carter, supra note 37, at 719 (referring to Minnesota's statute that bans assisted suicide but permits, along with Catholic Church, exemption for administration of medication to relieve another person's pain or suffering); see also Robert A. Sedler, Are Absolute Bans on Assisted Suicide Constitutional? I Say No, 72 U. DET. MERCY L. REV. 725, 729 (1995) (stating that since government has no valid interest in prolonging death, terminally ill people continue to suffer).


41 See Against Assisted Suicide, supra note 11, at 769 (asserting that high cost of pain management makes its availability limited to small number of patients with adequate health insurance); see also Susan Block & Andrew Billings, Patients Requests to Hasten Death: Evaluation and Management in Terminal Care, 154 ARCH. INTERN. MED. 2039, 2040 (1994) (stating that other symptoms of terminal illness are often inadequately controlled by physicians who lack expertise in palliative care or fail to take aggressive position toward assuring patient's comfort); see generally Burt, supra note 40, at 181 (contending that doctors do not inform patients about pain alleviation or provide palliative care).

42 See, e.g., Joanne Lynn et al., Defining the "Terminally Ill": Insights From Support, 35 DUQ. L. REV. 311, 312-14 (1996) (noting that Medicare hospice benefits only extend to patients that are deemed to only have life expectancy not exceeding six months).


44 See Compassion, 79 F.3d at 818 (discussing belief that patients who are terminally ill may be subjected to unnecessary pain and discomfort when their lives are mechanically extended with no medical benefits in return); see also Carter, supra note 37, at 718 (noting that doctors say that terminally ill patients, dying of lack of nutrition, do not suffer in stereotypical image of parched person scrambling in desert for water); Undying Pain: Relieving Death's Pain Will Reduce Calls for Help to Die, HOUSTON CHRONICLE, Jan. 19, 1997, at 2 (stating that many people drift into final sleep without significant discomfort).
stances, can be appropriately controlled within the confines of standard medical practice. Although potent medications can sometimes reduce alertness, there are psychostimulant medications that are available that might ameliorate this problem.

There are misconceptions both by the public and professionals about the management of pain, in addition to pain and suffering. Such misconceptions distort the current debate about physician-assisted suicide. Most individuals with terminal illness do not have to experience undue suffering. The Ninth Circuit’s opinion reflected the prevailing feeling, by both the public and professionals, that extreme pain and physical symptoms are inevitably associated with terminal illness. Public education and continuing debate are critical to dispelling these misconceptions. In addition, enhanced professional education is certainly necessary to ensure that competent pain management is available and accessible to all individuals.

One of the criteria for physician-assisted suicide is that the individual be terminal. There has been much discussion by reasonable minds who differ as to whether or not one can accurately predict whether an individual is terminal.

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45 See Grant & Linton, supra note 40, at 537 n.306 (noting that improvements in pain control have made cases of intolerable, untreatable pain rare); see generally Nancy J. Osgood, Assisted Suicide & Older People—A Deadly Combination: Ethical Problems in Permitting Assisted Suicide, 10 ISSUE L. & MED. 415, 428 (1995) (discussing terminally ill patients and availability of palliative care).


47 See Burt, supra note 40, at 166. Medical technology exists that will provide relief for terminally ill patients suffering from excruciating pain. Id. Often times, however, physicians neither utilize such measures nor discuss such techniques with their patients. Id. Moreover, this technology is sometimes not prescribed to those patients in need due to physicians’ insufficient knowledge concerning pain management and state and federal restrictions on availability of controlled substances. Id. at 167.

48 See, e.g., A Growing Move to Treat Chronic Pain Seriously, USA TODAY, Apr. 16, 1997, at 6D (noting that with the proper treatment, terminally ill patients’ pain can be controlled).

49 See Compassion, 79 F.3d at 818 (noting Washington legislature’s recognition that those terminal patients dependent on life sustaining medical technology experience extreme pain when their lives are extended by such means).

50 See id. (noting that holding in Compassion would limit right to physician-assisted suicide to terminally ill competent adults); Quill v. Vacco, 80 F.3d 716, 717 (2d Cir. 1996) (discussing physician-assisted suicide in limited context of terminally ill person’s rights), rev’d, 117 S. Ct. 2293 (1997).

I can tell from my personal experience, with Choice in Dying and with nursing homes, hospitals and physicians, that there is profound disagreement among professionals and others concerning whether an individual meets a certain definition of terminal illness. This is evident by the fact that the word "terminal" is described in different ways in various statutes.\textsuperscript{52}

The advanced directive statutes illustrate that there are at least seven different commonly used definitions of terminal illnesses. As a result, defining terminal illness might not be as easy as it initially seems.\textsuperscript{53}

Lastly, one of the cornerstones of the regulation of physician-assisted suicide is to ensure that physicians and their patients communicate clearly regarding not only physician-assisted suicide, but all of their treatment choices.\textsuperscript{54} Choice in Dying's experience, as well as mine, indicates that, at least in the area of withholding life sustaining treatment, patients frequently receive unwanted medical treatments that prolong their lives.\textsuperscript{55} Such conflict often continues between providers and patients. In fact, from the last report that we did, among the 922 case calls received during a 30 month period at Choice in Dying, sixty-five percent of such calls involved concerns over unwanted treat-

\textsuperscript{52} See GA. CODE ANN. § 31-7-172 (1983) (stating that therapeutic intervention is no longer appropriate if patient's medical prognosis is one with life expectancy of six months or less); MICH. COMP. LAWS § 333.5633 (West 1997) (describing terminal illness as condition in which patient's death is anticipated within six months); MINN. STAT. § 62A.616 (1996) (interpreting terminal illness to be diagnosis certified by physician that person has less than six months to live); NEB. REV. STAT. § 20-403 (1993) (defining terminal illness as incurable, irreversible condition that without life sustaining system, will cause death within relatively short time); N.J. STAT. ANN. § 26:2-96 (West 1996) (stating that terminal illness is defined as illness for which there is unknown cure, which ultimately ends in death, and is certified as such by two physicians licensed to practice medicine and surgery); OKLA. STAT. tit. 63, § 3101.3 (West 1996) (stating that terminal illness means incurable, irreversible condition that even with administration of life-sustaining treatment, will in attending physician's, in addition to another physician's, opinion result in death within six months); WIS. STAT. § 50.90 (1993) (defining terminal illness as medical prognosis that individual's life expectancy is less than twelve months).

\textsuperscript{53} See Coleson, supra note 4, at 60-63 (exploring three approaches to defining "terminally ill": (1) subjective determination; (2) statistical determination; and (3) disease threshold).


\textsuperscript{55} See Donald C. Dilworth, Dying Wishes Are Ignored By Hospitals, Doctors, TRIAL, Feb. 1, 1996, available in 1996 WL 13323062 (noting that many times physicians ignore patients' wishes not to be kept alive with life sustaining procedures, resulting in prolongation of patients suffering through receipt of unwanted medical treatment).
ment. Seventy-four percent of those instances involved a dispute, usually between the patient or the patient's family and the healthcare provider, over the use of life sustaining treatment. Choice in Dying and I are concerned that this lack of communication, reflected in the withholding or withdrawal of life sustaining treatment, will carry over into any discussion between the healthcare provider and the patient regarding physician-assisted suicide.

The above concerns need to be addressed and they need to be part of this continuous public debate. In fact, one of the reasons that we are all here today is to ensure that this essential public debate continues.

Thank you.