Sources for:

“George is humane.”

**On dying well: a paradoxical relationship with death**

*America*, March 16, 2015

Last year Brittany Maynard's controversial decision to "die with dignity" captured the national imagination and rekindled the contentious debate over the right to die. She was lauded by many for what they called her courage. The Washington Post columnist Richard Cohen praised her suicide, calling it "admirable," "sensible" and "dignified." Others have derided Ms. Maynard for what they considered cowardice, calling her "selfish" and "prideful." Nearly every angle of this story was exhausted as Ms. Maynard increasingly became a prop for argumentation. Though in many ways she was an outlier among those who have chosen assisted suicide, her case is important because our rapacious consumption of her suffering and death has revealed just how deeply conflicted we are about these profound human realities.

On the one hand, we naturalize death. We make it just another point on the continuum of life. At the same time, we fear death and push it to the margins of lived experience. The dead are gotten out of the house--or more often the hospital bed--and into the ground as quickly as possible. Yet on the other hand, death continues to be experienced as an evil, as a break, a foreclosing of the possibility to love a particular somebody. But the more we push death and dying to the peripheries, the more we consume the spectacle of death. Such a contentious and contradictory relationship is only exacerbated by the fact that suffering so often accompanies death, and we are as ill-equipped to encounter suffering as we are to face death.

For those who cannot see beyond the material horizon of death, suffering that does not appear to have proximate material benefit is emptied of the possibility of meaning.

A Peaceful Death?

Euthanasia is currently prohibited in the United States, but physician-assisted suicide is legal in five states. Oregon led the way in 1994, followed by Vermont, Washington, New Mexico and Montana. New Jersey and Connecticut are currently considering legislation that would legalize the practice of physician-assisted suicide. In Europe, the Netherlands was the first country to legalize voluntary active euthana sia, amending its Penal Code in 1985. Voluntary active euthanasia is distinct from physician-assisted suicide in that the doctor, and not the patient, administers a life-ending injection. Belgium and Luxembourg have since introduced similar legislation. In 2004, a Dutch doctor euthanized a Catholic nun, who was dying of cancer, against her will because he believed her religion prevented her from rationally assessing her situation.

In February of last year, the Belgian parliament voted to legalize euthanasia for terminally ill children with parental consent. Belgium legalized euthanasia for adults 12 years ago and now leads the way in expanding euthanasia laws to include children. In Lithuania, the health minister has recently proposed the possibility of euthanasia for poor people who cannot access palliative care. The logic of euthanasia and physician-assisted suicide tacitly asserts that suffering necessarily devalues human life. In an attempt to radically reconfigure and domesticate the mystery of death, a "death with dignity"--that is, a death without suffering--becomes preferable to a life that remains open to the possibility that suffering can intersect with love.

Arguments for euthanasia and physician-assisted suicide typically invoke the grammar of compassion, peace and dignity. We all hope the dying have a peaceful death. In fact, in the Liturgy of the Hours, Night Prayer ends with the petition, "May the all-powerful Lord grant us a restful night and a peaceful death."

With the advance of utilitarian idealism and medical technology, it seems that nothing but a peaceful death will be acceptable, wherein peace is reduced to the absence of pain, emotional and physical suffering or the loss of cognitive and physical abilities. This understanding of peace empties compassion of its original depth of meaning as co-experiencing, suffering with. This logic cannot account for the martyrs or for anyone who endures great suffering all the way to the end. Rather, the use of this grammar masks the insidious affirmation that the one who stands to lose all her abilities and suffer greatly is better off dead. Indeed, so thin an account of peace means that the Catholic nun who was euthanized against her will was in fact incapable of rationally assessing her situation.

The use of the term dignity to describe this death is deeply problematic, since it masks the reality of fear and equates dignity exclusively with radical autonomy, choice and cognitive capability. The result is the not-so-subtle implication that the person who chooses to endure diminishment and suffering dies a less dignified death. While the mendacious logic of this narrative of dignity is largely unexamined, the logic of absolute autonomy remains unquestioned.

Yet not all narratives are equal, and there is another narrative that is routinely neglected or, worse, rejected out of hand, a narrative grounded in the logic of the Cross. This is a narrative in which suffering unto death can be penetrated and transfigured by the mystery of love--particularly in cases like Ms. Maynard's, when one is surrounded by loving family and friends. This transfiguration occurs in hidden intimacies. Choosing to die early forecloses such possibilities. Had she not taken her own life with the assistance of a physician, she, like many who suffer terminal illness, almost assuredly would have been stripped bare of her abilities, perhaps even her mind. Indeed, there was nothing material for her to gain in suffering, only loss. Almost assuredly there would have been no inspiring recovery story to tell at the end. Rather, Ms. Maynard might have become unproductive, unattractive, uncomfortable. She would just have been. But she would have been present in a web of relationships. Even had she fallen unconscious, she likely would have been read to, washed, dressed and kissed. She would have been gently caressed, held and wept over. She would simply have been loved to the end.

BY JESSICA KEATING

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**Parents Should Have the Right to Choose Assisted Suicide for Their Children**

*Assisted Suicide*, 2012

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Advocates for aid-in-dying have largely focused their efforts on the rights of mentally-competent adults to end their lives when and how they wish. The two states that have legalized physician-assisted termination via statute, Oregon and Washington, explicitly limit the practice to terminally-ill patients *over the age of eighteen*. Such an emphasis on the suffering of adults is understandable. After all, the illnesses most likely to create a demand for lethal prescriptions, from cancer to ALS [amyotrophic lateral sclerosis, or Lou Gehrig's disease], increase in frequency with age. Unfortunately, much less attention has been paid to efforts to hasten the deaths of pediatric patients who lack any hope of recovery. That is why advocates for children should welcome an impressive study, published this week [March 3, 2010,] in the *Archives of Pediatrics & Adolescent Medicine*, which revealed a considerable interest in euthanasia among the surviving parents of children who had died from cancer. In interviews with 141 such parents, Dr. Veronica Dussel and her colleagues found that greater than 10% considered hastening their children's deaths, and that at least three families believed that physicians had expedited the deaths of their children in direct response to their requests. While the loss of a child to cancer is certainly a tragedy of the greatest magnitude—and one in which it is difficult to imagine finding any silver lining—the courage of these parents in sharing their views with investigators might prove the impetus our society needs to drive pediatric aid-in-dying out of the medical closet. In an era of parental rights and child welfare, maybe we are finally ready to grant suffering minors the right to die.

**The Double-Effect Approach**

The medical establishment's longstanding and inadequate solution to the suffering of terminally-ill patients, both children and adults, has been to rely upon the convenient ethical fiction of "double effect." According to the "double effect" principle administering life-shortening medications such as morphine to a patient is permissible if the primary intent is to ease pain—although a faster demise is a likely or inevitable secondary consequence. Thomas Aquinas first proposed this moral sleight-of-hand in the thirteenth century, when defending killings in self defense, and Pope Pius XII overtly endorsed such an approach to medical care in February, 1957. The American Medical Association and the American Academy of Pediatrics, which both oppose so-called active euthanasia, have embraced the doctrine as well. Yet the challenges of relying upon this clever if hazy principle far outweigh the benefits. Needless to say, many physicians will disagree about precisely when pain control ends and aid-in-dying begins—and the result may be that children continue to suffer. Fear of law enforcement drawing this same line in an overly-conservative manner may also scare some well-intentioned oncologists and pediatricians into withholding medication necessary for pain control. Few physicians, no matter how noble and dedicated, are willing to risk a second degree murder charge in order to incrementally reduce the suffering of a patient who will soon expire anyway. Yet even if the "double effect" approach could guarantee that all afflicted children might die without experiencing any physical pain or corporeal discomfort, which is highly implausible, such an approach would do little to staunch the emotional and existential anguish of the patient or her survivors.

In an era of parental rights and child welfare, maybe we are finally ready to grant suffering minors the right to die.

One powerful exchange that has been quoted extensively in the media since the appearance of Dussel's study is that between David Reilly, the father of a five-year-old boy who died of cancer in 1999, and his physician, Joanne Wolfe of the Dana-Farber Cancer Institute in Boston. If the child's soft-tissue tumor ever threatened to choke his son to a "horrible, horrible" death, Reilly reportedly asked, "Can we just get it over with quickly?" Wolfe refused. As a result, not only did Reilly endure the loss of his child, but also the solace of knowing that an "out" existed if such suffering ever became intolerable. Yet it is this hypothetical possibility of assistance with dying—as much as any tangible aid—that would provide some meaningful comfort to the parents of many critically-ill children. In the same way that more terminal patients investigate physician-assisted termination in Oregon and the Netherlands than actually use it, the greatest benefit of a legal right to die may stem from the sense of autonomy and empowerment that having such a right grants to individuals who have lost control of almost every other aspect of existence. For the parents of a critically-ill child, such an "escape hatch" might well prove particularly comforting. In contrast, feeling morally compelled to request terminal help that parents know is illegal might further compound their distress.

**The Rights of Parents**

One of the bedrock tenets of American law is that parents may make medical decisions for their children except in the rare and extreme circumstances where parental wishes and societal notions of child welfare conflict. In the case of young children who cannot understand medical matters, parents are permitted toconsent vicariously to their treatment. Our society takes such an approach to pediatric care because—excluding active threats to the public health—we generally believe that parents have a right to raise their offspring as they see fit, and that children are more likely to share the values of their mothers and fathers than those of medical personnel or hospital administrators. So if we are going to carve out an exception to parental authority with regard to end-of-life matters, we would need a compelling reason. Such a justification might exist in the extremely unlikely case where an older child left instructions opposing a hastened death or remained lucid and actively sought extraordinary care, and yet parents sought early termination anyway—a scenario which would clearly raise a compelling argument for overriding parental will. However, if an unconscious, terminally-ill child's views are unknown, or a dying child is simply too young to comprehend death, parents ought to have every right to declare "enough is enough" and to obtain assistance from a physician in bringing a family tragedy to a speedy and decisive conclusion. Moreover, the parents should be allowed to make such a request legally and publicly, without shame or stigma, rather than having to rely on the *sub rosa* [secret] tactics of brave but discreet providers.

In matters of child dying, as in child rearing, an enlightened society should be willing to say that parents know best.

In an ideal world, of course, no children would ever suffer from terminal disease. The cruel reality is that cancer alone kills more than two thousand kids each year in the United States, and thousands of others succumb to chronic genetic disorders, such as cystic fibrosis, or perish in ICU [intensive care unit] beds after sustaining irreversible trauma. These are real children—not hypothetical entities injured for the intellectual benefit of philosophers and theologians. Some opponents of pediatric aid-in-dying argue that legalizing the hastening of death will open the door to exploitation and that a horde of nefarious parents will use this opportunity to rid themselves of burdensome offspring. Strong evidence casts doubt upon these claims, as those jurisdictions that have legalized aid-in-dying for adults have not seen any such abuse of theelderly or disabled. Similarly, if the fear is that insurance companies and corporate hospitals will pressure families into terminating care prematurely—which they are just as likely to do in a world governed by the willful self-deception of "double effect"—then the proper solution is to curtail the power of hospital and health insurers, not to force unwanted life of minimal quality on our most vulnerable citizens.

Granting parents the right to hasten the deaths of their dying children certainty does not prevent either physicians or the courts from intervening in the unlikely event that a caregiver appears to be guided by base and ulterior motives. What establishing such a right does ensure is that children and parents will have one more weapon in their arsenal when confronting the tragedy of fatal illness. If I had a young child who had no prospect of regaining consciousness, I would want her existence ended as quickly and painlessly as possible. That is not to suggest that other reasonable people might choose differently. Up to the point that the public welfare is gravely compromised, those families who wish to keep comatose children alive should certainly be permitted to do so. In matters of child dying, as in child rearing, an enlightened society should be willing to say that parents know best.

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